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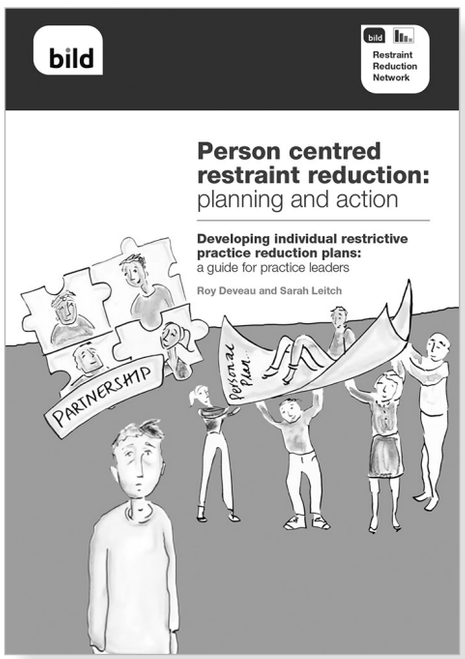
# Person centred restraint reduction: planning and action

*Roy Deveau and Sarah Leitch*

There are plenty of resources available to support organisations to implement successful restraint reduction strategies but only limited guidance available to help teams develop individual reduction plans.




This guide complements organisational resources and will be of use in services where people have restrictions placed upon them by those paid to support them. Some restrictions are, of course, necessary to keep vulnerable people safe, but there should always be a plan of how they can be reduced and restrictions should always be open to question. However, a commitment to reduction is not enough – ideas need to be turned into actions. This book is for practice leaders who can support colleagues to develop person centred reduction plans and make changes that have direct impact on people's lives.

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# ABSTRACTS

## WELCOME ADDRESS

### Diversity & belonging: celebrating difference

A. Schippers

*VU University Medical Centre Amsterdam, The Netherlands*

IASSIDD brings people together in 2018, at the agora of Athens, to exchange the most recent knowledge and insights in intellectual and developmental disability. Greece is widely recognized as one of the important cradles of Western civilization, and it is a country where disability is embedded in heritage. In Greek mythology, one of the gods – Hephaestus, the god of fire – had a disability. He had artificial supports of gold, was sometimes mocked, but was also known as a good mediator. Disability is part of humankind and has been throughout the ages, where it has been simultaneously supported, neglected, denied, and embraced. At the 5th European conference of IASSIDD, we offer an agora for all attendees, with and without disabilities, to celebrate the uniqueness of everyone, but at the same time to share knowledge and, above all, good company.

## INVITED SPEAKERS

### Disability studies and citizens with a label of "intellectual disability": how do we tackle some prominent questions concerning diversity & belonging?

G. Van Hove

*Ghent University, Belgium*

**Description**: Disability Studies originated from the movement of persons with physical impairments. In the first waves of Disability Studies, a great deal of attention was given to accessibility, equal (human) rights, voice, and participation. Following the introduction of the UNCRPD (the "crème de la crème" of disabled people's rights), some important questions still stand out, especially for persons with the label of intellectual disabilities. Some of the most intriguing questions are: Did we push politicians to ratify a convention that could be counterproductive for persons with intellectual disabilities?; Who is claiming the "voice" of those with the label of intellectual disability?; How do we involve persons with an intellectual disability, starting from the slogan "nothing about us without us"?; Is participation a final goal for persons with intellectual disabilities?; and How flexible are service systems for persons with intellectual disabilities with respect to the basic ideas of Disability Studies?

**Contribution**: Important questions such as these need to be examined using a combination of insights from research, theoretical concepts, and the perspectives of persons with intellectual disabilities, their family members, and their support staff.

### Celebrating difference at school in Greece: how can individual educational planning be used as a mainstreaming tool?

T. Asteri

*Institute of Educational Policy, Greece*

**Description**: In Greece, following release of the Ministry's circular in June 2016 on the mandatory use of Individual Educational Planning (IEP) within Special Educational Needs (SEN) Schools, practitioners and teachers have been scheduling individual interventions to monitor the learning progress of their pupils. There is a generally held view amongst SEN teachers and school advisors that the IEP acts as a substitute for curricula per se. However, the IEP is mostly needed to achieve mainstreaming goals in inclusive educational environments to assist teachers to differentiate teaching methods, instructional tools, and learning objectives.

**Contribution**: Useful planning and implementation of IEPs in inclusive educational settings is a multidisciplinary task that includes advocacy and cooperation between the school and the family. It needs to be scheduled step by step, keeping parents, practitioners, and teachers working together as a team along the way.

### Individual education plans as a tool to foster inclusive practices in schools?: a European perspective

T. Buchner

*University of Vienna, Austria*

**Description**: In this response to Dr. Asteri's speech, some key aspects of the Greek example are discussed within a broader European context. In various European countries, there have been efforts to facilitate individualised learning for children and young persons in schools. Some examples show that such approaches can contribute substantially to the development of inclusive practices in schools.

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Some of these policies and practices – as they related to the Greek experience – are identified, and the benefits and pitfalls linked to them are discussed.

**Contribution**: This commentary builds on the policies on individual education plans in Greece and, by sharing related experiences from different European countries, includes them in an international perspective.

## Exclusion vs belonging within diverse communities

K. Scior

*University College London, UK*

**Description**: A sense of belonging to a family or to a community is a core dimension of social inclusion for people with intellectual disabilities (ID). Recent decades have seen many positive changes in increasing the inclusion of people with ID and their options for belonging within diverse communities. Yet, all too often, children and adults with ID are still excluded from their communities and negative attitudes and discrimination remain everyday realities for many. Families and communities have the potential to be sources for "good" and "bad" – for advocating and supporting inclusion, or conversely for actively keeping persons with ID out. Several important factors promote inclusion and a sense of belonging, although the roles of culture and religion warrant particular attention.

**Contribution**: Real life descriptions from different parts of the world illustrate the effectiveness of efforts to work actively towards greater inclusion, and they highlight the role of self-advocates in such work.

## Feeling connected, being autonomous

P. Embregts

*Tilburg University, The Netherlands*

**Description**: Self-determination is an essential dimension of one's quality of life. To develop self-determination, social environments supporting the three basic psychological needs – autonomy, relatedness, and competence – are crucial. In a so-called autonomy supportive environment, control and pressure are minimized, while self-initiatives of people with intellectual disabilities are supported, choices are provided, and the other's perspective is taken into consideration. Given the fact that support staff are key people in the lives of many people with intellectual disabilities, they have a vital role in creating such an autonomy supportive environment. Building a trusting relationship between support staff and people with intellectual disabilities is imperative, and support staff can be trained in this respect. In addition to this formal network, family members are significant and key providers of support.

**Contribution**: Greater understanding is provided of the extent to which people with intellectual disabilities themselves experience (relational) autonomy and self-determination related to the support they receive from their formal (support staff) and their informal (family) networks.

## Living with autism: perceived needs and strength-based strategies implemented by families

K. Papanikolaou

*National and Kapodistrian University of Athens, Greece*

**Description**: The number of children and adults diagnosed with autism spectrum disorder (ASD) has increased dramatically in recent decades. ASD occurs in all racial and socioeconomic groups and, although it is frequently associated with intellectual disability, it is distinctive in its clinical expression, course, impact, and treatment. Some treatments and supports can improve the quality of life of people with ASD, but it is recognized that ASD is a lifetime condition. The multiple developmental and behavioral challenges and high rates of co-occurrence associated with autism can put a great deal of stress on families, who can frequently benefit from multidisciplinary advice and support. Addressing this broad issue requires: an understanding of current knowledge on the nature of ASD, the challenges associated with treatments and support, needed family supports, strategies parents can implement, and how caring for a child with autism and managing the needed professional care can affect family quality of life. The experience working with Greek families at an ASD outpatient clinic illustrate this range of topics.

**Contribution**: It is essential to have an understanding of ASD, and to recognize the challenges that people with ASD and their families face.

## Living well with autism spectrum conditions: how can we help?

M. Waltz

*VU University Amsterdam, The Netherlands*

**Description**: Children and adults with autism experience barriers to inclusion, participation and belonging in all sectors of life, including education, work, housing, and community life. Sometimes these barriers are physical, such as flickering Web interfaces and florescent lights that can trigger discomfort, disorientation, or seizures. Sometimes they are procedural, such as the use of confusing

multi-part instructions, or expectations that everyone can perform social interaction in the same way. Often, they are social, with normative beliefs and behaviours placing obstacles in the way of understanding and belonging. Until recently, most work in the field of autism has focused on changing people with autism rather than dismantling these barriers.

**Contribution**: The current focus on changing people with autism can be shifted. Practical accommodations can make places, services, and communication more accessible for children and adults with autism. Service providers, educators, and policymakers can make many environmental and behavioural changes that promote inclusion and belonging.

## Feeling at home: a mental health research agenda for and with people with intellectual developmental disabilities and their families

A. Hassiotis

*University College London, UK*

**Description**: It is said that people with intellectual developmental disabilities (IDD) are mainly consumers of research with little opportunity to take an active part in the process. I argue, using published evidence and examples from my own research lab, that people with IDD can: (1) help to form or influence research agendas, and (2) become part of the research process.

**Contribution**: I touch on the principles of co-production, the ways in which the public can put forward research questions that are meaningful to them, and how third sector organisations can partner with academic institutions in collaborative research practice. "Feeling at home" within an inclusive research framework has challenges, such as recruitment, training, and retention of people with IDD and their family carers, and enabling them to carry out their roles effectively. Infrastructure is needed to maintain patient and public involvement and long-term commitment to embed the values of inclusive research agendas within the working ethos of new generations of researchers.

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# ABSTRACTS

## TRACK 1: INCLUSION & BELONGING

## SYMPOSIA

## 1. SOCIAL AND OCCUPATIONAL NETWORKS OF PEOPLE WITH AN INTELLECTUAL DISABILITY

### 5857 | Social networks of people with a mild to borderline intellectual disability; their own perspectives

P. Embregts; I. van Asselt-Goverts; L. Hendriks

*Tilburg School of Social and Behavioral Sciences, Tilburg University, Tilburg, The Netherlands*

**Background**: The project aims to enhance the role of social networks in furthering the inclusion and participation of people with an intellectual disability (ID). It is important to examine how people with an ID perceive their own social networks in terms of structural (e.g. size and frequency of contact) and functional (e.g. type of support offered) characteristics.
**Method**: Data were collected by means of the Maastricht Social Network Analysis (MSNA), a self-report method to explore the social network characteristics of people with ID. Thirty-three people with mild to borderline ID participated, all of them lived independently in community for at least 2 years.
**Results**: Data showed that participants considered themselves to be the main initiator of contact with members of their social network. Professionals have an important place within the social networks of people with ID in providing both practical and emotional support. In addition, involvement in work or school appeared to be an important way of making friends.
**Conclusions**: The role of professionals in further stimulating the inclusion and participation of people with an ID is discussed, for example in providing opportunities for people with ID to meet people with shared interests, values, and backgrounds.

### 5547 | Emotional support in family networks: the perspective of individuals with mild intellectual disability

S. Giesbers; L. Hendriks; T. Tournier; R. Hastings; A. Jahoda; P. Embregts

*Tilburg School of Social and Behavioral Sciences, Tilburg University, Tilburg, The Netherlands*

**Background**: Informal support networks of individuals with mild intellectual disability (MID) have become increasingly important to enhance participation and social inclusion. These networks are primarily shaped by family. As research on family support provided to individuals with MID has been scarce, the aim of this study was to examine the way in which individuals with MID define their family contexts and more specifically how they perceive existing support relationships in these contexts.
**Method**: A random sample of 138 individuals with MID were interviewed individually about their family networks using an adapted version of the Family Network Method (FNM-ID). The FNM-ID examined (i) who people with MID consider as (significant) family members, and (ii) how people with MID perceive the existing (emotional) supportive ties among all network members. Network measures (i.e. density, reciprocity, composition) were computed using UCINET.
**Results**: Results of this study provide a better insight into family support and the context of structural interdependencies in which individuals with MID and their close family relationships are embedded.
**Conclusions**: Findings of this study lead to recommendations with respect to the optimization and use of family support in stimulating inclusion and participation and contribute to family support and social capital theory.

### 5687 | Occupational networks of people with ID: an exploration of the characteristics

K. van den Bogaard; E. Taminiau; P. Embregts

*Tilburg School of Social and Behavioral Sciences, Tilburg University, Tilburg, The Netherlands*

**Background**: Employment can contribute positively to the participation and inclusion of people with ID. Inclusive research is an emerging field of interest, providing employment opportunities to individuals with ID. In this study we aim to explore the characteristics of the occupational networks of people with ID involved in inclusive research (e.g. size, reciprocity between network members, perceived support)

and examine their influence on sustainable employment of people with an ID.

**Method**: We asked people with an ID working as a researcher in inclusive research to list their significant colleagues, to indicate from which colleagues they received practical and emotional support and to whom they offered these support themselves. An adapted version of the Family Network Method was used to explore these network characteristics.

**Results**: Results will increase our insight into occupational network configurations as perceived by people with an ID themselves.

**Conclusions**: This study will yield recommendations on further strengthening occupational networks of people with an ID working as a researcher, resulting in enhanced participation and inclusion through involvement in work.

### 5579 | Social and occupational networks as resources for sustainable employment of people with an intellectual disability

M. Voermans; E. Taminiau; P. Embregts

*Tilburg School of Social and Behavioral Sciences, Tilburg, The Netherlands*

**Background**: Despite great advances, barriers to participation and inclusion of people with intellectual disabilities (ID) continue to exist with respect to employment. The capability approach offers a useful framework to further participation of people with an ID. Based on the capability approach, we have explored what people with an ID consider valuable in work, to what extent they succeed in attaining these values and the resources they require.

**Method**: We conducted in-depth interviews guided by the capability approach with people with an ID. Data are extensively and systematically analysed using Interpretative Phenomenological Analysis (IPA), and including member-checks.

**Results**: Data increase our understanding of what is perceived valuable in employment by people with an ID themselves. In addition, data offer insight into the role of both the social and occupational networks of people with an ID as resources to attain effective participation in employment.

**Conclusions**: In enhancing participation and inclusion of people with an ID it is essential to connect to actual opportunities of people to participate in society. Guided by the capability approach, this study yields recommendations for enhancing sustainable employment and participation of people with an ID.

## 2. ENCOUNTERS AS A MEANS OF SOCIAL INCLUSION

### 5591 | Encounter as a way of re-conceptualising social inclusion

C. Bigby; I. Wiesel; F. Bredewold

*LaTrobe University Living with Disability Research Centre, Tasmania, Australia*

**Background**: Social inclusion of people with intellectual disabilities is a key social policy objective. It is an elusive goal, difficult to conceptualize and translate into concrete strategies. Research and practice has traditionally operationalized inclusion as a binary between presence in community places or relationships with community members. We explore the conceptual possibilities and fledging literature on Encounter as a means of opening new strategies to achieve inclusion of people with intellectual disability.

**Method**: Review of the theoretical sociological and urban studies literature on Encounter and the emerging research on the application of this concept as a means of understanding and promoting the social inclusion of people with intellectual disability.

**Results**: Encounters with strangers in public spaces provide opportunities for people with intellectual disability to be known and recognized in communities, as well as to step outside fixed and often stigmatised identities and explore more transient shared identifications with those they meet. They take many different forms, and can be convivial as well as exclusionary, reinforcing as well enabling difference to flourish.

**Conclusions**: Encounter offers a new conceptual framework to operationalize inclusion of people with intellectual disabilities and provide insights into support practices and design of community places that enable inclusion.

### 5568 | Responding to otherness: the need for experimental-relational spaces

G. Bos; T. Abma

*VU Medical Centre, Amsterdam, The Netherlands*

**Background**: The purpose of our presentation is to illustrate why it is crucial to strive for more 'experimental-relational spaces' for difference between people with and without intellectual disabilities in public space.

**Method**: We reflect on the experiences of the presenter during PhD research in 'reversed integration contexts' (2010–2015). In said contexts, people without intellectual disabilities live on formerly sheltered institutional terrains, near initial residents with severe intellectual disabilities. We present a narrative about encounters with Harry, an initial resident which fascinated the PhD-researcher. The narrative is interrupted by care-ethical reflections, and theoretical

insights drawn from Foucault (1984) and Meininger (2013) on 'heterotopia'. These interruptions take place in a dialogue between presenter and his promotor.

**Results**: The main lesson we would like to share in is that in our attempts to understand a 'strange other' and to do right by him, we should attune more bodily, trustfully and reflectively to his otherness. We illustrate this by three examples of a searching, sensitive response to Harry's non-verbal, bodily approaches.

**Conclusions**: Through this presentation we hope to create room for reflexivity and to engage the audience into re-thinking and re-interpreting the meaning and possibilities of neighbourhood encounters.

## 5649 | Convivial encounters in neighbourhood projects: contact between people with intellectual and psychiatric disabilities and neighbours

F. Bredewold; M. Jager-Vreugdenhil; E. Tonkens; A. Haarsma

*University of Humanistic Studies Utrecht, Utrecht, The Netherlands*

**Background**: In response to deinstitutionalization and normalization, social professionals are setting up neighbourhood projects to create opportunities for people with and without disabilities to meet and mingle. We studied which aspects and conditions in neighbourhood projects are necessary to create pleasant and convivial encounters between people with disabilities and neighbors.

**Method**: The findings are drawn from research on encounters between people with and without disabilities on four Dutch neighborhood projects. Forty-four interviews were conducted with people with and without disabilities, eight interviews with social professionals working at these places and participant observation at these locations where local agencies stimulate contact between neighbours with and without disabilities.

**Results**: We found that most people don't come to these locations for one-to-one friendships or contacts. They visit the projects because they find benevolence, conviviality and a warm place. We identified four aspects in neighbourhood projects to create convivial encounters: (i) a welcoming environment, (ii) generalized reciprocity, (iii) a shared purpose, (iv) clear but low demands.

**Conclusions**: Although the contacts on neighbourhood projects remain light and superficial, they are important because they represent bridges between two mostly separated worlds and they can reduce inequalities between people with and without disabilities.

## 5595 | Understanding programs that support convivial encounters for people with severe intellectual disabilities

C. Bigby; S. Anderson

*LaTrobe University, Living with Disability Research Centre, Tasmania, Australia*

**Background**: A scoping review found one third of interventions to support community participation could be conceptualized as creating convivial encounters; shared activities and social interactions with others without disabilities. This study analyzed participant outcomes and program logic of two services supporting convivial encounters for people with severe intellectual disabilities to evaluate effectiveness.

**Method**: Document review, participant interviews (10), program staff interviews (21) and open-ended participant observations were conducted. A program logic was constructed for each service and qualitative analysis of outcomes undertaken.

**Results**: Programs used similar strategies to facilitate convivial encounters. Significant planning at individual and program level was undertaken. Staff collaborated with local organizations to create individually-tailored mixes of opportunities for shared activities, engagement in specific tasks and social interaction, through community groups or classes, social enterprises or volunteering. Programs valued personal staff qualities, but undervalued and failed to articulate their skills. Service users experienced positive outcomes, including enjoyment, and a sense of belonging and contributing to the locality.

**Conclusions**: Staff skills required for this type of program are working with individuals; planning, task analysis, active support, support for decision making, and skills in working with communities such as networking, negotiation, and advocacy.

# 3. SOCIAL INCLUSION

## 5765 | Developing a self-report tool for assessing the social inclusion experienced by people with intellectual disability

R. McConkey; S. Menke; C. Peng

*Institute of Nursing and Health Research, Ulster University, Coleraine, UK*

**Background**: People with intellectual disability frequently experience social exclusion. To date few tools are available to assess self-reports of inclusion. Special Olympics commissioned this study to develop a tool they could use to compare the extent of social inclusion within their sports and how this impacted on athletes' inclusion in the wider community.

**Method**: Focus groups were held with over 90 athletes from six countries to identify their experiences of inclusion. From their responses, an interview-based questionnaire using a three-point rating

scale was then developed and field-tested with over 700 athletes from US, Germany, Poland, Ireland, Romania, Malta and Austria.

**Results**: Statistical analyses identified two main factors in athlete's inclusion in sports (Interaction with players and experience of exclusion) as well as a unitary factor that reflected community inclusion. Reliability and content validity tests were also undertaken. A two-part questionnaire is proposed consisting of 16 items relating to inclusion in sports (or in similar settings such as schools) and 12 items covering community inclusion.

**Conclusions**: The tool can be used to compare the extent of inclusion across different settings and to monitor changes in inclusion over time or the result of particular interventions, such as Unified Sports.

## 5767 | Promoting social inclusion through sport: the perceptions of Special Olympic coaches

R. McConkey; C. Peng; S. Menke

*Institute of Nursing and Health Research, Ulster University, Coleraine, UK*

**Background**: Special Olympics aims to promote the social inclusion of people with intellectual disabilities within its own organisation as well as the wider community. Their volunteer coaches play a key role in fostering inclusion especially in Unified Sports where players with and without disabilities compete on the same team. To date little attention has been paid to how coaches might do this both in the context of Special Olympics and indeed in the broader arena of sport coaching.

**Method**: Focus groups were held with 53 coaches in six countries (USA, India, Germany, Finland, Poland and Austria). From their responses, a self-completion questionnaire was developed and field-tested with a further 288 Special Olympic coaches involved in a range of sports from across seven countries in Europe and the USA.

**Results**: Factor analysis identified 19 items that best reflected actions that coaches could take to promote inclusion within sports clubs. The shortened scale had good psychometric properties.

**Conclusions**: The scale could be used as part of coach training courses inclusion and also to assess the impact of interventions designed to promote the inclusion of athletes with intellectual disabilities in mainstream sports or similar settings such as leisure clubs.

## 5895 | Attitudes towards inclusion: measuring attitudes of the general population towards people with intellectual disabilities

A. Shellard; L. DuBois

*Special Olympics International, USA*

**Background**: Special Olympics International (SOI) aims to change attitudes towards people with intellectual disabilities (ID) in order to promote more inclusive communities. In order to understand the impact of Special Olympics activities on attitudes, as well as the attitudes towards inclusion of people with ID, SOI implemented a general population survey.

**Method**: The survey was developed in consultation with experts in the field of attitudinal research and intellectual disability. Kantar Millward Brown used existing panels of the general population to implement the survey with 1500 people in each of the following locations: Austria, China, Finland, Germany, Great Britain, India, Ireland, Japan, Malta, Panama, Poland, Romania, South Africa, United Arab Emirates and the United States. Surveys were conducted in late 2017/early 2018.

**Results**: Results show that while people have generally positive attitudes towards people with ID, they do not view them as adults or leaders. The majority of respondents associated words, such as trustworthy and friendly, with ID but also lonely and isolated. Full results will be discussed with a focus on EU countries.

**Conclusions**: Findings suggest that while people with ID may be viewed positively, there is room for improvement with respect to meaningful inclusion as equals and peers.

## 5350 | Contingent respect for people with disabilities depending on the type of relationship

P. Kurtek

*Jan Kochanowski University, Kielcach, Poland*

**Background**: The aim of the report is to present a new research tool CoRe-D, a questionnaire used to study conditional respect for people with disabilities in Polish society. In addition, the report aims to examine the role of the type of relationship with a person with disability in the feeling of conditional respect.

**Method**: Items for the questionnaire were chosen based on the bottom-up analysis of the statements of 32 fifth-year students. These statements were relating to factors that, lead to increased or reduced of respect for persons with disabilities. A group of 217 respondents participated in a pilot study. An exploratory factor analysis distinguished three aspects of conditional respect: pro-social attitude, burdening others, aggressiveness. Results suggested the tool is reliable in these three aspects (ranging from 0.72 to 0.81), which allowed us to conduct further research on two groups of participants: those who are personally related to the person with disability and those who are not in a personal relationship with them.

**Results**: The results of the comparative analyses indicate different profiles of expectations in the examined groups and the mediating role of the type of disability.

**Conclusion**: Understanding the perspective of the people with disabilities is the basis for successful integration activities that achieve mutual respect.

## 4. SEXUALITY OF PEOPLE WITH AN INTELLECTUAL/LEARNING DISABILITIES: RESPONSES OF CAREGIVERS

### 5588 | Sexuality and adults with intellectual disabilities

M. Brown; E. McCann

*Faculty of Medicine and Health Sciences, Queen's University Belfast, Belfast, UK*

**Background**: A systematic review of published research studies was undertaken to identify the sexuality experiences and viewpoints of adults with intellectual disabilities as well as highlighting areas for future practice developments.

**Method**: A comprehensive search of databases from January 2006 to December 2016 was carried out. Studies had to address specific criteria including: peer reviewed papers, the use of appropriate research methods, and focused exclusively on the individual views and opinions of adults with an intellectual disability. The search of relevant databases yielded 230 hits. Following the application of explicit inclusion and exclusion criteria, 23 papers were included in the review.

**Results**: The results and analysis indicates that adults with intellectual disabilities experience dilemmas in relation to autonomy versus risk of harm, desire further knowledge about their sexuality, desire relationships/intimacy, wish self-determination to take control of their relationships, and wish to have access to encouragement/supports when necessary.

**Conclusions**: Adults with intellectual disabilities need education and support to express their sexuality and express their needs. There is a need for families and services to ensure the autonomy of expression is realised while having in place appropriate safeguarding procedures.

### 5396 | Public perceptions of sexuality and learning disabilities: the influence on support workers

E. Oloidi; R. Northway; J. Prince; M. Culwick

*University of South Wales, Faculty of Life Sciences and Education, Pontypridd, UK*

**Background**: Public attitudes and beliefs influence behaviour towards people with intellectual disabilities (ID) and social care workers (SCWs) are not insulated from such beliefs. These beliefs may influence SCWs' support of personal/sexual relationships for people with, however little research as examined this influence. The aims of this study were to explore the following questions: 'Do societal perceptions of ID affect SCWs' attitudes, beliefs and behaviours towards intimate relationships amongst adults with ID?', 'Do such perceptions impose limits on SCWs' efforts to support individuals' personal and sexual relationships?'

**Methods**: This paper reports stage one of a sequential mixed-methods study. Eighteen semi-structured interviews with SCWs were undertaken using Critical Incident Technique (CIT).

**Results**: Thematic analysis of all 18 transcripts was completed. Four dominant themes emerged: socio-cultural factors, the practice-policy gap, fear and prioritisation of safety needs.

**Conclusions**: Socio-cultural factors appear to lead to a gap between policy and practice, which then leads to fear and prioritisation of safety needs over other equally important needs such as personal and sexual relationship needs.

### 5395 | Public perceptions of sexuality and learning disabilities part 2: the influence on support workers

E. Oloidi; R. Northway; J. Prince; M. Culwick

*Faculty of Life Sciences and Education, University of South Wales, Pontypridd, UK*

**Background**: Public attitudes and beliefs influence behaviours towards intellectually disabled (ID) persons. Social care workers (SCWs) are not insulated from such influences. The impact on relationships amongst persons with ID has not been researched widely. The research questions examined are as follows: 'To what extent; are SCWs' perceptions regarding personal and sexual relationships amongst adult with ID influenced by socio-cultural factors, a perceived practice-policy gap, fear and concerns regarding safety?', 'Do the demographic characteristics of SCWs impact these influences?', 'Do SCWs attach conditions that limit personal and sexual relationships amongst adults with ID?'.

**Method**: A self-completion survey of SCWs ($n$ = 276). To analyze the data, Kruskal–Wallis, Mann Whitney $U$ and Chi-Square tests were used.

**Results**: Socio-cultural factors, a perceived practice-policy gap, and fear and safety needs influence SCWs' views concerning personal and sexual relationships amongst people with ID. Factors such as participant age, geographical location, service type and organisational sector lead to significant differences in some views. Relationships between responses to questions indicate that concerns regarding safety needs have a significant impact.

**Conclusions**: Improved policies and practice-based support that reduce staff fear regarding supporting personal and sexual relationships for people with ID are required.

## 5. STRENGTHENING SOCIAL NETWORKS OF PEOPLE WITH DISABILITIES

### 5381 | Mechanisms and influencing factors to strengthen social networks of persons with disabilities

E. Meys; B. Maes; K. Hermans; D. Nijs

*KU Leuven, Leuven, Belgium*

**Background**: This research project aimed to map the complexity and dynamics of the social network around a person with a disability, as well as examine the influencing factors for network development and support. This research is embedded in an academic workplace where researchers, professionals, persons with disabilities, and their network work closely together on research design, data-analysis, results and translation of results into daily practice.

**Method**: A conceptual model is constructed through (i) a systematic literature review with a focus on 'disability', 'independent living' and 'social network'; (ii) analysis of 14 case-studies, each consisting of a semi-structured interview with a person with a disability, two of his/her network members and his/her professional in an ambulatory home-based service. Interview topics focused on structural and functional characteristics of the social network around a person with a disability, expectations, needs and wishes of persons with disabilities and network members. The interviews were transcribed and coded using NVivo.

**Results**: Mechanisms and influencing factors were identified and described.

**Conclusions**: The developed conceptual model will be empirically-validated through monitoring of the identified influencing factors and mechanisms by a self-developed questionnaire.

### 6009 | Who cares?: research into maintaining, strengthening, and expanding the informal social networks of people with profound intellectual and multiple disabilities

A. Kamstra; A. van der Putten

*'s Heeren Loo, Amersfoort, The Netherlands*

**Background**: Social contacts are important for everyone and there is no reason to assume that this is not equally true for people with profound intellectual and multiple disabilities (PIMD). Yet, little information is available about the size, type and frequency of the contacts for this target group. In order to be able to maintain, strengthen or expand these contacts, more information is needed.

**Method**: Data are collected through questionnaires (205), interviews (24), observations (14) and analysing individual support plans (60).

**Results**: People with PIMD annually have contact with only five people outside of their living facility. These people are mainly family and parents are the most involved. Aging is related to fewer contact persons and a lower frequency of contact. Professionals pay little attention to maintaining and expanding the networks and indicate that, even though they think this is important, they do not know how to shape this. Furthermore, they do not consider it as a part of the daily care.

**Conclusions**: Social networks should be seen as a part of the daily care. Working on maintaining, strengthening and expanding these social networks, should be done in close collaboration with family.

### 5683 | The impact of austerity on the social networks of people with Intellectual and developmental disabilities

R. Harrison; R. Forrester-Jones; M. McCarthy

*University of Kent, Canterbury, UK*

**Background**: UK austerity policies of the last decade have resulted in cuts and changes to services for people with IDD, potentially leading to deficiencies in their social lives. The aim of this study is to provide empirical evidence regarding such changes in lives of people with IDD.

**Method**: Utilizing a mixed-methods design, 50 people with IDD across two geographical areas were interviewed about how their social networks had been affected by cuts in services using The Social Network Guide. How changes in individuals' social lives affect their own understanding of self, inclusion and belonging was also explored using Interpretative Phenomenological Analysis.

**Results**: Findings will be presented to include both quantitative and qualitative case study data on the social networks of people with IDD.

**Conclusions**: Empirical evidence of the experiences of people with IDD who experience cuts or loss to services can provide policy-makers with a better understanding of the importance of social networks to the lives of people with IDD, thereby influencing future policy and practice.

### 6028 | Fostering social inclusion and community engagement for people with intellectual disability

E. Lauer

*Center for Developmental Disabilities Evaluation and Research, E.K. Shriver Center, University of Massachusetts Medical School, USA*

**Background**: Friendships and community inclusion are important to health and well-being. However in the US, people with an intellectual disability (ID) too often are 'in' the community but not 'of' the

community, spending most of their time with paid staff and family members.

**Method**: Through a recent partnership between a state human service agency and a university, a qualitative evaluation was conducted to gain a better understanding of best practices and barriers in the state to support people with ID to make friends and participate in the community. Ten focus groups and four key informant interviews were conducted; emerging themes were coded across the data.

**Results**: Resulting themes included: the meaning of friendships, the impact of staff in forming friendships, balancing risk with state regulations and provider rules, and supporting transportation needs. Results were used to influence expectations in publicly-funded support services to people with ID through a position paper.

**Conclusions**: Expectations included: a person-centered approach to inclusion; balance of risk with opportunities; training of support staff; organizational policies and practices supportive of relationships with community members; state regulations and provider policies to promote social inclusion; and new strategies to enhance transportation options. Implications, lessons learned, and resulting service outcomes will be shared.

## 6. FRIENDSHIP AND ROMANTIC RELATIONSHIPS

### 5369 | Supporting the development of romantic relationships among young individuals with visual impairments

C.-N. Shpigelman; M. Vorobioff

*Department of Community Mental Health, Faculty of Social Welfare and Health Sciences, University of Haifa, Haifa, Israel*

**Background**: Having a romantic relationship is a basic human being right. However, individuals with developmental disabilities often experience obstacles in creating and maintaining romantic relationships due to socio-emotional factors as stigma and self-esteem. The aim of the study was to capture the subjective experiences of young individuals with developmental visual impairments, regarding their romantic experiences and the implications for their emotional well-being and quality of life.

**Method**: In-depth, semi-structured interviews were conducted with 24 participants aged 18–40, who were blind or had a congenital/early-onset visual impairment.

**Results**: Having a romantic relationship seemed to empower these young people and enhanced their self-image, sense of sexuality and sense of social belonging. Nevertheless, physical and social barriers, such as mobility difficulties, lack of communication skills, lack of beauty care skills, and stigma limited their opportunity to have a romantic relationship. Furthermore, it seemed that family members and peers can support or limit the opportunity for romantic relationship.

**Conclusions**: The findings emphasize the need to develop interventions that focus on the individual and community. It is important to enhance self-esteem and communication skills among this population. It is also important to promote attitude change on this issue among the general population.

### 5917 | How do adolescents with and without an autistic spectrum condition (ASC) experience friendship?

J. Ware; G. Cully

*Bangor University, Bangor, UK*

**Background**: It is generally accepted that friendship is an important contributor to quality of life and it is also widely reported in the literature that people with an ASC have difficulties in social relationships, and in particular in forming. This study sought to gain the views of adolescents with and without an ASC on their experience of friendship.

**Method**: Individual interviews were used to ascertain the views on friendship of 10 adolescents with ASC, all of whom attended the same mainstream secondary school. Interviews were audio recorded for later analysis. A comparison group of 10 adolescents without ASC from the same school responded to the same questions in the form of a brief questionnaire.

**Results**: The experiences and views of friendship of the young people with ASC are reported and compared with findings of previous studies. The views of the adolescents with ASC are also compared with those of their peers without an ASC who attend the same school.

**Conclusions**: This study illuminates the similarities between young people of the same age with and without an ASC as well as the differences between them.

### 6027 | Friendship dynamics for students with intellectual disabilities

A. Okrainec

*Brandon University, Brandon, Canada*

**Background**: This presentation examines how friendship figures prominently in development and learning. Developmental stages, frameworks, and hierarchies for friendship formation, as espoused by theorists and researchers, will be featured.

**Method**: Developmental patterns and stages in friendships for students with intellectual disabilities will be considered. Reasons

why researchers and practitioners should be interested in studying friendship development in children with Intellectual Disabilities will be emphasized. A synthesis of the extant literature about how friendships enhance the inclusion of students with intellectual disabilities will be presented. A review of sources included in scientific databases (ERIC, Mental Measurements Yearbook, PsycINFO, and PsyArticles) inform this comprehensive review.

**Results**: This in an 'application to practice' session in which the presenter identifies evidence-based practices, strategies, instruments, and procedures that hold potential for studying and promoting friendship patterns and dynamics of students with intellectual disabilities. Theory to practice applications as well as methodologies to promote the inclusion of students with intellectual disabilities will be advanced.

**Conclusions**: Novel ways to apply the Circle of Friends procedure will be explored. This presentation will be of value to educational practitioners and others interested in advancing the inclusion and belonging of students with intellectual disabilities.

## 7. DIGITAL INCLUSION

### 5631 | Internet use by people with intellectual disabilities: current priorities

S. Caton; M. Chapman; E. Koivunen

*Manchester Metropolitan University, Manchester, UK*

**Background**: This research aimed to determine priorities for support and research in the area of internet use and digital inclusion for people with intellectual disabilities.

**Method**: We carried out semi-structured interviews with 22 participants – 11 people with intellectual disabilities and 11 non-disabled professionals who work with people with intellectual disabilities. Interviews were audio recorded, transcribed verbatim and analysed thematically.

**Results**: The results have demonstrated that people with intellectual disabilities are commonly and frequently using the internet. Mobile devices (phones, tablets) are most commonly used and video streaming, browsing and social media are common usages. People with intellectual disabilities are confident in their internet use but professionals working with them have concerns about safety and are not always making use of existing guidance.

**Conclusions**: Use of the internet by people with intellectual disabilities is increasing rapidly. In order to support people to access online resources, research needs to keep pace with the changing activities, vulnerabilities and risks that people with intellectual disabilities might face by using the internet. This research highlights priorities for ensuring people who work with people with intellectual disabilities are able to confidently support them.

### 5647 | Exploring health website accessibility and usability with people with learning disabilities: a pilot project

M. Waight; W. Oldreive

*Health Education England, Thames Valley on Secondment from Berkshire Healthcare NHS Foundation Trust, UK*

**Background**: To examine methods to improve websites to allow persons with learning disabilities to obtain better information about health.

**Method**: Focus group members were recruited through a self-advocacy group. Weekly focus group sessions were held to discuss the following topics: how to learn about health and health services; different formats of information available and rating for preferences; examining websites including: layout, navigation, language content, pictures and multi-media support. Group sessions were recorded and transcribed. These were analysed for themes and the results were shared with the group to validate the findings.

**Results**: Present Health Trust websites are difficult for people with learning disabilities to use and access. Using easy read text supported with pictures and video is helpful. Narrative-based video has the potential to be a relevant tool for providing information. A format to discuss websites with people with learning disabilities has been developed for use with further groups.

**Conclusions**: This is a pilot project and the views of one group of individuals using the format developed further groups will be arranged to explore the subject further.

## 8. WAYS OF PROMOTING SOCIAL INCLUSION

### 5671 | A longitudinal study of barriers to social and community integration for older people with intellectual disabilities in Ireland

D. McCausland; R. Carroll; P. McCallion; M. McCarron

*IDS-TILDA, Trinity College Dublin, Dublin, Ireland*

**Background**: This study examined barriers to social and community engagement for older people with ID in Ireland over a 7-year period. We explored changes in rates of specific barriers to engagement over time and factors associated with differences between subgroups.

**Method**: Measures from the Intellectual Disability Supplement to the Irish Longitudinal Study on Aging (IDS-TILDA) ($n$ = 609) examined difficulties engaging in social activities outside the home and difficulties travelling around one's local community. Changes were examined between waves 1–3 of the longitudinal study. Bivariate and multivariate analyses explored associations with demographic, personal and social factors.

**Results**: Rates of difficulty increased over time suggesting an age effect. However, a range of different factors were found to influence social and

community engagement. Respondents with the greatest level of support needs experienced higher rates of difficulty engaging. Needing assistance, health considerations and physical ability, and communication/language problems presented the greatest barriers to social engagement.
**Conclusions:** : People with ID experience increasing challenges to social and community integration as they age. As Ireland and other countries move towards post-institutionalisation it is critical that supports to enhance the experience of community integration are targeted to those who need them most.

## 5561 | Demonstrating the potential of dogs to facilitate social encounters for people with intellectual disabilities

E. Bould; C. Bigby; P. Bennett; T. Howell

*La Trobe University, Living with Disability Research Centre, Melbourne, Australia*

**Background**: This pilot study provided support to adults with intellectual disabilities to regularly walk a dog in their community and evaluated the effectiveness to facilitate encounters with other community members.
**Method**: A matched pairs design was used. Eight participants in Group 1 had 14 one-hour outings with a handler and their dog, whilst eight participants in Group 2 had 14 outings with a handler alone, followed by five additional outings with a handler and their dog. Differences in the average number of encounters were compared when a dog was present and absent and the qualitative data provided insights into the nature of these encounters.
**Results**: Participants had significantly more encounters of a different and more convivial nature when they went out with a dog. The qualitative data suggested the dog also offered protection against negative factors, and gave participants greater confidence to engage in social exchanges, and be more quickly recognised in community places.
**Conclusions**: The finding that a dog walking program has the potential to encourage convivial encounters has implications for policy and practice, particularly due to the launch of the NDIS in Australia, which is likely to open up possibilities for more individualised interventions to support community participation.

## 5420 | Promoting community participation and equality for people with intellectual disabilities using assistive technology

J. Owuor; F. Larkan; M. MacLachlan

*Department of Psychology, National University of Ireland Maynooth, Maynooth, Ireland*

**Background**: The aim of the study was to explore how assistive technology can support social inclusion for people with intellectual disabilities (ID) in Ireland.
**Method**: A cross sectional qualitative study involving people with ID, key workers supporting people with ID, family members of people with ID and individuals working in or living close to community services accessed by people with ID. Individual face-to-face interviews to explore the participants' perspectives on how AT can support social inclusion (community participation and interpersonal relationships) for people with ID.
**Results**: AT such as Skype, Spotify, wheelchairs, or iPads enabled participants with ID to achieve tasks previously perceived too complex for them such as calling loved ones, personal grooming, independent traveling or preparing own meals. For family members and key workers, it was a pleasure to see people with ID achieve their goals. The resulting sense of achievement and satisfaction was a motivation for people with ID to actively partake in community life.
**Conclusions**: AT can be a bridge to community living and participation for people with ID. But structural, systematic, and individual barriers hinder the prospect of AT to moderate disability divide for people with ID.

## 5426 | Foster mobility with apps – BlueAssist in Switzerland

M.T. Wicki

*University of Applied Sciences of Special Needs Education, Zurich, Switzerland*

**Background**: Cloudina is a series of apps that support people with IDs in their daily activities. One of them, BlueAssist, exists of a unique icon with a question. It gives confidence to the user to ask for help and also to a fellow citizen to offer help. This research aims at investigating to what extent BlueAssist affects performance in terms of activities, social contacts and well-being of the users.
**Method**: An intervention study with a pre-post test was carried out. Tests found out how effective media releases and PR are on the helpfulness of passers-by. BlueAssist users and their caregivers answered questionnaires before the use of BlueAssist, four months after starting to use BlueAssist and six months later.
**Results**: Tests show that over time more people supported the person with ID. Moreover, BlueAssist is higher-rated by the people contacted regarding the person with ID in case of T2. The same applies to the manageability of the app. Results of the survey will be available in March 2018.
**Conclusions**: BlueAssist overall was rated very positive by the caregivers and users. The extent to which BlueAssist supports independent mobility is being discussed.

## 9. NATIONAL POLICY TO PROMOTE INCLUSION AND PARTICIPATION

### 5379 | Young adults with intellectual disability and their families' knowledge and experiences of the introduction of the National Disability Scheme in Queensland, Australia

J. Lloyd

*The University of Queensland, Australia*

**Background**: This study investigated how young adults with intellectual disability and their families obtained knowledge about the National Disability Insurance Scheme (NDIS) and how they perceived it would impact on planning for their futures.

**Method**: Case studies were conducted with 30 young adults with intellectual disability and their families in metropolitan, regional, and remote areas of Queensland, Australia. Semi-structured interviews were completed with the parent(s) and the young adults with intellectual disabilities.

**Results**: There was a range of knowledge and experiences, including having very little information/understanding, to being well-informed/resourced. Knowledge and information were sourced mainly from social or informal networks rather than formal networks and location was not always a limiting factor. There was caution about the impact and possible benefits of the NDIS.

**Conclusions**: There needs to be multiple approaches to engaging adults with intellectual disabilities and their families in the NDIS. There is a need for further investigation into the experiences of adults with intellectual disability and their families in planning processes and outcomes across time.

### 5890 | Health equity assessment of social inclusion policy

H. Church

*Health and Rehabilitation Sciences, Western University, London, Canada*

**Background**: This presentation demonstrates how a health equity assessment tool can be used as a framework for a discourse analysis to identify the unintended health equity impacts of social inclusion policy.

**Method**: Using the Health Equity Impact Assessment tool developed by the province of Ontario as an organizing framework, this discourse analysis examines social inclusion policy for people who have developmental disabilities in the province of Ontario, Canada. It analyses policy statements, briefings, legislation and reports related to the service and support provision as the province transitioned from primarily institutionalized care and service provision to community-based service and support provision spanning from 1971 to 2016.

**Results**: Efforts to use inclusion, community-based services and supports of people who have developmental disabilities as a means of cutting costs rather than on creating effective inclusion opportunities for participation in inclusive settings within the community have been problematic for people who have developmental disabilities and their informal caregivers.

**Conclusions**: Inclusion must include all members involved in the transaction. As demonstrated by reports and briefing notes in the province of Ontario, those in the inclusive setting also require supports to promote effective and meaningful inclusion.

### 5835 | Information and communication: a mutual approach to exercise legal capacity and promote access to justice for persons with disabilities

V. Mukupa

*The Judiciary, Zambia*

**Background**: The paper investigates how information/communication (verbal and non-verbal) may enable persons with disabilities to exercise legal capacity on an equal basis with others, and promote their participation in access to justice.

**Method**: It will first address disability-related barriers to exercising legal capacity specific to persons with disabilities and how it impacts access to justice.

**Conclusions**: These barriers may be overcome through procedural/other modifications to administration of justice and training of everyone involved. Adjustments include those required in expressing or interpreting will and preferences. Accessible information and communication may augment decision-making for persons with various disabilities and promote their participation in accessing justice on an equal basis with others.

### 5503 | Changes in living conditions of people with intellectual disability: a follow up after 15 years

Õ.U. Carlsson

*Department of Public Health and Caring Sciences, Disability and Habilitation, Uppsala Universistet, Sweden*

**Background**: A study in 2001 described living conditions of people with intellectual disabilities born 1959–1974 in Uppsala County, Sweden as compared to the general population in the same age group. The results showed that people with intellectual disabilities had worse living conditions compared to that of the general population. The aim of the present study is to conduct a follow up after 15 years. In addition to comparison between people with intellectual disabilities and the general population, information concerning the

living conditions of people with intellectual disabilities will be analyzed across gender, age and disabilities.

**Method**: Information of the living conditions of people with intellectual disabilities for 40 persons who participated in the study 2001 was obtained by relative and staff questionnaire reports. National statistics was used to collect data on the general population.

**Results**: Preliminary results will be presented.

**Conclusions**: This project reveals similarities and differences that are important to identify in a diversity perspective. It is important if people with intellectual disabilities should have the opportunity to live as others and in community with others.

## 10. COMMUNITY LIVING

### 5512 | Living in localities: do people with intellectual disabilities really belong in their neighbourhoods? A systematic review

G. Boland; E. De Paor; S. Guerin

*UCD Centre for Disability Studies, University College Dublin, Dublin, Ireland*

**Background**: Despite extensive research and traditional reviews on community participation, a focus on neighbourhood belonging is relatively recent for adults with intellectual disabilities (ID). This systematic review aimed to produce a comprehensive, high-level synthesis of knowledge gained from research published between 2000 and 2017, through the lens of neighbourhood connectedness.

**Method**: Following PRISMA guidelines, a structured search was completed of commonly used electronic databases in ID research on social inclusion (PsycINFO; ERIC; Medline; Cinahl Plus; Web of Science Social Science Citation Index; and Emerging Sources Citation Index). All abstracts/papers were reviewed by two researchers using pre-agreed inclusion/exclusion criteria to ensure consistency and reliability.

**Results**: The search identified 3600 abstracts, with 300 articles eligible for full text screening. Of these 29% were identified as relevant to this review. The challenge of measuring community participation for adults with ID was considered. Building on a review published in 2017 on interventions intended to facilitate community participation, the characteristics of inclusive neighbourhoods are examined.

**Conclusions**: Key messages from this body of knowledge included clarification of conceptual frameworks and definitions of community participation. The barriers to participation and factors that facilitate adults with ID to engage in their localities were highlighted.

### 5891 | Active citizenship through community living: the experience of people with intellectual disabilities

J. Siska; J. Beadle-Brown; S. Kanova

*Charles University Prague, Prague, Czech Republic*

**Background**: As part of a large scale project focusing on active citizenship for people with disabilities, the situation of people with intellectual disabilities (ID) was explored. This paper presents the findings from interviews with people with disabilities in nine countries and compares those with ID to those with other forms of disability.

**Method**: Semi-structured life-course interviews were conducted with 200 people with disabilities across four disability cohorts (Intellectual disability, Physical/mobility difficulties, visual impairments and psychosocial disabilities) and three age cohorts (1950s, 1970s and 1990s). Interview reports were analysed using content analysis.

**Results**: In comparison to other disability cohorts, people with intellectual disability who were interviewed were more likely to be living in shared or clustered services. They reported more limited choice over living situation and their support and less involvement in household and leisure activities and in the community. They rarely were employed and had generally followed trajectories marked by 'special' or segregated situations.

**Conclusions**: This paper expands our knowledge on what is known about the lived experience of people with disabilities. Suggestions of how this can be changed will be offered.

### 5966 | Belonging and unbelonging: personal accounts of life in the community following resettlement from an Assessment and Treatment Unit in England

S. Dowling; V. Mason-Angelow; B. Richards; J. Webb; V. Williams

*University of Bristol, Bristol, UK*

**Background**: This project gathered the views of people with learning disabilities and/or autism who had been living in inpatient settings and are now residing in the community. Representation of the perspectives of people with experience of Assessment and Treatment Units (ATU) has been limited, although there is a long-standing policy position to reduce the numbers of people living in ATUs.

**Method**: Biographical Narrative methods were adapted to collect data and inform analysis. Repeat narrative interviews were carried out with 19 people, 16 who had lived in ATUs and three parents of people recently discharged. Data was subject to narrative analysis to maintain the integrity of individual experiences; key themes were also drawn through thematic analysis.

**Results**: Belonging, being part of a community, experiencing self-determination and personal security, having choice and agency were reported as central to positive experiences in the community. Some participants also spoke of the value of the therapeutic interventions received as inpatients and after discharge. Un-belonging, characterized by distance from home community, loneliness and fear was found to impact people's well-being.

**Conclusions**: A home of one's own is just a starting point, on-going personalized support is needed to encourage a good life in the community.

## 5633 | The effect of a community-based model in increasing community living skills of adults in day activity centres

A.C.H. Wee; S. Ko; V. Manokara; N. Huda

*Movement for the Intellectually Disabled of Singapore (MINDS), Singapore*

**Background**: The program aims to provide opportunities for adults with moderate to severe intellectual disability (ID) to receive training and participate in activities within the community. The study explores the effect of the program on the community living skills of the participants.

**Method**: The Client Assessment Form-Revised (CAF-R) was used to select clients for the program and track their progress. Interviews were also conducted with the staff and caregivers to gather feedback on clients' progress. Eleven adult clients with moderate to severe ID participated in the program. The control group consists of 11 clients with similar CAF scores who did not participate in the program. Training was conducted in the community, focusing on community living skills such as social and interpersonal skills, money management skills and travelling skills. CAF-R data was collected every 6 months and interviews were conducted yearly.

**Results**: Compared to the control group, some clients showed an improvement in their CAF scores while others did not.

**Conclusions**: The findings indicate that the program improves community living skills of adults with ID. Limitations and future recommendations are discussed.

# 11. PERSPECTIVE AND WELLBEING OF (FAMILY) CAREGIVERS

## 5926 | Self-help groups for caregivers of children with developmental disabilities in Kenya: a pathway to empowerment

K. Bunning; J. Gona; C. Newton; S. Hartley

*University of East Anglia, Norwich, UK*

**Background**: The aim was to establish self-help groups as a vehicle to empower caregivers and their children with developmental disabilities working towards an improved quality of life in a rural part of Kenya.

**Method**: The three-year project adopted a participatory action research (PAR) design. There were 12 groups with an overall membership of around 150 caregivers. An extended set up phase enabled the development of the membership, group identity, distribution of roles (e.g. treasurer, chairperson, notes taker) and income generating activities. The groups met every week. A facilitated intervention addressing the topics of economic empowerment; sharing of personal situation; peer support; community inclusion; access to health; and access to education was implemented every month over a 6-month period. Evaluation measures focused on caregiver perceptions in relation to the child's disability and participation, social support and self-help group experience. The economic impact of the groups was also tracked.

**Results**: Preliminary findings revealed gains in perceived social support, changes in caregiver perceptions of childhood disability and community participation, and growth in income generating activities.

**Conclusions**: The potential of self-help groups to bring about the empowerment of caregivers and children with developmental disabilities in low-income countries will be discussed.

## 6019 | Being the son of a migrant family and having a disability: the voice of their families

T. Sgaramella

*University of Padova, Padova, Italy*

**Background**: Raising a child with a disability has multiple challenges for all mothers, being an immigrant mother intensifies these challenges.

**Method**: The study examined the challenges faced by families of migrant children with disability by giving voice to their mothers. Based on studies in the literature, a structured interview was proposed to nine mothers of children with disabilities. Their permanence in the Italian context ranged from 2 to 5 years. Children age ranged from 5 to 12 years old. The interview tapped three main areas: the needs experienced, barriers but also supports they experienced as mothers

of children with disability from their arrival to current situation, their past and current idea of disability.

**Results**: A qualitative analysis conducted on answers highlighted several themes: language and communication barriers, difficulties in navigating new systems, cultural differences, perception of supports, and emotional, instrumental and social support. The analysis conducted suggests the need for specific actions overcoming the gap and combining the culture of disability and the culture relating to country of birth.

**Conclusions**: Taking into account the history of the family and using a family-centred practice and strengths-based approach may reveal inclusive facilitating factors making them targets for specific integrative actions.

## 5357 | A systematic review of family led interventions for children with communication disabilities

M. Gatt; J. Bradshaw; N. Grove; G. Murphy

*Tizard Centre, University of Kent, Malta*

**Background**: The aim of this review is to determine which intervention programs provide favourable communication support for families and how the outcomes of intervention are related to underlying theories.

**Method**: A systematic review and meta-analysis of the literature of family-led interventions was conducted. The methodology consisted of selecting the identified studies according to predetermined inclusion criteria and analyzing the results following the NJC Evidence-based Data Entry Instrument. Nine group studies and 20 single-case experimental designs were included in the coding and analysis stage.

**Results**: A range of interventions including the use of parent and sibling training programs/approaches, storybooks, speech generated devices and micro-level interactions were reported. These focused on the development of pre-verbal skills such as symbolic play, imitation, turn-taking and joint engagement. Other studies reported specific language outcomes such as the development of pragmatic functions. Parent and sibling interaction skills reported included aided AAC modelling, use of pause time, open-ended questions, and expectant delay.

**Conclusions**: All the studies reported immediate positive outcomes of family training and interventions. Gaps in the research and implications for further research were discussed.

# 12. WAYS TO SUPPORT EMPOWERMENT

## 5490 | Inclusive development of Persons with Intellectual Disabilities (PWIDs) through empowerment of self-help groups

R.S.K. Mahamendisge

*Department of Social Service Sri Lanka, Battharamulla, Sri Lanka*

**Background**: This project aims to develop persons with intellectual disabilities as partners of social development through their participation.

**Methods**: In community-based rehabilitation programs were aided to develop self-help groups and empowered to give opportunities. These programs have become interested in sharing their views with like-minded people, working in teams and engaging in more activities. A national program in community-based rehabilitation implemented in Sri Lanka is geared towards encouraging employment and advocating for social, economic and political rights of their members.

**Results**: Twenty-five workshops were held in 331 Divisional Secretariats covering 25 Districts for which 1829 PWDs were participated. There are 637 PWIDs and their family members who participated. The workshop explained the process of updating the CBR Program and views/suggestions of PWDs were obtained to plan future programs.

**Conclusions**: Providing opportunities and empowering Persons with intellectual disabilities to contribute in the social developments will eventually help them to become decision-makers and contributing members of society. This empowerment could combat stigma against persons with disabilities and foster positive attitudes.

## 5622 | A psychological support to youngsters with IDD as a self-esteem individual and group improvement experience

F. Fea; D. Santangelo

*Associazione Scuola Viva - Easpd - Gladnet Best Buddies Italia, Italy*

**Background**: Young people with intellectual and developmental disabilities (IDD) face many difficulties with self-esteem, and some are stigmatised or not part of any social group. This study examines the impact of psychological support on the personal growth of two groups of children with IDD. One target is considered less severely delayed than the other as assessed through different methods of evaluation (Bartel, Vineland).

**Method**: The two groups composed of 20 young people with IDD, each with common characteristics, participated in research using techniques proposed by Carl Rogers, psychotherapist, in the early 1960s.

**Results**: Examples will be used to demonstrate how the functional feedback by the psychologist of the emotional contents expressed by the groups is highly relevant to growth.
**Conclusions**: By sharing emotions, the need to increase cooperation among the groups became fundamental to the success of the educational rehabilitation project, where main activities are based on relationship and socialization.

## 5759 | The overall effect of 'Acting as a Friend' program on parental satisfaction concerning improvement of social skills of children with autism, services and volunteers

A. Orfanou
*Greece*

**Background**: The purpose was to examine parental satisfaction concerning improvement of social skills of children with autism, quality of services and ability of volunteers participating in 'Acting as a Friend' program.
**Method**: Sixteen parents with 17 children (5–26 years old) with autism participating in this program. Instruments used included: (i) the 'SCQ' measuring social skills of children, (ii) the 'General Scale of Satisfaction' concerning program services and (iii) 'Satisfaction Scale for Parents of Children with Special Needs' about volunteers' abilities.
**Results**: Improved communication skills were noted for children located in special schools ($P = 0.027$) and children participating previously in the program ($P = 0.03$). Parental answers ranged from 'very good' to 'exceptional' regarding services and 'very satisfied' concerning volunteers' abilities of care and adequacy. Furthermore, fathers exhibited higher scores compared to mothers in care ($P = .018$) and general satisfaction ($P = .031$).
**Conclusions**: Overall, results support the beneficial effect of 'Acting as a Friend' program that appears the first of its kind in Greece and elsewhere, therefore, results of this study provide an initial overall picture of its effectiveness that could guide similar programs in the future.

## 5672 | Assessing the impact of person-centred planning on community integration for adults with intellectual disabilities in Ireland

D. McCausland; P. McCallion; M. McCarron
*IDS-TILDA, Trinity College Dublin, Dublin, Ireland*

**Background**: This study assessed the impact of PCP on the community integration of adults with ID. We aimed to determine the extent to which community integration was embedded as a goal in person-centred plans, their rate of achievement, and to identify factors associated with achievement of such goals.
**Method**: Quantitative analysis of the PCP process and outcomes for 200 adults using residential services of a provider in Dublin. Case studies of eight service users explored the process, outcomes, and impacts of PCP in greater depth; using interviews and focus groups with service users, family and staff involved in the development and implementation of PCPs.
**Results**: The vast majority of service users identified goals of community integration in their PCPs. Community integration was the most common type of goal in PCPs, and these goals were successfully achieved for the majority of individuals. Family, personal characteristics, resources and organizational factors were associated with achievement of community integration goals.
**Conclusions**: Person-centred approaches to service provision may be a means of achieving community integration for adults with ID. However, both natural and formal supports of family and service providers are needed to optimize outcomes for individuals, particularly those with the greatest needs.

# 13. INCLUSION AND PARTICIPATION OF CHILDREN WITH DISABILITIES

## 6063 | Inclusion tomorrow: prioritizing child-driven culture

S. Phelan; D. McConnell
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**Background**: Research on inclusion has focused almost exclusively on child culture produced by adults for children and negates the importance of child-driven culture, or culture produced by children themselves. Inclusion for children experiencing disability necessitates an understanding of child-driven culture and its implications for full inclusion in cultural life. The purpose of this critical analysis was to examine, reveal, and deconstruct taken-for-granted views on current inclusion policies and practices that limit children's opportunities for inclusion in child(-driven) culture.
**Method**: A critical analysis of child-focused inclusion policies and practices was conducted, informed by two theoretical perspectives: the new sociology of childhood and critical disability studies.
**Results**: The tendency to frame inclusion initiatives within a culture for children produced by adults becomes an issue when it infringes on children's rights to engage fully in cultural life. Opportunities for children experiencing disability to engage in child(-driven) culture are limited by adult vigilance, underestimation of abilities, lack of social supports, and a history of discriminatory experiences.
**Conclusions**: Little is known about inclusion in child(-driven) culture. A critical perspective has the potential to inform the (re)conceptualization of inclusion, child culture, disability, and the interplay between the three.

## 5495 | The disabled child: the desire to know and learn with one's peers

R. Scelles

*Université Paris Nanterre, Nanterre, France*

**Background**: Disabled children often experience difficulties in establishing diversified, elective, and evolving relationships with non-disabled and disabled peers. They then remain alone and solitary amid the groups around them. The typically-developing child goes through the school system with his/her peers, engaging in symmetrical and reciprocal interactions. Adults need to make sure that the disabled child is also given opportunities to obtain this support. A lack of freely-chosen relationships with others has an impact on inclusion processes, as well as the social, family and emotional life of disabled persons.
**Method**: Based on research work and clinical practice, the conference will open up the following avenues for investigation: (i) to support the development of skills in the disabled child to interact with her peers, (ii) to identify the conditions that will foster the emergence of co-learning between children and seek out what supports or hinders the advancement of relationships.
**Results**: The main goal is to stimulate co-learning between peers, and learning successful strategies to encourage peer interaction.
**Conclusions**: These are essential skills needed to live as best as possible in society and be a contributing and included member of one's generation.

## 5997 | Attitudes of parents towards kindergarten inclusion

M. Schmidt; K. Krivec; B. Čagran

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**Background**: Research on parents of young children with and without special needs (SN) has shown that they generally hold positive attitudes toward inclusion. This study examined attitudes of parents toward inclusion of children with disabilities in kindergarten.
**Method**: Participants were 202 parents from northeast Slovenia who have kindergarten children with and without SN. Parents' attitudes toward inclusion were assessed by questionnaire on 5-point Likert scales. Arithmetic means determined the degree of agreement with statements, and factor analysis of statements extracted common factors.
**Results**: Factor analysis regarding willingness to include children of various disability types identified two factors: children with sensory impairments and physical disorders; and children with intellectual disabilities and behaviour disorders. All parents were more accepting of the former than the latter. Factor analysis regarding functioning of children with and without SN in regular groups of kindergarten resulted in two factors: social-emotional integration; and exclusion in the area of learning, progress and development. The parents recognized more benefits in socio-emotional integration of kindergarten children.
**Conclusions**: All study parents had positive attitudes toward inclusion of children with SN in regular kindergarten, with some reservations relating to the child's disability type, special education support, and child behaviour.

## 5356 | Mother-sibling interactions and children with communication disabilities

M. Gatt; J. Bradshaw; N. Grove; G. Murphy

*Tizard Centre, University of Kent, Malta*

**Background**: This pilot study aims to describe the patterns of behaviour in interactions between children with communication disabilities, their mothers, and siblings.
**Method**: The study was a mixed study design. Three families of children with communication disabilities participated in the study. Maternal baseline questionnaires, sibling interviews and observations were carried out. In addition, children were video-recorded interacting with their mother and siblings. These observations took place within the home environment using preferred activities. Elements of video interaction guidance were used to code the data.
**Results**: A responsive communicative style was evident across dyads and triads within and across mothers and siblings with evidence of emotional responsivity and attunement. Mothers and siblings present with a range of behaviours which were in synchrony both with the mother's and child's responsivity and their emotional capacity to respond to each other.
**Conclusions**: The results of this pilot study suggest that a responsive communication style is predominant in mother-child-sibling interactions where a child has a communication disability. Limitations and implications for further research were discussed.

# 14. DIGITAL INCLUSION AND SUPPORT ONLINE FOR PEOPLE WITH A LEARNING DISABILITY AND FAMILY CARERS

## 6008 | Spanish caregivers' perceived benefits and risks of Internet use by people with intellectual and developmental disabilities

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*Universidad de Alicante, Spain*

**Background**: Internet access offers multiple benefits to people with intellectual and developmental disabilities (IDD) in their personal and social lives. However, it also involves potential risks. The aim of this study was to explore the perceptions that caregivers have about these issues.

**Method**: A cross-sectional survey design was conducted with professionals working with people with IDD at different service providers from the Valencian Community in Spain. Participants had to respond online to a five-point Likert scale with statements about the benefits and the risks of Internet use.

**Results**: Preliminary results show that professionals perceive the Internet more risky than beneficial for people with IDD. The major risks are communicating with people not known to them, being exposed to inappropriate or offensive pornographic content or providing too much personal information. Caregivers find Internet beneficial for keeping in contact with friends and family, developing technological skills and gaining understanding about their rights.

**Conclusions**: Results suggest some misconceptions about Internet and people with IDD, which may hinder them from fully participating in the society. Caregivers should be provided with the strategies to prevent and manage potential problems online and learn about the opportunities that the Internet can offer to people with IDD.

## 6018 | The wellbeing of family caregivers of people with intellectual disabilities who use online support groups

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**Background**: Caregivers of people with intellectual disabilities (ID) may face considerable challenges which can affect their wellbeing. The use of online support groups (OSG) may help mitigate such challenges. The primary objective of this study was to identify predictors of wellbeing amongst family caregivers of people with ID who use OSG.

**Method**: A cross-sectional survey gathered information from participants who identified themselves as a family caregiver of a person with an ID regarding their OSG use, perceived social support, empowering processes gained from OSG use, as well as their resilience, optimism and wellbeing.

**Results**: A significant positive relationship was found between resilience and wellbeing amongst the caregivers. A significant negative relationship between wellbeing and being motivated to use OSG due to a lack of understanding in offline life was also found. Caregiver levels of perceived offline social support negatively correlated with being motivated to use OSG in an attempt to achieve a sense of belonging and understanding from others.

**Conclusions**: Findings suggest lack of support in offline life can be a significant motivator for using OSG amongst carers of people with ID. Further study of how OSG use may foster resilience in caregivers is indicated.

## 6020 | Experiences of people with an intellectual disability of risk, restriction and resilience online

D. Chadwick

*Faculty of Education, Health & Wellbeing, University of Wolverhampton, Wolverhampton, UK*

**Background**: Research considering online risk and cybercrime in the lives of adults with intellectual and developmental disabilities (IDD) is still fairly sparse. Perceived vulnerability can increase digital exclusion for people with IDD. Risks have previously been classified as either contact, conduct and content but little is known about the experience of these specific types of risk for adults with disabilities. This study presents a qualitative study exploring experiences of risk of adults with IDD.

**Method**: Individual interviews were conducted with thirteen adults with IDD. Interviews considered online experiences of online risks. Data were audio recorded and analysed using thematic analysis.

**Results**: Three overarching themes of risk experiences, awareness and support to manage risks, and developing independence and resilience through online participation were identified. Accounts also identified concerns around online risks and caregiver gatekeeping as potential instrumental factors in digital exclusion.

**Conclusions**: Adults with IDD who have low support needs appeared more able to manage online risk than may be presupposed by a vulnerability-focused perspective. Enabling people and their caregivers to better understand and manage online risk appears a way forward for both research and practice.

# 15. MISCELLANEOUS

## 5571 | Hate crime and the community: place and wellbeing

P. Wiseman

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**Background**: People with intellectual disabilities have experienced legacies of exclusion and stigma; their positions within communities have been punctuated by discrimination. Hate crime has complex and myriad consequences for wellbeing and this paper will explore the impact of hate crime on wellbeing and community participation for people with ID.

**Method**: We collected qualitative data from 19 people with intellectual disabilities across Scotland and seven Police Scotland representatives. Semi-structured interviews were used to gain phenomenological understandings of people with intellectual disabilities', everyday experiences.

**Results**: This study found that hate crime had happened to all participants throughout their lives. There were key locations where targeting occurred more frequently. Participants were often so afraid to leave their homes that they became isolated, at times foregoing food shopping or socializing.

**Conclusions**: There has been very little research into people with intellectual disabilities' everyday experience of hate crime and the subsequent impact on inclusion and wellbeing. People with intellectual disabilities experience enduring levels of violence and harassment in communities that have a profound impact on every aspect of their wellbeing. Greater inclusion in communities is essential to overcome the attitudinal barriers that belie hate crimes and bullying.

## 5596 | A scoping review into the measurement of loneliness experienced by people with intellectual disability

K. Foss

*Australia*

**Background**: People with intellectual disability have impairments that limit their ability to interact and communicate with those around them. The experience of loneliness is associated with a number of negative outcomes and these are likely to apply to individuals with intellectual disabilities. Understanding their experience of loneliness is an important step in developing effective interventions. This paper addresses methods for collecting data on the experience of loneliness in this population.

**Method**: A scoping review was conducted for the years 2000–2017 using the data bases Psycinfo, Scopus and PubMed. Search terms were kept broad in an effort to identify all relevant material. Citations and reference lists were examined and followed up where appropriate.

**Results**: There were very few papers identified that explored the issue of loneliness in this population. Measurement approaches varied from gathering proxy data from family or staff engaged with the individuals to interviews with individuals themselves.

**Conclusions**: Further development of approaches to gathering data from individuals themselves is required to provide robust data about the experience of loneliness of people intellectual disability.

## 5543 | Contraceptive use among women with and without intellectual and developmental disabilities

M. Mitra; J. Wu; J. Zhang; S. Parish

*Brandeis University, Waltham, USA*

**Background**: To examine the differences in contraceptive use between women with and without intellectual and developmental disabilities (IDD).

**Method**: This study used data from the Massachusetts All Payer Claims Database. Women 15–44 years old with IDD who were continuously enrolled in a health insurance plan during 2012 and were at risk of unintended pregnancy were identified. We examined the percentage of women with IDD who used a 'most' or 'moderately' effective contraceptive method and women who used a long-acting reversible contraceptive (LARC) method. Chi-square tests and logistic regression were used.

**Results**: Women with IDD were significantly less likely to use a 'most' or 'moderately' effective contraceptive method (23.43% vs. 34.50%, $P < 0.0001$) and LARC (2.02% vs. 4.13%, $P < 0.0001$) compared to those without IDD. Women receiving Medicaid (OR = 0.51, $P < 0.0001$) and women with a lower income (OR = 0.73, $P < 0.0001$) were both less likely to use a 'most' or 'moderately' effective method, however, they were more likely to use a LARC method (OR = 1.56 and OR = 1.19 respectively, $P < 0.0001$).

**Conclusions**: Our findings highlight the need for further understanding of the contraceptive care needs of women with IDD.

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# ABSTRACTS

## TRACK 2: COLLABORATIVE RESEARCH SYMPOSIA

## 1. THEORY AND METHODS OF COLLABORATIVE RESEARCH

### 5460 | Inclusive research: the meaningful inclusion of people with intellectual disability in the research process

A.M. Callus

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**Background**: Inclusive research is about academic researchers collaborating with people with intellectual disability as co-researchers, using methods that take into account the latter's support needs. It offers a means of belonging for people with intellectual disability within Disability Studies, promoting their inclusion both through the areas of research that are chosen and through the methods employed to conduct the research.
**Methods**: This paper first sets out the principles of this approach to research as they have been established in the literature on inclusive research. It then builds on the existing literature by focusing on the pragmatic aspects of the inclusive research process, discussing how both academic researchers and co-researchers with intellectual disability can acquire the skills that facilitate collaboration in research projects that are truly inclusive.
**Conclusion**: The paper will thus discuss inclusive research as a learning process for all those involved, with a particular emphasis being made on the importance of reflexivity in order to ensure that the principles of inclusive research are being applied through practices that enable inclusion in meaningful ways.

### 5864 | Working together, learning together: collaboration in inclusive research

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**Background**: The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) aims for the full and effective participation of people with disabilities in society. For people with ID, involvement in inclusive research is a way to have their experiential knowledge represented. In inclusive research, collaboration between people with and without ID is essential. In this study, we examine this collaboration from the perspective of the people with and without ID involved.
**Method**: Based on the Dutch National Program for Disabled People, six inclusive research projects received four year funding. At different time points during this period of project funding, we explore the motivation to work together and factors experienced as enhancing or impeding effective collaboration using semi-structured interviews and questionnaires such as the multidimensional work motivation scale (Gagné et al., in press).
**Results**: Data increase understanding of collaboration in inclusive research on the level of the individual project members and (outcomes of) the project itself.
**Conclusion**: This study results in recommendations on furthering participation and inclusion of people with ID in society in general, and on effective collaboration between people with and without ID in inclusive research specifically.

### 5862 | Building a bridge between science and practice: structurally including experiential knowledge of people with an intellectual disability

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**Background**: The Academic Collaborative Center Living with an intellectual disability aims to empower people with an intellectual disability, by developing and sharing knowledge in collaboration between researchers, people with intellectual disabilities, their relatives and professionals (so-called practice-oriented scientific research).
**Method**: The Academic Collaborative Center Living with an intellectual disability entails a structural collaboration between 13 care organizations for people with ID, the advocacy organization for people with ID, and Tilburg University (the Netherlands).
**Results**: Our research agenda is jointly decided upon by researchers, people with an ID and professionals. In conducting research, the perspectives of people with an ID and/or their relatives are included in all projects, either as participants and/or as co-researchers. Moreover, people with an intellectual disability are represented in our management board and advisory groups.
**Conclusion**: We stimulate, conduct and implement practice-oriented scientific research. In equally valuing scientific, experiential and

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professional knowledge we thus try to build a bridge between sciences and practice.

## 5985 | Advancing public involvement in research – lessons from IDS-TILDA

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**Background**: Public involvement in research is carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. Contributors should be actively involved in decision-making and examples include, but are not limited to: identifying research priorities; serving as members of a project advisory or steering group; commenting and developing patient information leaflets or other research materials undertaking interviews with research participants; and assisting user and/or career researchers in carrying out the research. In 2017, the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) was chosen as a national exemplar of engaged research by the Irish Universities Association, Campus Engage and the EU-funded SPARKS initiative. Utilising IDS-TILDA, this session will present best practices for public involvement across the research life cycle.

# 2. THEORY AND METHODS OF COLLABORATIVE RESEARCH

## 5518 | Democratizing research – undoing the subaltern

G. Kremsner

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**Background**: This presentation gives insights into a research process which aims at full participation for all persons involved to increase the level of amalgamation between academia and society. This is particularly relevant as most of the researchers are not formally a part of the designated 'academic elite', meaning that they are not scientific university staff, but all of them share having experiences with being labeled (e.g. as 'persons with learning difficulties', 'migrants', 'refugees' and others) and excluded from society. More abstractly: They belong to the 'subaltern', to a class of individual persons 'who are not unified and cannot unite' due to constant domination and oppression.

**Methods**: The project seeks to democratize research by opening the floor to stories which necessarily have to be told. These stories are being analyzed by a team consisting of subaltern persons together with academic staff with the aim to increase not only the quality of outcomes, but also to enhance and adapt research methods to be used by a group of persons with mixed academic skills. Therefore, the research process itself will be researched with the aim to 'undo' the subaltern.

## 5677 | Working with co-researchers to understand the experiences of people using Shared Lives

S. Palmer; N. Brookes; L. Callaghan; G. Collins

*University of Kent, Canterbury, UK*

**Background**: The study aimed to investigate the feasibility of including users of Shared Lives (SL), a community based service whose main user group is people with an intellectual disability, as co-researchers in a study on the experiences and satisfaction of people using this service. Co-research, where service users are active partners in all stages of the research process, has been identified as an innovative methodology that adds value to research projects.

**Method**: Three co-researchers were recruited via the umbrella organisation, Shared Lives Plus. Their involvement included: development of interview schedules, interviewing other users of SL, supporting the analysis and dissemination of results. Reflections were gathered systematically from the research team and the co-researchers.

**Results**: Involvement of the co-researchers at the development stage helped ensure that the study captured the most pertinent and truest possible experiences of SL users being interviewed, whereas their input in the analysis allowed for insight and interpretation, strengthening the analysis of the PSSRU researchers.

**Conclusion**: In order to benefit most from co-researcher involvement, the PSSRU researchers needed to be flexible, adapting and responding to what each co-researcher is able to contribute. The benefits and challenges of working in partnership are discussed.

## 5653 | People with intellectual disabilities as researchers: establishing an inclusive research team

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*Flinders University, Bedford Park, SA, Australia*

**Background**: This study aims to explore the experiences of inclusive research team members' participation in an inclusive research project. The study explores the experiences of team members with and without intellectual disability in terms of their perceptions of the barriers and enablers to effective inclusive research processes.

**Method**: A critical ethnographic approach was employed for this study. The inclusive research team ($N = 8$) have undertaken research skills training and are developing and undertaking an inclusive

research project. Data collection to explore experiences included semi-structured interviews with team members, focus groups following research skills training, participant observation and field notes. Data is being collected prior, during and following the inclusive research project allowing observation of the teams experiences over time.

**Results**: Practical and ethical challenges associated with establishing an inclusive research team will be discussed, as will preliminary outcomes for participants including their expectations of participating in an inclusive research team and their experience of the research skills training.

**Conclusion**: Utilizing existing relationships within the disability sector to facilitate the establishment of an inclusive research team is important. Open dialogue with the ethics committee has been critical. This study demonstrates inclusive research can benefit from a considered approach to establishing the inclusive research team.

## 5808 | Studying 'Dit vind ik ervan!': the quality and impact of an explorative approach to service-users' experiences

G. Bos

*Vu Medical Centre, Amsterdam, The Netherlands*

**Background**: 'Dit vind ik ervan!' (This is how I feel about it!) is an increasingly popular Dutch approach for examining service-user-experiences (instead of -satisfaction) within support organizations. The core of this approach is an 'explorative dialogue' between a service user and their support worker about quality of life themes. The outcomes of this explorative dialogue are meant to enhance everyday care and support practices.

**Method**: With a collaborative and interpretative design, we study the quality (i.e. validity, trustworthiness and authenticity) and impact of 'Dit vind ik ervan!' between 2017 and 2019. Our primary focus is on the execution of the explorative dialogue; to what extent does this dialogue facilitate service-users to express their perspectives? Our multicenter study involves 1 university based coordinating researcher (PhD), 5 support organization based researchers and 25 couples of service-users and support workers.

**Results**: Preliminary findings show that the content and variety of the outcomes of the explorative dialogue are strongly linked with the performance of the support workers. Their everyday 'hands-on' approach to service-users might hinder support workers to adapt the necessary 'explorative attitude'.

**Conclusion**: It is essential that support workers are sufficiently trained to examine the experiences of the service users in an open, suspensive way.

# 3. COLLABORATIVE RESEARCH IN PRACTICE

## 5409 | Non-pharmacological interventions with people who have an intellectual disability and dementia: a collaborative study

K. Watchman; K. Mattheys

*University of Stirling, UK*

**Background**: This 3-year study investigates if non-pharmacological interventions result in positive changes in behaviour associated with dementia in people with intellectual disability.

**Method**: People with intellectual disability have been partners from the beginning of the study and are included as advisors ($n$ = 1) and co-researchers ($n$ = 4). Together, we are taking a participatory action research approach in 2 cycles: cycle 1 participants were 8 people in the early stage of dementia, whilst cycle 2 includes 15 participants who have an intellectual disability and advanced dementia. Procedures and measures: A goal-setting tool first identified appropriate non-pharmacological interventions for each individual. Pre- and post-behaviour change tools were completed alongside semi-structured interviews with 12 staff. Focus groups, intervention diaries and photovoice. Photovoice is a method of data collection enabling co-researchers with intellectual disability to take photographs that reflected their perception of each intervention with their peer.

**Results**: Data from cycle 1 is currently being analysed and will be presented at the conference. Early findings identified the extent of polypharmacy among participants leading to behaviour wrongly attributed to dementia, and digital exclusion with a lack of Wi-Fi access restricting choice of interventions.

**Conclusion**: Contribution to evidence of non-pharmacological interventions in dementia care and greater authority to co-researchers with intellectual disability.

## 5694 | Causes of aggressive and self-harming behavior: experiential knowledge of people with mild intellectual disabilities in forensic health care

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**Background**: In furthering participation of people with intellectual disabilities, increasing attention is paid to their experiential knowledge. Insight in experiential knowledge can be seen as a first step in the process towards collaborative research. Despite positive outcomes, little is known about the experiential knowledge of people with mild ID in forensic health care about aggressive and self-harming behaviour. In this study we aim to explore the experiential

knowledge of people with mild ID and forensics problems regarding the causes of their challenging behaviour.

**Methods**: We conduct interviews with people with ID admitted to a forensic hospital. After an incident of aggressive or self-harming behavior, respondents are asked for their perspective on what caused the incident and ways to prevent this behavior. Transcripts of the interviews are analyzed using the Leeds Attributional Coding System (LACS; Stratton et al., 1988).

**Results**: Data increased our understanding of the experiential knowledge regarding causes of challenging behaviour provided by people with an ID in forensic healthcare themselves. Based on the LACS, data offer insight into internal (intrapersonal) or external (context) oriented attributions.

**Conclusion**: Based on the acquired insight into experiential knowledge, this study yield recommendations for the further development of expertise-by-experience of people with mild ID in forensic health care.

## 5372 | Recruitment: It's challenging

K. White; R. Waters; A. Buchanan

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**Background**: Difficulties in recruiting people with intellectual disability to actively participate in research is a recurring topic of discussion that has been minimally investigated. Capturing this issue and its depth is essential to involving people with intellectual disability in research.

**Method**: Semi-structured interviews were utilised to obtain perspectives of recruitment from 12 academic researchers with substantial experience in the field. Data were analysed using Straussian grounded theory.

**Results**: The core category was 'Recruitment: It's challenging', informed by seven categories; differentiation of people with intellectual disability as a research population, lived experience of researchers, gatekeeping, ethical considerations, research design, collaboration, and rapport.

**Conclusions**: Researchers developed and employed strategies over time and experience in response to recruitment challenges. These strategies largely focused upon creating, strengthening and supporting a connection between themselves and people with intellectual disability. There is potential for future investigation and further development of strategies to improve recruitment.

## 5539 | Living with professional support: experiential knowledge of individuals with mild intellectual disability

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**Background**: Even though policy aims to increase informal networks of support to enhance inclusion of people with an intellectual disability (ID), staff continue to play a significant role in their support networks. This study established an in-depth account of the experiential knowledge of people with mild ID with respect to living with professional support.

**Method**: Six individuals with mild ID, living in community-based-settings, took part in semi-structured interviews. Interview schedules were developed in discussion with two experts-by-experience. The transcripts were analysed using Interpretative Phenomenological Analysis, which entails a detailed exploration of how participants give meaning to their support experiences.

**Results**: Three main themes emerged: what you mean to me (the place of relationships with staff in a personal history), making it work (relationships with staff in an organisational context), and staff support and my place in the world. Together these themes demonstrated that relationships with staff were often one of the closest and most significant social relationships participants have.

**Conclusion**: To enhance meaningful inclusion in the community, experiential knowledge of individuals with mild ID with respect to social relationships is helpful to optimize support of staff. Furthermore, recommendations regarding the inclusion of people with ID in IPA research will be discussed.

# 4. COLLABORATIVE RESEARCH AND CHILDREN

## 5749 | Inclusive Spaces 2.0 – combining drama and digital technologies in participatory research processes with young persons with varying abilities

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**Background**: The project 'Inclusive Spaces 2.0: My School and My Block!' involves researching social spaces in schools and communities in Vienna: What experiences do young people gather in their 'blocks'? And how do these impact the social spaces of schools? Students with varying abilities and professional researchers work together to investigate these questions, using innovative methods that connect to the lifestyles of young people. Using drama, mobile phones and tablets, students produce digital social cartographies of their 'blocks' and schools. Young persons use data as a catalyst to think about how social problems in their neighbourhoods could be addressed. In my paper, I will focus on the methodical approach used within the project and reflect on the processes of producing and analysing visual digital data with young persons. As I will show, such an approach allows 'digital natives' with varying cognitive abilities to take an active part in researching spaces together.

**Method**: Within the field of inclusive research, the use of new media and digital technologies has just begun. This paper will contribute to the reflection and elaboration of these approaches to inform future research endeavours.

## 5629 | Inclusion of chldren with communication and learning disabilities in a study of experiences of communication aid assessment

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*Manchester Metropolitan University, Manchester, UK*

**Background**: Children whose speech is insufficient for functional use may be offered augmentative and alternative communication (AAC). There is evidence that AAC can significantly enhance language and communication, however research also notes high levels of communication aid abandonment. The study aimed to involve children who use AAC in exploring their own experiences of AAC assessment in order to inform a decision-making heuristic.
**Methods**: Researchers with personal experience of using AAC contributed to design and data collection/analysis. Children aged 4–18 years were asked about their experiences of AAC assessment and recommendation. To be inclusive, in line with UNCRC and UNCRPD, a range of methods was used, including interviewer familiarization, semi-structured interviews using a 'Talking Mats' format and specially designed AAC storybooks. Data analysis involved Framework Analysis.
**Results**: Children were able to provide rich accounts of their experiences. Findings were combined with those from best-worst scaling and Discrete Choice Experiments, to inform development of the decision-making heuristic. The heuristic will be refined in discussion with stakeholders including people who use AAC.
**Conclusions**: Skilled interviewers and carefully planned techniques can enable children who use AAC to inform to researcher on decision-making processes within AAC assessment.

## 5775 | Involving children with an intellectual disability as active participants in research interviews

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*Faculty of Health and Social Care, Edge Hill University, Ormskirk, UK*

**Background**: This presentation stems from a study that investigated how children with an intellectual disability experience clinical procedures such as blood tests. The study aimed to actively involve children in interviews so as to elicit meaningful first-hand data on their experiences.
**Method**: In this qualitative Grounded Theory study, 13 children with a mild to moderate intellectual disability aged between 7 and 15 years took part in semi-structured, face-to-face interviews. Time was devoted to building rapport with children before interviews through informal conversation and playing games. An Easy Read information sheet about the study was reviewed and children asked any questions they had before providing assent. Children were then encouraged to choose whether to take part in the interview using the augmented communication tool known as Talking Mats or through verbal means only. Interviews were recorded and data was subjected to constant comparative analysis.
**Results**: Children became empowered enough to decide how their interview was conducted and the subtopics they discussed. Using an augmented communication tool enabled children with verbal communication difficulties to still be involved in an interview.
**Conclusion**: Adults should recognise the developing agency of children with an intellectual disability and promote their involvement in conversations and decisions about healthcare.

## 5508 | Investigating the Facebook posts of parents with children/young adults with autistic spectrum disorder

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**Background**: This phenomenological empirical study looks at the challenging side of parenting for parents who care for their children with autistic spectrum disorder (ASD). For many of the parents in this study day to day life involves them dealing with their child's behaviour alone and without support. Many behaviours exhibited by children with ASD can be destructive and violent often aimed towards Mum and Dad and often causes physical harm.
**Methods**: This study analysed with full permissions (taking a collaborative and participatory approach involving key members of the parenting community in phases of the study design and thematic analysis) the private Facebook (FB) conversations of a group of parents who regularly use a closed FB site to discuss issues in their lives, frustrations and the dangers they face in caring for their children day to day. This awareness raising offers new insights into the lived experience of parents of children with ASD.

# 5. COLLABORATIVE RESEARCH AND OTHER

## 5970 | Coping strategies of parents raising children with autism in Greece due to the economic crisis

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*Pediatric Institute, Agios Stefanos, Attica, Greece*

**Background**: The purpose of this study is to explore whether parents raising children with autism in Greece have experienced any difficulties due to the economic crisis and whether they have developed any coping strategies to deal with them.
**Methods**: This study includes a sample of six parents, who are raising six children with autism in Greece. To identify the difficulties that they face because of the economic crisis and the coping strategies that they developed, semi-structured interviews were used. The collected data were analyzed with the constant comparative method.

**Results**: The results indicate that all the participants experienced difficulties such as unsatisfactory provided services and reduced amount of money from the insurance funds. In order to deal with these difficulties, parents developed problem and/or emotion-focused strategies. Other important themes have also emerged during the interviews, such as that children's special education was based on private settings.

**Conclusion**: The most important implication of this study is the absence of satisfactory public services provided for children with autism in Greece, for instance speech and language therapy in school settings. A further examination should be carried out to identify special education services that will be more effective and beneficiary for these children and their families.

## 5943 | Implication of qualitative and quantitative research methods in video-analysis: a pilot study of research methods referring to persons with profound intellectual and multiple disabilities

N.-C. Chen

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**Background**: Persons with Profound Intellectual and Multiple Disabilities (in short: PIMD) are limited in expressing themselves, therefore deducing their behavior becomes difficult. The challenges faced: Quantitatively, the actions of a person with PIMD may represent several meanings. Qualitatively, researchers could be subjective in interpreting the behaviors of Persons with PIMD. The goal of this study is to combine previous methods with video analysis to understand persons with PIMD more.

**Methods**: Action research is used and the researchers themselves are actors. Discussion are facilitated with respect to the technique of video analysis to conjure a pattern when analyzing results. When obstacle arise, in-depth interviews are conducted to compare results of the video analysis. Finally re-analyze the research method to determine its viability.

**Results**: (1) The predetermined observation list enhances the researcher's perspective as it includes behavior of persons with PIMD and also the environmental context of each behavior. (2) Qualitative research method provides a means to interpret PIMD actions individually. (3) Quantitative methods strengthen the ability of generalizing the results of qualitative analysis. (4) Appearance of disabilities of Persons with Profound Intellectual and Multiple Disabilities are hetero, therefore the observation list must be individualized.

**Conclusion**: (1) The observation list used in the video analysis can be also used in education, care and therapy for assessment. (2) This method needs more application to achieve better precision and accuracy.

## 5846 | User involvement in promoting access to justice for persons with disabilities on an equal basis with others in Zambian

V. Mukupa

*The Judiciary, Zambia*

**Background**: The paper investigates how communication, verbal and non- verbal, may enable persons with disabilities to exercise legal capacity, on an equal basis with others, in all aspects of life. The paper will first focus on disability- related barriers to exercising legal capacity for persons with disabilities and how it impacts on access to justice. These barriers may be overcome through procedural and other modifications to administration of justice and training of everyone working in it. Adjustments include promoting communication and accessible information necessary for their effective participation. Persons with disabilities must seek legal redress and defend themselves before justice systems. They must be actively involved to give effect to their wishes, feelings and preferences. Augmentative and alternative communication such as gestures, sign language, emotions, sounds, etc are ways of expressing their wishes and preferences.

**Method**: Desk research and stakeholder consultation were used to investigate challenges and practical tools to exercising legal capacity and participation in accessing justice.

**Results**: Study results indicate that information and communication barriers was one of the major impediments to participating in access to justice.

**Conclusion**: Accessible information and communication is key in exercising legal capacity and participating in all stages of accessing justice. The research used competently engaged the relationship between communication and access to justice.

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## TRACK 3: FAMILY QUALITY OF LIFE SYMPOSIA

### 1. AGING WITH A DISABILITY AND MY AGING PARENTS

### 5378 | Ageing with a disability: what is life like in the middle years?

K. Tait; R. Hussain

*Macquarie University, Sidney, Australia*

**Background**: Adopting an ecological approach to service planning and delivery, the aim of this study was to investigate the perceived quality of life (QoL) of middle aged Australian adults (30–50 years) with mild to moderate ID/DD.

**Method**: A hard copy paper version of the QoL survey (Schalock & Keith, 2004), including demographic data, was collected from 302 participants. Designated carers assisted participants to complete the survey document if necessary.

**Results**: The QoL dimensions tested included items related to satisfaction, competence/productivity, empowerment/independence, and social belonging/community integration. This paper will provide both quantitative & qualitative data, including unsolicited hand-written comments by participants, which revealed that participants experienced several basic human rights restrictions in their day-to-day life, both in their work and home/residential settings, leading to a sense of loss of agency and control.

**Conclusions**: The findings will be of value for policy-makers, support workers, families, and advocacy groups, by providing rich insights about the QoL issues experienced by middle aged adults with ID/DD. Comparisons will be drawn with other Australian and relevant international studies that will help better understand the mechanisms needed for improving the QoL of this age cohort.

### 5681 | Measuring quality of life and quality of support of elderly persons with intellectual disabilities: development of two new questionnaires

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*KU Leuven, Leuven, Belgium*

**Background**: Persons with Intellectual Disabilities (ID) age into near normal ranges. Being able to evaluate their Quality of Life (QOL) and the quality of the support strategies they get, matters. Research reveals that QoL and Quality of Support (QoS) are coloured by specific age-and-ID aspects.

**Method**: We developed an itempool on the basis of a systematic literature review and of focus groups with elderly persons with ID, caregivers, and experts. It contained relevant QoL-outcomes, QoL-influencing support strategies, and characteristics of the elderly and their environment, specific to elderly persons with ID. Drawing from this pool, we developed two questionnaires.

**Results**: Both questionnaires are specific to persons with lifelong ID, older than 65 years (older than 50 years when Down syndrome or profound ID / PIMD). The QOL-EPID (Questionnaire on QoL for Elderly Persons with ID) examines the eight QoL domains of Schalock, plus an extra domain of Existential Wellbeing. The QOS-EPID (Questionnaire on Quality of Support for Elderly Persons with ID) examines support strategies on macro, meso and micro level.

**Conclusions**: The questionnaires are currently used in a survey in different Flemish care settings. They provide a new, specific way to measure QoL and QoS of elderly persons with ID.

### 5802 | Ageing in place together: older parents and their ageing offspring with intellectual disabilities

Y.-C. Chou

*National Yang-Ming University, Taipei, Taiwan*

**Background**: Little research has been conducted about ageing in place among old parents who cohabit with their ageing offspring with intellectual disabilities (ID). A census survey and the "housing pathways" framework are employed to examine which older parents would choose ageing in place instead of moving, and what factors are associated with such a choice.

**Method**: All old parents (≥65) cohabiting with their aging offspring with ID (≥40) were invited from two local authorities in Taiwan; 237 families completed our survey and 60 were involved in our in-depth interviews between May 2015 and July 2016.

**Results**: Qualitative findings reveal that ageing in the old place was more popular than moving. We found that the parents who prefer aging in place were more likely to be older, have house ownership and currently also live with their adult children without disability in addition to their offspring with ID. They also have higher levels of satisfaction with their life and current community, and these two variables were strongly related with each other and linked with their satisfaction with their housing and community identity.

**Conclusions**: In order to make ageing in place possible for these families, housing and support should be considered by current policies.

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## 5886 | Predictors of quality of life among parental caregivers of adults with autism

H. Church; C. Marsack

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**Background**: This study examined how Quality of Life (QOL) interacted with four types of burden: time, developmental, emotional and financial burdens among aging parental caregivers of adults who have Autism Spectrum Disorder (ASD).

**Method**: Participants (*N* = 320) completed a web-based survey, with an option to complete a follow-up interview. Of the 186 participants who indicated that they would be willing to participate in the interview, 51 participants were selected randomly.

**Results**: Developmental and financial burdens on caregiving were indicated as predictors of QOL among aging parental caregivers, using stepwise multiple linear regression. There was an inverse relationship between developmental burden and QOL of aging parental caregivers. Parental caregivers identified different finding in the qualitative portion of the study, citing experiences of burden among the four burden types.

**Conclusion**: These findings indicate a need for services and supports designed to lessen the burden experienced by aging parental caregivers of adults who have ASD.

# 2. BEING A MOTHER, BEING A FATHER – ABOUT OUR LIFE

## 5386 | "Something is wrong with my child": a narrative inquiry of becoming a father to a child with an intellectual disability

L. Marsh; P. Leahy-Warren; E. Savage

*Queens University Belfast, Belfast, UK*

**Background**: In recent years, there has been a growth of research on men's experiences of becoming fathers, most of which relates to a typically developing child without intellectual disabilities (ID). Few studies have specifically explored experiences of becoming a father of a child with an ID. The aim of this study is to present the narratives of Irish fathers, specifically within the context of leading up to the diagnosis and the actual diagnosis of a child's ID.

**Method**: Through a qualitative narrative inquiry design with ten fathers aged 31–48 years, and semi-structured interviews, participants shared personal stories of becoming a father to a child with an ID. Interviews were thematically analysed.

**Results**: Fathers are emotionally affected by the diagnosis of a child's ID, recalling the emotional downturn of shock, disappointment, grief, loss, denial, and blame, realising that "something was wrong with their child."

**Conclusions**: Healthcare professionals need to be cognisant of the emotional upheaval that such a diagnosis can have and be sensitive to fathers' needs in supporting them through this process. Further research involving fathers is warranted.

## 5613 | Experiences of parenting children with disabilities in Zambia

M. S. Chirwa

*University of Warwick, Zambia*

**Background**: This study sought to provide new insight into the lives and experiences of mothers of children with disabilities in the rural (Kaoma) and urban (Lusaka) settings of Zambia.

**Method**: Qualitative, biographical interviews were undertaken with 30 mothers whose child had a disability significant enough to qualify for intervention services at the time of the interviews. Data analysis was carried out concurrently with data collection.

**Results**: Disability is surrounded by stigma and prejudice and is associated with punishment and bad omen. The diagnosis of a child's disability had an impact on the mothers as it resulted in a liminal state and a biographical disruption, as they had to reorient their lives. Mother-blame was common and they were often ostracised by their significant others and the communities. Divorce was common especially among first-time mothers and was an unexpected disruptive event that had socioeconomic impact on mothers. Mothers bore the burden of caregiving in the absence of support from their partners. Some gave up their employment because of the demands associated with caregiving resulting in financial deprivation.

**Conclusions**: The study makes a deeper, and more nuanced, contribution to the scarce literature on mothering children with disabilities in Zambia and globally.

## 5817 | Support needs of Chinese mothers with a child with an intellectual disability

H. Su

*Central China Normal University, Wuhan, China*

**Background**: Most studies of family support of children with intellectual disability have been conducted in Western cultural background, while little is known about the experience of parents in Asian cultures. This study explored the needs of support of mothers of a child with intellectual disability in mainland China where support for families of a child with intellectual disability is quite limited.

**Method**: Individual in-depth interviews were conducted among twelve mothers of a school-aged child with intellectual disability who was attending a special school in Shenzhen, Guangdong Province.

**Results**: Five categories of needs under two thematic areas were identified: needs related to children, and needs related to mothers. The needs related to children included high quality of education, and future planning; the needs related to mothers included parenting skills training, psychological well-being, and respite service.

**Conclusions**: It was found that the needs that Chinese mothers reported are more child focused than parent or family focused. This study gives the government and service agencies an insight into the direction of future efforts to provide higher quality of support to parents of a child with intellectual disability in China.

## 5711 | The mental health of fathers of a son or daughter with intellectual disabilities: a meta-analysis

K. Dunn; D. Kinnear; A. Jahoda; A. McConnachie

*University of Glasgow, Glasgow, UK*

**Background**: To summarise the evidence related to the mental health of fathers compared to mothers of a person with learning disabilities, and to fathers in the general population.

**Method**: A meta-analysis was undertaken of all studies published 01/01/2001 - 01/07/2017 in four databases using terms on intellectual disabilities, mental health, and fathers. Papers were selected based on pre-defined inclusion/exclusion criteria.

**Results**: Of 5,544 results, seven studies met the inclusion criteria. Significant effects were found for the following comparison: The pooled effect size (95% CI) of depression among fathers versus mothers was -−0.30 (−0.45, −0.15) with marked heterogeneity (I2 = 85%). Non-significant results were found for the following comparison: the pooled effect size (95% CI) of anxiety among fathers versus mothers was −0.00(−0.25,0.25) with heterogeneity (I2 = 0%). The pooled effect size (95% CI) of depression among father carers versus fathers in the general population was 0.06(−0.21,0.09) with marked heterogeneity (I2 = 90%).

**Conclusions**: There is a significant difference between studies comparing depression of fathers and mothers, with fathers exposed to a lower risk of depression or poor general mental health. More data is needed in order to determine whether the mental health of fathers of a son/daughter with intellectual disabilities differs from fathers in the general population.

# 3. QUALITY OF LIFE OF PEOPLE WITH IDD – PERSPECTIVES FROM DIFFERENT COUNTRIES

## 5523 | Quality of life of adults with intellectual and developmental disabilities (IDD): a research study in Greece

L. Kartasidou; E. Pavlidou; E. Liapi

*University of Macedonia, Thessaloniki, Greece*

**Background**: The purpose of the study is to research the quality of life (QoL) of adults with IDD in Greece, which is of great significance, as there is an absence of research or bibliographical studies on the topic.

**Method**: The research tool used was the Quality of Students Life Questionnaire (Keith & Schalock, 1993) that was adapted in the Greek language (two-way translation), and approved by the authors. It consists of 120 questions and four dimensions: satisfaction, competence/productivity, empowerment/independence, and integration/social belonging. The sample consisted of 40 people with IDD living with their families and 46 supported in communities of independent living, aged 19–59 years.

**Results**: Findings of the study have shown that individuals with IDD experience dissatisfaction with their lives. Furthermore, the study focused on the factors that have significant negative impacts on their QoL, such as dependence on care giving environment, in order to examine and develop, in the future, more individual-centred practices for QoL programs.

**Conclusions**: The present study is an important step in assessing the QoL of adults with IDD in Greece, underlining the need to support educational person-centered programs for the development of life skills, for their successful transition to adult life.

## 5642 | Quality of life of adults with intellectual disability: a pilot study in the UK

A. Marouda; L. Kartasidou

*University of Macedonia, Thessaloniki, Greece*

**Background**: This research refers to the controversial term of quality of life. The aim was to evaluate the quality of life of adults with intellectual disability in the UK.

**Method**: The research tool used for this survey was the Quality of Students Life Questionnaire (Keith & Schalock, 1994) that consists of four subscales: Satisfaction, Well being, Social belonging, and Empowerment. The participants were 26 people with intellectual disability (ID), that were supported by a service run by Leonard Cheshire Disability in England. This service supports the participants through independent and supported living, day services, and activities.

**Results**: Results shown that people with ID experience a high quality of life, while in the Satisfaction scale is observed the highest score (25,73) and in the Social belonging scale the lowest score (22,23). There is, also, a medium to high correlation between the scales (highest correlation between Satisfaction - Empowerment: $r = 0.62/P = 0.01$, lowest correlation between empowerment-social belonging: $r = 0.23/P = 0.27$). In the Social Belonging scale, there were significant differences in demographic characteristics, such as work ($t = 2,28$, df = 24, $P = 0.03$) and type of ID ($t = 2,12$, df = 23,43, $P = 0.05$).

**Conclusions**: Comparative research with a bigger sample is suggested for future studies.

## 5370 | Young people with intellectual disability in India and enabling practices

T. Marshall

*University of Bristol, Bristol, UK*

**Background**: This ethnographic study of the everyday experiences of young people with intellectual disability in a northern Indian city explores the ways of being and doing that they – and those close to them – see as important. It identifies the supports and barriers to achieving these valued forms of social participation.

**Method**: The main methods are participant observation and interviews, conducted in non-government organisation (NGO) centres, young people's homes, and other community places, involving 32 young people, NGO staff, and the family members of 14 young people. Inductive, thematic analysis of the data follows.

**Results**: Supportive practices operate in family and NGO settings that enable young people to adopt roles and responsibilities that position them as active social agents who achieve some competence. However, in the "outside world" of neighbourhood, community, and work, such practices are largely – but not entirely – absent and young people's opportunities to find a place and achieve competence are limited.

**Conclusions**: The study concludes that a focus on extending enabling practices to a wider range of social settings has the potential to promote opportunities for intellectually disabled persons, along with better-established understandings of disabling barriers. Communities may thus become better able to include all their members.

# 4. FAMILY QUALITY OF LIFE: SUPPORTS, PROGRAMS, ACTIVITIES AND LIFESTYLE

## 5907 | The experience of Chinese-Australian parents in facilitated peer support group for caregivers of children with a disability

H. Su

*Central China Normal University, Wuhan, China*

**Background**: The benefits of peer support group for parents of children with a disability have reported by many parents from Western cultural background; little evidence has shown the appropriateness of peer support group for parents of a child with a disability from Asian culture. Aim: This study explored the experience of Chinese-Australian parents of a child with intellectual disability in MyTime program- a government funded Australia-wide facilitated peer support group program for caregivers of a child with a disability.

**Method**: Five Chinese-Australian parents who were enrolled in MyTime programs in two program setting in Sydney received individual semi-structured interviews. The data were analyzed thematically.

**Results**: The benefits of MyTime that the Chinese-Australian parents reported included: social and learning opportunities for children, increased parenting skills, psychological well-being, information sharing, and respite time. The homogeneity of children diagnosis, professional facilitators, and respect for cultural diversity within the group are factors that parents considered important to enhance the quality of this program.

**Conclusion**: Chinese-Australian parents of a child with a disability considered peer support group is helpful in various aspects which is consistent with parents from Western cultural background.

## 5626 | Caregiving burden among family caregivers of people with intellectual disability: insights from the SOPHIE study

D. Corby; M. Sweeney

*Dublin City University, Dublin, Ireland*

**Background**: The main aim of the SOPHIE study was to explore whether people with intellectual disability who take part in Special Olympics are healthier and happier than those who do not take part. A secondary aim was to consider issues relating to quality of life for family carers.

**Method**: Participants included 146 family carers who completed a detailed questionnaire on their personal circumstances including the amount of time spent caring and also volunteering with Special Olympics.

**Results**: The analysis of some elements of the family questionnaire indicates that the burden of care rests with families of people with intellectual disability. This can impact on their work life as well as their overall quality of life. A further finding is in relation to family carers and the level of involvement they have with Special Olympics as volunteers.

**Conclusions**: The impact of caring for a family member with intellectual disability is significant for family carers. Involvement with Special Olympics, while positive, also results in family members spending time supporting their relative, rather than having personal time.

## 5877 | FQoL from a cultural perspective among orthodox Jewish families

T. Taub; H. Gershoni; S. Werner

*Hebrew University of Jerusalem, Jerusalem, Israel*

**Background**: The purpose of this research was to get a better understanding of Family Quality of Life (FQoL) among orthodox Jewish families raising a child with a disability. Religion and spirituality play an important role in the lives of these families and are of great importance since they constitute a significant source of support.

**Method**: A thematic analysis was conducted retrieving written comments of parents from the open questions included in the

self-administered FQOLS-2006 questionnaire. Participants: 99 religious and ultra-orthodox Jewish parents, living in Israel, raising a child between the ages of 3–14 with a disability.

**Results**: Orthodox and ultra-orthodox families expressed different and unique needs for their FQoL such as recreational activities and support from others suited to their lifestyle. Their support from their immediate family and their community constitute significant sources of support that contribute to their FQoL.

**Conclusion**: Spiritual faith is a crucial source of support in accepting and raising a child with a disability among orthodox and ultra-orthodox Jewish families. Health professionals and service providers must have cultural: awareness, competency, knowledge, skills and sensitivity in order to best provide services and encourage families to utilize available and significant sources of support to enhance their FQoL.

## 5736 | Impact of family support on caregiving appraisal

T. Heller; C. Crabb; R. Owen

*University of Illinois at Chicago, USA*

**Background**: This longitudinal study examines the impact of formal family support on how family members appraise their caregiving burden, satisfaction, and self-efficacy over 2 years.

**Method**: Family members of Medicaid managed care enrollees with disabilities completed surveys over 2 years following the enrollees' move from fee-for-service to managed care. We only included family members who lived together ($n$ = 182). Outcome variables were three caregiving appraisal scales: caregiving burden, satisfaction, and self-efficacy. The models controlled for the outcome variables at time one. Demographic of the enrollee, caregiving demands, and unmet family support needs were independent variables.

**Results**: Linear regression results indicated that family members who were Black reported significantly less caregiver burden. Family members with more unpaid care time and unmet family support needs had significantly higher burden. Family members of enrollees with intellectual/developmental disabilities had significantly higher caregiver self-efficacy.

**Conclusions**: This study demonstrates the importance of providing family support that meets the needs of caregivers of adults with disabilities and results in a more positive appraisal of their caregiving experience. Family members experiencing lower burden and higher self-efficacy and satisfaction likely have better outcomes, along with enrollees.

# 5. EVALUATION & MEASUREMENT, INSTRUMENTATION ASSESSING QOL & FQOL

## 5413 | The early response tool: development and initial psychometric evaluation

M. Vassos[1,2]; K. Nankervis[1,2]

[1]*Endeavour Foundation, Queensland, Australia;* [2]*The University of Queensland, Queensland, Australia*

**Background**: This presentation will discuss the development of the Early Response Tool (ERT), and the findings from the initial psychometric evaluation of the ERT. The ERT was developed by the Centre of Excellence for Clinical Innovation and Behaviour Support, to identify the common day-to-day issues faced by parents when providing care for their child with a disability.

**Method**: One hundred and ninety-nine parents of children, adolescents, and young adults with a disability (autism spectrum disorder and intellectual disability, predominately), completed a questionnaire containing the 42-item ERT, measures of family quality of life, and parent mental health.

**Results**: Factor analysis uncovered that 36 of the ERT items fall within nine factors, with six factors displaying satisfactory internal consistency. Face validity was also supported, with 79% of parents agreeing that the ERT measures what it claims to. Concurrent validity was also demonstrated via significant correlations between the ERT, family quality of life, and parent mental health measures.

**Conclusions**: The measurement properties of the ERT are promising. With further development and evaluation, the ERT could be used as an early intervention tool to guide service planning for parents who may be experiencing significant parenting challenges (in an effort to promote positive parent/family adjustment).

## 5598 | Does the WHOQoL-BREF capture the issues relevant to quality of life of autistic adults?

I. Magiati; C. Wilson; D. Garland; D. Mason; H. McConachie; J. Parr; J. Rodgers; M. Uljarevic

*Singapore*

**Background**: The World Health Organisation measure of Quality of Life (WHOQoL-BREF) has been extensively validated internationally, but does it adequately capture the issues important to autistic people?

**Method**: Eight groups with 34 autistic adults were held in the UK, Singapore, and Australia, to examine the importance and relevance of the WHOQoL-BREF and WHO Disabilities module items for autistic people. Participants were invited via social media and local autism contacts. Group facilitators were from the autism community and/or autism researchers. The original WHOQoL-BREF and WHO disability module items were provided as a starting point for discussion

and participants discussed their relevance for autistic people. The semi-structured discussion transcripts were subsequently coded for emerging themes.

**Results**: Generally, many of the existing items were important and relevant for autistic people. At the same time, several themes emerged that may be more relevant for autistic people, including: other people's autism-related knowledge, particularly professionals'; access and barriers to external support; family support; sensory issues; "autistic" identity; and mental health issues.

**Conclusions**: The WHOQoL-BREF and Disabilities module items do address several issues important to autistic people. The specific themes that emerged also support the development of an "autism-specific" module and emphasize assessing mental health issues.

## 6. THEORY AND PRACTICE OF MODELS AND APPROACHES

### 5991 | "Growing confidence with uncertainty-interactional guesstimating": a constructivist grounded theory of family carers' experiences supporting profoundly intellectually disabled persons in decision-making

R. Ryan; B. Coughlan

*Member via Department of Nursing and Midwifery, Ireland*

**Background**: The purpose of this research was to gain more knowledge on family carers' experiences supporting persons, living with profound intellectual and multiple disabilities, in decision-making. The research occurred between 2012–2017 in the Republic of Ireland.

**Methods**: A qualitative exploratory "Constructive Grounded Theory" methodology guided the study design. Following ethical approval, (March 2012) data generated with family carer participants in 3 ways: (1) Individual interviews with 26 family carers, transcribed verbatim. (2) "A Carers Group" ($n$ = 6) which meet 6 times over a twelve month period (December 2012–2013) facilitated through a reflective inquiry of "dialogue and reflection". (3) Field notes of meetings, and carers' diary recordings contributed to the data. Data Analysis consisted of coding using the initial, focused and theoretical framework (Charmaz 2006) coding of transcripts and memoing. Three main categories emerged "Sensing a Union", "Framing representation" and "Steering activities" representing family carers' actions. Critical analysis yielded a model of supporting decision-making entitled "Interactional Guesstimating" representing family carers' experiences. This is the first constructivist grounded theory of family carers' experiences supporting persons, living with PIMD, in decision-making. This builds on previous theoretical and legal models. This research highlights the success and challenges of the nebulous concept that supporting decision-making is.

### 5450 | Enhancing the family-centered approach by means of training and feedback: a multiple case study

L. Vanderkerken; M. Heyvaert; P. Onghena; B. Maes

*KU Leuven, Leuven, Belgium*

**Background**: This study aimed to explain (1) how the family-centered approach (FCA) in home-based support for families with school-aged children with an intellectual disability can evolve through time, (2) which factors at the level of the family, the professional, their interaction, and the context facilitate or hamper its realization, and (3) how the FCA can be promoted by a bipartite intervention consisting of a family-centered (FC) training to family workers and the provision of feedback to family workers and families on their collaboration, family quality of life, and parental empowerment.

**Method**: A mixed methods multiple case study was conducted. Six families and their family workers were intensively followed for 1 year. In parallel with the bipartite intervention, both families and family workers completed questionnaires (three-monthly) and diaries (after each contact), and were interviewed about their collaboration. Data are analyzed by a case study approach, consisting of within-case and cross-case analyses.

**Results**: Changes in the level as well as the modalities of the FCA will be presented. The effective components, facilitating, and hampering factors will be discussed.

**Conclusions**: Suggestions for promoting the FCA in the family-professional collaboration will be formulated, together with some reflections on (the integration of) six family-centered principles.

### 5922 | Comparing models of personalised respite care: findings from an Irish population with mild/moderate disabilities

E. Nicholson; S. Guerin; F. Keogh; P. Dodd

*University College Dublin, Dublin, Ireland*

**Background**: Respite care is an essential support for people with disabilities and their families, however, there is limited evidence examining different models of respite care. Personalisation seek to services around the needs of individuals, however, this approach has scarcely been adopted for respite services. The present research sought to examine quality of life among adults with intellectual disabilities using different models of respite services in Ireland.

**Method**: Participants were people with mild/moderate intellectual disabilities ($n$ = 82) and their keyworkers. The primary variable was quality of life which was assessed using self-reported and proxy measures.

**Results**: Three distinct models of respite services were assessed (1) Traditional Residential respite; (2) Personalised Residential respite, and (3) Non-Residential Personalised respite. No differences emerged between the groups on self-reported quality of life,

however, the groups differed on a proxy measure of quality of life with respect to Rights, Emotional Well-being, Personal Development and Interpersonal Relationships.

**Conclusion**: The current data offers an initial exploration of self and proxy reported quality of life among persons with intellectual disabilities in receipt of respite care. Novel models of respite care which adopt a personalised approach may contribute to important quality of life indicators.

## 5853 | Exclusion of the family from social interferences: a psychoanalytic approach

D. Tsiakos; A. Avrampou; A. Resiti

*Psychotherapy Center of Southern Suburbs, Greece*

**Background**: The subject of the presentation is the way a family is usually excluded from social situations and interferences because of the negative emotions that parents feel due to the difficulties of the children in the autism spectrum.

**Method**: Mainly we will examine the above through a psychoanalytic point of view. The presentation will focus on the range of the negative and dysfunctional emotions and thoughts that the parents usually have such as shame, inadequacy, anger or grief, concerning the diagnosis, behavioral and sensory difficulties, cooperation and communication skills of the child in the autism spectrum as well as personal beliefs of the parents and social stereotypes regarding parenting and "normal" child behavior. Those emotions and thoughts have as a result a reduction or even exclusion of the family from social exposure and participation to social events and activities such as celebrations and parties, trips, shopping, theatre etc. The presentation will be based on quality data, gathered through personal clinical interviews with parents of children in the autism spectrum and will be presented through a psychoanalytic point of view based on developmental and existential theories, such as Yalom's existential approach and contemporary psychodynamic perspectives.

# 7. FAMILIES VIEWS & EXPERIENCES OF PROGRAMS AND SERVICES

## 5900 | Social inequalities and diagnostic experiences of mothers raising children with autism in Greece

S. Mavropoulou; A. Zissi; C. Dardani

*Queensland University of Technology, Brisbane, Australia*

**Background**: The purpose of this large qualitative study was to explore social inequalities in the diagnostic experiences of mothers raising at least one child with ASD in Greece.

**Method**: Individual semi-structured interviews were conducted with 75 mothers from three social class positions. A layered approach combining content analysis and template analysis was applied to the interview transcripts and revealed interesting similarities and differences among mothers from opposite social class positions.

**Results**: The majority of mothers identified the same early signs of autism and shared similar emotional responses to the hearing of the diagnosis. Mothers with high credentials and petit bourgeoisie mothers offered more elaborate accounts of the early warning signs of ASD, obtained a timely diagnosis and had positive interactions with professionals after the diagnosis. In contrast, mothers from the working class provided confusing accounts of their child's behavioral observations in the early years, and had experienced long delays and negative interactions with professionals during the diagnostic process.

**Conclusion**: These findings highlight the need for developing supports and services, which will pay special attention to the differentiated maternal diagnostic experiences as a result of their social class position.

## 6030 | Family views of alternative respite services: definitions, outcomes, and experiences

S. Guerin; E. Nicholson; F. Keogh; P. Dodd

*University College Dublin, Dublin, Ireland*

**Background**: The aim of this study is to explore families' perceptions of respite care for adults with intellectual disabilities (ID) and families. While respite has been conceptualized as a short residential break for the person with ID, allowing families a break from caring, different models of respite provision have developed.

**Method**: Participants were family members ($n$ = 32, predominantly parents) of adults receiving respite services from six organisations. The services were classified as non-traditional or alternative respite, including both residential and non-residential respite. Data were collected via semi-structured interviews.

**Results**: The results revealed that families showed diversity in the conceptualisations of respite services, with themes highlighting the importance of the break for both individuals with ID and families, as well as the focus on the needs of the individual with ID. This diversity is also evident in descriptions of the impact of alternative respite services and the key features of alternative services.

**Conclusion**: The present study reflects alternative respite as a diverse experience for individuals with ID and family members, as reported by families. The findings highlight a range of elements of respite and would support further consideration of the nature of respite services beyond the traditional conceptualization.

## 5909 | Service use and post-traumatic growth amongst parents of people with intellectual disabilities

I. Stern; S. Werner

*Hebrew University of Jerusalem, Jerusalem, Israel*

**Background**: Parents play an important role in supporting people with intellectual disabilities (ID) by seeking out services to meet their needs. Post-traumatic growth (PTG) relates to Positive psychological change experienced as a result of the struggle with highly challenging life circumstances. The aim of the study presented is to examine the relationships between parents' perception of services, service use and PTG.
**Method**: 187 parents of people with ID aged 13–25 completed questionnaires.
**Results**: High levels of PTG were found among parents. Parents perceived most services as available to them, 65% reporting using at least one (or more) since their child was born. No association was found between a perception of services availability to using them or to PTG. A significant association was found between actual use of services and PTG ($\beta = 0.24$, $P = 0.001$) showing that parents that use more services report of higher PTG.
**Conclusion**: Discussion about attitudes and use of services and its connection to PTG carry the potential to improve parents' wellbeing along with their ability to take care of their son/ daughter with ID.

# 8. OUR VOICES IN DESIGNING OUR LIVES TO PARTICIPATE AND BELONG

## 5951 | Are the support services supporting families headed by parents with intellectual disability?

S. Stefánsdóttir

*University of Akureyri, Iceland*

**Background**: The aim of the research was to gain a deeper understanding on, a) how professionals, in the support services, view their work in relation to parents with intellectual disabilities (ID), and b) how they go about supporting them in their parenting role.
**Method**: Qualitative interviews were conducted in different municipalities in Iceland. All interviewees were professionals working in services aimed at supporting parents with ID. Structured Grounded theory was used to analyse the data.
**Results**: The results indicate that professionals lack knowledge about parents with ID and ways to support them. Also there is a tendency to group parents with ID with parents that have "issues" or "not good enough parenting".
**Conclusion**: Little is known about the support services that parents with ID in Iceland are receiving. Still the services provided can have a major impact on the lives of the families headed by parents with ID as the child protection services rely on "improvements" in child rearing following the service. For parents with ID, successful parenting depends in many ways on the quality of the support they receive and therefore it should be provided by professionals that have knowledge and are sensitive to the parent's needs.

## 5635 | Reinforcing people with ID and their parents to make the transition to adulthood

N. Seghers; B. Maes

*KU Leuven, Leuven, Belgium*

**Background**: Designing your life as an adult requires from people with ID a new focus and specific behavior: thinking about strengths and needs, expressing own ideas and choices, dealing with uncertainty, and negotiating with informal and professional caregivers. Parents are challenged in a similar way, not only in supporting and coaching their child but also in considering their own engagement and role towards their child in the future.
**Method**: We set up a dual learning path for adolescents and their parents. Both groups had in the same period their own workshops with peers on the same topics: strengths, dreams and wishes, and informal network. The last workshop on communication and making choices was partly in mixed groups of persons with ID and parents. We made a process evaluation with the participants and a qualitative effect evaluation after 1 year.
**Results/Conclusions**: Peer-workshops give both adolescents and parents time and ideas to get a clearer view on what is important to consider in the transition to adulthood. It creates mental space and learning possibilities. It prepares them to communicate with each other in the individual transition process.

## 5467 | The sense of personal autonomy, self-esteem and personal wellbeing among people with complex needs, including people with IDD in comparison to people without disabilities: a participatory action research

D. Roth; E. Koren; H. Peretz

*Beit Issie Shapiro, Ra'anana, Israel*

**Background**: The aim of this study was to investigate whether there are differences in the sense of personal autonomy (PA), self-esteem (SE) and personal wellbeing (PWB) among people with complex needs, including people with intellectual developmental disability (DD) and people without disabilities (WOD).
**Method**: People with DD initiates this study due to their experiences of conflict with service providers and with their families "running their lives". They were members of the research team and took full part in all stages of the research. Participants in this study were 96 people with DD and 96 people WOD who completed

questionnaires. The 2 groups were matched on sociodemographic characteristics.

**Results**: Results indicated that people WOD rated significantly higher in comparison to people with DD on SE and on two domains of PA: self-awareness and the capacity for managing new situations. The only similar positive correlation found in both groups is between SE and PWB. Among the people with DD additional moderate correlations were found between domains of PA and PWB.

**Conclusion**: The study demonstrates the importance of self-esteem and personal autonomy skill building to increase PWB. Implications for different support systems (i.e. caregivers, families, and service providers) and mostly people with DD will be addressed.

## 5809 | "Dit vind ik ervan!": A dialogue based approach to gather quality of life experiences

A. Vorselman

*Siza, The Netherlands*

**Background**: "Dit vind ik ervan!" [This is how I feel about it!] is a practice-based approach for examining service-user-experiences within support organizations in the Netherlands. The core of the approach is the "explorative dialogue" between the service-user and the support worker. In this dialogue the service-user examines his experience with the care and support and what he feels is important (quality of life aspects). The support worker facilitates this examination, by asking open-ended questions and by attuning his (nonverbal) communicative attitude towards the service-user. The attendant deliberately does not mention his own opinion or values: the service-user's perspective is the central focus. The "explorative dialogue" yields much information and ideas about how to improve our services. As the support worker himself is the person who does the interview, the outcomes from the "explorative dialogue" can be used instantly. Apart from that, the information can be used for the further development of the support policy at organization level. In the Netherlands, this approach is becoming more important as 1/3 of the long-term service-users use it, about 35.000 people. Currently, researchers are studying the quality (validity and reliability) of the approach. Results will be used by all users and spread (inter)nationally.

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# ABSTRACTS

## TRACK 4: ARTS & REPRESENTATION

## SYMPOSIA

### 1. THE ARTS IN EVERYDAY LIFE AND PRACTICE: CHANGING IMAGES, IDENTITIES AND AGENCY OF INDIVIDUALS WITH A DISABILITY THROUGH THE ARTS

### 5352 | People with learning disabilities in TV

V. Mason-Angelow; B. Richards

*The University of Bristol, Bristol, UK*

**Background**: This research aimed to explore the role of people with learning disabilities on mainstream TV in the UK with a vision for "getting things changed". This research was run as part of the much larger "Getting Things Changed" project in the School for Policy Studies, University of Bristol.

**Method**: As an actress with learning disabilities herself, B. Richards took the lead on this research reflecting on her own experience; interviewing actors with and without learning disabilities, writers, commissioners and producers of TV in the UK; as well as running an online questionnaire for this population and the broader UK TV audience.

**Results**: People with learning disabilities appear to be under-represented in mainstream UK TV. The actors that have "made it" have done so due to luck and perseverance, often feeling type cast by the roles they are offered being confined to that of "someone with a learning disability".

**Conclusions**: This situation is caused by a combination of casting agents and producers neither seeing people with learning disabilities as actors in their own right nor the therefore inaccessible nature of the audition process.

### 5934 | Developing the personal stories of young people with complex communication needs through Storysharing®

K. Bunning; E. Bowes; R. Dunkerley; J. Hemmington; G. Wallington

*University of East Anglia, UK*

**Background**: The aim was to investigate the potential of a narrative-based intervention called Storysharing® on the personal stories told by young people with complex communication needs associated with severe-profound intellectual disabilities.

**Method**: A case series was conducted in a special school setting. Eight students, each partnered by a member of the teaching staff who had received training in the principles of Storysharing®, took part. There were opportunities for each dyad to develop and rehearse a chosen story of relevance and interest to the participant. Before and after measures involved video capture of personal narratives, followed by detailed transcription and applied linguistic analysis at the levels of discourse structure, pragmatics and narrative.

**Results**: Whilst there was some variation across the dyads, post-intervention revealed a greater balance in teacher-student contributions to the storytelling. The personal narratives demonstrated growth in teacher use of prompts and sensitive responding to student contributions. The stories told were more complete with a greater emphasis on action sequences, and story climax.

**Conclusions**: Storysharing® has the potential to support students with complex communication needs associated with severe-profound intellectual disabilities to become active participants in the sharing of their own personal stories.

### 6002 | Dramatic play and special education

P. Barmpagiannis; K. Makrykosta; N. Gioupis

*Greece*

**Background**: This paper is presenting the relevance between Dramatic Play, a laboratory-type approach, and special education. Through the dramatic play, the person's skills and abilities emerge and develop, several of which include emotional and interpersonal intelligence, emotional dialogue, cognitive and perceptual skills as well as functional communication.

**Method**: Based on theatrical training, the "inspirator" is given the opportunity to introduce and intervene in almost all areas of a learning that is based on action/activity. The team that is born is governed by the spirit of cooperation and a willingness on the part of the members to participate. Voluntary exposure to and a psychological investment in the process of free play, as well as applying personal experience through symbolic performance, are always the main pillars of sensitization and theater performance.

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## 5782 | The visual arts: Mediators of citizenship for individuals with a disability in the contemporary world

E. Joosa

*Arts of the Earth Learning Hub, Singapore, Singapore*

**Background**: The question of what it means for individuals with a disability to be recognised as active citizens in an increasingly global and visual world is central to the discussion of social and semiotic theory. For too long the cognitive interpretation and rationality of normative developmental measurement have obscured the authenticity of visual meaning-making of individuals with a disability. The concept of citizenship moves ideas towards contemporary ideologies and asks questions of how to negotiate rights and liberties for those with a limited voice. Current disability research lacks structured models that allow arts-based researchers to mediate representation and bring an understanding of the role of culture, symbolism and meaning in visual representation.
**Method**: Using examples from arts-informed research practice, a social and semiotic approach to practice based arts research enlarged ideas of how the symbolic nature of the arts mediates citizenship qualities.
**Results**: This study garnered dialogue of shifting perspectives and opportunities for representation in a real-life-world parallel
**Conclusions**: Social and semiotic approaches build on contemporary socio-cultural theories, have the potential to develop new scientific knowledge in the human sciences and have the opportunity to ask existential questions to support individual quests for citizenship.

# 2. ACTIVIST RESEARCH – GRASPING TACIT ACTIVISM

## 5871 | The use of bloganalysis towards change

H. Peels

*Middin, Rijswijk, The Netherlands*

**Background**: In collaboration with Beau, expert by experience and author of a blog on living with disabilities, the presented research aims to identify themes and experiences that contribute towards changing residential care for people with (intellectual) disabilities.
**Method**: The author presented the framework used in the research to analyse blogs in a collaborative design.
**Results**: Beau blogs about important themes on the reality of living in a residential setting in the Netherlands. Both on grand topics in life like identity, physical dependence and emotional needs; and small topics like outings and holidays. She identifies, both knowingly and unknowingly, gaps between what she considers needed to be able to live an autonomous life and the system of care she is dependent upon. An outline of these themes was presented here, using quotes from Beau's blogs to represent her experiences and thoughts.
**Conclusions**: By blogging with an insider's perspective Beau voices a much-needed view on living in a supported living setting. Her experiences can be used to reflect on the influence of (in)dependence on identity and belonging, the aims and fundamental ideas of good support and how organizational choices influence the lives of people with disabilities.

## 5875 | Drawing lab – a new research method

S. Sergeant

*Disability Studies in the Netherlands (DSiN), Amersfoort, The Netherlands*

**Background**: Through the Drawing Lab the author strives to grasp perspectives of people with intellectual disabilities on their lives, their quality of life, dreams and desires. In the Drawing Lab an environment is created in which people can talk on their lives through their drawing. Their agenda is set out through the image and the path they follow scanning and explaining their own drawing.
**Method**: The author designed the method of the Drawing Lab as a research method in which a failure free environment is build. Around 500 people participated in the Drawing Lab, found through stake holder meetings and through public events where random visitors were invited. People are randomly allocated a domain of quality of life (Schalock). The drawings created (and after-drawing-dialogues put in writing) in the Drawing Lab are analysed using emerging themes and patterns.
**Results**: Analysing the images the author discovered important themes people shared. Analysing the drawing processes and interviews the author also derived observations. Overarching results on the eight domains of quality of life are presented.
**Conclusions**: The drawing lab is a promising method to strengthen the voice of people to express important issues for quality of life, regardless of their intellectual capacities.

## 5878 | Painting Pictures – the power of imagery

H. Peels; S. Sergeant

*Vrije Universiteit, Amsterdam, the Netherlands*

**Background**: In this presentation the authors will guide the listeners through the outcomes of a critical dialogue on the use of imagery (both visual as verbal imagery). The outcomes are aimed at exploring the possibilities imagery harbours to better the dialogue on quality of life of people with ID.
**Method**: A critical dialogue was used to reflect upon the experiences with imagery in the previous research of the authors. Quotes from blogs, and drawings from the drawing lab, are used to enrich the critical dialogue.
**Results**: Reflecting on co-occurring changes in society, nature of caregiving and increasing appeal for empowerment for and by people

with ID, the authors discuss pivotal themes in the use of imagery (visual and verbal) as a method to engage in dialogue with young people with ID and improve their quality of life by developing an enabling (support) environment together.

**Conclusion**: The use of imagery harbours strong action-oriented power, both in building an inclusive environment and in building bridges between people with and without ID. Moreover, imagery offers the possibility to connect and experience the feeling of belonging through reflecting on existential themes in life.

## 5879 | The value and impact of collaborative research: Stories and discussion

Beau; J.J. Peels; H. Sandvoort; S.A.A. Sergeant

*Vumc, Amsterdam, the Netherlands*

**Background**: Four researchers give their insights on the act of collaborative research, on support and on Quality of Life of people with (intellectual) disabilities. Photographs, text, film and speech guide the viewers through the joys and challenges of collaborative research.

**Method**: Starting with a film we open up the discussion on the value and impact of collaborative research. Combined with the results presented in the other presentations in this symposium, we invite the listeners to reflect on and discuss their own views on collaborative research, the use of imagery and the Quality of Life of people with disabilities.

# 3. VISUAL TECHNOLOGY IN PRACTICE, RESEARCH AND LIVING

## 5945 | Using digital technology as a means of supporting creative person centred care for older adults with an intellectual disability

P. Dunne; E. Reilly; F. Lowe; R. Judge; S. Lynch; M. McCarron

*Daughters of Charity Disability Support Service, Dublin, Ireland*

**Background**: To understand the readiness, social and digital barriers, and facilitators to implementing digital life stories for persons with an intellectual disability.

**Method**: A multi-step approach was utilised. An easy read comprehensive survey was developed and distributed to 380 people with an intellectual disability across one organisation in the republic of Ireland. A suite of easy to use Apps supporting the creation of digital life story were identified and then pilot tested. A bespoke training program was developed and supplemented with a "Train the Trainer" manual giving instructions on the use of the selected apps and advice on using digital technology.

**Results**: A total of 287 people responded with 83% indicating that they wished to participate. Almost 70% had never used any form of technology. A total of 76 staff plus 17 volunteers undertook the train the trainer program and a digital life story was successfully created with 65 people with an intellectual disability over a two year period.

**Conclusions**: The success of digital life story was not dependent on computer literacy. Training of staff, engaging with the person, their family and friends, and embedding digital life stories as part of their personal care plan were critical prerequisites to success.

## 5377 | Night terrors and hallucinations: representing sleep disorders through video installation

B. Tait; K. Tait

*University of New South Wales, Kensington, Australia*

**Background**: Parents of children with ASD have rated sleep problems occurring four to six times higher than in the general population. With the exception of investigating the frequency of reported sleep problems in ASD, there have been limited attempts to understand an individual's experience of a night terror. This presentation offers an artist's representation of night terrors as a contemporary art form combining video technology with installation art.

**Method**: This post-modern video installation bridges the gap between the viewer and the artist, imprisoning both within the elements of repetitious night terrors. A soundtrack inspired by NASA accompanies looped scenes.

**Results**: The technique of video looping not only orients viewers' recognition of emotions evoked within a night terror but also replicates these sensations through digital media.

**Conclusions**: The relationship between the core features of ASDs and sleep problems remains poorly understood and is an area in obvious need of more careful investigation. However, by representing night terrors through a video installation, the artist has generated a shared experience, replacing sympathy for empathy in order to create a better connection, evaluation and viewer understanding of the etiology of this sleep problem.

## 6068 | Visible and invisible qualities left from fingerprints on products

S. Gurisik

*Istanbul Technical University, www.selcukiali.com, Istanbul, Turkey*

**Background**: This paper is about the coordination of Hand- Mind-Inner-self, during the process of designing/making and creativity. The journey of creativity is affected by different types of learning and knowledge, which the result product reflects; it can be considered as a kind of verification of the personal journey. The individual creative journey is like leaving behind fingerprints. The

personal touches leave marks up on the product and built up visible and invisible qualities of agency and identity. These visibly specified physical qualities (material, production-line) and invisible qualities; such as conceptual aspects and creativity can be perceived depending on the level of consciousness. Regardless, the qualities of the result of the products (art and design objects), the journey of creativity has more valuable halts for improved learning and teaching. The environmental situations can influence psychoanalysis and gain insights into the person. This journey of inner-self allows to find out personal abilities, help in the realization of the personal skills, and support to raise self-confidence and feeling valuable in the society.

**Conclusion**: Working for disabilities studies and train people for engagement in creative activity and evaluating the stages of creativity is not only valuable for the experts to analyse, but also lends support to individual realization of ability. This brief presentation might help to clarify our purposes and usage of to train hand-crafted activity of felt making in disabilities studies.

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## TRACK 5: HISTORY, IDENTITY & RIGHTS SYMPOSIA

## 1. RIGHTS AND DIGNITY

### 5363 | Procreative injustice. The access to reproductive rights for women with ID in Poland

A. Wolowicz-Ruszkowska

*The Maria Grzegorzewska Pedagogical University, Warsaw, Poland*

**Background**: The aim is to widen the social reflection on the theme of access to reproductive rights and the right to family life for women with ID.

**Method**: Qualitative research, nineteen in-depth interviews, and seven case study analysed using Grounded Theory.

**Results**: Women with ID are discriminated in access to above mentioned rights, both in social practice and legal regulations. It is visible in: undermining the right to making procreative decisions (sterilization, abortion, and administering contraceptives without informed consent), creating a social image of women with ID as incompetent mothers (social fear regarding the ability of providing appropriate childcare), limiting their influence on the child upbringing (increased control over motherhood, ID as a premise to take away the child).

**Conclusions**: In the theme of motherhood there are double standards regarding the treatment of women with and without ID. Different women in the same situation are required to possess different levels of competence. There is a dichotomy between the social determinism which dictates them to have children, and social mechanisms which preclude or discourage women with ID from becoming mothers.

### 5431 | Increased vulnerability: experiencing disability during flight

S. Subasi

*University of Vienna, Vienna, Austria*

**Background**: This paper tries to show how disability and forced displacement intersect for the families who seek shelter as refugees. During crisis, people with disabilities suffer due to discrimination, violence, exploitation or other handicaps, which makes them more vulnerable. By comparing two cases respectively from Austria and Turkey, this research examined and described the experiences of refugee families with children with disabilities by focusing on the quality of facilities, challenges, initiations, and the way policies and regulations find their way into practice.

**Method**: The case study method was used in this study by examining two cases in –depth and in a detailed way. From each country a refugee family with a disabled kid was the case. To get a fuller picture of the case several people related were interviewed and interview findings were triangulated with document analysis and observations. Disabled refugees, their relatives, consultants, camp leaders and volunteer care givers were data sources.

**Results**: The findings showed how similar disabilities are experienced differently in two countries.

**Conclusions**: The study yielded to a picture where disabled refugees and their families have country specific as well as global challenges, views and experiences. Having two countries gave the opportunity to compare the spaces and places.

### 5788 | Towards a "Paradigm Shift": exploring the implementation of supported decision-making in the CRPD in Cyprus and Australia

E. Kakoullis; K. Johnson

*Cardiff University, Cardiff, UK*

**Background**: This paper will explore cultural challenges States Parties to the UN CRPD may face in implementing the CRPD focusing on the implementation of Article 12(3). These challenges are important to people with disabilities making decisions with support, for their supporters, DPOs and law and policy makers.

**Method**: The paper is based on research undertaken in Cyprus and Australia. The research in Cyprus was on the ratification process for the CRPD.

**Results**: The findings showed that the way people with disabilities were seen and supported meant that there were problems in understanding issues of supported decision-making, which had implications for the implementation of Article 12(3). The research in Australia concerned financial supported decision-making. The study found that there were particular issues about providing financial decision-making support, including possible conflicts of interest, difficulties in finding supporters, the current law in Australia, lack of accessible information, and the need for training.

**Conclusions**: This paper will explore the cultural challenges that may arise in understanding and translating the text of the CPRD into action in particular States Parties. We conclude with a discussion of how some of these challenges may be met and interventions that are required if Article 12(3) is to be put into practice.

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## 2. STIGMA

### 5982 | Standing up for Myself: a psychosocial group intervention to increase the capacity of people with intellectual disabilities to manage and resist stigma

L. Richardson; L. Poole; K. Fenn; K. Scior

*University College London, London, UK*

**Background**: To develop a psychosocial group intervention "Standing up for myself" (STORM) for adults (16 + ) with mild to moderate ID, aimed at enhancing their capacity to manage and resist stigma and have a positive effect on their wellbeing, and assess the intervention's preliminary outcomes.
**Method**: Eleven third sector organisations in the UK piloted the intervention with people with ID (*N* = 67), with existing group facilitators from these organisations running the programme. The STORM intervention's impact on participants' mental health, self-esteem, and other psychosocial outcomes was assessed, and qualitative feedback from facilitators and group members collected.
**Results**: The STORM programme elicited positive responses from group facilitators and participants. Preliminary outcomes show small positive effects of STORM on participants' mental health, self-esteem and sense of social power.
**Conclusions**: The STORM programme appears successful in empowering people with ID to manage stigma they may face in ways that are personally meaningful, and to engage in acts of stigma resistance. Its potential as a public health intervention that can benefit large numbers of people with ID by engaging them as active agents in challenging stigma should be explored going forward.

### 5933 | Understanding and challenging stigma at multiple levels

K. Scior; S. Werner

*University College London, London, UK*

**Description**: Many positive changes have happened or are underway in recognising the rights of people with intellectual disabilities and increasing their inclusion. Yet negative attitudes and discrimination remain everyday realities for many. This paper presents a multi-level model of stigma associated with intellectual disabilities, encompassing the intrapersonal, familial, wider interpersonal, and structural level. It is proposed that research efforts to advance our understanding of intellectual disability stigma need to target these multiple levels, as do efforts to and develop and test interventions that challenge stigma.
**Contribution**: The model can provide a framework for the development of new research and interventions and help identify priorities for research and intervention.

### 5939 | Using film-based digital methods to challenge intellectual disability stigma in African countries

K. Scior; D. Odukoya; W. Chege

*University College London, London, UK*

**Background**: To test if film based digital interventions can contribute to efforts to raise awareness of intellectual disability and tackle stigma in African countries.
**Method**: Two parallel studies were conducted in Nigeria and Kenya. Altogether 1028 participants (*N* = 571 in Nigeria and *N* = 457 in Kenya) were recruited through social media and randomly allocated to watch either a 6-min film designed to increase awareness of intellectual disability, and to challenge stigmatising beliefs commonly found in African countries, or a control film. Attitudes were assessed using the Attitudes Toward Intellectual Disabilities questionnaire short version at baseline, post-intervention, and one-month follow-up.
**Results**: Attitudes in the experimental but not control group were more favourable after the film intervention. In both countries, participants who had watched the films focused on intellectual disability showed more positive attitudes on all three attitude components (affect, cognition, and behavioural intentions) compared to baseline; these changes were maintained at 1-month follow-up.
**Conclusions**: Despite barriers to conducting digital interventions and research in African countries, film-based, digitally delivered interventions appear to be an acceptable and feasible way to deliver anti-stigma initiatives and research and can make a useful contribution to wider efforts to challenge stigma.

### 5695 | Are people with IDD left out of disability studies?

V. Williams; B. Richards

*Norah Fry Centre for Disability Studies, University of Bristol, Bristol, UK*

**Description**: We have done research together with people with intellectual disabilities (IDD) for the last 20 years. But this research does not always fit with "Disability Studies". At a conference in Lancaster, UK in September 2016, a speaker said that she'd noticed research about IDD was not in the Disability Studies journals. Why are there two different worlds of research here?
**Contribution**: We will talk about inclusive research. How does it fit with the main ideas in Disability Studies? Our own recent research has looked at social practices, and how disabled people get left out. People with intellectual disabilities (IDD) can get left out, even in the Disability world. Things are often too hard to understand. We will show part of a video we have made for the journal "Disability & Society" to try to make things easier to understand for people with IDD.

## 3. NEW CONCEPTUALISATIONS & (INTELLECUAL) DISABILITY

### 5667 | The inter-relational model of disability: a new way of conceptualising disability

L. Elliott-Graves

*Goldsmiths, University of London, London, UK*

**Description**: This paper presents a new way of understanding disability through a new model devised to address the limitations of the social model in scholarship and practice. The Inter-relational model of disability asserts that the disability lies not in the barriers an individual faces alone in society and that the solution is not always structural social change. Rather, disability is the assembly of barriers two or more individuals face between them when limitations in their communication and understanding prohibit them from interacting effectively and fairly. Thus the "problem" of disability lies between the people interacting and the solution is for all parties to work to bridge the gap between them.
**Contribution**: This model can radically change the way we think of disability by emphasising a shared experience of disability between disabled and non-disabled individuals and revealing that disability exists not in the individual or their experience but within interactions and shared experiences. This model is radical in finding a way to remove disability completely from the identity of an individual with impairment by focusing on a specific and temporal experience of barriers and not a sum of experiences an individual accumulates.

### 5856 | Identity, intersectionality and intellectual disabilities

R. Northway

*School of Care Sciences, University of South Wales, Pontypridd, UK*

**Description**: Personal identity is shaped by many factors. In intellectual disability research and practice, however, the focus is primarily upon individuals being considered to have an intellectual disability. In many ways, this becomes a "master status" and a lens through which the lives of individuals are viewed but may not reflect how an individual self-identifies and overlooks the ways in which elements of identity interact and impact. Intersectionality offers an alternative analytical approach which focuses on the complex ways in which different factors intersect to shape life experiences. To date, however, intersectionality has not been widely used as an analytical tool in intellectual disability research.
**Contribution**: Intersectionality combines both critical inquiry and praxis: it has implications for research and practice. This presentation will use an intersectionality framework (Hill Collins and Bilge, 2016) to argue that adopting such an approach offers an important basis for intellectual disability research and practice. Six areas will be explored: social inequality, power, relationality, social context, complexity and social justice. Examples will be explored and an argument presented that wider adoption of an intersectional approach in both research and practice could promote greater social justice and protection of rights for people with intellectual disabilities.

### 5553 | Séguin and the arising of a formative approach of mathematics education for people with intellectual disabilities

E. Gil; A. Millán Gasca

*University of Zaragoza, Spain*

**Description**: We show the central role of geometry in the outlook of the French pedagogue and philosopher of education Édouard Séguin (1812-1880) regarding the education of children affected by some intellectual disability. He developed activities on geometrical comparison, as a first step in the transition from notions – concrete conceptions obtained thanks to perception of physical world – to ideas – abstract and existing only in human´s mind, emerging from connections among notions –. Séguin's exercises include linear drawing (firstly considered as propaedeutic to writing), as well as comparison and reproduction of geometrical compositions by means of physical materials (regular solids designed by him). He came to identify developing children´s geometrical intuition as "forceps of intelligence". With Séguin, the formative role of mathematics – as alternative to rote training that was usual in 19th century early instruction – was extended to the so-called idiot children.
**Contribution**: The introduction of primordial geometrical conceptions in education enhances arithmetics and is helpful in the transition from "useful" calculations to understanding, growing conciousness, and the discovery of the environment. Children with Down syndrome in Spain have shown engagement when working with them, and this approach could be extended to other kind of disabilities,following the path opened by Séguin.

### 5908 | How is intellectual disabilities conceptualised and operationalised in developing countries? Learnings from Lao PDR

S. Thoresen

*Curtin University, Australia*

**Background**: International development efforts are increasingly disability-inclusive. However, disability is poorly understood and there are a multitude of misconceptions, even more so around intellectual disabilities. This presentation draws on two research projects in Lao PDR related to improving the conceptualisation and operationalisation of disability in data collection and through capacity building through training of key stakeholders.

**Method**: Both projects included substantial quantitative and qualitative data collection around persons with disabilities in Lao PDR based on the Washington Group Short Set of Questions. This included data collected for the 2015 National Household Census and a large scale survey across three provinces in late 2015. This presentation presents findings from surveys and interviews with key stakeholders involved in data collection and data analysis, as well as information collected from key informants working across intellectual disabilities.

**Results**: These projects identified that the understanding of disability generally and intellectual disabilities specifically is developing, and there is a need for improved and consistent conceptualisation and operationalisation of intellectual disabilities, including data collection and dissemination, to improve local and international disability-inclusive development efforts.

**Conclusions**: Conceptualising and operationalising intellectual disabilities in Lao PDR has been challenging, and efforts should continue to build capacities across the sector.

## 4. SELF ADVOCACY

### 5600 | Exploring perspectives of persons with intellectual and developmental disabilities and their caregivers towards self-advocacy in Singapore

V. Manokara; J. Chan; L. Lai; M. Khoo; A. Ho; M. Lee

*MINDS, Singapore*

**Background**: Self-advocacy has been shown to contribute to improvements in outcomes such as employment, community inclusion and quality of life. Led by social service organisations and with government support, self-advocacy among persons with disabilities has been receiving greater focus internationally. In Singapore, a first self-advocacy group for persons with intellectual disabilities was set up in 2017. The aim of the present study is to explore views of self-advocates and their caregivers on self-advocacy in Singapore.

**Method**: Semi-structured interviews were conducted with 25 persons who are part of the self-advocacy group and 17 caregivers. Data collected was thematically analysed.

**Results**: Data analysis is ongoing and the findings will be presented at the conference. Preliminary findings indicate that self-advocates were empowered to speak up and exercise their rights and responsibilities as evidenced by the sharing of their experiences and that of their parents.

**Conclusions**: The findings have important implications in terms of justifying the continued support for self-advocacy in Singapore as well as improving instructional planning and curricular design for self-advocacy programmes.

### 5755 | History, identity & rights

B. Poudel

*National Rehabilitation Centre of the Disabled Nepal, Nepal*

**Background**: I was born with Polio in the country side of Nepal called Syangja District. My father was a person with intellectual disability and mother was a house-wife. I didn't get schooling until I was 12 because of poverty, disability and physical barriers. I used to work hard to prepare food, cleaning-house etc. as my parents used to go away for farming, grazing-cattle and cutting grass. There was no chance of treatment in a hospital due to lack of awareness about polio and because of my poverty. Superstitious beliefs and stigma about the causes of disabilities were widespread. Hardly, the God saved my life. Considering my disability and stigma, my parents migrated to plain-area of the country. After that, I started school and was always first in the class. At the age of 27, I completed my graduation and got a good job. My parents proposed that I marry a girl who had an intellectual disability. Although I was initially not interested to marry her, I was later convinced . After marriage, we and moved to Kathmandu. Now, we have a 5 years old son and we have proved ourselves as role models to change society with self-advocacy.

### 5925 | Pathways and barriers to self-advocacy - An empirical study in the UK and Hungary

G. Petri; J. Beadle-Brown; J. Bradshaw

*University of Kent, Canterbury, UK*

**Background**: The disabled people's movement has successfully influenced policies and public discourse about disabled people. Today, disabled people's organisations (DPOs) represent disabled people around the world. However, the voices of autistic self-advocates or self-advocates with a learning disability are rarely heard even within organisations claiming to represent them. Most DPOs are still controlled by professionals, parents or people with other disabilities. Furthermore, although the United Nations Convention on the Rights of Persons with Disabilities (CRPD) states clearly that disabled people should be involved in the planning, monitoring and implementation of the CRPD, recent research suggests that self-advocates are not involved meaningfully in DPOs fighting for human rights. In the presentation the position of self-advocacy within the broader disability movement will be analysed.

**Method**: Focus groups and interviews were conducted with 44 advocates and self-advocates in the UK and in Hungary.

**Results**: Findings indicate there are multiple barriers for those wishing to self-advocate. Financial status, identity, available support and organisational practices are all important factors that influence self-advocacy.

**Conclusions**: Based on data collected, a "Pathway Model" will be presented, along with a "Barriers Model to Self-Advocacy" that may help us develop better strategies to support those wishing to self-advocate.

## 5747 | Home environment that prevents growth of self-determination and supported decision making of people with disabilities in Japan: discrimination that torment parents and person with disabilities

H. Funaya; A. Nakao; M. Motoki

*Specified Nonprofit Corporation decent work labo, Japan*

**Background**: The idea of "Dignity of risk" does not exist in Japan. Surrounded with prejudice and discrimination, parents of disabled person often value protecting their children from risks rather then teaching them. The aim of this study is to reveal this situation and create an opportunity to search for effective action or service.

**Method**: The author created a questionnaire to reveal answerer's using parental role scale and from whom the answerer feels discriminated by, and distributed to 2000 people who are parent of persons with intellectual disabilities. The author used exploratory factor analysis with promax rotation to analyze the data. Results: For parental role scale research, factor analysis revealed "negative feeling" and "attachment" as significant factors.

**Conclusions**: Services should focus on parents' attachment rather than focusing on their negative feelings, and advocate the idea of "dignity of risk".

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## TRACK 6: INCLUSIVE EDUCATION & EMPLOYMENT

### SYMPOSIA

### 1. TEACHERS' PERSPECTIVES ON INCLUSIVE EDUCATION

## 5449 | A qualitative study of the perceptions of Classroom Teachers and Learning Support Teachers about the inclusion of children with autism in Greece

K. Tzatzaki; D. Filippatou; S. Mavropoulou

*Department of Primary Education, Faculty of Humanities and Social Sciences, University of Thessaly, Greece*

**Background**: The aim of this study was to compare the views of Classroom Teachers' (CTs) with those of Learning Support Teachers (LSTs) about the inclusion of students with autism in Greece.
**Method**: We explored crucial aspects of inclusion through the lens of the inclusionary model by Lipsky and Gartner (1997) by conducting individual semi-structured interviews with 20 CTs and 20 LSTs.
**Results**: Overall, the thematic analysis of teachers' responses revealed similarities in their perceptions of challenges (behaviour management, low academic achievement, level of autism, sensory and social difficulties), the factors facilitating inclusion (i.e. LST support, peer acceptance) as well as the positive outcomes of inclusion for students with autism, for peers and the teaching staff. Moreover, both groups reported the use of similar inclusive strategies (i.e., differentiated instruction). Interestingly, only LSTs highlighted the importance of the whole school staff collaboration and it was only CTs who mentioned that inclusion contributes to the alleviation of stigma for parents of children with autism. Last, there were mixed findings on participants' views on their collaboration with each other and with parents.
**Conclusions**: It seems that mutual support among CTs, LSTs and parents required for successful inclusion has not been achieved yet.

## 5605 | The lived experiences of teachers of children with intellectual and developmental disabilities (IDD) in inclusive schools in Accra, Ghana

C. Okyere; H. Aldersy; R. Lysaght

*School of Rehabilitation Therapy, Queen's University, Kingston, ON, Canada*

**Background**: This presentation will share the results of a study that sought to understand the lived experiences of teachers of children with IDD in four inclusive schools in Accra, Ghana.
**Method**: A qualitative approach was adopted that involved semi-structured interviews with 15 regular and two special educators.
**Results**: Teachers have positive and negative experiences in inclusion. Teachers' negative experiences includes challenges with children problem behaviors', support services and parents of children with IDD. Teacher's main positive experience is the satisfaction felt when children with IDD show progress in inclusion. Teachers shared their perspectives of strategies that might facilitate inclusion of children with IDD in Ghana in the future.
**Conclusions**: This study's findings may influence practices leading to attitude change among inclusive educators and help identify specific and appropriate strategies that are tailored to the unique characteristics of children with IDD. This may facilitate inclusive environments that accommodate diversity and embrace children with IDD in Ghana and across the globe.

## 6053 | "Society for all" in the opinion of teachers from special, intergrative and regular schools

M. Skura

*Warsaw University, Warsaw, Poland*

**Background**: To explore teachers' views on a "perfectly inclusive" world vision, the study analysed their outlook on an inclusive society and the importance of an inclusive education for marginalised groups.
**Method**: The research comprised of teachers working with SEN students: 43 from integrative schools, 45 from regular schools, 42 from special schools (those with ID and autism). The data was collected using a questionnaire and the IAS by Jerry S. Wiggins.
**Results**: All groups thought that people with disabilities needed help and support. Special schools teachers' disagreed that their group were afraid of the disabled. Special school teachers' believed that the presence of refugees in society could pose a danger, whilst

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teachers from regular schools thought they were really just economic migrants. All agreed that regular schools were not the best place for pupils with SEN, except for students with MID, refugees, and those from national and ethnic minorities. Special schools teachers thought that students with an ID and autism should be educated separately.

**Conclusions**: With varying degrees of emphasis all viewed the goal of an "education for all" and an "inclusive society" as being an unrealistic expectation in the near future.

### 5657 | The potential role of special schools in supporting inclusive education for students with disabilities

T. Iacono; M. Keeffe; C. McKinstry; A. Kenny; E. Wilson; O. Landry

*La Trobe Rural Health School, La Trobe University, Australia*

**Background**: We explored the potential role of special schools in enhancing inclusive education from multiple stakeholder perspectives, and within the context of recent Australian policy review.

**Method**: Thirty staff and parents associated with mainstream and special schools participated in individual interviews. Questions addressed current needs and the potential role of supports from special schools. Qualitative analysis was guided by a framework approach.

**Results**: There were four key themes. "Scan of the current situation" included student supports through varied funding, funding gaps, and diverse student need. Parent involvement required their own initiation. Lack in confidence and skills was reported by mainstream school staff. Positive practices arose from strong individual relationships and exchanges. "What is happening" included the roles played by allied health, specialist teachers, and education support staff; opportunities for classroom observations, professional development and access to resources were valued. "What could be implemented" included extending supports across all students with disability, tailored approaches and leadership for whole-of-school commitment. "What's needed" focused on capacity building, leadership, resourcing and agreements across schools and individuals.

**Conclusions**: Special schools engaged in varied practices to support mainstream schools, indicating the potential benefits of a systematic and well-resourced approach.

## 2. INCLUSIVE TEACHING

### 5995 | Teaching methods to enhance the quality of education for children with intellectual disabilities

A. Hakim Hawach

*Helpcenter for Children with Intellectual Disability, South Africa*

**Background**: Conferring to research, the profession of teaching requires exceptional training and capability in planning lesson in accordance to its didactics and methods, however, the representation of the lesson is often adjusted to the subject rather than it being adapted to the student.

**Method**: the sample consisted of children with ID, ages ranging from birth up to 18 years. Teachers would focus on finding methods that were accustomed to the students through mutual classroom supervision/observation of other's teaching style, followed by problem-solving discussions.

**Results**: Through the observations of teachers and discussions the central finding of the study was that teachers could acquire children's interest, attention and concentration by using simple techniques that enhance their quality of education.

**Conclusion**: Based on the teacher's findings, it is advised that teachers use methods such as videotaping and supervision to obtain information about their teachers' performances. Also it serves as a basis in workshops alongside completing the list of recommendations.

### 5911 | Action research on the field trip for students with developmental disabilities in an elementary school

H.Y. Lee

*Kongju National University, South Korea*

**Aim**: The purpose of this research is to find out the practical knowledge and implications of a special education teacher in the Action Research on the Field Trip for students with developmental disabilities in an elementary school.

**Method**: Participants were a teacher as a researcher, 4 teachers as observers, 4 students with developmental disabilities. The action research was used. The researcher conducted pre-education, on-site experiential learning, and post-education for 4 times. The data in the process of design, action, observation, conference/reflection, and re-action were collected and analyzed.

**Results**: There are five top categories, which are 'preview, there is an answer in the field', 'pre-education improves learning and functions, 'how to experience is more important than where to go'and

'the growth of teachers and parents', 14 subcategories, and 47 semantic units were derived.

**Conclusion**: First, teachers should know the place in advance through preliminary exploration. Second, pre-education improves both students'learning ability and life funcction. Third, systematic operation of the field experience study improved students'safety consciousness, speaking ability, and self-esteem.

## 5660 | The contribution that Social Role Valorisation can make to inclusive education reform

G. Mann; M. Cuskelly; K. Moni

*The University of Queensland, St Lucia, Qld, Australia*

**Background**: This paper takes the ten themes of Social Role Valorisation (SRV) and reconceptualises them in the educational context. Although SRV is a theory that has a long history in human services, it is relatively underused within education systems.

**Method**: Literature regarding students with intellectual disability, and findings from a series of recent inter-connected studies, are used to illustrate the relevance and utility of SRV theory to the inclusive education arena.

**Results**: SRV offers critical insights into the experiences of students with intellectual disability. It is a particularly useful lens for examining the devaluation and wounding that are experienced by students and their families in regular schooling systems.

**Conclusions**: Many experts in the field of inclusive education ponder the challenges associated with the implementation of inclusion in schools. SRV is an established and respected theory that, when translated into the educational context, has much to offer with regard to both understanding why genuine, valued participation in regular schools and classrooms is so difficult for students with an intellectual disability, and also how that might be achieved.

# 3. PERFORMANCE & SELF-DETERMINATION IN EDUCATION

## 5415 | The performance of children with Down syndrome on a quantity discrimination task

J. Porter

*University of Reading, Reading, UK*

**Background**: Children with Down syndrome (DS) can find everyday mathematical tasks challenging. Researchers have suggested they experience particular difficulties with the foundational ability to discriminate between quantities. Typically studies involve children responding within a matter of seconds to visual patterns presented up to 100 times. These conditions raise important questions about the distinction between Can Do ? or Does do ? The aim was to investigate children with Down syndrome's responses to a card game involving discrimination between quantities.

**Method**: Two groups of children with DS ($N$ = 17 mean CA 8y8m), and ($N$ = 30 mean CA 13y7m) played the card game involving discriminating between pairs of cards with random spots ranging from ratio 1:3 to 5:6.

**Results**: Two thirds of the older group performed well on the most difficult ratio of 5:6. Chronological age proved to be a predictor of attainment. There were however notable individual differences. Performance was not as good in the younger group. Consistent with other research, children performed significantly worse on small set sizes.

**Conclusions**: The implications are that using large sets and easy ratios (e.g. 1:3 and 1:2) is more likely to promote an understanding of the relative properties of number and support the acquisition of important everyday skills.

## 5391 | Becoming literate: who me?

K. Moni; J. Lloyd

*School of Education, The University of Queensland, St Lucia, Qld, Australia*

**Background**: Literacy has an important and essential place in the education of all children, adolescents and adults. Although much has been written about the importance of becoming literate, it is not a paramount concern in most post-school environment for those with intellectual disabilities (ID). Several authors have supported various levels of access to academic and social experiences (Cook et al. 2015) but few have provided data about actual academic gains. This presentation reports on the literacy gains of 222 young adults students with ID in three countries.

**Method**: Post school, all participants took a 2 year, 2 days a week literacy and technology program (LATCH-ON), developed and researched at The University of Queensland. The program's framework was the Four Resources Model and used a range of current teaching and learning strategies. A range of standardised assessments: receptive language, reading and word knowledge were used to monitor progress.

**Results**: Due to the various factors, a growth trajectory model was used to quantify the data. Students' progress between individuals as well as within individuals was shown across the 2 years.

**Conclusions**: Young adults with ID can continue to improve their literacy skills in educational programs.

## 5466 | Impact of the Self-Determined Learning Model of Instruction on self-determination of and outcomes for youth with ID

M.I. Wehmeyer

*University of Kansas, USA*

**Background**: The Self-Determined Learning Model of Instruction (SDLMI) is an evidence-based practice to enable adolescents with intellectual disability to self-regulate problem solving to set and attain educationally relevant goals. This session will synthesize data from several recent studies on the SDLMI with youth with intellectual disability.

**Method**: Data will be reported on multiple randomized trial control group studies examining the impact of the SDLMI on student self-determination, educational goal attainment, and school and adult outcomes, including community access and employment. Participants are adolescents with intellectual disability in multiple US States ($n$ > 750).

**Results**: Randomized-trial studies have shown that provided instruction using the SDLMI, students show (i) significant gains in self-determination and (ii) improved education and transition goal attainment and greater access to the general education curriculum, and (iii) significant gains in community access and employment 1 and 2 years post-intervention.

**Conclusions**: Promoting the self-determination of youth with intellectual disability has become best practice in special education. The SDLMI is an evidence-based practice that can be used by teachers to promote self-determination, improve student self-determination, and improve student school and transition outcomes.

## 5869 | Evaluation of a self-management training for people with intellectual disabilities

J. Sandjojo; A. Zedlitz; W. Gebhardt; J. Hoekman; J. den Haan; A. Evers

*Leiden Institute for Brain and Cognition, Raamwerk, Leiden University, The Netherlands*

**Background**: To help people with intellectual disabilities (ID) lead a more independent life, it is important to promote their self-management. This study evaluated the effectiveness of a tailored, goal-directed self-management programme for people with ID.

**Method**: Seventeen people with mostly mild ID worked on self-selected goals during their training. Questionnaires addressing independence, support needs, psychopathological behaviour, self-worth, and quality of life were collected 6 months before the training, at the start of the training, and 3, 6, 9, and 12 months later. In addition, it was evaluated to what extent participants reached their training goals.

**Results**: Participants' support needs significantly decreased once they started the training. Furthermore, participants successfully made progress in attaining their self-management goals. Their level of independence did not change over time, neither as the occurrence of psychopathological behaviour, self-worth, and quality of life.

**Conclusions**: The training was found to contribute to the attainment of self-management goals and to the reduction of support needs. Further implementation of the training could not only positively contribute to the lives of people with ID, but could also reduce the burden on their support network.

# 4. CHALLENGES AND STRIDES IN SPECIAL EDUCATION IN GREECE

## 5730 | From behavior analysis to systemic behavior analysis: a synthesis of paradigms toward achieving optimal outcomes for people with autism spectrum disorder (ASD)

A. Gena

*National and Kapodistrian University of Athens, Athens, Greece*

**Background**: At times when financial constrains are prevalent and yet the needs of people with disabilities imperative, we need to maximize the use of our resources. Such is the case of people with ASD in Greece. Our resources more limited than ever and the number of children with ASD growing at alarming rates as is the case worldwide. We propose that identification of highly effective interventions for people with ASD is crucial. The purpose of this presentation is to suggest the combination of two epistemological paradigms: the Experimental Analysis of Behavior and General Systems Theory in order to address the complex needs of people with ASD and their families efficiently and effectively. Behavior Analysis offers a wide array of therapeutic techniques that can be ultimately effective when used systematically, intensively, and early on. Systemic Family Therapy, on the other hand, may complement the behavior analytic approach by offering a wide range of therapeutic applications that may facilitate the inclusion and welfare of people with ASD in the family, the school system as well as in other social contexts.

## 5732 | Individual educational programming (IEP) for ASD school-age children: challenges and benefits

T. Asteri

*EN-US, Centers for Differentiated Diagnosis, Educational Support, Greece*

**Background**: Greek SEN law declares every SEN child eligible for free education, including an IEP to follow school and therapeutic progress. Although, austerity policies are getting the better out of public SEN policies, the Centers for Diagnosis and Support of SEN children (KEDDY) are still on the spot and are charged to construct IEPs to follow school progress and the major transitions.

ASD children need the coordination, good planning, and the team work required for an IEP. Nevertheless, rarely IEP is a tribute to ASD school progress. SEN personnel working at KEDDY consider themselves unqualified to write IEPs and, although mandated by law, IEP is still the best kept secret in the field.

**Method**: Planning and assessment needs, such as checklists, ABA tools and methodology to leverage personnel's time issues, commitment, and lack of team-work culture in the educational system will be discussed.

**Contribution**: Milestones and procedures that KEDDY personnel and school teachers need to take care when developing ASD Individualized Education Programs (IEPs). Critical points during planning to ensure a substantial impact to an ASD pupil's constraints, i.e., whole school approach, bridging curriculum to individual capacity, etc.

## 5729 | Using self-management to promote the inclusion of preschoolers with autism spectrum disorder

P. Galanis; A. Gena

*National and Kapodistrian University of Athens, Athens, Greece*

**Background**: Deficits in social skills hinder progress and meaningful school inclusion of children with Autism Spectrum Disorder (ASD). Self-management procedures have adequate empirical support as far as their effectiveness in promoting social skills, school readiness, and in decreasing disruptive behavior of children with ASD. The aim of the present study is to investigate the efficacy of a behavior-analytic treatment package, including self-management procedures, prompting, and reinforcing contingencies, on teaching three preschool boys with ASD to initiate interactions with their classmates as well as to respond to their peer's efforts for interaction.

**Method**: A multiple-baseline-across-subjects experimental design was used to assess the efficacy of the intervention. Treatment fidelity and social validity measures were carried out.

**Results**: The participants achieved high rates of social interactions with their classmates without requiring assistance from a shadow teacher. Children maintained their gains following the termination of treatment.

**Conclusions**: Self-management procedures can lead to positive outcomes giving children with ASD the opportunity to participate on equal terms in school activities with their classmates and as a result develop their sense of belonging to the school system.

## 5731 | Teaching theory of mind skills and emotion expression in children with ASD

E. Tsirempolou; A. Gena

*National and Kapodistrian University of Athens, Athens, Greece*

**Background**: A considerable body of research has demonstrated impairments in social and communicative abilities as well as difficulties in pretend play among children with ASD. Theory of mind (ToM) researchers claim that the fact that the child with ASD cannot fully understand mental representations has an effect upon his ability to recognize and evaluate his and others' emotional states, and also control and express his/her feelings. We aimed to assess the development of theory of mind abilities and its effect on the affective displays of children with ASD.

**Method**: Second order-false belief tasks as well as emotion expression have been taught in four school-aged children with ASD.

**Results**: It was found that reinforcement; prompting and modeling are effective in teaching ToM skills as well as emotion expression as a means of maximizing the effectiveness of ABA treatment.

**Conclusions**: ToM and emotion skills may be viewed as aspects that may be influenced by developmental and environmental factors leading to successful communication with other children and belonging to the society.

# 5. NEW PATHS TO INCLUSION IN HIGHER AND TERTIARY EDUCATION

## 5540 | Authoring inclusion, emergence & transformative learning: co-creating inclusive learning spaces in university course settings

O. Koenig

*University of Vienna, Vienna, Austria*

**Background**: Numerous studies have stressed teacher education as being pivotal for the development and success of inclusive education, yet "the paths that teachers travel as they learn to think inclusively" (Baglieri 2008, 601) has remained under-addressed in educational research.

**Method**: For about a decade, the presenter has been involved in the facilitation of inclusive and experimental seminars with pwid at the University of Vienna. The paper uses Transformative Learning (Taylor & Cranton 2012) and Constructivist Development Theory (Kegan 1994; Baxter-Magolda 2000) as a guiding framework to make sense of the presenters own personal learning's (via autoethnography) as well as those of students (via themed analysis of submitted personal reflections).

**Results**: The research highlights the process of student`s active learning of inclusion as a complex, co-created and emergent phenomenon which requires a supportive and non-coercive learning

environment. Being able to "learn" inclusion in a collaborative and inclusive setting in an "embodied" way, seems to be another important enabling factor.

**Conclusions**: In connecting Inclusive Education and Transformative Learning Theory the papers provides insights into the dynamics and enabling factors associated with preparing educational practitioners to become active agents (authors) in the needed transformations to shape inclusive learning settings.

## 6025 | Canadian inclusive post-secondary education programs

A. Okrainec

*Brandon University, Brandon, MB, Canada*

**Background**: In this presentation, Inclusive Post-Secondary Education Programs in Canada are featured. Post-secondary education is a typical opportunity for students with Intellectual Disabilities to gain the skills and the maturity to prepare for adulthood as well as a positive future. Inclusive Post-Secondary Education Programs rest on the concept of normative pathways, avenues ordinarily pursued by people without disabilities. Prior research has shown the benefits of normalized experiences for individuals with intellectual disabilities. These benefits exist not only for students with disabilities, but also for the student body and include a long-term impact on society.

**Method**: The current research will offer a detailed examination of access to post-secondary education at Canadian universities, as advertised on the universities' websites. A content analysis of the websites will be conducted to build a picture of the nature of post-secondary inclusive education programs available within Canada. Published research into post-secondary university experiences by individuals with Intellectual Disabilities at Canadian universities also will be reviewed.

**Results**: Future research questions relating to Canadian post-secondary education programs for students with intellectual disabilities will be identified.

**Conclusions**: The current study has the potential to contribute to research, policy, and practice regarding Inclusive Post-Secondary Education Programs across the globe.

## 6021 | Inclusion and participation of students with ID in higher education: a context based integrative approach

T. Sgaramella

*University of Padova, Padova, Italy*

**Background**: Interdisciplinary efforts have greatly contributed to augment the number of students with disability attending higher education in European countries. Nevertheless, students with disability attending university are still largely under-represented, in particular students with ID. Several initiatives and actions have been described in the literature which differ either in content and in the target persons that are involved. Some of them are focused on students with disability and are aimed at providing them counselling actions, increasing their knowledge and strategies. Some are aimed at equipping the universities of centers and services for diversity and inclusion. Finally, some of these actions are aimed at involving persons working and acting in the educational contexts (Colvin, 2015; Vogel, Fresko, & Wertheim, 2007; Soresi, Ginevra, Sgaramella, Ferrari, & Nota, in press).

**Methods**: Based on results from studies and reports available in the literature on disability and more specifically related to ID issues, actions implemented, together with dimensions addressed, will be described involving (i) Students with disabilities, (ii) Professionals and teaching staff, (iii) Peers tutors.

**Results**: The study suggests the relevance and potentials of choosing an integrated and context based approach.

**Conclusions**: Guidelines and strategies have been also summarized together with methodological suggestions for effective actions.

## 5777 | Lecturer perspectives of inclusive higher education for people with an intellectual disability

F. Rillotta; D. Haig

*Flinders University South Australia, Australia*

**Background**: This study aims to explore literature related to perspectives and attitudes of university lecturers towards inclusive higher education for students with intellectual disability.

**Method**: A scoping review was conducted in order to map existing literature associated with attitudes, perspectives and experiences of intellectual disability and inclusive higher education. Relevant keyword searchers were conducted across four databases. An overview and summary of common themes within existing literature in the area will be presented and research gaps identified. Most research has been exploratory, descriptive and qualitative. Since this is an under researched topic it was necessary to broaden the review to include research about perspectives and attitudes of the broader community, including university peers without intellectual disability and family members.

**Results**: Perspectives are varied, with some holding positive attitudes and others expressing concerns. This research found that inclusive higher education for people with intellectual disability is an under researched area and Lecturer perspectives have not yet been extensively reviewed.

**Conclusions**: Understanding the perspectives of university teaching staff is critical to ensure successful inclusion of students with intellectual disability. University staff play an important role in the university experience; therefore, it is important to research their attitudes, opinions and experiences.

## 6. TECHNOLOGIES SUPPORTING INCLUSIVE EDUCATION

### 5793 | Our school speaks AAC

A. Neeman; J.T. Najjar

*Oranim Teachers College, Israel*

**Background**: This study evaluates an Augmentative and Alternative Communication (AAC) implementation project in a school for students with Autism and Intellectual Disabilities. Assimilation of AAC in schools is essential for providing communication opportunities among the students. This process included providing knowledge and skills to the school staff. Outcomes and discussion will be presented.

**Method**: A mixed method was used to evaluate the effect of a 2-year project and its outcomes. In the first year, a leading multi-disciplinary team participated in a 60 h AAC educational training program. In the second year the leading team implemented AAC within the school. AAC assimilation was carried out in four different modules. The study examined the teachers' attitudes, AAC-knowledge and practicable abilities. Data was collected by analyzing the outcomes of discussions and questionnaires.

**Results**: Teachers who participated in all modules had the highest sense of AAC competence. These teachers were also the leaders in implementing AAC. All the teachers reported high degree of satisfaction.

**Conclusions**: This study provides an AAC intervention model for multi-disciplinary teams in schools. Validating the multi-dimensional intervention model is a starting point for implementing AAC in a variety of schools and within the community.

### 5889 | Co-designing on-line modules to strengthen the capacity of mainstream schools to support students with disability

T. Iacono; N. Hyett; K. Bagley; C. McKinstry; M. Keeffe; O. Landry

*La Trobe Rural Health School, La Trobe University, Australia*

**Background**: We aimed to evaluate the process and outcomes of co-designing on-line modules on collaboration in developing supports for students with disability across education and therapy services.

**Method**: Co-design workshops with parents, teachers and allied health professionals began with developing two authentic cases of primary school students with developmental disability. The two cases became the focus for designing supports for each student's developmental, academic and functional needs within and outside school. Data from participants is informing module content and design; surveys of external stakeholders following review of the modules will provide evidence of their usability and translation to student outcomes.

**Results**: Co-design participants found module content on policy, and research evidence for enhancing inclusive education useful, and the design features user-friendly. The case development process and outcomes reflect complementary expertise, and varied experiences regarding education and therapy services for children with disability. Group dynamics have evolved, as members considered their own and others' expertise and contributions to achieving the best student outcomes.

**Conclusions**: Collaboration around student-focused needs may require a shift in usual ways of working to ensure inclusive supports for students with disability. External evaluation will indicate the usefulness of modules for a wider group of stakeholders.

### 5594 | Mapping the design features of Assistive Technology for Cognition (ATC) specific to employment-related outcomes for individuals with intellectual and developmental disabilities to cognitive functions: a methodological enquiry

D. Damianidou; M. Arthur-Kelly; G. Lyons; J. Foggett

*The University of Newcastle, Callaghan, NSW, Australia*

**Background**: This research aims to map two constructs. The first construct is employment-related Assistive Technology for Cognition (ATC) design features (henceforth referred to as design features) for individuals with Intellectual and Developmental Disabilities (IDD). The second construct is cognitive functions (attention, memory, etc.). Cognitive functions are defined by the WHO's International Classification of Functioning, Disability and Health.

**Method**: The project will identify the relevant studies and extract the design features used. A map of these two constructs will be generated by using a survey of the authors of these studies. Finally, consensus will be sought between the authors on the mapping of the two constructs.

**Results**: This study's primary contribution is the formation of a common language and shared understandings for ATC researchers, support professionals, and users in the international community regarding these constructs. This study contributes a methodological inquiry into mapping these constructs, as methodological focused studies have not been previously reported in this research area. Additional contributions include the generation of a map of these two constructs which could later be used to assist both individuals with IDD and stakeholders to prescribe the employment-related ATC that best meets the individual's needs for a given employment task.

## 7. INCLUSIVE EDUCATION: POLICIES AND CHALLENGES IN DIFFERENT COUNTRIES

### 5752 | Education policies for children with intellectual disabilities in Nepal

R. Dhungana

*National Rehabilitation Centre of the Disabled, Nepal*

**Background**: The Constitution of Nepal-article 31 mentions the rights to inclusive education and employment of people with disabilities. The Government has adopted School Sector Development Plan and endorsed a policy of inclusive education. Some children with ID have been integrated into mainstream schools. Nepal's achievements in access to education and employment have not yet ensured for CwDs in quality education, including low participation in mainstream classrooms. Schools-particularly in rural areas, fail to ensure accessibility to provide inclusive teaching-learning activities, a situation is worsened even more by the earthquakes-2015. By the adopting of inclusive education-policy 2017, the Government has scheme of strengthening the institutional capacity to provide inclusive education for CwDs and establishing partnerships with non-state actors and local bodies to respond to the needs of children with diverse or intellectual-disabilities. This may include the creation of conducive conditions for the full participation of CwDs in mainstream-schools, which will promote inclusive education. There are still enormous challenges to bring CwDs in mainstream education. Still ID children have the least access to basic education. Key-issues are: Increasing their educational attainment entails institutionalizing support for inclusive post-secondary and life-long learning education and training on-the-job, employment, livelihood and inter-sectionality assessment for their self-employment.

### 5763 | Inclusive education and teacher qualification in Germany: data, models and policy

H. Goll

*University of Erfurt, Erfurt, Germany*

**Background**: Germany has one of the most differentiated school systems in the world. For each type of disability, there is a specialized school. This traditional system requires a categorical and highly specialized structure of teacher training. In 2009, the CRPD entered into force and lead to an increase of inclusive schools, while many special schools were closed.

**Method**: Data reveal significantly different rates of inclusion across the federal states. Only few regular schools accept students with profound intellectual and multiple disabilities, whereas special schools do not reject any applicant because of the high intensity of support or the severity of disability.

**Results**: Cooperational models between regular and special schools are frequently used to create partially inclusive environments for shared learning experiences.

**Conclusions**: The process of transition to an inclusive education in practice results in different models of teacher qualification and educational policy across the federal states of Germany.

### 5888 | Role of development partners in making education accessible for children with disabilities: case study from Ethiopia

J. Siska; J. Beadle-Brown

*Charles University, Prague, Czech Republic*

**Background**: The challenge of turning inclusive education from ideology to reality is well recognised. This paper draws on experience from Ethiopia, where there has been significant progress in making general education accessible to children with disabilities. The aim of this paper is to map strengths, weaknesses and lessons from a project funded by the Finnish government, supporting teacher education colleges and inclusive education resource centres.

**Method**: This case study brings together data from a range of different sources including official statistics on school attendance and progression, surveys and interviews with teachers and reflections of the project team.

**Results**: It was found that the project had enhanced professional capacity of schools and communities to accept children with disabilities leading to an increase in school enrolment of boys and girls with disabilities and a decrease in dropouts. However, a number of challenges in terms of sustainability of project results have been identified. These challenges, along with lessons for both design and evaluation of projects aimed at improving inclusive education will be discussed.

**Conclusions**: This study contributes to understanding of the practice of facilitating inclusive education for children with disabilities that will have relevance beyond Africa.

### 5893 | Crossroads – (forced) migration, disability, and education along borderlands

M. Proyer

*University of Vienna, Vienna, Austria*

**Background**: This study aims to shed light on the triangle (forced) migration, disability, and education of people living in physical border zones (using the example of Thailand/Myanmar). Additionally, borderlands can be interpreted and are explored as mental modes of transition (i.e. Austria) where people forced to flee live in passage between arrival and inclusion or exclusion from their host country's community. Qualitative collaborative transcultural study set along physical (so far Thai/Myanmar border) and mental (so far Austria) borderlands.

**Method**: Data conducted so far consists of interviews with rehabilitative staff working in camps along the Thai-Myanmar border, special education teachers in Thai schools near borders, people with disabilities and forced migration background in Austria. Research design and steps in analysis are coordinated in a Thai – Austrian transcultural research collaboration.

**Results**: Initial findings show that the intersection disability and forced migration has only been explored on a very basic level and further research is needed. Setting research against the background of actual and thought borderlands offers steps ahead.

**Conclusions**: Borderland studies have so far not been utilized in exploring the education of persons with disabilities at the nexus of (forced) migration. Thus, this study is to shed a new perspective on intersection.

## 8. EDUCATIONAL SUPPORTS

### 5398 | A role of educational setting in ToM development among children with MID and without disabilities

J. Smogorzewska; G. Szumski

*Poland*

**Background**: The main aim was to observe how ToM develops in different educational settings. The relationship was checked among children with and without disabilities.

**Method**: In the study 426 children (M age = 7.8, SD = 0.9) with mild intellectual disability (MID) and without disabilities (WD) participated. Children attended different educational settings: general education (without children with disabilities), inclusive (with 1–2 or 3–5 children with disabilities in the classroom), or special (for children with disabilities). Children participated in a longitudinal study with 3 measurement waves (10 months breaks). Each time children were asked to solve tasks from the ToM Scale, The Chocolate task, and The Faux Pas Test. Children took part in the study individually, in a quiet room.

**Results**: Children in all groups significantly improved their results in ToM across time. Learning in inclusive classrooms is more beneficial for all children than learning in other settings. Possible reasons for such result are: more diverse structure of the classroom, more occasions for contact with differently functioning children, more opportunities for helping each other.

**Conclusions**: The results are important for educational practice, they show inclusion as a beneficial environment for theory of mind development for children with and without disabilities.

### 5382 | Ducks on the Moon – a play with music: an arts-based inclusive educational research (ABER) project

S. Thompson

*University of Regina, Regina, SK, Canada*

**Background**: Burke's "Ducks on the Moon," (2010) is a one-person drama and non-fiction memoir, about disability to which seven songs were written and added. The aim of the transformation from play to musical was three-fold: firstly, to understand how artistic practices may impact understandings around parental acceptance of ASD/IDD; secondly, to document how the change from play to musical impacted its message; and thirdly, to explore teacher reactions to the musical as a part of inclusive education and arts education curricula.

**Method**: Performative Inquiry is a particular kind of ABER, in which an artistic practice is both a vehicle and artifact of research. After careful readings of the script, Thompson composed songs and the musical was twice performed as a preview. Two groups of participants watched the final run-through, inclusive education and arts education teachers. Focus group interviews were conducted with each group.

**Results**: Data were coded, categorized, and then presented thematically. Several themes emerged, including: the musical as professional development, as promotion of emphatic understanding of parents and mothers in particular, and the songs as reinforcing key inclusive educational concepts.

**Conclusions**: This study promotes teacher empathy for parents and guardians of those with ASD/IDD.

### 5387 | Social inclusion for a student with intellectual disability and mainstreaming educational interventions in middle school of Peloponnese

M. Drossinou-Korea; N. Panopoulos

*School of Humanities and Cultural Studies, Faculty of Philology, University of Peloponnese, Greece*

**Background**: The social inclusion for the students with intellectual disability (ID) have been a research object of the scientific community. In our work we describe the mainstreaming educational interventions in middle school of Peloponnese. Contemporary society has understanding of the ID as learning disabilities in the form of students experiencing school failure because of an inability to acquire, assimilate, or retain academic content. The social inclusion as a complex difficulty have been involved in the main topics of the Special Education.

**Method**: Applying the methodology of observation and intervention of students with ID we implement the Targeted, Individual, Structured, Integrated Program for Students with Special Educational

Needs (TISIPfSENs) by examining the mainstreaming educational interventions. We have focused on whether students with ID can been taught sight words with word decoding activities that will enable them to read these words in small texts.

**Results**: The results have shown that the social inclusion for students with ID can benefit from phonological word processing to read short texts mainstreaming such as comics into the educational interventions in middle school of Peloponnese.

**Conclusions**: The clash between understanding has created controversies to the students with ID, so, mainstream education interventions have come to bridge them.

## 6007 | Access to the curriculum for pupils with developmental disabilities learning through their second language in Wales

L. Jones; J. Ware; E. Tyler

*Bangor University, Bangor, UK*

**Background**: The complexity of supporting pupils with developmental disabilities (DD) who are learning English as a second language is increasingly recognised. In Wales, learners with ID may be learning through Welsh when this is their second language. There has been little research into how this group of pupils can be supported. This study aims to investigate factors affecting curriculum access for pupils with DD who are learning through their second language in Wales.

**Method**: The research adopts a mixed methods approach. In Phase 1, data were collected through lesson observations and semi structured interviews. In Phase 2 the practices, attitudes and perceptions of a much wider group of teachers were surveyed. Analysis of lesson observations and semi-structured interviews from Phase 1 were used to identify strategies used to support curriculum access for this group of learners.

**Results**: These formed the basis of the Phase 2 survey, which will provide further insight into current practices, exploring teacher attitudes and highlighting challenges teachers experience when providing curriculum access to learners of different ages.

**Conclusions**: The study will provide evidence on how children with DD can be supported to access the curriculum in bilingual settings, and enable the development of evidence-based practice.

# 9. SUPPORTED EMPLOYMENT AND JOB COACHING

## 5402 | Job coaches and specialists in supported employment

F. B. Jordán de Urríes

*Institute on Community Inclusion (INICO), University of Salamanca, Salamanca, Spain*

**Background**: Two studies have been developed with the objective of analyzing the professional skills, training and training demands of job coaches to enable the design of training according to their needs.

**Method**: For the first study, information was gathered from a sample of 58 job coaches and 23 supervisors through a questionnaire. The information gathered included several areas such as the previous training of the job coaches, their training demands, the relevance and workload of their professional competences. For the second study, a sample of 89 students of a job coach training course was used, analyzing from a qualitative approach their vision about their professional identity.

**Results**: The results have allowed first to determine a set of professional competencies of special relevance and needing a greater workload, and training needs. Second, we extracted information about the vision of the job coaches themselves in relation to five dimensions: Functions, Qualities, Skills, Knowledge and Professional identity.

**Conclusions**: A clearer vision of job coach competencies, training needs and professional identity has been obtained facilitating the implementation of an Online Training Program. Two promotions have been run with a great reception and success and with national and Ibero-American potential for delivery.

## 5403 | Practicapaces and Yotuel: University disability and employment

F. Borja Jordán de Urríes

*Institute on Community Inclusion (INICO), University of Salamanca, Salamanca, Spain*

**Background**: Two programs have been developed. First, the Program of Labor Practices for People with Intellectual or Development Disabilities (PWIDD), "PRACTICAPACES" with objectives of: (i) Increasing possibilities of accessing to the labor market for PWIDD and (ii) Increasing the possibilities of employment access for Occupational Therapy (OT) and Master's Degree (MD) students through practical work experiences. Second, the "YOTUEL" Shared Activities Program, focused on the promotion of participation, contact and knowledge of PWIDD, in an inclusive manner, with the students of the faculty, through the development of shared leisure activities.

**Method**: Practicapaces is focused on the practical training of PWIDD in specific areas based on the methodology of supported employment and collaboration of Fourth Course Students of OT and the MD in Disability Research. Yotuel encourages participation, contact and knowledge with a playful motivation, with suggestive activities for all, facilitating the participation of all, and preparing and sharing among all.

**Results**: Seven participants with IDD and seven students have participated in Practicapaces and about 100 people in Yotuel. Satisfaction of participants and personal outcomes in job competencies have been achieved.

**Conclusions**: More opportunities of real experiences for in PWIDD in real context in the university framework are needed.

## 5405 | Outcomes of the engage to change project-supported employment for young people with a learning disability or ASD

E. Vigna; S. Beyer; A. Meek

*Cardiff University, Cardiff, UK*

**Background**: The Engage to Change project helps young people with a learning disability or ASD in Wales to get placements and then paid jobs, using supported employment and internship methods. The paper presents data on placement and job outcomes over 2 years of E2C operation.

**Method**: Data was collected on young people registering on E2C, on the placements they attended, and the paid jobs they achieved. The nature and level of job coach involvement was collected and related to outcome. Data was collected on iPads by job coaches.

**Results**: The results are still being collected, but Year 1 data suggest there are positive relationships between job outcomes and hours of job coach input, time spent on job finding, and workplace support. Vocational skills were found to improve over time through work-based learning.

**Conclusions**: Job coach solutions can improve vocational skills, engage employers positively and gain paid jobs for people with a learning disability and ASD. Job coaching needs to be delivered at particular levels and incorporate key actions if it is to be successful. Strategies for changing investment to "what works" are briefly discussed.

## 5406 | Outcomes of the engage to change project SEARCH scheme in Wales over its first 2 years

A. Meek; S. Beyer; E. Vigna

*Cardiff University, Cardiff, UK*

**Background**: The Engage to Change project (E2C) helps young people with a learning disability or ASD in Wales to get placements and then paid jobs, using supported employment and internship methods. E2C currently offers two internship programmes using the Project SEARCH model of a 1-year internship with a large employer. The paper presents data on outcomes over 2 years of operation.

**Method**: Data was collected on young people registering on E2C Project SEARCH, on the placements they attended, and the paid jobs they achieved. Feedback came from interviews with young people and families, and questionnaires completed by mentors and departmental managers.

**Results**: Nearly 100, 10 week placements have been delivered. Feedback from families and young people is very positive, particularly about changes in the young person. Mentors and managers are positive but identify factors underpinning success of internships for them. Final data on job outcomes are still being collected but paid employment rates of over 60% have been achieved.

**Conclusions**: Internships can improve vocational skills and personal performance in work and life. Job coaching and targeting curriculum support are key. Strategies for engaging the employer, their operational managers, and mentors are discussed.

# 10. MENTORING AND (UN)EMPLOYMENT

## 5520 | Health and well-being outcomes from a community mentoring program for unemployed young adult males with intellectual disability (ID)

R. Cordier; A. Buchanan; B. Milbourn; N. Wilson

*Curtin University, Australia*

Unemployed males (aged 17–24) with ID.

**Method**: A quasi-experimental pre-post design was utilised to provide a social inclusion intervention of older community-based adults ($n$ = 22) being trained to mentor young adults with ID ($n$ = 16) over a 6-month period. Mentors supported the young adult to participate in a range of structured construction activities, develop work routines and join in social events at the community organisation.

**Results**: All mentees finished the 6-month program and many continue to participate in activities at the community organisation after the 6-month program. Mentees were individually supported at 7 different locations across Perth, Western Australia. We will report on program outcomes, including generativity and wellbeing (for mentors), and mental health, loneliness and work related skills (for mentees). All mentees have now added the experience from the program onto their CVs as they develop their employment skills.

**Conclusions**: Mentoring programs at community-based organisations are ideal places for unemployed people with ID to learn work related skills, develop work routines, and become more socially confident.

## 5521 | Community based mentors talk about their role and experiences when mentoring unemployed young adult males with intellectual disability (ID)

N. Wilson; A. Buchanan; B. Milbourn; R. Cordier

*Australia*

**Background**: To discuss the perspectives of older male mentors in an Australian intergenerational mentoring program for unemployed males (aged 17–24) with mild-moderate ID. Mentors were provided training to offer individual guidance, on the same weekday and same duration of time, for activity and social participation to mentees over a 6-month period.

**Method**: Individual interviews with older male mentors were conducted by a researcher not known to the mentors; interview data were thematically analysed using the constant comparative method.

**Results**: All mentors reported how they enjoyed being a mentor and felt that the young adult males with ID greatly benefited from their guidance. Mentors perceived that the development, over time, of work-like routines was one of the most important parts of the program, rather than either the attainment of skills or the participation in social activities. Mentor training and graded support from trained researchers was a vital part in the success of the program.

**Conclusions**: Formal mentoring programs at community-based organisations can help unemployed young adult males with ID develop work skills, routines and social awareness as well as building self-confidence.

## 5522 | Young unemployed adult males with intellectual disability (ID) and their caregivers talk about the impact of a mentoring program on their lives

A. Buchanan; N. Wilson; B. Milbourn; R. Cordier

*Curtin University, Australia*

**Background**: Young adult males with ID participated in a mentoring program where they received support from older male mentors as they developed work skills-routines and increased opportunity for positive social interaction. This paper presents the views of mentees and their caregivers about the program and the impact on the mentee's life and future employment prospects.

**Method**: Individual interviews with mentees and a primary caregiver were conducted in the community and subsequent interview data thematically analysed.

**Results**: All mentees stated that they thoroughly enjoyed the program and felt immense pride in the skills they had learnt, the tools they could now use, and the various things they made. All mentees have now added useful and meaningful content to their CVs as they continue to seek ongoing employment. Caregivers reported that mentees experienced an observable lift in their self-confidence and had also developed or honed other skills, such as travel skills and work routine behaviours.

**Conclusions**: Young unemployed adults with ID face significant barriers to gaining employment including stigma and lack of opportunities. Mentoring programs such as this offer them the chance to develop skills, build confidence and add to their CVs in a structured way supported by trained mentors.

# 11. VOCATIONAL EDUCATION AND EMPLOYMENT FOR ADULTS

## 5845 | "Me and My Age": A seniors course for people with intellectual disabilities, promoting good health in old age

L. Kristiansen

*Norwegian National Advisory Unit on Ageing and Health, Norway*

**Background**: About 50 Norwegian people with intellectual disabilities, 31–67 years old, have been participating in a new 2-day course (2017/2018), to learn about promoting good health in older age. To maintain good health and be prepared for changes that may come, it is advisable to have knowledge about aging, who to contact when health challenges occur, and how to live healthy and well-adapted.

**Method**: The course has been held in smaller groups, with appropriate information, with a nurse and a social educator as teachers.

**Results**: A systematic evaluation indicates that the course was very useful and informative for everyone involved. The course follows the recommended guidelines for facilitated education prepared by Inclusion Europe, Lifelong Learning Program.

**Conclusions**: The goal of "Me and My Age" is to offer senior courses to people with intellectual disabilities, and to develop easily accessible and customized information about health in older age. This can increase knowledge for both people with intellectual disabilities and their service providers. This present and proposed presentation at the 5th IASSIDD Europe congress will be about our experiences from the 8 first courses, what went well, which challenges occurred, and; some advice for others wanting to start a seniors course.

## 6055 | Employment as perceived by adults with intellectual disabilities: a focus group research

K. Ćwirynkało; U. Bartnikowska; A. Żyta; S. Przybyliński

*University of Warmia and Mazury in Olsztyn, Poland*

**Background**: Work has been considered as an essential element of personal identity that shapes individual behavior and allows an individual to gain independence, economic self-sufficiency, create social

networking and community inclusion. This paper draws attention on the perception of employment as expressed by adults with intellectual disabilities (ID).

**Method**: Using a qualitative approach and a focus group methodology, the authors have undertaken research with 48 adults with mild to moderate ID. The research questions were as follows: (i) What definitional frameworks for employment are given by adults with ID? (ii) What contextual factors and environmental demands are identified by adults with ID as influencing their own and other people with ID career opportunities? (iii) What supports and support needs for employment are described by adults with ID? In order to address the research questions, six focus group interviews were conducted between June 2017 and January 2018.

**Results**: The results show some crucial categories: self-awareness of being an adult (and belief that work is a natural element of an adult's life), individual strategies of job searching, passions and professional skills, health state, and gender as well as local opportunities and vocational rehabilitation as factors differentiating career opportunities.

**Conclusions**: Implications for practice are discussed.

## 5863 | Change in employment status of adults with ID in Ireland: data from the IDS-TILDA study

R. Stancliff; E. McGlinchey; P. McCallion; M. McCarron

*University of Sydney, Australia*

**Background**: To examine changes in employment status of adults with an intellectual disability longitudinally across 2 Waves of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA), to understand the predictors, and outcomes of employment.

**Method**: 753 adults with ID participated in Wave 1 of IDS-TILDA, of which 701 completed Wave 2. Measures included demographics, employment, health status, social participation, and life satisfaction. Bivariate and multivariate analyses explored the relationship between employment and health and social factors.

**Results**: Of the 41 participants who had a mainstream job in wave 1 for whom employment data were available in wave 2, 63% were still working in a mainstream job at wave 2. Of the 81 who were in sheltered employment in Wave 1, 16.7% were in sheltered employment in Wave 2. Change in health status was a predictor of employment status, but age and living circumstances were not.

**Conclusions**: Mainstream employment is experienced by only a minority of individuals from IDS-TILDA. Investigation into the services used after a change in employment status is needed.

# 12. EMPLOYMENT: VOICES OF PERSONS WITH INTELLECTUAL DISABILITY

## 5789 | Supported employment: the experiences of people with intellectual disabilities and/or mental health problems

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*Department of Special Education, University of Thessaly, Volos, Greece*

**Background**: This study aimed to explore the experiences of workers with intellectual disabilities and/or mental health problems involved in supported employment programs in Greece. Specifically, the participants' perceptions of facilitators and barriers to obtaining and maintaining employment during their involvement in the programs, as well as their future work-related expectations were examined.

**Method**: Fourteen workers, 9 with intellectual disabilities and 5 with mental health problems, participated in the study. Participants' age ranged from 26 to 51 years and they were recruited from three supported employment agencies in Greece. Individual semi-structured interviews were conducted and the data were analyzed using thematic analysis.

**Results**: Most of the participants with intellectual disabilities experienced confusion and anxiety during the adaptation period to the workplace and almost half of them faced challenges related to interpersonal relationships. Those with mental health problems experienced difficulties and unpleasant feelings during the job search period. Assistance in finding suitable jobs was provided to the participants with mental health problems, while on-the-job training was available for those with intellectual disabilities. All participants highlighted the importance of maintaining employment.

**Conclusions**: The findings can inform efforts on developing employment services that promote social inclusion and quality of life of people with disabilities.

## 5529 | Involvement and co-production leading to a working life

T. Doukas

*Choice Support, UK*

**Background**: This case study explores the notions of involvement and co-production leading to employment and personal fulfilment.

**Methods**: We use video interviews and participant-observation methodology for a close-up examination of the real-world context and other complex conditions to get an in-depth understanding of Laura's life, an artist with intellectual disabilities, who at the age of 30 moved into her own flat and made the big leap to independent living and was supported to launch her career with three part-time social care jobs alongside her art commitments. This methodology

presents different aspects of Laura's journey, the obstacles and successes with emphasis on how the supporters negotiated each step. We also discuss the notions of involvement and co-production as a creative and imaginative means for organisations to shift the balance of power and decision to people with learning disabilities and their families.

**Contribution**: This study illustrates the potential that people can achieve with persistence, training and the right support. From an organisational point of view, the notions of co-production and involvement create a process by which people are able not only to be actively and genuinely involved in defining the issues of concern to them but become integral part in making decisions about factors that affect their lives.

## 5929 | Participation in employment: vocational education for persons with PIMD (profound intellectual and multiple disabilities)

C. Keeley

*University of Cologne, Germany*

**Description**: The topical subject of participation presently dominates the public and scientific discourses on disability issues and leads to a changing awareness in the care systems. This can also be seen in the field of work and employment. In recent years efforts have been made to enhance the participation of people with disabilities in working life. However, current debates seem to neglect the concerns of persons with PIMD. If vocational activity is seen as an essential part of human life, it is crucial to consider ways and means of participation for everyone and, likewise, to give persons with PIMD opportunities to explore and develop this field for themselves.

**Contribution**: A substantial contribution to this could be made by vocational education. With respect to the lifelong right to education, vocational education can contribute to expanding possibilities for persons with PIMD to take part in working life. There are different didactic approaches existing in adult education as well as in education for persons with learning disabilities but they are not applied to conceptualise vocational education for persons with PIMD. The (literature) review should provide the analysis of existing approaches and their options of adaption for vocational training for this group of people to demonstrate how participation in employment for these individuals can be realized.

## 5799 | A socio-cultural case study approach to school to work transition: developing person centred job skill modules

E. Joosa; K. Devi; H. Talib; G. Teo; G. Veeramari; W. Seow

*Arts of the Earth Learning Hub, Singapore*

**Background**: This paper presents a transdisciplinary case study approach to the development of culturally sensitive workplace inclusion modules for early childhood teacher aides in Singapore. The study features a socio-cultural theoretical framework of job-skill modules that were developed as a means of transition support. On the job assessment of learnt concepts and evaluations of weekly responses of the four participants provided the data.

**Method**: The method takes on a socio-cultural-ecological framework which developed out of a combined research cum teaching approach, entrenched by current epistemologies. The analysis focused on categorising different, relevant characteristics of students' engagement and responses to the modules.

**Results**: The findings revealed the multi-layered systemic issues and the complex human-environment systems that involved students' adaptations, responses and interactions within the workplace. Analysis of their engagement allowed further strategy building, participation and on the job application.

**Conclusions**: The data emphasise the importance of evaluative case study research in school to work education and transition. The study might assist those engaged in research-based teaching to develop culturally appropriate approaches to improving sustainable inclusion practices in the workforce. Although further evidence in the field of school work support is needed, this presentation induces ideas for culturally sensitive practice-based research in school to work transition.

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## TRACK 7: HEALTH & BEHAVIOURAL ISSUES SYMPOSIA

### 1. Health 1

### 5513 | Poor oral health in adults with intellectual disabilities and its determinants

D. Kinnear; J. Morrison; L. Allan; A. Henderson; L. Macpherson; A. Sherriff

*University of Glasgow, UK*

**Background**: Adults with intellectual disabilities experience extensive health inequalities; some evidence suggests they also have greater dental treatment needs. We investigated prevalence and determinants of poor oral health in adults with intellectual disabilities.

**Method**: The adult population (16 years+) of people with intellectual disabilities living within one geographical area, were recruited. Each participant underwent a dental examination. We compared this with dental data on the Scottish general population (Scottish Health Survey). Descriptive statistics on prevalence and determinants of poor oral health were generated.

**Results**: 560 adults with intellectual disabilities participated; 298 males (53.2 %) and 262 (46.8%) females, aged 46 years (16–79). 178 (31.8%) were edentulous (complete absence of teeth) compared to 384 (15.1%) of the general population; this inequality was evident from early adulthood, and widened with progressive age groups. Edentate adults had more severe intellectual disabilities, took antipsychotic medication, and lived in both the least and most deprived areas. Type of accommodation, autism, and problem behaviours did not predict being edentate.

**Conclusion**: Adults with intellectual disabilities need proactive supportive oral care to avoid their ability to eat and quality of life deteriorating from this largely avoidable condition, regardless of where and with whom they live.

### 6023 | What type of toothbrushes are used by adults with ID to clean their teeth? Results from Wave 3 of IDS TILDA

P. McCallion; C. MacGiolla Phadraig; J. Nunn; M. McCarron

*Temple University School of social Work, USA*

**Background**: This study aims to report the frequency of tooth-cleaning techniques used by people with intellectual disabilities (ID) to maintain their oral health. A better understanding of the nature of oral-care by adults with ID would allow for accurate interventions to improve oral-care.

**Method**: Adopting a cross-sectional survey design, participants with ID aged 50 years and older in Wave 3 IDS-TILDA were asked if they had support brushing their teeth and what oral hygiene aides they used.

**Results**: 245 (40.2%) people with ID reported that they clean their teeth without assistance; 133 (21.8%) clean teeth with assistance; 127 (20.9%) were totally dependent on another person to clean teeth and 15.6% ($n$ = 95) had no teeth to clean. Only 2.3% ($n$ = 14) used floss or interdental cleaners; 388 (63.7%) reported using standard toothbrushes; 4.9% used modified toothbrushes ($n$ = 30); 8.0% used electric toothbrushes and 4.5% used other techniques.

**Conclusion**: Despite some evidence that modified and electric toothbrushes are associated with better oral health for people with ID, there does not seem to be widespread adoption of these aides. Oral-hygiene interventions should aim to introduce these aides, while accommodating the widespread use of conventional brushes. Interdental cleaning is concerningly low.

### 6003 | Contextual and conceptual conditions and potentials of professional nursing care in special schools

T. Czerwinski

*University of Cologne, Department curative educations, Professorship Barbara Fornefeld (PhD), DE*

**Background**: The present qualitative study focuses on the disciplines of education and nursing-care from a holistic and system-constructivist approach. Based on exploratory research, it examines the current structural and conceptual conditions as well as the development potentials of nursing-care structures at special schools with particular regard to their relationship to pedagogical processes.

**Method**: A research strategy was specifically developed for the current study to optimally use the triangulation of research methods and perspectives. The conditions of care-structures at special schools were observed and analyzed on the basis of 60 care situations; a special emphasis was put on the evaluation of 40 guided multi-perspective interviews with nurses, school directors, and teachers.

**Results**: Based on interviews in 30 special schools, the present evaluation of the data proves the great significance of caring for the students at special schools and reveals differentiated intersubjective results which contribute to new perceptions of the understanding of "educational nursing-care".

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**Conclusion**: As a final consequence, comprehensive recommendations could be made for the development of a future concept of educational nursing-care.

## 5964 | Laxatives use and constipation among intellectually disabled older people, prevalence, pattern and association: a cross-sectional observational study

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*Trinity College Dublin, Ireland*

**Background**: Chronic constipation is a prevalent issue in older people with intellectual disabilities (ID). Laxative use has not been adequately studied in these individuals. The aim was to examine the prevalence, pattern and dosage of laxatives among a representative sample of older adults with ID.

**Method**: Data was extracted from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA), wave two (2012–2013). Descriptive statistics, bivariate analyses and logistic regression were carried out.

**Results**: Among overall cohort *n* = 677, chronic constipation is 38.5% (*n* = 257). 281 participants (41.5%) received 431 laxatives (mean 1.53 ± 0.736), among them 74.3% (*n* = 209) reported chronic constipation. There were 40% (*n* = 113) of the users on 2+ laxatives, within which, 59% (*n* = 67) were using combination from same laxative class. Laxative users were significantly different in most demographic and clinical characteristics compared to non- users. Chronic constipation, living in residential care, exposure to anticholinergics and following soft liquidized food were significant correlates with laxative use.

**Conclusion**: Chronic constipation and the use of laxatives were highly prevalent. Use of more than one agent from the same pharmacological class was surprisingly frequent. There is an urgent need for evident- based treatment guidelines specialized for people with ID to provide effective quality of care.

# 2. HEALTH II

## 5514 | Multi-morbidity in a cohort of adults with intellectual disabilities, with and without Down syndrome

D. Kinnear; J. Morrison; L. Allan; A. Henderson; E. Smiley; S.-A. Cooper

*University of Glasgow, UK*

**Background**: Most physical ill-health and multi-morbidity studies in people with intellectual disabilities are small scale or methodologically limited. We investigated prevalence of multi-morbidity in adults with intellectual disabilities with and without Down syndrome.

**Method**: The adult population (16 years+) with intellectual disabilities living within one geographical area were recruited. Participants underwent a comprehensive health assessment. Descriptive statistics were generated.

**Results**: 1,023 people with intellectual disabilities participated; 562 (54.9%) males and 461 (45.1%) females aged 43.9 years (16–83). 186 (18.2%) had Down Syndrome. Mean number of physical health conditions/participant was 11.04; the five most prevalent were visual impairment, obesity, epilepsy, constipation and ataxic/gait disorders. 98.7% had multi-morbidity; the pattern of multi-morbidity differed to that in the general population, and was across the entire adult life course. The extent of multi-morbidity was similar in the adults with and without Down syndrome but disease clusters differed.

**Conclusion**: Using a robust study design, we report high prevalence of health conditions and multi-morbidities. Multi-morbidity increases complexity of medical management that secondary health care services and medical education are not yet geared towards, being focused on single conditions. As multi-morbidity patterns differ from the older general population, attention is needed to develop suitable care pathways/guidelines.

## 6044 | Addressing diversity and complexity in developing guidelines for the health care of people with intellectual and developmental disabilities

W. Sullivan; L. Salvador-Carulla

*University of Toronto, Canada*

**Background**: Diversity and complexity in the health care of PWIDD require types of reasoning and judgments that often draw on broader sources of knowledge than those typically considered for evidence-based medicine (EBM). These include abductive and means-ends reasoning and knowledge of the diverse perspectives and contexts of PWIDD. Systems thinking explains why, in addition to typical EBM-type knowledge, healthcare professionals need to consider expert knowledge, knowledge of the perspectives of PWIDD and their caregivers, and knowledge of local health and support systems to make sound medical and ethical judgments. These sources of knowledge can account for variability, uncertainty, ambiguity and emergence of new factors in health care of PWIDD who are a heterogeneous and diverse group of patients and often have unique and complex health needs.

**Conclusion**: Expanding the sources of knowledge considered in developing guidelines for the health care of PWIDD improves their capacity to help clinicians address diverse and complex health needs of PIWDD. We give an example of this, in developing the 2018 Canadian consensus guidelines for primary care of PWIDD.

## 5507 | Survival rates and hospitalization rates of people with down syndrome born in Scotland 1990–2015: a population based cohort study

L. Hughes-McCormack; R. McGowan; J. Pell; D. Mackay; A. Henderson; L. O'Leary

*University of Glasgow, Institute of Health and Wellbeing, UK*

**Background**: To describe survival rates and hospitalisation patterns for children and young people with Down syndrome in Scotland over a 25 year period.

**Method**: All live-births of individuals with Down syndrome, 1990–2015, identified via Scottish regional cytogenetic laboratories, each age-gender-neighbourhood deprivation matched with 5 non-Down syndrome controls, using Scotland's unique NHS identifiers (CHI). Record-linkage to routinely collected hospital statistics data (Scottish Morbidity Records 01), and National Records of Scotland death data.

**Results**: 1,458 people with Down syndrome, 689 females (47.3%) and 769 males (52.7%). In total, 96 (6.6%) people with Down syndrome had died compared to 23 (0.4%) without Down syndrome. 1,162 (78.5%) with Down syndrome had been admitted to hospital at least once, compared to 3,362 (52.1%) controls. Average hospital stay was 3.5 days for people with Down syndrome and 1.6 days for controls. Further analyses are in progress.

**Conclusion**: Children and young people with Down syndrome have high admission rates, highlighting need for family support. Survival of people with Down syndrome is improving: information on survival trends is important for families, and for service planners.

## 5506 | Prevalence and general health status of people with intellectual disabilities in Scotland: a total population study

L. Hughes-McCormack; E. Rydzewska; A. Henderson; C. MacIntyre; J. Rintoul; S.-A. Cooper

*University of Glasgow, Institute of Health and Wellbeing, UK*

**Background**: To investigate in a whole country population (1) prevalence of intellectual disabilities, and age of identification, (2) general health status compared with the general population.

**Method**: Data was from Scotland's Census, 2011. We calculated the prevalence of intellectual disabilities by age; reported general health status; and the extent of health-related limitations to daily activities. We conducted logistic regressions to determine the odds ratios of intellectual disabilities predicting poor general health, and the associations with age and gender.

**Results**: 26,349/5,295,403 (0.5%) had intellectual disabilities; 15,149 (57.5%) males and 11,200 (42.5%) females; 5,234 (0.6%) children (0–15), and 21,115 (0.5%) adults (16–75 + ). Identification of intellectual disabilities rises until age 5 years, with a further small rise by age 9. Children and adults with intellectual disabilities reported poorer general health (47.9% and 40.3%), than the general population (2.1% and 13.8%), and were more limited in activities by their health. Intellectual disabilities had an odds ratio of 9.2 (95% CI: 8.9–9.4) in predicting poor general health.

**Conclusion**: People with intellectual disabilities have poorer general health than other people, especially children and young people. Accurate information on population prevalence and health status is essential to plan appropriate resources.

# 3. HEALTH III

## 5562 | Do congenital heart defects contribute to the reduced life expectancy of females with Down syndrome?

E. Glasson; R. Hussain; D. Dye; A. Bittles

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**Background**: There is a highly significant excess of male births in Down syndrome. Yet males with Down syndrome outlive females. To investigate whether congenital comorbidities contribute to these findings, comprehensive demographic and health data have been collated on all Down syndrome births in Western Australia (WA) from 1980 and 2009.

**Method**: Data on 1,045 Down syndrome cases were identified from the WA State Disability Services files, and co-analysed with information from three complementary State health sources containing codes for Down syndrome: Hospitalisations, Death Records, and Birth Defects.

**Results**: At birth the male/female sex ratio was 1.22. Across the study group at least one birth defect was diagnosed in 852 (81.6%) of Down syndrome cases, with a sex ratio of 1.24. Congenital heart defects (CHD) accounted for 34.8% of all birth defects, and among the 379 individuals with at least one CHD the sex ratio was 0.94.

**Conclusion**: No convincing explanation has been advanced for the greater longevity of males with Down syndrome, which is contrary to the pattern observed in the general population. The present data suggest that, at least in a proportion of cases, the reduced life expectancy of Down syndrome females may be associated with CHD.

## 5517 | Prevalence and types of unexplained symptoms in adults with intellectual disabilities

D. Kinnear; M. Osugo; J. Morrison; L. Allan; S.-A. Cooper

*University of Glasgow, UK*

**Background**: Medically unexplained symptoms and signs are common in the general population, and respond to appropriate managements, but is less investigated in adults with intellectual disabilities. We investigated types and prevalence of unexplained symptoms and signs in adults with intellectual disabilities, and associated factors.

**Method**: In a population-based study, adults (16 years+) with intellectual disabilities living within one geographical area were recruited. Detailed health assessments systematically considered symptoms and signs. Descriptive analyses generated types and prevalence of unexplained symptoms and signs; regressions determined associated factors.
**Results**: 1,023 people with intellectual disabilities participated. Medically unexplained symptoms and signs were present in 664 (64.9%), 3.8 times higher than the general population. 470 (45.9%) had multiple unexplained symptoms or signs. Some were similar to reports in the general population (e.g. dyspnoea, dyspepsia, headache, nausea, dizziness), whereas others were not (e.g. dysphagia, ataxia, polyuria, oedema, skin rash). Unexplained symptoms and signs were independently associated with older age, female gender, not having Down syndrome, extent of intellectual disabilities, and more GP visits, but not with living in deprived areas, type of living/support arrangements, number of hospital visits, smoking, autism, problem behaviours, or mental disorders.
**Conclusion**: People with intellectual disabilities have substantial additional unexplained painful/disabling symptoms and signs.

## 5465 | Pilot feasibility study of the Walking Away from Diabetes program for adults with ID in two further education colleges

A. Maine; M. Brown; A. Dickson; M. Truesdale
*Xxxxxx*

**Background**: People with ID remain at high risk of developing type 2 diabetes (T2D) due to lifestyle associated risk factors, such as diets high in saturated fats and low physical activity levels. Structured educational interventions have been adapted to the needs of people with ID which target ongoing T2D self-management. However, there are no adapted programs which aim to prevent T2D through reducing risk factors. The present study initiates the addressing of this gap.
**Method**: Two further education colleges in Scotland were recruited to take part in a feasibility study using the Walking Away from Diabetes program for people with ID. A process evaluation was conducted which assessed recruitment, retention, acceptability and accessibility, using the discussions from four focus groups of students and teaching staff. Baseline ambulatory activity and physical activity knowledge was recorded as secondary measures.
**Results**: Results of the demographic data and analysis of focus groups will be presented, highlighting the student and teaching staff experiences of participating in the program.
**Conclusion**: Findings will be discussed alongside mainstream studies and adapted self-management programs. Implications for further research, policy and practice will be raised.

## 5375 | Making reasonable adjustments to osteoporosis assessment and screening for people with intellectual disabilities

J. Finlayson
*Glasgow Caledonian University, UK*

**Background**: People with intellectual disabilities (IDs) are a high risk population for developing osteoporosis, due to factors which are Specific to this population (Down's syndrome, antiepileptic medication and immobility). They experience barriers to accessing osteoporosis assessment and screening (gold standard DXA scans). The aim was to identify and implement reasonable adjustments with a convenience sample of adults with IDs and their supportive carers, to enable DXA bone scans.
**Method**: 30 adults with IDs (mean age 44 years) completed DXA bone scans once reasonable adjustments (e.g. use of a hoist or more time during appointment) had been identified and implemented. Post-scan, participants, their supportive carers, and the osteoporosis health professionals provided feedback.
**Results**: 29 adults with IDs completed a hip and spine DXA scan, and 1 participant completed a wrist and forearm DXA (as a reasonable adjustment), but their individual bone scan result was unclear. Of the 29, osteopenia/osteoporosis was detected in 23 (79%). The vast majority of participants were very/happy with their reasonable adjustments, and all ($n$ = 8) osteoporosis health professionals found them to be very/important and very/easy to implement.
**Conclusion**: People across all levels of IDs can complete DXA scans once reasonable adjustments have been identified and implemented.

# 4. HEALTH IV

## 5932 | The role of the community intellectual disability nurse in supporting access to acute healthcare: an exploration

S. Rees; R. Northway
*University of South Wales, Pontypridd, UK*

**Background**: To explore how Community Intellectual Disability Nurses (CIDNs) support adults with Intellectual Disabilities (ID) in Wales to access acute healthcare.
**Method**: Two stage mixed method study. Stage one comprised qualitative interviews with CIDNs ($n$ = 14) using Critical Incident Technique (Flanagan, 1954). These were thematically analysed. Stage two employed quantitative questionnaires completed by CIDNs ($n$ = 102). Data was entered into SPSS and analysed using descriptive statistics.
**Results**: 4 key themes were identified: Proactive/Preparatory work; Therapeutic Relationships; Coordination and Influencing healthcare outcomes. Analysis of questionnaires highlighted the differences in

the role of the CIDN in terms of grading and if there was an ID acute liaison nurse employed within the health board.

**Conclusion**: CIDNs have an important role to play in supporting people with ID to access acute healthcare although their role varies where ID acute liaison nurses are employed. Countries where there are no specialist ID nurses may wish to consider how the liaison role can be promoted within their healthcare system to improve access to acute care for people with ID.

## 5930 | Developing machine learning models to predict poor bone health among people with intellectual disabilities

E. Burke; R. Carroll; M. O'Dwyer; J. Walsh; P. McCallion; M. McCarron

*School of Nursing and Midwifery, Trinity Centre for Ageing and Intellectual Disability, Trinity College Dublin, Ireland*

**Background**: To develop a machine learning model that identifies the presence of poor bone health in adults with ID.

**Method**: Using data collected as part of the Intellectual Disability Supplement to the Irish Longitudinal Study on Aging consisting of objective measurements and interview responses pertaining to health and wellbeing, we constructed machine learning models for use in predicting the presence of poor bone health based on generic features and risk factors that had previously been identified. We compared various common modeling strategies such as Random Forest and Gradient Boosted Machines (GBM) using an 80:20 (training: test) split and k-fold cross-validation for training with k = 5. The resulting models' predictions on the test set allowed the most effective model to be selected.

**Results**: GBM trained on an upsampled training set outperformed the other candidate models, achieving an accuracy of 0.74, a sensitivity of 0.82 and a specificity of 0.50. By comparison, the best performing random forest model achieved an accuracy of 0.72, sensitivity of 0.82 and specificity of 0.46.

**Conclusion**: The final model that has been selected will feed into further work to develop a proof of concept for a clinical tool in predicting poor bone health based on generic input features.

## 5691 | Is the MOBID-2 Pain Scale usable for adult people with intellectual disabilities

S. Skorpen

*Norwegian National Advisory Unit an Ageing and Health, Vestfold Hospital Trust, Norway*

**Background**: To assess pain in adult people with intellectual disabilities (ID) is challenging due to the reduced capacity to self-report. The Mobilization-Observation-Behaviour-Intensity-Dementia (MOBID-2) pain scale is a validated tool used to assess pain among people in the general population with severe dementia. The form is based on touching and observation. We wanted to investigate if the pain scale is usable for people with ID.

**Method**: The pilot study was performed in two residentials (shared accommodation). Sixteen caregivers received training and follow-up on how to use MOBID-2. After three weeks, they received a Questback via email with seven questions. The response rate was 81%.

**Results**: 84.6% of the respondents evaluated the MOBID-2 form to be intuitive and easy to use. 61.5% found it difficult to assess intensity of the pain and fill in the form. 61.5 % uncovered pain using the MOBID-2. However, 41.7% found it difficult to use the pain scale on residents who became anxious and were sceptical about new routines.

**Conclusion**: Based on the positive preliminary results from this pilot study, we need to investigate MOBID-2 in a larger project to evaluate the reliability and validity of this pain-scale assessment tool for people with ID.

# 5. HEALTH V

## 5825 | Many unplanned healthcare visits among older people with Down syndrome despite medical guidelines being in place for 20 years

E.F. Wallen; A. Axmon; M. Sandberg; G. Ahlström

*Karolinska Institutet, Stockholm, Sweden*

**Background**: Down syndrome is a well-researched syndrome with unspecific-age medical guidelines published since more than 20 years back on common comorbidities. The aim was to survey patterns of unplanned visits to in- and outpatient specialist healthcare among older people with Down syndrome.

**Method**: Individuals with Down syndrome with service and support according the LSS-law, alive and at least 55 years old in the end of 2012 ($n$ = 472) were included. Data on healthcare utilization were collected from the national patient register (NPR) for the time 2002 – 2012, recorded according ICD10 chapters. Data was collected on outpatient and inpatient specialist healthcare; planned or unplanned and recorded diagnosis, primary and secondary.

**Results**: A total of 3841 registrations were identified during the 11 years, 55% (2101) were planned visits, 44% (1684) unplanned and 1.4% (56) un-known. Unplanned visits were mostly internal medicine and 60% of these were inpatient healthcare ($n$ = 259). Only 45% had a planned visit to an eye clinic during this 11 year period. Fewer individuals than expected had several earlier reported common comorbidities. The two most common primary diagnoses were pneumonia and epilepsy. Pain and fractures were also present frequently.

**Conclusion**: Raised awareness about the medical guidelines is needed.

## 5621 | Experiences of healthcare professionals involved in out-of-hours care for people with intellectual disabilities

M. Heutmekers; J. Naaldenberg; H. van Schrojenstein Lantman-de Valk; W. Assendelft; G. Leusink

*Radboud university medical center, Department of Primary and Community Care, Section Health and Intellectual Disabilities, Nijmegen, the Netherlands*

**Background**: People with intellectual disabilities (ID) have a higher risk of demanding out-of-hours general practitioner (GP) care, and have different needs in this setting, intended for urgent requests when compared to the general population. There is abundant evidence on barriers to safe and assessable healthcare for people with ID. It is however unknown how healthcare professionals experience the out-of-hours service use of people with ID, and how they see ways forward.

**Method**: GPs, triage nurses, and daily care professionals were interviewed using a structured interview guide on their experiences with people with ID requesting out-of-hours care based around two GP services in The Netherlands. The interview guide included questions on an case from recent experience, the most commonly presented health problems, effects on everyday practice, and suggestions for improvement of care.

**Results**: Themes common to GPs, triage nurses, and daily care professionals were structured in a framework. Themes distending from their everyday experiences in out-of-hours care for people with ID include partnership, workload, and reasonable adjustments.

**Conclusion**: Shared experiences will be useful to scrutinize support and care practices to the specific needs of people with ID. Suggestions for improvement will guide further research on reasonable adjustments to out-of-hours GP services.

## 5564 | Breast Screening, mental capacity and women with intellectual disabilities

C. Bates; P. Triantafyllopoulou

*The Tizard Centre at The University of Kent, Canterbury, Kent, UK*

**Background**: Participation in breast screening is considerably lower for women with intellectual disabilities (ID) compared to the general population. Barriers to screening include poor mobility and behavioural difficulties. The aim of the study was to fill in the research gap exploring the relationship between mental capacity and breast screening for women with ID.

**Method**: The current study was a cross sectional survey. Eight different support providing charities within England and Wales were included. In total, data from 131 women with ID were collected. Participants, or their staff if they lacked capacity, completed an online or paper survey.

**Results**: The findings indicated that women who lacked capacity were less likely to engage in breast screening. It also demonstrated that the processes outlined in the Mental Capacity Act (2005) were not always followed, women were not routinely being assessed if there was doubt regarding their decision-making ability and best interest, meetings were not always held if the person lacked capacity regarding breast screening.

**Conclusion**: Further research is needed to give a broader understanding of how professionals make decisions surrounding breast screening for women with ID if they are unable to decide this independently.

## 5754 | Health and lifestyle within Nepal and its relationship to intellectual disabilities

R. Dhungana

*National Rehabilitation Centre of the Disabled Nepal, Nepal*

**Background**: In Nepal, the estimates of the prevalence of disabilities vary, and there is sparse information especially about people with intellectual disabilities. Existing data suggest higher rates of prevalence of ID in the more remote northern area due to use of non-iodized salt, lack of health facilities and extreme poverty. Still Nepal has a superstitious belief about the causes of ID and are widespread that prevent people from accessing physical and mental health. When pregnant women in remote areas and low income groups are deprived of nutritious foods and proper health services, the children are at higher risk to be born with sensory, physical, and intellectual disabilities due to mutations and also lack of health promoting behaviors. Additionally, those with intellectual-disabilities are not able to lead a dignified life as they are mocked and isolated by their family and society. The health disparity in terms of determinants of health (genetic-social-circumstances-individual-behaviors-environmental, and health-care access) has a higher prevalence of-adverse conditions; inadequate-attention, focus on health-promotion and access to quality-health care services.

**Conclusion**: Healthier lifestyles, better nutrition, medical advances, involving-supporters, health care access and greater surveillance of health-risks, health-promotion and monitoring can bring an outcome of improved health, being empowered, and enhanced-quality of life and reduce health-disparities.

## 6. HEALTH VI

### 5768 | A trans-national study of obesity and underweight in European children and adults with intellectual disabilities

M. Sadowsky; R. McConkey; A. Shellard

*Special Olympics International, USA*

**Background**: Increased levels of obesity have been reported for people with intellectual disabilities, but existing information is largely drawn from selected, mostly high-income countries. Likewise, a few studies internationally have focused on underweight among these children and adults.

**Method**: Data on obesity and underweight were analysed from over 20,000 children and adults with intellectual disabilities, living in 61 countries throughout Europe and Eurasia, who attended Special Olympics, Healthy Athletes events in the past 10 years.

**Results**: Higher rates of obesity were found among athletes compared to the general population in nearly all countries. Binary logistic regressions identified higher levels of obesity for adult athletes living in high income countries compared to middle income countries (27.0% vs. 6.7%) whereas rates of underweight were higher for both youth (15%) and adults (10%) in middle income countries where the incidence of poverty was higher compared to high income countries (4.5% youth and 3.7% adults).

**Conclusion**: Contrasting intervention strategies tailored to national circumstances are needed to address these dual challenges across Europe and Eurasia in order to help people with intellectual disabilities achieve healthy weight.

### 5745 | Effects of lifestyle change interventions for people with intellectual disabilities: systematic review and meta-analysis of randomized controlled trials

M. Willems; A. Waninge; Thessa I.M. Hilgenkamp; P. Empelen; Wim P. Krijnen; Cees P. Schans

*Hanze University of Applied Sciences, Groningen, the Netherlands*

**Background**: Promotion of a healthy lifestyle of people with intellectual disabilities (ID) is important, however the effectiveness of lifestyle change interventions is unclear. This research examined the effectiveness of lifestyle change interventions for people with intellectual disabilities.

**Method**: Randomized controlled trials (RCT) of lifestyle change interventions of people with ID were included in a systematic review and meta-analysis. Data on study and intervention characteristics were extracted, as well as data on the outcome measures and results. Internal validity of the selected papers was assessed using the Cochrane Collaboration's risk of bias tool.

**Results**: Eight RCT's were included. Multiple outcome measures were used, whereby outcome measures targeting environmental factors and participation were lacking and personal outcome measures were mostly used by a single study. Risks of bias were found for studies. Meta-analyses showed some effectiveness for lifestyle change interventions and a statistically significant decrease was found for waist circumference.

**Conclusion**: Some effectiveness was found for lifestyle change interventions for people with ID. However, the results were only statistically significant for waist circumference, so current lifestyle interventions may not be optimally tailored to meet the needs of people with ID.

### 5824 | Lifestyle approaches for people with intellectual disabilities: a systematic multiple case analysis

A. Waninge; R. Steenbergen; Cees P. Schans; R. Wijck; J. Jong

*Hanze University of Applied Sciences, Groningen, the Netherlands*

**Background**: It is unknown to what extent crucial factors for successful implementation of a healthy lifestyle (physical activity and nutrition) are taken into consideration by health care organizations supporting persons with intellectual disability (ID). Therefore, the aim of the study was to analyse intervention components, levels of influence, explicit use of theory, and conditions, for sustainability of currently used lifestyle interventions within lifestyle approaches of health care organizations.

**Method**: In this descriptive multiple case study of nine health care organizations, qualitative data of the lifestyle approaches with accompanying interventions and their components were compiled with a newly developed online inventory form.

**Results**: Included were 59 interventions, of which 31% aimed to improve physical activity, 10% nutrition, and 59% a combination of both. Most interventions aimed at the educational component, and less at evaluation, daily, and generic activities. Most interventions targeted people with ID and professionals; social levels were underrepresented. Although 52% of the interventions were structurally embedded, only 17% were theory-driven.

**Conclusion**: Implementation of a healthy lifestyle within health care organizations supporting people with ID could be improved by using comprehensive, sustainable, theory-driven approaches aiming at multiple levels.

### 5668 | Pilot feasibility study of the walking away from diabetes program for adults with ID in two further education colleges

A. Maine; M.J. Brown; A. Dickson; M. Truesdale

*Queen's University Belfast, Glasgow Caledonian University, Edinburgh Napier University, UK*

**Background**: People with ID remain at high risk of developing type 2 diabetes (T2D) due to lifestyle associated risk factors, such as diets high in saturated fats and low physical activity levels. Structured educational interventions have been adapted to the needs of people with ID which target ongoing T2D self-management. However, there are no adapted programs which aim to prevent T2D through reducing risk factors. The present study initiates the addressing of this gap.
**Methods**: Two further education colleges in Scotland were recruited to take part in a feasibility study using the Walking Away from Diabetes program for people with ID. A process evaluation was conducted which assessed recruitment, retention, acceptability and accessibility, using the discussions from four focus groups of students and teaching staff. Baseline ambulatory activity and physical activity knowledge was recorded as secondary measures.
**Results**: Results of the demographic data and analysis of focus groups will be presented, highlighting the student and teaching staff experiences of participating in the program.
**Conclusions**: Findings will be discussed alongside mainstream studies and adapted self-management programs. Implications for further research, policy and practice will be raised.

## 7. HEALTH VII

### 5980 | Using quality improvement to ensure best practice use of medication for challenging behaviour

I. Hall; N. O'Kane
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**Background**: To use a systematic quality improvement methodology to ensure that medication is only used for people with intellectual disability who have challenging behaviour in accordance with the NICE (UK National Institute for Health and Care Excellence) best practice guidance on Challenging Behaviour.
**Method**: We used a systematic approach designed by the Institute of Healthcare Improvement. We audited our compliance with the NICE guidance, and where gaps were identified we made use of change ideas developed with staff working directly with people with intellectual disabilities. We used Plan Do Study Act (PDSA) cycles to achieve rapid and reliable improvements, explicitly testing ideas and measuring change on a week-to-week basis.
**Results**: The series of PDSA cycles enabled us to improve the recording of the indication for medication and its review to ensure that any medication was a necessary part of a holistic intervention package that included psychosocial interventions, to ensure that healthcare needs were met, including medication monitoring, and to improve the implementation of Positive Behavioural Support.
**Conclusion**: Using Quality Improvement methods enabled us to significantly reduce the risk of inappropriate medication use for Challenging Behaviour.

### 5833 | Classification of intellectual disability according to domains of adaptive functioning and between-domains discrepancy in adults with epilepsy

J. van Ool; F. Snoeijen-Schouwenaars; I. Tan; H. Schelhaas; A. Aldenkamp; J. Hendriksen
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**Background**: In the DSM-5, the diagnostic criteria of intellectual disability (ID) include three domains of adaptive deficits: the conceptual, social, and practical domain. We explored the associations between epilepsy characteristics and both ID domains and domain discrepancies (i.e., substantial intra-individual differences between domains).
**Method**: Among 189 adults with epilepsy and ID, each domain of adaptive deficits was assessed separately, using subscales of the Vineland-II for the social and practical domains, and cognitive instruments for the conceptual domain. A set of standardized criteria is proposed to identify an ID domain discrepancy.
**Results**: An ID domain discrepancy seemed present in 33% of subjects, particularly in those with moderate ID (53%). The discrepancy was most often at the expense of the social domain, and was significantly related to a focal (localized) epilepsy type and a mixed seizure type. Epilepsy characteristics that are indicative of more severe epilepsy were significantly related to more severe impairments in conceptual, social and practical adaptive behaviour.
**Conclusion**: With a substantial proportion of the subjects suffering from both ID and epilepsy with an ID discrepancy, professionals should be aware of this concept and take all domains of ID into account when studying or working with this vulnerable population.

### 5826 | What about psychogenic non-epileptic seizures in adults with intellectual disability and epilepsy? A matched case-control study

J. van Ool; A. Haenen; F. Snoeijen-Schouwenaars; A. Aldenkamp; J. Hendriksen; H. Schelhaas
*Epilepsy Centre Kempenhaeghe, the Netherlands*

**Background**: To describe the characteristics of psychogenic non-epileptic seizures (PNES) in adults with epilepsy and intellectual disability (ID), and to analyse differences regarding psychosocial functioning and epilepsy severity between individuals with and without PNES.

**Method**: Medical records of 240 individuals with ID living at an epilepsy care facility were screened for PNES and evaluated by a neurologist. A control group consisting of subjects with epilepsy and ID, without PNES, were matched according to age, sex and level of ID. The subject's nursing staff provided characteristics of PNES, epilepsy and psychosocial functioning, retrieved from patient charts or collected by standardized questionnaires.

**Results**: The point prevalence of PNES was 7.1%. The subjects with PNES were most often female, had a mild or moderate level of ID, showed higher levels of depressive symptoms, experienced more negative life events and had more often an ID discrepancy as compared to controls. Stress-related triggers were recognized in a large majority.

**Conclusion**: PNES appears to be a relatively rare diagnostic entity among inpatients with both epilepsy and ID. It may be under diagnosed, however, given the complexity to diagnose PNES in this population. Diagnostic challenges of PNES and a reinforced behavioural pattern as (sub) category are discussed.

## 8. HEALTH VIII

### 5946 | Engaging with 'Easy Read' health literature: an exploration of the profiles of literacy skills demonstrated by adults with intellectual disabilities (I/DDs) and the strategies they utilized for understanding written information about healthy eating

S. Buell

*University of East Anglia, UK*

**Background**: This was an observational exploratory study that aimed to establish qualitative variations in patterns of reading skills and strategies utilized by participants when they engaged with 'Easy Read' material about healthy eating.

**Method**: Sixty adults with IDs undertook a developmental reading assessment that measured reading accuracy, speed and comprehension. Scores were calculated and descriptively analysed. All participants were then given an 'Easy Read' document and answered eight questions about the information it contained. Strategies utilized by participants were observed and noted, for example, whether they choose to read aloud or silently, whether responses included pointing to specific pictures or words and how often and how successfully participants scanned the text or referred back to it for answers to questions.

**Results**: A varied range of reading profiles was revealed and clear patterns of participant engagement with the adapted texts were evident. Two thirds of participants demonstrated a preference for reading aloud and a similar proportion visually scanned the text for answers.

**Conclusion**: The diversity of reading skills and the patterns of learned reading behaviour revealed a range of individual abilities that might combine and compensate to uniquely support personal construction of meaningful information from adapted 'Easy Read' texts.

### 5873 | Physical-activity support for people with intellectual disabilities: a cross-sectional study examining the direct support professionals' perspective

L. Bossink; A. van der Putten; C. Vlaskamp

*Department of Special Needs Education and Youth Care, University of Groningen, the Netherlands*

**Background**: There is growing recognition that interventions aiming at promoting physical-activity participation for people with intellectual disabilities should also target their physical and social environment. A large and essential part of this physical and social environment can be attributed to the support provided by direct support professionals. This study investigated the degree and type of behavioural determinants for direct support professionals in regard to their support of physical activity and its relationship to personal and contextual factors.

**Method**: A total of 247 direct support professionals participated in the study. Data concerning the behavioural determinants were collected by means of a theoretically based questionnaire. Relationships to personal and contextual factors were analysed using item response theory analyses.

**Results**: Results are not yet available.

**Conclusion**: It is anticipated that the findings provide important targets for a comprehensive approach to changing direct support professional behaviour and thus promoting the support of physical activity in people with intellectual disabilities. Implications will be discussed.

### 5868 | Facilitating motor activation in people with intellectual and multiple disabilities

A. van der Putten

*University of Groningen, Groningen, the Netherlands*

**Background**: People with intellectual disabilities (ID) are at risk to be physically inactive. Especially when the level of ID increases and also motor disabilities are prevalent, support lacks structural implementation of movement-oriented activities. Therefore, these people can hardly benefit from the positive effects physical activity can generate. The aim of this presentation is to give an overview and introduction of knowledge and projects that contribute to movement oriented support in people with ID and with special attention to people with profound intellectual and multiple disabilities.

**Method**: Knowledge and projects will be categorized into the different domains of the socio- ecological framework of Sallis et al., (2006): characteristics of the targeting individuals, social environments, organizational, physical environments and policies.

**Results**: Three projects will be introduced: 1. Evaluation of the implementation of a movement intervention. 2. Analysis of life style approaches implemented in health care organizations. 3. The role of direct support professionals.

**Conclusion**: This presentation provides a framework that overviews current knowledge available to increase physical activity levels in people with ID, which can be the basis of discussion and further developing of interventions. This knowledge can be implemented into the support of people with ID.

## 5842 | Evaluation of implementation of a motor activation program for people with profound intellectual and multiple disabilities

H. van Alphen; A. Waninge; A. van der Putten

*Department of Special Needs Education and Youth Care, University of Groningen, Groningen, the Netherlands*

**Background**: The support of people with profound intellectual and multiple disabilities (PIMD) rarely focused on motor activation, which negatively influences the functioning of people with PIMD. The authors developed and implemented a 12-week needs-led motor activation program for people with PIMD. The aim was to evaluate the implementation of this program.

**Method**: The motor activation program consisted of four elements with individual motor profiles resulted in everyday motor activation and 3–5 goal oriented motor activities per week evaluated on an individual level. The implementation process and the programs of nine participants with PIMD within a 24-hour residential facility in The Netherlands were analysed.

**Results**: The motor activation program was implemented and performed for an average of 8.6 weeks (min = 8.0, max = 10.0) for five participants. Only 1–3 elements of the program were implemented for four participants in a 12-week period. During the congress we will discuss the different approaches of support professionals in the implementation process, the type of motor activation performed and the gains in goal attainment.

**Conclusion**: This study will increase the knowledge about factors that facilitate or hamper the implementation and performance of a motor activation program in the support of people with PIMD.

# 9. HEALTH IX

## 5710 | Adults with learning disabilities in the "Mental Health and Learning Disability Inpatient Bed Census", Scotland, 2014 and 2016

K. Dunn; A. Henderson; S.-A. Cooper

*University of Glasgow, UK*

**Background**: The aim was investigate psychiatric hospital admissions for adults with intellectual disabilities compared with other adults, in 2014 and 2016.

**Method**: The data source was Scotland's "mental health and learning disability bed census", conducted on 29.10.14 and 31.3.16. Descriptive statistics were generated, comparing adult in-patients with and without intellectual disabilities.

**Results**: On the Census dates, 301 (7.6%) patients in 2014, and 266 (7.2%) in 2016 had intellectual disabilities. In 2014, ~14.9/1,000 of all adults with intellectual disabilities were in-patients, compared with ~0.9/1,000 without intellectual disabilities, (~13.2/1,000 compared with ~0.8/1,000 in 2016). More adults with, compared to without, intellectual disabilities were admitted for >5 years (2014: 38.2% versus 11.4%; 2016: 36.7% versus 11.7%), more were subject to delayed discharge (2014: 20.3% versus 6.6%; 2016 22.7% versus 6.3%), and more were detained under the mental health act (2014: 66.9% versus 36.7%; 2016: 75.4% versus 41.4%). Distance from home was similar for patients with and without intellectual disabilities. 2014 and 2016 data were similar.

**Conclusion**: Population admission prevalence, and higher mental health act detentions suggest the adults with intellectual disabilities were admitted with more severe mental illness. Little progress was made in reducing delayed discharges between 2014 and 2016; policy-driven concerted multi-agency action is needed.

## 5552 | People with learning Disabilities in Scotland: 2017 Health Needs Assessment update report

M. Truesdale; M. Brown

*Edinburgh Napier University, UK*

**Background**: To update the Scottish 2004 Health Needs Assessment report to provide policy makers, service planners, service commissioners and funders and practitioners with a broad overview of the evidence of the health needs of adults with learning disabilities.

**Method**: Searching research databases, manual hand and library searches and reviewing and scanning references in existing published papers since the publication of the 2004 Health Needs Assessment report undertook the selection of studies and evidence extraction.

**Results**: The past decade has seen a significant increase in the number of research studies on the wide range of health needs of people with learning disabilities. Researchers have undertaken systematic reviews, syntheses and meta analyses of the research evidence, thereby building up a comprehensive picture and understanding of the true scope and extent of the health inequalities and health needs of people with learning disabilities and the actions necessary to address them.
**Conclusion**: Priority areas for future research are highlighted for the Scottish Government, Third Sector organizations, Directors of Public Health and Health and Social Care Partnerships for consideration and action to progress work to improve the health of people with a learning disability in ways that are appropriate, meaningful and equitable.

## 5536 | Health and social profile of people with intellectual disabilities living in non-intellectual disability long term care settings

S. Todd; J. Bernal; R. Worth; J. Shearn
*University of South Wales, UK*

**Background**: To describe the population of people with intellectual disabilities (ID) living in non-ID long term care settings.
**Method**: 70 non-ID care settings in the UK participated in the study, supporting 1838 people. Within this population, 162 people (8.8%) were reported to have ID. Demographic and health data on those people with ID were obtained.
**Results**: These findings are based only on initial analysis of data. Almost one half of the sample had lived in another care setting prior to their current place of residence. Of those, the majority had moved there from an ID setting. 55% had no recent contact with ID services and this rate was negatively related to length of stay. The average length of stay in their current setting was 5.5 years. Data will be reported on health status and future perceived health status.
**Conclusion**: (Tentative) there appears to be a drift from ID to non-ID services in later life. The age structure of this latter population of people with ID is considerably older that of those living in ID settings. Given this and the reported health profile of this population, non-ID settings are also significant in the provision of end of life care to this population. These factors highlight the need for more research within this sector of care.

## 5424 | Health status and use of medical services of people with disabilities – a longitudinal study

M.T. Wicki
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**Background**: Hardly anything is known about the health status and use of medical services of people with intellectual disabilities (ID) in Switzerland. The aim of the study is a longitudinal assessment of health status and use of medical services of older people with disabilities (age 50–65), living independently or in residential homes.
**Method**: A representative longitudinal survey (t0, t1) with 500 people with disabilities (defined as persons with disability pensions) in six regions of Switzerland was carried out between July and October 2017 to assess context factors, health status and use of medical services. The second phase will be conducted between July and October 2018.
**Results**: First results will be available in March 2018.
**Conclusion**: This study will provide novel insights into health status, development of health status and use of medical services of older people with disabilities in Switzerland. It will be possible to compare this data with the health status and use of medical services of the general population and to identify possible discrimination of people with disabilities.

# 10. HOSPITALIZATION OF CHILDREN

## 5983 | Provision of hospital care to children without and with intellectual disabilities in England: Are we delivering an equitable service?

K. Oulton; F. Gibson; L. Carr; A. Hassiotis; C. Jewitt; C. Kenten
*Great Ormond Street Hospital NHS Foundation Trust, UK*

**Background**: There has yet to be a comprehensive review of how well the needs of children and young people with intellectual disabilities are met when using hospital services. We describe the organizational context for healthcare delivery to them and their families, in England. We also report staff perceptions of their ability to identify the needs of these families and provide high quality hospital care to meet these needs.
**Method**: An anonymised online survey ($n$ = 2261) and individual interviews ($n$ = 65) were conducted with staff working with this population in 24 hospitals.
**Results**: Uncertainty and variation exists within and across hospitals regarding what is currently available and accessed in terms of the organizational policies, systems and practices in place to support this patient group. Staff perceived this population to be included less, valued less, and less safe than those without intellectual disability. Staff also reported having less confidence, capability and capacity to meet the needs of this population compared to those without intellectual disability.
**Conclusion**: Children and young people with intellectual disabilities may be invisible, unheard and disadvantaged with respect to receiving individualized high-quality hospital care that meets their needs. Understanding the impact this has on them and their families is imperative.

## 5977 | Staff perceptions of meeting the needs of children and young people with intellectual disabilities in hospital; Building a model for use in clinical practice

J. Russell; F. Gibson; C. Kenten; J. Wray; K. Oulton

*Great Ormond Street Hospital for Children, NHS Foundation Trust, UK*

**Background**: This study aims to understand staff perceptions of the capacity of hospitals to meet the needs of children and young people with intellectual disabilities.

**Method**: Free text from a staff survey (*n* = 2243) conducted in 24 children's and non-children's hospitals in England were analysed thematically to ascertain perceptions of what their hospital does well (*n* = 742) and could do better (*n* = 805) to meet the needs of children and young people with intellectual disabilities. Themes were mapped to an existing model of individualized care, developed from single site research, to understand how staff approach care for this population.

**Results**: Staff identified personnel characteristics, practices and resources they require to meet the needs of these patients, such as access to training, equipment, specialist advice and flexible or double appointments. The themes mapped closely onto the current model for individualized care, with the exception of one area – focusing on the little things.

**Conclusion**: The findings suggest increasing staff access to training could have the greatest impact on capacity. The model has potential for use in clinical practice in hospitals, by defining the components of individualized care for this group that will assist the identification of their needs and address barriers to accessing healthcare.

## 5968 | Associations between intellectual disability nurse provision in children's hospitals and staff perceptions of care

K. Oulton; J. Russell; C. Kenten; J. Wray; F. Gibson

*Great Ormond Street Hospital NHS Foundation Trust, UK*

**Background**: Current best practice United Kingdom guidance has highlighted that clinical staff in all children's wards should have access to information, support and advice from a senior intellectual disability nurse. The aim of this study was to identify the extent of intellectual disability nurse provision in specialist children's hospitals in England and associations between provision and staff perception of care.

**Method**: Using mixed-methods, views about the care of children and young people with intellectual disability were collated from staff in 15 specialist children's hospitals and the results were compared on the basis of whether or not a dedicated children's intellectual disability nurse was in post. Forty-eight senior staff were interviewed and 1681 staff completed an anonymised online survey.

**Results**: Eight children's hospitals (53%) had dedicated intellectual disability nurse provision in place. Findings suggest that whilst intellectual disability nurse provision may impact staff capability to care for children and young people with intellectual disabilities, this does not appear to be the case for staff capacity, confidence or how children and young people are valued within the hospital, their safety and access to appointments.

**Conclusion**: The impact of dedicated intellectual disability nurse provision in specialist children's hospitals in England requires further investigation.

## 5944 | Parents of children and young people with intellectual disabilities: What it means for them to be partners in their child's hospital care

K. Oulton; D. Sell; F. Gibson

*Great Ormond Street Hospital NHS Foundation Trust, UK*

**Background**: The aim of this study was to explore the experiences of parents of children with intellectual disabilities during their child's time in hospital. This group of patients frequently experience recurring hospital admissions and/or appointments. Whilst there is some evidence of parents feeling under-utilized or over-burdened by hospital staff, little is known of what their own needs are during this time.

**Method**: Individual interviews, informal discussions and observation were conducted with twelve parents of nine children and young people aged 4–21 years with intellectual disabilities, as part of a larger ethnographic study.

**Results**: When asked about their own hospital experience, parents focused predominately on their relationship with healthcare professionals. Poetry will be used to illustrate key themes that emerged from the data: reflecting the importance parents placed on building a genuine partnership with professionals, as reflected by the acronym PARTNER: (1) Preparation, (2) Accessibility, (3) Respect, (4) Trust, (5) Negotiation, (6) Expertise, (7) Reliability.

**Conclusion**: Involving parents as partners in care helps them feel informed, involved, reassured and valued. Without this, parents experience uncertainty, anxiety, frustration and anger, with the feeling of being expected to provide care rather than being a true partner with professionals.

# 11. SPORT AND EXERCISE I

## 5986 | Effects of sports and daily activity on leisure time, mobility and quality of life of adults with intellectual disability

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**Background**: The main aim of this study (2016–2018) is to highlight the effects of a sports and movement related daily routine, towards independent mobility, leisure time activities and quality of life. The concept is based on low-threshold activities, which do not require a lot of effort to attend to.

**Method**: The participants are adults with intellectual disability (*N* = 242) and live in different living arrangements (ambulant and stationary). Before, during and after the intervention (18 months), participants of the intervention and control group are (among other components) questioned about their leisure time activities, experienced barriers, mobility as well as their overall quality of life.

**Results**: First results of this ongoing study show little sports related leisure time activities. Especially people in group homes, which highly depend on the offers provided by the institution, show significantly fewer steps per day (r = 0.233**) and are less mobile (r = 0.240**) than persons in assisted individual living arrangements.

**Conclusion**: The results show the necessity of such concepts. Taking part in little sports related leisure time activities, the lack of self-determined choices as well as experienced barriers can lead to a rather sedentary lifestyle and therefore to higher health risks and less social interaction.

## 5739 | Promoting health and wellness: Special Olympics fitness programming

M. Sadowsky

*Special Olympics International, USA*

**Background**: One key component of the Special Olympics (SO) global health strategy concentrates on more consistent access to fitness opportunities. In collaboration with local SO Programs and fitness experts, Special Olympics International (SOI) has endorsed three fitness models that have been successfully piloted and developed resources to support individuals with ID to achieve better health and improve their fitness.

**Method**: Local SO Programs measured participant height, weight, and blood pressure, and collected data on health behaviours before and after the fitness intervention. These results will be presented by age, gender, location, and fitness model.

**Results**: Data shows evidence of improved health. Among adults who had a hypertensive reading at baseline, 38.4% (*n* = 48) had improved to a normotensive status by the time of the post-test. Results will be updated to include the latest available data.

**Conclusion**: Special Olympics Fitness programming has a significant impact on individual health outcomes for people with ID. Evidence of lifestyle changes has implications for service providers who work with people with ID, such as clinicians. More fitness programming designed specifically for a person with ID needs to be promoted in communities throughout the world to reduce disparities.

## 5689 | Physical fitness is predictive for survival in older adults with intellectual disabilities

A. Oppewal; T. Hilgenkamp

*Intellectual Disability Medicine, Department of General Practice, Erasmus MC University Medical Centre Rotterdam, the Netherlands*

**Background**: The life expectancy of people with intellectual disabilities (ID) is increasing. However, low physical fitness levels of people with ID may negatively impact their life expectancy. Therefore, the aim of this study is to investigate the relationship between physical fitness and survival.

**Method**: In the Healthy Ageing and Intellectual Disabilities study, physical fitness levels of 900 older adults with ID (61.5 ± 8.1 years) were measured at baseline. Mortality data was collected over a 5-year follow-up period. Cox proportional hazard models were used to determine the association between each physical fitness test and survival, adjusted for age, sex, level of ID, and Down syndrome.

**Results**: Over the follow-up period, 172 (19.1%) participants died. Better manual dexterity (HR=0.96 [0.94–0.98]), visual reaction time (HR=1.57 [1.28–1.94]), balance (HR=0.97 [0.95–0.99]), comfortable (HR=0.65 [0.54–0.78]) and fast (HR=0.81 [0.72–0.91]) gait speed, grip strength (HR=0.97 [0.94–0.99]), and cardio-respiratory fitness (HR=0.997 [0.995–0.999]) were associated with survival (lower mortality risk). Auditive reaction time, muscular endurance and flexibility were not associated with survival.

**Conclusion**: We showed for the first time that physical fitness was independently associated with survival in older adults with ID. These results stress the need for being physically fit at older age to reduce mortality risk.

## 6006 | Health system indicators for use by Special Olympics International in their health programs

L. Taggart; R. McConkey

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**Background**: As part of measuring the effectiveness of the variety of health programs and activities that Special Olympics International (SOI) deliver for individuals with ID, SOI is also interested in identifying the system indicators that create opportunities for inclusive health of all people with ID.

**Method**: A series of 1:1 interviews with SOI staff and a Delphi survey with IASSIDD and AAMDD members were used to identify these indicators. This study was embedded within a social-ecological framework.

**Results**: Examples of these health indicators included: ID is a mandatory topic in the training of health professionals; people with ID are involved as co-trainers for health staff; policy statements and practice guidelines are available for staff in how to make

reasonable adjustments; and feedback is sought from people with ID about their inclusion in the health system. It is unlikely that any one indicator or set of related indicators will produce a tipping point by which a system could be considered to be inclusive of people with ID.

**Conclusion**: These national health system indicators could be used to measure how successful people with ID are included in healthcare and other systems (housing, education and social welfare systems), as well as included within civil society.

## 12. SPORT AND EXERCISE II

### 5876 | Accelerometer counts and energy expenditure during walking in healthy adults with and without ID

T. Hilgenkamp[1,2]; M. vanMaurik[1,2]; A. Oppewal[1,2]

*[1]Intellectual Disability Medicine, Department of General Practice, Erasmus MC University Medical Centre Rotterdam, the Netherlands ; [2]Department of Kinesiology and Nutrition, University of Illinois at Chicago, USA*

**Background**: We investigated the usability of accelerometers to measure the intensity of walking in individuals with and without ID, by analyzing the relationship between accelerometer counts and the measured energy expenditure.

**Method**: Our study included 36 participants, among whom 17 were healthy adults with mild-moderate ID. Energy expenditure and accelerometer counts were measured during three separate 6-minute-walking bouts (over ground comfortable walking speed, and 3.2 km/h and 4.8 km/h on a treadmill).

**Results**: No significant correlations were found between accelerometer counts and energy expenditure relative to body weight in either group for any of the speeds ($P > 0.05$).

**Conclusion**: This study used a standardized, reproducible method of evaluating energy expenditure in adults with ID and a control group and compared it to accelerometer counts. We did not find any correlations between accelerometer counts and energy expenditure in either group, potentially due to large variability in both outcome variables. Future research is needed with a larger sample size, to determine the validity of physical activity measurement in individuals with ID. The research leading to these results has received funding from the People Programme (Marie Curie Actions) of the European Union's Seventh Framework Programme (FP7/2007–2013) under REA grant agreement no. °625455.

### 5690 | Gait of adults with intellectual disabilities, and its association with physical fitness and falls

A. Oppewal; T. Hilgenkamp

*Intellectual Disability Medicine, Department of General Practice, Erasmus MC University Medical Centre Rotterdam, the Netherlands*

**Background**: We assessed the gait characteristics of adults with ID, and the association of these characteristics with physical fitness and falls.

**Method**: Gait characteristics of 31 adults with mild to moderate ID (42.77 ± 16.70 years) were assessed with the GAITRite at comfortable speed (CS), fast speed (FS), and while dual tasking (DT). Fitness was assessed (body composition, muscular endurance, strength, balance, Short Physical Performance Battery) and falls were collected over a three-month follow-up period.

**Results**: Gait characteristics of adults with ID were comparable to those seen in the general older population of on average 20 years older. Adults with ID did have a broader base of support and more variable gait. Gait at CS was associated with body composition, gait at FS with the other fitness components. Dual tasking affected gait. This was not predictive for falls, although medium effect sizes were found (0.31–0.48).

**Conclusion**: The finding that fitness seems to be more important for gait at more challenging conditions and that dual tasking affects gait, is important for safe community participation. This must be considered while interacting with adults with ID during daily activities. More research is needed to better understand the relationship between gait, fitness and falls.

### 5791 | Attendance of a resistance-training program in adults with an intellectual disability

S. Weterings[1,2]; A. Oppewal; T. Hilgenkamp

*[1]Intellectual Disability Medicine, Department of General Practice, Erasmus MC University Medical Centre Rotterdam, the Netherlands; [2]Abrona, healthcare provider for people with an intellectual disability, Huis ter Heide, NL*

**Background**: To assess which factors influence the overall attendance of a 6-month whole body progressive resistance exercise training (PRET) program for adults with an intellectual disability (ID) with cardiovascular disease (CVD) risk factors.

**Method**: Twenty-four adults with a mild or moderate ID with at least one CVD risk factor (diabetes, hypertension, dyslipidaemia, and/or overweight/obesity) exercised twice a week for one hour for 24 weeks. The PRET program consisted of a whole-body workout of seven resistance exercises. After a familiarization phase, the training intensity was increased from novice level to vigorous intensity. Every training session, the attendance or absence was noted, along with the reason for absence. At the end of the program we asked about the participant's experiences with the PRET program with a questionnaire. This information was used to gain more insight in the factors influencing attendance.

**Results**: The factors influencing the overall attendance or absence of a training session of the PRET-program will be presented. (Results available in May 2018).

**Conclusion**: The results from this study can be used as a practice based outline for future intervention studies and/or in daily practice when conducting health programs at both individual and group level for adults with ID.

## 5792 | The reliability of measuring muscle strength in adults with an intellectual disability

S. Weterings[1,2]; A. Oppewal; I. Razzaq; T. Hilgenkamp

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**Background**: Muscle strength is an important factor of overall fitness. The aim of this study was to assess the reliability of a muscle strength measurement of the leg extension, the maximal voluntary contraction (MVC), for adults with an intellectual disability (ID) with cardiovascular disease (CVD) risk factors.

**Method**: Twenty-four adults with a mild or moderate ID with at least one CVD risk factor (diabetes, hypertension, dyslipidaemia, and/or overweight/obesity) performed the MVC test of the leg extension twice. Each MVC test contains at least three measurements. If one measurement was >10% lower than the highest measurement an extra measurement was performed, with a maximum of five measurements per test. The MVC was measured with a Handheld Dynamometer (Microfet 2) according to the break-method.

**Results**: The reliability will be presented as the association between both MVC tests of the leg extension with the intra class correlation coefficient (ICC agreement). Furthermore, the Bland and Altman plot will be presented to display the Limits of Agreement between both MVC tests.

**Conclusion**: The results from this study can be used when measuring muscle strength in future research or in daily practice in adults with ID.

# 13. PSYCHOTROPIC MEDICATION I

## 5962 | Associations of medicine use with falls and bone health in older adults with intellectual disabilities

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*Trinity College, Dublin, Ireland*

**Background**: Older adults with ID may be exposed to medicines that may contribute to falls/frailty, particularly sedative and anticholinergics, which may be association with falls, antiepileptics, which may be associated with bone loss. To examine associations between higher Drug Burden Index (DBI): a cumulative measure of sedative and anticholinergic medicines and falls and to examine associations between exposure to antiepileptics and bone status.

**Method**: Medication data (self/proxy report) was drawn Wave 2 (2013/2014) of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA); a representative study of persons >40 with ID. Multivariable regression examined DBI and falls in the previous 12 months. Bivariate analysis examined associations between antiepileptics and objectively measured osteopenia/osteoporosis ($n$ = 575).

**Results**: Of 677 with medicines data, there was no significant association ($P$ = 0.731) between higher DBI and falls in the previous 12 months: OR 1.11 (95% CI 0.61–2.05). There was a significant association between antiepileptics ($P$ < 0.001) and objective measures of osteoporosis/osteopenia, 52.3% with antiepileptics having objective osteoporosis.

**Conclusion**: Many older adults with ID are exposed to multiple medicines that may place them at risk of poor bone health and falls. Findings highlight the importance of regular review of medicines for adverse effects.

## 5999 | Development of a systematic prescription-deprescription tool for adults with intellectual disabilities

S. Lonchampt; F. Gerber; J.-M. Aubry; J. Desmeules; M. Kosel; M. Besson

*University of Geneva; Geneva University Hospitals, Switzerland*

**Background**: Adults with intellectual disabilities (AWID) suffer from more concomitant somatic and psychiatric disorders than the general population. Although there is limited evidence for the efficacy of psychotropics and standardized procedures for their prescription are lacking, AWID are often poly-medicated during prolonged periods. This can lead to severe side effects, inefficient use of resources and lack of implementation of alternative, more adapted approaches.

**Method**: After an extensive search of the literature, our group developed a systematic tool for prescription/deprescription in AWID.

**Results**: The systematic tool is aimed at helping physicians to remove inappropriate treatments, introduce lacking treatments and optimize their administration in order to improve their safety and efficacy. We selected five items for the tool: pain, sleep disorders, gastrointestinal disorders, problem behaviours and deprescription of psychotropic drugs. The items were selected based on their relevance in the population of AWID and on the literature. The choice of the treatments discussed in the tool is based on pharmacological considerations, ease of administration and cost.

**Conclusion**: The scarcity of the literature on prescription/deprescription procedures in AWID underscores the need for standardized procedures and tools. The next step will be to validate the tool using a Delphi method.

## 5870 | Patterns of antipsychotic utilization and associations with behaviours, with challenges in older adults with intellectual disability: a cross sectional study.

M. O'Dwyer; N. Galvin; P. McCallion; M. McCarron; M. Henman; J. O'Connell

*Trinity College Dublin, Ireland*

**Background**: High-risk medicines (HRMs) may be associated with side effects/significant harm when used in error. Older adults with intellectual disabilities (ID) are susceptible to adverse outcomes associated with HRMS. The aim was to compile an evidence based list of HRMs, evaluate the prevalence of HRMs among older adults with ID, identify associations between HRMs and clinical and demographic characteristics.

**Method**: Medication data (self/proxy report) was drawn Wave 2 (2013/2014) of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA); a representative study of persons over 40 with ID. HRMs were identified by literature review and stratified into four categories. Bivariate analysis examined associations between HRMs and clinical/demographic factors.

**Results**: Of 677 with medicines data, 86% (*n* = 582) had ≥1 HRM, mean (±SD) 2.7 (±2.0). The most common HRMs were antipsychotics, 45.1% (*n* = 305), medicines with narrow therapeutic index (e.g. carbamazepine, warfarin) (52.4%, *n* = 305), medicines with risk of toxicity (e.g. paracetamol, lithium) (45.1%, *n* = 263). There were significant (*P* < 0.001) associations between exposure to 4 + HRMS and older age, severe/profound ID, institutional settings, epilepsy or mental health condition.

**Conclusion**: Older adults with ID were exposed to HRMs. Education of doctors, pharmacists, nurses, caregivers and adults with ID is required to ensure medication safety.

## 5993 | Use of high risk medicines among older adults with intellectual disabilities: A cross-sectional study

M. O'Dwyer; N. Galvin; P. McCallion; M. McCarron; M. Henman; J. O'Connell

*Trinity College, Dublin, Ireland*

**Background**: High risk medicines (HRMs) may be associated with side effects/significant harm when used in error. Older adults with ID are susceptible to adverse outcomes associated with HRMS. Aim: Compile an evidence based list of HRMsEvaluate the prevalence of HRMs among older adults with IDIdentify associations between HRMs and clinical and demographic characteristics.

**Methods**: Medication data (self/proxy report) was drawn Wave 2 (2013/2014) of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA); a representative study of persons over 40 with ID. HRMs were identified by literature review and stratified into four categories. Bivariate analysis examined associations between HRMs and clinical/demographic factors.

**Results**: Of 677 with medicines data, 86% (*n* = 582) had ≥1 HRM, mean (±SD) 2.7 (±2.0). The most common HRMs were antipsychotics, 45.1% (*n* = 305),medicines with narrow therapeutic index (e.g carbamazepine, warfarin) (52.4%, *n* = 305), medicines with risk of toxicity (e.g. paracetamol, lithium) (45.1%, *n* = 263). There were significant (*p* < 0.001) associations between exposure to 4+ HRMS and older age, severe/profound ID, institutional settings,epilepsy or mental health condition.

**Conclusion**: Most older adults with ID were exposed to HRMs. Education of doctors, pharmacists, nurses, carers and adults with ID is required to ensure medication safety.

# 14. PSYCHOTROPIC MEDICATION II

## 5941 | Psychotropic drug use in older adults with intellectual disabilities who have dementia in Ireland

M. O'Dwyer; J. Hughes; P. McCallion; M. McCarron; M. Henman

*Trinity College Dublin, Ireland*

**Background**: There are concerns that antipsychotics and other psychotropics may be prescribed inappropriately in older adults with intellectual disabilities (ID) and dementia. The aim was to determine the prevalence of psychotropic use among older adults with ID and dementia over time.

**Method**: Data was drawn from Wave 1 (2009/2010) and Wave 2 (2013/2014) of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA); a representative study of persons over 40 with ID. Medication data (self/proxy report) was available and psychotropics examined were antipsychotics, antidepressants, anxiolytics, hypnotics. Participants/proxy reported a doctor's diagnosis of dementia.

**Results**: At Wave 1, of those taking medicines with data (*n* = 736), 6.3% (*n* = 46) reported dementia, after loss to follow-up, of 677 with data at Wave 2, 10.9% (*n* = 74) had dementia. At Wave 1, of 46 with dementia, 45.7% (*n* = 21) had antipsychotic use, and at Wave 2 of 74 with dementia, 54.1% (*n* = 38) had antipsychotic use. Antidepressants were the second most frequently reported class: 43.5% (*n* = 20) at Wave 1, 39.2% (*n* = 29) at Wave 2.

**Conclusion**: A significant proportion of older adults with ID and dementia reported psychotropic use, with antipsychotic use being commonplace. Findings highlight the importance of review of psychotropics to prevent inappropriate prescribing.

## 5480 | Development of the tool appropriate prescribing of psychotropic drugs (TAPP)

J. Jonker

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**Background**: The aim of this study was to develop a self-report instrument for prescribers to assess the quality of their prescriptions of psychotropic drugs in people with intellectual disabilities (ID). This instrument may enhance the process of reduction of inappropriate psychotropic drug use in this population.

**Method**: The project group consisting of a pharmacist, a nurse and two physicians developed a draft of the instrument. In a Delphi procedure a panel of psychiatrists, ID physicians and pharmacists consented on the final draft of the instrument. The Research and Development/University of California at Los Angeles (RAND/UCLA) methodology for agreement was used. A second panel assessed the relevance of the domains of the instrument without needing consensus.

**Results**: In the first Delphi round respondents reached agreement on 47 of 58 statements scored on a 9-point scale, with median values between 7 and 9, controlled for the inter-percentile range adjusted for symmetry (IPRAS). Agreement was reached about the terminology, the age limits of children and elderly and of the domains dose, duration of therapy and duplication. We will present the final draft of the TAPP and the preliminary results of the validity, reliability and usability of the tool.

**Conclusion**: The TAPP is a promising instrument that will help prescribers to optimize, and not just reduce, psychotropic drug use in people with ID.

## 5478 | The long-term effectiveness of Risperidone in reducing challenging behaviours: a RCT

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**Background**: We aimed to study the long-term effectiveness of Risperidone in reducing challenging behaviours in people with intellectual disabilities, by studying the effects of discontinuation of behaviour and side effects.

**Method**: In this study Risperidone was double blind and placebo-controlled discontinued. In the placebo group, participants discontinued Risperidone stepwise to a placebo in fourteen weeks, followed by an eight-week blind follow-up and eighteen-week natural follow-up. The control group maintained their baseline dosage, but could discontinue after the blinded follow-up. During the study premature de-blinding, behaviour scored on the irritability subscale of the Aberrant Behaviour Checklist (ABC) and side effects (metabolic, neurologic, hormonal side effects) were monitored.

**Results**: In total, 25 participants were included in the study, of which eleven were in the discontinuation group. Of the eleven participants two were de-blinded prematurely compared to three in the control group. The discontinuation group did not differ significantly on the irritability subscale over time with the control group. However, they did show a worse total ABC score at de-blinding. At de-blinding, only weight was lowered over time in the discontinuation group compared to the control group.

**Conclusion**: To conclude, discontinuation of Risperidone is possible, despite an increase in challenging behaviours.

## 5773 | A multicenter double blind, placebo controlled randomized off-label antipsychotic withdrawal trial in people with intellectual disabilities and challenging behaviour

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**Background**: There is a gap between the available evidence and the policy drive to reduce antipsychotic prescribing to people with intellectual disability (ID) and challenging behaviour. We postulate 3 possible mechanisms for antipsychotic withdrawal failure: (1) The influence of the subjective interpretation of behavioural symptoms. (2) It cannot be excluded that some people with ID might benefit from antipsychotic treatment. (3) When antipsychotics are withdrawn after long-term treatment, withdrawal symptoms might occur.

**Method**: A multicenter double blind, placebo controlled randomized off-label antipsychotic withdrawal trial (RCT) is currently being carried out in the Netherlands in collaboration with the HA-ID consortium and financially supported by ZonMw (project number: 848016008). Participants are randomized to one of two groups: the withdrawal (placebo) group or the control group.

**Results**: A summary of our study protocol, including some specific outcome measures and the process of medical ethical review will be presented. Inclusion of participants and obstacles during the setup and execution of the study will also be discussed.

**Conclusion**: As far as we know, this study is the first multicenter double blind off-label antipsychotic withdrawal RCT investigating possible mechanisms for antipsychotic withdrawal failure in people with ID and challenging behaviour.

## 15. PSYCHOTROPIC MEDICATION III

### 5417 | Discontinuation of off-label used antipsychotics; results and determinants for success or failure

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**Background**: To investigate physicians' considerations regarding their patients' eligibility to discontinue off-label antipsychotics, to study discontinuation trajectories of those who were eligible to discontinue and to identify participant-related determinants for success or failure in discontinuation.

**Method**: Participants in living facilities of ID service providers were aged >6 year and used off-label antipsychotics >1 year. Antipsychotics were discontinued in a time frame of 14 weeks. Data collection took place at baseline, at 4, 8, 12, 16, 22, 28 and 40 weeks after the first dose reduction in all participants, whether or not they were able to completely discontinue. The primary outcome measure was the Aberrant Behaviour Checklist.

**Results**: Of 997 antipsychotic drug users 499 were eligible to discontinue; 129 participated in the study and 60% of those were able to discontinue in 14 weeks, with on average no behavioural worsening. At 40 weeks 40% were still completely off antipsychotics. Ill health was associated with failure in discontinuation. Considerations of physicians, differences between those who succeeded and those who failed in discontinuation, and determinants for successful discontinuation will be presented.

**Conclusion**: Reduction of off-label antipsychotics in people with ID may be improved, when physicians manage ill-health conditions of their clients.

### 5549 | Trends in antipsychotic and antidepressant prescribing in children and adults with intellectual disabilities, and children with autism throughout Scotland, 2010–2013

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*University of Glasgow, UK*

**Background**: To investigate antipsychotic and antidepressant prescribing in children/young people with intellectual disabilities, and with autism, compared with other children and with adults with intellectual disabilities; and trends over time.

**Method**: Observational study of all pupils (4–18 years) in Scotland's annual school census (2010–2013), and 25% of Scotland's adults with intellectual disabilities in general practice records (2004–2014); both record-linked to national Prescribing Information System data on en-cashed antipsychotics and antidepressants.

**Results**: Child/young person analyses are in progress. For adults with intellectual disabilities, antipsychotic use fell from 24.3% (292/1,201) in 2004, to 16.4% (665/4,065) in 2014. However, follow-up of the same individuals ($n$ = 549) found similar antipsychotic use of 23.3% in 2004 and 25.9% in 2014, whilst antidepressant use rose from 9.8% to 22.2%.

**Conclusion**: Adults with intellectual disabilities are unlikely to be withdrawn from antipsychotic drugs once commenced, but rates of new prescriptions are falling. Adult increases in antidepressant use may reflect general population patterns, but further research is needed to understand this. It is important to identify trends in psychotropic use in children/young people, and the at-risk age of onset, given the potential consequences for the developing brain, potential serious side effects and long-term usage.

### 5418 | Staff-factors related to psychotropic drug use of people with intellectual disability

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**Background**: Staff's thoughts on effects of psychotropics on challenging behaviour might be related to their clients' drug use. We aimed to investigate whether staff's knowledge of psychotropics and feelings towards challenging behaviour were associated with results of antipsychotic drugs discontinuation, and whether a staff-learning-intervention on this topic was related to decrease of inappropriate psychotropic drug use.

**Method**: We used a self-designed questionnaire in a survey on knowledge of support staff and in a prospective open label, off-label antipsychotics discontinuation study. Here we studied the influence of staff-related variables on success or failure in discontinuation. Also, we investigated the influence of a learning-intervention on the appropriateness of their clients' psychotropic drug use.

**Results**: Of 194 support professionals, 6% had sufficient knowledge, a majority had false beliefs on the effects of psychotropics on clients' behaviour and 60% indicated they were in need for education. When clients attempted to discontinue their drug use staff's feelings of depressive mood and anger were associated with less and more knowledge with more chance of successful discontinuation. Effects of the learning-intervention will be presented.

**Conclusion**: Staff's thoughts on effects of psychotropics on clients' behaviour should be taken into account in attempts to reduce inappropriate psychotropic drug use.

## 16. GENETIC OR RARE CONDITIONS I

### 6068 | Learning from facial expressions of emotion among persons with Down syndrome, Williams syndrome and autistic spectrum disorder

K. Goldman

*Israel*

**Background**: Socio-emotional adaptation facilitates well-being and communal belonging. In this study we compared the use of facial expressions of emotion as sources of information to facilitate adaptive responding among individuals with Williams syndrome (WS), Down syndrome (DS) and autistic spectrum disorder (ASD), functioning in the range of ID.
**Method**: A feedback-learning task incorporating two levels of difficulty was administered to 12 participants with WS, 19 with DS, 18 with ASD and comparison groups of typically developing children at similar developmental levels. After choosing one of two objects, participants received feedback in the form of facial expressions (happy or angry) or in non-social form (icons) and then repeated or corrected their choice.
**Results**: Participants with WS responded accurately when using facial expressions as feedback, but only when cognitive demands were low. The accuracy rates of those with ASD were slightly lower, but less affected by an increase in task demands. Participants with DS responded correctly to the happy face, but only half responded accurately to the angry face.
**Conclusion**: Adaptively responding to facial expressions of emotion involves the interplay of emotion recognition with cognitive abilities and style. Differences between the three groups in the nature of this interaction will be discussed.

### 5735 | Vagus nerve stimulation for the treatment of problem behaviour in people with Prader-Willi Syndrome

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**Background**: Prader–Willi Syndrome (PWS) is a genetically determined neurodevelopmental disorder characterized by intellectual disabilities and problem behaviours alongside severe hyperphagia. These behaviours have a significant effect on the quality of life of those with PWS and those who support them. An earlier study found unexpected anecdotal reports of beneficial effects of vagus nerve stimulation (VNS) on problem behaviours in two people with PWS; we investigate this further.
**Method**: Five individuals with PWS wore an external VNS device for four hours per day. The numbers of problem behaviours were recorded monthly and semi-structured interviews conducted twice in both the baseline and active phases.
**Results**: We observed a reduction in number of problem behaviours as a result of VNS. Caregivers in semi-structured interviews also noted a beneficial effect where improvements in temperament, social functioning and problem behaviours were reported. These improvements suggest that VNS may have potential as a novel treatment for problem behaviour in PWS.
**Conclusion**: We offer insight into the mechanisms underpinning behavioural problems faced by people with neurodevelopmental disorders, suggesting that changes in these behaviours may be mediated via vagal projections and their effects on specific neural networks and functioning of the autonomic nervous system.

### 5779 | Iceberg alert: undetected health problems in adults with Prader-Willi syndrome – multidisciplinary care could prevent "unexplained deaths"

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**Background**: In Prader-Willi Syndrome (PWS), up to 4% of young adults die every year. PWS is a complex genetic disorder, characterized by hypotonia, intellectual disability (ID), hormone deficiencies and hyperphagia. The mean age of reported deaths is 29.5 years. Mortality is often unexpected. In some cases, cause of death is related to rapid consumption of food. In half of the patients, the cause of death turns out to be cardiovascular origin or obesity-related respiratory failure. These severe complications can be prevented if PWS-associated obesity is managed effectively in a multidisciplinary setting.
**Method**: The multidisciplinary outpatient clinic (MOPC) for adults with PWS aims to prevent complications and reduce mortality in PWS. We have analysed the clinical data.
**Results**: Untreated diabetes, hypothyroidism and obesity were frequent findings, among the first 90 patients visiting the MOPC. Although 43% was obese (BMI above 30 $kg/m^2$), 23% exercised less than 30 min/day and 29% were not on a diet. 50% had untreated hypogonadism, and 65% had insufficient dairy intake.
**Conclusion**: We detected a striking number of untreated health problems among adults with PWS. The MOPC for adults with PWS will prevent painful and expensive complications and reduce mortality in this vulnerable patient population.

### 5967 | Social behaviour among adults with Down syndrome: Is it mediated by psychopathology?

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**Background**: The first aim of this study was to develop a new tool to measure social behaviour skills among adults with intellectual disability (ID) and second was to examine the possible mediation effect of psychopathology between Down syndrome (DS) etiology and social behaviour skills.

**Method**: Five hundred eighty adults with ID participated in this study. For each participant, the referent caregiver completed the Social Behaviour Questionnaire (SBQ) and the Reiss Screen for Maladaptive Behaviour. Data of the whole sample on SBQ were analysed in order to test the factor structure of this new tool. Mediation analyses involved two subgroups of participants: participants with DS ($n$ = 92) and participants with ID of non-specified etiology ($n$ = 328).

**Results**: Factor analyses suggested retaining a four-factor structure of the SBQ. Down syndrome was associated with a higher level on SBQ global and subscales scores, showing more preserved social behaviour skills in this group. However, this association completely disappeared when the mediation effect of psychopathology was controlled.

**Conclusion**: These results suggest that higher social skills commonly associated to persons with DS are actually due to the lower level of psychopathology of these individuals.

## 17. GENETIC OR RARE CONDITIONS II

### 5978 | Beneficial effect of betaine treatment in 2 adult patients with creatine transporter deficiency

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**Background**: Creatine transporter deficiency (CTD) is caused by mutations in SCL6A8 and causes intellectual disability. No approved treatment exists. We describe 2 half-brothers both suffering from CTD and intellectual disability, both improving after betaine treatment: A 36-year old male with ID and epilepsy developed progressive speech loss, feeding difficulties, weight loss and motor disturbances. Supplementation with a commercial product reportedly containing cyclocreatine showed improved balance, speech and feeding. After the product became unavailable after 11 months, his condition deteriorated. Later, an analysis showed that the product contained betaine 79,2% and creatine 17,7%, but no cyclocreatine. Treatment with betaine, increasing to 10 grams daily, started, and his balance and feeding improved. At age 31 the other patient showed lack of energy and feeding difficulties with a considerable weight loss. He was treated with betaine 8 grams daily, and after 2 months he had gained weight and was able to resume his protected work.

**Conclusion**: Betaine supplementation is a possible new treatment for CTD patients. In our patients the treatment was effective and well tolerated, although the mechanism of its effect is unclear. Further studies with betaine supplementation in this patient group seem warranted.

### 5936 | Natural course in Dutch adult patients with Angelman syndrome

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**Background**: Angelman syndrome (AS) is a neurogenetic disorder characterized by severe cognitive impairment, ataxia, speech impairment and characteristic appearance. Data on natural course in adulthood are scarce. The aim of this study is to describe the evolution of AS in adulthood.

**Method**: Data was collected through questionnaires, physical examination and medical records. Eighty-seven patients (43 males, 44 females, median age 33 years) (range 18–83 years) with genetically confirmed AS were included. Six patients from one large family are reported separately.

**Results**: Sleeping problems (55%) and behavioural problems (86%) persisted in adulthood in a considerable number of patients. Epilepsy was a continuous concern in 53% of patients, with 10% of adults suffering from poorly controlled epilepsy. 71 patients were able to walk independently, however a decline in mobility was observed in 52% of patients. Besides 54% of adults had scoliosis and over 50% appeared to visual function problems. Constipation was a problem in 88% of patients.

**Conclusion**: This is the largest cohort of clinically studied adult patients reported to date. Adults with AS have many debilitating health problems. Mean areas of focus are epilepsy, scoliosis, vision, constipation, behaviour, sleep and mobility.

### 5921 | A novel UBE3A micro deletion in a large family

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**Background**: Angelman syndrome (AS) is a rare genetic disorder, clinically characterized by intellectual disability, lack of speech, ataxia and facial characteristics. Mutations in the maternally inherited UBE3A gene are known to cause AS.

**Method**: Clinical symptoms and genotype of Dutch adult patients was studied. Questionnaires, physical examination and medical records were used. For two patients deceased at the time of the study, interviewing legal representatives retrieved clinical data. Eight patients from one large family were found to have a novel maternally inherited UBE3A micro deletion.

**Results**: Affected members from this family exhibited a phenotype which does not meet the clinical criteria of AS. Although all affected family members were cognitively impaired, they were able to a large extent to speak in sentences. Facial appearances were not characteristic of AS. Mild ataxia was observed in 2 patients only and 2 patients suffered from epilepsy. Behavioural problems were only present in one patient and sleeping problems were not found.

**Conclusion**: We are reporting on a large family with several family members affected by a novel maternally inherited UBE3A mutation. Phenotypes in these patients did not match clinical criteria of AS. Affected patients did however all have a moderate to severe cognitive impairment.

## 18. GENETIC OR RARE CONDITIONS III

### 5830 | Growing up with Fragile X Syndrome – concerns and care needs in young adulthood and implications for transitional care

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*the Netherlands*

**Background**: Little is known about the worries and the healthcare needs of young adult male and female patients with Fragile X Syndrome and their caregivers. More information on care needs will assist in providing optimal transitional and adult care for this vulnerable patient group.

**Method**: A qualitative study was performed using semi-structured group and individual interviews with young adult patients aged 18–30, and parents of young adults. Concerns and healthcare needs in medical, psychological and socio-economic domains were discussed. Themes were organized using the International Classification of Functioning, Disability and Health (ICF).

**Results**: In total, 33 parents (20 of males, 1 of a female) and 5 patients (1 male, 4 females) participated. Results indicated many and diverse worries, with different outcomes for males and females. In both groups parents reported high stress levels, difficulties with their parental role, and a lack of knowledge of FXS in care providers.

**Conclusion**: The concerns and care needs of young adults with FXS and their parents revealed concerns on various domains, requiring gender-specific, multidisciplinary transitional care and adult follow-up for patients with FXS. Additionally, parental stress requires more attention from care providers.

### 5823 | The relationship between emotion regulation and temper outbursts in individuals with neurodevelopmental disorders

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**Background**: Temper outbursts are prevalent in several neurodevelopmental disorders and have a negative impact on wellbeing. Here, we explored the relationship between such outbursts and emotion regulation, which has been widely proposed but rarely examined. 31 individuals with a neurodevelopmental disorder (NDD group; Down syndrome or ASD; mean CA 14.9y, range 8–22; mean MA 7.8y, range 4–15; 58% male) and 459 typically developing (TD) individuals were recruited. Following cleaning, data from 410 TD children remained (mean CA 10.2y, 6–17y, 46.8% male). Participants played a modified ultimatum game (UG), in which decision-making drew on emotion regulation and self-reported on habitual emotion regulation. Non-parametric bootstrapping was applied to individually match NDD participants to two sub-samples of typical peers based on mental and chronological age. Parents reported on NDD participants' temper outbursts, allowing classification according to associated negative impact. Comparison of groups based on more or less negatively impactful outbursts suggested less effective emotion regulation in those with more impactful temper outbursts. However, there was substantial individual variability in which UG parameters indicated most emotion regulation deficit.

**Conclusion**: Further work must unpick differences in how emotion regulation is achieved by different individuals with NDDs and the impact of this on clinically important behaviour.

### 5712 | The association between emotional dysregulation and mental health outcomes in Rubinstein-Taybi syndrome

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**Background**: Anxiety and mood disorders have been reported in over 65% of adolescents and adults with Rubinstein-Taybi syndrome (RTS). Emotional dysregulation has been implicated in the development of mental health difficulties in the general population, including anxiety and low mood. This study combines cross-sectional and longitudinal analyses to examine associations between emotional dysregulation and mental health outcomes in RTS.

**Method**: 48 parents of individuals with RTS completed a cross-sectional questionnaire study in 2010. The Mood, Interest and Pleasure Questionnaire (MIPQ) and Behaviour Rating Inventory of Executive Function (BRIEF-P) were employed. These measures, along with the Anxiety and Depression and Mood Scale (ADAMS) were repeated in 2017.

**Results**: In the cross-sectional analysis, low mood was associated with poorer inhibitory control ($R = -0.43$, $P = 0.002$) and poorer emotional regulation ($R = -0.42$, $P = 0.002$) on the BRIEF-P. Low mood was not associated with any of the other BRIEF-P subscales, or ability level. This finding is consistent with the longitudinal data.
**Conclusion**: Emotional regulation is important to consider in the aetiology of mood disorders in people with RTS, as well as other rare genetic syndromes that have a heightened prevalence of mental health difficulties.

## 5590 | Behavioural dysregulation in children with tuberous sclerosis complex (TSC) and associations with caregiver well-being

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**Aim**: TSC associated neurodevelopmental disorders (TAND) include intellectual disability, ADHD, challenging behaviour and autism spectrum disorder. Caregivers of children with TSC report elevated stress, which is associated with features of TAND. This study examined behavioural dysregulation in children with TSC, and its association with anxiety and depression symptomatology in caregivers.
**Method**: Thirty-one children with TSC (4–14 years) participated. A delay of gratification task, go/no go task and The Activity Questionnaire assessed impulsivity and overactivity and the Challenging Behaviour Questionnaire measured self-injury and aggression. Caregiver well-being was assessed using the Hospital Anxiety and Depression Scale. Scores are contrasted to 29 typically developing (TD) children (3–15 years).
**Results**: Children with TSC were more impulsive and overactive, showed more challenging behaviours and performed less well in the delay of gratification task, than TD children of comparable chronological age or ability. No differences were found on the go/no go task. Greater caregiver-reported impulsivity was correlated with increased depression and anxiety scores in TSC caregivers (but not TD caregivers).
**Conclusion**: We found evidence of broad behavioural regulation difficulties, supporting existing descriptions of TAND, including novel evidence from direct behavioural assessment. Impulsivity in particular, may be associated with poorer caregiver well-being.

# 19. GROWING OLDER I

## 5505 | Health status and health disparities experienced by individuals with intellectual disability who are aging

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**Background**: Individuals with ID are living longer, and according to national official statistics, 32,500 individuals with ID aged 45 years and over are living in Spain. The main goal of this project is to provide basic knowledge about their health characteristics by using a self-designed questionnaire.
**Method**: 6,147 individuals aged 44 years or older have been identified from 76 different organizations through a multi-stage sampling procedure. A complete examination of healthcare needs and disparities is being carried out with 973 individuals.
**Results**: On 590 persons with ID aged 44 and older are presented. Some results point out that 31.5% rate their health as bad, and 59% present some chronic health condition. 49.7% present a mental health issue, being disruptive impulse control and conduct disorder the most frequent (16.9%) closely followed by mood disorders (16.6%). Only 32.4% of those with a dual diagnosis are receiving psychological services apart from medication. Access to specialized health services is rated as problematic by 40% of the sample.
**Conclusion**: Research has the potential to identify medical conditions that are more likely to occur in aging persons with ID. This information would be very useful for reducing costs associated with secondary or tertiary prevention efforts.

## 6026 | Ten years of data: The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing

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**Aim**: To assess achievement of successful ageing over 10 years.
**Background**: The intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) is designed to gather data to identify the principal influences on and contributors to successful ageing.
**Method**: Three waves to date of interviews with a nationally representative sample of people with ID from across Ireland. Use of descriptive statistics and regression to describe, pinpoint predictors and measure incidence and prevalence of chronic conditions as well as to ascertain the social and person-centred lives and living situations of people aged 40 years and older with ID.
**Results**: High levels of access to health care professionals, and uptake of screenings has been found that now match or exceed general population levels. There are also concerning levels of dementia, osteoporosis, constipation and other chronic conditions as well as high levels of polypharmacy. Levels of community engagement and realization of person-centred community living also need improvement.
**Conclusion**: The data being gathered and monitored by IDS-TILDA is providing the tools to both advance public policy and practice goals for people with ID as they age and offers an opportunity to systematically measure both success and continuing or expanding concerns.

## 5819 | Tracking utilisation of health services by people with Intellectual Disability as they age

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**Background**: A correlation between ageing and increased health service use (HSU) by general older population is well documented and increasingly challenges health care delivery. Increased longevity of people with ID means similar trends in health service use may arise.

**Aim**: Examine HSU by older people with intellectual disability in Ireland over a 10-year period and compare to Ireland's general older population.

**Method**: HSU data from three waves of the Intellectual Disability Supplement to the Irish Longitudinal study on Ageing (IDS-TILDA) were examined for changes in utilisation during the period 2007–2017 as was the association with age of participants. Comparisons were made to similar time period data available from the general population ageing study (TILDA).

**Results**: Use of GP services was relatively stable across waves and similar rates found for general and ID older population. However, for the 65–69 years age group there was a decrease in GP use increases in emergency department and hospital admissions.

**Conclusion**: Managing upward trends in emergency department and hospital admissions for people with ID aged 65–69 years may require greater investment in community based primary care.

# 20. GROWING OLDER II

## 5639 | Defeating dementia together

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**Background**: UK ethics committees define those with intellectual disabilities (ID), including the Down Syndrome (DS) population, as a vulnerable group. This often results in automatic exclusion of those with DS in research with the assumption they lack capacity to consent. Our research group aims to actively engage participants with DS to increase and maintain our current cohort for collection of important longitudinal data.

**Method**: To recruit participants and their families, an experienced ID Research Nurse is employed. To gain meaningful consent, researchers developed accessible information to aid participant's decision making whilst monitoring fluctuating capacity over time. For engagement researchers created newsletters for caregivers and participants, video interviews with participants about their research experiences and incentives such as a 'passport' allowing participants to track their research journey.

**Results**: DS participants have repeatedly taken part in multiple studies since 2011. One current study recruited 28 participants from previous imaging studies with a low withdrawal rate (4/32 invited). Participants independently promote dementia research through magazine articles, charity fundraisers and local news interviews.

**Conclusion**: Although prioritising participant engagement is demanding, it allows this 'vulnerable group' to feel valued through developing resourceful relationships with researchers whilst contributing to dementia research together.

## 5636 | Genotype and phenotypic association of TREM2 and Tau in Down syndrome dementia

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**Aim**: In Down syndrome (DS) the amyloid precursor protein (APP) is encoded in triplicate and Aβ accumulation plays a key role in the pathogenesis of Alzheimer's disease (AD). However, other genes including tau, TREM2, Apolipoprotein E and HLA-DR allelic variants, also affect dementia pathology. The aim was to understand the influence of specific genetic haplotypes on DS dementia pathology. Methods Using serum samples from a well-characterised cohort of people with DS ($n$ = 47) we genotyped TREM2, Tau, ApoE and HLA-DR by SNPs analysis and investigated protein expression and its co-relation between inflammation and disease pathogenesis. Two DS participants had the AD-associated TREM2-R47H mutations, and a morphologically extreme phenotype of erythromyeloid cells. Using post-mortem derived DS brain tissues ($n$ = 18) and age matched controls, we also investigated tau and TREM2 pathology.

**Results**: Those with high-risk haplotypes (TREM2 C/T, Tau H1/H1 and ApoE e4) were more prevalent among participants with DS with an earlier age of onset of dementia. Serum TREM2 levels were found to decreased with age (~35%) whereas phosphorylated-Tau (p-tau) levels increased. In the temporal cortex Tau accumulation initially presenting as neuropil threads (NTs) and later as neurofibrillary tangles.

**Conclusions**: We provide evidence that peripheral TREM2 originating from erythromyeloid cells significantly determines AD neuropathology in DS.

## 5958 | A 10-year longitudinal follow-up of dementia in persons with Down syndrome

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**Aim**: To examine dementia characteristics, age at onset in persons with Down syndrome (DS) over a 10-year period.

**Method**: All people with DS included in the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) were followed since Wave 1, in 2009. Cognitive tests included the Test for Severe Impairment and the Brief Praxis Exam. Adaptive behaviour was measured using the Daily Living Skills Questionnaire. All Participants were asked if they received a doctor's diagnosis of dementia.

**Results**: in all three Waves of IDS-TILDA, the prevalence of dementia increased from 15.8% in Wave 1, to 29.7% in Wave 2 (2014) to 35.5% in Wave 3 (2017). The incidence of dementia was 22.5% between Wave 2 and 3, with a mean age of onset of 52.3 years compared to people with ID of other aetiologies with a mean age of onset at 65.5 years in this study.

**Conclusion**: The risk of dementia in people with DS is lower than previously reported in other research, however, of those with DS and without a diagnosis of dementia, 47% had never had a dementia assessment. Longitudinal follow-up appears effective in supporting early identification of dementia in this population.

## 5858 | Patterns of dementia and epilepsy in adults with Down syndrome in Ireland: data from IDS-TILDA

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**Aim**: To examine patterns of onset of dementia and of epilepsy in adults with Down syndrome in Ireland over a ten year period. Method Data from 3 waves of the IDS-TILDA study were collected with 149 participants with Down syndrome in Wave 1, 135 in Wave 2 and in 109 Wave 3. Data was collected on diagnosis of dementia and of epilepsy across the 3 waves along with data on level of intellectual disability, functional limitations, and scores on objective cognitive tests.

**Results**: In Wave 3, 35.5% ($n$ = 38) of people with DS had a doctor's diagnosis of dementia, which rose from 15.6% in Wave 1. Of those without a diagnosis of dementia, 47% had never had a dementia assessment. For those with Down syndrome, prevalence of epilepsy without dementia was low at 13.7%, however among people with Down syndrome with dementia, the prevalence of epilepsy rose to 54.8%.

**Conclusion**: This data confirms the high rates for both dementia and epilepsy in this population and that one appears to influence the other. Of concern, however, was the high number of those with DS who had never had a dementia assessment.

# 21. GROWING OLDER III

## 5774 | Mental health disorders in an older, Irish population with Intellectual Disability – results from Wave 3 IDS-TILDA

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**Aim**: To report the findings on mental health status in an older, Irish, intellectually disabled (ID) population.

**Method**: Six hundred and nine older individuals with ID participated in this third wave of IDS-TILDA. A computer assisted interview included items on areas including health, social circumstances, medication and associated factors. The Glasgow Depression Scale (GDS-LD) and the Glasgow Anxiety Scale (GAS-LD) were completed by the individual or in association with their proxy.

**Results**: Over half of participants (51.9%) reported a diagnosis of a mental health disorder; anxiety being reported by a third and depression by 15.8%. The prevalence of mental health disorders in those with Down syndrome (DS) was half that (26.2%) of the overall group. Two thirds (77.5%) reported their emotional and mental health to be good, very good or excellent. The GDS-LD indicated that 10% had symptomatology consistent with a depressive disorder and 15.1% reported above threshold scores for anxiety on the GAS-LD.

**Conclusion**: Mental health disorders are prevalent in older people with ID; anxiety and depression being most commonly reported.

## 5781 | Overweight & obesity and, interrelated chronic health conditions in older adults with an Intellectual Disability: results from Wave 2 IDS-TILDA

J. Ryan

*Trinity College, Dublin (IDS TILDA), Ireland*

**Aim**: To explore the relationship between overweight/obesity and interrelated chronic health conditions in older adults with an intellectual disability (ID).

**Method**: Data for this paper was drawn from the second wave of the IDS-TILDA study. A longitudinal study examining health determinants among older adults with intellectual disability in Ireland. Data included objectively measured (OM) BMI and waist circumference, which were examined in relation to doctor's diagnosed obesity related disease. Chi-squared automatic interaction detector analysis was applied to identify the most influential variable on overweight/obesity.

**Results**: A prevalence of 66.7% of overweight/obesity was identified with 69.6% identified as at risk of cardio-metabolic conditions according to their waist to hip ratio. Higher levels of overweight/

obese were identified among women (69.9%), those with a mild ID (84.9%) and those under 50 years (69.5%). Cardiovascular disease, for example 18% OM with hypertension, 9.3% with diabetes and over 7% reporting stroke/TIA were evident.

**Conclusion**: Obesity is recognised as one of the most pressing societal challenges of the 21st century. From this study it can be seen that those who are overweight/obese have increased risk of multiple health consequences.

## 5861 | Changing chronic health conditions among older adults with ID: results from 3 waves of IDS-TILDA

M. McCarron; E. McGlinchey; R. Carroll; P. McCallion

*University of Dublin, Trinity College, Ireland*

**Aim**: To examine changes in the incidence, prevalence and patterns of multimorbidity in adults with ID, to better understand how the numbers and type of chronic health conditions change as people age.

**Method**: Data was collected for 609 individuals over three waves of IDS-TILDA on diagnoses of chronic health conditions, specifically 12 chronic health conditions identified in the Charlson Comorbidity Index.

**Results**: Rates of multimorbidity increased slightly to 74.2% in Wave 3, from 71.05% in Wave 1. The highest number of chronic conditions experienced by an individual was 7. Multimorbidity increased from 60.6% in those under 50, to 72.7% in those aged 50–64 and 83.9% in those aged 65 and over. Mental Health was the most common condition at 52.2% followed by gastrointestinal disease 47.4%, and neurological disease at 39.6%. Disease patterns were different than those found in Wave 1 where eye disease was the most common condition. The presence of several chronic conditions at baseline were predictive of the onset of additional chronic conditions over time.

**Conclusion**: Multimorbidity remained high in this population with increasing complexity in patterns of co-morbid conditions.

## 5399 | Is mental health status affected by chronic diseases in older people with intellectual disability?

R. Hussain; S. Wark; M. Janicki; T. Parmenter; M. Knox

*Australian National University, Australia*

**Background**: Authors explore the impact of certain chronic diseases/disorders which are linked with poor mental health amongst older people with intellectual disability (PwID).

**Method**: Cross-sectional face-to-face survey of 392 adults aged > 60 years living in community settings in urban and rural regions of Australia. Mental health composite score (MCS) was derived from MoS-SF12, a QoL instrument with high internal and external validity.

**Results**: Mean age was 65.2 years (SD 4.4); males = 62.7%. MCS values were close to population norm (X = 50.4, SD 9.9) but showed a wide range (18.1–70.8) indicating very poor mental health for some study respondents. MSC values did not differ significantly between urban and rural residents. Prevalence of chronic diseases/disorders was: arthritis (40.4%), diabetes (25.6%), asthma (16.1%), coronary disease (14.8%), chronic pain (26.9%), sleep disturbance (22.3%), and falls (29.2%). MCS values were significantly lower for chronic pain, sleep, and falls; whereas, mean MCS was lower for coronary disease and hearing loss, but not statistically significant. Respondents with multiple co-morbidity had lower MCS.

**Conclusion**: Primary care management of chronic diseases/disorders for older PwID is important. The clustering of certain chronic conditions calls for health promotion strategies to improve mental health of older PwID.

# 22. GROWING OLDER IV

## 5883 | A comparison of drug burden measures on physical function scores in a cohort of older adults with Intellectual Disabilities

J. O'Connell; E. Burke; M. Henman; P. McCallion; M. McCarron; M. O'Dwyer

*Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing, School of Nursing and Midwifery, Trinity College, Dublin, Ireland. School of Pharmacy and Pharmaceutical Sciences, Trinity College, Dublin, Ireland*

**Aim**: To measure the association between two measures of drug burden, Drug Burden Index (DBI) and Anticholinergic Cognitive Burden (ACB) on two physical function measures in a cohort of older adults with intellectual disabilities (ID).

**Method**: Data for this study is drawn from Wave 2 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA), a representative study of older adults with ID in Ireland. DBI and ACB scores were tested as dichotomous (no exposure, any exposure) and ordinal variables (no exposure, low exposure, high exposure) to measure associations with grip strength (kg) and timed up and go (seconds).

**Results**: Grip strength was not significantly associated with exposure to DBI or ACB medications ($P = 0.778$, $P = 0.618$) after adjusting for confounders. Similarly, there was no association between adjusted timed up and go and exposure to DBI or ACB medications ($P = 0.808$, $P = 0.594$).

**Conclusion**: There was no association between DBI and ACB exposure and grip strength or timed up and go measurements, which is different to evidence in older adults without ID. This could be a result of low levels of physical activity and the effect of ageing.

## 5924 | Using chi-square automatic interaction detection modelling to identify predictors of osteoporosis among adults with Intellectual Disability

E. Burke; R. Carroll; M. O'Dwyer; J. Walsh; P. McCallion; M. McCarron

*School of Nursing and Midwifery, Trinity Centre for Ageing and Intellectual Disability, Trinity College Dublin, Ireland*

**Aim**: To identify predictors of osteoporosis among older adults with intellectual disability.

**Method**: The sample was drawn from the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA). Bone quality was measured by quantitative ultrasound (QUS) as part of an objective health suite of assessments. CHAID analysis was performed to determine the significance of literature supported predictors for poor bone quality drawn from the data of the IDS-TILDA study including physician diagnosed chronic health conditions, dietary intake and frequency, medication use and activity levels.

**Results**: In total 575 participants completed QUS. The prevalence of osteoporosis was 41%. Three major predictor variables reached significance to be included in this model, difficulty walking 100 yards ($P$-value < 0.0001), taking AED medicines ($P$-value = 0.004) and taking proton pump inhibitors ($P$-value = 0.043). This model had an overall classification accuracy of 70.8% with its ability to classify osteoporosis at 72.5%.

**Conclusion**: The findings support a need for robust risk assessment and for clinical practitioners to not only consider the obvious risks but also specific concerns for people with ID in order to better target preventative strategies to decrease future risk of fragility fractures.

## 5627 | Thicker retinal structure in Down's syndrome and its relationship with ageing

M. Walpert; E. Normando; M. Cordeiro; S. Zaman; A. Holland

*University of Cambridge, UK*

**Aim**: To investigate retinal thickness in people with Down's syndrome (DS) in relation to ageing, cognitive abilities and dementia status and in comparison to age-matched controls. Alzheimer's disease (AD) research has found reduced retinal thickness in patients with AD compared to age-matched controls. People with DS have very high prevalence of early-onset AD. Retinal changes have the potential to be a biomarker of AD, which could be used as a proxy outcome measure in clinical trials.

**Method**: 50 adults with DS completed optical coherence tomography examinations of the retinal nerve fibre layer (RNFL).

**Results**: Results were compared to 36 age-matched control participants. Neuropsychological tests were also completed in the DS group. Results: Results showed significantly thicker retina across almost all areas in people with DS compared to age-matched controls. This result was consistent across all age groups and correlations with age showed that the DS group did not show typical age-related RNFL thinning, as was seen in the control group.

**Conclusion**: The results of this study suggest that there are underlying pathologies which may be influencing the thickness of the retina in people with DS, this could be related to amyloid-beta depositions and associated factors, including inflammation and cell death.

## 5612 | Protocols to detect and initiate assessment and treatment of dementia in people with intellectual disabilities

F. Larsen; E. Langballe

*Norwegian National Advisory Unit on Ageing and Health, Vestfold Hospital Trust, Tønsberg, Norway*

**Aim**: The number of elderly with intellectual disabilities (ID) will increase significantly, and more people with ID will experience dementia in the future. Research shows that in Norway, 8 out of 10 people with ID who are suspected of suffering from dementia are not assessed. The aim of this study is to identifying protocols that should be established in municipal health services to detect and initiate assessment and treatment of dementia in people with ID.

**Method**: Employees representing the municipal health services from all the health regions in Norway participated in a qualitative interview survey.

**Results**: The survey shows lack of implementation of protocols, a lack of knowledge by service providers in identifying early symptoms of dementia, and a lack of involvement by GPs, may be some of the main reasons for the failure to make assessments and for not receiving the appropriate treatment and care.

**Conclusion**: To detect early signs of dementia, a comprehensive and systematic approach should be established and include observation, documentation, information, and intervention. With the correct diagnosis, municipalities will be better prepared to provide appropriate resources, avoid malpractice and reduce constraints for the individual with ID, their relatives, and the health services concerned.

# 23. DEATH AND DYING I

## 6046 | Expecting the unexpected. Awareness of impending death among adults with Intellectual disabilities and paid carers in social care settings in the UK

J. Bernal; S. Todd; J. Shearn; K. Hunt; W. Rhian

*University of South Wales, UK*

**Aim**: To determine the proportion of deaths of adults with ID where either the dying person or direct care/support staff (CS) were aware death was likely. To examine the effect of awareness on place of death and CS satisfaction with End of Life Care (EOLC).
**Method**: Providers of social care for adults with ID in the UK supplied data on deaths over an 18 month period and contact details of a staff member who had known the deceased person well. Data from a CS-completed VOICES LD and a questionnaire designed for this study were obtained for 157 deaths.
**Results**: A minority were aware, partly reflecting different causes of death. Of 157 deaths in the study period, staff believed 17 were aware they were dying. Staff were aware that 67 had an illness that might lead to death. 28% of deaths followed less than a week's illness. CS awareness was associated with home deaths and with higher levels of overall satisfaction with EOLC.
**Conclusion**: Possible reasons for the low levels of awareness are explored. Research and practice in EOLC for people with ID must include unexpected deaths. Better identification of those at risk might allow earlier access to curative and EOLC.

## 5704 | Hidden lives and deaths: people with ID living in generic care settings

S. Todd; J. Shearn; R. Worth
*University of South WalesHidd, UK*

**Aim**: To investigate the nature of death of people with ID living in non-ID adult care settings.
**Method**: 70 non ID care settings in the UK participated in the study. Within this population, 162 people (8.8%) were reported to have ID. Demographic and health data on those people with ID were obtained. This was repeated within 12 months and data also obtained on deaths that occurred within this time period.
**Results**: Preliminary analysis suggests that the people with ID were almost 20 years younger than other people in those settings. Almost one quarter were identified as being at likely risk of dying within 6 months. At Time 2, 22 people (17.6%) with ID had died. Their average age of death was 71.7 years (SD=7.97). Of those perceived to be at likely risk of death, 25% had died. Data on end of life care for this population are currently being analysed.
**Conclusion**: People with ID living in non ID settings maybe be amongst the oldest of older people with ID. It is conceivable that although not a predominant provider of carer, such services may be playing a significant role in end of life care to people with ID.

## 5697 | Talking about dying with people with ID who have experienced a bereavement: a UK survey of support staff

S. Todd; J. Bernal; J. Finlayson; C. Lam; L. Taggart; I. Tuffrey-Wijne
*University of South Wales, UK*

**Aim**: To investigate the extent to which people with ID who have experienced a bereavement are informed about it.
**Method**: Support staff in supported living and residential settings completed an online survey ($n$ = 724, 64% response rate), supporting over 6,000 people with ID across the UK. Those answering "yes" to the question whether any of their clients had experienced a bereavement during the past 12 months ($n$ = 693) were asked further questions about this.
**Results**: In 33% of cases, the person with ID was not told that the person was dying. Most respondents recognised the benefits in preparing a person with ID for the death of a significant other in their life. Almost two third of people were told of the eventual death within 24 hours (66.3%) and were involved in the subsequent funeral (64.5%). Most reported that they felt confident in dealing with the bereavement experiences of people with ID.
**Conclusion**: The data suggest that there has been a major shift in practice concerning the bereavement experiences of people with ID. Most were told beforehand that a significant other would die soon, informed about the death soon after it occurred and participating in grief rituals.

## 5587 | Talking about dying with people with ID who have a terminal illness: a UK survey of support staff

J. Bernal; J. Finlayson; C. Lam; L. Taggart; S. Todd; I. Tuffrey-Wijne
*University of South Wales, UK*

**Background**: To investigate the extent to which people with ID who have a terminal illness are informed of their diagnosis and prognosis.
**Method**: Support staff working in supported living and residential settings completed an online survey ($n$ = 724, 64% response rate), supporting over 6,000 people with ID between them. Recruitment was through contacting managers of ID service providers from all four UK countries ($n$ = 25). Those answering "yes" to the question whether any of their clients had died during the past 12 months, or was currently terminally ill, were asked further questions about this.
**Results**: Over a quarter of respondents ($n$ = 205) had experienced death or terminal illness among their clients during the past year, reporting 199 deceased (of which 114 were non-sudden deaths) and 76 terminally ill clients. Over half of people with ID whose death was expected were told about their illness, but only 20% were ever told that they would die of it. However, 36% of respondents thought that the person "definitely" or "probably" realised that they were going to die.
**Conclusion**: People with ID whose deaths are expected by staff are mostly uninformed about their own impending death. This has implications for their involvement in end-of-life decision making.

## 24. DEATH AND DYING II

### 5425 | Validity and reliability of an advance-care planning tool for people with IDs

M.T. Wicki

*University of Applied Sciences of Special Needs Education, Zurich, Switzerland*

**Aim**: Research shows that people with ID are hardly involved in end-of-life decisions. The goal of this study was to use a person-centred future-planning tool to explore the usefulness, validity and reliability of advance-care planning (ACP) for people with IDs.
**Method:** A volunteer sample of 60 persons rated the capacity to consent to treatment of 4 persons with ID's. Sensitivity, specificity and percentages of agreement were calculated, and inter-rater reliability was assessed using Fleiss' kappa and Krippendorff's alpha.
**Results**: The sensitivity value was 62%, the specificity value was 95%. The percentage of agreement (P(a)) for all participants was 69.75%, Fleiss' kappa was k = 0.396 and Krippendorff's alpha was $\alpha = 0.395$. Finally, 72% of the participants found the tool very or partly useful for ACP for people with IDs.
**Conclusions:** Documented interviews help persons with IDs to declare their wishes and values regarding end-of-life issues. The interviews help carers and relatives to identify those individuals who had the capacity to consent to treatment. It is useful for physicians, caregivers and relatives to interview people with IDs about end-of-life decisions and to document these interviews systematically.

### 5928 | Where you live and die?: A comparisons of end of life outcomes for expected deaths in people living in social care ID settings

S. Todd; E. Jones; K. Lower; R. Forrester-Jones; J. Shearn; R. Worth

*University of South Wales, UK*

**Aim**: To investigate factors that shape end of life care outcomes for people with ID.
**Method**: 53 deaths of people with ID were identified from a larger representative sample of deaths in the UK (*n* = 156). These 53 deaths were deaths that had been expected for three months or more. They were evenly distributed between care homes and support living settings. Data were obtained on individual an setting characteristics, and end of life care outcomes.
**Results**: Decedents living in care homes were significantly more likely to die in the setting in which they lived than people living in smaller supported living settings. There were few demographic differences between decedents across these two settings. Setting factors, in particular staff: client ratio and size of staff group explained most of the variance in outcome.
**Conclusion**: Although supported living services offer enhanced opportunities for ordinary living, they seem less well able to support people with ID at the end of life. There are suggestions that staff development is a major area for improving EoLC outcomes for people with ID. The results in this paper suggest that resources may be just as or more important.

### 5810 | Predictors of mortality in Down Syndrome: results after 15 years of follow-up in a longitudinal cohort study

A. Coppus

*Radboud University Medical Center, the Netherlands*

**Aim**: During the last decades the life expectancy of people with Down Syndrome (DS) has increased to an average of 60 years in developed countries. Knowledge of factors influencing mortality in older people with DS is limited. The aim of this longitudinal population based study on older people with DS is to study determinants of mortality.
**Method**: Therefore we conducted a study of 506 persons with DS, aged 45 years and older, who were enrolled from December 1, 1999 to December 1, 2003 in a community-based study on DS and ageing. All participants were monitored until they died (76%), up to the reference date of January 1, 2017 (mean follow-up survivors 15 years). We studied the prevalence and incidence of dementia as well as mortality in the demented and the non-demented.
**Results**: The high risk levels for dementia among people with Down syndrome was confirmed in these data.
**Conclusion**: Age and dementia were found to be the most important predictors of mortality in this study cohort.

## 25. MENTAL HEALTH I

### 5504 | Prevalence of mental health conditions and relationship with general health in a whole country population of 26,349 people with intellectual disabilities, compared with the general population

L. Hughes-McCormack; E. Rydzewska; A. Henderson; C. MacIntyre; J. Rintoul; S.-A. Cooper

*University of Glasgow, Institute of Health and Wellbeing, UK*

**Aim**: To determine (1) prevalence of mental health conditions and, (2) relationships with general health in a total population with and without intellectual disabilities.
**Method**: Data were drawn from Scotland's Census, 2011, on intellectual disabilities, mental health, and general health. We calculated prevalence of mental health conditions, and conducted logistic regressions on intellectual disabilities predicting poor mental health, and on general health status predicting poor mental health, adjusted for age and gender.

**Results**: 26,349/5,295,403 (0.5%) had intellectual disabilities; of whom 12.8% children, 23.4% adults, 27.2% older adults had mental health conditions compared with 0.3%, 5.3%, 4.5% general population. Intellectual disabilities predicted mental health conditions: OR=7.1 (95% CI 6.8–7.3). General health was associated with mental health conditions within the intellectual disabilities population; fair health OR=1.8 (95% CI 1.7–1.9), bad/very bad health OR=4.2 (95% CI 3.9–4.6), but to a lesser extent than within the whole population. Female gender reduced the likelihood of mental health conditions: OR=0.89 (95% CI 0.89–0.95); and increase in age group up to 64 years predicted mental health conditions.

**Conclusion**: This large-scale, whole-country study findings are important, given the previously stated lack of confidence in comparative prevalence results with the general population, and the need to plan services accordingly.

## 5538 | The role of social support in posttraumatic coping in people with Intellectual Disabilities

D. Rittmannsberger; B. Lueger-Schuster; G. Weber

*University of Vienna, Austria*

**Aim**: In the general population, positive social support is a main protective posttraumatic factors. There are only two studies aiming at replicating this effect in people with Intellectual Disabilities (ID). So far, a mediating protective effect of social support has not be found. One possible explanation is that the type of social support that people with ID receive is disadvantageous. Our hypothesis is that people with ID receive a high amount of unsupportive acknowledgement. We aim to assess the role of posttraumatic social support.

**Method**: We will assess social reactions to disclosure of traumatic events and the type of posttraumatic social support received in qualitative interviews with ten people with ID. Their influence on symptoms of trauma sequelae will be assessed.

**Results**: Preliminary results are expected before July 2018. Reported posttraumatic social support will be categorized in 'turning against', 'unsupportive acknowledgement', and 'positive reactions'. We expect that there is a mediating effect of social support on symptoms of trauma sequelae.

**Conclusion**: This study will identify which types of social support are perceived as helpful by people with ID and gain an understanding on the mechanisms by which they mediate trauma sequelae. These results have implications for designing training for professional carers.

## 5461 | A pilot randomised control trial of Eye Movement Desensitisation and Reprocessing (EMDR) vs. Waiting List Control for DSM-5 Posttraumatic Stress Disorder (PTSD) in adults with intellectual disabilities

T. Karatzias; M. Brown; L. Taggart; M. Truesdale

*Edinburgh Napier University & NHS Lothian Rivers Centre for Traumatic Stress, UK*

**Aim**: The present study reports on the first ever pilot trial of EMDR versus WL for DSM 5 PTSD in people with IDs.

**Method:** A total of 29 participants were randomised to either EMDR ($n$ = 15) or WL ($n$ = 14). Participants were assessed at pre-post – and 3 – month follow – up on measures of traumatic stress, depression, anxiety and general distress. Qualitative interviews were also conducted with completers and non-completers on treatment experience.

**Results**: Participants in the EMDR group received a mean of 6.8 (Sd = 1.4) sessions. A proportion of 40% dropped out from the EMDR + WL group and 29% from the WL group. At post – treatment 60% in the EMDR group were diagnosis free versus 27% in the WL group. At 3 – month follow – up 47% in the EMDR group and 27% in the WL group were diagnosis free. Qualitative findings confirmed that EMDR is an acceptable treatment for people 1 with IDs and DSM 5 PTSD.

**Conclusion:** A definitive trial on EMDR for DSM 5 PTSD is recommended.

## 5393 | A multicentre randomised controlled trial for bright light therapy in adults with intellectual disabilities and depressive symptoms: first results

P. Hamers[1,2]; D. Festen[1,2]; H. Hermans[1,2]

*[1]Intellectual Disability Medicine, Department of General Practice, Erasmus University Medical Center, Rotterdam, NL; [2]Amarant Group, Healthcare organization for people with intellectual disabilities, Tilburg, the Netherland, NL*

**Aim**: There are only a few options to treat depressive symptoms in adults with intellectual disabilities (ID), especially in the severe/profound ID population. As pharmacological treatments are not always desirable or usable, this study investigates the effect of Bright Light therapy (BLT) in adults with ID and depressive symptoms.

**Method**: A multicenter randomised controlled trial (RCT) was carried out in the Netherlands. Participants were randomised over three groups. Group I received two weeks of BLT in the morning (10,000 lux), additional to their care as usual. Group II: received two weeks of BLT in the morning (< 499 lux), additional to their care as usual. Group III: only received care as usual (control group). Depressive symptoms measured at baseline, right after the end of BLT and four weeks after the end of BLT were our main outcome measures.

**Results**: Data collection of this study ended in November 2017. In total, 41 participants have been included in the past two years. The first results on its effect on depressive symptoms will be presented for each intervention group.

**Conclusion**: As far as we know, this study is the first multicenter RCT investigating BLT to decrease depressive symptoms in adults with ID.

## 26. MENTAL HEALTH II

### 5654 | Psychologists' adherence and carer experiences with best practice in Intellectual Disabilities and co-morbid mental Ill health – oral presentation research report

J. Man

*Macquarie University, Australia*

**Aim**: This PhD research explored Australian psychologists' perceptions of best practice in dual disabilities and its alignment with practice guidelines and carer experiences.

**Method**: The first study explored assessment practices, training needs and barriers to evidence based practice implementation of Australian psychologists via an online survey. Study two involved focus groups with psychologists exploring their perceptions of best practice, adherence to practice guidelines and impact of organisation factors. The final mixed method study explored carers' experiences with mental health and disability services, carer mental health literacy and barriers to seeking help.

**Results**: Overall, findings suggest psychologists were aware of best practice principles and reported clinical practices that aligned with international and Australian practice guidelines. Psychologists reported limited confidence in mental health diagnosis with individuals with intellectual disabilities and the need for further training. Carers also displayed high mental health literacy and few attitudinal barriers to help seeking.

**Conclusion**: Further clinician training and addressing organisational barriers to best practice implementation are needed. Findings also have implications for service models of care, policy and practice based evidence.

### 5617 | Feasibility of tandem-delivered psychoeducation for service users and staff: a case series of a tablet-based intervention

L. Vereenooghe; K. Westermann

*Bielefeld University, Germany*

**Aim**: People with intellectual disabilities may have a limited cognitive understanding of mental health problems and mental well-being. We aimed to explore the feasibility of a brief tablet-based psychoeducational intervention for use by people with ID and their care-givers.

**Method**: Five participant pairs were formed by adult service users with mild to moderate ID living in residential facilities and a nominated care-giver. Service users, supported by their care-giver, completed four weekly 30-minute sessions of the psychoeducational programme. The intervention introduced four concepts: self-concept, community participation, behavioural activation, and cognitive restructuring.

**Results**: Quantitative within-subjects analyses evaluated self-reported and proxy-reported quality of life, behaviour problems, mood, and self-efficacy. Qualitative analysis of the acceptability and feasibility of the intervention, using the client change interview, yielded recommendations for further development of the intervention.

**Conclusion:** The findings suggest that tablet-based psychoeducation may be feasible and acceptable to people with ID. Further development of the intervention would benefit from a collaborative approach with both service users and staff is desirable prior to evaluating its efficacy in a larger sample.

### 5592 | A pilot study to evaluate a group intervention for boys with Autism Spectrum Disorder (ASD) bullied in mainstream school

C.K. Giannoulis; L. Shostak; J. Ronayne

*Independent practitioner, Greece*

**Aim**: This presentation describes the development and evaluation of a cognitive behavioural anti-bullying group programme.

**Method:** The intervention was directed at 11–16 year old boys with ASD who were being bullied within mainstream school. The group programme aimed to teach youngsters strategies to manage bullying and improve their confidence and resilience. A pre-test/post-test single group design was utilised. Primarily qualitative methods were used to evaluate the impact of the intervention 6–24 months post completion.

**Results**: Qualitative analysis of semi-structured interviews with 8 youngsters and their parents was completed. Both the participants and their parents reported benefits of attending the group, including bullying-related positive changes (e.g. improved self-awareness, reduced isolation and enhanced ability to cope with incidents of bullying) and high levels of user satisfaction with the service.

**Conclusion:** Young people with ASD attending mainstream school are at risk of experiencing bullying and the associated long-lasting negative effects on their well-being. Group programmes promoting self awareness and self management may have a useful role in empowering youngsters to build resilience and manage these experiences effectively. Within societies that value diversity, it is vital that bullying behaviour is addressed in schools so that truly inclusive cultures are established within education establishments.

## 5771 | Promoting carers' well-being using acceptance-based interventions for carers of children with intellectual disabilities; a pilot project

I. Skourti; L. Brosh

*Central and North West London NHS Trust, UK*

**Aim**: It is well known that carers of children and young people, whose behaviour is deemed as challenging, experience high levels of stress. In an attempt to promote greater resilience to the carers we are working with, and to ensure the integrity of our interventions, we run workshops for carers based on the principles of Acceptance and Commitment Therapy (ACT).

**Method**: Participants were parents of children with intellectual disabilities, accessing specialist tier 3 CAMHS Learning Disability services in the UK. The workshops involved two 4-hour group sessions on consecutive weeks. One follow up individual appointment 4–6 weeks following the group took place, to measure progress and obtain feedback.

**Results**: To assess the outcomes of our intervention, we used a qualitative feedback form, a general measure of psychological acceptance and a goal-based outcome. The preliminary analysis of the qualitative feedback of a small group of participants suggests that parents found the workshops useful, and an acceptance-based intervention may positively affect their psychological adjustment.

**Conclusion**: This intervention appears to promote carers' well-being and may also offer an important contribution to the wider implementation of the Positive Behaviour Support (PBS) framework.

# 27. MENTAL HEALTH III

## 5915 | The setting of a specialised service for people with intellectual disabilities and mental health

E. Guaia

*Consultant Psychiatrist Intellectual Disability and Mental Health Unit Norther Sydney Mental Health Drug and Alcohol Cameron Building, Macquarie Hospital, Australia*

**Aim**: Setting up a new service for people with intellectual disability and mental health requires building a network between the existing services. With the introduction of National Disability Insurance Scheme, the support for people with a learning disability has moved to a new system where each person needs are offered with an individualised access and with provisions that are based on needs and individual preferences.

**Method**: The mental health component otherwise has always required a specific approach that involved not only the specific support to the individual with Id and Mental Health problem as these in people with ID are three times more common and require a tailored approach that involves a holistic approach.

**Results**: Due to the historic divide between health and support services in Australia, the mental health component has not been fully developed and psychiatrists did not have the opportunities to be specifically trained and as well this has happened to mental health professionals.

**Conclusion**: This presentation will highlight the experience of the author on setting up a new service from the beginning providing the preliminary framework and the progress since the early setup and as well the challenge relevant to establish a new model of service.

## 6016 | Relations between social and emotional competence and mental health problems in adolescents with intellectual disabilities (ID)

S. Sekusak-Galesev; A. Zic-Ralic; L. Pintaric-Mlinar; N. Lisak

*Faculty for Education and Rehabilitation Sciences, University of Zagreb, Croatia*

**Aim**: 1. To determine relations between social and emotional competence and mental health problems in adolescents with ID 2. To determine relations between social and emotional competence and mental health problems in adolescents without difficulties 3. To analyze differences in structure of canonical factors between two samples.

**Method**: Participants: sample of adolescents with ID (100); sample of adolescents without disabilities (100) Procedures: Special teachers will assess socio-emotional competence and mental health with two scales. Data processing: Descriptive analysis, Canonical correlation analysis, Multivariant regression analysis Measurement instruments: Scale of emotional development—Short (Spook at all., 2016) and Scale for developmental-psychiatric diagnosis in persons with ID (SRPD, Došen, 2002).

**Results**: There are statistically significant correlation between social and emotional competence and mental health in sample with ID, but not in typical sample. There are significant differences in canonical structure between two samples. There are different predictors of mental health problems between two samples.

**Conclusion**: This research plan is implemented for the first time in Croatia and enrich scientific knowledge as we find out specific factors and predictors which can contribute to better socioemotional competence and better mental health in adolescents with ID in relation with adolescents without disabilities.

## 5368 | Substance abuse among outpatients with ID: adapting treatment methods through multiprofessional collaboration

P. Björne; A. Edvardson

*City of Malmö, Sweden*

**Aim**: The frequency of drop out among clients with cognitive disabilities such as ID, borderline intellectual functioning and/or autism at

an outpatient care centre for persons with substance abuse, aroused questions. The manager and therapists at the centre wanted to develop the treatment methods, thus making them more accessible. The aim of the study was to explore how, through multiprofessional collaboration with a cognitive scientist, treatment methods could be modified for clients with cognitive disabilities.

**Method:** The manager and therapists collaborated with a cognitive scientist during one year. The therapists presented client cases and jointly explored possible adaptations of methods with maintained method integrity. Between meetings, therapists adjusted client sessions and documented the impact on clients.

**Results**: The therapists found that clients with ID, BIF and/or autism were able to engage in the therapeutic partnership when context changes were supported, visual aids were provided and time for client sessions was adapted to individual needs. Continued collection of statistics will show if the adapted treatment methods will affect drop outs among clients with ID/BIF or autism.

**Conclusion:** Multiprofessional collaboration with a researcher can be an efficient way of adapting client work, making treatment methods more accessible to clients with ID/BIF.

## 5716 | Results of a multi-component walking programme for children with intellectual disabilities: a randomised feasibility study

L. Taggart; A. Johnston

*University of Ulster, Northern Ireland, UK*

**Background**: We developed a 12-week multi-component walking programme for children with ID (9–13 years) based upon COM-B behaviour change model and the social ecological model. Components of the programme included: the use of peer role models with ID (15–19 years), incremental walk programme, use of paedmoeters and creating walk zones within the school.

**Aim**: To undertake a randomised feasibility study of the walking programme compared to routine school input targeting physical activity.

**Method**: Two school in N Ireland were randomly allocated to receive the walking program and one school acted as the control group.

**Results**: There was minimal attrition (7%) and adherence to the 12-week multi-component walking program was 78.5% across the 2 schools. There was poor compliance to accelerometer wear time however all other outcome measures were appropriate and acceptable. There were positive trends in vigorous physical activity, increase in step account and in physical fitness. **Conclusion:** It was feasible to deliver this 12-week multi-component programme within a school setting. This is the first study to develop and test a school-based multi-component walking programme for children with ID.

# 28. MENTAL HEALTH IV

## 5975 | Enhancing staff knowledge of positive behaviour support for adults with Intellectual Disability in Hong Kong

P. King Shui Wong

*The Chinese University of Hong Kong, Hong Kong*

**Aim**: Positive behaviour support (PBS) is increasingly viewed as the preferred service approach for people with intellectual disability (ID),however knowledge and skills are insufficiently widespread in Hong Kong. This paper reports findings from a PBS project carried out with a Disability Service Agency in Hong Kong, as part of a wider study evaluating effectiveness of PBS training. The current study aims to examine changes in staff knowledge after the tier one staff training.

**Method**: In total, 238 participants from various positions (both direct support workers and professionals) who work with adults with ID attended the PBS training workshop. A pre-test/post-test design was adopted. Participants rated their knowledge on the author-constructed 3-item scale before and after the training.

**Results**: Showed that participants achieved statistically significant positive changes in the domains of perceptions of challenging behaviours ($P = 0.000$), active participation in PBS intervention ($P = 0.014$) and the total score ($P = 0.000$).

**Conclusion**: The findings provided initial evidence of the effectiveness of staff training that enhances PBS knowledge of Chinese rehabilitation personnel of various positions. The content and pedagogy of the staff training will be discussed.

## 6017 | Effective occupational therapy with young people with complex mental health / learning disabilities

M. Avantaggiato-Quinn; S. McAnelly

*Northumberland Tyne & Wear NHS Foundation Trust Northumbria University, UK*

**Aim**: This relativist research enhances understanding of the phenomenon of effective occupational therapy with children and young people (CYP) with complex mental health needs/learning disabilities, in the lived experience of occupational therapists.

**Method**: Assuming an interpretivist epistemological perspective, a Heideggerian (1962) interpretive phenomenological methodology guided a reflexive relational approach (Finlay and Evans, 2009) to in-depth interviews carried out with eight OTs working in specialist CYP services in England. Using threefold analytic.

**Method**: Thematic (Van Manen, 1997), metaphorical and Lifeworld (Ashworth, 2003), results were contextualised using an occupational perspective of health (Wilcock and Hocking, 2015).
**Results**: Effective OT identified issues of occupational injustice and child centredness. Primarily supporting the development of the young person's sense of occupational being through having an authentic relationship and time and space during occupational therapy. Opportunities to improve health through occupational doing were created through micro-grading of activity-based interventions. Grading the environment enabled OTs to facilitate CYP to set and reach personally meaningful goals to become the experts in themselves and develop a sense of self-hood and occupational belonging.
**Conclusion**: Enhancing understanding of occupational therapy with CYP, offering recommendations to refine OT practice with CYP to celebrate diversity through improving participation in meaningful occupations.

## 6024 | Using hidden Markov models to better understand transitions in both depression and loneliness

P. McCallion; A. Wormald; E. Cleary; M. McCarron
*Temple university, USA*

**Aim**: To understand transitions in both depression and loneliness.
**Background**: Depression and loneliness in older adults with intellectual disabilities are reported as somewhat higher than for the general population but the transition to depression or to loneliness and the reverse transition from depression to no depression or from loneliness to no loneliness have not been fully explored.
**Method**: This study uses the longitudinal data from the first three waves of the intellectual Disability Supplement to The Irish Longitudinal Study on Ageing to examine the transition to depression, reverse transition from depression to no depression and also repeated transition from no depression to depression after experiencing a reverse transition during a study period. Covariate-dependent Markov models used the logistic link function based on the Chapman-Kolmogorov equation.
**Results**: Similar to prior reports for the general population, differences by age and by gender appeared to influence transitions in both loneliness and depression.
**Conclusion**: Depression and loneliness have emerged as major health concerns with the potential to have long-term impact in terms of risk for chronic conditions and lower life satisfaction. The findings here help to further identify those at risk and the times in one's life when risk may be greatest.

# 29. CHALLENGING BEHAVIOUR

## 6033 | Intervention MOMENT: developing family resources to cope with challenging behaviours

E. Kontu; J. Virtanen; V. Tyyskä-Korhonen; R. Pirttimaa
*University of Helsinki, Finland*

**Background**: Intellectual and developmental disabilities are often linked with behavioural challenges, for which families seek solutions. Several programmes are available to support positive behaviours. The project MOMENT (Hetki) a resource-driven model is being developed. The aim is to develop a model for intervention to support family resources. Understanding siblings' behaviour is also promoted. The model includes individual guidance for the family members and intense co-operation in peer-group activities, with the aim to increase the family's means of solving problems.
**Method**: The intervention and the developmental work are carried out through action research, and the usefulness of the intervention is evaluated through family and group interviews. In addition, information is obtained through observations. In addition, the behaviour of a single child is monitored. Data are also collected during professional discussions. Thirty-three families are involved in the development of the intervention and the research.
**Results**: Results will be collected throughout 2018.

## 6004 | Reestablishment of the Institutional Model? Organisational and individual aspects regarding services for persons with challenging behavior

M. Reichstein
*Germany*

**Background**: Following the ratification of the UN CRPD the support systems for persons with intellectual disability undergo substantial changes in many countries. While many persons with intellectual disability can benefit from the recent development certain groups seem to bear a higher risk of being excluded from newly developed service models. In this context persons who show so-called challenging behavior appear to be especially vulnerable. Support models for persons with intellectual disability are being intensively discussed in Germany at the moment.
**Method**: The presentation will refer to results from a recently finished research project on services for the aforementioned group. In this context, both structural aspects and the individual situation and quality of life were covered with a mixed-methods approach. A representative quantitative study among service providers in North Rhine-Westfalia (Reichstein & Schaedler 2016) showed a wide acceptance of custodial measures up to closed accommodation with

legal approval among service provision organizations. In this context, there might be a risk of restrictive institutional models to become reestablished with a drastic impact on individual quality of life. Those negative impacts have been found in interviews with the target group.

**Results**: Results have been structured referring to the quality of life model by Schalock and Verdugo (2002).

## 5684 | Self-injurious behaviour and service receipt in young adults with autism: a ten year longitudinal cohort study

C. Richards

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**Aim**: Autism spectrum disorder (ASD) is a risk marker for self-injurious behaviour (SIB). However, despite the deleterious consequences of self-injury, there are limited data describing the trajectory of self-injury over time in this high risk group. Thus, the present study aimed to describe the course of self-injury in individuals with ASD over ten years, assessing correlates of poor outcome and associated access to services and intervention.

**Method**: Parents and carers of 67 individuals with ASD (median age = 20.5) completed questionnaires relating to self-injury at T1 and ten years later at T2. Analyses were conducted to evaluate the persistence of SIB and behavioural and demographic characteristics associated with persistence. At T2, data were gathered on service and intervention access in the preceding ten years.

**Results**: Self-injurious behaviour was significantly persistent over ten years ($P < 0.01$) and persistence was predicted by higher levels of impulsivity and overactivity at T1. Persistence in self-injury over ten years was not associated with increased access to service or appropriate interventions.

**Conclusion**: Self-injury is persistent in ASD and predicted over ten years by reliable, observable risk markers. However, despite the availability of evidence-based interventions, service receipt is not matched to the level of need in this group.

## 5471 | Knowledge translation intervention with supervisors to reduce injuries to DSP

B. Temple; T. Martin; C. Dube; L. Anne Fuga

*University of Manitoba 89 Curry Place Winnipeg, Manitoba, Canada R3T 2N2, CA*

**Aim**: The main aim of this study was to evaluate the effectiveness of an educational knowledge translation intervention with supervisors of community homes to reduce injuries.

**Method**: The participants were 7 supervisors of community homes, with responsibility for at least 20 staff. The intervention with supervisors comprised self-study of 4 modules and a workshop. The intervention group was compared to the rest of the population of supervisors. The direct support staff was surveyed regarding their satisfaction with the support they received following an injury related to challenging behaviour and the support for use of the training they received to prevent injuries, as well as a measure of workplace engagement. The supervisors evaluated the usefulness of the modules and the usefulness in their ability to support their staff.

**Results**: Overall, the supervisors felt that the modules were valuable resources and that all people working in their roles should receive this education. The final survey results of the group homes from the intervention group and comparison homes will be described.

**Conclusion**: Supervisors are in an ideal position to emphasize the training that is provided to direct support staff to prevent challenging behaviours and support their staff who have been injured.

# 30. AUTISM I

## 5574 | Children and young people with autism – observational study of general health status in a whole country population

E. Rydzewska; L. Hughes-McCormack; A. Henderson; S.-A. Cooper

*University of Glasgow, UK*

**Aim**: To investigate 1) identified prevalence of autism by age and gender, 2) general health status and its relationship with age and gender in a whole country population of children and young people aged 0–24 with and without autism.

**Method**: The data source was Scotland's Census 2011. We calculated the percentage of children/young people identified with autism by age/gender. We described their general health ratings, and calculated odds ratios (OR: 95% confidence intervals) of autism predicting poor (fair/bad/very bad) general health in the general population. We then calculated OR of age and gender predicting poor general health within the autism cohort.

**Results**: Of 25,063/1,548,819 (1.6%) children/young people with autism, 19,880 (79.3%) were males and 5,183 (20.7%) females. Identified prevalence rose with age, peaking at 11 y (2.9%). 21.9% with autism, and 1.9% without autism had poor health; autism had an OR = 11.3 (11.0–11.7) for predicting poor general health. Girls with autism had poorer health than boys (OR = 1.6: 1.5–1.8).

**Conclusion**: Autism diagnosis is improving at younger ages, but children may still not be identified until late primary or secondary school age. Identification is important given educational needs, and for vigilance/awareness of substantially poorer general health so that suitable managements are provisioned.

## 5577 | Children and young people with autism – observational study of comorbidity in a whole country population

E. Rydzewska; L. Hughes-McCormack; A. Henderson; S.-A. Cooper

*University of Glasgow, UK*

**Aim**: To investigate prevalence of comorbidities and their relationship with age and gender in a whole country population of children and young people aged 0–24 with and without autism.

**Method**: The data source was Scotland's Census 2011. We calculated the percentage of population with autism, and their extent of comorbidities. We calculated odds ratios (OR: 95% confidence intervals) of autism predicting comorbidities, adjusted for age and gender. We then calculated OR for age and gender in predicting comorbidities within the cohort with autism.

**Results**: 25,063/1,548,819 (1.6%) had autism; 19,880 (79.3%) males and 5,183 (20.7%) females. Autism had an OR = 5.4 (5.0–5.8) for predicting deafness/partial hearing loss, OR = 1.6 (1.5–1.6) for blindness/partial sight loss, OR = 49.7 (47.5–52.0) for intellectual disabilities, OR = 15.7 (15.0–16.5) for mental health conditions, OR = 15.8 (15.1–16.6) for physical disability, and OR = 3.9 (3.8–4.0) for other conditions. Females with autism were more likely to have each additional condition than males.

**Conclusion**: Children and young people with autism are more likely to have health problems than their peers without autism, substantially so for intellectual disabilities, mental health conditions, and physical disability. Females with autism may have more severe autism than males.

## 5576 | Adults with autism – observational study of general health status in a whole country population

E. Rydzewska; L. Hughes-McCormack; A. Henderson; S.-A. Cooper

*University of Glasgow, UK*

**Aim**: To investigate general health status and its relationship with age and gender in a whole country population of adults aged 25+ with and without autism.

**Method**: The data source was Scotland's Census 2011. We investigated general health status in adults aged 25 + with and without autism. We calculated odds ratios (OR: 95% confidence intervals) of autism predicting poor (fair, bad, or very bad) general health in the general population, and OR of age and gender predicting poor general health within the autism cohort.

**Results**: Of 6,649/3,746,584 (0.2%) adults aged 25 + known to have autism, 4,610 (69.3%) were males and 2,039 (30.7%) females. 46.8% with autism, and 23.7% without autism reported poor health; autism had an OR = 5.1 (4.9–5.4) for predicting poor general health, or OR = 7.5 (6.9–8.2) when the interaction with age was included. Poor health was common across the entire life course for adults with autism; in the population with autism, females and older people had poorer health.

**Conclusion**: Poor general health merits attention across the full life course for adults with autism. There has been little previous research on this topic, and our findings suggest more is needed in order to accurately plan for appropriate service provision and supports.

## 5578 | Adults with autism – observational study of comorbidity in a whole country population

E. Rydzewska; L. Hughes-McCormack; A. Henderson; S.-A. Cooper

*University of Glasgow, UK*

**Aim**: To investigate prevalence of comorbidities and their relationship with age and gender in a whole country population of adults aged 25 + with and without autism.

**Method**: The data source was Scotland's Census 2011. We investigated the extent of comorbidities in the adult population with and without autism. We also calculated odds ratios (OR: 95% confidence intervals) of autism predicting comorbidities in the general population, and OR of age and gender predicting comorbidities within the autism cohort.

**Results**: There were 6,649/3,746,584 (0.2%) adults aged 25 + known to have autism in Scotland, of whom 4,610 (69.3%) were males and 2,039 (30.7%) females. Autism had an OR = 3.3 (3.1–3.6) for predicting deafness or partial hearing loss, OR = 8.5 (7.9–9.2) for blindness or partial sight loss, OR = 94.6 (89.4–100.0) for intellectual disabilities, OR = 8.6 (8.2–9.0) for mental health conditions, OR = 6.2 (5.8–6.6) for physical disability, and OR = 2.6 (2.5–2.8) for other conditions. Contrary to findings within the general population, female gender predicted all conditions within the population with autism.

**Conclusion**: Adults with autism are substantially more likely to have comorbidities than other adults. Clinicians need heightened awareness of comorbidities to improve detection and suitable care, particularly given the added complexity of assessment in people with autism.

# 31. AUTISM II

## 5880 | Female experiences and behavioural presentations of Autism Spectrum Conditions: a systematic review

E. Gale; J. Bradshaw; F. Gullon-Scott; Peter E. Langdon

*University of Kent, UK*

**Aim**: Females are typically diagnosed less and later than males. There is little consensus regarding female presentations of autism. This research explored the presentation of autism in adolescent and adult females, with particular focus on experiences and behavioural presentations.

**Method**: A systematic review of the literature was conducted. Four databases were searched. The search terms included "autis*, female, women and girl". Inclusion criteria: Adult/Adolescent participants, all research designs (except case studies), peer-reviewed, focusing on experiences or behavioural presentations. Papers on genetics and cognition were excluded.

**Results**: Twenty-three papers were included. Differences in diagnosis and presentation were explored. As females are generally expected to be more socially skilled than men, autistic women reported less acceptance of their social difficulties. Camouflaging and imitation were specific coping strategies that developed. Females were reported to have fewer identified repetitive/restricted interests but it remains unclear whether repetitive/restricted interests are present but less likely to be identified. Females reported higher levels of mental health difficulties.

**Conclusion**: Improvement in awareness of female presentations, and access to diagnostic pathways may improve with screening tools that are designed to identify people (including women) who are more difficult to diagnose, taking into account issues identified above.

## 5743 | A Feasibility randomized clinical trial (RCT) of a manualized intervention targeting elopement (running away) in children with Autism Spectrum Disorder

M. Scheithauer; N. Call; J. Lomas Mevers; L. Scahill

*Marcus Autism Center, Emory University, USA*

**Aim**: Elopement is an incredibly prevalent concern among individuals with autism spectrum disorder (ASD) and can be incredibly dangerous. There are examples of successful treatments, but most use single-subject design or summaries of clinical data. This study had two primary aims to advance research elopement treatment: (1) evaluate the feasibility of a RCT of a manualized behavioral intervention for elopement and (2) determine initial efficacy of the intervention in reducing elopement, decreasing caregiver stress, and improving home-safety.

**Method**: We enrolled 24 children with ASD who frequently eloped. The manual was implemented across 12 weeks in a home setting. It included psychoeducation, instructions for home safety, a functional behavior assessment, and a function-based treatment.

**Results**: Primary outcome measures of feasibility were adequate: > 80% completion and integrity and adequate acceptable. Preliminary efficacy showed improvement on the irritability subscale of the Aberrant Behavior Checklist, the child-domain of the Parenting Stress Index, and home safety Results from the clinical global improvement scale are also discussed.

**Conclusion**: Results suggest that an RCT with this population is feasible and the intervention shows promise for future larger sample efficacy trials.

## 6010 | Review of the efficacy of sensory integration therapy in autism through the practice of occupational therapy

E. Maglari

*Pediatric Institute, Ltd, Greece*

**Aim**: 42–88% of individuals with ASD present Sensory Processing Disorders (SPD) (Baranek, 2002). A common type of SPD is sensory modulation difficulties which cause and/or contribute to behaviors such as self-stimulatory, stereotypical, self-injurious, and/or sensory avoiding behaviors in an effort to control, avoid and exert meaning from sensory overload (Roberts et al. 2007). Hyperactivity, aggressiveness, poor attention, dyspraxia and high arousal levels are also associated with SPD (Tomchek & Dunn, 2007).

**Method**: Sensory Integration theory and practice developed by Dr. A. Jean Ayres, focuses on the neurological processing of sensation and how dysfunction impacts on the organization and expression of functional behaviors and actions. (Schaaf & Miller, 2005, Watling & Diaz, 2007).

**Results**: Sensory Integration treatment targets the enhancement of the sensorimotor foundations of attention, regulation, learning, praxis, social, and emotional skills through active participation in meaningful activities and appropriately orchestrated sensory environments (Schaaf & Nightlinger, 2007). Since sensory integration therapy is widely used in ASD, it is necessary to investigate its efficacy (Yell et al. 2008).

**Conclusion**: This presentation will focus on the efficacy of sensory integration in autism as implemented by the profession of occupational therapy.

## 5987 | Occupational and speech language collaboration using sensory integration in individuals with autism spectrum disorder

E. Maglari

*Pediatric Institute, Ltd, Greece*

**Aim**: Sensory Processing Disorder (SPD) affects all aspects of speech-language and feeding skills in people with ASD. (Willems et al. 2007) Children with ASD and Speech Language Impairment (SLI) frequently present vestibular, tactile and visual-auditory sensory processing difficulties, as well as sensory modulation difficulties that affect attention, imitation, comprehension and production of language (Guenther, 2006). Difficulties in auditory discrimination and/or hyper-responsiveness, oral tactile hyper-responsiveness, sensory-based dyspraxia and in multisensory processing develop and/or contribute to lesser or greater problems

in receptive and expressive language, articulation, and feeding skills as well as in communication and social abilities (Pfeiffer et al. 2011). Dr. A. Jean Ayres developed the theory and practice of Sensory Integration.

**Method**: Review of 16 articles between 1981 and 2011.

**Results**: The findings support that sensory integration treatment can benefit the development of speech, language and social skills in ASD (Case-Smith & Holland 2009; Atchison 2007).

**Conclusion**: This presentation focuses on the role of the speech language pathologist in identifying ASD individuals with SPD and the importance of the co-treatment with occupational therapists trained in sensory integration for the development and improvement of speech language and feeding skills.

## 32. CRIME AND OFFENDING BEHAVIOURS

### 5615 | Young people with intellectual and other developmental disabilities who display harmful sexual behaviour: a case series report

A. Malovic; G. Murphy

*Tizard Centre, University of Kent, UK*

**Aim**: Up to 40% of adolescents within specialist services for harmful sexual behaviours (HSB) are thought to have IDD. Hackett's Research to Practice Review (2014) found access to services, especially for those with IDD, to be inadequate, resulting from poor recognition of the offence, lack of care pathways and services (Fox, 2013). Part of the reason for this is our lack of knowledge and understanding of those young people with IDD (NSPCSS, 2016) and how they might be distinguished from the neurotypical cohort.

**Method**: Data were accessed from a case series of a cohort of young people with IDD who have been referred to specialist services for HSB, run by a major UK national charity based in London.

**Results**: Up to 20 case reports were reviewed, with 6 main themes identified and analysed. These pertained to the adolescents' demographics, family constitution, nature of HSB, victims, own victimisation and other risky behaviours.

**Conclusion**: Overall, the adolescents in this cohort had wide-ranging experiences of abuse and neglect in their own histories. They were most likely to display impulsive HSB towards people and family members in their immediate environment.

### 5614 | Keep Safe: the development of a manualised group CBT intervention for adolescents with intellectual disabilities who display harmful sexual behaviours

A. Malovic; R. Rossiter; G. Murphy

*Tizard Centre, University of Kent, GB*

**Aim**: A significant proportion of adolescents within specialist services for harmful sexual behaviours (HSB), are thought to have IDD. UK national reports have highlighted the need for the development of specialist programmes as there is a lack of evidence or practice-based interventions. This study focuses on the development of Keep Safe, a manualised CBT group intervention for adolescents with IDD who display HSB.

**Method**: An expert-consensus methodology based on the Delphi method was used. The iterative process for the manual draws on the slim practice-based evidence from UK, North America and Australasia. Keep Safe comprises six modules distributed through 36 term-time young people's sessions, alongside 18 concurrent parental/ carer sessions (some joint).

**Results**: Four initial sites volunteered as feasibility leads, and 2 more were added as recruitment was more difficult than foreseen. Only a small number of young people ($n$ = 7) have engaged in the group programme so far. However there were improvements in sexual knowledge and attitudes, and fewer harmful sexual behaviours amongst the young people who completed the Keep Safe programme.

**Conclusion**: The main focus of Keep Safe is to enhance well-being and reduce harm. It appeared successful as a pilot study and a larger trial is needed.

### 5534 | Adapted sex offender treatment programmes for men with autism spectrum conditions: clinician views

C. Melvin; G. Murphy; Peter E. Langdon

*University of Kent, UK*

**Aim**: Clinicians working with individuals with autism spectrum conditions (ASC) who display sexual offending behaviours can face challenges during treatment, potentially as a result of the cognitive and behavioural profile associated with ASC. This research explored the views and experiences of those running adapted sex offender treatment groups with men with ASC.

**Method**: Semi-structured interviews with group facilitators ($n$ = 13) focused on engagement and response to the core components of the treatment programme (e.g. increasing victim empathy, addressing cognitive distortions), and gathered the experiences of those working with men with ASC who display sexual offending behaviours.

**Results**: Grounded Theory was used to develop a model conceptualising the potential impact of ASC on treatment outcomes and future risk. Benefits of attending a group included: the presence of other group members, a forum to develop pro-social roles and relationships, and increased opportunity for monitoring. Challenges regarding empathy, specifically emotional empathy, and shifts in cognitive distortions were felt particularly pertinent to those with ASC, as well as questions over internalisation of therapy.

**Conclusion**: Despite identification of a number of challenges, adapted sex offender treatment programmes were considered beneficial for

men with ASC, especially in light of a dearth of evidenced-based alternatives.

## 5481 | The face validity of an initial sub-typology of adults with Autism Spectrum Disorders Detained in Hospital

M.-F. Barnoux; R. Alexander; S. Bhaumik; J. Devapriam; C. Duggan; Peter E. Langdon

*Tizard Centre, University of Kent, UK*

**Aim**: We have previously proposed that individuals with ASD detained within hospitals may be categorised into eight subtypes distinguished across three factors (i.e., psychopathy, psychosis, and behavioural problems). The aim of the current project was to investigate the face validity of these subtypes.

**Method**: Using both a focus group and consensus rating exercise with clinicians, people with ASD, and family members/carers the validity of the subtypes were examined.

**Results**: Our findings indicated that these subtypes possess face validity.

**Conclusion**: Further findings and the implications for future research will be considered, along with the clinical and forensic risk implications.

# 33. SEX AND SEXUALITY

## 5953 | "Sexual education of children with intellectual disability and autism at school age"

N. Apteslis

*Greece*

**Background**: Parents are particularly concerned about the sexual development and sexual behavior of their children. The aim of our research was to investigate and compare the views of parents of children with and without mental disability/autism regarding the sexual education of children with intellectual disabilities/autism at school age.

**Method**: The target population was considered to be the parents of children with and without mental disability/autism in school age who are attending educational structures of the Greek state (school age for children with mental disability 6–22 years). The participants in our survey were 308 parents of children without disabilities and 306 parents of children with disabilities.

**Results**: The results of our research revealed that parents' beliefs depend mainly on age, older parents of children with and without mental disability were more positive in the sexual education of children with intellectual disability and the educational level, the higher, greater acceptance was shown in the sexual education of mentally disabled children by the parents of both groups.

**Conclusion**: Both groups of parents believe that sexual education will help mentally disabled young people make correct sexual decisions and develop healthy interpersonal relationships.

## 5470 | Sexuality and relationships education for people with ASD – pilot programme implementation

M. Brown; G. Murphy; M. McCarthy

*Tizard Centre, Cornwallis North East, University of Kent, Canterbury, Kent, UK*

**Aim**: Sex and relationships education (SRE) has been integrated into the National Curriculum for UK schools for the past two decades, but tends to be mainstream orientated. There has been a limited amount of research into the appropriateness of present SRE programmes for pupils with ASD. This study has involved the development of an SRE programme for ASD pupils, based upon information gained through previous studies in order to reduce participant vulnerabilities.

**Method**: The development of a 9 sessions pilot programme, cognisant of the views of ASD pupils and teachers, was undertaken. The programme accessed a range of materials from different sources which were adapted further for individuals with ASD. Two pilot sites allowed recruitment of pupils with ASD (from those schools who took part in previous two studies.) Pre and post intervention data obtained using two measures (Sex-K-ID and SAKS).

**Results**: Results for both schools indicated significant gains in respect of sexual and social knowledge relating to sexuality. Pupils in both schools ($n$ = 9; $n$ = 13) showed significant gains on the Sex-K-ID after the pilot programme. One school also showed significant gains on the SAKS.

**Conclusion**: Further roll-out of the pilot programme is planned to evaluate its effects more widely.

## 5469 | "I wish I had learnt to keep myself safe" – Sexuality and Relationships Education (SRE) for People with ASD-Pupil Views

M. Brown; G. Murphy; M. McCarthy

*Tizard Centre, Cornwallis North East, University of Kent, Canterbury, Kent, UK*

**Aim**: Sex and relationships education (SRE) has been integrated into the National Curriculum for UK schools for the past two decades, but tends to be mainstream orientated. There has been a limited amount of research into the appropriateness of present SRE programmes for pupils with Autistic Spectrum Disorder (ASD). This study has explored the views of pupils with ASD regarding SRE programmes.

**Method**: Focus groups incorporating pupils with ASD were performed to gain pupil insight into the SRE programmes they had received and the areas they felt were required to keep them and others safe that were not present in the programmes.
**Results**: Thematic analysis of focus groups identified themes, including: lack of appropriate mainstream SRE programmes for pupils with ASD, issues relating to social and relationship aspects of sexuality, inconsistency in implementation of SRE resulting in insufficient levels of skills being learnt by pupils with ASD to keep safe.
**Conclusion**: A new SRE programme is needed specifically adapted for pupils with ASD to effectively cover the areas highlighted by pupils with ASD.

### 5468 | Sexuality and relationships education for people with autistic spectrum disorder – staff perspective

M. Brown; G. Murphy; M. McCarthy
*Tizard Centre, Cornwallis North East, University of Kent, Canterbury, Kent, UK*

**Aim**: Sex and relationships education (SRE) has been integrated into the National Curriculum for UK schools for the past two decades. SRE aims to teach about the emotional, social and physical aspects of growing up, relationships, sex, human sexuality and sexual health. Such a curriculum tends to be mainstream orientated, taught in large classes, with limited exploration and clarification for those who need it. There is concern that the development of incomplete knowledge and skills places the pupil with Autistic Spectrum Disorder (ASD) in a difficult, and potentially vulnerable, position.
**Method**: A literature review performed in relation to SRE and ASD formed the background to the study. Face to face semi-structured interviews occurred with head teachers or PSHE co-ordinators from 15 schools for pupils with ASD in London, Surrey and Sussex. These were analysed for common themes.
**Results**: Results highlighted a number of themes, including: programme implementation difficulties, attitude issues amongst staff, carers/parents, and individuals with ASD impacting upon programmes, staff support and training.
**Conclusion**: Development of an appropriate SRE programme is needed. Pupils with ASD will be involved in the next phase of the study.

## 34. PROFOUND INTELLECTUAL AND MULTIPLE DISABILITIES

### 5785 | Catalysts and barriers to school staff responsivity toward students with significant intellectual and developmental disabilities (SIDD)

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**Aim**: Children with SIDD are characterized by substantial language delays and depend on pre-symbolic and early symbolic means for communication. The way and the extent of the communication partners' response to a child's communication (responsivity) has been recognized as a key component in language development. The purpose of the study was to examine two models that would map possible catalysts and barriers to school staff's responsivity towards communication of students with SIDD. The models included staff member, student and environmental variables.
**Method**: Interactions between 120 school staff members and 43 students ages 9 to 16, with SIDD, were videotaped, during 258 routine school sessions. Staff behaviors were coded qualitatively and quantitatively. Staff and student variables were collected using questionnaires.
**Results**: Individual encounters and group encounters models were analyzed using exploratory path analysis, revealing different variables involved in each of the two types. In the individual encounter model student's verbal ability were the main predictor for responsivity. In the group encounter model, correlation between variables and responsivity were mediated by a latent variable- 'availability'.
**Conclusion**: The models present two extremities of communication environments involving different variables. Discussion will address the variables that serve as catalysts and barriers across both models.

### 5371 | Assessing engagement and responsiveness of children with profound/multiple disabilities

K. Tait; J. Sigafoos
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**Aim**: To examine the extent to indices of engagement/responsiveness of five, 9–13-year-old, children with profound/multiple impairments varied in relation to differing levels of environmental stimulation.
**Method**: Each child was observed across three different environmental conditions that varied in terms of the amount and type of stimulation provided. The child's level of engagement/responsiveness was rated under each condition from videotapes using the Pittsburgh Participation Scale.
**Results**: A number of potential indices of engagement/responsiveness varies reliably and consistently in relation to the amount and type of environmental stimulation being provided. Indices of engagement/responsiveness were more frequent under conditions of higher levels of environmental stimulation.
**Conclusion**: These results suggest that children who appear largely passive and unresponsive can show subtle, yet reliable and consistent, signs of engagement/responsiveness in response that vary in relation to different levels of environment stimulation. The presence of these indicators might signal times when the child is actively engaged and thus perhaps more likely to be responsive to instruction.

## 5674 | The relation between physical fitness, activity and motor development in children with intellectual disability

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**Aim**: The purpose of this study was to determine the relationship between physical fitness, physical activity and motor development in children and adolescents with moderate to severe intellectual disabilities (ID).

**Method**: Children and adolescents (2–18 years) with moderate to severe ID, attending specialised day care centres in the Netherlands, were invited to participate. Data on physical fitness, physical activity and motor development were collected by respectively the modified 6-minute walk test (6 mwt), accelerometry, and the gross motor scale of Bayley Scale of Infant Development (BSID). Linear regression analyses were used to study the association between physical fitness, physical activity and motor development, corrected for age, sex and level of ID.

**Results**: For 59 participants (38 boys, age 9.4 ± 4.2 yrs) data on all three variables (6 mwt, accelerometer, BSID) were collected. Increased fitness was positively associated with physical activity and motor development ($\beta = 0.34–0.48$, $P < 0.01$). No significant association was found between physical activity and motor development.

**Conclusion**: Both motor development and physical activity are associated with physical fitness in children with moderate to severe ID. Further research should focus on the effect of increasing physical activity and motor development for the improvement of physical fitness, and thereby health.

## 5494 | Evaluation cognitive polyhandicap or cognitive evaluation for people with PIMD

R. Scelles; D. Mellier; D. Guedon; N. Guenolé; A. Boissel; A. L. Poujol

*Université Paris Nanterre, France*

**Description**: Person suffering from PIMD confronts the professional with questions whose complexity can lead the latter either to a form of relinquishment, and/or to abandoning any evaluative approaches whatsoever in the field of cognition or emotional life. ECP (Evaluation Cognitive Polyhandicap or cognitive evaluation for people with PIMD) is an assessment tool that enables the psychologist, in cooperation with other professionals and the parents, to contribute to a better understanding and evaluation of competences and deficiencies and analyse the signs of mental suffering. This avenue allows an intervention to be implemented based on a scientifically validated method and tools.

**Contribution**: The aim is to avoid three pitfalls: 1. Overestimating the skills and so being led to offer her activities she cannot make her own. 2. Underestimating her skills and, in that case, leading to her being deprived of help in terms of education and care. 3 Abstaining from any assessment. The ECP was validated in 130 cases. It addresses children, adolescents and adults and encompasses the emotional and affective dimensions. The present communication sets out the methodology for construction of the tool, its indications, its advantages and limits.

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## TRACK 8: POLICY & PRACTICE SYMPOSIA

### 1. Service System Functioning

### 5979 | Understanding human service organizations

P. Arvidsson

*Malmo University and The City of Malmo, Sweden*

**Description**: Comparative international studies on systems of support, is commonly based on quantitative data. Scientific knowledge is traditionally fragmented into separated fields and disciplines, particularly evident in the field of disability research. This ongoing study uses actor-network theory (ANT) as a comprehensive theoretic perspective, bridging together natural science and social sciences. It outlines the basic entities for a dynamic qualitative approach, exploring how the organizing and production of support is assembled and constituted. ANT emphasizes nonhuman objects capacity to interact in actor-networks. A significant remark, if doorsteps, medical substances and assistive devices are present and prominent in the everyday life. The methodological design comprises a variety of qualitative methods and is actively involving practitioners and service users in the co-production of empirical data and new knowledge. Progressively developing a detailed map of relations and a specific conceptual apparatus, it depicts what characterizes controversies, translations and associations in complex networks, such as human service organizations.
**Contribution**: The results can be used as a basis for continued and collaborative research, but also serve as practical guidelines for politicians, professionals and private stakeholders. In conclusion, this study asserts that an in depth understanding of human service organizations, will contribute to improve the quality of the support they provide.

### 5847 | Organization and experiences of people with disabilities and their carers with implementation of the Chronic Care Act

M. Herps; H. Herman Nap; M. Minkman

*Vilans, National Centre of Expertise for Long-term Care in the Netherlands, The Netherlands*

**Aim**: The Chronic Care Act, implemented in 2015, mandates the use of instruments such as individual support plan meetings, independent support brokers and collaboration with informal carers to enhance person-centered support. In this study, we evaluate practice and experiences of people with disabilities, their carers and managers of organizations providing care under this Act.
**Method**: A stratified random sample of the total amount of service providing organizations was selected. We held seven focus groups with professionals ($n$ = 64), four focus groups with volunteers ($n$ = 12) and individual interviews with people with disabilities ($n$ = 16), relatives ($n$ = 9) and staff ($n$ = 23). An online survey was filled in by 136 managers.
**Results**: Instruments of the new law are relatively unknown by the respondents and are perceived of little value compared to meaningful daily activities and a comfortable living environment. People with disabilities do experience increasing self-control, yet it is unclear to which extent this is related to the instruments within the new Act.
**Conclusion**: The instruments provided in the Act are not experienced as providing person-centered support by service users, and difficulties arise when the support of informal carers is not being realized.

### 5969 | Life course, welfare services delivering, and managerial state: evidence from Taiwan's ICF data of IDD

E.C.-F. Lai

*Department of Social Welfare, National Chung Cheng University, Taiwan*

**Background**: For scrutinizing relations among IDD's life course, welfare service practice, and state regulation, this presentation analyses the data collected by ICF and its derivative instrument for assessing needs and entitling welfare service delivery in Taiwan.
**Method**: The work represents the data (3399 samples) with quantitative methods for understanding the relationships among outcome of classifying and certifying disabilities, the upshot of needs assessment, and status of delivering welfare services. For corresponding to statistical outputs, it also analyzes literature related to policy discourse of disability.
**Results**: The preliminary finding is that not real needs or outcomes of classifying and certifying but (forced) entitled welfare service program embedded in People with Disabilities Rights Protection Act as the institutionalization of life course influences (re)distribution of resources and welfare policy practice. The second is that the bureaucratic actor as manager re-classifies consciously and conveniently whom has or has no needs by unspoken rules of client flow management against the principle of bio-psycho-social model of ICF.

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**Conclusions**: The author will further examine the results of this finding with a critical discourse underpinned by (re)distribution policy principles with considering the heterogeneity of IDD's needs.

## 2. SERVICE SYSTEM ISSUES

### 5796 | Dimensions of support: can we get the best of both worlds?

J. Bradshaw; J. Beadle-Brown; C. Bigby; L. Richardson; B. Whelton

*University of Kent, UK*

**Background**: This research aimed to explore engagement, empowerment, warmth and rapport in services for people with severe and profound intellectual and developmental disabilities.
**Method**: Participant observations were carried out over 12 months, in two services which provided support for nine service users.
**Results**: The quality of support varied between and within services. Each service showed different elements of good support but in one setting people were more likely to be engaged and taking part in activities around the house and the garden as well as some community activities and relationships were a focus but interactions between staff and the people they support were less warm and respectful. In the other service the communication was more warm and respectful. The focus was on getting people out into the community but within the home people were less likely to be engaged in meaningful activities and relationships. Factors which might explain the difference between the two services and implications for implementation of person-centred approaches will be explored.
**Conclusions**: This research contributes to our understanding of the relationship between service culture, staff practices and user outcomes.

### 5580 | Austerity and the lives of people with Intellectual and Developmental Disabilities (IDD): a thematic synthesis of current literature

M. Malli; L. Sams; R. Forrester-Jones; G. Murphy; M. Henwood

*Tizard Centre, University of Kent, UK*

**Background**: The Global Financial Crisis of 2008 resulted in many western economies adopting severe public expenditure reduction policies, including cuts in health and social care funding. Our aim was to provide a holistic picture of the impact of austerity policy on the lives of people with IDD, and the collateral effects on the people who support them (particularly family carers).
**Method**: A systematic review of international papers resulted in 11 articles which met the inclusion criteria. These were thematically analysed.
**Results**: Available funding to support people with IDD is poorly aligned to their care needs. Cuts in disability services have adversely affected the well-being both of people with IDD and their informal carers. People with IDD have lost social support and opportunities for community participation, and in consequence are experiencing social isolation. The retrenchment of statutory services has led to increased demands on family carers' time and commitment, which negatively influences their wider roles including parental responsibilities, and labour market participation.
**Conclusions**: Our review highlights the emerging issues and provides the foundations for further discourse and underlines the need for further research on the effects of austerity on people with ID and their family carers.

### 5959 | Becoming less eligible? Intellectual and developmental services in the age of austerity in the UK

R. Forrester-Jones; L. Sams; M. Malli; R. Harrison; G. Murphy; D. Raper

*Tizard Centre, University of Kent, UK*

**Background**: Many people with IDD in the UK are excluded from social services and we are concerned that more people may not be receiving the care they need due to recent government austerity policies. Our aim is to investigate what has happened to people who have lost care (including community based services, personal budgets, LA funded/provided care and care from the independent sector).
**Method**: We interviewed 70 individuals about their use of services using the Client Service Receipt Inventory. We also asked them about their well-being and quality of life using: the Quality of Life Questionnaire; Social Network and Employment Scale; Rosenberg self-esteem scale; and the Glasgow Anxiety Scale. We also qualitatively explored what individuals' daily lives were like without care compared to when they received care.
**Results**: We experienced challenges gaining access to some local authorities. The data collected so far suggests that people with IDD are losing care and this is affecting their quality of life.
**Conclusion**: Our initial review of the interview data suggests current policy may be having an adverse effect on the lives of people with IDD and their carers. The data is currently being analysed and further findings will be available in due course.

## 5708 | The use of quality information (QI) in commissioning in services for adults with intellectual disabilities (IDD)

B. Whelton; A. Turnpenny; J. Beadle-Brown; L. Richardson

*Tizard Centre, University of Kent, UK*

**Background**: To explore which sources of quality information (QI) is used in the commissioning/monitoring of services for adults with IDD in England, and how these sources are used.

**Methods**: Semi-structured telephone interviews with 12 commissioners. Commissioners were a mixture of local authority (LA) and clinical commissioning group (CCG) from across England. Interviews were recorded and transcribed verbatim. Transcripts where thematically analysed.

**Results**: Four global themes were identified: (i) Fragmented (sources/content) Commissioners use a wide ranging number of sources; (ii) Quality was viewed differently by different commissioners; one dimensional vs Multi-level (surface/in-depth approach); (iii) Inconsistency/variability in the commissioning/reviewing/monitoring of services; and (iv) Need for sharing information.

**Conclusions**: Formal and informal sources of QI were used by. Austerity poses a risk to this process, with a risk that commissioners will have less time to weigh up the information from different sources. There is inconsistency and variability in practice depending which are impacted by local demographics. Commissioners currently have differing ideas of what quality looks like, and this may have an impact on the commissioning of services.

# 3. ENHANCING PROFESSIONAL PRACTICES

## 5414 | Senior managers' actions to influence frontline staff practice/experiences: a Delphi study

R. Deveau; P. McGill

*Tizard Centre, University of Kent, UK*

**Background**: To hear directly from senior organisation managers (SM) how they influence frontline staff (FLS) practice and experiences.

**Method**: A three round Delphi study was conducted from May 2017 to January 2018. The first round asked about direct and indirect SM contacts with FLS and decision making. Round 2 clarified responses to themes arising from round 1, and round 3 examined degree of consensus on themes.

**Results**: Eleven senior managers participated including 8 CEO, from 6 charities and 5 independent organisations providing services to an average of 1085 people with ID. A range of face-to-face contacts between SM and FLS included personal visits to services and formal consultative meetings. Non-face-to-face contacts included range of mostly digital communications e.g. CEO briefings and blogs to spread corporate values and celebrate success. Three participants described informal meetings to assess the informal values/views of FLS. The focus for decisions were system and management focussed and less so on individual staff or service users. Round 3 showed 100% consensus on the importance and difficulty of intervening and understanding informal organisational cultures, and in linking short term reactive decisions with long term strategies to improve frontline services.

**Conclusions**: The role and actions of most senior managers in ID organisations has not been subject to research, despite the likely importance of such roles and personnel. This study shows the potential for Delphi Methodology to influence participants' thinking as well as collect data. The importance of informal organisational cultural factors reached 100% consensus regarding its importance for managers to understand and influence.

## 5751 | Staff behaviours valued by service users: views of people whose behaviour challenges

T. Evans

*BILD British Institute of Learning Disabilities, UK*

**Background**: The quality of the relationship and rapport between people with intellectual disabilities and challenging behaviour and those who support them may be an important variable in the incidence and maintenance of challenging as well as adaptive behaviour. This study aimed to determine what staff characteristics, qualities and behaviours are valued by people with intellectual disabilities and challenging behaviour. Hearing the points of view of people labelled as "challenging" of staff members' behaviour, in terms of that which they do and don't value is important.

**Method**: The views of seventeen people with intellectual disabilities and challenging behaviour were sought using semi-structured interviews. A thematic analysis of the interview transcripts was completed, staff characteristics and behaviours being coded leading to the identification of themes and sub-themes.

**Results**: Participants described various positive staff characteristics, most notably "kind". They also valued being helped, staff not controlling them, understanding what was important to them and making time to provide attention as being most important to them.

**Conclusions**: The results could be used to inform person specifications for staff recruitment, job descriptions and staff training, importantly because these are the characteristics, qualities and behaviours identified as desirable by people with intellectual disabilities themselves.

## 5821 | How performance can enhance the quality of social care for people with IDD

L. Elliott-Graves; T. Doukas

*University of London, London, UK*

**Background**: We present the ways in which performance can enrich relationships between carers and service users with IDD by increasing opportunities for touch between them. The research responded to the carers' concerns that the service users experience "touch hunger" due to policies and a lack of confidence on the part of the carers.

**Method**: Using observations, interviews, and a group feedback session, the paper presents results drawn from qualitative and quantitative data from the carers and the people with IDD they support.

**Results**: Performance work in the form of drama games and dance has successfully increased touch between carers and service users by making touch sanctioned and more free flowing. Carers were able to add between 10 and 60 min of touch per week for the people they supported compared to 0–3 min per week before these activities were introduced. The carers reported that planned and risk assessed performance/touch activities gave them more confidence in continuing this work but all of them identified the need to receive on-going training in devising and delivering successful performance/touch activities.

**Conclusions**: We advocate the benefits of using performance to increase touch in care settings but heed the need for further research and training for staff.

## 5599 | Effectiveness of a brief mindfulness training for staff supporting persons with intellectual disabilities (ID)

V. Manokara; J. Chan

*MINDS, Singapore*

**Background**: Existing literature posits that staff supporting persons with ID experience high stress levels, burnout, poor mental well-being and poor sleep. Further, disability support staff who go through a structured mindfulness programme are found to experience lower stress and cope better at work. The aim of the study is to explore the effectiveness of a 1-day brief mindfulness training for staff who work with persons with ID across the lifespan in Singapore.

**Method**: The participants attended a 1-day mindfulness training and the effects of the training were assessed across several variables. The Personal Stress Scale, the Five Factor Mindfulness Questionnaire, the Warwick-Edinburgh Mental Well-being Scale, the Pittsburgh Sleep Quality Index and a single-item burnout measure were administered to participants 2 weeks prior to the training as well as 1 week and 2 months post-training.

**Results**: The preliminary results show that the 1-day brief mindfulness training was effective in reducing the stress levels of staff who support persons with ID.

**Conclusions**: The findings could lend support to having a shorter and more cost-effective version of mindfulness training as a useful means to reduce stress in disability support staff. Limitations, practice implications, and recommendations for disability organisations are discussed.

# 4. ADVANCES IN THE RESEARCH OF THE SIS-C WITHIN THE SPANISH CONTEXT

## 5682 | What domains, dimensions and items should be used to assess extraordinary support needs in children with intellectual disabilities?

V. Guillen; E. Vicente; V. Arias; A. Amor; V. Aguayo; M. Verdugo

*University of Cantabria, Cantabria, Spain*

**Background**: During childhood, extraordinary support needs derived from disabilities are added to other needs directly linked to child's development. However, children with disabilities, as other children, must have guaranteed health, safety, respect, education and social participation in its different areas of functioning. Our aim is to present a powerful assessment tool, developed in the Spanish context, able to comprehensively identify the support needs of children with intellectual disabilities.

**Method**: This scale is an adaptation of the SIS-C. After performing an exhaustive process of development, the scale was administered to 814 children. Data obtained allowed us to know the measurement effectiveness of the instrument and the relevance of its different areas, items, and response dimensions.

**Results**: The instrument showed high reliability and validity, however, not all the response dimensions are providing useful information and we found an important interdependence among items and domains that should not be ignored. Also, it seems necessary to: (i) better know what ordinary/extraordinary support needs are; (ii) include different scale versions for different ages and specific disorders (autism, cerebral palsy).

**Conclusions**: This scale accurately measures support needs in children with intellectual disabilities, however, it is important to continue researching to get a better tool.

## 5780 | Evidence on content and construct validity of a list of indicators describing typical-development supports needs

A. González; M. Verdugo Alonso; B. Martínez; V. Guillén Martín; V. Aguayo Romero; M. Fernández Sánchez

*University of Salamanca, Salamanca, Spain*

**Background**: The full accuracy of the Supports Intensity Scale-Children's version (SIS-C) requires a precise distinction between

common-development vs. extraordinary support needs. Thereby, the American Association on Intellectual and Developmental Disabilities has created a List of Indicators describing typical-development children's support needs parallel to SIS-C. The aim of this work was to translate, adapt, and present the List of Indicators' content and construct validity evidence in Spain.

**Method**: Two-hundred twenty-two teachers showed their agreement with each indicator's description using a 5-point Likert-type rating-scale. The Bangdiwala's weighted statistic and Bangdiwala's agreement charts were calculated at indicator level in order to test content validity evidence, while construct validity preliminary analyses involved item response theory for testing the rating-scale's appropriateness.

**Results**: indicators showed evidence on content validity, showing a high agreement among judges with the events to categorize, suggesting that experts considered the indicators as a source that describes accurately typical-development support needs. However, construct validity evidence preliminary analyses showed a lack of monotonic order between rating-scale categories, indicating the pertinence of its reviewing.

**Conclusions**: The importance of assessing rating-scale in a test validation context and the further research lines in the issue common vs. extraordinary support needs are presented in this study.

## 5854 | Application of the support intensity scale to children with intellectual disability and physical impairments

V. Aguayo; V. Arias; M. Verdugo; A. Amor; V. Guillén; M. Fernández

*INICO-University of Salamanca, Salamanca, Spain*

**Background**: Within the validation process of the of the Supports Intensity Scale-Children's version (SIS-C), one of the pending challenges yet to be addressed is whether the SIS-C can assess not only support needs of children with intellectual disabilities, but also those of children with additional challenges, such as motor impairments or sensory problems. To fill this gap, the present study was done. Our objective was to investigate the metric properties of SIS-C in a sample of children with cerebral palsy.

**Method**: A total of 170 children aged between 5–16 years old with cerebral palsy and other health conditions were assessed using the Spanish version of the SIS-C.

**Results**: Scale and item-level analyses revealed that the structure of SIS-C is similar to that obtained in studies of children with intellectual disability. However, for optimal performance of the scale, several items should be adapted to specific characteristics of children with cerebral palsy.

**Conclusions**: Possibly the construct of support needs operates in children with cerebral palsy similarly to children with intellectual disabilities. However, for its proper assessment, several adaptations of the existing measures are necessary.

# 5. ABOUT PEOPLE WITH INTELLECTUAL DISABILITIES

## 5758 | Analysis of factors influencing the incidence of intellectual disability aged 0–6 in China based on the data of Status and Needs of Persons with Disabilities Survey 2017

L. Yang; H. Li

*Renmin University of China, Bejing, China*

**Background**: This presentation summarizes the findings of a logistic analysis of the causes and factors contributing to the incidence of intellectual disabilities in children age 0–6 in three cities in China since 2000.

**Method**: Quantitative analysis, using logistic analysis, was carried out using medical insurance records from Beijing, Shanghai, and Guangzhou.

**Results**: The incidence of intellectual disability is mainly affected by the community type (rural and urban), policies, and types of medical insurance.

**Conclusions**: The incidence rate of intellectual disability can be reduced by: (i) improving health care, especially rehabilitation for children under the age of 6; and (ii) adjusting policies to better fit the needs of specific urban and rural communities.

## 5820 | Disability and ethnic minority

C. Linehan; M. O'Donovan; A. Ryan; D. Jurj; E. Njume Sone

*University College Dublin, Ireland*

**Background**: This presentation aims to create awareness of the support needs of individuals with disabilities from ethnic minorities, a growing, yet under-served population. The collection of data on both disability and ethnicity globally is variable, a situation leading to the invisibility of this population. There are reasons, by accident and design, why individuals may prefer not to be enumerated. Issues of data protection, citizenship, and varying definitions abound.

**Method**: In the absence of reliable data, however, attempts to describe this population, and their support needs, remain challenging. The limited research in this field focuses largely on determinations of prevalence of disability among those from ethnic minorities and provides evidence of disparities in access to services.

**Results**: In discussing these issues, this presentation will also provide case studies from a recent seminar on this topic in Ireland to illustrate the support needs of these individuals and their families.

**Conclusions**: The presentation aims to reignite a fledgling discourse on the support needs of a growing population of individuals from ethnic minorities in Europe who experience disability. Specifically, the presentation aims to develop a network of international researchers via the IASSIDD Comparative Policy and Practice SIRG to progress pan-European research in this area.

## 5859 | A qualitative case study of people with mild intellectual disabilities in the Netherlands

M. Breed; S. Woelders

*VUmc Netherlands, Amsterdam, The Netherlands*

**Background**: In this research, we focused on the professional support for people with mild intellectual disabilities with complex psychosocial problems. In the Netherlands, two care organizations developed much experience to provide support to this group. The staff members who are supporting the clients do not use a fixed or documented method of working. However, the way of supporting the clients seems to have a positive outcome. In an earlier phase of our research, we studied the practice of the staff members and described the valuable elements in a methodological guideline, called LifeWise. In this current research, we aimed to enhance our understanding of this guideline in daily practice. How do clients, caregivers and people in the social network of clients experience the support? What are the valuable elements? How do they correspond with the described guidelines of LifeWise?

**Method**: We used a responsive research design to explore all the different perspectives of the stakeholders in the care situation. Six case studies focused on the different stakeholders with special interests in including the insights of clients. We used several methods to include the voice of clients: participant observation, informal interviews, semi-structured interviews, and focus groups.

**Results**: In the first phase of our research, we described the complexity of the daily practice and the emergent way of working for the professionals. The guidelines in the first phase are: to support, to facilitate, personal activation, and to implant. In our extended research, we combined the guidelines with more specific situations in the case studies. We focused on the importance of the care relation and the voice and influence of the client within this relation.

**Conclusions**: To improve the quality of care for people with mild intellectual disabilities, we need to focus more on the perspective of the clients themselves. By including the perspectives of the clients and their network, we can gain a more complete understanding of the guidelines of LifeWise.

# 6. MOVING INTO AN EXPERIENCING ADULT LIFE

## 5404 | Professional and personal perspectives on the transition from residential education to adult support

P. McGill; N. Elson; S. Tomlinson; N. Gore; J. Zubrickiene

*University of Kent, UK*

**Background**: In the UK some children and young people with intellectual and developmental disabilities spend part of their childhood in residential schools/colleges, often some distance from their homes. This project aimed to: explore the perspectives of young people, family carers, education and local government staff on the transition process to adult support; and investigate the factors that influence the type and location of the support received after transition.

**Method**: Semi-structured interviews with samples of young people and family carers who had recently been through the transition process and education/local government staff involved in planning and coordinating transition. Interviews with the four samples were transcribed and thematically analysed.

**Results**: Young people and family carers reported mixed experiences. Difficulties included a lack of advance planning and systematic involvement in the transition process. Education/local government staff described a range of difficulties in planning and organising good transition experiences. Out-of-area adult placements were reported to arise especially where there was a lack of specialist local provision.

**Conclusions**: The results contribute to our understanding of transition processes and support the further development of arrangements that enable young people, as far as possible, to receive the support they need within their own communities.

## 5616 | Support needs of young people with mild intellectual disabilities in transition to adulthood

M. Koks; J. Naaldenberg; G. Leusink

*Radboudumc, Nijmegen, The Netherlands*

**Background**: This study gains insight into experiences of and support needed by young adults with mild intellectual disabilities (ID) transitioning into adulthood. Young adults with mild ID face several challenges when reaching adulthood. The Dutch support system greatly relies on their self-management skills and to support from their social network – two aspects that are not self-evident in this group. Also, provided support and continuity in care can be suboptimal.

**Method**: This qualitative study collects life histories of ten young adults with mild ID who recently turned 18, focusing on their experiences and on received and needed support when transitioning into adulthood. Life histories are discussed with 10 relatives and 10 professional caregivers of the participants with mild ID. Co-researchers with mild ID are involved in designing and executing this research.

**Results**: Preliminary results indicate that all participants felt faced with increased responsibilities when reaching age 18. They experienced important changes concerning education and work, independent living, and receiving adequate care. Young adults needed professional and/or social support with these changes, and their parents desired clarity about support available.

**Conclusion**: Emerged themes indicate that young adults with mild ID are focused on their futures, so their support should be future-oriented and tailored to their specific needs and possibilities.

## 5458 | Models of socio-professional and community services supporting self-determination of people with ASD or ID

M.-H. Poulin; M. Caouette; J. Proulx

*Université du Québec en Abitibi-Témiscamingue, Canada*

**Background**: At the end of their schooling, people with autism spectrum disorder or intellectual disability are normally supported by public rehabilitation services. In the last 20 years, however, many community organizations have also developed socio-professional integration services. This study aimed to evaluate and propose innovative models of socio-professional and community services.

**Method**: To do this, we first conducted a review of the scientific literature on service models that have demonstrated their effectiveness in the Canadian province of Quebec and elsewhere in the world. In parallel with this approach, we have identified and documented all existing service models in five regions of Quebec.

**Results**: A total of 105 different services were documented. Then, we conducted an in-depth evaluation of five service models considered innovative in the light of the effectiveness criteria derived from the literature review. This evaluation was based on the analysis of documents (e.g. programs, activity reports) and individual and group interviews with various stakeholders: service managers and service stakeholders; partners, clients, parents.

**Conclusions**: The analysis of the data made it possible to propose service models with effective characteristics and potential for generalization to all regions of Quebec and to make recommendations on clinical and organizational practices.

# 7. FAMILY AS SUPPORTS IN DISABILITY PRACTICE

## 5551 | Research on family support of persons with intellectual disabilities in China based on the data of Status and Needs of Persons with Disabilities Survey 2017

L. Yang; H. Li

*Renmin University of China, Bejing, China*

**Background**: This presentation examines factors affecting the degree of disability in a Chinese population, and identifies ways to improve policies for persons with intellectual disabilities.

**Method**: A systematic quantitative analysis, using an ordered logistic regression model, was used to conduct an analysis of data contained in the Status and Needs of Persons with Disabilities Survey 2017.

**Results**: The degree of intellectual disability is mainly affected by the age of the child or adult, the type of community where people live, and the specific policies that determine identification and support for people with disabilities.

**Conclusions**: Since the degree of disability is related to age, community type (which in China may be related to endemic and facilities), and policies, efforts should be made to improve the facilities, and to improve rehabilitation policies.

## 5526 | Managers' views of families' roles in decision making

M. Cuskelly; A. Jobling; K. Moni; M. McMahon

*University of Tasmania, Australia*

**Background**: This project aimed to explore the views held by managers of a broad ranging service for adults with intellectual disability of the roles that parents play in decision making related to the present and future life of their adult child.

**Method**: Twenty-eight managers in a service for adults with intellectual disability were interviewed using a semi-structured interview. Interviews were transcribed and content analysis was undertaken. Leximancer was used to assist with the analysis.

**Results**: Families were seen to be central to decision making about the current opportunities available to the adults using the service. Some respondents saw the level of responsibility taken by families to be detrimental to the development of skills and to the life directions of some of the young adults in the service. A number of managers distinguished between younger and older parents when discussing decision making responsibility, with older parents being identified as reluctant to share this responsibility with their son/daughter.

**Conclusions**: The nature of the engagement between families and service managers may influence the type and quality of services received by service users. Managers have some capacity to assist develop opportunities for self-determination in adults with intellectual disability.

## 5593 | "It's a very emotional thing": family carers' experience of decision-making about services for people with intellectual and developmental disabilities

A. Turnpenny; L. Richardson; B. Whelton; J. Beadle-Brown

*Tizard Centre, University of Kent, UK*

**Background**: This study aims to explore how information on quality and characteristics of services is considered in decision-making about support for people with intellectual disabilities and developmental disabilities by family carers or advocates in England.

**Methods**: Qualitative semi-structured interviews were conducted with 12 family carers and four advocates in England. Transcripts were analysed using thematic network analysis.

**Results**: Three global themes were identified. The first global theme brings together different aspects of finding and using quality information in the decision process, with a focus on challenges and barriers. The second global theme considers factors that limit choice and highlights individual factors, markets, systemic reason as key issues. The third theme is about the emotional aspects of the decision making that are associated with uncertainty, loss of control, and the pressures/stress.

**Conclusions**: Implications for personalisation and better support for family carers in care management are discussed.

## 5973 | Family carers' experiences of personalised accommodation and support for people with intellectual disabilities

R. McConkey; E. Garcia-Iriarte

*Institute of Nursing and Health Research, Ulster University, UK*

**Background**: Previous studies suggest that relatives of people with intellectual disabilities prefer them to move to supervised living arrangements such as group homes. In Ireland, personalised arrangements are emerging but family carers have had little exposure to this option. This qualitative study explored family carers' experiences when their relative moved to personalised support.

**Method**: Individual semi-structured interviews were conducted with the relatives of 18 people who had moved in the previous year. With eight relatives, the interviews were repeated up to 18 months later. Thematic content analyses on interview transcripts were conducted by two researchers.

**Results**: Relatives spoke favourably of the new arrangements. A core theme emerged of enabled independence with subthemes of greater self-reliance, increased confidence, more social inclusion and gains for the relatives. Reservations focussed on the need for more support hours, managing risk and loneliness.

**Conclusions**: Family carers appreciated the benefits of these new service models.

# 8. ISSUES IN AGING

## 5423 | Disability and ageing: service provision and service development

M.T. Wicki

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**Background**: As medical care has improved, people with lifelong disabilities have a higher life expectancy. Thus they are more likely to die over a prolonged period from incurable, chronic illnesses that occur more frequently in old age. The aim of the study was to analyse the situation on care provision for older people with intellectual disability (ID) in a region in Switzerland.

**Methods**: A three-step multi-method-design was used: A database was extracted from governmental statistics and analysed. A cross-sectional survey of all residential homes, nursing homes, daytime nursing, has been conducted. In addition to that, people with disabilities were interviewed and relatives answered questionnaires.

**Results**: Persons with ID would like to stay at home as long as possible, but higher care requirements lead to entrance in residential homes or nursing homes. 47.4% of the residents in residential homes for people with disabilities are older than 50 years. Challenging factors are communication, challenging behaviour, daily structuration, pain and symptom-management.

**Conclusions**: To handle difficulties presence of trained medical and pedagogical personnel, co-working with relatives and legal representatives, as well as interdisciplinarity are needed.

## 5581 | Moves of elderly persons with intellectual disabilities

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*Center for Participation Research, Catholic University of Applied Sciences North Rhine-Westphalia, Germany*

**Background**: Moves in old age are riskful transitions with some impact on social participation and self-determination. The research project aims to analyze the frequency and destination of moves from persons with ID older than 50 years.

**Method**: The analysis was based on administrative data of all persons over 50 years who got any kind of social aid for integration in

Westphalia, Germany. For each individual the address and support arrangement at the beginning and the end of the years 2014 and 2015 were compared.

**Results**: Between 4.6% and 7.6% elderly persons with ID moved per year. A lot of moves took place within the same kind of residential setting. Inter-setting relocations led frequently to community-based group homes or specialized nursing homes. But a considerable number also moved to more independent living arrangements. Movers to nursing homes had primarily lived in larger institutions before. Elderly persons who previously lived with family members moved most often to community-based group homes.

**Conclusions**: As in the general population, well-planned moves should maintain or improve a person´s quality of life. To ensure ageing in a chosen place, settings have to adapt more effectively to the special needs of ageing persons with ID.

## 6052 | Towards a better practice of retirement for people with intellectual disabilities?

J. Engeland[1,2]

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**Background**: The study aims to increase knowledge of experiences of retirement for people with intellectual disabilities. How can service providers better facilitate for a positive, self-determined, and inclusive experience of retirement? This may generate better practice and ease the transition for retirees with intellectual disabilities.

**Method**: Semi-structured in-depth interviews with seven people with intellectual disabilities retired from sheltered employment 1–2 years prior to the interviews was analysed with systematic text condensation.

**Results**: Participants experiences lack knowledge, self-determination, and inclusion prior to retirement. They stated that others made the decisions for them. Several participants experienced the transition as abrupt, although satisfaction and self-determination as retirees increased. Learning more about ageing and retirement, and being included in the decisions may lead to an easier and self-determined transition to retirement. Results from the study will be published in Scandinavian Journal of Disability Research in 2018.

**Conclusions**: Increased understanding of experiences of retirement could improve practice so that people with intellectual disabilities may experience a better transition to retirement. This study shows that there is a need for a more inclusive policy and individual guidance in the retirement process to facilitate for a better transition to retirement.

# 9. SKILL DEVELOPMENT IN PEOPLE WITH INTELLECTUAL DISABILITIES

## 5794 | Mastering digitalization in residencies for people with intellectual disabilities: development of professional training in Care V.E.T.

B. Klein; A. Baumeister; N. Papastamatiou; A. Sofios; M. Panzironi; M. Hromin

*Frankfurt University of Applied Sciences, Germany*

**Background**: Ongoing digitalization of products, work and living environments has a major impact on residencies for people with intellectual disabilities. With the rise of sensor-based products and their cross-linking with their surrounding new work and living potentials come up for these residencies, especially with respect to quality of life and autonomy of residents and new work possibilities for professional staff. In order to grasp the potential of these new developments professional staff need appropriate qualification. The purpose of the Erasmus+ Strategic partnership for vocational education and training Care V.E.T. is to develop an innovative career-oriented vocational education programme for the staff level “supported living operators” utilizing online and work-based pedagogical approaches.

**Method**: For this training programme a plug-and-play toolkit is developed which allows hands-on-learning and handling of sensors and corresponding applications. The concomitant curriculum provides advanced skills in assistive technologies, social network development, self advocacy and therapeutic roleplay.

**Results**: Participants gain higher vocational qualification according to the Bruges Communiqué. Graduates of the Care V.E.T training will be certified as “Supportive Living Operators” at EQF-level 2 and 3.

**Conclusions**: The training course meets quality assurance requirements according to ISO-Standard 17024:2012.

## 5843 | iParticipate: a European survey on the use of assistive technology in persons with profound intellectual disabilities

S. Nijs; B. Maes

*KU Leuven, Leuven, Belgium*

**Background**: This study aims at investigating which factors are associated with the underutilization of assistive technology in the group of persons with a profound intellectual disability. Because of their dependence on professionals in using these devices, the knowledge, beliefs and intentions on technology use of professionals is the main focus.

**Method**: An online survey for professionals working with persons with profound intellectual disabilities was distributed in Europe. The survey was composed based on previous research and adapted to the specificity of the group of persons with profound intellectual disabilities. The survey was sent to professionals by organizations and research centers. In total 195 participants completed the survey.

**Results**: Assistive technology is mostly used for communication and leisure activities in persons with profound intellectual disabilities. Professionals indicate that various environmental, staff, client, and device factors impede technology use. Variability was found between the various aspects of these factors having an impact on technology use according to professionals.

**Conclusions**: These insights in barriers and facilitators of technology use, experienced by professionals, and understanding the factors that influence professionals' acceptance or abandonment of technologies will inform services on priorities for staff training and program planning and can enhance the maximum use of technologies.

## 5948 | Adaptive and socialization skills focused policy alternatives enhancing service delivery to children with ID in developing countries

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*Public Sector Capacity Building Program, Klong Luang, Thailand*

**Background**: This research aims to explore policy alternatives and attributes that help improve service to children with intellectual disabilities (ID) in Thailand.

**Method**: The target population was children with ID age 2–7, who had IQ below 70–75, and who had significant limitations in two or more adaptive skills. The research studies 315 children with ID registered in fun and sport activities, under Special Olympics (Thailand) during January – May 2018. Service delivery measures consider child and social setting factors. Policy formulation emphasizes social perceptions, behaviors, and processes of inclusion. Practices of key actors to promote inclusiveness and visibility of outcomes from social inclusion activities are vital to set standards for social service policy for children with special needs.

**Results**: It was found in a previous study that sport activities and proper health screening strengthen social skills and positive behaviors for self-care. Individualized educational programs promote engagement of parents/caregivers and children without ID. Children with ID will experience relationship with peers without ID, and have an opportunity to practice sport activities at home with support given by parents/caregivers. On the whole, parents, teachers and staff of governments' perceptions on community inclusion of children with ID were supportive to continue sports intervention activities.

**Conclusions**: The current study helps to reconfirm that increased sport abilities influence adaptive skills. As well, strengthened social skills help people with ID to interact better with others in their communities in Thailand.

## 5678 | An inventory of assessment practices in support of people with profound intellectual and multiple disabilities

M. Wessels; A. van der Putten

*University of Groningen, The Netherlands*

**Background**: Assessment is essential for adapting support to the needs, abilities and preferences of people with Profound Intellectual and Multiple Disabilities (PIMD). However, because of the complex interrelatedness of disabilities of people with PIMD, assessment in people with PIMD is complex and requires a multidimensional framework. The aim of this study is to compose an international overview of what assessment procedures are used in support of people with PIMD, to what goals and whether assessment takes into account the specific needs and characteristics of this group.

**Method**: An online questionnaire about assessment procedures that are used in practice was developed and was sent to health care organizations in several countries.

**Results**: Results show the different types of assessment procedures that are used, for what purposes, and which barriers are experienced in assessment. Moreover, the psychometric qualities for different procedures are presented and whether these procedures are adapted to the needs of people with PIMD, for example by integration of information from different sources.

**Conclusions**: This study will increase our knowledge about to what extent assessment procedures take into account the specific needs and characteristics of people with PIMD and underlines the importance of adapting support to these needs and characteristics.

# 10. STRATEGIES TO SUPPORT DECISION-MAKING BY PEOPLE WITH INTELLECTUAL DISABILITIES

## 5563 | Developing an evidence-based practice framework to guide support for decision making

C. Bigby; J. Douglas

*La Trobe University, Living with Disability Research Centre, Melbourne, Australia*

**Background**: This paper details the development of an evidence-based Support for Decision Making Practice Framework that can be applied

by informal or paid supporters of people with intellectual disabilities or ABI. These two groups share in common stable rather than declining cognitive impairment characterized by difficulties with executive function, self-direction and communication of varying severity.

**Methods**: The framework was derived from a research program modelled on the Medical Research Council four-phase approach to development and evaluation of complex interventions. In phase one we systematically reviewed the literature; and qualitatively explored the experiences of support for decision-making from the perspectives of people with cognitive disabilities and their supporters in several grounded theory studies that included 32 adults with cognitive disabilities and 75 supporters. Phase two (feasibility and piloting) results supported phases three (evaluation) and four (implementation) which are currently underway.

**Results**: The framework outlines the steps, principles and strategies involved in support for decision-making. It focuses on understanding the will and preferences of people with intellectual disabilities and guides those who provide support including families, support workers, guardians and health professionals.

**Conclusions**: This framework applies across diverse contemporary contexts and is the first evidence-based guide to support for decision-making.

## 5650 | Care managers' use of quality information to promote choice in decision making about services for people with intellectual and developmental disabilities

L. Richardson; A. Turnpenny; B. Whelton; J. Beadle-Brown

*Tizard Centre, University of Kent, UK*

**Background**: This paper explores the use of information on the characteristics and quality of services in the care management process; in particular it considers how care managers source and use information in order to offer choice in relation to accommodation and support for people with intellectual and developmental disabilities.

**Methods**: Qualitative interviews with eight care managers from two local authorities in the South East of England were analysed using thematic network analysis.

**Results**: The analysis produced three global themes: first "shaping choice" describes the role of the care management process in determining opportunities for choice. The gathering and interpretation of quality information is explored in the second global theme. "Choice in principle" is the third global theme, which describes how the processes already described shape the opportunities for choice.

**Conclusions**: Implications for the production and use of information on the quality of services and future policy and practice in relation to care management for people with intellectual and developmental disabilities are discussed.

## 5661 | 24/7 online support for people with intellectual disabilities: its usefulness and value

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*Philadelphia Care Foundation, Department of Medical Humanities, VU University Medical Centre, Amsterdam, The Netherlands*

**Background**: Services for people with intellectual disabilities (ID) increasingly use Telecare applications. The Dutch service provider Philadelphia Care Foundation implemented an online videoconferencing program (DigiContact) in which independently living people with ID can contact specially trained support workers 24/7. Through research we aim to get insights into the usefulness and value of this program for its users.

**Method**: In this ongoing inclusive research project we mainly use qualitative methods like interviews. During our first two studies we interviewed both online support users and support workers.

**Results**: People use the online support for a broad variety of support needs, involving four categories: mental health, social contacts, practical issues and physical health. For example, users indicate that they can release stress and frustrations whenever and as often as necessary, resulting in less accumulation of psychological tension. The online support has various meanings and uses for different individuals, each having their own set of support needs and available (formal and informal) sources of support.

**Conclusions**: Our results suggest that 24/7 online support is a useful (additional) way of providing services to independently living people with ID. It has the potential to bring added value to a system of support around a person.

## 6014 | Pilot projects on supported decision-making: an international comparison of efforts to implement article 12 UN CRPD

C. Latimier

*University of Kent, Tizard Centre, UK*

**Background**: Several pilot projects around the world have been designed with the objective to demonstrate that models of supported decision-making can be a viable alternative to substitute decision-making models (like guardianship). Research and evidence-based practices are needed to pinpoint the components of supported decision-making and to evaluate the law reforms, the practice, and the models that are being tested. Although there are growing discussions about supported decision-making, the lack of, and need for, empirical evidence that evaluates the different models of supported decision-making is needed.

**Method**: Semi-structure interviews with project staff and pilot projects material were carried out. Qualitative and quantitative data from eight pilot projects were compared for commonalities, differences and limitations.

**Results**: Preliminary results show that these pilot projects often lack coordination with legislative changes and do not necessarily provide input for law reforms. Pilot project results bring crucial evidence

about the capacity of people with intellectual disabilities to make complex decisions, and about what support can look like in practice.
**Conclusions**: Pilot projects are not always critically looked at from the perspective of their compliance with the UNCRDP and the principles of universal legal capacity enshrined in its Article 12. More and larger-scale pilot projects will be needed to demonstrate that supported decision-making is a viable alternative.

## 11. APPROACHES TO SUPPORT FOR PEOPLE WITH ASD

### 5610 | Young people with learning disabilities/autism leaving residential education in England: what happens and where do they go?

S. Tomlinson; P. McGill; N. Gore; J. Humphreys; N. Elson
*Tizard Centre, University of Kent, UK*

**Background**: A significant number of young people with learning disabilities or autism are placed in residential educational settings in England, however little is known about these young people's transition to adult services. This research aimed to provide information about transition outcomes from a residential school/college for young people with learning disabilities/autism.
**Methods**: Residential schools/colleges were asked to complete questionnaires about young people with learning disabilities/autism (aged 16+) who had transitioned within the past 1–3 years. Questionnaires focused on the young person's characteristics, their residential educational placement and placements following transition.
**Results**: Questionnaires were returned for 312 young people. Of these, 299 had a learning disability and 191 had an Autism Spectrum Condition. The majority of educational placements were out-of-area, as were around half of the adult placements following transition. Young people typically transitioned to residential care, supported living, a residential college, or the family home. Additional findings are presented about both the residential educational placements and adult placements.
**Conclusions**: These data provide an overview of transition outcomes for a large sample of young people who have recently transitioned from a residential school/college, with trends in placement practices highlighted.

### 5730 | From behavior analysis to systemic behavior analysis: a synthesis of paradigms toward achieving optimal outcomes for people with autism spectrum disorder (ASD)

A. Gena
*National and Kapodistrian University of Athens, Athens, Greece*

**Background**: At times when financial constrains are prevalent and yet the needs of people with disabilities imperative, we need to maximize the use of our resources. Such is the case of people with ASD in Greece. Our resources are more limited than ever and the number of children with ASD growing at alarming rates as is the case world-wide.
**Method**: We propose that identification of highly effective interventions for people with ASD is crucial.
**Results**: The purpose of this presentation is to suggest the combination of two epistemological paradigms: the Experimental Analysis of Behavior and General Systems Theory in order to address the complex needs of people with ASD and their families efficiently and effectively.
**Conclusions**: Behavior Analysis offers a wide array of therapeutic techniques that can be ultimately effective when used systematically, intensively, and early on. Systemic Family Therapy, on the other hand, may complement the behavior analytic approach by offering a wide range of therapeutic applications that may facilitate the inclusion and welfare of people with ASD in the family, the school system as well as in other social contexts.

### 5901 | Longitudinal descriptive study of treatment utilization among children dually diagnosed with autism spectrum disorder and fragile X syndrome

M. Yingling
*University of Louisville, Louisville, USA*

**Background**: Little is known about the treatment utilization of children dually diagnosed with autism spectrum disorder (ASD) and Fragile X syndrome (FXS). Study aims are to: (i) record demographics of children dually diagnosed; (ii) document the time-lag between diagnosis and onset of early intensive behavioral intervention (EIBI); and (iii) describe utilization of EIBI and speech-language (SLT), occupational (OT), and physical (PT) therapy.
**Method**: We integrated administrative, Medicaid claims, and Census data to compile a dataset of children diagnosed with ASD and FXS who enrolled in an EIBI Medicaid waiver in the U.S. between 2007 and 2015 ($N$ = 17). We used univariate descriptive statistics in SAS v 9.4 to examine utilization across 30 months.
**Results**: Average age of diagnosis was 40.8 months, and an average of 990 days lapsed between ASD diagnosis and EIBI onset. Prior to EIBI enrollment, SLT and PT utilization were stable while OT utilization increased. Post-enrollment, SLT and OT in-home

utilization peaked during the second month, PT utilization remained stable, and SLT and OT utilization steadily declined. EIBI utilization steadily increased and was higher than in other studies of this type.

**Conclusions**: Future research on treatment utilization among children with ASD requires attention to children with dual diagnoses.

## 5499 | Impact of transition to adult services on family quality of life in caregivers of individuals with autism spectrum disorder

T. Wang; V. Manokara

*National Institute of Education, Nanyang Technological University, Nanyang, Singapore*

**Background**: The aim of the present study is to examine the profile of FQOL in caregivers of 18–20 year old individuals with ASD, in Singapore. The study also explores the effects of transitioning from school to adult services, on FQOL.

**Method**: The FQOLS-2006 was sent to caregivers 2 years ago and baseline data on FQOL was collected. The survey will be administered again. The data collected will then be analysed to identify which domain of FQOL caregivers rated the lowest and what are the factors associated with higher FQOL. A comparison will be done to see how FQOL has changed over the period where the individuals transitioned from school to adult services.

**Results**: The study is ongoing and the findings will be presented at the conference.

**Conclusions**: Examining FQOL over a period of time enables us to identify whether current support and services have been efficient in supporting caregivers. In addition, it informs resource distribution for policy makers and service providers with regards to individuals who transition from schools to adult services.

# 12. CONNECTING DIVERSE FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDER TO EMPIRICALLY SUPPORTED PRACTICES

## 5897 | Effects of child, family, and neighborhood characteristics on utilization of speech-language, occupational, and physical therapies among children with autism spectrum disorder

M. Yingling; B. Bell

*USA*

**Background**: Public funding of services for children with autism spectrum disorder (ASD) is increasing in the U.S. Yet we know little about children's utilization of speech-language (SLT), occupational (OT), and physical (PT) therapies during the month of diagnosis. Study aims are (i) to examine the probability of utilizing Medicaid-funded SLT, OT, and/or PT during the month of diagnosis and (ii) to determine the relationship between child, family, and neighborhood characteristics and utilization.

**Method**: We integrated state administrative, Medicaid claims, and Census data to compile a dataset of children who enrolled in a Medicaid waiver between 2007 and 2015 ($N$ = 1968). We measured utilization as at least one unit of SLT, OT, or PT billed to Medicaid during month of diagnosis and conducted analyses using a contextual logistic regression model.

**Results**: Most children (71%) used therapy during the month of diagnosis, including 66% SLT, 33% OT, and 18% PT. Intellectual disability, age of ASD diagnosis, calendar year diagnosed, family socioeconomic status, and urbanicity were related to utilization during the month of diagnosis.

**Conclusions**: Findings indicate that most children receive therapy by month of diagnosis. Yet future research is needed to explain relationships detected and understand children's simultaneous utilization of multiple therapies.

## 5903 | Feasibility of a behavior management training program for Syrian refugee caregivers of children with autism

S. Dababnah; S. Habayeb; B. Baker; D. Hussein

*University of Maryland, Baltimore, MD, USA*

**Background**: To test the feasibility and acceptability of a culturally sensitive, community-based intervention developed specifically for children with autism and their families affected by trauma.

**Method**: We recruited 20 participants (nine parents and 11 teachers) to participate in 12-week Parent-Teacher Cooperatives in a large city in Turkey. We used qualitative grounded theory methods to analyze interviews with each participant after intervention completion.

**Results**: Fourteen participants completed the program (70%). All interviewees were women and Syrian refugees. Local political events, transportation costs and safety, and illnesses affected attrition and attendance. All participants reported satisfaction with program content, including gains in autism knowledge, behavior management skills, and social support. Most participants noted minor challenges in the program, such as applying skills to nonverbal children. The majority of participants made recommendations for program improvement, including a need for services outside urban areas.

**Conclusions**: This study provided preliminary evidence that Parent-Teacher Cooperatives are feasible and acceptable among a sample of Syrian refugee parents and teachers in Turkey. More research is needed to rigorously test program outcomes. Future implementation

studies should provide online or home-based options to accommodate participants unable to travel due to distance, political unrest or safety.

## 6000 | Engaging fathers of children with ASD in a parenting intervention: perspectives from fathers and staff

R. Hock; R. Bickerstaff; A. Holbert; K. Decelle

*College of Social Work, University of South Carolina, USA*

**Background**: Fathers' involvement in parenting is associated with a host of positive outcomes for youth with disabilities. Yet fathers are under-represented in most parenting programs, particularly those that include mothers and other co-parents. The aim of this qualitative study is to explore the factors that promote father engagement in a parenting program for families of children with Autism Spectrum Disorder (ASD).

**Method**: We conducted semi-structured phone interviews with 18 fathers and 4 (female) program staff who participated in the Autism Parent Navigators program. We used a constant comparative approach to analyze interviews and compare the engagement experiences of fathers and staff.

**Results**: Fathers emphasized the practical information they received (about local services, etc.), flexible scheduling, program length (6 sessions) and the mothers' initiative as central to their engagement. Program staff highlighted the importance of directing questions to fathers and balancing parents' participation in activities. They also described difficulty in assessing fathers' (vs. mothers') engagement during sessions. Both fathers and staff recommended strategies for improving father engagement.

**Conclusions**: This study yields important insights about parenting program structure, content, and processes that could enhance fathers' engagement. Additionally, the differences between father and staff perspectives on engagement may inform staff training needs.

# 13. SUPPORT ISSUES FOR INDIVIDUALS WITH COMPLEX NEEDS

## 5435 | Challenging behaviour and organizational drivers

J. de Bruijn

*Board Member of Prisma, Care Organization for People with IDD (www.prismanet.nl), The Netherlands*

**Background**: Hospitalization is a significant factor in health care. More relevant, however, is the constitutional relationship between specific organizational dynamics such as housing, staff, and company internal logistic systems, and challenging behaviour such as aggression, addiction, and resisting care. This study clarified drivers of care organizations that contribute to, or sustain, challenging behaviour (CB) of people with IDD.

**Method**: A case study of an organization for people with IDD analyzed the relevant drivers and the known research, and their (in)direct impact on clients with challenging behaviour.

**Results**: The case study identified and clarified three organizational drivers that sustain and contribute significantly on challenging behaviour: (i) team attitude (boundaries) – team members are clearly not aware of their own personal boundaries in dealing with CB; (ii) inconsistency in policy – the policy of our organization on CB is not clearly implemented; and (iii) organizational systems – clients have to adapt to the organizational context, instead of the other way around.

**Conclusions**: By addressing critical drivers, a fundamental change in perspective of organizations can occur.

## 5515 | Out-of-area placements and delayed hospital discharge for people with intellectual disabilities and complex needs

A. MacDonald

*Scottish Government, Learning Disability Policy Section, UK*

**Background**: This presentation describes a 2-year Scottish Government project, for adults with intellectual disabilities and complex needs, living in out-of-area placements or whose discharge was delayed from hospital-based assessment & treatment units. The aim was to collect national data and use this to inform government policy, particularly in relation to models of community-based support.

**Method**: Data were collected from Health & Social Care Partnerships across Scotland in relation to numbers and characteristics of this group. Data were analysed and findings summarised.

**Results**: Approximately two-thirds of the group were male; nearly half had autism; and more than two-thirds had a severe or moderate intellectual disability. Data demonstrated that the main reasons people were admitted to hospital or moved out-of-area were service breakdown due to challenging behaviours and lack of local specialist services. The main barriers to people being discharged or returning to live in their local area were lack of suitable accommodation and lack of service providers with the required skills.

**Conclusions**: These data will inform Scottish Government policy for people with intellectual disabilities and complex needs to develop more local and sustainable models of community-living.

## 5787 | Critical issues for people with cognitive disability who have complex support needs

L. Dowse

*UNSW, Sydney, Australia*

**Background**: People with cognitive disability who experience interconnected disadvantage associated with mental ill health, challenging behaviour, drug and alcohol misuse, histories of trauma, abuse and violence, inter-generational, cultural and circumstantial disadvantage, homelessness and/or incarceration face particular challenges in obtaining equitable access to comprehensive and effective supports. This presentation outlines the conceptual argument for recognition that complexity of support needs for this group is primarily related to the lack of capacity or willingness of services and the systems underpinning them to accommodate and address these interconnected support needs.

**Method**: Utilising linked statistical data, population estimates and real life qualitative case study the paper presents a snapshot of current knowledge about people with complex support needs in Australia.

**Results**: Utilising this data the paper presents the argument for understanding complex support needs as not simply additional needs, but rather as qualitatively different, requiring unique and specialist approaches to support.

**Conclusions**: As systems of social care transform under the influence of the "personalisation" agenda, it is this group who arguably have the most to gain, but whose human rights are most at risk because of their interconnected experiences of disability and significant contextual, social, and systemic disadvantage.

## 5679 | Empowering support workers to enable people with profound intellectual and multiple disabilities to engage in activity at home

D. Haines

*University of Brighton, UK*

**Background**: People with profound intellectual and multiple disabilities may not always be well-supported to engage meaningfully in activity at home (Mansell 2010), arguably an occupational injustice (Townsend & Wilcock 2004). Research aimed to understand how occupational therapists seek to improve such support and encourage support workers and managers to adopt professionals' recommendations.

**Method**: A single, purposively-selected case of supporting engagement in activity at home was investigated using a critical ethnographic case study method. An occupational therapist worked with five people with profound intellectual disabilities and their support workers over 1 year. Data were collected using ethnographic methods (participant observation, interviews and document analysis).

**Results**: The case's story highlights challenges encouraging others to follow recommendations as intended (Cross & West 2011). Its two overarching themes are how shifting support and leadership cultures impact on engagement in activity; and how occupational therapy seeks to create and sustain cultural change by working with support workers in a collaborative and empowering way.

**Conclusions**: Staff occupational risks, in particular of burnout where roles are conflicting or ambiguous (Vassos & Nankervis 2012) may need to be addressed whilst promoting occupational justice for residents. The complexity of achieving implementation fidelity may be under-estimated.

# 14. DUTCH PERSPECTIVES ON (REDUCTION OF) COERCIVE MEASURES

## 5772 | New Dutch Care and Coercion Act: consequences for caregivers and clients

B. Frederiks

*VU University Medical Centre, Amsterdam, The Netherlands*

**Background**: The aim of the New Dutch Care and Coercion Act is to protect the rights of persons with an intellectual disability in an effective and fitting way, also taking into account the Convention on the Rights of persons with Disabilities. Caregivers however worry about the complexity and bureaucracy of the procedures of the New Act. One of the new procedures is the registration of all 9 forms of involuntary care resulting in an external reporting system of involuntary care which is now missing in the Netherlands. The purpose of this reporting system is to ensure that clients receive proper legal protection.

**Method**: In commission of the Dutch Ministry of Health, Welfare and Sport we examined the consequences of the reporting system for caregivers. This study consisted of a literature study, an expert meeting and a Delphi-study.

**Results**: Academic papers clearly demonstrate that external reporting of involuntary care has not yet become properly established, either in the Netherlands or elsewhere, such as in the UK.

**Conclusions**: This study gives insights into the new Dutch legislation about external reporting of involuntary care and will help to further the process of developing an effective system for reporting involuntary care.

## 5882 | Development of a tool to support professionals in involving the perspective of people with profound intellectual and multiple disabilities in decisions about restrictive measures

P. Embregts; W. van Oorsouw; C. Hertogh

*Tranzo, Tilburg School of Social and Behavioral Sciences, Tilburg University, The Netherlands*

**Background**: Decisions regarding the use of restrictive measures applied to people with profound intellectual and multiple disabilities (PIMD) rely heavily on professionals and relatives. We have developed a tool aimed to support professionals in conscientiously involving the perspective of people with PIMD in these decisions.

**Method**: Results derived from previously conducted studies amongst relatives and professionals served as input for further data collection. We interviewed professionals regarding daily decisions, implicit and explicit routines with respect to the use of restrictive measures. Additionally, observations were conducted in two residential group homes for people with PIMD. To validate analyses of the derived data, we conducted a focus group with professionals and policy makers.

**Results**: Based on our data we developed a web-based tool providing professionals with information about the concept restrictive measures, possible behavior the use of restrictive measures might elicit in people with PIMD and guidance on how to involve the perspective of people with PIMD in decisions regarding the use of restrictive measures.

**Conclusions**: The use of this tool in practice will increase a conscientious estimation and involvement of the perspective of people with PIMD in decisions about the use of restrictive measures and will thereby promote their level of autonomy and self-determination.

## 5965 | Effects of a multidisciplinary approach on the reduction of coercive measures in care for people with intellectual disabilities: a randomized controlled trial

B. Schippers

*VU University Amsterdam and 's Heeren Loo, The Netherlands*

**Background**: Multi-component approaches intervening on all parts that cause or sustain coercive measures are indicated to be successful on the reduction of these measures. However, little is known about the effects such interventions.

**Method**: A randomized controlled trial in a large Dutch healthcare organization was conducted. The sample consisted of 30 residential facilities, of which 16 in the experimental group and 14 in the control group. Throughout the course of the study information from a mandatory registration system was used to assess coercive measures applied in daily care. Registrations related to standardized 76 coercive measures, which are classified according to the characteristics of the measures.

**Results**: The effect of the multi-disciplinary expert team was demonstrated by a significant reduction of coercive measures in the intervention group ($b = 1.419$, $t = 2.874$, $P = 0.009$). It appeared that the effect did not focus on one or more classifications of coercive measures, but rather concerned all types of measures.

**Conclusions**: Systematic reduction of coercive measures can be achieved through a multidisciplinary approach involving intervention on client, employee and organizational level.

## 5884 | Promoting the self-realisation of people with moderate ID: the perspective of relatives on rules applied in daily care

E. Taminiau; A.P. van der Meulen; C. Hertogh; P. Embregts

*Tranzo, Tilburg School of Social and Behavioral Sciences, Tilburg University, Tilburg, The Netherlands*

**Background**: Respect for self-realisation is key in providing good quality care to people with intellectual disabilities. However, in providing care and support to people with moderate ID, professionals and relatives might apply rules, which can be perceived restraining by people with ID themselves. In this study, we aim to explore the perspective of relatives of people with moderate ID on applied rules in daily care.

**Method**: We conduct semi-structured interviews with relatives of people with moderate ID. Qualitative analysis is carried out during data collection, to provide the use of increasing insights in each consecutive phase of data collection.

**Results**: Preliminary analysis indicate that respondents initiate or consent with rules in daily care in case these rules prevent their relative with ID from harm, provide safety or result in an indistinctive appearance. Additionally, respondents are not inclined to amend rules when their relative with ID indicate disagreement.

**Conclusions**: Awareness of the perception of relatives about rules applied to people with moderate ID is essential to engage in an open dialogue between relatives, professionals, and people with ID themselves about ways to promote their self-realisation in care and support.

## 15. NURSING PRACTICE IN INTELLECTUAL DISABILITY

### 5455 | Factors that influence intellectual disability nursing interventions: content analysis of policy and practice documents in the United Kingdom

I. McGlade

*NHS Grampian, Glasgow Caledonian University, UK*

**Background**: The aim of this review of UK policy and practice documents was to gain understanding of factors that influence intellectual disability (ID) nursing interventions.

**Method**: Government and National Health Service (NHS) websites, and higher education ID nursing pre and post-registration training programmes, were searched from 2000 onwards, to identify relevant policy and practice documents. Documentary content analysis was conducted to identify themes relevant to ID nursing interventions.

**Results**: Eleven themes were identified: improve and develop ID nursing; improve outcomes for people with IDs; involve people with IDs as experts; ID nurses have high competence (particularly in complex situations); ID nurses as advocates; ID nurses demonstrate passion and dedication; ID nursing specialist/advanced practice/transforming roles; ID nursing research is limited; negotiation skills of ID nurses; enhancing life skills of younger and older people with IDs; ID nurses working in/with the NHS/private/voluntary sector.

**Conclusions**: Documentary analysis of policy and practice provides useful guidance on ID nursing development, but does not provide sufficient body of evidence to support ID nursing in every day practice. ID nursing research is also required to inform best practice for interventions.

### 5388 | Redeveloping the professional practice standards for nursing people with intellectual disability (ID): mapping the diversity of ID nursing practice

N. Wilson; P. Lewis; M. Wiese; K. O'Reilly; H. Jaques

*School of Nursing and Midwifery, Western Sydney University, Australia*

**Background**: To review the existing landscape of professional nursing practice standards in the Australian context, and to explore how they can inform the future development of ID-specific professional practice standards.

**Method**: A search was undertaken of all speciality nursing associations in Australia for registered nurses professional practice standards. Available standards were analysed for their content and structure, followed by a thematic mapping against the existing professional practice standards for ID nursing.

**Results**: Many professional practice standards for registered nurses are broadly reflective of the over-arching professional standards that govern nursing, but often use different terminology. Commonly mapped practice domains are: professional practice, clinical practice, interdisciplinary coordination, professional development, quality research, and clinical and community leadership. The ID professional practice standards have several major gaps, but are strongly focussed on meeting individualised needs.

**Conclusions**: To better meet the health and wellbeing needs of people with ID, future ID registered nursing standards must evolve and be more reflective of the diverse practice contexts and differences between ID nursing and other professional practice areas.

### 5389 | A 30-year overview of the uniqueness and diversity of intellectual disability (ID) nursing as reported by the research literature

K. O'Reilly; N. Wilson; P. Lewis; M. Wiese; H. Jaques

*School of Nursing and Midwifery, Western Sydney University, Australia*

**Background**: To conduct an audit of the peer-reviewed literature about the uniqueness and diversity of ID nursing in the context of the changing Australian disability service landscape.

**Method**: A search was undertaken of all the peer-reviewed literature between 1986 and 2017 using the broad search terms "intellectual disability" and "nursing".

**Results**: There is a limited body of literature about ID nursing. Opinion pieces predominate, with a small body of qualitative research and few experimental studies. The available literature suggests that ID-nursing is more about the need for expert relational strategies rather than technical nursing skills. Specific practice areas reported in the literature include pain assessment, infection control, diabetes, mobility decline, and continence care. The development of the profession over time and the changing education needs have evolved to reflect changes in governance.

**Conclusions**: Evidence-based nursing interventions are needed to better support the health and wellbeing of people with ID. The limited experimental research about actual practice is a major concern. The speciality practice of ID nursing, particularly in the Australian disability context, should aim to expand the scope and quantity of empirical research about the uniqueness and diversity of this field.

## 5390 | Nurses working in disability-specific settings and/or roles: perceptions about caring for people with intellectual disability

P. Lewis; M. Wiese; H. Jaques; K. O'Reilly; N. Wilson

*School of Nursing and Midwifery, Western Sydney University, Australia*

**Background**: To explore the perceptions of nurses working in disability-specific settings and/or roles, of nursing people with intellectual disability (ID) living in Australia.

**Method**: Individual interviews were conducted with 18 nurses working in ID-specific settings and/or roles across the state of NSW. Participants were asked to discuss what it is that sets ID nursing apart from other nursing specialties, as well as the rewards and challenges of their roles. Questions were also asked about professional practice standards for ID nursing. Data were analysed thematically.

**Results**: Seven themes reflected ID nurses perceptions: Advocacy, capacity, client profile, collaborations, person-centred care, familiar relationships, and intersection with the National Disability Insurance Scheme. Although written practice standards are important for the novice nurse, over time they become more intrinsic to the nurse's approach to practice. Nurses reported variable understanding of professional practice standards designed for ID nursing, but also a belief in their importance.

**Conclusions**: The nurses' experience of care accounts for the specific needs of people with ID and points to the importance of developing new professional practice standards that acknowledge the changing landscape of service provision for people with ID in Australia.

# 16. DEINSTITUTIONALIZATION ISSUES IN IRELAND

## 5811 | Reflections by adults with ID on living arrangements during a deinstitutionalisation programme in Ireland

C. Linehan; S. O'Doherty; M. Tatlow-Golden; S. Craig; M. Kerr; R. McConkey

*University College Dublin, Ireland*

**Background**: To explore the views of adults with intellectual disability to different types of living arrangements during a programme of national deinstitutionalisation in Ireland.

**Method**: Participants: 42 adults with ID receiving full time residential supports from five disability organisations. Procedures: Participants were invited to attend focus groups which lasted 1 h in duration. Support workers were present only if requested participants. Measures: A standard format of topics were presented to each group exploring their views on common supported living options for adults with intellectual disability.

**Results**: Participants discussed common experiences of changing living arrangements throughout adulthood; changes which were experienced with little prior consultation. While most were satisfied with their current living arrangement, those who were awaiting a move to more independent living from institutional settings expressed dissatisfaction. Views on various living arrangements varied, bar opinion on institutional living where the only positive commentary emanated from some individuals currently living in these settings. Participants identified inadequate staff support as their main barrier to community living.

**Conclusions**: Participants' preferences typically reflected their own experiences of their living arrangements. These findings indicate a need to support individuals in exercising an informed choice regarding their preferred living arrangement in adulthood.

## 5815 | Reflections by support staff to the implementation of a programme of national deinstitutionalisation in Ireland

C. Linehan; S. O'Doherty; M. Tatlow-Golden; S. Craig; M. Kerr; R. McConkey

*University College Dublin, Ireland*

**Background**: To explore disability support staff's perception of the implementation of a nationwide programme of deinstitutionalisation in Ireland.

**Method**: Participants: 94 direct support staff and clinicians attached to seven disability service providers. Procedures: 11 focus groups were hosted for staff working in institutions, large organisations providing a range of residential living arrangements, and smaller community-based organisations. Measures: A standard set of topics were asked across all focus groups.

**Results**: Marked differences were noted in the organisational cultures of the participating agencies, with institutional services reporting a more hierarchical structure. Differences were also noted in the preferences participants from different organisations held for different types of living arrangements, albeit both clustered housing and community group homes were generally perceived negatively. Barriers to moving to community living were identified at systems level (e.g. insufficient planning and time for implementation); community level (e.g. attitude of the receiving community); service level (e.g. changing job profiles); and individual level (e.g. inadequate support).

**Conclusions**: The findings reveal widespread differences in the organisational culture, perception of common living arrangements, and perception of implementation barriers by type of disability provider. Resistance to the implementation of community living should be expected from some providers and addressed accordingly.

## 5818 | Commissioners' and senior agency personnel's views on the implementation of a nationwide programme of deinstitutionalisation in Ireland

C. Linehan; S. O'Doherty; M. Tatlow-Golden; S. Craig; M. Kerr; C. Lynch

*University College Dublin, Ireland*

**Background**: To explore Commissioner and Senior Agency Personnel's views to the implementation of a nationwide programme of deinstitutionalisation in Ireland.

**Method**: Participants were six state commissioners and 19 senior agency personnel employed in two of Ireland's eight health regions. These regions differ markedly in their progression to community services. Semi-structured interviews, ranging 44–128 min, were individually conducted with each participant. A standard set of topics were asked across all interviews.

**Results**: Commissioners described a challenging environment characterised by poor communication, low morale and weak leadership. Attempts to drive change were hampered in some cases by a lack of autonomy, in others by a lack of engagement. Senior agency personnel described their frustrations at the coalface of implementation during a time of economic recession. Services were described as under-resourced, inflexible, poorly planned and experiencing little consultation with mainstream providers who are identified in policy as key stakeholders. Despite these challenges, clear differences in ethos, local policy, and infrastructure were apparent between the two health regions.

**Conclusions**: At a time of unprecedented change with the Irish disability services programme, valuable lessons can be learned from the experiences of those who are further travelled on the road to community-based services.

# 17. RESIDENTIAL LIVING AS HOMES AND SUPPORT VENUES

## 5550 | Understanding the culture of supported accommodation services: staff views

J. Beadle-Brown; J. Bradshaw; C. Bigby; L. Richardson

*University of Kent, UK*

**Background**: This paper explores staff perceptions around observed dimensions of support and aims to develop our understanding of staff culture within supported accommodation services. It is part of a larger study and builds on our findings from participant observations where services differed on dimensions of engagement, empowerment, warmth and rapport.

**Method**: Individual interviews were carried out with frontline staff and practice leaders from two services, following 12 months of participant observation. Interviews were recorded, transcribed and thematically analysed.

**Results**: Major themes included responses to new ideas, working together and leadership styles. For some, creativity and new ideas were welcomed, even from new staff. For others there was initial resistance, which sometimes gave way to acceptance over time. Some staff acknowledged the importance of sharing knowledge, experience and responsibility in approaches to problem solving. Finally, some staff were given more direct guidance around practice, whereas others were left to find their own way. Relationships between practice and reported views will be explored.

**Conclusions**: This research furthers our understanding of key dimensions of culture in supported accommodation services and how these may impact on outcomes.

## 5606 | Differentiating residential settings of adults with ID in Germany: a quantitative analysis

F. Dieckmann; A. Thimm; T. Hassler

*Center for Participation Research, Catholic University of Applied Sciences North Rhine-Westphalia, Germany*

**Background**: During the last two decades the residential settings of adults with ID have become more diverse in Germany. The study analyzed how adults with ID of different age-groups distribute over the various residential settings.

**Method**: The study focused on Westphalia (8.3 million inhabitants). Administrative data for each adult with ID receiving social aid for integration ($n$ = 30 093) and statistical reports of the service providers were analyzed. Surveys were conducted to collect primary data in regular and specialized nursing homes.

**Results**: In 2014, 36.3% of the adults with ID lived with relatives (but only 8.9% of the ≥65 years old persons). 24.0% (32.4% of the ≥65 years) resided in community-based group homes. 18.9% lived alone, with a partner or in a shared flat with a supporting service. Still 10.2% (but 20.6% of the ≥65 years) resided in large institutions with more than 80 cohabitants. Among elderly with ID, nursing homes have become a widespread place of residence (21.9% of the ≥65 years).

**Conclusions**: The process of deinstitutionalization has led to a diversity of residential solutions for adults with ID in Germany. But many community-based settings are still not prepared to cope with changing needs of their ageing clients.

## 5645 | Whose home is it anyway? Where I live and quality of life outcomes in older individuals with ID

P.O. Headhra; C. Linehan

*UCD Centre for Disability Studies, University College Dublin, Ireland*

**Background**: Ireland is implementing a nationwide programme of de-congregation. Most (72%) of those moving from congregated settings are aged 40 years and older. While evidence exists documenting quality outcomes related to different living arrangements, a paucity of evidence exists about the impact of different living arrangement on older persons with ID.

**Method**: This presentation will present data from Ireland's national ID database on living arrangements for older individuals with ID.

**Results**: These arrangements include living in the family home, where most adults live with ageing parents; congregated settings, where one in four older adults are supported; dispersed community housing, the most common form of supported accommodation in Ireland; and generic nursing homes, where only a fraction of older persons with ID are living but where numbers are increasing, an issue which is causing concern among the disability field.

**Conclusions**: This presentation argues that consideration is now required on the quality outcomes afforded to older individuals with ID being supported in common living arrangements, most especially those options being offered to individuals moving from congregated settings. What quality outcomes should be examined to assist in this determination and how can the voice of older individuals with ID be ensured in this discourse?

## 5673 | Shared lives: a multi-method study of a community service for people with intellectual disabilities

N. Brookes; L. Callaghan; G. Collins; S. Palmer

*PSSRU, University of Kent, UK*

**Background**: Adult placement, known in the United Kingdom as Shared Lives (SL), has a long history throughout Europe and beyond. In England in 2016 over 8000 people with intellectual disabilities were being supported to live in the community in this way. There is little research in this area, and this study aimed to generate information about the effectiveness of SL.

**Method**: Data were collected from people supported by SL using a number of well-being measures and qualitative interviews. The economic case was explored through individual case studies, using data from the measures and service use information. The experiences of people providing support were also captured through interviews. Both quantitative and qualitative analysis techniques were used.

**Results**: Overall, social care related outcomes, capability and mental well-being were good amongst participants, and examples of how SL had made a positive difference to their lives were provided. SL appears to result in good outcomes within a cost envelope less than for alternative provision. SL carers highlighted the skills and support required, and the unique dynamic of formal care in a family setting.

**Conclusions**: The study is on-going but suggests that SL is meeting people's needs and has promising aspects which merit further study.

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# ABSTRACTS

## TRACK 9: LIVING WITH DISABILITIES SYMPOSIA

## 1. OJKO-PROJECT: LONGITUDINAL STUDY OF THE DEVELOPMENT OF YOUNG CHILDREN WITH SIGNIFICANT COGNITIVE AND MOTOR DEVELOPMENTAL DELAYS

### 5851 | Analysis of the expressive communication behaviours of young children with significant motor and cognitive delays

A. Dhondt

*KU Leuven, Leuven, Belgium*

**Background**: This study aimed to explore and describe a specific way of analysing the early communicative skills of young children with PIMD. We were specifically interested in early markers of intentional communication and characteristics of their expressive communicative behaviours.

**Method**: All participants (*n* = 50, 6–59 months) are known to have significant cognitive and motor delay. Data collection was undertaken during home visits, using several instruments. Video samples used for assessing communication were recorded in a structured setting (ESCS), a semi-structured setting (BAS), both in interaction with a researcher, and in a free interaction with a primary caretaker (CBRS-R & MBRS-R). The collected data were analysed with a coding scheme based on the Communication Matrix (Rowland & Fried-Oken, 2012).

**Results**: By using the theoretical framework of the Communication Matrix, we aimed to obtain a clear view on the specific communicative functions the participants use and how these relate to each other. In addition, the modalities to communicate those functions were analysed. This study furthermore revealed the similarities and differences between the children in expressive communication behaviours.

**Conclusions**: This paper is part of the OJKO-project and contributes to a more specific knowledge on the communicative abilities of very young children with PIMD.

### 5919 | Parent–child interaction: a micro-level approach in children with a significant cognitive and motor developmental delay

I. Van Keer

*Catholic University of Leuven, Leuven, Belgium*

**Background**: Research shows that parents of young children with a significant cognitive and motor developmental delay are generally responsive towards their child, that children show low levels of interactive engagement, and these variables can be correlated. Adapting a micro-level approach, we aimed to go beyond macro-level and correlational analyses by charting the frequency, intra-individual co-occurrence and inter-individual temporal dependency of specific interactive behaviours.

**Method**: 29 parent–child dyads (with children aged 6–59 months) were video-taped during a 15-min unstructured play situation. Based on a self-developed coding scheme, interactive behaviours were coded continuously and analyzed using a dynamic network approach.

**Results**: More socially-oriented behaviour(al cluster)s are less frequent in children, especially related to looking at as well as touching, the partner. Socially- and object-oriented behavioral clusters are generally independent from each other and instigate/maintain the same type of cluster in the interaction partner. Generally, children's socially oriented behavior(al cluster)s seem to need a parental "trigger," while parents will more often socially engage with their child on their own initiative and continue this behaviour even when the child is less responsive.

**Conclusions**: Further action-oriented research is needed to confirm this study's results and translate them into concrete guidelines for parents.

### 6012 | Emotional development of young children with a significant cognitive and motor developmental delay

B. Maes

*KU Leuven, Leuven, Belgium*

**Background**: Children with a significant cognitive and motor developmental delay are a vulnerable group in the development of emotional and behavioural problems. This study aimed to evaluate the emotional development of these children at young age.

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**Method**: 35 unique parent–child dyads participated in the study. Children between 6 months and 4 years old were included. The emotional development of the children has been evaluated with the Scale for Emotional Development Revised (SED-R) by interviewing their parents.

**Results**: The analyses showed that the SED-R is a suitable instrument to make an assessment of the emotional development of young children with a significant cognitive and motor delay. We presented the distribution of children over the different developmental phases for each domain and overall. The results also indicate the most vulnerable aspects of the emotional development of these children.

**Conclusions**: The SED-R enables parents and professionals to assess the basic emotional needs of their child with a significant cognitive and motor developmental delay and to take these needs into account in their education and support. The global score of the SED-R should be interpreted with caution, since the emotional development of these children is often not harmonious.

## 6013 | Analyses of the development of children with profound intellectual and multiple disabilities: methodological challenges

A. van der Putten

*University of Groningen, Groningen, The Netherlands*

**Background**: The way children with profound intellectual and multiple disabilities (PIMD) develop is unknown. Therefore, the OJKO project was started in order to analyse the cognitive, communicative, socio-emotional and motor development of these children. Several challenges related to methodological issues were faced. The aim of this presentation was to give an overview of these methodological issues related to the analyses of the development of these children.

**Methods**: Approximately 50 children (aged between 1 and 6 years) with significant cognitive and motor developmental delay were included. Children were assessed on described developmental domains five times during a 2 year period. With this information, the development of children who will be characterized as children with PIMD was analysed.

**Results**: Methodological challenges related to recruitment and inclusion criteria of the children were seen. Because their development is unknown, inclusion of those children who will develop as children with PIMD is difficult. Also instruments with sound psychometric properties to asses development in these children with intellectual, motor and sensory disabilities are not widely available. Finally, challenges were experiences with longitudinal and related data of small samples with large heterogeneity.

**Conclusions**: Findings from this project may be useful in related studies.

# 2. SUPPORT AND INTERVENTIONS FOR CHILDREN WITH ID AND/OR AUTISM

## 5452 | Reactions to comfort by parent versus stranger in children with significant developmental delays

S. Vandesande; G. Bosmans; C. Schuengel; B. Maes

*KU Leuven, Leuven, Belgium*

**Background**: According to attachment theory, children seek proximity to and stress relief from specific attachment figures. The classical measurements to observe these attachment behaviours fall short among children with limited physical and/or verbal abilities. The current study examined the extent to which young children with severe intellectual disabilities (ID) reacted differentially to comfort provided by the parent versus a stranger, using both observation and psychophysiology.

**Method**: In video-taped experiments at home, 46 children (1–8 years of age) with a severe or profound ID, were confronted with four stressors, after which comfort was provided by a parent or stranger. A sensor sock measured galvanic skin response continuously to assess the (change in the) arousal state of the child during each episode of the experiment.

**Results**: An intraindividual, as well as an interindividual perspective, has been applied to answer the central research question. Various profiles in childrens' reactions to stressors and comfort are identified.

**Conclusions**: Due to the user-friendly character of the sensor sock, physiological monitoring seems feasible. The complementary use of behavioural observation and psychophysiological measurements sheds light on the reactions to comfort, among children with limited physical and/or verbal abilities, and informs practice about strategies to enhance stress regulation in this target group.

## 5432 | Co-produced accessible self-help guides for children with learning disability and mental distress

C. Mander

*Solent NHS Trust, Southhampton, UK*

**Background**: This collaborative quality improvement project aimed to develop and evaluate accessible resources to support and promote self-management whilst families await specialist interventions.

**Method**: Engagement events were conducted with parents, children and siblings who had lived experience of managing mental distress within the home environment. Baseline data from the Learning Disability Child and Adolescent Mental Health Service (CAMHS-LD)

was reviewed in relation to the range, frequency, intensity and cost of their interventions. A co-production model was then utilised to develop the self-help guides.

**Results**: Sleep was identified as the key topic for the on-line prototype. Patents wanted a demonstration video, which included professional guidance alongside stories from families with lived expereince, as well as Easy Read documents. The impact on siblings and the need for a child friendly resource was highlighted. A range of children worked with the team in designing an animation to support good sleep strategies. The impact of the sleep self-help guide will be fully evaluated over a 12 month period, through service user feedback and a review of CAMHS-LD activity data.

**Conclusions**: With increasing demand on services, creative family-centred solutions, that are sustainable and deliverable at pace and scale, are essential to supporting self-management.

## 5839 | iDo-Hygiene: an application for improving daily skills

A. Neeman; O. Hetzroni

*Oranim Teachers College, Tivon, Israel*

**Background**: This exploratory study examined the impact of iDo-Hygiene, an iPad application, on hygienic skills among individuals with developmental disabilities in the home environment.

**Method**: A mixed-methods study examined usage patterns of the application and the changes in participants' skills among six children with developmental disabilities ages 6–15 who need assistance with their daily hygienic skills. Participants' use of iDo-Hygiene was documented for 20 consecutive days. Pre-and-post interviews with the parents were conducted, as well as daily parental reports regarding use and changes in hygienic skills.

**Results**: Results show daily use of the application. All participants demonstrated an improvement in their daily hygienic skills. Parents reported that this application enabled them to become part of an intervention program with their child.

**Conclusions**: The main benefit of this study is the fact that only 20 days of intervention contributed to a change in participants skills. This study enabled parents to participate in an intervention incorporating an innovative technology in the natural environment by providing tools to assist them in daily life.

## 5804 | A qualitative evaluation of Early Positive Approaches to Support (E-PAtS) for parents of children with learning or developmental disabilities

N. Gore; J. Bradshaw

*University of Kent, Kent, UK*

**Background**: It is difficult to reduce behaviours that challenge once they have emerged and become engrained. The current study qualitatively evaluated the piloting of a recently developed support programme called E-PAtS (Early Positive Approaches to Support). E-PAtS is an 8, 2.5-h session programme for carers who have a young child (0–5 years old) who has a learning or developmental disability. It is co-produced with and co-facilitated by family carers and aims to support wellbeing and resilience for caregivers and positive development for their children. This paper described the programme development and the early qualitative evaluation.

**Method**: 33 family carers were invited to take part in focus group and individual interviews post-intervention. A semi-structured format was used to explore participants' experience of the group, any changes following attendance, and suggestions for future development of the programme.

**Results**: Themes included: Saying the unsayable; You have to have been through it; Knowledge is power; Feeling better and Gaining skills.

**Conclusions**: Themes related closely to the underlying mechanisms and processes targeted by E-PAtS. Providing early support to parents provides positive outcomes. Results informed our understanding of the logic model and future developments.

# 3. SUPPORT FOR ADULTS WITH ID

## 6045 | Applying systems thinking to support inclusive healthcare decision making

W. Sullivan; J. Heng

*University of Toronto, ON, Canada*

**Background**: Supported decision making has been advanced to include people with intellectual and developmental disabilities (PWIDD) as agents of their health care. This approach understands autonomy as relational and enlists family and other trusted caregivers as interpreters of a PWIDD's communication and intentions.

**Method**: We add a systems approach to thinking about supported decision making. Healthcare decision making involves two teams—the primary care provider with other care providers, and the PWIDD with family and other trusted caregivers. These constitute a "complex adaptive system". Decisions are co-produced

in such systems but centred on the PWIDD's health needs and intentions.

**Results**: Applying systems thinking to supported decision making extends practice from interpreting the PWIDD to supporting deliberation. Members of the "two teams" in health care, including the PWIDD, can learn to improve deliberation as relationships develop and adaptation to diverse healthcare situations occurs.

**Conclusions**: These considerations add a dimension to supported decision making (deliberation). They show how supported healthcare decision making is attainable for PIWDD of diverse abilities for the variable and complex decisions that need to be made. Support systems can also enhance the abilities and inclusion of PIWDD in decision making over time.

## 5655 | Host families: one approach to individual supported living (ISL) arrangements for adults with intellectual disabilities

S.H. Thoresen; E. Cocks; A. Thomson

*Curtin University, Australia*

**Background**: Over the past decade, researchers at Curtin University have investigated individual supported living (ISL) arrangements as a meaningful and nurturing approach to support adults with intellectual disabilities having their own homes. This research explored a relatively novel approach, referred to as a host family arrangement, where an adult with intellectual disabilities has a formal living arrangement with a family outside their own biological family.

**Method**: This research drew on material collected as part of a larger study of 130 ISL arrangements across Australia. Information was collected using the ISL Manual, a battery of outcome measures, and a qualitative pathway interview. The presentation used illustrative vignettes or short case studies related to host family arrangements.

**Results**: Of the 130 evaluations, 6 were developed as host family arrangements, some of which had continued for a very long time (one more than 20 years). Host family participants received more hours of support than other study participants (range 94–233 h/week compared with mean of 49 h/week among all participants), possibly related to a higher level of support need.

**Conclusions**: A host family arrangement is an effective way to support adults with intellectual disabilities having their own homes through ISL arrangements.

## 5516 | Cognitive impairment and homelessness

B. Stone; S. Dowling; A. Cameron

*University of Bristol, Bristol, UK*

**Background**: Cognitive impairment is a known risk factor for homelessness. Once homeless, cognitively impaired persons often struggle to get support, and difficulties are confounded by the complex interplay with mental health, substance use, and poverty. Cognitive impairment is rarely explored in homelessness research. This paper aims to bridge this gap by presenting findings from a scoping review developed in relation to current doctoral study.

**Method**: A systematic search of databases was conducted for keywords relating to cognitive impairments in the homeless. 44 sources were selected for review. Sources were subject to quality appraisal and data was extracted in line with review questions.

**Results**: Cognitive impairment was disproportionately overrepresented in the homeless. Aetiology of impairments was delineated by acquired and developmental causes. This presentation examined cognitive impairment as both a risk factor to and perpetuator of homelessness. It focused on findings relating to developmental disability, in particular autism, where a discourse surrounding childhood has led to "higher functioning" adults being overlooked by diagnostic and support services.

**Conclusions**: This presentation concludes with a discussion of rehabilitation, including implications for service delivery and future research. Further qualitative research is needed to explore the lived experience of cognitively impaired, homeless people.

# 4. ADOLESCENTS WITH ID

## 5784 | Communication breakdowns and repair strategies among adolescents who use AAC: environmental and personal considerations

O. Hetzroni

*Department of Special Education, University of Haifa, Haifa, Israel*

**Background**: Unsuccessful interactions are considered communication breakdowns, which leads the communicator to attempt using repair strategies to resume communication. The purpose of this study was to investigate use of repair strategies among adolescents who use augmentative and alternative communication (AAC). Communication breakdowns and repair strategies were examined along with environmental factors, staff, and student characteristics.

**Method**: 12 students (15–21 years), who have been using AAC systems for at least 2 years, were videotaped in natural situations during school activities. Each participant was videotaped eight times for 15 min throughout the school day. Video sessions were transcribed and coded to identify communication breakdowns and repairs.

**Results**: Results show that "ignore" was the most frequently used type of communication breakdown. There were more modifications used as a repair strategies than repetitions by individuals who use AAC. Results demonstrate relations between communication breakdowns and the types of repair strategies used across different environments, staff members, and student characteristics.

**Conclusions**: Results demonstrate that type of communication breakdown, communication partner skills and attention, and the type of the original message of the AAC user, are significantly related to the decision whether to repair communication breakdown or terminate interaction. Further results and implications were discussed.

## 5688 | Men with intellectual disabilities: life after leaving prison

G. Murphy; M. Barnoux; E. Blake; P. Triantafyllopoulou

*Tizard Centre, University of Kent, Kent, UK*

**Background**: In the UK, it has been reported that 7% of people in prison have intellectual disabilities (ID). Yet on leaving prison, anecdotally, they often seem to receive very little support. This research aimed to explore services, quality of life and well-being 1 year after leaving prison in men with ID.

**Method**: Men screened positive for ID and due to leave prison, were recruited from NHS Trusts and prison establishments across the UK. Ex-offenders were interviewed at two time points about their social networks, service utilisation, quality of life, well-being, and offending behaviours.

**Results**: Even at the first time point (T1), 10 weeks after leaving prison, many men had been re-arrested & some had returned to custody. Of those still living in the community at T1, most had very empty lives, little support from services, and they were often above the clinical cut-off for depression and anxiety. At 1 year follow-up (T2), most of these indicators were worse, support from services was scarcer, lives were emptier, more had been re-arrested and levels of depression and anxiety were still very high.

**Conclusions**: The findings suggest ex-offenders with ID are extremely under-supported upon leaving prison and are at risk of re-offending.

## 6034 | Transitioning to adulthood with a mild intellectual disability: young people's experiences, expectations, and aspirations

E. Salt

*University of Glasgow, Glasgow, UK*

**Background**: Very little attention has been paid to the views and experiences of young adults with mild intellectual disabilities on the topic of transitioning to adulthood. The following study was therefore undertaken to explore how young adults with mild intellectual disabilities conceptualise, relate to, and experience the process of becoming an adult.

**Method**: 8 young adults (16–19 years) with mild to borderline intellectual disabilities from Edinburgh, Scotland participated in semi-structured interviews. Results were analysed using interpretive thematic analysis.

**Results**: 4 main themes were identified: "Old in some ways, young in others"; "The march of time"; "My disability makes it harder"; and "I deserve trust and respect."

**Conclusions**: In contrast to previous research, the participants concerns were surprisingly similar to those commonly expressed amongst young adults without disabilities. Self-perceived adult identity appeared to be affected by the participants' personal definitions of adulthood, as well as by social comparisons with both peers and adults. Finally, while the majority of participants expressed concerns about their capacity to cope with responsibility, most nevertheless felt optimistic about their potential for adopting full adult status in the future.

# 5. AGEING AND SUPPORT IN LATER LIFE

## 5524 | Exploring the caregiving roles of siblings supporting adults with intellectual disabilities

L. Esther; T. Melissa

*MINDS, Singapore*

**Background**: As adults with intellectual and developmental disabilities age, their elderly parents' ability to provide support to their adult children dwindles; siblings are a possible alternative source of caregiving support in such circumstances. This paper aims to assess current roles of siblings as informal caregivers, and their preparedness in providing extended caregiving support in future.

**Method**: Semi-structured interviews were conducted with 27 adults, whose ages ranged from 26 to 69. The participants have siblings who have been diagnosed with an intellectual and/or developmental disability, and are attending a sheltered employment service. The "preparedness of caregiving scale," by Archbold, Stewart, Greenlick, and Harvath (1990), was also administered to the participants.

**Results**: The study is ongoing and the results will be presented at the conference.

**Conclusions**: The findings of the study have potential implications regarding interventions to build the capacity and capability of siblings in providing caregiving support. Limitations and policy recommendations are also discussed.

## 5971 | The utility of Digital Life Stories in maintaining meaningful communication across the continuum of dementia for persons with Down syndrome

P. Dunne; E. Reilly; F. Lowe; R. Judge; M. McCarron

*Daughters of Charity Disability Support Service, Ireland*

**Background**: To demonstrate through a series of case studies the effectiveness of digital life stories in supporting meaningful communication across the continuum of dementia.

**Method**: Individuals who were enrolled in a specialist Memory Clinic for people with an Intellectual Disability in the Republic of Ireland were purposefully selected and introduced to Digital Life Story using iPad technology. A bespoke multi-medium platform comprising of photographs, text, audio, music and film was created for each individual. Digital life stories were used as a tool for communication between persons with dementia and their family, friends and paid carers. Visual narrative and feedback was gathered from participants and their social network.

**Results**: Each case study presents a different stage within the continuum of dementia ranging from independence to total dependence. Digital life stories facilitated meaningful communication across this continuum, strengthening relationship-based care and the bond between the person and their carer.

**Conclusions**: Digital life stories have been shown to be a very powerful means of facilitating meaningful communication thus supporting relationship-based, person centred dementia care. Critical ingredients for success include the training of staff, engaging with family, personalising supports and embedding digital life stories in day to day care plans.

## 5584 | The experiences and needs of staff working with people with ID who are dying or bereaved

I. Tuffrey-Wijne; J. Bernal; J. Finlayson; C. Lam; L. Taggart; S. Todd

*Kingston University & St George's, University of London, London, UK*

**Background**: What are the views, experiences, training and support needs of staff working with people with ID who are dying or bereaved?

**Method**: Staff from 25 supported living and residential service providers across the UK ($n$ = 724) completed an online survey about their experiences with clients who had recently died, were terminally ill, or were recently bereaved.

**Results**: 28% of respondents reported finding it difficult to talk about death. The majority felt confident talking about death with someone with ID (58%), working with bereaved clients (68%) or working with terminally ill clients (57%). A third of staff who described supporting a client who had died or was terminally ill or had been bereaved ($n$ = 313) found the experience distressing. Most (71%) had felt well supported in coping with the situation. The nature of staff support and training needs will be discussed.

**Conclusions**: Whilst it is reassuring that many staff feel confident working with people affected by death and loss, it is important to note that a large minority do not. Working with dying or bereaved clients can be distressing, with staff needing significant support.

# 6. INDEPENDENCE & SELF-DETERMINATION

## 6031 | Accessible written information resources for adults with intellectual disability: compiling the evidence to inform good practice

K. McVilly; J. Anderson; S. Koritsas; H. Johnson; M. Wiese; R. Stancliffe

*University of Melbourne, Australia*

**Background**: The 2006 United Nations' Convention on the Rights of Persons with Disabilities enshrines the right to access to information, and obliges signatory states to promote the "design, production and distribution of accessible information…" (Article 9). Furthermore, the United Nations' 2030 Development Agenda focuses on establishing, among other things, "just, peaceful and inclusive societies by promoting public access to information" (Goal 16). While the importance of easy access to information is universally agreed, what defines accessible written information (AWI), and the extent to which information that is purported to be accessible remains in contention.

**Method**: As the precursor to a larger project, a systematic review of the peer-reviewed literature was conducted. This was complemented by a review of the grey literature. The process was informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA), and the Social Care Institute of Excellence (SCIE). Three primary research databases were used (Web of Science, Academic Search Complete, and ProQuest), as well as Google Scholar.

**Results**: There was a paucity of empirical evidence to guide good practice. Many elements combine to make information accessible, including use of language and images as well as the formatting of documents and the materials used for the production of documents. However, there is no clear consensus that using pictures with text improves comprehension, even though this is common practice.

**Conclusions**: Without accessible information, the rights of people with disability cannot be upheld. Using easy language and pictures is a good start. However, the creation of truly accessible information is far more complex. Technology might provide part of the answer, and better enable the individualisation of information. However, working with communication partners appears very important. Further research, to provide an evidence based for practice is required.

## 5874 | Promoting independence in people with intellectual disabilities: results from a focus group study

J. Sandjojo; W. Gebhardt; A. Zedlitz; J. Hoekman; J. den Haan; A. Evers

*Leiden Institute for Brain and Cognition, Leiden University, Leiden, The Netherlands*

**Background**: People with intellectual disabilities (ID) often struggle with handling their own affairs, whereas they value being independent. This focus group study concentrated on the concept of independence, its advantages and disadvantages, the requirements for promoting independence in people with ID, and currently experienced barriers.

**Method**: 7 focus groups were conducted with either people with borderline to mild ID ($n$ = 7), legal representatives ($n$ = 13), or support staff ($n$ = 17). Various aspects regarding promoting independence were discussed. Verbatim transcripts were analysed qualitatively.

**Results**: People with ID require support from others, but most want to be more independent. A greater level of independence could have several advantages, such as an enhanced self-worth and a better mood. When promoting independence in this population, more support and time seem necessary, next to a clear, step-by-step tailored approach and good communication between all involved parties. Furthermore, several risks and barriers need to be taken into account.

**Conclusions**: There is a demand for promoting independence in people with ID. Interventions need to be developed that are tailored to the needs and abilities of people with ID. A stepwise approach and good communication between all people involved are also essential.

## 5436 | The (critical) role of family and school context in promoting self-determined actions

C. Mumbardó-Adam; C. Giné; J. Guàrdia-Olmos

*Universitat Ramon Llull., Barcelona, Spain*

**Background**: Researchers have asserted that contextual factors impact self-determined actions, but few studies to date have comprehensively examined both personal and environmental factors across students with and without disabilities, leading to incomplete information on the influence of context in shaping self-determination. This study purports to address this need by modelling the effects of personal and environmental (opportunities at school and at home) variables on the essential characteristics of self-determination (volitional actions, agentic actions, and action control beliefs), as defined through Causal Agency Theory.

**Method**: Data was obtained from 591 Spanish students with (59.8%) and without (40.2%) intellectual disability. Participants responded to the Spanish version of the Self-Determination Inventory and the AIR Self-determination scale. Mediation and moderation models were tested to explore the causal relationship amongst variables.

**Results**: School and home opportunities to engage in self-determined actions were found to shape youth action control beliefs that acted as a mediator between opportunities and volitional action.

**Conclusions**: Empirical evidence on the role of beliefs in self-determination development has the potential to inform intervention programs on building empowerment beliefs and adjusted expectations that promote the use of self-determination-related skills, as long as the context renders the person opportunities to do so.

## 6049 | Perception of self-determination and adults with intellectual disabilities – experiences of Polish self-advocates

A. Żyta; K. Ćwirynkało; U. Bartnikowska

*University of Warmia and Mazury, Poland*

**Background**: Part of the shift from institutional care of people with disabilities towards their inclusion in community "has included an increasing emphasis on individual choice, empowerment, and self-determination" (Cloutier, 2006). Self-determination has been perceived as a central concept in most educational programmes and policies for people with disabilities. It is the hallmark of adulthood and an important attribute needed for achieving a good quality of life.

**Method**: We drew upon a research project whose authors examined the perception of self-determination of members of self-advocacy groups in Poland. We conducted three focus group interviews with 30 adults with intellectual disabilities. Using a qualitative approach, we interviewed self-advocates to talk about their self-determination and experiences with families, support staff and local community members.

**Results**: Self-advocates tended to experience possibilities to develop their autonomy and learning skills necessary to achieving higher level of self-determination during their meetings and workshops. However, a number of them did not have possibilities to develop individual autonomy and independence, including making their individual choice in their homes, living with their parents or/and other family members.

**Conclusions**: This study suggests that adults with intellectual disabilities can develop their level of self-determination with appropriate support of support staff and family members.

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# TRACK 10: OTHER MISCELLANEOUS TOPICS

## 1. MEDICAL, SENSORY AND SAFETY ISSUES PERTAINING TO PEOPLE WITH INTELLECTUAL DISABILITIES

### 5837 | Association of central adiposity and menopause status among older women with an intellectual disability in Ireland

J. Ryan

*Trinity College Dublin, Dublin, Ireland*

**Background**: Examine waist circumference among pre and post-menopausal women with intellectual disability (ID) through the lens of a wellness model.

**Method**: In total 55.5% (*N* = 392) women participated in the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA). This study examines health and wellbeing among older adults with ID in Ireland. Anthropometric measurement of waist circumference was categorised according to WHO cut-offs; central adiposity was defined as a waist circumference >80 cms. Menopause status was categorised as pre (reporting continuation of menses) and post (self-reported 12 month of amenorrhea).

**Results**: 59% (*n* = 262) had experienced menopause and of those 82.5% (*n* = 132) waist circumference were categorised substantially at risk of metabolic conditions. Anthropometric waist measure however showed very little difference between the pre and post-menopausal women (93.2% vs 93.8%). Of interest, all women with waist circumference >80 cms and who had experienced the menopause had a doctors diagnosis of diabetes.

**Conclusion**: Central adiposity increases risk of multiple chronic ill health. Evidence from this study illustrates the substantial risk to those involved relative to increased waist line, for example diabetes. Identifying such risks will inform behaviour and lifestyle change.

### 5394 | Topological mapping of in vivo amyloid deposition on cortical thinning patterns in Down Syndrome

E. Mak

*Cambridge University, Cambridge, UK*

**Background**: Adults with Down Syndrome (DS) often have co-existing Alzheimer's disease (AD) neuropathologies, which are considered to be consequent upon the triplication of chromosome 21. While levels of amyloid deposition (Aβ) have been associated with worse clinical prognosis and cognitive impairment, their implications in terms of influences on brain morphology are yet to be clarified.

**Method**: In this PET-MRI study involving 44 DS adults who underwent [11C]-PiB PET and T1-MPRAGE, we investigated the (i) global overlap of Aβ binding with patterns of cortical thickness; (ii) local associations between Aβ and structural changes; and (iii) applied principal component analysis (PCA) to reveal spatially-distant relationships between dominant components of Aβ and cortical thinning.

**Results**: The global topology of increased [11C]-PiB BPND significantly overlapped with decreased cortical thickness. Locally, [11C]-PiB retention was negatively correlated with cortical thinning, predominantly within temporo-parietal regions. Multivariate PCA revealed spatially-distant associations between the dominant components of Aβ and cortical thinning.

**Conclusions**: Contrary to the prevailing evidence in established AD, our findings collectively implicate Aβ in patterns of cortical thinning that recapitulated the "cortical signature" in AD. Further longitudinal studies are necessary to confirm our cross-sectional observations, and disentangle the spatiotemporal relationships between Aβ and downstream neurodegeneration in DS.

### 5872 | Facilitation motor activation in people with intellectual and multiple disabilities

A. van der Putten, A. Waninge

*Department of Special Needs Education and Youth Care, University of Groningen, Groningen, The Netherlands & Hanze University, Applied Sciences in Health Care and Nursing, Groningen, The Netherlands*

**Background**: People with intellectual disabilities (ID) are at risk to be physically inactive. Especially when the level of ID increases and also motor disabilities are prevalent, support lacks structural implementation of movement oriented activities. Therefore, these people can hardly benefit from the positive effects physical activity can generate. The aim of this presentation is to give an overview and introduction of knowledge and projects that contribute to movement oriented support in people with ID and with special attention to people with profound intellectual and multiple disabilities.

**Method**: Knowledge and projects will be categorized into the different domains of the socio- ecological framework of Sallis et al., (2006): characteristics of the targeting individuals, social environments, organizational, physical environments and policies.

**Results**: Three projects will be introduced: 1. Evaluation of the implementation of a movement intervention, 2. Analysis of life style

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approaches implemented in health care organizations, 3. The role of direct support professionals.

**Conclusions**: This presentation provides a framework that overviews current knowledge available to increase physical activity levels in people with ID, which can be the basis of discussion and further developing of interventions .This knowledge can be implemented into the support of people with ID.

## 2. SUPPORT, INITIATIVES, EXPERT OPINIONS AND TRAINING ISSUES FOR PARENTS WITH DISABILITIES

### 5721 | Parenting: Successful support for parents with learning difficulties in England

B. Tarleton; D. Turney; W. Merchant; N. Tilbury

*University of Bristol, Bristol, UK*

**Background**: The aim of the research was to investigate how professionals work "successfully" with parents with learning difficulties in England.

**Method**: 8 families in 3 local authority areas were the focus of the study. These parents consented to take part in the research and allowed us to talk to professionals involved in their support (average 5 per parent). The parents and professionals took part in qualitative interviews about how the parents were supported and what had worked well, as well as any barriers to positive support. Interviews were also undertaken with managers and service commissioners.

**Results**: The professionals revealed very positive understandings of parents with learning difficulties, i.e. that parents would need support to learn and to be the best parent they can be. They understood the importance of relationship based on-going support, which responded flexibly to individual parents' support needs. Professionals worked in multi-professional teams around the families.

**Conclusion**: Professionals positive understanding and response to parents' needs supported engagement with parents and lived out the core themes within the English Good Practice Guidance on Working with Parents with Learning Disabilities (WTPN, 2016, DoH and DE 2007).

### 5646 | Parenting—When technology, parenthood and intellectual disability meet: An innovative pilot project

A.-C. Villeneuve; D. Lussier-Desrochers; M. Aunos

*Université du Québec à Trois-Rivières, Canada*

**Background**: Parenthood may be challenging for parents with intellectual disability (ID). However, when addressing their learning needs, they can ensure the well-being of their children (Wade, Llewellyn & Matthews, 2008). Unfortunately, specialised parenting program are not widely available (Feldman & Case, 1997). On the other hand, research has shown that technology can contribute to learning new skills and promote self-determination of individuals with ID (Lussier-Desrochers *et al*., 2017). Using technology may be a cost-effective solution while being consistent with promising practices. Yet few authors have studied how technology can address the needs of those parents. This innovative study explores effectiveness of technological devices to support parenthood of parents with ID.

**Method**: A mixed longitudinal multiple case design will be used in order to explore how technology may support the parenthood of five parents on a six-month period. As this project is currently in progress, the method and theoretical background will be the focus of this presentation.

**Conclusions**: This innovative project will deepen a research area actually seldom documented. It may support the implementation of cost-effective interventions and, ultimately, directly promote the social participation of parents with ID by involving them in the choice of solutions addressing their parenting needs.

### 5720 | Mellow Futures – adapted parenting programme for mothers with learning difficulties

B. Tarleton; D. Turney

*University of Bristol, Bristol, UK*

**Background**: This evaluation investigated the appropriateness and impact of the Mellow Futures programme for new mothers with learning difficulties

**Method**: 30 mothers, who took part in the pilot programmes in England and Scotland, consented to take part in the evaluation. Mothers and a key professional in their life, invited with the mother's consent, took part in interviews at the start and completion of the programme regarding the mother's situation, the level of concern (from child protection services) regarding the welfare of the baby, and impact of the programme.

**Results**: The professionals believed that the welfare of the majority (26) of the babies had improved during the programme and the mothers were more attuned to their baby, more self-confident, and more engaged with other services. Mothers also reported enjoying the programme and understanding more about their baby and how to care for them. They had made friends and valued the supportive relationships with the programme facilitators and mentors who met with them weekly during the programme.

**Conclusions**: It appears that the Mellow Futures parenting programme had a positive impact on mothers and the welfare of their babies.

## 5451 | An intervention using the preparing for Parenting Toolkit: "Children – what does it involve?" and the Real-Care-Baby simulator among students with ID – a feasibility study

G. Janeslätt; M. Larsson; B. Höglund

*Uppsala University, Uppsala, Sweden*

**Background**: In Sweden, the proportion of teenagers among mothers with intellectual disability (ID) is six fold higher (18%) compared to mothers without ID (3%). Yet there is limited knowledge about how students with ID can be supported in their decisions about reproduction and parenthood. The purpose of this study was to investigate the feasibility of an upcoming trial to evaluate an intervention using the Parenting Toolkit: "Children – what does it involve?" and the Real-Care-Baby (RCB) simulator among students with ID.aaa

**Method**: A before-and after study including six students (aged 17–20) with ID. The intervention was provided for 8 weeks. Data comprised a report from the RCB, a tape recorded interview and two questionnaires: Infant simulator Attitude scale and the General Self-Efficacy Scale (GSE).

**Results**: The intervention material needs further adaptation, but was considered feasible. The questionnaires and the interviews were all completed in a satisfactory way. Preliminary analysis shows that attitudes to parenthood changed after the intervention, indicating support in informed decisions.

**Conclusions**: It is feasible to evaluate the intervention using a randomized study, adding to our knowledge about possible intervention strategies regarding reproduction and parenting among students with ID.

# 3. PERCEPTIONS AND ATTITUDES TOWARD PARENTS WITH INTELLECTUAL DISABILITIES

## 5441 | Attitudes and discourse concerning parenting by people with ID in Austria

R. More

*University of Klagenfurt, Klagenfurt, Austria*

**Background**: Belonging can be experienced through home and family, which have always been diverse settings, but only more recently has family diversity become a mainstream subject – discussed and displayed in media, politics and society. Whilst diversity has become a trope for the modern family, many women and men with ID in Austria are still being discriminated against concerning reproductive choices and parenting. The aim of this study was to gather insights into present discourses and attitudes towards parenting with ID in Austria, and their meaning for support services and family life.

**Method**: This presentation is based on empirical findings from a multi-perspective dissertation in the field of social pedagogy and inclusion. Interpretative phenomenological analysis of Internet comments and interview data was employed.

**Results**: Parenting by people with ID is still a controversial societal subject in Austria. To some extent, professionals are aware of prejudices and stereotypes marginalising parents with ID.

**Conclusions**: For social acceptance as well as adequate parenting support, public and professional awareness is required, especially in the context of Austria's long history of trying to prevent reproduction and parenting by people with ID. Further research is needed on (prevented) possibilities for women and men with ID to become parents and raise their children successfully.

## 5367 | Able or unable: how do professionals statute on the parenting capacity of mothers with intellectual disabilities?

M. Aunos; L. Pacheco

*Université du Québec à Montréal, Canada*

**Background**: Studies have demonstrated that too often children have been removed, cases have stayed open longer, and parents have been judged as less cooperative when a parent was diagnosed with an intellectual disability. Parenting capacity assessments are often where those determinations are made. aim of this study is to objectively review conclusions and recommendations as presented in parenting capacity assessment reports written by either child welfare or rehabilitation workers.

**Methods**: Thirteen parenting capacity assessments from eight different families were analysed. Outcome results were compared according to who mandated the report using Mann-Whitney or Fisher's exact test. Qualitative analyses were also conducted.

**Results**: Conclusions make up for approximately 10% of reports. There were significant differences in the conclusions, as all reports mandated by ID services concluded that parent was deemed capable with support, and all reports mandated by Child Welfare concluded that the mother was incapable of providing sufficient care for her children. Furthermore, ID service reports demonstrated more "positive" strengths-based statements in the conclusion and fewer impediments, while CW services reports presented fewer strengths-based statements and more impediments.

**Conclusions**: These results allow for recommendations in regards to the assessment process and training for professionals who perform these assessments.

## 5373 | Attitudes of direct support staff regarding couple relationships of people with intellectual and developmental disabilities: implications for the provision of supports

R. Neuman

*Zefat Academic Collage, Israel*

**Background**: In adulthood, couple relationships are an important aspect of quality of life, and should thus be accessible to people with IDD. In practice, despite the reports about the desire of people with IDD to form couple relationships, only few receive the appropriate support. One of the main obstacles facing people with IDD is their dependence from support staff; people with IDD describe high levels of staff surveillance, restricting their opportunities to form relationships. The present research tried to tackle the complexity of direct staff attitudes towards couple relationships of adults with IDD. It is assumed that an in-depth understanding of the direct support staff perceptions will enable us to examine where changes in attitudes are called for, in order to enable people with IDD to have an open, and free of inhibitions, accessibility to couple relationships, while not discarding their role as supporters.
**Method**: Interviews were held with 30 direct support staff regarding their attitudes towards couple relationships of adults with IDD.
**Results/Conclusions**: Based on the findings, recommendations for the provision of supports were made.

# 4. LEGAL ISSUES PERTAINING TO PEOPLE WITH INTELLECTUAL DISABILITIES

## 5364 | Quality of intervention plans of parents with intellectual disabilities who receive services from both a rehabilitation center and child welfare

M. Aunos; L. Pacheco; N. Poirier; G. Goupil

*Université du Québec à Montréal, Canada*

**Background**: Families headed by parents with ID often receive services from both Child Welfare and specialized services. By law, intervention plans are obligatory and are meant to structure services. The aim of this study was to evaluate the content of intervention plans and assess if each objective is operationalized, is oriented towards parenting skills development, and incorporates child welfare concerns.
**Methods**: Twenty-six intervention plans and 125 independent objectives were reviewed and analyzed using two grids. These grids report on impediments and supports, and follow best practices regarding intervention planning. Descriptive and content analyses were performed by four independent decoders.
**Results**: On average, each family had several intervention plans. However, many intervention plans did not include concrete and measurable objectives, or a clear description of means, performance criteria and timeline. Few objectives concerned parenting skills development, as most looked at work or daily living skills.
**Conclusions**: Decisions regarding the maintenance of ties or reunification of families are often made based on the capacity of parents to incorporate suggestions as detailed in their Intervention plans. Thus, the results of this study have huge implications for clinical practice and research.

## 5366 | Quality of parenting capacity assessments: writing style and assessment process

M. Aunos; L. Pacheco; S. Ornawka

*Université du Québec à Montréal, Canada*

**Background**: Parenting capacity assessments are used in court cases to determine the custody status of children of parents with intellectual disabilities. For decades, research in this field has illustrated the inadequacy of many parenting capacity assessments. However, none of these studies have evaluated parenting capacity assessments. The aim of this study is to objectively look at the quality and writing style of parenting capacity assessments done by specialised services and by child welfare agencies.
**Methods**: Thirteen parenting capacity assessment reports were analysed using four different grids created based on best practices in the field of parenting and report-writing. Analyses included qualitative and quantitative tests using Mann-Whitney test, Fisher's exact test and Wilcoxon test in order to compare elements from child welfare and specialised services.
**Results**: Significant differences were found: child welfare agencies used IQ testing to justify parenting incompetence, while all specialised services included in-vivo observations. Quality of the content of report was poor for both groups, and most did not use validated instruments.
**Conclusions**: Report writing is essential for providing a true picture of the strengths and specific needs of families. These results have huge implications for professionals' clinical practices and research.

## 5706 | Parents with ID: custody deprivation and the evidence-making power of the broader child protection system

J. Rice; H. Sigurjónsdóttir

*University of Iceland, Reykjavik Iceland*

**Background**: The aim of this presentation is to discuss certain systemic issues within child protection concerning how information about the parenting capabilities of parents with intellectual disabilities is collected and assessed.

**Method**: This paper is part of a larger project which analysed court documents pertaining to child custody deprivation and parents with ID, interviews and selected cases studies.

**Results**: We highlight how negative assumptions of parenting with an ID taints the entire child protection system broadly understood. This includes the notifications of neglect, to the collection of information from surveillance, to parenting assessments and the final decision making process. The evidence upon which custody deprivation is based is often decontextualized and comprised of the input from a diverse collection of agents, many of whom lack knowledge in the area of parenting with an ID.

**Conclusion**: There is a need to expand the critical analyses of child protection as it concerns parents with ID to include the range of agents and institutions that share the role of collecting evidence of parental "incompetence" that informs the child protection process.

# 5. GOOD PRACTICE, PROFESSIONAL ENGAGEMENT AND COLLABORATION IN WORKING WITH PARENTS WITH ID

## 5492 | Parenting with Intellectual disabilities in Taiwan: capabilities, challenges, and the ethics of engagement

B.-W. Chen

*Taiwan*

**Background**: This research contributes to the existing literature by examining the under-explored terrain of parenting and child-rearing with intellectual disabilities in Taiwan. It challenges the unfair presumptions that debar entitlements of parenthood for the marginalized. Theoretical perspectives on capabilities (Nussbaum 2006; Kulick and Rydstrom 2015) are used to explicate how parental capabilities of individuals with disabilities can be developed and supported.

**Method**: In-depth interviews with 15 parents with intellectual disabilities were used to chart the capabilities and challenges of parenting with disabilities. Comparing insights from significant others (e.g. children, facilitators, professionals and authorities etc.) were provided for developing a fuller understanding.

**Results**: First, I question the stigmatization of parents with intellectual disabilities as "naïve children" that are disqualified for parenthood, while simultaneously pathologizing them as "foxy users" that exploit the welfare benefits. Second, I identify a network of facilitations and parental training programs that support the marginalized for flourishing parenting and child-rearing with dignity. The intersection of disability with gender, class and urban/rural divide will also be addressed.

**Conclusions**: In analyzing parenting with disabilities, this research hopes to re-draw the boundaries of hierarchy and dignity in the affective economy of "ideal parenthood" and its compulsory existence.

## 5651 | Getting it right? Exploring the persistent challenges in adopting a "whole family" approach to supporting families affected by parental learning disability

G. MacIntyre

*University of Strathclyde, UK*

**Background**: Over the last 10 years evidence has suggested that taking a family focused approach that acknowledges the needs of parents, as well as children, is the most effective way to support families Published for the British Institute of Learning Disabilities where one or both parents has a learning disability (MacIntyre and Stewart, 2012; Wade et al, 2008). That said, barriers to supporting families remain. This paper aims to explore the reasons for this.

**Method**: It draws on data from a national survey to identify the reasons for this. Forty-seven surveys were returned and an additional 15 key informant interviews were conducted to explore the issues raised in more depth.

**Results**: Practice varies across Scotland. Good practice centres on early identification and intervention allows workers to focus on carrying out preventative work. A number of barriers remain around identifying parents, a lack of accessible information, and poor practice in relation to joint working.

**Conclusions**: Taking a whole family approach is essential, yet families continue to fall between the gaps in services. It is argued that conceptualising families as "vulnerable" contributes to these challenges. While being labelled as vulnerable is essential to access services, it impacts negatively on assumptions about capacity to parent.

## 5956 | Using social practice theory to understand "successful" professional engagement and involvement with parents with learning difficulties when there are concerns about parenting

D. Turney

*University of Bristol, Bristol, UK*

**Background**: This paper discusses the application of Social Practice Theory (SPT) to a new context: "successful" professional practice with parents with learning difficulties (LDs) when there are child protection concerns. This is a significant area as parents with LDs are disproportionately represented in child protection and care proceedings. So it is important to understand "what works," why and how, in order to promote best practice and effect change where necessary.

**Method**: SPT offers a framework for understanding how everyday professional practices are constructed, how they cohere, connect or co-opt people into particular ways of doing things, and how they continue through time.

**Results**: Starting from examples of "success" and using data gathered from interviews with 8 families, the professionals they worked with, senior managers and service commissioners, SPT was used to analyse how parents and professionals worked together, identifying the factors that appear to contribute to "successful" working.

**Conclusions**: SPT provides a useful conceptual and analytical framework for exploring how professionals work with parents with LDs and the complex interactions and processes involved. Understanding how "meanings," "know-how," and "resources" interact to create and maintain "successful" practices offers valuable insights into how/where it might be possible to leverage change and improve families' experiences of services more generally.

## 5726 | Collaborating for the benefit of families headed by parents with intellectual disabilities: a service pathways initiative

M. Aunos; D. McConnell; L. Pacheco; A. Savage; M. Feldman; T. Laliberté

*Université du Québec à Montréal, Canada*

**Background**: Five out of every 1000 children aged 14 and under are in foster care, and out of these five children at least one was taken from a parent with intellectual impairment. Families headed by parents with intellectual disabilities face multiple disadvantages and often have many agencies working with them. The purpose of this study is to determine a strategy to build systems' capacity to accommodate the support and learning needs of parents with intellectual impairment and, in turn, improve the life chances of their children.

**Method**: Mainly, over the course of three stages semi-structured interviews will be conducted with parents and workers, followed by in-depth interviews and multidisciplinary focus groups with professionals. Parents with intellectual disabilities, workers and managers in readaptation centers, child welfare and community organizations will be actively involved throughout the project.

**Results**: A description of the process in which data is gathered will be presented. Key elements brought forward by participants (managers, parent reference group, workers) will brought forward.

**Conclusions**: A research-informed strategy aimed at building system's capacity to intervene with parents with intellectual disabilities will be developed with all stakeholders' participation.

# 6. SUPPORT AND CARE FOR TERMINALLY ILL PEOPLE WITH DISABILITIES

## 5587 | Talking about dying with people with ID who have a terminal illness: a UK survey of support staff

J. Bernal; J. Finlayson; C. Lam; L. Taggart; S. Todd; I. Tuffrey-Wijne

*University of South Wales, South Wales, UK*

**Background**: To investigate the extent to which people with ID who have a terminal illness are informed of their diagnosis and prognosis.

**Method**: Support staff working in supported living and residential settings completed an online survey ($n$ = 724, 64% response rate), supporting over 6,000 people with ID between them. Recruitment was through contacting managers of ID service providers from all four UK countries ($n$ = 25). Those answering "yes" to the question whether any of their clients had died during the past 12 months, or was currently terminally ill, were asked further questions about this.

**Results**: Over a quarter of respondents ($n$ = 205) had experienced death or terminal illness among their clients during the past year, reporting 199 deceased (of which 114 were non-sudden deaths) and 76 terminally ill clients. Over half of people with ID whose death was expected were told about their illness, but only 20% were ever told that they would die of it. However, 36% of respondents thought that the person "definitely" or "probably" realised that they were going to die.

**Conclusions**: People with ID whose deaths are expected by staff are mostly uninformed about their own impending death. This has implications for their involvement in end-of-life decision making.

## 5586 | Recruiting care workers from ID services to talk about death and loss: Insights from a national survey

C. Lam; J. Bernal; J. Finlayson; L. Taggart; S. Todd; I. Tuffrey-Wijne

*Kingston University & St George's, University of London, London, UK*

**Background**: Care workers from disability services are often described as gatekeepers to inclusive research, rather than as valuable research participants themselves. This paper reflects on the strategy to recruit care workers to a national survey, identifying key aspects of successful staff recruitment.

**Method**: We conducted a UK-wide online survey investigating support workers' experience of death, dying, and bereavement among their clients. Recruitment utilized a phased top-down approach: (i) Seek approval and support from senior management. (ii) Contact middle managers; guide them in choosing care workers to complete survey. (iii) Middle manager email survey link to care workers; care workers complete survey online.

**Results**: Over 700 participants were recruited over a 6-month period (63.8% response rate). Results show that care workers were willing to engage and had many opinions to share when managers were supportive. Flexibility to complete the survey in their own time, with the help of technology, was also useful.

**Conclusions**: It is important to factor in enough time for recruitment (months) to allow participants from all phases to engage. Care workers are invaluable participants to ID research and provide unique and indispensable insight into best practice for talking about loss with people with ID.

## 5585 | Advance Care Plans (ACP) for people with ID at the end of life: a UK survey of support staff

I. Tuffrey-Wijne; J. Bernal; J. Finlayson; C. Lam; L. Taggart; S. Todd

*Kingston University & St George's, University of London, London, UK*

**Background**: To what extent are ACPs used with people with ID who have been diagnosed with an irreversible terminal condition?

**Method**: Online survey of staff working in supported living and residential settings across the UK ($n$ = 724). 190 respondents had supported clients with ID who had (during the past 12 months) died of, or were currently suffering from, an irreversible terminal condition; these were asked further questions about the use of ACP.

**Results**: The person's own wishes and preferences around treatment, care, place of death or funeral are roughly twice as likely to be discussed with family or staff (between 37% and 58%) than with the person themselves (between 17% and 27%). Among respondents who reported documentation of the person's wishes ($n$ = 99), the most common was recording of funeral wishes (60%), followed by where s/he would like to die (32%).

**Conclusions**: Comprehensive ACP includes discussing care and treatment choices during the final illness. However, aspects of ACP most frequently included for people with ID are related to death and post-death planning, including funerals. We will discuss possible reasons and consequences of the low proportion of people with ID who are involved in their own ACP.

## 5570 | Euthanasia for people with ID and/or autism spectrum disorder (ASD) in the Netherlands, 2012-2016

I. Tuffrey-Wijne; L. Curfs; I. Finlay; S. Hollins

*Kingston University & St George's, University of London, UK*

**Background**: Euthanasia is legally possible in the Netherlands, provided that statutory due care criteria are met, including "unbearable suffering without prospect of improvement" and "voluntary and well-considered request." There is post-euthanasia scrutiny of all cases, and annual reporting, by the Euthanasia Review Committee (RTE). We investigated whether any particular difficulties arise when the due care criteria are applied to patients with ID and/or ASD.

**Method**: The 416 case summaries available on the RTE website (2012-2016) were searched for ID (6 cases) and ASD (3 cases). Direct content analysis was used on these case summaries.

**Results**: Assessment of decisional capacity was given in eight cases, but few details given; overall, capacity tests in these cases did not appear to be sufficiently stringent. For most, suffering was due to an inability to cope with changing circumstances or increasing dependency; in several cases, suffering was described in terms of characteristics of living with ASD, rather than an acquired medical condition. Treatment refusal was a common theme, leading physicians to conclude that euthanasia was the only remaining option.

**Conclusions**: The Dutch euthanasia due care criteria are not easily applied to people with ID and/or ASD, and do not appear to act as adequate safeguards.

# 7. EMPOWERMENT AND SELF-DETERMINATION OF PEOPLE WITH INTELLECTUAL DISABILITY AND THEIR FAMILIES

## 6065 | Parental involvement and students' outcomes: a study in a special education (SPED) school in Singapore

E. Er

*Metta School, Singapore, Singapore*

**Background**: This study is the first in Singapore to adopt the revised Hoover-Dempsey and Sandler's (2005) comprehensive theoretical model to (i) explore the relationship between parental involvement (PI) and educational outcomes in students with developmental disabilities; (ii) determine the effects of family structure and socioeconomic status (SES) on PI and (iii) investigate factors that inform PI.
**Method**: First, Pearson's correlation was used to determine the association of PI and educational outcomes in students. A two-way ANOVA was conducted to examine the effects of SES and family structure. Subsequently, standard multiple regressions were conducted to assess the extent to which family demographic variables and parent motivational variables predicted parental involvement.
**Results**: Pearson's correlation coefficients between PI and educational outcomes of students were statistically significant. There was a significant interaction between SES and Family Structure on PI. The model as a whole explained a total of 56.5% of the variance with statistically significantly predicted scores.
**Conclusions**: Hoover-Dempsey and Sandler's Model provides a framework for understanding the relationship between parents and their children. Taken as a whole, parents are influenced by multiple, complex factors when being involved with their children. As such, parents may require more than financial assistance to encourage their involvement.

## 5705 | "I can't just have someone tell me what it's like, I have to see it for myself, really": experience of decision-making about services by people with intellectual and developmental disabilities

B. Whelton; A. Turnpenny; L. Richardson; J. Beadle-Brown
*University of Kent, Kent, UK*

**Background**: This study aims to explore whether/how people with intellectual disabilities and development disabilities (IDD) in England use quality information (QI) in (i) deciding where to live/from whom to receive support and (ii) what factors are important when making these decisions.
**Methods**: Qualitative semi-structured interviews were conducted with 11 people with IDD and/or autism. Transcripts were analysed using thematic network analysis (Attride-Stirling, 2001).
**Results**: People with IDD did not have access to formal sources of QI. Some people were only presented with one option. Two global themes were identified: "finding information" and "decision-making." Individuals gained information via three sources: Gatekeepers, Visits, and Lived Experience. "Decision-making" to escape their current situation, attributes of the new situation, barriers, and what is important.
**Conclusion**: There is little evidence of individuals using traditional QI sources. Decisions are based on restricted choice filtered through gatekeepers and informal sources such as visits. For some individuals they only gained relevant information through lived experience.

## 5527 | Some people with learning disabilities are queer. Get over it!

T. Doukas
*Choice Support, London, UK*

**Background**: This study looks at the story of Alice, a male-to-female transitioning woman with intellectual disabilities. For the last couple of years, Alice has suffered from gender dysphoria and she has been supported to explore gender transitioning. Alice's support team has helped her to consider her choices and decisions and they used their imagination and the right attitude throughout the process, from visits to the gender clinic and psychologist, to getting hormonal treatment and voice coaching. The supporters also employed the Josephine & Jack Project, as a creative means to support sexual choice and the law around mental capacity, equality and education.
**Method**: Using video diaries and direct interviews, the study explores different time phases in Alice's transition, describing details of the transitioning process, and the barriers encountered by Alice. The methodological approach focuses on Alice, however, there is emphasis on different aspects of the support provided to her during the transition. Results: The aim of this case study is to share and raise awareness about sexual choice for people with intellectual disabilities.
**Conclusions**: With the right support, others can claim their sexual rights to fulfil their self-determination and autonomy and, ultimately, be in control of many aspects of their lives.

# 8. QUALITATIVE RESEARCH IN INTELLECTUAL DISABILITIES

## 5707 | The subjective experiences of women with intellectual disabilities and offending behaviour living in a secure setting

E. Williams; J. Rose
*University of Birmingham, Bristol, UK*

**Background**: In the UK, services supporting individuals with intellectual disabilities (ID) are changing with a drive towards community care and reducing inpatient provision. This research aimed to consult women with ID, living in a secure hospital, to explore their housing experiences and hopes for future home and care environments.

**Method**: Seven participants' experiences and the meaning they assigned to these experiences were explored through semi-structured interviews. Their narratives were analysed utilising Interpretive Phenomenological Analysis.

**Results**: Four superordinate themes emerged from the analysis: (i) hospital as helpful, (ii) hospital as undesirable, (iii) a sense of belonging, and (iv) "I want to be as independent as I can." The subtheme "importance of people" emerged throughout with illustrations of why people are important relating to each superordinate theme.

**Conclusions**: The women interviewed experienced living in hospital as both helpful and undesirable. They identified several helpful aspects of hospital, including receiving specialist support for their complex needs. They desired independence, freedom of choose, personal space, familiarity, and support from individuals who understand their needs. Whilst it is recognised that hospitals cannot be homes for people, they do have a function providing specialist support to some individuals who have committed serious crimes so that they can safely be supported in the community after appropriate treatment.

## 5709 | The meaning of social care for adults with learning disabilities from minority ethnic groups in the UK: cultural affordance, social relationships and narratives of independence

M. Larkin; G. Unwin; B. Stenfert-Kroese; J. Rose

*Aston University, Aston, UK*

**Background**: The relationship between adults with intellectual disabilities from minority ethnic groups and their local social care services was explored.

**Method**: Qualitative analyses were conducted, which focus upon understanding the service-users' perspectives on this relationship. 32 adults took part in semi-structured interviews about their lives and the role support services played in them. The transcripts were analysed within a Pluralist framework drawing on Template Analysis, then pursuing more focused analyses using lenses from phenomenological, narrative, and discursive approaches.

**Results**: Participants were generally positive about the services which they received, and preferred to evaluate services in terms of their continuing good relationships with specific people providing the support. Respondents were often much more sophisticated users of cultural resources and identities than they are given credit for by the conventions of cultural competence training. It is argued that the concept of "cultural affordance" may be useful for service-providers in future. Finally, our analysis describes three distinctive narratives about independence (Stability; Progress; Resistance).

**Conclusions**: Resources were developed which service providers and researchers can use with people with Intellectual disabilities in order to facilitate mutual understanding, service planning, and service delivery from the work presented here.

## 5713 | How do psychologists experience working with staff in care settings for people with intellectual disability?

N. Smith; B. Stenfert-Kroese

*University of Birmingham, Birmingham, UK*

**Background**: While psychologists working with people with an intellectual disability routinely work with care staff in residential care homes, there is a lack of research investigating how psychologists can effectively assess, collaborate, and engage with staff groups. This research seeks to explore psychologists' experiences of working with staff in residential care homes in order to develop an understanding of how psychologists manage the work, and to help generate clinical solutions to psychological problems.

**Method**: Seven clinical psychologists and one counselling psychologist were interviewed using a semi-structured interview focusing on participants' interactions with staff. Interviews were transcribed and analysed using Interpretative Phenomenological Analysis.

**Results**: Themes common across participants included "development and maintenance of a therapeutic relationship," "theory and emotion," "perceived restrictions," "safety," "developing an identity as a psychologist," "support and shared experiences," "motivation," and "conflict and the roles of a psychologist."

**Conclusions**: Participants experienced several barriers to carrying out effective psychological work with staff in residential care homes. The various ways they have sought to address these are discussed. A preliminary model is proposed to describe what is needed for psychologists to be effective when working with staff in residential care homes.

## 5827 | Using interpretative phenomenological analysis in research with people who have intellectual disabilities

J. Rose; K. Malik; E. Hirata; H. Roughan; M. Larkin

*University of Birmingham, Birmingham, UK*

**Background**: This paper is a review of the appropriateness of using Interpretative Phenomenological Analysis (IPA) in research with people who have intellectual disabilities, particularly focussing on the assessment of the quality of this research.

**Methods**: A comprehensive search strategy of three electronic databases (MEDLINE, PsycINFO and CINAHL) was conducted by applying specific inclusion and exclusion criteria. Inclusion criteria were:

adults over the age of 18 with an intellectual disability, data derived from individual interviews or group interviews, published in English in a peer reviewed journal, it was explicitly stated that only IPA was used to interpret the data. Exclusion criteria were: views of carers or staff were included within the research. A guide to assess the quality of IPA research was also developed for this review based on previous research.

**Results**: 29 papers met the inclusion criteria for this review. Quality assessment indicated that the studies were of varying quality. There were 22 papers of at least acceptable quality. The papers in general were not transparent with regards to the ability levels of their participants.

**Conclusions**: IPA is an appropriate methodology to use with people with intellectual disabilities. Future researchers using this methodology are urged to improve transparency around the intellectual abilities of the participants being recruited into the research.

## 9. INNOVATIVE METHODOLOGIES TOWARD SYSTEMATIC STUDYING OF INTELLECTUAL DISABILITY

### 5972 | Data-driven instructional methodology: effectiveness on students with ASD and on staff members in the Day Center, Hara II

I. Tsiouri; K. Ziarra

*Day Center HARA II, Larissa, Greece*

**Background**: We will present the structure and services of the Day Center HARA II, a unit managed by the Association of Parents, Guardians and Friends of Individuals with Autism at the Province of Larissa in Greece, that serves preschool and school-aged children with ASD.

**Method**: The basic elements that comprise this process were: (i) Systematic presentation of individualized instructional opportunities of reciprocal interaction of the therapist with the student, (ii) Recording, visualization and constant inspection of data for each student, (iii) Recording of the teachers' presentation of instruction with regular feedback on their teaching skills, and (iv) Summative data review across students, on a monthly and annual basis, which allows for evidence based conclusions in reference to the effectiveness of the Individualized Educational Programs and the accuracy of applying scientifically driven instructional tactics and procedures.

**Results**: The presentation will demonstrate the effectiveness of systematized instructional methodology on: (i) the learning rate of the students across educational domains, (ii) the therapist's instructional effectiveness and (iii) the evaluation of the Unit as a system, through self-monitoring and evaluation.

**Conclusions**: The long term goal is the maintenance of high-quality services that address the educational needs of the students, while promoting social and school inclusion.

### 5984 | Adaptive behaviour related to basketball sport performance through the observation of athletes with intellectual impairment

K. McCulloch; D. Van Biesen; I. Noens; Y. Vanlendewijck

*University of Leuven, Leuven, Belgium*

**Background**: To identify how different behaviour themes within adaptive behaviour (AB) impact basketball performance in athletes with intellectual impairment (II).

**Method**: A sample of ten male Australian athletes (age = 23.80 years ± 1.99; years playing = 10.70 ± 3.97; IQ = 55.83 ± 7.81; AB = 2.43 ± 7.44) with II were observed over six days during the International Federation for Athletes with Intellectual Impairment (INAS) World Basketball Champions held in Italy between the 21st-26th November 2017. Video footage was collected during four training and four game situations. A Delphi study was performed to itemise the most relevant behaviours from the Adaptive Behaviour Assessment System, 3rd Edition (ABAS-3) for basketball performance. An observation protocol with a strict training procedure was established from this Delphi study to quantify behaviours. These behaviours were task focus (TF), emotional control (EC) and following instruction (FI). An acceptable Inter-Rater Reliability was established at 0.80. Field notes were recorded.

**Results**: A loss of EC (particularly due to individual error) and a loss of TF were more prevalent during the game situation, whereas a loss of FI was more prevalent during the training situation.

**Conclusions**: Limitations in AB were identified in the context of sport which may have had a negative effect on basketball performance in male athletes with II.

### 5717 | Barriers and challenges to conducting randomised controlled trials with adults with intellectual disabilities: Experiences of the experts

L. Taggart; P. Mulhal

*University of Ulster, Ulster, UK*

**Background**: There is a lack of evidence for many interventions provided to people with ID. They are routinely excluded from mainstream trials. To address both issues, a better understanding of the challenges of conducting trials with people with ID is needed. The study aims to explore the methodological and practical challenges that can be expected while conducting RCTs with adults with ID.

**Method**: Twelve semi-structured interviews were conducted with international experts in the field of ID research/RCTs. Participants came from a range of clinical and academic backgrounds, from the UK, USA, Europe and Australia, had an average of 16 years experience, and had conducted an average of 3 trials in this field.

**Results**: Seven themes emerged relating to challenges concerning: (i) the uniqueness of the participants, (ii) ethics and consent, (iii) the RCT methodology itself, (iv) systemic issues, (v) a lack of technical understanding, (vi) attitudes and perceptions, and (vii) integrating evidence into practice.

**Conclusions**: Many of the challenges can be overcome with reasonable adjustments. The challenges that may be harder to overcome are the attitudes and perceptions that people hold towards the utility of RCTs with ID populations.

## 10. PARENTS WITH INTELLECTUAL DISABILITIES

### 5442 | The edge of diversity: (re)producing dis/ability in terms of parenting competence

R. More

*University of Klagenfurt, Klagenfurt, Austria*

**Background**: Every child has the right to be cared for by his or her parents, as far as possible (UN-CRC, Article 7) and therefore belongs with them. Despite people with disabilities being entitled to parenthood, to the same extent as citizens labelled as non-disabled (UN-CRPD, Article 24), parents with ID are overly engaged with child protection, according to international research. Contrary to celebrating human diversity, discrimination based on normativity, both regarding parenting competence and disability, might be responsible. This presentation draws from empirical findings from a multi-perspective doctoral dissertation. The aim of this research is to understand links between normative and ableist constitutions of parenting and the label of ID, as well as outlining perceived edges of diversity.

**Method**: Interpretative phenomenological analysis of Internet comments and interviews with professionals supporting parents with ID.

**Results**: Subjective definitions of parenting competence are linked to traditional gender roles, idealistic standards and abstract concepts of independence, ignoring the fact that all parents depend on others. People with ID are viewed as dependent, and therefore unfit parents.

**Conclusions**: Ableist perspectives on parenting by people with ID intertwine with normative definitions of parenting competence. More flexible models of parenting competence and dis/ability are needed to adequately support diverse families bringing up their children.

### 5365 | How to respond to the needs of mothers with intellectual disabilities: different perspectives about the use of community resources centers

M. Busson; M. Aunos; N. Poirier

*Université du Québec à Montréal, Canada*

**Background**: Mothers with intellectual disabilities (ID) have multiple needs that are not directly related to their cognitive limitations. For instance, they might be confronted with social isolation, poverty and discrimination (Aunos *et al*., 2004; McConnell *et al*., 2010). The quality and type of support offered will be critical in expressing their parental competence. The main objective of this study is to explore the needs of mothers with ID in their use of community resource centers.

**Method**: Descriptive quantitative and qualitative analyses were used to evaluate semi-structured interviews administrated to eight mothers with ID, 10 rehabilitation caseworkers and 30 participants from community resources centers.

**Results**: Overall, several needs were raised that indicate a poor use of community resources. Mothers and caseworkers have a lack of knowledge of the existing resources. However, mothers want to use services offered by community resources centers with appropriate support. Despite respondents positively perceiving mothers' integration into community resources provision, all indicated many needs in term of support and adaptation.

**Conclusions**: The results of this study have implications for clinical practice and research. Better knowledge of the needs and supports required by mothers with ID would allow adaptations for better use of community resource centers.

### 5619 | Parents with intellectual disabilities: perceptions of peer support

I. Strnadova; S. Collings; J. Loblinzk

*University of New South Wales, Australia*

**Background**: The aim of this study was to explore parents with intellectual disabilities' perceptions and experiences with peer support. The research questions guiding this study were: (i) How do parents with intellectual disabilities perceive peer support?, (ii) What types of peer support are preferred by parents with intellectual disabilities?

**Method**: This inclusive research study was led by two academic researchers and one researcher with intellectual disabilities. Twenty-six parents took part in interviews, which were analysed using inductive content analysis.

**Results**: Peer supporters mentioned by the participating parents presented a very varied picture, and included people who would be considered "informal" support (such as family members, friends or neighbours), as well as people (or organisations) who rather fall under umbrella of "formal" support (groups for people with intellectual disabilities, paid support workers).

**Conclusion**: The findings reveal that the way the participating parents perceived peer support was different to how it is defined in professional literature and service provision. In experiences and perceptions of the participating parents peer support included emotional and practical support, however the aspect of being provided by people with similar experiences was not as important. What mattered was the way peer support was delivered.

## 6064 | Impact of loneliness on parents with intellectual disability

D. McConnell; L. Pacheco

*University of Alberta, Alberta, Canada*

**Background**: Parents with intellectual disability (ID) are at risk for loneliness. The purpose of this study was to investigate the impact of loneliness, to be distinguished from perceived social support, on the parental functioning of parents with ID.

**Method**: This study is nested within a large, multi-stage, multi-method project investigating the service pathways of parents with ID in Quebec and Alberta, Canada. A sample of 400+ parents, including 100+ parents with ID, are expected to take part in Stage-1, involving a comprehensive survey of family ecology and support needs. Using Stage-1 data, a series of hypotheses are to be tested.

**Results**: Lonely people tend to be hyper-vigilant for social threats. This hyper-vigilance may drain a parent's self-regulatory resources, potentially resulting in more harsh and erratic parenting. Additionally, lonely parents may not derive the same reward from positive interactions with their child/-ren and consequently, warm and responsive parenting may not be positively reinforced.

**Conclusions**: Parents with ID are often assumed to lack parenting skills. However, parents typically know more parenting than they use. Stress impairs self-regulation, and self-regulation is key to translating knowledge into action. Addressing loneliness may enable parents with ID to apply the skills they possess more consistently.

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## DEMONSTRATIONS

### 5814 | Assistive creative technology at Wac arts: How to deliver innovative technology and digital arts project with people with IDD

C. Mollet; T. Edwards; L. Elliott-Graves

*Wac Arts, UK*

**Background**: Wac Arts is a centre of excellence in performing arts and media. We use innovative technology including Touchboards, Soundbeams, Skoogs, Beamz and specialist software in order to include even the most isolated or hard to reach participants with IDD in our activities. We often adapt existing technology by creating what we call Assistive Creative Technology (ACT) systems.

**Method**: We delivered fun activities that brought the participants together and gave them ownership over the process and the outcome. Rather than seeing technology as something that isolates individuals and shuts down communication, we used it to bring participants together, enhance collaboration and support the communication of our young people in all our projects.

**Results**: We presented a video of the wide range of activities we have developed such as ipad orchestras, 360 film projects, live radio broadcasts and green screen films.

**Conclusions**: By presenting the unique ways in which we use technology at Wac Arts, we aimed to teach other practitioners with little or no experience in this area how to develop similar activities with people with IDD by using technology (even a single ipad or tablet) to enhance communication, participation and ownership for people with IDD through creative activities.

### 5479 | Online learning intervention 'Psychotropic drug: changing views, changing actions'

J. Jonker

*Centre for Intellectual Disability and Mental Health, Assen, The Netherlands*

**Background**: This demonstration will show the online learning intervention 'Psychotropic drug: changing views, changing actions', based on four case studies in the field of Intellectual Disability (ID) mental health care. The intervention starts with the presentation of the case and is followed by questions and feedback to provide insight into the actions of users. This intervention was developed for the study 'Psychotropic drug knowledge of direct care staff of people with ID'. Previous studies showed that knowledge of direct support professionals regarding psychotropic drugs was related to the appropriate use of psychotropics of their clients. In addition, a recent study showed that the knowledge of direct support professionals was insufficient and they needed more training on psychotropic drugs. This intervention was developed to improve the knowledge of direct support professionals.

**Conclusion**: Participants of the demonstration will learn how direct support professionals can improve their knowledge of psychotropic drugs and how they can apply the knowledge in their own daily practice. The learning intervention can be used in organizations for people with ID to improve the knowledge of direct support professionals and to facilitate appropriate drug use of people with ID.

### 6069 | Achieving global citizenship – co-production and inclusiveness

V. Kalopisis; T. Doukas; S. Duffy

*Citizen Network international, http://www.citizen-network.org, Athens, Greece*

**Background**: Citizen Network is an international movement, established in 2016 to bring together people and organisations that want to create a world where everyone matters, where everyone can be a citizen. We believe that Citizenship and the acceptance it brings can be the key to truly belonging, being valued and living a meaningful life. As members of Citizen Network, we share resources, learn from each other and work together to create new projects, research and campaigns. But above all, we commit ourselves to behave and act as citizens, cooperating and taking responsibility for the communities in which we live. Citizen Network operates in Greece since 2017. In a long period of socioeconomical crisis, we want to bring together all the great people out there who are doing brilliant work under adverse circumstances and advance citizenship for people with disabilities and for the many others who face oppression, stigma and exclusion. Our aim is to recognise, connect and support positive innovation and be more effective in advocating for these changes within Greek society.

**Method**: In the context of the IASSID Conference, we will have the chance to present to a wider audience some of these positive initiatives, which create a new space for dialogue, acceptance and coexistence, such as: Puzzle –A social enterprise aiming to bring a breath of fresh air in the field of social care provision in Greece (http://puzzle-se.eu/). Myrtillo – A cafeteria and arts centre which is an innovative self-supporting business and training entity, where all employees –with or without disability-are jointly responsible for its viability (http://www.myrtillocafe.gr/). SKEP

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– A nongovernmental organisation of self advocates implementing disability awareness programs through experiential learning (http://www.skep.gr). I-living – A group of self advocates promoting the Independent Living philosophy in Greece (https://www.facebook.com/gr.iliving/). Margarita – An innovative vocational training centre, which opens the way for the integration of people with intellectual disabilities into the labour market (https://www.eeamargarita.gr/en/). In addition, people who have experienced social isolation will take the floor to showcase that they have the right to be treated as citizens and that they can make a positive contribution to our communities. Together we change attitudes, fight against ignorance, stereotypes and prejudices and cultivate respect, solidarity and belonging.

## 5931 | Storysharing®: Helping people with complex communication needs to tell their personal stories

K. Bunning; J. Harwood; N. Grove

*University of East Anglia, UK*

**Background**: This demonstration explored a narrative-based intervention called Storysharing® that is concerned with the development and sharing of personal stories.

**Method**: A mixture of video presentation and discussion formed the main content.

**Results**: Storysharing® offers a refreshing perspective on how to support people with severe-profound intellectual disabilities. It moves beyond basic functional communication and focuses on supporting the telling of personal stories.

**Conclusions**: We all share personal stories with the people around us – both the inconsequential happenings and remarkable things that happen to us – on a daily basis. In fact personal stories make up about 65% of everyday conversation, but where are the stories of people with restricted communication skills associated with intellectual disability? This presentation demonstrated how Storysharing® provides new options for individuals functioning at the early stages of communication development that promote: a sense of self through recall and re-enactment of experiences; interpersonal relations with the people who matter in their lives; and inclusion in their local communities.

## 5400 | Guided by scent

M. van Welbergen; M. Waanders

*Bartimeus, The Netherlands*

**Background**: Smell is a mostly forgotten sense. We all use it every day, but we're often not aware during the act. And what if you have intellectual and sensory disabilities?

**Method**: In our demonstration, we will tell you about scent. There are many ways in which the daily life of people with multiple disabilities can be supported by the use of scent. For example, scent can be used to give a secure feeling, enhance their alertness, help them recognize a certain person, a special room or a special activity, and bring joy. In our presentation we will explain about this, and let you experience scents. You will receive practical information about how to use the olfactory sense in daily practice.

**Results**: We will tell you about our project with people with deafblindness and their use of scent. About a young man who uses the smell of rose oil to improve his sleep pattern, and another man who has grown his own herbs to use them with cooking.

**Conclusions**: We hope to inspire you to start using the sense of smell to support persons with intellectual and sensory disabilities.

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# ABSTRACTS

## ROUNDTABLES

### 5696 | Working together for change: what does it take to make social practices more inclusive?

V. Williams; B. Tarleton; S. Dowling

*Norah Fry Centre for Disability Studies, University of Bristol, UK*

**Background**: This roundtable is about practices involving people with IDD, exploring vignettes from 'Getting Things Changed', a multi-strand research project about the gap between policies and practices.

**Method**: Examples will focus on (1) managing everyday life, (2) becoming a musician, and (3) receiving support as a parent. We will first present some of our ideas about social practices, how they come to 'misfit' people with IDD, and conversely how they can be changed to become inclusive. The roundtable will be open to researchers or practitioners from any country, and we welcome people with IDD themselves; we will engage the audience directly to explore your own solutions in some of the areas we have researched. Our roundtable will use video extracts and 'acted' vignettes from our research, based on our experience of working with actors with IDD. Participants will be asked to reflect on the ways in which their ideas can be used to make changes in their own countries.

**Conclusions**: We wish to take forward the ideas and findings of our research, to stimulate creative thinking about how people with IDD can re-shape the way things get done.

### 5894 | Special Olympics' role measuring social inclusion and attitudes towards people with intellectual disabilities

A. Shellard; R. McConkey

*Special Olympics International, Washington, DC, USA*

**Background**: Special Olympics seeks to create change by being a driving force for social inclusion, meaning that communities are inclusive for everyone, including people with intellectual disabilities (ID). For the past 50 years, Special Olympics has made critical strides towards breaking down these barriers for people with ID. As Special Olympics celebrates its 50th anniversary and enters its next 50 years, we want to work towards a tipping point for creating inclusive communities.

**Method**: Special Olympics representatives, research partners, and members of Special Olympics' attitudes research advisory committee will share Special Olympics' current work in measuring social inclusion and attitudes towards people with ID.

**Results**: The audience will discuss how Special Olympics and IASSIDD can work together to create a research agenda that leads to broader inclusion.

**Conclusions**: With 5.7 million athletes with ID and Unified Partners, and more than 1 million volunteers, Special Olympics has the potential to contribute to the field through its research and evaluation efforts. This discussion will help Special Olympics and IASSIDD activate their partnership with a mutual goal of improving social inclusion of and attitudes towards people with ID.

### 5601 | A consensus statement on how to conduct inclusive health research – how to move forward?

T. Frankena; T. Buchner; C. Linehan; P. Embregts; R. Northway; E. Joosa

*Research Group Intellectual Disabilities and Health, Radboud University Medical Center, The Netherlands*

**Background**: Individuals with intellectual disabilities (ID) seek their right for participating. As a result, research in the field of ID requires discourse about their position as participants and informers.

**Method**: A consensus statement on inclusive health research was developed by 40 experts with, and 17 experts without ID in three consecutive rounds: (1) an initial feedback round, (2) a roundtable discussion at the 2016 IASSIDD World Congress, and (3) a final feedback round. The statement provides researchers with guidelines regarding attributes, potential outcomes, reporting and publishing, and future research directions, for designing and conducting inclusive health research. The roundtable will comprise three parts: (1) the statement and its practical application, (2) researchers with and without ID will have the opportunity to share their current and future inclusive studies, and (3) the discussion will be opened on how inclusive (health) research can move towards a more collective approach.

**Conclusion**: This roundtable presents the consensus statement and its practical application. It provides inclusive researchers the opportunity to share their experiences and initiate discussion on how to move towards continuous global discourse. It aims to jointly identify how inclusive research can establish an ongoing international working group.

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## 6067 | Creating knowledge

S. Sergeant; H. Peels; E. Joosa; A. Schippers; G. Van Hove

*Disability Studies in the Netherlands, The Netherlands*

**Background**: The action-oriented nature of Disability Studies asks for sound, solid and inclusive methods for gathering scientific data. Research shows that people with intellectual disabilities – and with them many more people – profit from creative, non-verbal ways to express their thoughts, opinions and experiences. These data however, and the methods in which they are gathered, are still too often deemed 'odd' in mainstream science. In this roundtable we would like to discuss how we could actively make creative methods of data gathering more broadly accepted. Possibly we invite more presenters to our Roundtable.
**Method**: The presenters will use the data to prepare a statement on the use of creative methods, following the principles of Universal Design for Learning.

## 5556 | Reflections on the development of QOL and FQOL

R. Brown; I. Brown; A. Schippers; R. Faragher

*IASSID Academy, Canada*

**Background**: Quality of Life (QOL) within IDD has been studied for just over 50 years. Principles, assessments, and strategies have been documented in considerable detail, and provided indicators for practice. QOL is being raised in relation to children's education. Family Quality of Life (FQOL) research has underscored the plight of many families with children around the world. Critical lifespan issues are emerging in the translation of such research into practice, and represent challenges for frontline personnel.
**Method**: Three speakers briefly outline the challenges and suggest possible action. The chair poses questions to the speakers followed by open discussion; What are the current issues in QOL/FQOL? What are the dilemmas facing frontline practitioners and primary carers? How can research and clinical knowledge be put into practice at the frontline level? What challenges arise in terms of knowledge generation and transfer? Discussion is encouraged on marginalized groups around the world. To what extent are the QOL challenges in IDD common to related disabilities and families facing distress?
**Results/Conclusions**: The presentations and discussions are recorded and expect to be published for the use of those involved in transfer of knowledge and practice.

## 5748 | Inclusive education of persons with intellectual disabilities in schools in Europe: state of the states

T. Buchner; D. Corby; S. Thompson; M. Shevlin; H. Goll; J. Šiška; M. O' Donovan

*University of Vienna, Austria*

**Background**: Inclusive education in schools can be considered as one of the core aims of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Thus, over the course of the last years, most European states took serious efforts to make their education systems more inclusive (Smyth, Shevlin, Buchner et al. 2015). However, it remains unclear how far these processes have developed on a European level, especially in relation to children and young people with intellectual disabilities.
**Method**: Hence, the roundtable will map figures and recent developments in the field of inclusive education of students with intellectual disabilities in schools in different European countries.
**Results**: Scholars from different European countries will present statistical data on inclusive education in schools (primary to secondary education second stage), support structures in inclusive education settings and recent policy developments in the field.
**Conclusions**: Participants in the audience will be encouraged to report on the status quo, policy and practice in their own countries, in order to create a mapping on developments across Europe.

## 5618 | Post- secondary and third level education for people with intellectual disabilities

D. Corby; T. Buchner; S. Thompson; M.-A. O'Donovan; W. Plaute

*School of Nursing and Human Sciences, Dublin City University, Ireland*

**Background & Method**: A vignette will be presented on the approach the Republic of Ireland, Canada and Austria take to the inclusion of people with intellectual disabilities in post-secondary and third level education with a brief explanation of the policy position and programme examples. A panel will initiate audience discussion to gain an understanding of the approaches taken in different countries to create inclusion at this level of education. This discussion is important as countries need to adopt the principles associated with education for people with disabilities under the United Nations Convention on the Rights of Persons with Disabilities, and (UN General Assembly 2007). There is also a moral imperative for people with intellectual disability to be included in education (Uditsky and Hughson 2012), which is linked to social transformation and equality (Centeno 2012). By sharing experiences across different countries participants can learn from each other and use this knowledge to advance opportunities in their own countries. Participants will be encouraged to discuss both policy and practice.

**Contribution**: We expect to exchange information and encourage participants to consider contributing to a paper which maps the situations across European countries regarding the Inclusion of people with intellectual disabilities in education at this level.

## 5554 | Mathematics education for learners with Down Syndrome

R. Faragher; E.G. Clemente; E.M. Martinez; T. Rieckmann; A. Zimpel

*The University of Queensland, Australia*

**Background**: Recognising the difficulties that people with Down Syndrome have in dealing with numbers, some researchers have explored the topic from a mathematics education perspective.
**Method**: The researchers participating in the Roundtable have undertaken studies that involve changes at three levels: (1) in the goals of teaching, moving from functional to formative ones; (2) in the content chosen, broadening the field of mathematics teaching to include geometry and algebra that appear to be more suitable to the cognitive profile of people with Down syndrome; finally (3) in the use of methodologies that enhance mathematical thinking and move away from pure mechanization in the search of deeper understanding.
**Results**: All these studies share an optimistic view of the power of mathematics to develop thinking skills. The inclusive approach to teaching mathematics is fundamental for these studies, as it gives the motivation to the students and to the teachers, to work on the same topics as the schoolmates with required adjustment.
**Conclusions**: The presentations will give a brief overview of new directions in mathematics education research in the field of Down syndrome. Discussion will solicit audience views on the research and implications for practice. Potential outcomes include further research and international collaborations.

## 5994 | Working with children and families with intellectual disabilities – addressing mental health through multidisciplinary approach

N. Sheppard; E. Zacharia

*Tavistock and Portment NHS Foundation Trust, UK*

**Background**: In MOSAIC CAMHS we offer specialised CAMHS for 0–18 year olds, living in a borough in London, UK who have a significant disability. The service aims to improve the emotional health and wellbeing of children, young people and their families. There is a skilled workforce of doctors, nurses, psychologists, family therapists, psychotherapists, and social workers employed in the public sector. We offer assessments and treatment for emotional and behavioural difficulties in childhood and adolescence.
**Method**: This proposal concerns a roundtable presentation where 3 MOSAIC CAMHS clinicians from 3 different disciplines (Psychology, Psychiatry and Child Psychotherapy) will discuss different interventions with families using clinical examples. We wish to present our specialized service to other professionals, to share and exchange experiences, successes, and dilemmas in working with children with disabilities who struggle with emotional and behavioural difficulties.
**Conclusion**: We hope to show that our multidisciplinary way of working enriches our understanding of mental health and disability and contributes to offering a service that is thoughtful and respectful of individual needs. We also hope to open up a discussion about the specificities of working with this population and exchange experiences with professionals internationally who are working in or are interested in setting up similar services.

## 5714 | What can mortality data tell us about health inequalities at end of life?

P. Heslop

*University of Bristol, UK*

**Background**: Mortality data can provide important insights about the end of life care needs of people with intellectual and developmental disabilities (IDD). Information relating to causes of death, place of death, care home use at end of life and other indicators can help with the planning and delivery of services and can support local drives towards improving end of life care. This discussion will focus on what mortality data tells us about the end of life care in Wales and Ireland.
**Method**: Stuart Todd from Wales, using UK population based data, will consider the links between the nature of death and place of care for people with IDD, and the implications of this, for end of life care provision. Mary McCarron will draw on Irish Data from IDS TILDA to present information on approximately 100 older adults who have died across the first 10 years of IDS TILDA.
**Conclusion**: The roundtable will discuss what the findings from these studies suggest about improving end of life care for people with IDD, and will draw on the experiences of attendees in how to optimize end of life care for this population.

## 5670 | Update on what we know about mortality of people with intellectual and developmental disabilities

P. Heslop

*University of Bristol, UK*

**Background**: Our understanding about inequalities in mortality of people with intellectual and developmental disabilities (IDD) is

growing, although still in its infancy. The last decade has seen an increase in our understanding about age and cause of death, and the reason for disparities between people with IDD and the general population. This discussion will update our knowledge about the age and cause of death of people with IDD in Canada, the Netherlands and England.

**Method**: Shahin Shooshtari will present population-based mortality data (2013–2015) for a cohort of 8,629 people with IDD living in Manitoba, Canada. The mortality rates and most common causes of death compared to the general population will be presented and discussed. Maarten Cuypers from the Netherlands will present Dutch population based mortality data (2012–2016) about people with IDD compared to matched cases from the general population. Pauline Heslop will present data about the deaths of people with ID in England, identified through the national mortality review programme.

**Conclusion**: The roundtable will discuss the similarities and differences across these countries and some of the potential reasons for this, with a particular focus on what the data tells us about potential areas for improving the health and care of people with IDD.

## 5463 | Clinical effectiveness of staff training in positive behaviour support

A. Hassiotis; I. Hall; V. Cooper; M. Poppe

*UCL Division of Psychiatry, UK*

**Background**: This is one of two roundtables that will discuss psychosocial interventions for challenging behaviour in adults with intellectual disabilities (ID). Challenging behaviour is not only common in about 20% of individuals but has significant consequences for the person and his/her family carers. It is also costly and there are several debates as to how it best understood and managed. Positive Behaviour Support is an internationally utilized psychosocial intervention and we believe that our work will be of interest to many researchers worldwide as there are implications for delivery and policy.

**Method**: The audience will be engaged via Q&A in response to the presentations which will be based on the clinical effectiveness findings of the trial and a parent perspective. The audience will have the opportunity to reflect on the practice as this is available in each of the participants' countries in planned exercises/group work.

**Conclusion**: The roundtable is directly relevant to the congress themes of inclusion and diversity as those adults who present with challenging behaviour are some of the most excluded in society. By sharing, learning and evidence-based practice, the panel will give participants motivation and knowledge about how to pursue similar work in their own settings and services.

## 5464 | Process evaluation, costs and interventions for challenging behaviour

A. Hassiotis; J. Crabtree; A. Bosco; S. Ailey; R. Hunter

*UCL Division of Psychiatry, UK*

**Background**: This roundtable will present service and patient perspectives on the delivery of the intervention (staff training in positive behaviour support), the costs associated with interventions and will also showcase a new ongoing investigation using a different psychosocial intervention based on problem solving. As before the perspectives are multi-professional and will add significant new knowledge to what is already known about challenging behaviour and related research.

**Method**: The audience will be engaged via Q&A in response to the presentations which will be based on cost and delivery/implementation findings of two interventions. We also plan to hold group exercises to draw on participant experience and expertize.

**Conclusion**: The roundtable is directly relevant to the congress themes of inclusion and diversity and gives an international perspective on the adaptation or development of theory driven interventions, which are at the heart of first response to challenging behaviour. By sharing insights with the panel members, the audience will gain knowledge of the barriers and facilitators in intervention delivery in routine care.

## 5419 | The controversy in prescribing psychotropic drugs for challenging behaviour

G. de Kuijper; A. Hassiotis; J. de Jonge

*Centre for Intellectual Disability and Mental Health, The Netherlands*

**Background**: The prescription of psychotropic drugs in people with intellectual disability (ID) and challenging behaviour (CB) is controversial. Approximately 45% of adults and children receive medication, which is twice the range of people with a diagnosis of mental disorder. In daily practice many clinicians struggle to comply with guidelines to discontinue long-term psychotropic drug use in this indication, when presented with their own or caregivers' experiences of behavioural changes during and after discontinuation. Points of view may differ between professionals and caregivers how to interpret and manage these changes. It may be difficult to balance between the need for ongoing psychotropic drug administration and the health risks as a consequence.

**Method**: These controversies will be assessed by discussing four statements on conditions that may legitimize psychotropic prescribing, presented by a psychiatrist and a social worker from two different European countries. Parents are explicitly invited to join this roundtable and contribute to the discussion.

**Conclusion**: This discussion will add to a more nuanced approach on long-term off-label psychotropic use, in cases of psychological or

behavioural symptoms which cause burden to the client, and paid or family caregivers.

## 5453 | Researching and organising practice leadership

P. Björne; R. Deveau; J. Beadle Brown; B. Murphy

*City of Malmö, Sweden*

**Background**: The quality of services for persons with severe and multiple IDD and challenging behaviours depends on organizational factors, such as the provision of practice leadership. Implementation of research and best practice has been shown to be difficult to maintain, especially when the everyday work providing support and service is not directed.

**Method**: The roundtable proposes to discuss the following questions together with the audience: (1) How do we organize services for persons with the greatest needs? (2) How are the practices led, direct care staff supported, feedback given on practices, skills developed and maintained over time? (3) Is the leadership congruent with how the services are organized and the expected outcomes? (4) How could research explore this congruence, e.g. through observation? (5) How could research inform the development of evidence based practices, service and leadership organization, e.g. through practice feedback?

**Results**: This symposium will explore different research approaches and organisational development of practice leadership, and aims at delineating some of the more pressing research areas in the field of leadership in services for persons with severe and multiple disabilities.

**Conclusions**: It is of importance to pool research findings with practitioners' experiences, in order to develop applied research programs.

## 5885 | Facilitating the development of community based services in Europe: the role of research

J. Beadle-Brown*

**University of Kent, UK; La Trobe University, Australia*

**Background**: Unlike earlier waves of deinstitutionalisation, current programmes in Europe are often funded by EU, are externally advocated and predominantly human-rights driven but with little information on implementation and impact. Contribution to scientific and applied knowledge. This discussion will explore how researchers can support the movement towards community living. Who will be involved? The roundtable will be facilitated by members of the Comparative Policy and Practice SIRG.

**Methods**: Agnes Turnpenny will provide an overview of deinstitutionalisation programmes in Central and Eastern Europe; Gabor Petri will present findings from an evaluation of the deinstitutionalisation programme in Hungary; and Christine Linehan will provide an update on the transformation of intellectual disability services in Ireland. How audience will be engaged in discussion? The audience will be invited to share experiences of how researchers have been involved in promoting community living as well as ideas of how the SIRG could influence practice in this field. What the discussion will achieve? This discussion spans the topics of policy and practice, quality of life and living with a disability. The discussion will inform the activities of the CPP SIRG.

## 5887 | Mapping the situation of people with IDD – how can we better support the implementation of the UN CRPD

J. Beadle-Brown*

**University of Kent, UK; La Trobe University, Australia*

Why this discussion is important to the field of ID Since the adoption of the UNCRPD in 2006, a number of large comparative studies have highlighted the lack of available data on the situation of people with disabilities. Issues such as lack of agreed terminology on service types has also made comparative research challenging. Contribution to scientific and applied knowledge. It is hoped this discussion will lead to the development of country-specific maps useful for researchers, policy makers and campaigners. Who will be involved? The discussion will be facilitated by members of the Comparative Policy and Practice (CPP) SIRG. Short presentations by members of the SIRG (Julie Beadle-Brown, Jan Šiška and Christine Linehan) will provide some context. How the audience will be engaged in discussion? The audience will be invited to share any research that might be useful in mapping the situation of people with IDD, and their views on how the SIRG could produce and maintain maps of the situation in different countries. What the discussion will achieve? The discussion will inform the work programme of the SIRG. Information generated could form a useful source of evidence with which to monitor the implementation of the CRPD.

## 5790 | Getting your research published: guidance to make the process more efficient

B. Salmons; J. Rose; A. Langa

*International Journal of Developmental Disabilities (IJDD), Singapore*

**Background**: The International Journal of Developmental Disabilities (IJDD) is a leading publisher of papers contributing to the enhancement of the lives of those with intellectual disabilities (ID). The journal was founded in 1952 by Herbert C. Gunzburg, an early pioneer in ID, as a regional journal which then grew to become the British Journal. More recently, it was renamed the IJDD to acknowledge

its global reach. Currently, the journal is published by Taylor and Francis. The aim of this roundtable will be to help demystify publication in any journal.

**Method**: A brief presentation will be made on getting a paper published in a peer reviewed journal with examples of different types of articles (i.e. regular research manuscripts, review papers) and their journey from pre-submission to publication. Perspectives of guest editors for special issues will also be presented.

**Results**: The submission process and the practice of peer review will be discussed in an interactive manner and guidance will be provided on engaging with a journal editor in general when submitting papers to any journal, as well as how to accommodate the reviewers' requests and comments.

**Conclusions**: The steps needed to achieve successful publication in an ethical fashion also will be described.

## ROUNDTABLE DISCUSSION

### 6070 | Using research & innovation to turn disability policy into practice: shaping a joint research agenda through multi-stakeholder collaboration

A. Kadyrbaeva

*European Association of Service Providers for Persons with Disabilities, Brussels, Belgium*

**Description**: Evidence-based policies, demand-driven research and knowledge-based practices are concepts that are essential for delivering high quality social care & support services for persons with disabilities, including IDD. They, however, require a high level of collaboration and coordinated work by all actors, e.g. service users & families, service providers, policy practitioners and researchers. The discussion will focus around the question of how to make such collaboration work in a sustainable and effective way. Service providers' representative (EASPD), will start the discussion by presenting the sector's research needs and well as its newly established network "European research platform for inclusive community planning and service development for people with disabilities (EURECO)." Other stakeholders (service users, researchers, other service providers, policy practitioners) will engage in a discussion by sharing their perspectives on opportunities/challenges/future path for a platform such as EURECO and contributing ideas to shaping a common research agenda and concrete collaboration projects.

**Contribution**: Expect outcome of discussion: raising awareness of the needs, expertise and expectations of different stakeholders on research & innovation in inclusive disability services; encouraging to join the EURECO network to push for more international collaboration & knowledge exchange to facilitate translation of research into practice.

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## POSTER PRESENTATIONS

## SESSION 1: "INCLUSION & BELONGING" & "HEALTH & BEHAVIOURAL ISSUES"

### 5624 | Autism, attachment and parenting: means of establishing belonging to the family

A. Stefanaki; A. Gena
*UK*

**Background**: Attachment experiences are critical for human emotional and cognitive development. Children with Autism Spectrum Disorder (ASD) have severe and pervasive impairments, which may affect the attachment relationships with their parents. The aim of this study is to investigate the attachment patterns of both mothers and fathers with their children with ASD in a natural setting and to suggest a parent training program based on behaviour analytic strategies that focus on promoting the quality of parent-child interactions based on information pertaining to their attachment patterns.
**Method**: The sample of this study will include six families that have a child diagnosed with ASD. The children's age will range from four to six years. Parents will complete questionnaires focusing on the attachment, their parenting style, parenting communication and stress. In addition, their interaction with their children -through play in a home setting - will be observed and videotaped.
**Results**: A multiple-baseline design will be used and the results are expected to reveal how parents understand their child's attachment signals and will be taught to use them to improve parenting skills.
Poster presentation – research report

### 5680 | Social networks and the lives of people with IDD: a thematic synthesis of current literature

R. Harrison; R. Forrester-Jones; M. McCarthy
*UK*

**Background**: Diverse social networks support individuals' wellbeing and inclusion. In the light of current austerity policies across Western economies, a systematic literature review was undertaken to ascertain the factors that influence the social networks of people with IDD in the UK in order to inform policy and practice.
**Method**: A systematic review of UK-based papers was undertaken. 18 articles relating to people with IDD were studied in relation to the effects of social networks on wellbeing and inclusion.
**Results**: Strong, stable social networks positively influence wellbeing and inclusion. Factors such as living in the community and regular access to community-based activities do not necessarily appear to influence the wellbeing and inclusion of people with IDD in terms of social networks. Policy does not in itself effectively address the building or maintaining of social networks and the interpretation of policy by support staff often entrenches exclusion.
**Conclusion**: This review highlights the continuing importance of social networks in the lives of people with IDD and the need for further discourse and research on the ways in which social networks can be built and maintained.

### 5692 | Supported loving: building an international network

C. Bates
*UK*

**Background**: Supported Loving is a national network of people with and without intellectual disabilities (ID), it was established following a PhD study highlighting how people with ID often need support to develop and maintain loving relationships. Our aim is to explain about the network, generate international interest and strengthen the network.
**Method**: Supported Loving was formed in February 2017 and is a thriving network, with over 150 members across the UK. Our members come from diverse backgrounds including self-advocates, academics, social care, sexual education and health service. We hold quarterly network member meetings, comprising of a mix of presentations, discussions and practical exercises.
**Results**: The network has featured on mainstream news outlets including a short film on UK's Channel 4 and BBC radio and at academic conferences. The Network generated interagency with shared expertise to solve issues. The network provides a supportive space for researchers to discuss their research. Network members have a committed approach to improving support in this area and this is evident in changes in practice, developing new policies or proving training to staff and people with ID.
**Conclusion**: The network enables researchers to share findings directly with staff which assists in facilitating changes to direct practice.

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## 5722 | Diversified language program leading to communicative fluency and social inclusion

M. Bardounioti; K. Bertou; D. Rodopoulou; E. Tsirempolou; A. Gena

*National and Kapodistrian University of Athens, Institute of Systemic Analysis of Behavior, Greece*

**Background**: One of the most crucial deficits of children with ASD is language impairment and difficulties in social interaction, affecting child's adjustment in family environment and school context.
**Method**: A diversified curriculum was applied using behaviour- analytic techniques that involve a great number of goals oriented to facilitate language expression skills in a 4 year-old girl diagnosed with ASD and severe language deficits. Specifically, the intervention aimed to enhance the production and comprehension of oral speech, to develop descriptive language and to increase communicative initiatives.
**Results**: Therefore, using a diversified curriculum attributes to surpassing severe language deficiencies in children with ASD, leading to successful communication with other children and inclusion in mainstream schools.
**Conclusions**: These preliminary findings may be useful in designing short-term individualized treatment plans aiming to improve language deficits in children with ASD.

## 5728 | Teaching social skills to a child with ASD as a means of belonging to group of peers

I. Batistaki; E. Tsirempolou; A. Gena

*National and Kapodistrian University of Athens, Greece*

**Background**: A considerable body of research has demonstrated impairments in social and communicative abilities as well as difficulties in making friends among children with ASD. These impairments have been linked to children's difficulty to form relationships. The study aims to assess and teach social skills to a child with ASD such as emotion expression and cooperative play.
**Method**: Social skills have been taught in a child with ASD in a multiple-baseline design across response categories.
**Results**: It is anticipated that reinforcement; prompting and modelling would be effective in teaching social skills.
**Conclusions**: Teaching social skills may be viewed as a factor that leads to successful communication with other children and belonging to peer groups.

## 5990 | A study to approach and enhance social interaction to children with autism through athletic activities

K.H. Autismos Kastoria; S. Kuriaki; K. Chrysoula; K. Kalliroi; K. Sofia; L. Chrysa

*Nikolaidi, Greece*

**Background**: In this paper, we present an event that was being held for the last four years (2014–2017) in the Day Centre for Children, adolescents and young adults with autism of municipality of Kastoria due to the World Autism Awareness Day (2nd of April).
**Method**: In particular, the Centre organized athletic activities for children with autism and their classmates and the event, was being evaluated per year, by the teachers involved through the completion of a questionnaire. The events created in order to examine the luck of social integration students with autism face and the goals of the athletic activities were a. to evaluate the percentage of satisfaction of the students who took part in the activities, b. to collect data regarding the reasons the students without autism decided to participate and c. to estimate the resonance the organization created to the students that participated.
**Results**: The results showed that children without autism that participated for four years were quite satisfied (75%) and the amount of students involved was highly increased every year. With the completion of the event, students comprehend the social difficulties children with autism have to face along with their effort to integrate in their social environment.

## 6011 | I'm flying too!

A. Gena; K. Giannoulis; C. Panagiotakou; A. Drosinou; A. Kentikeleni; I. Porfyris

*National and Kapodistrian University of Athens, Greece*

**Background**: Air travel can be a stressful experience for children with Autism Spectrum Disorder (ASD) and their parents. The current psychoeducational programme is an innovative, collaborative initiative among the Onassis Foundation, Athens International Airport and the University of Athens.
**Method**: The programme aims to familiarise youngsters with ASD with the multitude of procedures involved in air travel and to desensitize them to the anxiety they invariably experience in airports, because of the many sensory challenges found therein. The youngsters' families will be involved in every step of the project.
**Results**: The programme incorporates a number of interventions known to be effective in autism care. The interventions include innovative Social Stories, an individualized desensitization programme for each youngster coupled with graded exposure to target air travel-related anxiety. The programme includes a practice test run at the airport, before culminating in an event held at the airport in

which participants will board an airplane and observe a cockpit without actually flying.

**Conclusion**: Our contribution is threefold: 1) to desensitize youngsters with ASD with steps involved in air travel, 2) to educate stakeholders including airport staff and raise their awareness of ASD and 3) to create relevant resources, including information pamphlets and social stories.

## 5905 | The effects of modified Yoga programme on attention, flexibility and posture in persons with Intellectual Disability (ID)

A. Ramachandran; M. Anthonysamy

*Movement for the Intellectually Disabled of Singapore, Singapore*

**Background**: Attention, flexibility and posture are some of the challenges faced by persons with ID as they lack temporal and spatial orientations. There is evidence of yoga contributing to improvements in kinesthetic control and attention in typically developing children as well as those with autism. However there is paucity of studies exploring these effects in persons with ID. The aim of this study is to understand the effects of modified yoga programme in improving the attention span, posture and flexibility in persons with ID.

**Method**: A single blinded quasi experimental study design. 20 persons with intellectual disability will be included based on their adaptive functioning level. Video guided analysis during classroom performances, postural assessment and finger to floor test for posture and flexibility respectively are used to establish baseline and assess post-programme outcomes.

**Results**: The study is ongoing and the findings will be presented at the conference.

**Conclusion**: The findings of the study could have implications to incorporate yoga as part of the training programme and/or as an intervention strategy.

## 5764 | Coaches are the jam in the sandwich in a PBS workforce development framework

S. Leitch

*British Insititute of Learning Disabilities, UK*

**Background**: This poster presents a snapshot of our experiences of working with more than 100 organizations to support the implementation of Positive Behaviour Support (PBS). It includes findings from an independent evaluation. The UK government promotes PBS as best practice for supporting people with Intellectual Disabilities (ID) and behaviour that challenges. This is welcome but also challenging. Workforce development programmes need to support large numbers of staff and different service structures and be cost effective. Skills learned in the classroom have to be transferable. The models of implementation of PBIS in the US and Active Support in the UK helped us think about how a PBS competence framework could be applied and maintained in practice on a large scale.

**Conclusion**: We argue that practice leadership using a coaching model and ongoing support through communities of practice are integral to embedding developing and maintaining practice standard. We have created a workforce development framework that recognizes the significance of PBS Coaches who can support their colleagues to translate policy and expert advice into direct practice ensuring the most effective and enabling support for people with ID.

## 5718 | Sexual education of an adolescent with autism spectrum disorder and intellectual disability

M. Staveri; G. Gkogkos; A. Gena

*National and Kapodistrian University of Athens, Greece*

**Background**: Providing sexual education for youth with Autism Spectrum Disorder (ASD) is very important as it sets a foundation for social, physical, and emotional development. Yet, it is a rather neglected area because of misconceptions about the sexual needs of people with ASD. The aims of this study were: (a) To apply an individualized sexual education program to an adolescent with ASD, (b) to assess the effectiveness of behaviour analytic procedures, such as prompting, and reinforcement contingencies in acquiring appropriate sexual behaviour and (c) to examine the effects of improved sexual behaviour in decreasing problem behaviour.

**Methods**: Principles and therapeutic procedures that derive from the Applied Behavior Analytic model (Discrete trial teaching, Shaping, Task analysis, Prompting procedures, Reinforcement contingencies).

**Results**: 100% appropriate responding across all three response categories.

**Conclusion**: With the introduction of intervention, there were rapid changes in all target responses in the desired direction. Further research is needed on systematic replication with additional participants and extension of the intervention procedure to female participants.

## 5701 | Fruit and vegetable intake of children and adolescents with moderate to severe intellectual disability

M. Wouters; H. Evenhuis; T. Hilgenkamp

*Reinaerde, Utrecht, the Netherlands Intellectual Disability Medicine, Department of General Practice, Erasmus MC University Medical Centre Rotterdam, The Netherlands*

**Background**: The purpose of this study was to determine the fruit and vegetable intake of children with a intellectual disability, and to study its relation with overweight.

**Method**: Participants were 128 Dutch children (83 boys, age 2–18 years) with moderate to severe ID attending specialized day care centres. Parents were asked to answer questions about the vegetable and fruit intake of the children, weight status was based on measured BMI. Descriptive statistics were used to compare the intake with the Dutch guidelines for daily recommended intake and with the intake of typically developing children. The association between nutritional intake and weight status was calculated using Chi square test.

**Results**: For 104 participants the questions of fruit and vegetable intake were answered. According to the guidelines, 67% [56–75%] of the participants ate sufficient fruit and 23% [15–32%] ate sufficient vegetables. Comparing to the general population, this percentage is higher for fruit intake and comparable for vegetable intake. No association between intake and overweight was found.

**Conclusion**: Many children with moderate to severe ID do not eat enough fruit and vegetables, in particular the number of participants eating sufficient vegetables was very low. Therefore, vegetable intake should be the focus of interventions.

## 6037 | Prevalence of dementia in old persons with down syndrome and other intellectual disabilities

R. Kuwano; S. Terada; S. Takeshita; T. Inoue; A. Choju; S. Suemitsu

*Asahigawaso Medical Welfare Center, Japan*

**Background**: The life expectancy of people with intellectual disability (ID) including Down syndrome (DS) has increased dramatically in recent years. Although aging is at the highest risk for dementia, there are few cases of prevalence/incidence concerning dementia with DS and other ID in Japan. We began to estimate how many people with ID develop dementia.

**Method**: Total 244 participants who gave their written informed consent were enrolled for this study. Caregivers in the institutions gathered the data of the frequency of dementia by the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) and the doctors that diagnosed some cases where obtained from the questionnaire survey.

**Results**: All participants with ID including DS were living in full-time or daytime institutions and group homes. The median age of participants (age range: 19 to 81 yrs) was 44 yrs. We found that three people with severe ID were diagnosed with dementia and two with moderate ID were diagnosed with dementia and mild cognitive impairment. They are over 60 yrs, which is a similar age to the general population.

**Conclusion**: Further analysis is needed to determine an age at onset of dementia and the relation between dementia and the degree of ID in a large sample size.

## 5702 | Can tibia length predict actual height in children with moderate to severe intellectual disabilities?

M. Wouters; H. Evenhuis; T. Hilgenkamp

*Reinaerde, Utrecht, the Netherlands Intellectual Disability Medicine, Department of General Practice, Erasmus MC University Medical Centre Rotterdam, The Netherlands*

**Background**: The aim of this study was to determine the agreement of actual height, and estimated height from tibia length among children with moderate to severe intellectual disabilities (ID).

**Method**: Standing height and tibia length of 114 children and adolescents with moderate to severe ID (2–18 years) were measured in cm. Estimated heights were calculated using three prediction equations. Agreement between actual and estimated height was determined using absolute difference, intraclass correlation coefficients (ICC), and Bland-Altman plots.

**Results**: Absolute differences between estimated and actual heights ranged from 0.0 cm to 20.5 cm. ICCs ranged from 0.92 to 0.98. The Bland-Altman plot showed no systematic bias, but the limits of agreement were wide (±9.0 - ±17.1 cm).

**Conclusion**: Agreement between estimated height using tibia length and actual height is acceptable on group level, but on the individual level the error is too big to use in clinical practice.

## 5703 | Predicting sedentary behaviour of children with intellectual disability with a proxy-questionnaire on screen-time

M. Wouters; H. Evenhuis; T. Hilgenkamp

*Reinaerde, Utrecht, the Netherlands Intellectual Disability Medicine, Department of General Practice, Erasmus MC University Medical Centre Rotterdam, The Netherlands*

**Background**: The purpose of this study was to determine the usability of a questionnaire on screen-time to predict daily sedentary behaviour in children with moderate to severe intellectual disability (ID).

**Method**: Participants were 128 Dutch children and adolescents (83 boys, age 2–18 years) with moderate to severe ID attending specialized day care centres. Parents were asked to answer questions on the screen-time of the children, and sedentary behaviour was measured with ActiGraph GT3x+ accelerometers. Linear regression analysis was used to study the association between the screen-time (questionnaire) and sedentary time (accelerometers), corrected for age, sex and level of ID.

**Results**: Valid data on the questionnaire and accelerometer were collected for 57 children (37 boys, Age 9.2 ± 4.3 years). According to the questionnaire, the participants had 2.8 ± 1.9 hours of daily screen-time. Total sedentary time according to the accelerometer was 8.8 ± 1.5 hours a day. No association was found for screen-time and sedentary time ($\beta$= 0.026, p = .84).

**Conclusion**: A questionnaire on screen-time cannot be used to estimate the sedentary time during the day for children with moderate to severe ID.

## 5648 | The role of the learning disability coordinator in a general hospital – A reflection

M. Waight

*Health Education England, Thames Valley on secondment from Berkshire Healthcare NHS Foundation Trust, UK*

**Background**: This poster will present a reflection on the role of the learning disability co-ordinator within an acute general hospital in England following a six month placement within the service as part of the Consultant practitioner programme run by Health Education England – Thames Valley.
**Method**: It will examine the different aspects of the role including support for people with learning disabilities, their families and carers, ensuring compliance with the Mental Capacity Act including the need for reasonable adjustments to be made and ensuring that medical decisions are made in the best interest of the patient. Hospital staff, providing information and resources for medical staff within the hospital and acting as a liaison between hospital and relevant community learning disabilities staff/teams.
**Results**: It will examine the knowledge required to undertake this role. Case studies from the six month placement will be used.
**Conclusion**: Through examining the role of the learning disabilities co-ordinator the poster will look at the value of that role for people with learning disabilities when in hospital and will also question if this is purely a nursing role and how it could be developed.

## 5640 | Challenging behaviour among children with intellectual disabilities: prevalence and risk markers

D. Simó-Pinatella; C. Mumbardó-Adam

*Ramon Llull University, Spain*

**Background**: The present study aims to investigate (a) the prevalence of challenging behaviours (aggression, stereotypy, self-injury, disruption, withdrawal and non-collaboration), and (b) identify those personal and contextual risk markers, such as type of disability or place of residence and association with the occurrence of challenging behaviours in children with intellectual disabilities.
**Method**: Fifteen professionals participated by responding to two questionnaires via an interview format regarding students enrolled in a special education school (N = 205) in Catalonia, Spain. Categories of challenging behaviours were calculated across ages were explored and logistic regressions were performed to determine whether a set of independent variables predicted each of the six categories of challenging behaviours.
**Results**: Sixty percent of the sample was identified as engaging in some form of challenging behaviour. Both personal and environmental factors within this school were identified as significant predictors of at least one form of behaviour.
**Conclusion**: Findings highlight the need to invest in further research to identify personal and environmental variables that may act as risk markers for challenging behaviours. This knowledge will inform the supports provision and services customization in a specific educational setting.

## 5641 | Teachers' perspectives when addressing challenging behaviour exhibited by children with autism: what really helps?

D. Simó-Pinatella; C. Günther; C. Mumbardó-Adam

*Ramon Llull University, Spain*

**Background**: This study aims to identify (a) teachers' supports, (b) barriers to their teaching activity and management of challenging behaviours (CB), and (c) variables that could be identified as potential support that could improve their experiences.
**Method**: Ten teachers from special and mainstream schools participated in this study. We employed a qualitative phenomenological design by using a snowball sampling procedure. The sample was completed once saturation was reached. Thematic analysis was used as a method for identifying, analyzing and reporting patterns within data.
**Results**: Support in developing teachers' activities and dealing with CB involved (a) CB knowledge and management, (b) human resources and (c) school management. However, when exploring events or situations that acted as barriers, three subthemes aroused: (a) behaviour misunderstanding, (b) relationships and (c) school organization. Finally, teachers identified three main areas where more resources and time should be invested: (a) CB knowledge and expertise, (b) shared language and perceptions and (c) leadership team.
**Conclusion**: The identification of available supports and their capacity to answer to behavioural needs arise as a compulsory step to provide teachers with better CB management skills. School organization also plays a substantial role in answering to students with autism behavioural needs.

## 5998 | Risk factors of injuries experienced by adults with learning disabilities who live with paid support in Scotland

E. Petropoulou; J. Finlayson; D. Skelton

*Institute of Applied Health Research, Glasgow Caledonian University, UK*

**Background**: Risk factors for injuries and especially falls, have been extensively researched in the general population, but little is known of the extent of the issues in adults with learning disabilities (LDs).

The aim of this study was to work in partnership with service providers in the United Kingdom who have procedures in place to monitor injuries; this provides opportunity to learn about the injuries being reported and recorded and to identify risk factors for injuries.

**Method**: A longitudinal study, with both retrospective and prospective phases was conducted on 536 adults with LDs living with paid support in the community. Sixty-eight potential risk factors were examined, and potential predictors were identified using univariate analysis and entered into a multiple logistic regression.

**Results**: Incident injury was predicted by having poor balance or coordination, needing special aids in any room, receiving antipsychotics, polypharmacy, whilst having a heart condition, and living with the family, reduced risk.

**Conclusion**: These findings are first steps towards understanding the considerable burden of injuries in this population, and towards informing interventions to prevent injuries in adults with LDs in the future. A greater focus on implementing evidence based assessment tools of injuries is recommended.

## 5609 | e-Inclusion: the accessibility of online mental health interventions

L. Vereenooghe; K. Klose

*Bielefeld University, Denmark*

**Background**: Computerized therapies for mental health problems are on the rise, yet people with intellectual disabilities (ID) are often not considered as their target audience. This study explores the accessability of two mainstream online interventions, MoodGYM and GET.ON training for depression, for people with ID.

**Method**: Eight adults with mild ID were invited to review the accessibility of the interventions websites. Reviews were conducted in pairs, over two or three meetings, and recorded. Participant feedback regarding website accessibility and useability was evaluated using thematic analysis.

**Results**: Participants' reviews of the websites highlighted the need for adequate knowledge and skills to use the interventions. Emerging themes centred around understanding of the content and ability to use the interface.

**Conclusion**: The findings are discussed in light of the universal design principles for technological interventions, the frequent exclusion of people with ID from studies evaluating mainstream computerized therapies, and the recent development of interventions specific for people with ID.

## 5545 | Challenges for registered dietitians working with food related health promotion for adults with IDD in supported housing

P. Adolfsson; P. Ek; Ö. Umb-Carlsson

*Uppsala University, Spain*

**Background**: Nutritional problems are common in people with intellectual and developmental disabilities (IDD) in Europe. To counteract that the Registered Dietitians (RD) should be engaged more frequently, the aim of the study was to describe the challenges for RDs working with nutrition related health promotion for adults with IDD in Sweden.

**Method**: A web-based questionnaire with mostly open-ended questions was developed. Swedish RDs with experiences of nutrition related health promotion for people with IDD were invited to participate in the study. 54 RDs answered the questionnaire.

**Results**: Several challenges to manage nutrition related health promotion for adults with IDD in supported housing were identified: lack of common routines for RDs working in this field; the nutritional problems are often severe before RDs are consulted, the RDs have limited possibilities to make home visits to ensure that all housing staff know the instructions and implement them properly; RDs have limited opportunities to follow-up the adherence of the given guidance and RDs need more knowledge of the living conditions of people with IDD.

**Conclusion**: To meet the challenges the RDs need specific, systematic national work procedures in order to successfully promote nutrition related health of adults with IDD in supported housing.

## 5535 | Satisfaction with health care services of older adults with intellectual disabilities

L. García; P. Navas; M.Á. Verdugo; S. Llorente

*INICO, Universidad de Salamanca, Spain*

**Background**: To analyze the satisfaction of adults with intellectual disability (ID) who are aging (i.e., older than 45 years old) regarding primary and specialized medical care, and the barriers experienced when accessing these services.

**Method**: A self-designed questionnaire was administered, which collected data regarding the health status of people with ID aged 45 years old and over. A total of 1,065 relatives and/or professionals belonging to 83 Spanish organizations completed the questionnaire.

**Results**: The indication or prescription of diagnostic and therapeutic procedures was, within most used primary care services, the one that registered the lowest level of satisfaction, with an average score (out of 10) of 5.13 (SD = 3.91). Regarding the perceived barriers of these services, lack of qualified health professionals was pointed out by 62.2% of the sample. Within specialized healthcare services, psychiatry received the lowest score (M = 7.48, SD

= 2.04). In this case, 63% of individuals perceived the lack of qualified health professionals as the main barrier experienced when accessing this service.

**Conclusion**: Our findings point to the need to identify specific lines of action to improve planning of health care services, which should be focused on training professionals.

## 5511 | Poor oral health in adults with intellectual disabilities and its determinants

L. Ward; D. Kinnear; S.-A. Cooper; A. Henderson; A. Sherriff; L. Macpherson

*Institute of Health and Wellbeing, University of Glasgow, UK*

**Background**: Adults with Intellectual disabilities may experience poorer oral health and more serious consequences of it compared to the general population, but existing research is conflicting. This study investigates the extent to which they experience poorer oral health, access to preventative dental health care, and factors thought to cause poorer oral health than the general population, medication and comorbidity determinants.

**Method**: Secondary analysis of pseudonymised, individual-level data from an adult cohort with intellectual disabilities (n = 3,891), record-linked to dental treatments, medication dispensed, and primary care long-term condition data; compared with age, sex, neighbourhood area matched general population controls. Analyses using descriptive statistics and regression models.

**Results**: Scotland has exceptional routinely collected health data and Safe-Haven infrastructure, allowing these complex linkages. Analyses are in progress and results on linkage procedures will be presented. Preliminary results will focus on dental extractions, restorations and other treatments, access to dental check-ups, use of xerostomic-inducing drugs/anticholinergic burden, sugared liquid medicines, co-morbidities affecting periodontitis, and multi-morbidity.

**Conclusion**: These are novel linkage methods, with utility to answer a range of future research questions. Measuring oral health and its determinants will be informative for adults with intellectual disabilities, carers supporting their oral hygiene, policy makers, and health professionals.

## 5498 | Cancer screening and treatment in people with intellectual disabilities: a systematic review

M. Grozavescu; P. Triantafyllopoulou

*Tizard Centre, University of Kent, UK*

**Background**: People with Intellectual Disabilities (ID) have limited access to cancer screening and treatment services compared to the general population. The aim of this systematic review was to summarize the available research related to people with ID and cancer, to identify factors influencing cancer screening likelihood for people with ID as well as barriers to effective participation in screening and treatment procedures.

**Method**: In total 25 studies, meeting the inclusion criteria and quality assessment were incorporated in the review. 24 studies looked at cancer screening and 1 study looked at cancer treatment.

**Results**: The factors associated with cancer screening rates in people with ID were: ID severity, age, living situation, physical comorbidities and healthcare registration. Barriers to effective participation in screening and treatment procedures were reported to be lack of knowledge and awareness of cancer and its implications, communication and consent issues, and organizational inefficiencies.

**Conclusion**: The current review revelled the inequality of cancer screening and treatment for people with ID. Increased focus into providing efficient cancer services to people with ID is needed along with further research to develop our understanding on the topic and improve life expectancy and quality of life for people with ID.

## 5488 | A review of toileting assessment viewpoints of people with intellectual disabilities

S. Kim

*Kanagawa University of Human Services, Japan*

**Background**: A review was conducted to clarify assessment viewpoints related to toileting of people with intellectual disabilities (ID) who cannot express their health conditions.

**Method**: Initially, the literature was reviewed with the Cochrane Library and EBP books of people with ID were checked. Then, the electronic database were searched using the key words "toileting," "intellectual disabilit*, " and "assessment" in: (1) MEDLINE, (2) CINAHL, (3)SocINDEX, (4) Healthsource, (5) Eric in English; and in: (6) Medical-center-magazine on WEB, (7) the-latest-nursing-index-web, (8) Medical-online, (9) JDreamIII, and (10) CiNii in Japanese in December 2017. After confirming the abstracts, the full paper was read if found necessary. Studies of toilet training or disease treatment were excluded. Six papers from 21 articles were finally analyzed including 2 English and 4 Japanese papers, and a matrix was created.

**Results**: The studies were present since 2000. Assessment viewpoints such as 1) the profile of toileting issues (POTI) and 2) to provide prompts immediately before and after excretion behaviour were used to assess toileting issues of persons with ID.

**Conclusion**: Matson (2011), pointed out that there were few studies related to the toileting issues of IDs. Further studies are needed to develop an assessment tool using only observation items.

## 5477 | The effect of discontinuing off-label antipsychotic drug use on health-related quality of life

L. Ramerman

*Centre for Intellectual Disability and Mental Health/GGZ Drenthe, The Netherlands*

**Background**: The aim was to study the effects of discontinuing off-label antipsychotic drugs on Health-related Quality of Life (HQoL) in people with intellectual disability and to study the associations of HQoL with side-effects and challenging behaviours.

**Method**: Two discontinuation studies on antipsychotics, prescribed for the management of challenging behaviours, were combined. Both studies discontinued antipsychotic drugs in 14 weeks. Measurements were at baseline, post-discontinuation and at 40 weeks follow-up. In both studies behaviour (Aberrant Behavior Checklist (ABC)) and side-effects (dyskinesia (AIMS), akathisia (BARS), parkinsonism (UPDRS), autonomic symptoms (SCOPA-AUT), blood pressure and pulse) were monitored. QoL was measured by the RAND-36.

**Results**: Mental subscales of the RAND-36 were associated with irritability- and lethargy- scales of the ABC. The physical subscales of the RAND-36 were associated with parkinsonism, urinary problems, dysphagia and temperature dysregulation. In the group that unsuccessfully discontinued antipsychotics, the mental subscales deteriorated at discontinuation, but recover at follow-up, while the physical subscales improve slightly in the group that successfully discontinued.

**Conclusion**: During the long-term use of antipsychotic drugs, QoL is associated with irritability and lethargy, and with parkinsonism, urinary problems and medication use for diabetes mellitus and hypertension. When antipsychotic drugs are successfully discontinued, HQoL remained equal.

## 6040 | Monitoring the physical health of children with learning disabilities prescribed antipsychotics

S. Webster; A. Collins; A. Hassan

*CAMHS department, Cwm Taf Health Board, South Wales, UK*

**Background**: To evaluate the quality of monitoring of physical health of children with learning disabilities who are prescribed antipsychotics and factors that influence adherence to current guidelines for children.

**Method**: A retrospective analysis of 109 active clinical cases of children with learning disability attending a tertiary service was performed, benchmarking against NICE guidance (NG11).

**Results**: Data analysed highlighted poor documentation of physical health checks before initiation of antipsychotics (37%). A full cardiovascular screen was successful in only 12.9% of cases and baseline blood investigations were performed in 45–62% of individuals across the first 12 months. Side effects of treatment with medication dose changes were appropriately discussed. The rate of rise in BMI of children per year on medication ranged from 1 $kg/m^2$ to 6.9 $kg/m^2$. A clear trend was evident of over 60% of male cases became obese or morbidly obese after initiation of antipsychotics.

**Conclusion**: The risk to cardiovascular and metabolic disease remains a health priority for these children, despite the necessary benefits from antipsychotics. This project addressed the need to justify why children with severe learning disabilities may need adapted guidance based on balancing the risk- benefits of prescribing and quantitatively monitoring the use of antipsychotics.

# SESSION 2: "FAMILY QUALITY OF LIFE", "HISTORY, IDENTITY & RIGHTS" & "INCLUSIVE EDUCATION & EMPLOYMENT"

## 5422 | The personal and contextual factors influencing quality of life

L. Gomez; L. Moran; M. Alcedo; V. Arias; P. Navas; M. Verdugo

*Universidad de Oviedo, Spain*

**Background**: The aim of this research is testing what variables have the greatest impact on the quality of life domains for children and adolescents with intellectual disabilities (ID).

**Method**: The participants were 1,060 people with ID receiving support and services in organizations and educational centres. Participants were between 4 and 21 years of age (M = 13.6; SD= 5.0). Almost two-thirds (64.2%) were male, and one-fourth (25.8%) had a comorbid diagnosis of autism. The KidsLife Scale was applied to assess QOL according to the eight-domain quality of life model.

**Results**: Comorbid diagnosis of ASD, high levels of ID and support needs, together with being female, were the best predictors of lower quality of life-related personal outcomes in several domains for children and adolescents with ID, however, comorbid diagnosis of ASD is also a predictor of significant better material wellbeing.

**Conclusions**: This study helps to illuminate the complex relationships between the various QOL domains and the variables that can influence QOL. Although it is necessary to continue investigating the role of other potential covariates, it should be stressed that ID severity and support needs seem to have the most significant impact on QOL in people with ID and autism.

## 5528 | Supporting people with profound and multiple learning disabilities

T. Doukas; A. Fergusson; M. Fullerton; J. Grace

*Choice Support, UK*

**Background**: People with profound and multiple learning disabilities are, like everyone else, unique individuals, but sometimes, they are excluded from planning their own support, because their needs are often not understood. These service standards were developed by a group of families, carers, sector professionals, and experts, interested in improving the quality of support and the lives of people with profound and multiple disabilities.

**Method**: We will present a brief overview of the standards and the rationale behind their creation. We will demonstrate examples of the implementation of the standards in different settings, and we will showcase innovative ways to involve people with profound and multiple learning disabilities in a variety of decision and choice making activities. The aim of the standards is to ensure people with profound and multiple learning disabilities, of any age, have access to consistently high-quality support throughout their lives.

**Results/Conclusions**: These standards are designed to be used by educational, health and social care providers and commissioners of these services – to work together to ensure consistently good practice in all settings and respect the right of people with profound and multiple learning disabilities to be included.

## 5603 | Experiences of the parenting sole and support in mothers with cognitive limitations who have children in placement

K. Jöreskog; H. Lindstedt; P. Adolfsson; G. Janeslätt

*Uppsala University, Spain*

**Background**: Mothers with intellectual disability (ID) frequently have a variety of parenting skill deficits, and their children have an increased risk of being placed in care. There is a lack of knowledge about the parenting role if they get the support needed to maintain the relation to the child, and if the support is adapted to the cognitive limitations of the parent. The aim was to describe experiences of parenting role and support received of mothers with cognitive limitations who have children in placement.

**Method**: An explorative and qualitative design was used. Women with cognitive limitations (n = 11) who had a child in placement were interviewed. Data was analyzed with qualitative content analysis.

**Results**: The analyses yielded three categories: (1) I am a mother, (2) I am dependent upon an incomprehensible system, (3) I reluctantly accept my situation. Ten subcategories describe the experiences of the parenting role and support received.

**Conclusions**: The mothers struggle to maintain their parenting role, reconsidering their situation in an incomprehensible system. They do not get the support needed and the support received is not adapted to the cognitive limitations of the mother.

## 5620 | Practical study on relationship support for parents and siblings of children with disabilities

M. Abe

*Hokkaido University of Education, Japan*

**Background**: This study developed a support program for siblings of children with disabilities, and examined its effectiveness for promoting family relationships.

**Method**: Participants included seven siblings (7–11 years) who had brothers with autistic spectrum disorder and/or an intellectual disability. The program was conducted over six-two-hour sessions. Each session began with an icebreaker game. After that, participants discussed problems associated with their brothers' disabilities and shared specific subjects about themselves and their family. At the end of each session, each sibling expressed their impressions about their family in a portfolio picture book. Parents were shown the book after every session, and they wrote comments for the siblings. The siblings were interviewed and asked to complete the same questionnaire before and after the program. Their mothers were also interviewed about relationship between the siblings and family members.

**Results**: After analyzing the parent-child interaction represented in the portfolio books and the data from the questionnaires, the majority of the siblings' informal support expectations for their mothers increased; mothers also reported that their communication with siblings was activated, and that their perception about the siblings had changed.

**Conclusions**: The developed program is effective in improving relationships siblings and their parents.

## 5628 | The cycle of internalized learning (CIL) in adulthood: The application of the CIL meaningful teaching model, typically used with young learners, as a tool for adults with IDD to acquire life skills

R. Neuman; S. Reiter

*Zefat College, IL, USA*

**Background**: The Cycle of Internalized Learning (CIL) was based on humanistic philosophy (Reiter, 2000, 2016), and was developed for children with disabilities, as the national guidelines for learning life skills in special education, in Israel. The aim of the study is to apply the model with adults.

**Method**: Eight direct support staff took part in a pilot study in an introduction program on the principles of the CIL model. They were asked to choose relevant issues and try to implement the model with the residents they are in charge of (adults with IDD living in community homes).

**Results**: In a focus group staff described their experiences with the implementation of the CIL. They described two main outcomes, one was a change in their understanding of how meaningful learning occurs in adults with IDD; the other was their decision to step back and challenge residents to make their own decisions, and their own judgments concerning their behaviour.

**Conclusions**: Direct care staff internalized a new way for the support they provide adult community residents, based on a humanistic orientation.

## 5669 | Evaluation of "Mothers in Spite of All": a group intervention for mothers with cognitive limitations who have children in placement

H. Lindstedt; G. Janeslätt; K. Jöreskog; P. Adolfsson

*Uppsala University, Spain*

**Background**: Mothers with cognitive limitations have an increased risk of having their child in placement. An Australian intervention model, "Parents on the outside," was developed for helping the mothers to get peer support in their 'new' parenting role. The intervention was adapted for use in a Swedish habilitation service context. The purpose was to collect experiences of mothers with cognitive limitations with children in placement after participating in a group intervention, "Mother in spite of all," focusing their parental role and visiting children in foster care.

**Method**: Eleven mothers who had participated in the group intervention were interviewed after eight sessions. Interviews were analyzed with qualitative content analysis.

**Results**: The analyses resulted in four categories: (1) I am the mother of my child, (2) I accept my situation, (3) I depend on a system, and (4) I got challenged by the group intervention. Twelve subcategories describe the experiences of the parenting role and received support. Two themes emerged: dependent and refocused mothers, and grateful and capable mothers.

**Conclusions**: The mothers expressed gratefulness and a sense of capability. There is an indication of positive change in their parental role and an acceptance of the situation.

## 5723 | A long-term group psychoeducation therapeutic program for parents of children with ASD: benefits to the family as a system

S. Kollia; A. Gena; E. Tsirempolou

*National and Kapodistrian University of Athens, Greece*

**Background**: Families of children with Autism Spectrum Disorders (ASD) experience unique stressors in their everyday life, mainly derived from their child's social, communicative and behavioural dysfunctions, in conjunction with the limited resources in comprehensive therapeutic interventions. The aim of this study is to investigate the efficacy of a long-term group psychoeducational intervention in parents of children with ASD.

**Method**: In the psychoeducational group-therapeutic intervention, four couples of parents of children with ASD will participate. The intervention will include information about the nature and the psychological characteristics of ASD, stigma and self-stigmatization, communication and problem-solving skills. Three self-reported questionnaires will be used: Family Assessment Device, Family Rituals Scale, and Family Burden Scale.

**Results/Conclusions**: A multiple-baseline design across response categories will be applied and results are expected to reveal decreases in all three parameters under study. Qualitative analysis of the level of understanding of the nature, causes and treatment of ASD, as well as of the self and social stigma management is expected to show improvement in all domains.

## 5724 | Parent training for young children with autism spectrum disorder: A systemic, naturalistic behaviour-analytic model

A. Drosinou; A. Angelopoulou; A. Gena

*National and Kapodistrian University of Athens, Greece*

**Background**: The continuously increasing prevalence of ASD, the severity of this disability, and the high cost for its treatment, accentuates the need for substantially-researched therapeutic services for children with ASD and their families. The aim of the study is to assess the effectiveness of a Systemic, Naturalistic, Behavior-Analytic parent-training model, which aims to improve: (a) crucial skills in children with ASD, (b) parental input during parent-child interactions, and (c) the parent-child interaction skills.

**Method**: Two male pre-schoolers with ASD and their mothers and fathers were the participants in this study. One child was receiving behaviour analytic intervention, whereas the other was receiving eclectic treatment. A single-case experimental multiple baseline design across response categories was implemented. Three categories of variables were used: (a) child-related, (b) parent-related, and (c) parent-child interaction.

**Results**: There were considerable improvements in all variables for which training was provided, but also in a wide array of variables

for which treatment was not provided, for all the participants. Treatment effects generalized across several parameters and maintained through time.

**Conclusions**: This study, which derives from the combination of Behavior Analysis and General System Theory, in conjunction with the Developmental Approach, demonstrates multiple benefits pertaining to the progress of children with ASD and the family's wellbeing.

## 5766 | Letting go to move forward: Well-being of families dealing with empty nest transition

I. Zrnic; S. Komenda; G. Weber

*University of Vienna, Austria*

**Background**: The aim of this longitudinal study is to assess family quality of life (FQL; Brown et al., 2003) in parents and their children with intellectual disabilities (IB) dealing with the transition from childhood to adulthood. As this process is associated with child's increased autonomy we tested the Basic Needs Model (BNM; Ryan & Deci, 2000) and linked it to FQL.

**Method**: The sample (N = 33) consisted of (adult) children with ID and their parents living in Austria. Parents took part in a workshop for relatives coping with empty nest transitions. Participants filled out questionnaires one week before, as well as four weeks and four months after the workshop. In addition, structured interviews were conducted with (adult) children with ID (N = 12). Qualitative data related to the content of the workshop was collected.

**Results**: The results reveal relations between FQL, health, quality of parental relationship and caregiver stress. Among (adult) children with ID the BNM is confirmed. Self-determination is also related to children's maladaptive behaviour and need for support.

**Conclusions**: The results will be used to facilitate this transition for all parties involved through better understanding of individual needs. Major implications for optimizing family support and independent living will be drawn.

## 5786 | Effects of a caregiver-assisted group music intervention for adults with mild to borderline intellectual disability (MBID): A cluster randomized controlled trial study protocol

G. Ritzen-Smeets

*Philadelphia, NL, USA*

**Background**: In various patient groups, active music intervention has been found to improve mood, social interaction, and quality of life (QoL), and has a positive effect on self-esteem and belonging. Among children, there is even some tentative evidence that music interventions improve executive functioning (EF). In adults with ID, some associations have been reported between music and (inter) personal skills and wellbeing. However, no experimental study has been found that investigated a caregiver-assisted group music intervention among adults with MBID. Given this observed shortfall in the quantity and quality of experimental research, more well-conducted studies are needed to assess the effectiveness of music interventions for adults with ID.

**Method**: The present study points to ways in which music workers and care staff can share skills, ultimately enhancing relationships among residents and between residents and staff. This is a Cluster Randomized Controlled Trial to examine the effect of a caregiver-assisted group music intervention on various outcome measures, such as QoL, EF, and social support, among adults with MBID (age 18–65) compared to an active control group and care as usual. Various advisory groups were held to design the music intervention. The intervention, including its strengths and weaknesses, will be presented in more detail.

Poster presentation – research report

## 5855 | Indicators of quality of life in adults with brain injury defined by health professionals

M. Fernández; L. Gómez; V. Aguayo; B. Arias; A. Amor; M. Verdugo

*University of Salamanca, Spain*

**Background**: Brain injury can affect the proper development and functioning of the person who is affected, also causing a negative impact on his or her quality of life (QoL) and that of their relatives. Since service-provider professionals should focus on the rehabilitation strategies for improving QoL in these people, taking into account their characteristics, the objective of this work is to develop a list of specific QoL indicators for this population.

**Method**: A discussion group, conformed by 13 professionals, assessed a list of indicators derived from an exhaustive literature review of QoL indicators. A content validity analysis was carried out on the resulting list, using a Delphi methodology, with 14 expert judges at ABI.

**Results**: A set of 35 specific indicators of QoL evaluation was obtained in adults with brain injury. The degree of agreement obtained among the expert judges was very high (M = .82).

**Conclusion**: Guiding rehabilitation and intervention strategies around these specific indicators will allow professionals who offer services to this population to develop good practices, thus allowing people with ABI to experience a gradual improvement in their QoL.

## 5916 | Short 'relief' for carers: An exploration of a third sector care organisation in the UK

L. Sams
*UK*

**Background**: Government cuts in funding and social care services in the UK have led to the rise of third sector care organisations. The aims of this study were threefold: firstly to explore what 'relief' actually means within the context of family carers, secondly to describe how a small NGO provided short relief to family carers of adults with IDD who had experienced cuts in their care and thirdly, to map the outcomes for carers, service users and service staff.
**Methods**: The sample included 44 individuals, including 22 service-users with IDD, 8 staff, and 14 carers. The 22 service-users took part in a one-to-one interview which included the Social Network Guide. 14 carers completed the postal questionnaire, and 8 staff completed a postal questionnaire.
**Results**: The findings suggested that the service was of benefit to service-users, carers and staff. In particular the NGO provided a valuable source of social networking for those attending and carers reported that the service met their expectations. Supporting quotes from all three samples are presented.
**Conclusion**: Third sector care is likely to become more important in the UK and evidence-based knowledge about them is essential. Recommendations for further practice are described.

## 5923 | Longitudinal study of quality of life in people with brain injury

A. Hernández; M. Verdugo; M. Fernández
*University of Salamanca, Spain*

**Background**: As a consequence of acquired brain injury, there are changes in the person`s life, which usually have a very significant negative impact on their quality of life. Bit by bit, medical models are being complemented with multidimensional quality of life designs, such as Schalock and Verdugo (2013). Follow it, the scale of quality of life for people with brain damage has been created (CAVIDACE). The objective of this research is to carry out a longitudinal analysis that study the quality of life in this population and its evolution over time, as well as analyze factors that affects quality of life.
**Aim and Methods**: (a) Construction of the self-report version of the scale, (b) Systematic review of the literature, and (c) Construction of a protocol for the evaluation of the most relevant factors. In the coming months, we are going to applicate the scale and the protocol in CEADAC and some FEDACE centres over 12 months.
**Results**: Quality of life levels are expected to improve 12 months after brain injury.
**Conclusion**: An in-depth analysis of the results obtained, may improve the quality of the work of the services and, therefore, the quality of life of the users.

## 5974 | Psychophysiological measures of stress in parents of children with autism: A systematic review

C. Padden; C. Concialdi-McGlynn; S. Lydon
*University of Kent, UK*

**Background**: Parents of children with autism often report heightened stress and physical health problems, yet the majority of existing research has utilised parental self-reports of stress and health. Therefore, a systematic review was conducted to synthesise the literature describing psychophysiological measurement of stress in this population.
**Method**: Systematic database searches identified 15 studies for inclusion. Data were extracted on: (a) control group characteristics; (b) caregiver and care recipient characteristics; (c) setting; (d) physiological measures employed; (e) physiological outcomes; and (f) stressor type. A measure of methodological quality was also applied.
**Results**: Studies included 847 parents, mostly female (72%). None included a control group of parents of children with other disabilities. Most studies (73%) assessed baseline physiological activity, with others assessing physiological reactivity to an experimental stressor. A pattern of blunted physiological activity emerged within the reviewed studies. However, there was some variation, with some reporting normal or even higher physiological activity.
**Conclusion**: Findings suggest dysfunction of the hypothalamic-pituitary-adrenal-axis and autonomic nervous system for some, but not all, parents of children with autism. Further research is needed to evaluate characteristics that might impact on physiological responses, and to determine whether blunted physiological activity is adaptive or maladaptive.

## 5659 | A review of studies on self-esteem of people with autism spectrum disorder

S. Ogawa
*University of Tsukuba, Japan*

**Background**: Trends and problems of studies on self-esteem of people with autism spectrum disorder (ASD) were investigated.
**Method**: Documents were collected using CiNii Articles, which is the Japanese academic literature database, and ERIC (peer-reviewed only), Web of Science, Pub Med, which are the overseas academic literature databases. We(I) conducted a keyword search by setting "autism spectrum disorder/self-esteem" and "ASD/self-esteem," among others. The number of articles and research trends depending on the period was examined using the 53 articles that were identified by the search.
**Results**: In Japan, studies on self-esteem of people with ASD have been started since the 2000s, and 0 to 2 articles are written annually. Overseas, studies on self-esteem of people with ASD have

been conducted since the 1990s, and the number of studies has been steadily increasing. Especially from 2015 to 2017, the number of papers related to self-esteem of people with ASD is significant, accounting for about half of the total number of articles in ASD people's self-esteem.

**Conclusions**: It was suggested that further studies should be conducted on self-esteem of people with ASD from various viewpoints such as contingencies of self-worth and stability of self-esteem.

## 5942 | Leadership of people with intellectual disability promoting policy and legislation

D. Roth[1]; Y. Kraiem[2]; S. Sadovnik[2]

*[1]University College London, UK; [2]Director of Research and Evaluation, Beit Issie Shapiro, Israel*

**Description**: Self-advocacy groups of PWIDD have been active in Israel in the last 6 years. A national group was formed 3 years ago with members of local groups serving as their representatives. This presentation will focus on an evaluation of their activities in the Israeli parliament to promote policy and legislation. Israel ratified the UNCRP in 2012, which initiated the ministry of justice to revise the law of legal capacity (article 12). The PWIDD national group agenda was to assure that legal decisions would be "life evidence-based". The group underwent training about the law, parliamentary procedures and presentation formats. They took part in the legislative committee discussion where they had to "fight" to have their voices heard. They addressed two major issues relevant to them: Supported decision making instead of the present (almost automatic) guardianship and the obligation of the court to hear PWIDD, their desires and needs before ruling on guardian cases.

**Contribution**: 1. A model of accessing and teaching PWIDD about policy and legislation so that they can take an active and a leadership role on issues which affect their lives. 2. Evaluation results will be presented, as well as a digital video of the process.

## 5960 | Work, day care, and retirement - A PhD project on seniors with intellectual disabilities in Norway

J. Engeland

*Norwegian National Advisory Unit on Ageing and Health, Vestfold Hospital Trust, Norway; Department of Social Work and Health Science, Faculty of Social Science and Technology Management, Norwegian University of Science and Technology, Norway*

**Background**: Work participation is an important goal of Norwegian policy. The study will generate knowledge about participants with intellectual disability in supported and adapted employment and day care due to functional level and health, with focus on seniors. An additional aim is to better understand experiences of retirement for people with intellectual disabilities.

**Method**: The study includes a registry study of participants in supported and adapted employment, and day care and their functional level and health, and interviews with retirees with intellectual disabilities.

**Results**: Preliminary analysis of registry data shows that many seniors with intellectual disabilities are not registered in day activities. Analysis will include the impact on health and functional level on daily activities. Participants interviewed described that retirement positively affected health, satisfaction, and self-determination, but they experienced the transition as abrupt. Results from analysis of registry data will be presented at the conference.

**Conclusions**: Increased knowledge about participants in supported and adapted employment, and day care may influence policymaking regarding activities for people with intellectual disabilities. Increased knowledge of ageing and retirement among this population and individual guidance might improve their transition to retirement.

## 5416 | Responses of children with Down Syndrome in the development of an inclusive game

J. Porter

*University of Reading, UK*

**Background**: To develop an App that supports children with Down Syndrome in attending to differences in quantity through an inclusive game. Our research question was "How do children interact with features of the game that are added to make it more inclusive ?"

**Method**: 64 children with DS played the digital game over the course of 3 iterations of its development. Observational data was collected on how children interacted with the game and analysed using sociocultural theory to consider the motives, meanings and interests of the children alongside aspects of the ipad introduced to support learning.

**Results**: The observations revealed the interrelationship between children's cognitive and affective responses to the digital game, raising important issue of the different meaning of errors or mistakes for individuals.

**Conclusions**: With adjustments to the design, learners can be actively engaged to the point of exceeding expectations in an area in which previous research has indicated difficulty (Paterson 2001; Paterson et al. 2006). However our observations also illustrate how mistakes can lead to the adoption of inadequate response strategies and the perseveration of failure. The design and responsiveness of an App is therefore particularly important in providing the appropriate levels of challenge.

## 5589 | Promotion of accessible curricular design: an experience at the University of Cantabria (Spain)

V. Guillen; A. Ibañez; E. Diez; S. Sanchez; E. Vicente

*University of Cantabria, Spain*

**Background**: The development of Universal Design for Learning and the implementation of curricula accessible to all students, including people with disabilities, are priorities in the university context. Besides, future professionals in the field of education, who are now being trained, demand coherence between theory and teaching practices.

**Method**: We made a critical analysis of the subject "Psychology of Disability"(included within the Teaching in Primary Education Degree, University of Cantabria), where the importance of accessibility is highlighted. This analysis was performed through 'EvalDUA', a self-evaluation tool based on the 'Self-Check. Curriculum', created by CAST.

**Results**: After analyzing data, we concluded the subject was not sufficiently accessible and it was necessary to incorporate universal design principles. We made several changes related to providing information through different modalities and in a format that allow for adjustability by the user. After making these changes, all students (with and without special needs) said they better understood what 'Universal Design for Learning' is, and how to implement it as future teachers, and they also improved their grades as students of this subject.

**Conclusions**: This work contributes to understand the importance of teaching Universal Design for Learning by using Universal Design for Learning principles.

## 5955 | Educational material kits using a low-cost eye-tracking device for students with severe physical impairments

I. Kobayashi

*Tokyo Gakugei University, Japan*

**Background**: Educational software with eye-tracking devices has attracted the attention of educators to enhance the visual activity and communication of students with severe physical impairments. Low-cost devices and educational software have been applied especially widely in recent years. Nevertheless, educators must expend much time and effort to set up these products in educational environments. This study was conducted to construct educational material kits to facilitate the use of such products in educational settings.

**Method**: We prepared kits consisting of an eye-tracking device, a personal computer with mounting tools, and some applications at low or no cost, all satisfying the system requirements, along with a brief manual prepared for educators. Subsequently, the kits were applied at two schools for students with physical impairments. To evaluate the kits, semi-structured interviews were conducted for educators at schools.

**Results**: Educators at both schools gave positive reports with respect to the system setting, educational use, and manual. However, some requests were the inclusion of calibration of devices for individual students along with data analysis of educational activities.

**Conclusions**: Results demonstrated that our educational kits were useful. However, we would like to develop the kits further to improve their ease of use.

## 5643 | "How do I feel about my professional situation": A questionnaire promoting participation of people with intellectual disabilities in their professional projects

A.T. Veyre; E. Porcher; P. Magnenat; G. Petitpierre

*Département de Pédagogie Spécialisée, Université de Fribourg, Switzerland*

**Background**: Allowing people with intellectual disabilities to express their opinions on job satisfaction is important to enhance employment opportunities, provide optimal support, and increase individual well-being. The aim of this study is to create a questionnaire allowing workers with intellectual disabilities (ID) to speak about their professional situation.

**Method**: Thirty items were selected in different validated tools (n = 7). The consultation of an expert group composed of professionals (n = 7) and workers with intellectual disabilities (n = 4) led to the selection of the most relevant items. Thereafter, focus groups were conducted with 4 workers with ID to translate items into easy to read and understand language. Finally, the test–retest reliability has been assessed among 40 participants tested twice, with 3 weeks in-between the first (T1) and second (T2) testing days.

**Results**: Results suggested to retain ten items which cover the following topics: overall satisfaction, work accomplished (work rhythm, tasks performed) interactions and vocational project. Test-retest reliability analysis is currently in progress.

**Conclusions**: This new instrument could be very useful for professionals and for workers with ID. It supports self-determination enabling people to express themselves on their vocational situation and opens opportunities to discuss about their professional project.

## 5927 | Resigned job satisfaction in people with intellectual disabilities

A. Kocman; G. Weber

*Faculty of Psychology, University of Vienna, Austria*

**Background**: Recent reviews indicate high levels of job satisfaction among employees with ID across settings. However, as postulated by Bruggemann, these ratings may result from reduced

expectations of the employee due to a perceived lack of choice over employment options rather than highly positive attitudes towards the current job. Our study aimed to assess the prevalence of resigned job satisfaction and its measurability by traditional job satisfaction questionnaires.

**Method**: 129 employees from sheltered workshops in Luxembourg completed a questionnaire consisting of three measures of job satisfaction (JIGS, JDI, and RSMWS) along with questions assessing resigned job satisfaction.

**Results**: Despite expressing high job satisfaction in the job satisfaction measures, 56.6% of respondents indicated that they would prefer working somewhere else if they had the option to do so. Respondents indicating these aspirations showed significantly lower levels of job satisfaction than coworkers displaying no turnover intentions on all three measures. Yet, both groups indicated high overall job satisfaction.

**Conclusions**: This study provides initial evidence for a high prevalence of resigned job satisfaction among employees with ID. Moreover, it provides additional support for the validity of the JIGS, JDI and RSMWS for the assessment of job satisfaction.

## 5801 | The effect of indoor climbing on strengthening the employability of persons with intellectual disability (ID) (2018–2019)

V. Tillmann; R. Vreuls; V. Anneken

*Germany*

**Background**: Indoor-climbing can have different effects on a physical, psychological and social level (e.g. responsibility, teamwork, self-determination), which are important skills in the working environment. Therefore the aim of this study is to evaluate possible effects of indoor-climbing on employability and occupational self-efficacy of people with ID. No such data has been yet collected in Germany.

**Method**: The participants (n = 210) are people with ID working at sheltered workshops. The study design is a RCT with an intervention (2x/week indoor-climbing) and 2 control groups (10 months), in which one CG follows an alternative sports program (2x/week). Self-made/modified items on employability and occupational self-efficacy are used at two measurement periods.

**Results**: Data from t1 will show baseline and first data on the employability and occupational self-efficacy of people with ID. First preliminary results show that the participants score poorly on several employability subscales (e.g. professional development) and the occupational self-efficacy items.

**Conclusions**: The preliminary results indicate that participants face difficulties with gaining important skills (e.g. by further-training) necessary for the working environment. Therefore it is important to investigate, if a procedure like indoor-climbing is effective to gain relevant skills for self-determent occupation and in best-case participating in the regular labour market.

## 5913 | Life of people with developmental disabilities living as workers

H.Y. Lee; T.-G. Kim; K.-W. Lim

*Korea*

**Background**: The purpose of this study is to understand the lives of individuals with developmental disabilities as employees in aspects of their life at work, salary, relationship with colleagues, and leisure activities by using photovoice method.

**Method**: The photovoice research method was implemented for qualitative research. There are five participants who are employed at a special education school. The participants were interviewed four times according to the subjects of career, salary, relationship with colleagues, and leisure activity.

**Results**: The 58 units were categorized into 14 sub-categories, which were classified once more into four upper categories of 'My work, My life', 'Salary, My confidence', 'People around me and myself', 'Leisure, rest and recharging'.

**Conclusions**: First, the participants understood the role of their positions at work and felt joy, difficulties, and achievement. Second, the salary gave confidence to participants, but they could not manage the salary by themselves. Third, relationships of the participants with their colleagues were very limited and they spent most of the time with their family. Fourth, leisure activities of the participants were very fragmentary and did not make an explicit difference before acquiring their employment.

## 5602 | Exploring the efficacy of a functional skills curriculum for adults with intellectual and developmental disabilities in Singapore

M. Kishore

*MINDS, Singapore, Singapore*

**Background**: The Functional Skills Curriculum was designed as an experiential learning program for adults with moderate to severe intellectual and developmental disabilities to develop their self-care skills, social and work execution skills. The objective was to enhance the adaptive functioning level of adults in an Employment Development Centre using a structured curriculum with the aim of increasing their likelihood of transitioning into open employment.

**Method**: International literature was reviewed to identify curriculum competencies which are essential for adults with intellectual disabilities in work settings. 7 participants aged at least 18 years old, who were undergoing post-school transition, were selected for this pilot study. Pre-training baseline functioning was assessed before participants went through a three-month training programme covering academic, vocational, daily living and social skills competencies. Individual learning outcomes were obtained.

**Results**: The majority of participants demonstrated progress in all four competency areas when they were assessed post training.
**Conclusions**: The functional skills curriculum could be useful in providing systematic evidence-based training to improve the adaptive functioning level of adults in vocational training and placement centres. Practical implications, limitations and future improvements are discussed.

## SESSION 3: "POLICY & PRACTICE", "LIVING WITH DISABILITIES" & "PARENTING & OTHER MISCELLANEOUS TOPICS"

## POSTER PRESENTATION – NEW CONCEPTUALIZATION OR THEORY

### 5383 | Promoting diversity and belonging through interdisciplinary leadership training

S. Sharon; J. Turner
*Wayne State University, USA*

**Description**: Michigan shares the U.S. national need for more highly qualified professionals who have knowledge and experience in the use of evidence-based practices to meet the special health care needs of children and adults with neurodevelopmental disabilities including autism (ASD/DD). The Michigan Leadership Education in Neurodevelopmental Disabilities (MI-LEND program) is a consortium of six universities serving over 181,800 students. The purpose of the MI-LEND is to improve the health of children with ASD/DD by training individuals to assume leadership roles in their respective fields and work across disciplines. Diversity perspectives are integrated into all aspects of the training program including recruitment, didactics, mentoring, journaling and assignments. Contribution: As a result of their participation, trainees are expected to: (1) identify key social determinants impacting families and children with ASD/DD; (2) explain how addressing bias and providing culturally appropriate care can influence well-being; and (3) describe impact of policy and structural/institutional factors influencing care. This poster session will describe how diversity perspectives are embedded into the LEND program with an aim of promoting diversity and belonging for children with ASD/DD and their families. Challenges related to measuring successful outcomes will also be discussed.

### 5410 | Jenny's Diary: supporting conversations about dementia with people who have an intellectual disability

K. Watchman
*University of Stirling, UK*

**Background**: People with Down syndrome are at increased risk of developing dementia as they age, yet there are few good practice examples of how to have a conversation about the diagnosis. Jenny's Diary aims to support conversations about dementia with people who have an intellectual disability. This visual and easy-read resource is a full-colour booklet with an accompanying set of postcards. Content disseminates previous research findings of the author, which included identifying that a diagnosis of dementia is often not shared with people who have intellectual disabilities.
**Method**: Actors with intellectual disabilities played the role of 'Jenny' who has dementia, and her partner, friends and sister developed in the context of person-centred and individualised support for Jenny, and with a focus on maintaining the relationship with her partner, Jenny's Diary is developed in 3 parts.
**Results**: Part 1 reviews a typical week for Jenny and introduces strategies that may help her as dementia advances. Parts 2 and 3 suggest a model that may be applied in practice, or within families, to talk to Jenny and her partner about the dementia diagnosis.
**Conclusions**: Jenny's Diary was awarded Self-Management Resource of the Year, 2017 in Scotland and is freely available to download in English, Chinese Mandarin, Norwegian, Italian and German.

### 5502 | Disparities experienced by individuals with intellectual disability and extensive support needs

P. Navas; M.A. Verdugo; A. Aza; S. Martínez Torres
*Institute on Community Integration, University of Salamanca, Spain*

**Background**: Individuals with significant intellectual disabilities constitute a particularly vulnerable group. Although they represent 0.16% of Spain total population, authorities responsible for social policy are unaware of their needs.
**Methods**: Researchers' main goal was to analyzed the results yield by two surveys carried out in Spain: the Disability and Dependency Situations survey, EDAD (INE, 2008), and the System for Autonomy and Care for Dependency, SAAD (IMSERSO, 2016). The EDAD survey provides weighted data on 47.019 adults with significant ID. The SAAD system includes information on 30.378 adults with severe and profound ID receiving services.
**Results**: Despite 90% had limitations to perform activities of daily living, only 15% received technical aids that met their needs; individuals with significant ID require 111 hours of personal care per week which explains why 54.7% of family members have experienced a worsening in their health status; only 6 out of 100 individuals have ever worked

throughout their lives and, unlike other European countries, residential services are still the main option offered to those with extensive support needs.

**Conclusions**: People with significant ID are still experiencing disparities. The needs of those with the highest support needs should be moved further up the government agenda.

## 5525 | Occupational, health, and safety cost savings as a result of implementing positive behaviour support

M. Vassos; S. Wardale; G. Cornish

*Endeavour Foundation, The University of Queensland, Queensland, Australia*

**Background**: In 2016, challenging behaviour exhibited by people with an intellectual disability accounted for one-third of Endeavour Foundation's occupational, health and safety (OHS) costs. The aim of this study was to ascertain whether the implementation of positive behaviour support had an impact on reducing OHS costs within Endeavour Foundation.

**Method**: Positive behaviour support practice was audited for 23 Endeavour Foundation clients whose challenging behaviour has resulted in staff injury and/or illness. Practice was audited using a checklist tool, with case file reviews and staff interviews conducted to complete the tool for each client. Scores on the tool were then linked with the 2016/2017 OHS costs associated with each client.

**Results**: 61% of the sample represented clients who were supported via positive behaviour support, with an average score of 69% on the checklist tool. Of interest, only 29% of the 2016/2017 OHS costs for the whole sample were attributed to this group. Considering the initial investment to implement positive behaviour support, the OHS cost saving equated to an estimated $21,661.04 per client.

**Conclusions**: Given the funding constraints reported by the disability service sector, this study demonstrates the positive financial impact of implementing positive behaviour support within a disability support organisation.

## 5532 | Transition of adults with ID to long-term nursing homes: Indicators for moving and decision-making

S. Schaeper; B. Rodekohr; A. Thimm

*Center for Participation Research, Catholic University of Applied Sciences North Rhine-Westphalia, DE, Germany*

**Background**: The care systems for elderly and for persons with ID are strictly separated in Germany. The number of adults with ID living in long-term nursing homes is increasing due to insufficient opportunities to combine resources from both care systems. The study explores the reasons for moving and the process of decision-making.

**Method**: A quantitative study included data from the regular nursing homes in two districts. Age, duration of residence and reasons for moves were explored by a postal survey in 26 specialized nursing homes for persons with ID. Interviews with service users, relatives and management focused on the decision-making processes and service users' participation.

**Results**: Increasing needs for nursing care and the incapacity of disability services to cope with their clients´ changing needs often lead to transitions. In many cases, also economic interests of the service providers and the funding agency are crucial for the relocation in old age. The results show various organizational procedures and strategies of decision-making.

**Conclusions**: Strategies to counsel and to involve elderly persons with ID in the decision-making process as well as concepts to incorporate and improve nursing care in the existing residential services for persons with disabilities are badly needed.

## 5567 | Trends and variations in per capita expenditure on adult intellectual disabilities health and social care services across Scotland, and by urban/rural class

M. Okon; A. Henderson; D. Kinnear; S. Cooper

*Institute of Health and Wellbeing, University of Glasgow, UK*

**Background**: To investigate expenditure on adult intellectual disabilities services, regarding: (1) whether there is a year-on-year impact of austerity measures; (2) variations across Scotland; (3) relationships with extent of rurality of the area.

**Methods**: Expenditure data was extracted from Scottish Local Government Financial Statistics and Scottish Health Service Costs. Per capita expenditure was calculated using adjusted Scotland's Census 2011 data.

**Results**: There was a 3.41% real term decrease in expenditure on adult intellectual disabilities services (>£32 million) from 2012/13 to 2014/15. In 2014/15, per capita expenditure on adult intellectual disabilities health care ranged from £1,211–£17,595; social care ranged from £21,147–£83,831; and combined health and social care ranged from £37,703–£85,929. Per capita expenditure on combined health and social care was greater in rural areas, with more on social care though less on health care.

**Conclusions**: Austerity has impacted on Scotland's expenditure on intellectual disabilities services, by not keeping abreast of rising living costs. It varies considerably across Scotland: a post-code lottery of inequality. In 2016, Scotland integrated health and social care services and budgets and the impact of this is yet to be seen: we now have baseline expenditure data to support future research on post-integration outcomes.

## 5719 | Establishing a therapeutic relationship as a means of maximizing the effectiveness of ABA treatment for children with ASD

M. Ratsi; E. Tsirempolou; A. Gena

*National and Kapodistrian University of Athens, Greece*

**Background**: Even though Behavior Analysis is considered to be an optimally effective treatment for children with ASD and the experience of the therapist is a critical variable for the treatment outcome, very little is known about the skills and attributes of a competent therapist. In addition, it has been demonstrated that traditional staff training procedures are not particularly effective when training therapists to apply behaviour analytic treatment to children with ASD. The purpose of this study is to identify treatment variables that attribute to establishing a therapeutic relationship with children with ASD and to train therapists accordingly.

**Method**: Data will be collected during child-therapist interactions during therapeutic sessions.

**Results**: The analysis of the data is anticipated to yield both types of variables: those that attribute to building a therapeutic relationship and those that may impede it. Therapists that may have difficulty in establishing a therapeutic relationship will be systematically trained to acquire skills that have been identified as beneficial for the child-therapist interaction.

**Conclusions**: Specific skills, such as using voice differentials, differential reinforcement, and providing frequent teaching improve the therapist-child relationship and consequently maximize therapeutic benefits.

## 5898 | The impact of autism and intellectual disability on hospital outcomes for adults

T. Johnson; S. Ailey; S. Hohmann

*Rush university Medical Center, USA*

**Background**: Adults with autism and/or intellectual disabilities (ID) have unique needs during hospitalizations. In this study, we evaluated the impact of autism and/or ID on hospital LOS for patients hospitalized in academic medical centres.

**Method**: This was a retrospective matched cohort study of patients age $^{3}$ 18 discharged from academic medical center members of the Vizient Clinical Database between January 2011 and December 2016 with secondary diagnosis codes of autism and/or ID matched to patients without. Patients were matched on hospital, MS-DRG, age and gender. Generalized linear models were fit to test the association between presence of autism and/or ID with length of stay (LOS) controlling for patient characteristics and hospital.

**Results**: The cohort included 505,167 patients; Of the 253,122 with coexisting autism and/or ID, 32% were age 31–50, 55% male, and 67% White. The mean LOS was 7.9 ± 13.6 days for patients with autism and/or ID and 6.6 ± 10.2 days for patients without these conditions ($p < 0.001$). In the adjusted model, coexisting autism and/or ID was associated with 21% longer LOS.

**Conclusions**: More research is needed to understand the extent to which more intensive medical care and/or challenges in post-discharge care coordination contribute to longer LOS.

## 5992 | Barriers to assessment and intervention for people with autism in Nigeria

E. Nwokolo; G. Murphy

*Tizard Centre, University of Kent, Canterbury, Kent, UK*

**Background**: The aims of this study are to address the gap in literature around the identification of possible barriers to assessment of and intervention for individuals with autism in Nigeria, to examine the impact of awareness, education, income and beliefs on assessment and intervention or lack thereof and to determine what role the lack of professionals and services have played in assessment and intervention for individuals with autism.

**Method**: There were 3 groups: (1) parents who had a child with ASD; (2) professionals who either worked with or knew an individual with ASD; (3) general population made up of individuals from various levels of the social strata. Questionnaires were physically distributed to and collected from the participants.

**Results**: There is no gold standard tool for accurately diagnosing autism in Nigeria, knowledge gaps exist in the understanding and implementation of intervention procedures and there is a lack of professionals, adequate services, beliefs and cost served as barriers to assessment and intervention.

**Conclusions**: There is a need for a sustainable means of developing professionals in the country, to raise the level of awareness amongst healthcare professionals, families and the general populace on the symptoms and presentations of ASD as well as a need for a reorientation of specific attitudes and beliefs of parents, professionals and the general populace towards disability.

## 6042 | CAMHS LD adherence to STOMP guidelines

A. Collins; S. Webster; A. Hassan

*Cwm Taf University Health Board, Wales Deanery, UK*

**Background**: A tertiary service specialising in CAMHS LD was developed in South Wales in 2012. The RCPsych developed STOMP guidelines to limit the overmedication of adult patients with LD. The aim of this project was to assess the suitability of these guidelines and develop them to meet the needs of our younger CAMHS population.

**Method**: A case review of all active patients was completed. Demographic details, diagnosis and prescribing records were reviewed. Adherence with the STOMP guidelines was recorded. Where adherence was poor, notes were explored to find a potential cause.

**Results**: Out of 109 patients, 62 were prescribed antipsychotic medication. There were high rates of documenting a clear indication for medicating (98.39%), discussing side effects (95.08%) and providing regular monitoring (96.77%). Most patient care plans considered if medication was still required (66.13%). Assessing capacity and gaining formal consent was low (11.29%). The use of off-label medications was not discussed with patients often (4.55%).

**Conclusions**: CAMHS focuses consultations on family units. Consent is gained from discussion with the family as a whole but needs formalising. Capacity assessments are relevant for over 16 year olds. Moving forward CAMHS LD specific STOMP guidelines should be developed.

## 6056 | Palliative care for people with intellectual and multiple disabilities - a survey of research and practices

S. Schaeper; S. Jennessen; H. Schlichting

*Center for Participation Research, Catholic University of Applied Sciences North Rhine-Westphalia, Piusallee 89, D-48147 Muenster, Denmark*

**Background**: Persons with ID are underrepresented in palliative care services in Germany. The research project explores the situation both in palliative and disability services with a special view on the service users and their relatives.

**Method**: The multi-perspective design includes data collection, semi-structured interviews with experts, service users and relatives, focus group discussions with service users and concepts of person-centred planning. Participatory research is guaranteed by a supervisory board of service users.

**Results**: The number of persons with ID dying in residential homes is increasing. The death rate in the analysed group in this setting is 18.8 (per thousand), while the death rate in the general adult population in Germany is 13.4. Professional capacity in many cases does not yet meet special needs in end-of-life care sufficiently. Group discussions with persons with ID on the other hand show quite clear concepts of dying and wishes according to adequate support in this vulnerable situation.

**Conclusions**: Crossing network lines between the support systems is crucial for adequate capacity building. Pedagogical expertise is needed to ensure participation esp. for persons with profound and multiple disabilities, which is a core subject corresponding to the human rights in the end of life.

## 5559 | Developing an independent travel training programme (ITTP) for persons with intellectual disabilities (PWID)

P. Ramakrishnan; M. Chockalingam; V. Manokara; A.K. Ramachandran; S.W. Yang; G. Tan

*Movement for the Intellectually Disabled of Singapore, Singapore*

**Background**: In Singapore, the government's direction is to promote inclusion of persons with disabilities into the community. However, there is a significant barrier in terms of the lack of structured and evidence-based travel training for PWIDs.

**Method**: The ITTP was developed with the aim of allowing PWIDs in Singapore to travel independently and safely in the community. The programme was developed based on documented retrospective clinical needs data as well as existing disability travel training literature and best practice models. Regular consultation was undertaken with an expert panel consisting of Occupational Therapists, a psychologist, a teacher, and a job coach. The panel was purposively selected to critique and obtain consensus on the content through three structured iterations based on Delphi's methodology. The programme content was presented to a stakeholder group consisting of PWIDs, Caregivers and Staff.

**Results**: The programme was piloted and the outcomes evaluated.

**Conclusions**: The ITTP is the first systematically developed, evidence-based travel training programme in Singapore. Benefits include increased job and leisure opportunities as well as social inclusion. Greater accessibility to the community also reduces dependency on caregivers.

## 5727 | Bridging differences in executive function (EF) of children with ASD

A.-M. Theodoropoulou; E. Tsirempolou; T. Bozini; A. Gena

*National and Kapodistrian University of Athens, Greece*

**Background**: A considerable body of research has demonstrated impairments in (EFs) among children with ASD. EFs have impact on crucial aspects of real-life, as every day adaptive behaviour, school achievement, and social competence. The aim was to assess and establish skills associated with EFs such as working memory, flexibility and cognitive inhibition in children with ASD.

**Method**: EFs tasks have been taught in two school aged children with ASD in a multiple-baseline design across response categories.

**Results**: It was found that reinforcement; prompting and modelling are effective in teaching EFs.

**Conclusions**: EFs abilities may be viewed as an aspect that may be influenced by developmental and environmental factors leading to successful communication with other children and to a feeling of belonging to wider society.

Poster presentation – new conceptualization or theory, or exemplary practice

## 6047 | Exploring parental understanding of self-determination by people with severe or profound intellectual and multiple disabilities: a life course perspective

J.v.T. van Serooskerken; A. Willemen; C. Schuengel; P. Embregts; A. van der Putten

*Free University Amsterdam, The Netherlands*

**Background**: The self-determination theory by Deci and Ryan (2000) states that intrinsic motivation and self-regulation follow from satisfaction of three basic psychological needs - autonomy, competence, and relatedness. Self-determination develops as children interact with their environment; they discover volition and desires which can be turned into goals. However, for children with severe or profound intellectual and multiple disabilities (SPIMD) opportunities for self-determination may be diminished. Little is known about the extent to which people with SPIMD achieve (a level) of self-determination, and if so, in which life domains. This study sought to obtain data to fill this research gap.

**Method**: In the first of a series of qualitative and quantitative studies, parents of people with SPIMD were interviewed about their views of their child's self-determination. Study design and preliminary findings were presented.

**Results**: As children grow up, autonomy becomes a salient issue. Parents of typically developing children can draw on common expectations and examples. For parents of children with SPIMD, answers are more difficult to find.

**Conclusions**: Qualitative and quantitative descriptions of self-determinations of people with SPIMD may therefore address an important gap.

## 5500 | A new self-determination scale developed based on stakeholders' consensus

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**Background**: There has been reasonable progress in international studies on self-determination. Research shows that the implementation of strategies and curricula to teach skills associated with self-determination is a relevant predictor of positive outcomes. However, there is debate about how to delimit and empirically validate the dimensions and components that operationalize the construct and allow for its assessment. The aim of this study is to obtain and validate a solid measurement tool based on stakeholders' consensus.

**Method**: This study consists of two phases: first, a Delphi study involving panels of experts to develop a scale; and then a validation phase testing the scale with a broad sample to validate it.

**Results**: First results from the Delphi study suggest that the items of the scale obtain a high level of agreement among judges (using the Bangdiwala's agreement statistics), and the pilot study shows that the scale items are sufficiency reliable (using Cronbach's alpha).

**Conclusions**: This tool is expected to have multiple uses, from evaluating individual strengths and weaknesses, to planning educational strategies and evaluating their effectiveness.

## 6041 | Association between activity limitations and quality of life in children and adolescents with cerebral palsy

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**Background**: The ICF model has led to an evolution of the Cerebral Palsy (CP) concept and it has increased the importance of functional assessment and Quality of Life (QOL). Previous studies have explored the relation between QOL and functional status but the results are contradictory. The purpose of this study was to investigate the relationship between activity limitation and QOL in children and adolescents with CP.

**Method**: Data were collected from 80 children aged 8–18 years with CP. Activity limitations were assessed using functional classification systems, including the Gross Motor Function Classification System (GMFCS), the Manual Ability Classification System (MACS), the Communication Function Classification System (CFCS), and the Eating and Drinking Classification System (EDACS). QOL was assessed using the Spanish version of KIDSCREEN-27. Descriptive statistics were used to examine the general characteristics of the children with CP. The Spearman rank correlations were used to analyze the correlations between the functional classification systems and QOL.

**Results**: We found significantly positive relationships between the different scales of activity limitations and QOL outcomes.

**Conclusions**: Comprehensive information about how activity limitation is associated to QOL should provide professionals a better understanding of children with CP.

## 6057 | Femininity as defined by females with intellectual disability – a focus group research report

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**Background**: Although there is a growing interest in the issues of gender in disability studies, there has been little research on femininity or masculinity in the context of intellectual disability.

**Method**: The paper focuses on the perception of femininity presented by female self-advocates with intellectual disabilities living in the north of Poland. It is the report of the research undertaken with three focus groups of females who took part in focus interviews (a

total amount of participants – 30 women aged of 21–60). The main research question was: 'how do females with intellectual disabilities conceptualize femininity'?

**Results**: The main themes that emerged from the data collected in the interviews include: the females' identification with femininity, their perceptions of femininity, female role models and roles associated with it, visible superficialities and personality traits typical of women. The results indicate that femininity was often compared with masculinity and the perception of femininity by participants is evidently inspired by their own experiences and patterns occurring in their surroundings. The results showed a high level of gender identity of female participants with intellectual disabilities.

**Conclusions**: It is assumed that the high level of gender identity could be explained by their belonging to a group of self-advocates in which the participants' self-awareness is intentionally developed.

## 5750 | Using activity schedules to promote independence in a child with ASD

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**Background**: Independence is a pivotal skill since it facilitates the participation, social interaction, and belonging of people with Autism Spectrum Disorder (ASD) to family and community systems. Our aim was to investigate the effectiveness of a behaviour-analytic multi-component approach - including procedures such as activity schedules, prompting, and reinforcement – toward the improvement of: a) on-task behaviour, b) disruptive and repetitive behaviour, and c) social interaction skills of a pre-school boy with ASD.

**Method**: A reversal (ABAB) single-case experimental design was used to assess the efficacy of the intervention. The participant was trained in a therapeutic setting to use an activity schedule in order to independently complete a number of tasks. Treatment fidelity, social validity, generalization to home setting and maintenance assessments were fulfilled.

**Results**: Intervention was shown to: (a) increase on-task behaviour, (b) improve social interaction skills, (c) decrease repetitive behaviour, and (d) reduce the dependence on prompting procedures.

**Conclusions**: The results offer parents, teachers and therapists effective means of increasing positive behaviour and autonomy of the participant with ASD, contributing to improving quality of life.

## 5744 | Study on the awareness of aging of people with intellectual disabilities: Comparison between persons with intellectual disabilities and healthy persons by questionnaire survey

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**Background**: The current research and practice are carried out on elderly persons with intellectual disabilities. However, these practical reports are based on the findings by the researcher and caregivers. It is necessary to know what kind of awareness concerning aging in person with intellectual disability.

**Methods**: Comparative studies were conducted using a subjective aging consciousness scale for persons with intellectual disabilities (n = 143) and healthy persons (n = 119) in age from 30s to 60s, who have jobs and are living in town including group homes. For the Likert scale, the questionnaire were composed of self-writing formulas and others-writing formulas. The statistical analyses, t-test, spearman rank correlation analysis, and principal component analysis, were performed by using IBM SPSS 24.0.

**Results**: The main component provided significant scores, lower in "change due to aging" composed of 12 items such as "Memory ability and comprehension has gone", and higher in "positive awareness of aging" composed of 3 items such as "growing as a human", among persons with intellectual disabilities than healthy persons, respectively.

**Conclusion**: In addition to a rule of thumb, although the subjects are limited, a questionnaire survey by the Likert scale is also useful for the support on people with intellectual disability.

## 5914 | The effects of key word signing on expression of manual sign and speech of non-verbal children with developmental disabilities

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**Background**: The purpose of this study is to understand the effects of key word signing on the expression of manual sign and speech of non-verbal children with developmental disabilities.

**Method**: Participants were three non-verbal children with developmental disabilities. Multiple baseline design between subjects was conducted. Key word signing is a technique of simultaneous communication whereby the communication partner of the user will use both natural speech and also produce manual signs for the words that carry the most important information.

**Results**: First, the key word signing had effects on the expression of manual signs of non-verbal children with developmental disabilities. The frequency of the number of different manual signs and total number of manual signs were increased through the intervention.

Second, the key word signing had effects on the expression of speech and vocalization of non-verbal communication children with developmental disabilities. Even though the frequency of speech and vocalization were low due to the short intervention, significant vocalization and speech were continuously shown in the phases of intervention and maintenance.

**Conclusion**: Systematic KWS techniques are necessary to children with non-verbal developmental disabilities.

## 5397 | The children's social understanding scale: An advanced analysis of a parent-report measure for assessing ToM

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**Background**: The main aim of the study was to further validate the Children's Social Understanding Scale (CSUS), a parent-report measure prepared by Tahiroglu and colleagues, and to fill in some gaps in existing results.
**Method**: Four hundred and eighty parents of children with mild intellectual disability (MID, N = 238) and without disabilities (WD, N = 242) from elementary schools in Poland, with a diverse educational level, took part in our study. We conducted a confirmatory factor analysis (CFA), invariance and reliability analysis, and we validated the CSUS using laboratory ToM tasks, as well as language and social skills measures.
**Results**: After conducting a CFA, we were able to prepare a suitable model with a shortened version of the scale (35 items). The model turned out to be invariant in both subsamples. Children without disabilities had significantly higher results in comparison to children with MID. We were able not only to obtain good reliability of the measure, but also high test-retest correlation between results in a longitudinal study after 10 months.
**Conclusions**: The CSUS can be used as an additional measure for ToM development for children without disabilities and children with mild intellectual disability.

## 5443 | Parents with ID and the meaning of parenting competence: a multi-perspective doctoral dissertation

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**Background**: The poster outlines research questions, design, preliminary findings and conclusions of a doctoral dissertation in the field of social pedagogy and inclusion, as research is still in progress with a duration from 2017 to 2020. The overall research question investigates the meaning of attitudes, expectations and requirements concerning parenting competence for parents with ID and professionals supporting these families in Austria. The research aim was to locate resources and barriers for supported parenting for parents with ID in the service system, primarily focusing on parents' perspectives, supplemented by societal attitudes and professional insights.
**Method**: Data are gathered in four phases: analysing internet comments, interviewing professionals who have supported parents with ID, interviewing parents themselves and conducting focus group discussions with parents with ID. Part of the research is collaborative by involving parents with ID as co-researchers. Interpretative phenomenological analysis is applied to collected data with the collaborative part being, in consultation with co-researchers, more openly interpreted in group settings.
**Results**: Up-to-date findings will be presented on the poster, drawing from results of at least the two earlier phases of the dissertation.
**Conclusions**: Emerging conclusions and their relevance for science and practice will be discussed in context of current results.

## 5572 | A decade of excellence in providing end of life care to people with intellectual disabilities

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**Background**: The Palliative Care for People with Learning Disabilities (PCPLD) Network in the UK has brought practitioners together to share best practice since 1998. Since 2008, the PCPLD Network has given an annual award for outstanding practice in end-of-life care for people with ID. We reviewed past winners in order to identify trends in service development and to elicit key aspects of best practice.
**Method**: Content analysis was carried out on the full nomination submissions of all winning highly commended initiatives.
**Results**: 13 teams, individuals or projects have won the award, and 7 were highly commended. Of these 20 examples of best practice, 8 were cases where an individual with ID received outstanding care at the end of life, and 12 were service developments, including sustained collaboration between palliative care and ID services, interprofessional training, and the development of materials and resources.
**Conclusion**: Collaboration is the key to excellence. Award winners demonstrated creativity and sensitivity in ensuring that the person with ID was at the centre of his/her own care. There has been a promising trend of service improvements. Our challenge now is ensuring that lessons are learnt and good practice is replicated across all geographical areas in the UK.

## 5573 | Developing research priorities for palliative care of people with ID in Europe

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**Background**: Empirical knowledge around palliative care provision and needs of people with ID is extremely limited. We aimed to develop an agenda for research priorities for palliative care of people with ID in Europe.

**Method**: A two-day workshop was convened with 16 academics and clinicians in the field of palliative care and ID from 6 European countries. Round-table presentations and discussions about the current state of the art was followed by developing consensus research priorities using nominal group technique.

**Results**: 40 research priorities were proposed and collapsed into 11 research themes. The most important research themes were: investigating issues around end of life decision making; mapping the scale and scope of the issue; investigating the quality of palliative care for people with ID, including the challenges in achieving best practice; and developing outcome measures and instruments for palliative care of people with ID.

**Conclusions**: The identification of priority areas for future research in ID, death, dying and palliative care will help researchers to focus limited resources and research expertise on areas where it is most needed. The next steps are to cross-validate these research priorities with people with ID, carers, clinicians, researchers and other stakeholders across Europe.

## 6001 | Prevalence of self-reported autism spectrum disorders (ASD) in adults with attention deficit hyperactivity disorder (ADHD)

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**Background**: Multiple studies have shown a high rate of comorbid ASD symptoms (30–65%) in ADHD populations of children. However, conceptual and diagnostic issues remain to be clarified. Moreover, one clinically important issue concerns missed ASD in adults with ADHD, leading to inadequate treatment and treatment resistance.

**Method**: We assessed ASD traits in a group of 99 adults attending a specialist outpatient service for adult ADHD. ASD was assessed with the Autism Spectrum Quotient (AQ) and the Empathy Quotient (EQ) self-reports.

**Results**: Cut-off scores of AQ (6/98 participants, 6%) and EQ (26/99, 26%) were crossed. Three male participants (3/99, 3%) had both above threshold AQ and EQ scores and need to be considered as ASD-HRG with an AQ mean score at 37.0 (sd=4.58) and EQ at 20.7 (sd=9.71).

**Conclusions**: Our results indicate that unknown ASD symptoms are prevalent in ADHD patients. The ASD-HRG has similar scores as ASD groups in AQ and EQ validation studies, which suggests a high risk of ASD in those individuals. However, further studies with a larger sample size are needed to validate this finding.

## 6038 | Differences in leisure activity diversity and preferences between children with and without special educational needs

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**Background**: Leisure activity preferences of children are related to participation. The aim of this study was to examine the differences of diversity and preferences of participation in leisure activities outside school in children with and without special educational needs (SEN).

**Method**: 45 children with SEN and 45 children without SEN completed the CAPE/CAP. To analyze the discrepancy between diversity and preference scores, t-tests were performed.

**Results**: Similar levels in diversity and preference of participation were found in both groups. There was no significant difference in discrepancy scores between children with and without SEN (informal activities 9.9 ± 5.3 vs. 10.6 ± 5.6, formal activities 5.4 ± 2.5 vs. 6 ± 2.8, self- improvement activities 2.2 ± 1.8 vs. 2.5 ± 2, skill based activities 3.8 ± 1.8 vs. 4 ± 2.3, social activities 2 ± 1.9 vs. 2.1 ± 1.9, physical activities 5.4 ± 2.6 vs. 5.7 ± 2.5 recreational activities 2.1 ± 1.8 vs. 2.6 ± 1.6).

**Conclusions**: The findings of this study reveal interesting insights in participation patterns of children with SEN, as this group was equally able to participate in leisure activities outside school in comparison to the group without SEN.

## 5906 | Students' possession of mobile phones and instructions on Internet safety in special needs schools for intellectual disabilities in Japan: A questionnaire survey

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**Background**: With the spread of the Internet, people faces new risks. The number of children who own mobile phones has been increasing, and a large number of children access the Internet. This tendency is also seem among children with intellectual disabilities. In Japan, the educational administration has been completely unable to manage this trend. Instruction on Internet safety is required in school.

**Method**: A questionnaire survey was administered to all special needs schools for students aged 13–18 with intellectual disabilities in Japan. One teacher from each school was asked about the current situations of students' possession of mobile phones and instructions on Internet safety.

**Results**: While the ratio of students who own a mobile phone aged 13–15 has doubled since a previous survey conducted in 2011 (Eda et al., 2012), there has been no increase for students aged 16–18.

Internet safety instructions were delivered "in classes" (49.4%), "as part of instructions of daily living" (70.3%), and "as and when trouble occurred" (54.4%). All ratios were larger than the previous survey from 2011.

**Conclusion**: The age at which children own mobile phones is becoming lower. As the next step, further research about the quality of instruction on Internet safety is necessary.

## 6070 | CISCOS: multidisciplinary study course translating global policy into local practice

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**Description**: CISCOS (Connecting Inclusive Social Planning, Community Development and integrated Service Provision for Persons with Disabilities) is an EU-funded project aimed at developing a cross-border and multidisciplinary teaching and training concept combining staff qualification for support service providers & local governments with academic training of university students. This alliance facilitates the exchange, flow and co-creation of knowledge between higher education institutions, service providers & local authorities on how to fully embrace the inclusion paradigm embodied in UNCRPD & EU Disability Strategy and turn it into practice.

**Contribution**: CISCOS addresses challenges for implementation of innovation faced by relevant actors of the disability service provision sector. Uncertainty on implementation strategies under conditions of economic restrictions is raising in local governments, but even more in disability service providers. The project develops locally oriented solutions, to speed up the implementation of UN CPRD, bringing in multi-stakeholder knowledge and perspectives, combining scientific knowledge with practical needs, through an integrated approach. It makes the knowledge triangle work (education, research and innovation) and fosters the innovation capacity of local care provision sector, resulting in more integrated, flexible and individualised services. Through inter-sectoral local cooperation, CISCOS gives inclusive conceptual answers for service provision and corresponding organizational transformations processes.

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