

Theme: Participation Over the Lifespan
Symposium 1.1. Dementia & Intellectual Disabilities

Sharing the diagnosis of dementia: breaking bad news to people with intellectual disabilities

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Aim: Dementia strategies in the UK state that everyone should be given their diagnosis. However, people with intellectual disabilities (ID) are often protected from bad news. Our aim was to explore whether, and how, people with ID and dementia should be helped to understand their diagnosis. **Method:** In 2012, Tuffrey-Wijne published a new research-based model for breaking bad news to people with ID. We applied the model to people with dementia, and explored how dementia affects the processing of bad news. **Results:** A central feature of the model is the concept of building understanding establishing the person's current knowledge framework; breaking bad news into very small chunks; and assessing which of these need to be added to the person's knowledge framework. This knowledge framework consists of past, present and future dimensions. For people with dementia, the boundaries between these dimensions are increasingly blurred; resulting in specific information support needs. **Conclusion:** Information about dementia should be shared with people with ID, but in a way that takes account of their current framework of understanding. Assessment of this framework will help to decide how to approach the person's experience of the past, and how far to meaningfully discuss the future.

Why's my friend doing that? Raising awareness of dementia in adults with ID using computers

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Aim: The purpose of this study was to review the process undertaken to raise the awareness of a group of illiterate adults with intellectual disabilities (ID) about dementia and its effects on their housemates. **Method:** A case study approach was used. It examined the process undertaken from referral to screening and the provision of information. This included reference to: personalised information targets; individualised computer programs and interfaces; raising staff awareness; as well as the review process undertaken. **Results:** A range of custom-made programs were developed for each individual with ID and were accessed via a single computer. A range of screens were included for discussion and their function reviewed. Staff supporting the group indicated that the adults with ID were less concerned at the behaviour of their friend and the fact that he/she required more staff time. Staff supporting the home fed back that they found the materials educational. **Conclusion:** Different people were able to understand different amounts of information. All were able to access materials that were tailored to their sensory and language needs. It is important to include people in the process of their own information creation.

Strategies to reduce the marginalisation of people with intellectual disabilities and dementia

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Aim: The aim of the study was to identify factors that may contribute to the further marginalisation of people with an intellectual disability (ID) after a diagnosis of dementia. **Method:** A longitudinal study of three individuals with an ID and dementia was undertaken. Each participant was visited, and their interactions observed, on a monthly basis in their own home over a 3 year period. Thematic and case study analysis identified areas of commonality and difference in experience. **Results:** Not talking about the diagnosis of dementia with the individual, or explaining the changes they were experiencing, had a negative impact on well-being. This was evidenced through the lack of recognition of a sense of self, or identity, in the participants. The lack of adapted communication as dementia progressed was observed to be a further isolating factor. **Conclusion:** Findings suggest that there is potential for an increased risk of marginalisation at an individual, social and cultural level for people with an ID and dementia. An increased crossover of learning between ID services and dementia services is recommended along with a wider evidence base about appropriate models of care and the experiences of people from their own perspective.

Screening for dementia: a feasibility study of the NTG-EDSD in German-language

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Aim: Assessing dementia in persons with intellectual disability (ID) is challenging. Recently, a new instrument was developed by the American

National Task Group on Intellectual Disabilities and Dementia Practices (NTG), the NTG-Early Detection Screen for Dementia (NTG-EDSD). The goal of this study was to establish a sound and usable German-language translation of this instrument and to conduct a first feasibility study. **Method:** The NTG-EDSD was translated into German in a stepwise approach by five experts in ID, dementia, clinical practice, or research. For the feasibility study, 221 professional carers for ageing persons with ID in Austria and Germany completed the NTG-EDSD and an additional questionnaire assessing its feasibility and utility. **Results:** Overall feasibility evaluations showed good results. Reported problems and suggestions for improving and/or amending the NTG-EDSD were collected and are discussed with respect to the practicality of the instrument. **Conclusion:** Due to the differing premorbid cognitive level of persons with ID, a baseline assessment followed by periodic re-assessments is recommended when screening for dementia. The NTG-EDSD follows this recommendation and was well received by professional carers. It could become a valuable tool in screening for dementia, which is a necessary prerequisite for delivering adequate interventions and care.

Symposium 1.2. People with Profound Intellectual and Multiple Disabilities

Story garden: an exploratory research on the story experiences and experiencing with stories for persons with PIMD

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Aim: The study aims to explore the theoretical idea of a story garden built at the Maria Social Welfare Foundation in Middle Taiwan; analyze the process of meanings construction when persons with profound intellectual and multiple disabilities (PIMD) encounter the story, and develop storytelling strategies applied by care educators in daycare for persons with PIMD. **Method:** Research data was collected by field/participant-observation and in-depth interviews with care educators. A hermeneutic-phenomenological approach was used to describe and analyze the collected data. **Results:** Through localized materials of sound, scent, taste and story, persons with PIMD can immerse themselves into the story's events. During storytelling, they either interact with the story through role-play; or experience the story through observation. Storytelling helps persons with PIMD expand their living world and promote cultural participation. Meanwhile, PIMD embed new meaning to the original story and diversify it. **Conclusion:** Story Garden integrates care, rehabilitation, and education and enables different professionals to work under the same fundamental structure of the story's connotations. Moreover, story experiencing intensifies the care providers' ability to educationalize caregiving and their interaction with persons with PIMD.

Generation and elimination of fear: dialogue between dentists and persons with PIMD

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Aim: We set out to explore how persons with profound intellectual and multiple disabilities (PIMD) swing dynamically between generation and elimination of fear during routine dental care; and how dentists can support them to overcome the dental fear. **Method:** This study took place at the special care dentistry in Kaohsiung Medical University Chung-Ho Memorial Hospital. The research subjects were selected by purposive sampling. Two adults with PIMD and non-verbal communicative ability participated. Research data was collected by observation from videos of dental visits and in-depth interviews with both parents and dentists. A hermeneutic-phenomenological approach was used to describe and analyze the collected data. **Results:** The dentists and persons with PIMD form the emotion and atmosphere of the environment through dialogue. This environment controls the release of the fear of the dental visit. The skills of dialogue such as visual contact, touch, and voice during dental treatment influence the quality of doctor-patient relationship. **Conclusion:** Dental fear is independent of age, gender, and disabilities. Some can hide the expression of fear easily, but some cannot. The doctor-patient dialogue supports persons with PIMD to face dental fear and co-exist with it.

Evaluating the effect of person characteristics on joint attention behaviors of people with profound intellectual and multiple disabilities

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Aim: There is a need to know the extent to which the low rate of joint attention behavior of people with profound intellectual and multiple disabilities (PIMD) is related to person characteristics of both interaction partners. The purpose of this study is to find out how joint attention skills are manifested in people with PIMD during an interaction and to investigate which individual factors promote or hinder this ability to use joint attention behaviors. **Method:** Video

observations of 42 one-on-one interactions between a client and a support worker on the one hand, and a client and the researcher on the other hand, were coded continuously. Individual characteristics of the person with PIMD were measured using the Uzgiris-Hunt Scales. The partner's sensitivity and responsiveness were measured using the Maternal Behavior Rating Scale.

Results: Results are not yet available. **Conclusion:** We first expect that clients who have not yet acquired basic communicative skills and the developmental age required for joint attention will show less joint attention behaviors. Second, we expect that a big amount of responsiveness and sensitivity of the interaction partner will have a positive influence on the rate of joint attention behaviors of people with PIMD.

Symposium I.3. Ageing and Intellectual Disabilities

Perspectives on ageing by people with intellectual disabilities and their family carers in Belgium

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Aim: The goal of the study was to hear the perspectives of people with intellectual disabilities (ID) and their family carers about ageing and services. **Method:** We conducted two focus groups using a framework of Appreciative Inquiry (AI). The first group consisted of two people with ID, two family members, two healthcare professionals and two frontline staff; the second consisted of two people with ID, two family members, three healthcare professionals and one frontline staff. AI explores ideas that people have about what is valuable in what they do and tries to work out ways this can be built on. It emphasizes appreciating the activities and responses of people rather than concentrating on their problems. **Results:** Perspectives of people with ID focussed mainly on their current occupational, leisure and social activities and how this can be facilitated and maintained as they get older. The carers' perspective focused on the satisfaction and wellbeing of their son/daughter with ID. Carers discussed their intense caring relationships and the need to have compassionate, knowledgeable, skilled and respectful frontline staff and professionals. **Conclusion:** It is important to listen to users and carers in developing training programmes for frontline staff and professionals.

What do people with intellectual disabilities and their family carers say about ageing?

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Aim: The goal of the study was to hear the perspectives of people with intellectual disabilities (ID) and their family carers about ageing and services. **Method:** A focus group was conducted with five people with ID and five family carers using the framework of Appreciative Inquiry (AI). AI is a simple but radical approach to understanding the social world. AI concentrates on exploring ideas that people have about what is valuable in what they do and then tries to work out ways in which this can be built on. The emphasis is on appreciating the activities and responses of people rather than concentrating on their problems. **Results:** People with ID focussed mainly on their current occupational, leisure and social activities and how this can be facilitated and maintained as they get older. The carers' focused on the satisfaction and wellbeing of their son/daughter with ID. Carers discussed their intense caring relationships and the need to have compassionate, knowledgeable, skilled and respectful frontline staff and professionals. **Conclusion:** Users and carers have a major role to play in developing training programmes for frontline staff and professionals.

Ageing and intellectual disability: a European perspective

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Aim: The E-Dignities project explores life conditions of people with intellectual disabilities (ID) across different European countries and the challenges related to their ageing process. This project explored strategies for improving the quality of life of people with ID. **Method:** Service providers and academics from seven European countries (Austria, Belgium, France, Italy, Luxembourg, Portugal and the United Kingdom) were involved in the reciprocal learning process and participated with users, carers, service providers and commissioners. The project focussed on four areas where change happens in the period of ageing (health, living conditions, occupation and social relationships) assessing the implications of change in four areas of intervention: user involvement, development of services, preparation of staff, and improvement of social cohesion.

Results: Ageing is a process and this need to be considered as a lifelong process for people with ID. The key findings and recommendations focus on user involvement and personalisation in all aspects of health and social care and service development will be discussed. **Conclusion:** The challenge is to respond to the special needs of people with ID in the framework of a general rights-based approach. In other words, whatever is good and accessible for any person should be guaranteed to people with ID.

Symposium I.4. People with Profound and Multiple Disabilities

Correlates of physical and mental health of family carers of people with profound intellectual and multiple disabilities

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Aim: This study aimed to investigate the wellbeing of family carers of people with profound intellectual and multiple disabilities (PIMD) and identify those background characteristics, supports and concerns that correlate with and predict their wellbeing. **Method:** A survey was distributed to family carers of people with intellectual disabilities to gather information about their wellbeing, support, concerns and background characteristics. 555 family carers responded to the survey. This study presents the findings pertaining specifically to those family carers who reported that their family member had more severe or profound cognitive impairment ($N = 96$). Descriptive, correlational and regression analyses were conducted to identify their primary concerns and correlates of their physical and mental health. **Results:** The primary concerns of this group of family carers includes lack of home help, respite care, easy to understand information, clinical services, and flexibility in service provision. The factors predictive of mental and physical health amongst the family carers, including interpersonal, financial and service supports, will be reported. **Conclusion:** Supports family carers of people with PIMD receive appeared to relate to their mental and physical health. Suggestions for developments in supports to benefit such family carers will be given.

Do they agree? How parents and professionals value the support provided to persons with profound intellectual and multiple disabilities

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Aim: The importance of collaboration between parents and professionals in the support of persons with disabilities is widely acknowledged. This acknowledgement however does not necessarily lead to good collaboration in practice. In order to know how collaboration with parents of children with profound intellectual and multiple disabilities (PIMD) can be established, insight in what parents and professionals find important in the support provided to the child with PIMD is needed. The purpose of this study is to analyze agreements and differences in how parents and professionals value the support provided to the child with PIMD. In addition, we examined which child, parent or professional characteristics influence the opinions of both the parents and the professionals. **Method:** A sample of 151 parents whose child with PIMD is receiving support from a large residential facility in the Netherlands completed an adapted version of the Dutch Measure of Processes of Care for Parents (MPOC-PIMD) and 154 professionals (senior direct support staff, physicians, therapists and healthcare psychologists) completed an adapted version of the Dutch Measure of Processes of Care for service providers (MPOC-SP-PIMD). **Results:** Results are pending. **Conclusion:** Implications of the findings will be discussed.

The impact of rearing a child with PIMD: research into time use of parents

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Aim: Families have their own daily routine for living, working and socializing. A child with a profound intellectual and multiple disability (PIMD) is dependent on others in all aspects of life and therefore has a strong impact on the daily routines of his or her family. In this study, detailed knowledge is gathered on the impact of a child with PIMD on the daily activities of parents, such as care and household tasks, paid work, and leisure activities. **Method:** At least 30 parents (both mothers and fathers) of children with PIMD in the Netherlands registered their activities using a time use application on their smartphone. The time use application consisted of a diary in which participants could fill in their time use for 10-min intervals (what activity, with whom). The daily time use of these parents will be compared with a sample of parents of children without a disabilities. **Results:** The most important finding of this study will be presented, starting with an overview of time use of parents on three main categories: care tasks, personal time and leisure time. **Conclusion:** This study gives insights into the time use of families raising a child with PIMD.

Symposium 1.5 Quality of Life and Services

Engineering change in the culture and practices of a service for people with intellectual disability

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Aim: The aim of this study was to establish a person-centred approach to the support of 22 service users living in a large residential centre in Ireland and in the process bring about a decisive shift in the culture that operated in the service. **Method:** An action research approach was used that involved the research team conducting a collaborative inquiry with 22 of the more than 300 residents in the service together with their relatives and support staff. Over a 10-month period, 114 meetings were held that explored what person-centred planning might mean for each participant. A concomitant inquiry process took place with middle managers in the service. **Results:** Inquiry group members identified that community engagement and the participation of family members was important in the successful implementation of person-centred planning. However overcoming organisational barriers was seen as crucial to enacting change. **Conclusion:** The combination of using an action research approach to implement person-centred planning offers the chance to improve the quality of life of people with intellectual disability and to make changes in the culture at a micro level within an organisation

Evaluating quality of life and subjective wellbeing in children with PIMD

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Aim: The aims of this study were to evaluate objective quality of life indicators and subjective wellbeing of children with profound intellectual and multiple disabilities (PIMD). This group has only to a limited extent been included in the quality of life research. We especially wanted to examine the relationship between objective and subjective quality of life components and dimensions, as well as the influence of individual and service characteristics. **Method:** Seventy two children with PIMD participated in this study. The QOL-PIMD, the MIPQ and a self-developed questionnaire on child and service characteristics have been filled in by staff members who know the person very well. Next to this direct observations of the child's expressions of emotions have been done during daily situations. **Results:** The results on the objective quality of life indicators and the two measures of subjective wellbeing will be presented, as well as the correlation between them and their influencing factors. **Conclusion:** The study demonstrates the necessity of evaluating different dimensions of quality of life in persons with PIMD. The methods that have been used yield information that is useful to design interventions that may increase the quality of life and the wellbeing of these persons.

Quality of life in families with children with a disability

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Aim: There is a general assumption of low quality of life (QOL) of families living with children with a disability. We set out to test this assumption and to identify factors that might predict lower QOL in these families. **Method:** We conducted a systematic review of relevant literature via medline and solit (1988–2013) as well as manual searches. We screened the abstracts for results of QOL and correlated factors. We summarized the results by describing common findings. **Results:** The QOL of families living with children with a disability is on average comparable to that of other families. The severity of the disability does not correlate with QOL whereas challenging behaviour does. Health parameters of mothers do not correlate with the presence of a disability in the child as such, but with certain special conditions connected to a disability. For example, reduced mobility of the child is associated with complaints of low back pain in mothers. Being a working mother and having a higher family income are protective factors. **Conclusion:** Families living with children with a disability do not in general suffer from low QOL, but have to manage a time consuming caring job. Coping strategies and resilience help to overcome the challenges.

The practical use of video interaction guidance to improve communication, interactions and knowledge transfer between people with PIMD, staff and family members

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Aim: We examine the use of Video Interaction Guidance (VIG) to help improve communication, interactions and knowledge transfer between people with PIMD, staff and family carers. **Method:** A shared review of the videos of both staff and family member was undertaken to provide the opportunity for the staff and family member to discuss communication, interaction and sharing information. **Results:** VIG improved the knowledge and understanding of staff

working with individuals with PIMD in the first instance. The sharing of the videos allowed shared perspectives of the person with PIMD between the staff and the family members. **Conclusion:** VIG is a practical method that can be used within services to improve communication, interactions and knowledge transfer between individuals with PIMD, staff and family members.

Symposium 1.6. Longitudinal and Population-Based Studies in IDD

The mental health of parents of 11 year old children with and without intellectual and developmental disabilities

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Aim: The aim of the study was to estimate the prevalence of and risk factors for mental health problems in a sample of mothers and fathers of 11 year old UK children with and without intellectual and/or developmental disabilities. **Method:** Secondary analysis of Wave 5 data from the UK's Millennium Cohort Study (total $n = 13,287$) as conducted. Intellectual disability was identified from the results of cognitive testing at age 11. Autism spectrum disorder (ASD) was identified from parental (primarily maternal) report. Parental mental health problems were identified from self-report using the K6 screen. **Results:** Data from Wave 5 will be released in February 2014. Prevalence rates (with 95% confidence intervals) will be presented. The association between child, family and contextual factors and the risk of parental mental health problems will be estimated separately for parents of children with intellectual disability, parents of children with ASD and parents of 'typically developing' children. **Conclusion:** Implications of findings will be discussed.

Financial burden of families raising children with intellectual and developmental disabilities in the United States of America

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Aim: There are few population-based studies in the US about the costs families incur related to raising their children with intellectual and developmental disabilities (IDD). This study aimed to determine the financial burden of such parents. **Method:** We analyzed data from the 2009/2010 National Survey of Children with Special Health Care needs, which is a sample that is representative of US states and the nation as a whole. We compared financial costs associated with children with IDD and the larger population of children with special health care needs. **Results:** The sample included 7951 children with IDD and 32,291 children with other health conditions. In contrast to parents of children with other health conditions, those raising children with IDD had higher total annual costs for their children's health care; and were more likely to experience financial problems due to their child's health, need mental health services, stop or reduce work to care for the child, avoid changing jobs because of health insurance concerns, and need extra help coordinating the child's care. **Conclusion:** Parents of children with IDD are at significantly elevated risk of incurring high caregiving costs. Public policies to support families are urgently needed.

Marriage, separation and after: a longitudinal study of families who have children with disabilities in Norway

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Aim: Most research on families of children with disabilities is from US and UK, and a review paper from IASSIDD pleads for studies from other contexts. This study examines patterns of separation as well as topics rarely addressed in disability research but frequently in recent general family research, such as timing of marriage, remarriage and the gendered responsibility for care after separation in Norway. **Method:** The study is based on a longitudinal dataset of 600 families who have children with disabilities born 1993–1995. These families are compared to all families of children at the same age and point in time through secondary analysis of large datasets (register and large scale surveys). **Results:** Parents of children with disabilities formalise their partnership earlier than other families and they are less likely to separate early. Among these parents, the pattern of remarriage is more dependent on the age of the child, and the pattern of post-separation gendered care is similar to other families. **Conclusion:** The family structure of children with disabilities is both different and similar to other families. The interpretation of the results will be discussed.

Comparing carers of people with an intellectual disability, mental health problems and dementia: sociodemographic profile and psychological adjustment

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Aim: We set out to compare the sociodemographic profile and psychological adjustment among three groups of informal carers: those caring for individuals with an intellectual disability (ID), for individuals with a mental health (MH) problem, and for individuals with dementia. **Method:** Secondary analysis of the English Survey of Informal Carers in households was conducted. The survey includes a randomly selected sample of English households. There are 258 carers of individuals with ID, 309 carers of individuals with MH, and 237 carers of people with dementia. Multi-level models examined differences in carers' sociodemographic profiles and psychological adjustment while accounting for clustering of carers within households. **Results:** Analysis is currently under way. We will report results from comparisons on carers' age, gender, ethnicity, employment, education and socioeconomic status. We will explore group differences in self-reported quality of life, impact on physical, psychological health, and leisure activities, while accounting for the impact of sociodemographic factors and caring load. **Conclusion:** The impact of informal caregiving is relatively well documented, especially in relation to non-caregiving. The present findings will provide insight into potential differences and similarities among these specific caregiving groups.

Symposium I.7. Behaviour of Children with IDD and the Impact on Parents

A content validation of the family impact questionnaire for Swedish families rearing children with intellectual and developmental disabilities

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Aim: The goal of the study was to examine the relevance of the Family Impact Questionnaire (FIQ) for parents rearing children with intellectual disabilities in Sweden. It asked how the FIQ domains correspond to parents' narratives about their everyday life. **Method:** Interviews with seven parents of four preschool aged children were analyzed using a combined inductive and deductive approach. **Results:** The analysis resulted in five main themes, all based on the domains of the FIQ. In four of these, most of the predefined subthemes were retained. One domain, financial impact, was not mirrored in the interviews. Three of the main themes received a total of seven additional inductive subthemes. **Conclusion:** Many FIQ-items focus on parents' emotional reactions to the child's behaviour. In the interviews, parents described such reactions but also elaborated on how they understood and handled feelings and accompanying thoughts. Parents described ongoing internal processes in the form of bad conscience, worry, grief and resignation as well as descriptions of personal development and the emergence of a positive outlook towards life with the child. Parents gave extensive descriptions of their contacts formal support systems. Depending on the outcome, these experiences were invariably linked to emotional reactions, negative as well as positive.

Parental causal attributions for child misbehaviour and their relationship with parenting strategies: a comparison between parents of children with IDD and typically developing children

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Aim: Research suggests that parental causal attributions for child behaviour influence parenting strategies. The study aimed to investigate this relationship in parents of children with intellectual disabilities (ID) compared to parents of typically developing (TD) children. The study specifically focused on attributions of control by separating these from attributions of responsibility, blame and intent. **Method:** Fifty-one parents of children with ID and 69 parents of TD children completed the Written Analogue Questionnaire to measure causal attributions and the Parenting Scale to measure parenting strategies. **Results:** Parents of children with ID viewing their child as more in control over misbehaviour reported using more ineffective strategies compared to parents of TD children. Parents of children with ID feeling more responsible for their child's misbehaviour reported using less ineffective strategies, while this relationship was not found for parents of TD children. **Conclusion:** The results advance understanding of how parents perceive behaviour problems in children with ID and the role these perceptions play in parental behaviour management strategies. More importantly, these perceptions affect strategies differently for parents of children with ID compared to parents of TD children, highlighting that interventions should be adapted to the specific needs of parents of children with ID.

Use of harsh parenting practices in parents of children with disabilities

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Aim: We investigated whether parents of children with disability resort to harsh parenting practices, such as yelling, slapping or hitting their child, to a greater extent than control parents. We also explored, within the group of parents of children with disabilities, whether child disruptive behaviour problems and socio-economic disadvantage were associated with increased use of harsh parenting practices. **Method:** The present study investigated harsh parenting practices using self-report data from Swedish parents of children with disabilities (30 mothers and 14 fathers) and control parents (145 mothers and 25 fathers). Parents answered an online survey comprising questions about parenting practices and child behaviour. **Results:** There was no difference in harsh parenting practices between parents of children with disabilities and control parents. However, more fathers of children with disabilities than control fathers admitted some use of violence. In parents of children with disabilities, only child disruptive behaviour problems predicted harsh parenting practices. **Conclusion:** When meeting parents of children with disabilities, professionals should address parenting practices and needs for constructive discipline strategies, especially in relation to children with disruptive behavior problems. Preventive interventions and parent training programmes should be tailored to suit the needs of parents of children with disabilities.

The relationship between challenging behaviour, cognitions and stress in mothers of individuals with intellectual disabilities

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Aim: There is a lack of measures to examine mothers' perceptions of challenging behaviour. The psychometric properties of the Challenging Behaviour Perception Questionnaire (CBPQ; Williams & Rose, 2007) was investigated to assess its applicability to mothers. The study also examined whether maternal cognitions mediated the effect of challenging behaviour on parenting stress. **Method:** 46 mothers of children and young adults with intellectual disabilities (ID) completed questionnaires regarding their child's challenging behaviour, maternal cognitions and stress. A subsample of participants completed the CBPQ approximately 2 weeks later. **Results:** Examination of the psychometric properties of the CBPQ resulted in a 24-item measure with six subscales. Coefficients at subscale level ranged from 0.70 to 0.85 for internal reliability and 0.39 to 0.93 for test-retest reliability. Evidence of concurrent validity was also found. The overall mediation models for aggression/destruction and self-injurious behaviour were significant. The CBPQ Consequences client subscale was the only independent significant mediator for both behaviours. **Conclusion:** The CBPQ is a promising measure of mothers' perceptions of challenging behaviour. There is some evidence to suggest that mediation models differ in accordance with topography of behaviour.

Symposium I.8 People with Profound Intellectual and Multiple Disabilities

Effects of the high quality communication intervention in people with dual sensory and intellectual disabilities

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Aim: The quality of the interpersonal communication of people born with a combination of visual, hearing and intellectual disabilities is often poor. Many people struggle to make themselves understood and to experience togetherness and mutuality in social interactions. Support, both to the person with dual sensory and intellectual disabilities and their interaction partners may help to overcome these difficulties. **Method:** We developed an intervention program, based on theories of the development of intersubjectivity and the intervention model contact. The High Quality Communication intervention was implemented for 12 participants with a combination of visual and hearing disabilities. Six participants functioned at an estimated developmental age of 2 years or below. The intervention was carried out in two phases, with video-feedback coaching as the main intervention ingredient. **Results:** Comparison of the repeated measures in the baseline, intervention and follow-up conditions revealed significant effects in participants on dyadic interaction, shared emotion, referential communication, meaning negotiation, shared meaning, declarative communication and the sharing of past experiences. **Conclusion:** The new High Quality Communication intervention has the potential to increase social participation of people with multiple disabilities.

Social networks of persons with (severe) profound intellectual and multiple disabilities: the current situation of the professional support in personal files

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's Heeren Loo & University of Groningen, Department of Special Needs Education and Child Care, Groningen, The Netherlands

Aim: The total study aims to develop a protocol for establishing and maintaining social networks for people with profound intellectual and multiple disabilities (PIMD). The first step focusses on the role of the professionals in the maintenance and expansion of the social networks of persons with PIMD living in a residential facility in the Netherlands, as displayed in personal files. More specifically, we asked: what is the current situation in personal files, written by professionals, concerning the area of social networks of people with PIMD? **Method:** Files of 64 people with PIMD, living in a residential facility, were examined using inductive analysis. Informed consent was given by parents or legal representatives. The mean age of the people with PIMD is 47.1 years. All text concerning social contacts, that is contacts with people other than professional support staff, were included and coded using 'open coding'. **Results:** Professional support concerning social networks of people with PIMD in personal files will be presented. **Conclusion:** The findings will be discussed in relation to the protocol for establishing and maintaining social networks for people with PIMD and the steps that are needed to come to such a protocol.

Children with profound intellectual and multiple disabilities in interaction with peers with PIMD and siblings

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Aim: Social peer interactions may positively influence various developmental and quality of life outcomes. Children with profound intellectual and multiple disabilities (PIMD) mostly get in contact with peers with PIMD. If children with PIMD get the chance to interact with typically developing peers it is mostly with their siblings. This study compares interactions between children with PIMD to interactions with siblings. The influence of the behaviour of the sibling on the behaviour of the child with PIMD is also investigated. **Method:** Seventeen children with PIMD are observed in spontaneous interactions with a peer with PIMD and a sibling. The video recordings are coded continuously making use of self-constructed observation schemes. **Results:** Results on the behaviour of the children with PIMD and the siblings will be presented. **Conclusion:** We expect to observe more peer-directed behaviours of the children with PIMD during interactions with siblings and to observe a broad range of attention directing behaviour in the siblings.

Symposium 1.9. Engaging People with ID in Research

People with intellectual disability and phenomenological research: a review of the literature

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Aim: The aim of this study was to critically review the phenomenological research undertaken exclusively with people with intellectual disability (ID). **Method:** Nineteen studies reported between 2000 and 2013 that sought the experiences of people with ID were systematically reviewed. This is accomplished by firstly identifying the studies, the influencing philosophy or theory, and then reviewing them by applying the Critical Appraisal Skills Programme (CASP) questions. The review includes an identification of the research aims, appropriateness of methodology, design, recruitment strategy, data collection, relationship between researcher and participant, ethical considerations, rigour of data analysis, statement of findings and the value of the research. **Results:** Phenomenological research is being used exclusively with people with mild/moderate ID. Different philosophical or theoretical influences contribute to the choice of research method however there is also significance to aspects such as the location of the research. Researchers need to be cognisant of the ethical considerations, data collection, and method of analysis and in particular the value of the research. **Conclusion:** People with ID have and can be included in phenomenological research with results having the potential to inform practitioners and improve services.

How to meaningfully include children and young people with ID in research

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Aim: Despite established recognition of the rights of children and young people (CYP) to be consulted about their experiences and involved in decisions about their care, the voice of those with learning disabilities (LD) remains largely unheard. We describe strategies for including CYP with LD in an ethnographic study about their hospital experience. **Method:** Potential participants were offered study information in a variety of formats, including a talking photograph album. The use of an interactive button during the assent process enabled CYP to indicate their understanding of the project and preference for participation non-verbally. A number of techniques individually tailored to each child's cognitive and communicative ability were used during data collection, facilitating both choice and engagement. **Results:** Five CYP, aged 7–21, gave their assent to participate. Four completed at least one data collection activity and one child was discharged before completing any activities. Through interacting directly with participants, the researcher gained an understanding of the hospital experience from their unique perspective that would not have emerged through other methods of data collection. **Conclusion:** It is valuable and possible for CYP with LD to be meaningfully included in research if researchers view their knowledge as valid, have sufficient time to fully engage with them and pay specific attention to their preferences, abilities and individualised needs.

Doing research together: a study about the views of people with intellectual disabilities and non-disabled researchers that collaborated in research about transition to adult life

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Aim: The objective of this study is to explore the perceptions and views of both people with intellectual disabilities (ID) and non-disabled researchers that collaborated in a 1-year research project about transition to adult life among people with ID. **Method:** We designed and implemented one questionnaire for people with ID, one questionnaire for researchers, two focus groups with people with ID, three group interviews with researchers, and one focus group with all the participants together. Thematic analysis was applied to the data obtained. **Results:** Advisors with ID valued this experience as an opportunity to learn new skills, to freely express on matters that affect them, and to engage in a socially valued activity. Researchers considered that the participation of people with ID contributed to improve the quality of the research and will allow developing research in which people with ID will be able to participate in a more active role. **Conclusion:** The research provides a better understanding of inclusive research processes. In addition, it helps us to establish strategies aimed at increasing the participation of people with ID in research.

Symposium 2.1. Sexuality and People with IDD – I

People with intellectual disabilities talk about sexuality: important implications for the development of sex education

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Aim: Existing sex education programs have failed to involve people with intellectual disabilities (ID) in the development of these programs. Not involving the target population in development decreases the likelihood that the sex education program will be effective. This exploratory study was conducted to assess the perspectives of people with ID on several sexuality-related topics. **Method:** Semi-structured interviews were held with 20 people with ID covering topics such as sex education, relationships, sex, social media, parenthood and support. NVivo 9 was used to analyze the interviews per topic. **Results:** Few participants reported having received sex education. Their knowledge regarding sex education tends to be superficial and is mainly limited to topics such as safe sex, contraception and sexually transmitted infections. Their knowledge of safe sex does not always translate to safe sex behavior. **Conclusion:** There is a need for high quality sex education. Sex education should be lengthier and taught more frequently, focusing on a variety of sexuality-related topics. Furthermore, sex education should include the improvement of sexuality-related skills. To increase the likelihood of program effectiveness it is advisable that a theory and evidence based framework, such as Intervention Mapping, be used for program development.

Sexuality and privacy among people with an intellectual disability: a qualitative study

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Aim: Considering sexuality, people with intellectual disabilities (ID) have an important contribution to make. This study describes the experiences of people with ID in the Netherlands with sexuality and privacy. People with ID have sexual rights. One of these rights is the right to privacy. The research question is limited to the question: How do people with ID experience their right to sexual privacy? **Method:** To answer this question, a qualitative study was performed in which 15 people with a mild ID were interviewed via semi-structured interviews. In this study 10 participants were men and 5 were women (average age = 45.6 years). The interview topic list was based on the literature on sexuality and privacy. **Results:** The role of staff members, sex and having a relationship were prominent themes in the interviews. Most participants were satisfied with their situation. **Conclusion:** The literature emphasizes a lack of privacy in the lives of people with ID. In this study most participants seemed to be content with their sexual privacy. This contradicts earlier findings.

Using picture books to help people with intellectual disabilities learn and talk about sexuality

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Aim: Books Beyond Words (BBW) is an award winning series of books developed in the UK, which tell stories in pictures without written words to help people with learning and communication difficulties explore and understand their own experiences and feelings. It includes 10 titles on issues related to sexuality, including falling in love, safe sex, sexual abuse and HIV. Our aim is to describe different ways in which carers and staff can use BBW effectively with people with intellectual disabilities (ID). **Method:** The use of the picture books requires interaction between the reader (person with ID) and his/her supporter. In recent years, a range of methods have been developed in order to help supporters use the books, including training sessions, a website, and book clubs where people with ID can read and discuss the books together. **Results:** The books, including books on sexuality, are now read in at least 12 book clubs in the South of England and in therapy and education settings. The presentation will include video examples of effective use of the books. Feedback on the website, training sessions and book clubs has been positive. **Conclusion:** The use of BBW is enhanced by multiple strategies.

'Accidental counsellors': transition staff supporting the sexuality of young adults with intellectual disabilities

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Aim: Problematic sexual behavior can be a significant barrier to social and economic participation for people with intellectual disability (ID). There is inadequate information about the sexuality and relationship education in transition to adulthood programs. **Method:** Focus group interviews were conducted with transition to adulthood program staff from three programs. Digital recordings were transcribed verbatim and thematically analysed using grounded theory. **Results:** Socio-sexual issues were common among young adults with ID in transition programs. Transition staff constructed sexuality as problematic and were part of an often ad-hoc response that relied more upon personal and professional perspectives than on any evidence-based framework. While staff viewed sexuality support and education as outside their professional remit, they became 'accidental counsellors' informed primarily by their personal perspectives. **Conclusion:** Transition to adulthood programs are important sites for the development of socio-sexual knowledge and skills. Staff in these programs are currently under-prepared for the role of sexuality and relationship educator or mentor and young adults have little access to best-practice, evidence-based and gendered programs in these sites. A comprehensive approach to sexuality and relationship education and information is needed in transition to adulthood programs that includes staff, families and young adults with ID.

Symposium 2.2 Sexuality and People with IDD – 2

Becoming the sexual person I want to be: an analysis of young adults' with intellectual disabilities' experiences, understanding and use of sexuality and relationship education and information

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Aim: There is inadequate knowledge about the sexual health status of people with intellectual disabilities (ID) and the efficacy of sexual health education,

information and support approaches they have experienced. **Method:** Young males and young females with ID attending adult transition programs participated in group interviews delineated by gender. Interviews focused on experiences of sexuality education, quality of information and education and perspectives on the most appropriate modes of education. Data were thematically analysed using a constant comparative approach. **Results:** Young adults had narrowly formed ideas about sexual health, sexuality and relationships gained through school, transition services or family based education. Gendered messages of safety had translated to fear about sexual and reproductive health, sexual and relationship choices and about their capacity to determine the parameters of an intimate relationship. They had few avenues for rehearsing and honing their knowledge and ideas about sex and relationships. **Conclusion:** Current approaches focus on risk reduction and are delivered in an ad-hoc way. Further research is needed to develop an approach that gives young people access to sexual health education and information that they can use and a support network that can help them make sense of and apply this knowledge.

Family caregivers' responses to sexuality and relationship support needs of young adults with intellectual disabilities

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Aim: There is scant literature on family caregivers' responses to the sexuality and relationship support needs of young adults with intellectual disabilities (ID) in South Africa. This paper presents results of a study of family caregivers' responses to these issues in Cape Town. **Method:** Grounded theory methodology was used with in-depth interviews and focus group interviews as methods of data collection. Participants involved male and female family caregivers. **Results:** The preliminary results show that family caregivers struggle with initiating sexuality and relationships education for the young adults with ID and they do it on an ad hoc basis mostly when the former asks questions or when there is some problem regarding sexuality and relationships issues. Dealing with menstruation and birth control is a major concern for family caregivers of female young adults with ID who feel that sterilisation is the best option for them and their charge. There are also strong cultural differences in the way family caregivers respond to these issues. **Conclusion:** Culturally sensitive approaches to support family caregivers with skills to provide their charge with sexuality and relationships education are imperative as well as the need to address the family caregivers' own concerns in handling these issues.

Identifying effective methods for teaching sex education to people with intellectual disabilities: a systematic review

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Aim: Sex education for people with intellectual disabilities (ID) is important. However our knowledge about effective methods for teaching sex education to this population is limited. This study reports the results of a systematic review identifying useful methods for sex education for people with ID. **Method:** Twenty papers were included based on two criteria: the topic was effectiveness of sex education programs and the population that was being studied were people with ID. **Results:** Useful methods for increasing knowledge, improving skills and improving attitudes were reported. However, generalization of skills to real-life situations is often not achieved. There are indications that maintenance of knowledge and skills needs extra attention. Detailed descriptions of the program materials, program goals and the methods used in the program were lacking. **Conclusion:** Although there is some evidence for effective methods improving knowledge, attitudes and skills with regard to sex education, it is unclear under which conditions the methods work, due the lack of detailed descriptions. It would therefore be preferable that this information is also provided in the papers or in online supplements.

Women who love: an explorative study on the lived experiences of lesbian and bisexual women with a mild intellectual disability in The Netherlands

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Aim: Empirical research on homosexuality among people with an intellectual disability (ID) is limited and very little is known regarding the personal experiences of lesbian and bisexual women with ID. This study set out to answer the question: What are the lived experiences of a specific cohort of lesbian and bisexual women with ID in the Netherlands? **Method:** To answer this question, a qualitative study was performed in which eight lesbian and bisexual women with mild ID were interviewed via semi-structured interviews (average age = 37 years). The interview topic list was based on the literature on

(homo)sexuality. **Results:** Participants reported positive and negative experiences, and talked about their lesbian and bisexual identity. Most participants reported that they experienced difficulties in finding a partner. Participants were not openly lesbian or bisexual in all settings; most participants were afraid for negative reactions at work or from people in their neighbourhood. There is a need for specific sex education. **Conclusion:** Specific problems impact the lives of lesbian and bisexual women with mild ID: their search for a suitable partner, being openly lesbian or bisexual, and specific sex education.

Symposium 2.3 Siblings of People with IDD

Exploring the differences in carer strain in sibling and parent carers of older people with an intellectual disability in Ireland

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Aim: The aim is to explore the differences between parent and sibling carers in terms of the carer strain that they experience as a result of this caring. **Method:** Data on 41 carers (nine parents and 32 siblings) was collected including; demographic information, the experience of caring, carer health and other care giving obligations. Data was drawn from the first wave of the Intellectual Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) Carer's Study. Descriptive statistics explored differences between parent and sibling carer experiences of carer strain. **Results:** Carer strain, measured using Robinsons' 13 item Caregiver Strain Index, was present in 15 carers of whom 14 were siblings; 94% of 'strained' carers also had two or more chronic conditions. The needs of the person cared for also influenced carer strain. **Conclusion:** The findings of this preliminary exploratory study illustrate the differences between parent and sibling carers of people with ID, in terms of care strain as well as interactions with carer chronic disease. Policy makers and service planners must consider these carer strain concerns among sibling carers as they assume family care of people with ID as they age.

Self-reported behaviour problems and sibling relationship quality by siblings of children with autism spectrum disorder

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Aim: The aim of the study was to examine self-reports of siblings of children with autism spectrum disorder (ASD) about their own behavioural and emotional problems and sibling relationships. **Methods:** Siblings (7–17 years) and mothers from 94 families with a child with ASD were recruited. Mothers reported on family demographics, behavioural and emotional problems in the child with ASD, and their own symptoms of depression. Siblings reported on their relationship with their brother or sister with ASD. Adolescent siblings also self-reported on their behavioural and emotional problems. **Results:** Compared to normative data, siblings reported only slightly elevated levels of behavioural and emotional problems. Regression analyses explored family systems relationships, with sibling self-reports predicted by the behaviour problems scores for the child with ASD and maternal depression. Maternal depression did not emerge as a predictor of siblings' self-reported sibling relationships or their behavioural and emotional problems. Higher levels of behaviour problems in the child with ASD predicted decreased warmth/closeness and increased conflict in the relationship. **Conclusions:** There was little indication of clinically meaningful elevations in behavioural and emotional problems in siblings of children with ASD. There was some indication that sibling relationships may be at risk where the child with ASD has significant behaviour problems.

Adolescent siblings of children with intellectual and developmental disabilities in Norway: unique experiences and typical childhood

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Aim: The aim was to explore experiences of adolescent siblings of children with intellectual and developmental disabilities (IDD). In particular, we set out to determine the extent to which they reported stressful experiences, or that parents that were too busy caring for their disabled sibling. We also sought to identify differences from other adolescents regarding self-perception, relations to parents and friends, and career incentives. **Method:** In-depth interviews ($n = 15$) and questionnaires ($n = 100$) completed by siblings in Norway in 2012. The questionnaire included a number of measures employed in large scale surveys of young people in Norway (Young in Norway, three waves 1992–2010). **Results:** Results suggest two diverging images. On the one hand siblings tended to confirm pessimistic images about stressful experiences and the need to

take on more responsibilities than peers. On the other hand their self-presentation was that of a typical adolescent. This was confirmed by measures on self-perception, relations to parents and friends, and career incentives. **Conclusion:** The interpretation of the diverging images is informed by the so-called 'sociology of acceptance' proposed by Bogdan and Taylor in the 1980s.

Caring for an adult sibling with intellectual or developmental disabilities: factors affecting the decision to assume care

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Aim: Sibling caregivers are increasingly significant within developmental disabilities policy and practice. Over 70% of persons with intellectual and developmental disabilities (IDD) live with family. Up to 20% already reside with siblings. As persons with IDD and their caregiving parents age, more families rely on adult siblings for care. This study aimed to explore decision-making dynamics and retrospectively evaluate information and service needs, service satisfaction, and satisfaction with the decision to provide care. **Method:** A web-based survey was completed by 1073 adult sibling caregivers across the United States. Results were analyzed using ordinary least squares regressions, with interaction effects examined to identify impacts of sibling caregivers' stage of life on sibling decision-making satisfaction. **Results:** Sibling relationship strength was associated with decision-making satisfaction, contingent upon stage of life. Total service receipt was positively related to decision-making satisfaction. Though reported service need outstripped receipt by a 4:1 ratio, service receipt was associated with respondent satisfaction. **Conclusion:** Access to services improves satisfaction with the decision to provide care.

Symposium 2.4. Communication and Language Issues for People with IDD

Training parents to support the communication and participation of children with intellectual disability who use a speech-generating device (SGD)

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Aim: The aim was to examine the effects of parent training on the interactions between parents and their children with communication impairment and intellectual disability. **Method:** A multiple-baseline design across three participants, and one A-B-A single case design were used. Four families of children with disability (5–16 years) were recruited. All children had been recently prescribed a speech-generating device. Parents and children completed twice-weekly home-practice sessions that were observed by the lead researcher via webcam. During the intervention period, parents watched six training videos concerning the use of responsive communication styles, device modelling/teaching, and motivation strategies. They also received guidance and feedback from the researcher around their practice. The research team later coded the session videos for interaction characteristics. **Results:** Children's participation and engagement with their device was affected both by changes in parental responsiveness, and parents' use of device modelling/teaching strategies. Trends varied greatly between families, and themes from follow-up interviews with parents highlighted the importance of personalised intervention strategies. **Conclusion:** While interventions targeting parental interaction style and parent-implemented teaching can improve children's communicative participation, individual characteristics must be taken into account. Parents emphasised that professional guidance in tailoring generic communication strategies to their family was an essential component.

Maintaining a Dyad between a toddler with communication disorders and his parent as a primary caregiver using augmentative and alternative communication

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Israel

Aim: We investigated the effects of a parent education program based on a Dyad Communication Model (DCM) including augmentative and alternative communication (AAC) strategies on the communication dyad between parents and toddlers with communication difficulties. **Method:** The experimental group ($N = 21$) experienced an intervention based on the DCM with AAC strategies. The control group experienced a parent-education program that instructed them in baby-massage (BM) strategies. Pre-and post intervention sessions were videotaped and analyzed to assess dyads and determine the efficiency of each intervention. **Results:** The number of messages in the DCM group increased significantly in comparison with the BM group. The feedback provided by both parents and toddlers more than doubled. The number of messages of the parents and toddlers and the ratio between those messages became more balanced, with additional changes in the number of words used by the parent, joint attention, joint engagement and latency time of parent waiting for

responses from the toddler. **Conclusion:** An intervention program based on the DCM can enhance the ability of the parent to understand the communication intents of their toddler, and enable the expressions of toddlers to express communication attempts, thereby contributing to the construction to successful communication dyad.

Systematic review of parent-implemented language interventions

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Aim: There is a need to systematically review the effects of parent-implemented early language intervention studies aimed at facilitating the communication and language development of children with a developmental delay (DD) aged 1–5 years. **Method:** We carried out a literature search in several databases. Studies were assessed for level of evidence and the effectiveness of these studies was evaluated. **Results:** Seven intervention studies met the inclusion criteria. Interventions comprised the Hanen Parent Program, Responsive Education/Prelinguistic Milieu Teaching, Enhanced Milieu Teaching and the Environmental Language Intervention Strategy. A substantial proportion of children with a DD had a diagnosis of Down syndrome (DS). Several studies reported significant effects of intervention on communication behavior (favouring intervention groups over control groups), but no studies reported significant effects on vocabulary production. Children with DS had fewer benefits on communication behavior from the interventions compared to other children with a DD. **Conclusion:** Intervention programs aimed at facilitating the communication and language development of children with a DD appear to improve communication abilities but no significant effects on expressive language development were found.

The role of speech-language therapists in adults with intellectual disability

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Aim: While early intervention is acknowledged as crucial by the United Nations Convention (Article 26), information pertaining to Speech-Language Therapy in adulthood is limited. This paper aims to describe how Speech-Language Therapists may support adults with intellectual disability (ID) in South Africa. **Method:** Five individuals with ID were interviewed with regard to the Speech-Language Therapy and communication intervention they required as adults. **Results:** Individuals often received Speech-Language Therapy in childhood for concerns relating to articulation and delayed communication. A trend linking early intervention to increased educational opportunity and ultimately increased employment opportunity emerged. As the individual enters adolescence and adulthood the therapy focus would shift to communication in the work and leisure environments as well as developing accommodations in these environments. Therapy would assist with the development of literacy skills, improving social communication skills and encouraging the use of technology in the workplace. Therapy aims therefore develop as the individual ages and encounters new communicative environments. **Conclusion:** The role of Speech-Language Therapy for adults with ID is poorly understood and services are underutilized in South Africa. It continues to evolve and is required across the lifespan for different purposes and at different life stages.

Symposium 2.5 Positive Behaviour Support, Art and Sport

Positive stories: implementing the positive behaviour framework in Western Australia

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Aim: This paper is a case description detailing the development implementation of the Positive Behaviour Framework (PBF) in Western Australia. The paper presents an innovative approach to sector-wide culture change in disability services. PBF is a government initiative for facilitating sector engagement in the use of a comprehensive and consistent, evidence-based approach for responding to the needs of people with disabilities who exhibit challenging behaviours. Meeting this challenge has instigated a more positive focus for general service design and delivery. **Method:** We use case description to demonstrate sector-wide strategic planning for change. We illustrate some of the key episodes in this journey with positive cases of inclusion and through analysing these stories from an integrative and inclusive perspective. **Results:** This demonstration case first describes PBF and its conceptual foundations in the Positive Behaviour Support approach to human services. An outline of the historical background that led up to the development of the PBF is presented. Finally, we describe the current state of the PBF rollout and its broader implications for communities. **Conclusion:** PBF is a strategic plan for disability sector reform that is

contributing positively to the lives of people with disability and the community in Western Australia.

Stability of esthetic preference of landscape and portrait art images and photographs in people with intellectual disability

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Aim: Empirical studies on esthetic preferences of clinical groups are scarce, especially for individuals with intellectual disabilities (ID). The aim of this study is to detect differences in the stability of esthetic preference between people with ID and people without. **Method:** 20 participants without ID and 20 participants with ID are ensured to have no visual perception deficits by using a control task at the beginning of the first session. Afterwards four sets with eight images each (landscape photographs, portrait photographs, landscape paintings, portrait painting) are presented successively. Participants are asked to sort the images of each condition according to their esthetic preference. Two weeks later, the same participants are asked to perform an explicit-memory task in which an image presented within a preference condition and a new distractor image are presented. Following this the esthetic preference procedure introduced two weeks before is repeated in order to determine a stability of esthetic preference. **Results:** Differences between both groups according to the stability of preference are expected as well as differences within the comparison group between the different conditions. **Conclusion:** The acknowledgement of esthetic experience in people with ID can have an impact on the inclusive living and accommodation environment.

Effects of inclusive sports in Austria

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Aim: Inclusion should pervade all aspects of social life, especially school sports and sports organisations. The three case studies show examples of implementing inclusive sports in schools and their combined results. **Method:** The method used in this project is based on action research by Stenhouse and Elliot (1972) and Altrichter/Posch (1989). This method was chosen because the practice-orientated research approach allows the authors to reflect upon their findings and directly implement them in their work, examine their viability and further develop them within their own occupational field. **Results:** All case studies revealed that inclusive sports for adolescents with and without special needs are possible and viable. It positively influences students with special needs in their personal development and strengthens their self-confidence. Both parents and teachers are supportive of this project. However, a lack of resources in schools and in organising inclusive sports events is a hindering aspect.

Conclusion: Positive and unexpected effects of this project are evident in a teacher's efforts for inclusive sports in schools in Styria, the regular participation of approx. 25 schools in the five or six inclusive sports events organised annually, and the further development of inclusive sports on an international level through European school sports projects.

Symposium 2.6. Families and Parenting

Parenting in families of school-aged children with autism spectrum disorder: an observational study

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Aim: Parents of children with autism spectrum disorder (ASD) face specific challenges in parenting. They often have to fulfill multiple and demanding parental roles. Nevertheless, research investigating the behavioral aspects of parenting children with ASD is scarce. The current study aims to characterize parenting behaviors among parents of children with ASD, and to explore whether parenting behaviors are associated with specific child characteristics. **Method:** Data were collected from 30 mothers and their school-aged child with ASD, and a matched control sample of mothers and their typically developing child. Parenting behaviors were examined in the home situation, by unstructured and structured tasks. The coding system contained seven general parenting dimensions and four scales to measure maternal autonomy support. Several child characteristics were measured through questionnaires and individual assessments. **Results:** Preliminary results indicate that mothers of children with ASD ($n = 24$) differ significantly on three parenting domains compared to the control group. They obtained lower scores on Warmth and Provision of Structure, and higher scores on Negativity. **Conclusion:** Both similarities and differences seem to be present in parenting behaviors between mothers of a child with or without ASD. In further analyses, associations with child characteristics will be explored.

Exploring parenting behaviour in families of children and adolescents with autism spectrum disorder and/or intellectual disability

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Aim: Parents of children with autism spectrum disorder (ASD) or intellectual disability (ID) are confronted with specific challenges in raising their children. The aims are to explore differences in parenting behaviour among mothers of children with or without ASD/ID in association with the child's age, and to examine whether and how behaviour problems are related to parenting behaviour. **Method:** In this exploratory questionnaire study, families of children with ASD ($n = 548$), with ASD and ID ($n = 114$) and with ID ($n = 101$) are compared with 437 families with a child without ASD or ID (age range: 6–18 years). **Results:** Currently, only data on children without ID have been analysed. MANOVAS with diagnosis and age groups as factors showed that mothers of children with ASD exhibited different parenting behaviour in several domains (e.g., rule setting, discipline, adapting the environment) compared to the control group. Age was differently related to parenting behaviour in the ASD versus control group. Furthermore, associations between externalizing or internalizing behaviour problems and parenting behaviour were found. **Conclusion:** Results indicated that parenting behaviours were significantly impacted by the ASD diagnosis and age of their children. Directions for future research and practical implications will be discussed.

What do families from ethnic minorities with children who have an intellectual disability need from local authorities: a report from Rotherham

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Aim: We sought to explore and articulate the feelings of Pakistani parents of children with intellectual disability (ID) about the services they receive. We wanted to highlight deficiencies, indicate likely remedies and inform future practice. **Method:** A focus group (seven women and one man) was convened. Education, translation services and social worker input to the families were discussed. The session was recorded and the transcript analysed using a thematic approach to highlight the main areas of concern. **Results:** The focus of translation services in the local authority prioritised Eastern European languages to the detriment of non-English speaking Asian families. It was also apparent that reliance on the wider/extended family for support in Asian communities is not as widespread as might have been thought with reference to the literature. Many care staff still hold misconceptions about what is and is not appropriate cultural care for individuals from diverse ethnic groups. **Conclusion:** Demographic trends indicate that cultural diversity is increasing nationally in the UK population. It is also the case that the population with ID is increasing in some ethnic groups. Care staff will therefore need more knowledge and awareness about the cultural needs of the populations they serve.

The experience of motherhood by women with intellectual disabilities

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Aim: The aim of this study was to broaden social reflection on motherhood as experienced by women with mild and moderate intellectual disabilities (ID). It offers an innovative approach to disability research in Poland. **Method:** A qualitative approach based on 20 in-depth interviews analysed using Grounded Theory and Symbolic Interactionism was used. **Results:** The risk discourse is a distinct feature of the reproductive path as researched in this particular group of women which manifests itself in social evaluation indicating a lack of responsibility, intolerance to plans of motherhood, social distance and nullifying the right to be a mother. The motherhood of women with ID is seen as a social practice in which both mother and child are in some way dependent on others. **Conclusion:** The study shows that disability is a challenge for femininity because it requires a specific change in woman's social roles (motherhood). The result of experiencing 'shared mothering' is its fragmentation and the complicatedness of the definition.

Symposium 2.7. Communication & Story-Telling with People with PIMD

Developing German traditional folk stories into multi-sensory experiences: cross cultural exchanges and shared knowledge and expertise

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Aim: The concept of 'mehr-Sinn[®] Geschichten' storytelling enables people with profound intellectual and multiple disabilities (PIMD) in different countries to

experience cultural participation. The aim of the UN Convention on the Rights of People with Disabilities is to realize cultural and social participation also for people with PIMD. Since there is a lack of appropriate offers, the concept of 'mehr-Sinn[®] Geschichten' has been developed. Its basic assumption is that stories appeal to all people, young and old. To make traditional fairy-tales also understandable for people with PIMD, they are adapted into sensual experiences. **Method:** On the basis of video analyses, the German-Scottish cooperation project tries to find out whether the 'mehr-Sinn[®] Geschichten' can be transferred into other cultural areas. Stories are translated into the target languages, and the narrators are trained in different methods how to tell 'mehr-Sinn[®] Geschichten'. They are evaluated according to their respective possibilities of participation, and results and experiences are exchanged. **Results:** Video analyses prove that the concept and method of 'mehr-Sinn[®] Geschichten' can contribute to cultural and social participation. **Conclusion:** By means of 'mehr-Sinn[®] Geschichten', cultural and social participation for people with PIMD becomes possible.

Communication breakdowns and repair strategies among children with severe intellectual and developmental disabilities

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Aim: The aim of this study was to examine the type and frequency of repair strategies and the frequency of communication initiations used by children with severe intellectual and developmental disabilities (IDD) and to examine them in relation with environmental characteristics, i.e., intensiveness of the relationship between the communicational partner and the child (daily versus weekly) and the type of communication breakdown. **Method:** Twelve children ages 9–16 with severe IDD were videotaped during school activities with staff who met the children on a weekly or a daily basis. **Results:** Four types of communication breakdowns and four repair strategies, repetition being the dominant strategy, were used. The two types of staff members differed significantly in their use of one communication breakdown (requesting clarification) while the children differed significantly in their use of substitution as a repair strategy. The children used significantly more responses than initiations. Communication partners in the school demonstrated significantly more behaviors that prompted responses rather than initiations by the children. **Conclusion:** Children with severe IDD use repair strategies when faced with communication breakdowns, and can adjust some types of repairs to the communication breakdown type and partner. Communication environment might be characterized by preempting, with limited challenges that can promote initiations by the children.

Adapting traditional Scottish folktales in a multi-sensory way and using and evaluating them in schools and adult services for people with profound intellectual and multiple disabilities

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Aim: Our goal was to enable people with profound intellectual and multiple disabilities (PIMD) to access, experience and engage with traditional Scottish Folktales. **Method:** Working in partnership with a Scottish storyteller, four traditional Scottish Folktales were identified, adapted and piloted in both schools and adult services. Observations, a semi-structured questionnaire and video footage were used to evaluate the outcomes of each story in both settings. **Results:** Individuals in both children and adult services responded well and engaged with the stories on a personal level but as a project the approach used by staff in both settings was very different. **Conclusion:** Multi-sensory storytelling is a valuable tool for engaging with people with PIMD. It provides opportunities to motivate and encourage staff development. The project contributed to the enhancement of staff skills and staff awareness in communicating with people with PIMD.

The benefits of participating in exchanges between two organisations and universities: the outcomes for people with profound intellectual and multiple disabilities

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Aim: We aim to describe the process and outcomes of collaborative working between PAMIS, University of Dundee and Kubus, University of Koln.

Method: Both organisations and universities have been involved in collaborative work around multi-sensory storytelling. **Results:** Two main projects have emerged from this collaborative work; one exploring the use of personalised multi-sensory stories and the other exploring the use of cultural multi-sensory stories. These projects have far-reaching benefits for people with profound intellectual and multiple disabilities (PIMD), providing them with a range of resources which engage them with literature.

Conclusion: Collaborative working in the area of PIMD is highly important for research and practice.

Symposium 2.8. Accessible Communication and Information for People with IDD

The easy read project: an investigation into the accessibility value of health-based 'easy read' literature

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Aim: Access to written information is vital to support wellbeing and participation in decision making about health. This study aims to investigate what makes 'easy read' material easier to read than mainstream material for people with intellectual disabilities (ID). **Method:** Stage 1 comprised a structured survey of the properties of 'easy read' literature, followed by a multi-level linguistic analysis (quantitative and qualitative) of text samples from 'easy read' material and matching mainstream versions from the UK Department of Health website. Data were analysed and differences between 'easy read' and mainstream documents were compared. **Results:** Significant differences between 'easy read' and mainstream texts on quantitative multi-level linguistic measures largely support the hypothesis that 'easy read' material is less linguistically complex than its mainstream comparator. Qualitative discourse analysis reveals 'easy read' material to be more restricted, more directive and less inclusive than similar information in mainstream format. **Conclusion:** Initial findings from linguistic analyses demonstrate the need to readdress some of the commonly held principles for the production and use of 'easy read' material. Stage 2 of the study involves people with ID undertaking a series of reading comprehension tasks informed by the results of Stage 1.

Television viewing habits and preferences of adults and young people with intellectual disability: a survey using a Talking Mats® – questionnaire

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Aim: Watching television is a popular leisure activity in the U.K. The aim of this study was to investigate the television viewing habits and preferences of adults and young people with intellectual disability. **Method:** A survey was conducted using a Talking Mats® – Questionnaire (TM-Q) that was devised and piloted for the purpose. An interactive resource, the respondent expresses their views by placing picture symbols on a carpet mat displaying a rating scale. Twenty-eight adults and young people participated. Administration of the TM-Q was video recorded. The data were analysed and factors of age, gender and communicative ability examined. **Results:** Television watching occupied a large amount of participant leisure time. The communicatively less able group watched significantly more television than the more able group. Many favoured watching with friends and family, and socially interacting. The most popular genre of programme was 'Soaps' and the least – 'News and Politics'. Age and gender of participants did not appear to be factors in their habits and preferences. **Conclusion:** Television watching occupies a high proportion of time and represents a social activity for many. 'Communicative ability' as a factor in television watching as a leisure pursuit warrants further investigation.

Effectiveness of computer-based simulations on learning of social and communication skills by children with IDD and ASD

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Aim: The aim of the study was to investigate the effectiveness of software simulations for enhancing basic social communication skills of children with intellectual and developmental disabilities (IDD) and autism spectrum disorder (ASD). **Method:** Three simulations composed of everyday situations: greeting a familiar adult, answering the phone, and participating in the ball game were prepared. 85 children with IDD and ASD participated in 30 sessions in one of four conditions. Participants were videotaped before and after intervention in the natural environment. Behaviors were coded and analyzed to assess basic social communication skills, eye contact, and communication goals.

Results: Significant difference was found between social communication behaviors before and after intervention with no difference between conditions. Communication goals were more evident after intervention across situations. Eye contact increased after intervention in active computer-based intervention with prompting. **Conclusion:** The opportunity to practice simulations taken from everyday life in a structured mode provided the children with a useful environment for learning basic social communication skills and demonstrated the potential of using simulations for enhancing basic social communication skills and transferring the knowledge to the natural environment.

Social media and intellectual disabilities

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Aim: Social media has considerable potential to empower people with intellectual disabilities (ID) and to advocate for their participation and inclusion into society. However, this issue has received little attention in research. The aim of the study was to 'hear the voices', including experiences and difficulties, of adults with ID who use Facebook. **Method:** We conducted a self-report online survey to reach a substantial pool of people with ID ($n = 58$) who use Facebook. The survey included 49 multiple-choice questions focusing on Facebook use and perceptions, and three open-ended questions about the personal experiences of the respondents. **Results:** Respondents with ID visit Facebook at least once a week (67.2%) with no assistance from a caregiver or friend (82.8%), and use it primarily for connecting with people they meet in face-to-face settings rather than people they meet only online (10.5%). Most of them enjoy using Facebook while at the same time they perceive it as an inaccessible environment. **Conclusion:** The survey revealed the benefits as well as difficulties associated with using Facebook by people with ID. Future development of social networking sites should be accommodated to their needs, including simplified version, voice-control programs, and more graphics.

Symposium 3.1. Support Plans and Future Planning for People with IDD

Future planning for people with intellectual disabilities and their ageing family carers in Switzerland

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Aim: Many individuals with intellectual disabilities (ID) live at home with their families. When caregivers grow older, planning for the future represents an important issue to these families. Research indicates that many families do not make plans for future living arrangements. DeBrine et al. (2009) developed a training programme to support these families in their planning. The purpose of this study is to translate and adapt this training to Swiss conditions and to evaluate the intervention. **Method:** The intervention, which supports aging caregivers and adults with ID, consists of a legal and financial training session, followed by five small-group trainings. Pre-test and follow-up surveys were conducted with 17 families participating in the full intervention and 30 control families, taking part only in legal and financial training. **Results:** Outcome measures include future planning activities, discussion of plans with individuals who have ID and choice-making of individuals with ID. The intervention significantly contributed to families completing a letter of intent. At the same time, it increased the extent to which caregivers discussed plans with their relatives with disabilities. **Conclusion:** The training programme supports individuals with ID and their caregivers in planning for the future.

Content analysis of individual support plans for people with intellectual disabilities

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Aim: The study aimed to analyse the person-centeredness, goals, strategies and resources that are described in individual support plans. **Method:** 215 individual support plans (ISP) from eight organizations in the Netherlands were included in this project. All plans were analysed using qualitative and quantitative methods. We looked at the format, the information that was included, the way the plans relate to quality of life domains, the resources that are being used to achieve goals and the relation between support needs and goals. **Results:** Organizations use very different formats for ISP; there is a wide variety in the type and amount of information that is found in ISP. Goals that are set are most frequently related to the domain of physical well-being; and resources are predominantly professional (paid) staff with low involvement of social network resources. **Conclusion:** There is no consensus on what information should be included in an ISP and how this information should be structured. ISP seems to be more an organization-related practice than a person-related support instrument.

Life designing with intellectual disability: domain-specific goals and determinants in adolescents and young adults with intellectual disabilities

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Aim: Current times require individuals to deal with several uncertainties when designing their future. This poses additional challenges to individuals experiencing disability in everyday life. The aim of our study was to describe life designing profiles by analyzing dimensions of future time processing and life goals. **Method:** Forty-six adolescents and young adults with mild to moderate intellectual disability (ID), age ranging from 14 to 40 and comparable for disability severity, were involved. They were given an interview concerning processing of short and long term future time intervals, and future goals (such as work and family hopes). Statistical analyses were conducted on the number of goals across life domains, dimensions of future goals and future time processing in the two groups. **Results:** The number of goals differed across life domains; time processing ability was variable and, more specifically than age, influenced the ability to set, analyze and describe future goals. Confidence and positive attitudes toward the possibility to realize work goals were limited. **Conclusion:** These dimensions are relevant components in future life construction of young adults with ID. They should be systematically addressed in order to decide specific targets of actions, such as interventions on time processing and/or goal definition and construction.

Future time perspective in parents of children and adults with intellectual disability: the role of future planning and quality of life dimensions

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Aim: The aim of the present work was to examine future time perspective in parents who take care of a family member with a disability and its role on quality of life experienced. **Method:** Fifty parents of children or adults with chronic, lifelong disability were interviewed. The Long-Term Personal Direction Scale (Wessman, 1973), the Achievability of Future Goals Scale (Wessman, 1973) and PROSPERA (Soresi, et al., 2012) were used to address these issues. All study participants were also given the Quality of Life Questionnaire (Soresi and Nota, 2007). **Results:** Statistical analyses showed that parents of children with intellectual disabilities (ID) exhibited more marked difficulties in setting goals and in planning strategies for achieving them in the long term; they showed instead a higher sense of achievability of future goals. On the other hand, quality of life experienced by parents of adults with ID was differentially related to their future time perspective profile. **Conclusion:** Length of care, transitions expected in the near future and uncertainty about personal life duration may differently influence dimensions of future time perspective and quality of life experienced by parents of persons with disabilities as a function of their sons' age, thus suggesting different support needs.

Symposium 3.2 Parenting and Families

Parents with intellectual difficulties in Norway: an explorative study

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Aim: Parents with intellectual and/or cognitive difficulties have attracted little attention in Norway. The reason is that they have been seen as an extremely small group. However, results from other countries suggest that this image is likely to be false. The aim of this study is threefold: to construct a more realistic picture of prevalence, to discuss supports and actions from health services and child protection, and to explore experiences of parents. **Method:** A register-based study of people with a diagnosed intellectual disability (ID) combined with case studies in eight municipalities, including local anonymous mapping of parents, focus group interviews with health services/child protection, and individual interviews with parents. **Results:** This group of parents is larger than earlier assumed. They are largely unattended. Working procedures in child protection is not adapted to the needs of these families, but parents tend to be very cooperative. **Conclusion:** The need for a more systematic approach to parents with ID and their children is discussed.

'You've Seen Us!': masculinities in the lives of boys with intellectual disability

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Aim: The aim of this study was to explore whether boys with intellectual disabilities (ID) have ideas of what it means to be a boy, what influenced this and what ideas the boys had about their futures as men. **Method:** Using an approach based on grounded theory, group and individual interviews were conducted with 21 boys in seven groups from a special school during transition into adult life. Innovative methods were used to provoke discussion. These discussions were recorded and then transcribed. **Results:** Findings reveal a developing construct of masculine identity that could be identified as the way we do boy. This is described in four themes: changes, ideals, experiences, and vicariousness. The four themes were instrumental in assisting the boys to think about their identities. However, the opportunities to practice their developing masculinity was limited and the boys talked about their struggles when their attempt to do this resulted in the uncovering of their difference and vulnerability. **Conclusion:** The work concludes with an explanatory theoretical framework for working with boys and men with ID about their masculinity.

A qualitative analysis of the experiences and needs of parents supporting young adolescents with intellectual disability through puberty and emerging sexuality

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Aim: Parents have a central role assisting their children with intellectual disability (ID) with the physical, social and sexual changes during puberty. However there is an absence of literature exploring parental support needs in managing this transition. This study aimed to describe how parents of young adolescents with ID feel they are best supported. **Method:** Using a qualitative descriptive study design, six mothers of adolescents aged between 11 and 15 with ID participated in open-ended interviews. The interviews elicited mothers' experiences of supporting their children through puberty and their views on the type of support and resources needed. Interviews were transcribed and then themed and coded based on the framework developed by Miles and Huberman (1984). **Results:** Emerging themes include normalising pubertal change, the need for individualising education and resources for each family, parental reluctance to think about sexual behaviour in their child and the difficulty for parents in visualising their child in intimate relationships in the future. **Conclusion:** This information highlights the challenges parents face in considering sexuality beyond pubertal changes in their adolescent child with an ID and will inform the development of focused health education services to better support these families.

Symposium 3.3. Subjective Well-Being and Quality of Life

Subjective wellbeing and its correlates among adults diagnosed with comorbid intellectual disability and ADHD

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Aim: The aims of the present study was to empirically explore subjective well-being (SWB) and its correlates among adults diagnosed with comorbid intellectual disability (ID) and attention deficit hyperactivity disorder (ADHD), using the theoretical framework of the Theory of Subjective Well-being Homeostasis (Cummins & Nistico, 2002). **Method:** Two-hundred and forty-six adults with ID completed questionnaires measuring their ADHD symptomatology, SWB, self determination, personal and vocational traits, functional limitation, social exclusion, and community participation. Correlations, multivariate analysis, and logistic regressions were utilized to explore SWB determinants. **Results:** The main findings of SWB within the normative range support the applicability of the theory of subjective well-being homeostasis for understanding SWB in individuals with comorbid ID and ADHD. Moreover, internal and external buffers explained a significant part of the variance in SWB scores. No gender differences were found in reported SWB. However, men's SWB was strongly associated with perception of daily functioning and productivity, while women's SWB was associated with self-determination and was negatively affected by feelings of social isolation and unmet social needs. **Conclusion:** Implications will be discussed.

Bio-psychological, family and school factors in childhood as predictors of adult success and quality of life of persons with borderline IQ

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Aim: In this longitudinal study, we explore whether it is possible to predict quality of life of adults with borderline ID from bio-psychological, family and school characteristics at 13 years of age. **Method:** Participants included Forty-nine 13-year-olds from regular schools with IQ 69-85. Their health status, motivation, social skills and the parents' social economic status (SES) and their aspirations regarding the child's education were assessed. Twenty-one children were transferred to special schools; 28 spent their entire education in regular schools with undiagnosed SEN. Outcomes and quality of life were assessed 23 years later, at 36 years of age. **Results:** The best predictor of adult outcomes was childhood health, IQ, motivation and the parents' SES. For QOL it was childhood health and the parents' SES. **Conclusion:** The role IQ plays depends on the criteria of the success; although IQ efficiently predicts material aspects of the life success, SES and health in the childhood are better predictors of QOL.

Youth and adults with intellectual and developmental disabilities: their own perceptions about their quality of life

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Aim: There is a need to know how youth and adults with intellectual and developmental disabilities (IDD) perceive their quality of life, in order to promote their rights to participation and social inclusion. **Method:** This is a qualitative research study. Data gathering utilized focus groups to gather information about the self-perception of 14 youth and adults with IDD, concerning their quality of life. Participants attended at two working centers in Viña del Mar and Santiago de Chile. The analyses for the textual data were performed by using the Atlas/Ti 7 Software. For the integration and description of the findings, a content analysis as proposed by Mayring (2000) was carried out. **Results:** Participants mentioned seven domains of the model proposed by Schalock and Verdugo (2002): emotional and physical wellbeing, personal development, self-determination, rights, social inclusion and interpersonal relationships. Material well-being was not mentioned. **Conclusion:** It is necessary to involve people with IDD to describe their quality of life and what support they require to be causal agents in their lives.

Empowerment of self-determination

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Aim: We sought to improve the quality of life and to empower the self-determination of care receivers in order to develop a self-improving organization, where pro-active staff members act to improve care and support. **Method:** Action research was used to improve practice. In this project, care receivers and caregivers came with ideas in co-creation to improve the quality of life of care receivers. Specially trained coaches helped to develop these ideas, including the necessary finances. The direct caregivers executed the plan themselves. **Results:** An enormous improvement is achieved by 140 projects, that were developed so far with a budget of 150.000 Euros a year, which is 0.002% of the total budget. Results were measured per project by establishing a baseline before and a follow-up measurement afterwards. **Conclusion:** With this project a strong incentive was given to support empowerment and emancipation of both care receivers and caregivers, now and in the future. Top down a clear mission statement was communicated and top down the caregivers were encouraged to perform their demand-based care and support. The direct caregivers were supported by the higher management, instead of getting orders on how to execute their work.

Symposium 3.4. Self-determination, Social Planning, Mutual Caring and Volunteering

An exploration of mutual caring relationships involving individuals with intellectual disabilities

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Aim: This project builds upon the current knowledge base regarding the experiences and needs of individuals in mutual caring relationships. Due to an increase in longevity the incidence of mutual caring is growing, but the extent of this increase is unknown. For individuals with intellectual disabilities (ID) this caring role is often associated with a number of challenges such as increased

feelings of isolation, receiving little or no information that is accessible and easy to understand, and not being recognised for their role as a carer. **Method:** Semi-structured interviews are currently being undertaken to explore professionals and mutual carers' perspectives regarding the roles, experiences, needs, relationships, and service provision for individuals in mutual caring relationships. **Results:** Results are not yet available. **Conclusion:** This research has the potential to have an impact on the lives of mutual carers at many levels. This could be at an individual level through the promotion of positive practice and could also have a wider impact in contributing to an evidence base that can be used by policy makers to inform and shape future policies. This impact could also extend to identifying gaps in current service provision and exploring additional resources needed to meet the needs of carers and carers with ID.

Considering weak interests: participative practice in social planning strategies with persons with intellectual disabilities

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Aim: Social planning processes are still dominated by the perspective and interests of financiers, service providers and local politics. The political influence of persons with intellectual disabilities (ID) as service users is limited. The research project 'SoPHiA' on inclusive social planning strategies for elderly persons with and without lifelong disabilities surveys so-called 'weak interests' of persons with profound and multiple disabilities. **Method:** The project identifies measures for participation in planning procedures on different levels, i.e. interviews, group discussions, workshops, open space discussions in the community. It focusses especially weak interests as base for social planning. Different methods, i.e. assisted or representative forward-looking statements, will be sampled. **Results:** Persons with 'weak interests' can be enabled to experience different levels of participation and to articulate their vision of living in the community. They have very clear conceptions of their needs to realize self-determined ways of constructing everyday life concerning social services, daycare as well as leisure activities and social relationships. **Conclusion:** The participation of all (potential) service users is difficult to realize and necessary for planning adequate and inclusive service arrangements for elderly persons with and without lifelong disabilities.

Self-determination: conceptions of youth and adults with intellectual or developmental disabilities

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Aim: Knowing how people with intellectual or developmental disabilities (IDD) conceive self-determination and how they experience it daily will allow us to create opportunities for community involvement thus be causal agents in their lives. **Method:** A qualitative study was undertaken. The data gathering used the technique of focus groups to collect information about the self-perception of youth and adults with IDD, on the concept of self-determination and how they experience it in their daily lives. Participants were 14 individuals with IDD who attended two work centers in the towns of Viña del Mar and Santiago de Chile. Analyses were performed by using the Atlas/Ti 7 software. Content analysis was used to describe and integrate the findings based on the model proposed by Wehmeyer (2001), which suggests that the main characteristics of self-determined behavior is characterized by autonomous functioning, self-regulation, psychological empowerment and self-realization. **Results:** The conception of what self-determination is related to making decisions and to a lesser extent to problem solving. **Conclusion:** Self-determined behavior from the conception of people with IDD, raises the need to provide opportunities for participation in the making of their own decisions and independent living, thus promoting the achievement of personal outcomes.

Supporting volunteering activities by Swiss adults with intellectual disabilities

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Aim: This study explores the challenges, opportunities and support needs of volunteers with intellectual disabilities (ID) in order to develop recommendations to support volunteering by people with ID in Switzerland. **Method:** A cross-sectional online survey was sent to 750 placement offices and service organisations for people with ID (responding quote was 32%) and semi-structured interviews were conducted with six volunteers with ID in Switzerland. **Results:** Few people with ID are engaged as volunteers in Switzerland. Organisations that offer volunteering opportunities to people with ID formulate communication strategies and tend to allow volunteers with ID more time to complete their tasks. Volunteering is influenced by individual motivational factors, such as a desire for recognition or previous mistreatment.

People with ID need appropriate support to be able to volunteer.
Conclusion: Volunteering is one way in which people with ID can participate in society and receive recognition for their efforts. People with ID require appropriate information and guidelines. Services need ideas in order to develop tailored volunteering activities and information on how to offer specific forms of recognition. It is important that individual and social requirements are met.

Symposium 3.6. Growing Older and People with IDD – I

End of life care for people with intellectual disability

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Aim: Increase in the life expectancy of a person with an intellectual disability (ID) has also resulted the morbidity and mortality patterns shifting. These changing health demographics are resulting in an increasing need for the provision of, and access to, end of life care. The purpose of the current study was to explore and examine the needs of people with ID and their support network as they approach the end of their life. **Method:** A series of focus groups, composed of both paid and unpaid carers across rural and metropolitan areas of Australia, discussed the end of life needs of people with ID and their network of family, friends and supporters. **Results:** The paper will report preliminary findings of the research, with a focus on how a dignified and supportive end of life for people with ID can be provided across both rural and metropolitan localities. **Conclusion:** End of life care for people with ID is an area receiving an increased research focus, however the differences between rural and metropolitan areas are still largely unexplored. Key differences in issues such as service access require remediation to better meet the needs of individuals.

A GIS-based planning tool for the socio-spatial analysis of the elderly population with and without disabilities and their support

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Aim: The growing number of elderly people with or without lifelong disabilities and the plea for inclusion require a collaborative planning approach for services on the community level. For developing a policy that enables all inhabitants to age in place, planning bodies are supposed to have an overview of diverse subpopulations within a community and of the local structures of the different service systems. **Method:** A geographic information system (GIS) is used to analyze and visualize spatial aspects of social data. A GIS integrates district-related data about social institutions and services from the aged care and the disability support sector as well as data about the elderly population in general and specific data about those with lifelong disabilities. The data stem from various administrative sources. **Results:** A GIS is designed for an urban and for a rural district, including care services for the elderly, services for persons with disabilities, counseling services, agencies for volunteers, meeting points as well as demographic data and projections. **Conclusion:** GIS-based tools help to overcome separated paths of local planning. They may also improve the cooperation within the local administration if various departments use, combine and add data for other purposes.

Inclusive social planning for elderly persons with lifelong disabilities in the community

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Aim: To meet age-related challenges, planning policies for care arrangements for persons with lifelong disabilities have to develop inclusive strategies. To make welfare resources available for persons with disabilities, the attempt to bridge policies has to start in the field of social planning. **Method:** The analysis of documents on the existing local procedures of planning in an urban and a rural community reveals different routines and cultures. Based on a first initiating meeting with interested citizens and stakeholders in the selected communities, topic-related working groups will meet throughout a year to identify local resources and challenges and to propose local solutions for effective support arrangements for elderly persons. **Results:** Preliminary results of the ongoing project show significant differences in practices of social planning between urban and rural settings and indicate conflicting interests and differences of power. A participatory approach is essential to make sure that weak interests are considered. **Conclusion:** Social services have to prepare for a growing number of elderly persons with lifelong disabilities. Inclusion in the

field of social planning is an important task for the future and an open-ended collaborative process.

Written policies on end-of-life care in residential homes for adults with intellectual disabilities

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Aim: Due to the increasing longevity, people with intellectual disabilities (ID) are likely to die over a prolonged period of time because incurable, chronic illnesses occur more frequently with old age. The objective of the study was to analyse the presence, content and implementation of policies on end-of-life care in residential homes accommodating people with ID in Switzerland. **Method:** A cross-sectional online survey with directors of all residential homes in Switzerland ($N = 437$) was conducted between October 2012 and January 2013. The response rate was 58%. Descriptive statistics and chi-squared tests were used to analyse data. **Results:** One third of the residential homes provide care to their residents until they die. Written policies on end-of-life care are available in 31 residential homes. The implementation of the written policies on end-of-life care is ongoing. Little training on end-of-life care has been conducted. **Conclusion:** It is important to systematically provide training on end-of-life care within the residential homes for adults with ID in Switzerland. Further research on the impact of written end-of-life care policies on self-determination in end-of-life decisions of people with ID will be done.

Symposium 3.7. Growing Older and People with IDD - 2

Ageing-in-a-chosen-place: commonalities and dissonance in life choice-making in elders with and without intellectual disability

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Aim: This study aimed to explore perceptions of ageing amongst people who were ageing both with and without lifelong intellectual disabilities (ID). The comparative study was undertaken with older adults, residing in either rural or urban areas of Australia with a focus on the facilitators of and impediments to ageing-in-place. **Method:** Qualitative interviews were conducted with 46 self-nominated older participants, aged over 55 years (21 female, 25 male) both with ($n = 34$) and without ($n = 12$) ID (eligible for mainstream aged care support) and 40 (32 female, eight male) of their carers using semi-structured interview guides developed for the project. Participants were living either at home or in aged-care facilities and data were also collected on key demographic factors, service availability, and life histories. **Results:** Preliminary findings show the concept of 'ageing-in-a-chosen-place' rather than 'ageing-in-place' is of importance to both groups. The capacity underpinning that choice (due to socio-economic and geographical factors) seemingly begins to differentiate the experiences. **Conclusion:** As life expectancy continues to rise around the world support structures based around assessed individuals' needs are necessary. Such support models must consider the differential availability of supports based on geographic location and the channeling of public funds to areas with deficient public services.

The relationship of person-environment fit to older adults' perceptions of autonomy, competency and satisfaction

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Aim: The overlay of age-related cognitive and physical impairments onto existing intellectual and physical disabilities, a paucity of informal social relationships, a limited education and low income levels place the current generation of aging adults with intellectual disabilities (ID) at risk of premature behavioral limitations and increased dependency. This presentation will report on the qualitative component of a mixed method study investigating the relationship of person-environment fit to older consumers' perceptions of autonomy, competency and satisfaction. **Method:** Face-to-face, in home interviews were conducted with 91 consumers aged 40 through 91 living in group homes, supervised apartments and supported living settings. The consumer interview, developed by the researcher, collected demographic and descriptive information regarding the participant and their home environment, and qualitative information regarding global feelings surrounding the participant's experience of the home. A multi-stage data analysis process identified emergent themes. **Results:** Consumer concerns included issues related to autonomy versus dependence, belonging versus isolation, residential permanency versus transience, and social inclusion versus exclusion. Issues of environmental accessibility, ownership and privacy arose repeatedly.

Conclusion: Consumers need positive task performance experiences. Appropriate person-environment fit fosters opportunities to experience both self-reliance and interdependence.

Exploring carers' experience of end of life for people with intellectual disabilities as they age

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Aim: To explore carers' experience of death of a nationally representative sample of adults aged 40+ with intellectual disabilities (ID), drawn from the National Intellectual Disability database in Ireland. **Method:** Wave two data collection for the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing identified 40 deaths amongst 753 initial participants. Close caregivers of decedents were interviewed about their end of life experiences using semi-structured interviews, informed by the VOICES questionnaire. To date 17 female and 23 male decedents with an average age of 61.85 (range = 45–85, SD = 11.41 years), mainly with moderate (50%) or severe or profound (42.5%) ID have been identified. Descriptive analysis using *svs* version 20 was triangulated with content analysis of qualitative material generated by caregivers. **Results:** A profile of an ID service, residential-setting-dwelling group of older adults, with primarily moderate, severe and profound ID, presenting with chronic conditions and multi-morbidity at end of life emerged. Further results are forthcoming and will be of particular note, due to the population-based longitudinal approach taken in the study. **Conclusion:** Results will inform care planning and policy development for end of life care provision for this ageing population, presenting with complex needs at end of life.

When ageing in place is no longer viable: transitions to a higher support home for persons with an intellectual disability and dementia

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Aim: The study describes an example of decision making processes and outcomes of a planned transition for women with intellectual disabilities (ID) and dementia moving into a specialized dementia unit. **Method:** A case study was constructed of the transition process for twin sisters aged 57 years, both with a moderate ID and a diagnosis of dementia who moved to a specialized dementia unit. Data was gathered using staff and family interviews on presenting concerns, decision-making processes, design and implementation of the transition and outcomes. **Results:** Successful implementation of a transition in care was realized using a dementia-capable, person-centred approach, and with collaboration between staff and families in the prior and in the specialized placement. **Conclusion:** Transition processes can be very stressful for the person with dementia, their families and their care givers. This case study demonstrates the value of a person-centred model for transitions that genuinely helps persons with an ID and dementia as they move from one setting to the next.

Symposium 3.8. Ageing, Retirement and Longevity in People with IDD

Retirement from mainstream employment: older workers with intellectual disabilities and their plans for life after work

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Aim: It's been nearly 30 years since Disability Employment Services (DES) were introduced in Australia to support people with intellectual disabilities (ID) to gain and sustain jobs in the mainstream workforce. Many of the pioneer workers with ID who entered employment as young adults are now retiring or heading toward retirement. This study explores the perceptions of retirement of these workers, their aspirations for life after work and what retirement planning they have undertaken. **Method:** Semi-structured individual interviews were undertaken with 14 people with ID aged over 40. Participants include those currently working in the mainstream workforce with support from a DES, and those who have recently retired. **Results:** Difficulty with transport to community based retirement activities and lack of information on available options were barriers for many participants. Some participants expressed clear ideas on activities they would like to pursue in retirement but did not appear to have, within their existing formal and informal networks, the resources or support required for them to engage in these activities, particularly in relation to desired volunteering roles. **Conclusion:** These results will be utilised in developing a person-centred pilot program to support older workers with ID as they transition from mainstream employment into retirement.

Life expectancy of persons with intellectual disabilities in Germany estimated by exponential regression

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Aim: Specific age-related mortality rates are necessary to project the future age structure of persons with intellectual disabilities (ID). This study aims to calculate age-related mortality rates and the average life expectancy of persons with ID in Germany by an exponential regression. **Method:** For two samples person-related data for the years 2007–2010 were analyzed. The first sample includes all adult persons with ID receiving support in residential institutions or group homes in Westphalia (about 13,500 persons per year). The second sample consists of 11,000 adults with ID in various residential settings in Baden-Wuerttemberg. For both samples tables on age-related survival rates for males and females with ID were created. **Results:** The average life expectancy of men with ID in Westphalia is 70.9 years, in the Baden-Wuerttemberg sample it is 65.3 years (general male population in Germany for 2007–2009: 77.3 years). Women with ID reach a life expectancy of 72.8 years in Westphalia and 69.9 years in Baden-Wuerttemberg (general female population: 82.5 years). **Conclusion:** Comparing the results with other studies, the trend of increasing life expectancies of persons with ID is confirmed. Persons with ID still have a lower average life expectancy than the general population, partly due to subgroups with well-known low life expectancies.

Looking at ageing and retirement options for adults with intellectual disabilities

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Aim: The aim of the study was to examine what people with intellectual disabilities (ID) would like to do in their old age/retirement, and family carers' aspirations for their relative. **Method:** The study was conducted within one region of the UK (Northern Ireland) and comprised of nine focus groups with adults with ID and eight focus groups with families. Data were analysed using Newell and Burnard's thematic content analysis Framework (2006). **Results:** Findings highlighted a number of key areas: being involved in planning for the future, feeling empowered, feeling safe/secure, maintaining knowledge/skills, having meaningful relationships/support, and maintaining good health and wellbeing. Findings from service users/families revealed similar aspirations for both, although families indicated their worry/stress about planning for the future for their son/daughter with ID and their feelings of frustration/isolation with ID/health services. **Conclusion:** The findings from this study link with previous work on ageing and ID as well as the WHO Active Ageing Framework (2002). This study allows for recommendations to be made to improve the service provision, as well as establishing what supports need to be put in place to ensure an effective transition from adult services to one geared to meet the needs of older persons with ID.

Development of a support program for relatives of seniors with intellectual disabilities in Norway

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Aim: The aging process starts at an early age for some people with intellectual disabilities (ID). For relatives this involves additional challenges. In Norway, little has been done by public authorities to establish information and support programs for relatives of people with ID who are getting old. **Method:** A project was initiated between non-governmental organizations (NGO), service providers and a specialist healthcare service to develop support programs for relatives of seniors with ID. Through education and sharing experience, participants have gained knowledge and support to cope with the practical and emotional aspects of their situation. A quantitative survey was conducted to evaluate the support program model and a qualitative survey to investigate how relatives experience aging in their family members with ID. **Results:** The project demonstrated that relatives need information and support. It was challenging to make the municipalities aware of the support program. The parents were worried about the quality of care their children would receive after their own death. **Conclusion:** The program was perceived as useful. Today municipalities and NGO's can apply for financial and practical support from Norwegian authorities to arrange the program locally through the national Dementia Plan 2015.

Symposium 3.9. Movement, Participation and QOL for People with PIMD

Profound intellectual and multiple disabilities

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Aim: The Swedish personal assistance system makes it possible for persons with severe disabilities, including children with profound intellectual and multiple disabilities (PIMD), to receive a subsidized personal assistant. This assistant may be either external or parental (i.e. a father or mother paid as a personal assistant for his or her child). Participation in activities beyond the household, i.e. a child's societal integration, is important for the child's development, including those with severe disabilities. This study explores whether the types and frequency of activities for children with PIMD are related to his or her type of personal assistant (i.e. external or parental). **Method:** A descriptive, comparative study was undertaken. A questionnaire was answered by 60 families providing quantitative data about personal assistance type and the child's activities. **Results:** The children with external personal assistants participated more frequently in community-related activities than children with just parental personal assistants. **Conclusion:** Participation in activities beyond the household is not just important for healthy development. It is also imperative for a child's social inclusion. Thus, the planning and implementation of personal assistance must be mindful of the activity type and frequency in which the child participates.

Motor activation and the role of theory in people with severe or profound intellectual disabilities

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Aim: The needs of people with severe or profound intellectual disabilities (ID) place specific challenges on therapists who provide service delivery in the motor domain. Theories of motor control, motor learning, and motor development could provide a guide to clinical practice. The question arises as to which theories are actually used by therapists in the management of people with severe or profound ID. **Method:** A systematic review of empirical studies published between 1982 and 2012 was conducted with four databases (MEDLINE, PsycINFO, ERIC and CINAHL). In addition, semi-structured interviews were conducted with 50 physical therapists. **Results:** Few studies included in the review were driven by explicit theoretical considerations, with little information about how theory was used and no obvious association with intervention content or effect. When theory was implicitly used in the intervention studies, it tended to reflect a behaviourist perspective. Most therapists perceived theory to be important as a guide to practice, however, they generally did not have a consciously thought out systematic approach to doing so. The most frequently used theoretical model was a remedial approach.

Conclusion: Gaps were identified in the literature and therapists' responses suggesting the need to test (current) theories and build on them.

Evaluating quality of life of children with multiple disabilities: issues and methodological questions

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Aim: Research work conducted in France to construct a quality of life (QOL) scale suited to 6–14 year-old children with multiple disabilities serves as a basis to discuss the relevance of such scales for that particular population, whose communication skills are extremely poor. **Method:** A QOL scale was devised with help from focus groups run with parents, siblings and professionals so as to evaluate quality of life for children with multiple disabilities via what is said by proxies. This hetero-evaluation scale included five domains and 55 items and was validated with 113 children from across 19 French institutions. **Results:** While the tool's construction methodology proved workable, its limits need to be recognised with an apparent need for it to be supplemented by a more 'clinical' tool. **Conclusion:** exploration of the subjective experience of children with multiple disabilities using proxies and an assessment mechanism opens up perspectives for the consideration of an innovative use of such tools and/or the need to devise new methods.

Practice-based movement-oriented interventions in people with profound intellectual and multiple disabilities: lessons to learn

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Aim: The importance of being physically active for people with intellectual disabilities (ID) is widely recognized; being physically active generates positive results for physical and mental health and overall development. However, research shows that people with profound intellectual and multiple disabilities (PIMD), are hardly stimulated to be physically active in daily life. This means that their opportunities to be engaged in everyday activities are limited besides the negative consequences on their cognitive, social and emotional development and their health. Recently, several movement-oriented interventions were implemented in practice in order to stimulate people with PIMD to be more physically active. **Method:** Data were gathered (by observations and existing instruments) about three practice-based movement-oriented interventions, implemented in the support of persons with PIMD, namely 'activity plans', 'motor activation integrated in general activities' and 'motor experience'. We analysed their general content, theoretical basis and effects on alertness, challenging behaviour, functional abilities etc. **Results:** Results will be presented. **Conclusion:** The described movement-oriented interventions are hardly theory driven. Their content differs and is only briefly described or documented. However, different effects at several domains are seen in practice in people with PIMD.