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378 Roundtables

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Roundtables
Theme: Health

Challenges in health surveillance

E. Emerson (eric.emerson@lancaster.ac.uk)**, H. Ouellette-Kuntz,
C. Hatton & G. Glover**
Centre for Disability Research and Policy, University of Sydney, Lidcombe, NSW, Australia

Purpose: To identify and discuss: (i) key challenges in developing systems to monitor the health of people with intellectual disabilities; (ii) potential solutions to these challenges. **Rationale:** The session will be chaired by Eric Emerson. The first part of the session will consist of two 15 min presentations. Helene Ouellette-Kuntz will provide an overview of the key challenges faced when developing the H-CARDD Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario. Following this Gyles Glover and Chris Hatton will provide an overview of the key challenges faced by the intellectual disability work stream in Public Health England. Following these there will be a facilitated discussion of issues arising from the presentations and the experiences of roundtable participants.

The development of European norms for palliative care of people with intellectual disabilities

I. Tuffrey-Wijne (ituffrey@sgul.ac.uk)**, L. Curfs, A. Dusart,
C. Hoenger, L. McEnhill, D. McLaughlin, D. Oliver, S. Read,
K. Ryan, D. Satgé, B. Straßer & B. Westergaard**
Kingston University and St George's, University of London, London, UK

Purpose: The European Association for Palliative Care (EAPC) approved a 2-year taskforce on palliative care for people with intellectual disabilities (2012–2014). This roundtable aims to discuss the development of consensus norms for palliative care of people with intellectual disabilities in Europe. **Rationale:** Draft norms were agreed with a steering group of 14 experts in nine countries. These were sent via an electronic survey to a 'group of experts' across Europe, who indicated their level of agreement with each statement and provided further comment. The norms were accepted if there was sufficient agreement among all respondents. The draft norms consisted of 52 items in 14 categories: equity of access, communication, recognising the need for palliative care, assessment of total needs, symptom management, end-of-life decision making, involving those that matter, collaboration, support for families and carers, preparing for death, bereavement support, education/training, and developing/managing services. Eighty usable survey responses were received from 17 European countries. There was sufficient agreement to accept the norms, although several suggested changes in wording were agreed with the steering group. The final norms are awaiting approval from the EAPC Board of Directors. Further study is needed to assess the barriers and to achieving these consensus norms throughout Europe.

Primary health care and community based living

H. van Schrojenstein Lantman-de Valk (hennylantman@xs4all.nl)**,
A. Coppus, M. Mastebroek, E. Bakker-van Gijssel &
M. Heutmekers**
The Netherlands

Purpose: The evidence for health inequities in people with intellectual disabilities (ID) are abundant. Within primary health care, general practitioners not only have high workloads but also feel limitations in providing tailored health care for this vulnerable group. The expertise of ID physicians is available, but could be used more effectively. Currently there are serious budget cuts within health care in our country. At the same time, the emancipation of people with ID results in advocates who want to speak up for themselves. This inspired us to search for evidence based support to improve primary care and to support practice by a dedicated primary health care clinic for people with ID. **Rationale:** Worldwide, there is concern how to diminish the health inequities for this group. We want to discuss our results regarding research within primary health care so far with a broader audience so as to inspire and to learn from other groups. Results to be presented are: (i) Health information exchange within primary health care; (ii) The quality of out of hours care for people with ID; (iii) Preventive health screening; (iv) Experiences form a dedicated down syndrome clinic; (v) First results from our primary health care clinic.

Palliative care for adults with ID in Europe

M.T. Wicki (monika.wicki@hfh.ch)**, S. Meier, J. Adler, I. Tuffrey
Wijne, M. McCarron & L. Probs**
University of Applied Sciences of Special Needs Education, Zurich, Switzerland

Purpose: The aim of this roundtable is to discuss results of recent studies and projects focusing on the issue palliative care for people with ID in Europe. **Rationale:** There is a growing interest in the palliative care needs of people with ID. During the last decade several studies highlighted the barriers and disparities that people with ID face at the end of their lives. The European Taskforce on Palliative Care for People with ID formulated European standards and a white paper which will be presented by Irene Tuffrey-Wijne. Various material was developed to promote self-determination on end-of-life decisions for people with ID. Some of them are presented by Monika T. Wicki who will also provide first results of the Swiss study PALCAP. Several training programs have been set up and evaluated. One training program, developed in Switzerland, is presented by Laetitia Probst. Mary McCarron will discuss palliative care for people with ID and dementia. The roundtable gives an overview of the state of the art and activities in European countries. The possibility will be given to discuss planned projects and the idea for developing a survey to compare data from different European countries.

Theme: Law and Liberty of the Person

Access to specialised victim support services for women with disabilities who have experienced violence

S Mandl (sabine.mandl@univie.ac.at)**, C. Sprenger, A. Schachner,
R. Traustadottir, S. Woodin, S. Sha & M. Schröttle**
University of Vienna, Vienna, Austria

Purpose: To discuss how to provide a full barrier-free access to specialised victim support services for women with disabilities (different impairments) who have experienced violence and improve the quality of services. **Rationale:** The EU project is carried out by four countries, Austria (lead), Germany, UK and Iceland. On all national levels research is being conducted and is serving as a basis for comparative studies. The methodology comprises desk research on the legal and policy framework and two empirical phases (on individual and structural level). To get a better insight in the violent experiences of women and their access to victim support services, focus group discussions as well as in-depth interviews were carried out. On the level of victim support services an online-survey and expert interviews were conducted. These results can already be presented. In a next step, good-practice examples will be identified and recommendations formulated for policy makers and specialised victim support services. So far women with disabilities confirmed the research hypothesis that they are faced with various barriers when addressing victim support services. Victim support services have to be more sensitized and informed about the needs of women with disabilities in order to be able to provide appropriate support measures.

Equal recognition before the law: reflections on the significance of Article 12 of the Convention on the Rights of Persons with Disabilities

M. Redley (mr382@medschl.cam.ac.uk)**, I.C.H. Clare &
A.J. Holland**
Department of Psychiatry, Unversity of Cambridge, Cambridge, UK

Purpose: There is a need to consider the implications of Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD), which asserts that all people with disabilities, including those with intellectual disabilities, have a right to equal recognition before the law and that legal capacity be treated as a universal attribute adhering to all persons no matter the circumstances. **Rationale:** The arguments presented by the Committee on the Rights of Persons with Disabilities in their recent defence of Article 12 are contrasted with the law in England and Wales, which not only permits substitute decision-making, but also permits both deprivations of liberty and detention against a person's will. The arguments for and against the CRPD's affirmation of universal legal capacity are assessed in terms of the likely risks and benefits to persons with an intellectual disability. The CRPD's starting point must be a presumption of both legal capacity and mental capacity. However, ignoring the impact that some disabilities can have on a person's capacity to make one or more decisions undermines the CRPD's credibility, while also putting people's health and welfare at risk.

End-of-life issues and euthanasia and persons with PIMD

C. Vlaskamp (c.vlaskamp@rug.nl) & **P. Rijkhoek**
University of Groningen, The Netherlands

Purpose: To draw up a position paper on end-of-life issues in reference to people with PIMD, with specific focus on euthanasia. Contents of the position paper will be tri-fold: medical / legal / ethical issues. **Rationale:** This issue involves parents/siblings who are caught in the dilemma of seeing their child/sibling with PIMD suffer endless pain and misery, and wishing it could end; and unbearable suffering of parents to face their child/siblings death. People with PIMD and their parents/families may encounter specialist physicians in hospitals who argue against resuscitation or even use of antibiotics that may be needed (presumably because the physician thinks life with PIMD is meaningless), but it might also be that parents wish their child's suffering needs to be ended. Legal issues arise when parents request euthanasia. We would like to discuss medical / health issues, and make clear what boundaries there are in trying to relieve suffering. We would like the input from several countries and several professions to find similarities or differences in ethical, medical and legal issues regarding euthanasia or other end-of-life issues. Also, parents will be important in contributing to this discussion.

Theme: Living in the Community

The role of ideology in service development and design

J.D. Beadle-Brown (j.d.beadle-brown@kent.ac.uk) **& C. Hatton**
Tizard Centre, University of Kent, Canterbury, Kent, UK

Purpose: This roundtable will discuss current ideologies being used to drive services and support for people with disabilities across the world and will consider the need to rekindle the ideological drive behind the development of community based services. **Rationale:** One of the core drivers of change in the process of deinstitutionalization has been ideology, in particular normalization. Recent mapping by the Comparative Policy and Practice SIRG has shown trends towards slowing or complete arrest of the process of deinstitutionalization and in some cases a trend towards re-institutionalization. As part of understanding the reasons behind these trends this roundtable will bring together IASSID members to discuss the need to rekindle the ideological drive and the reasons why the UN Convention does not appear to be as strong a driver as normalization used to be. Four short presentations will serve to raise key ideological approaches, issues and challenges. They will focus on current the role of normalisation, human rights based approaches, person-centred approaches and 'post-ideological' emphases on cost-effectiveness. Results from a survey of IASSID members will be presented. The discussion will feed into a paper on this topic for a Special Issue of JPPID and potentially an SIRG position statement.

Social inclusion in the neighbourhood: bonding and bridging multiple perspectives

T. Overmars-Marx (t.overmars-marx@vu.nl), **A. Brummel, F. Bredewold, R. Taha Mcheimech & V. Cobigo**
Faculty of Social Science, VU University Amsterdam

Purpose: Social inclusion in the neighbourhood of people with IDD demands a multidisciplinary approach to understand the complex interactions between individuals and their community. Despite decades of research on this subject, some questions remain unanswered. How important are neighbours and (informal) networks for social inclusion? What do they contribute to social inclusion? Could theories of social capital (e.g. Bourdieu, Putnam) contribute to a better understanding of social inclusion? **Rationale:** In this session, we explore and discuss the knowledge and experiences from different countries and point out issues for both practice and research. We want to link researchers, students, policy makers, professionals, caregivers and advocates in order to stimulate an international discussion across disciplines and lived experiences. Attendees will complete a questionnaire on their definition of neighbourhood and community. Our aim is to present and discuss the contribution of various groups to social inclusion: neighbours, informal support systems, small groups and grassroots organizations in the neighbourhood. We also question the differences between neighbourhood and community. These questions and their implications for research and practice will be examined with the participation of attendees, and will be summarized in a working paper.

Reducing the use of restraint and restrictive approaches to support ordinary community living

R. Deveau (roydeveau@aol.com), **A. McDonnell, P. McGill, K. Poon & L. Webber**
Tizard Centre, University of Kent, Canterbury, Kent, UK

Purpose: For people with intellectual disabilities exhibiting challenging behaviour(s), being subject to restrictive approaches (e.g. physical and mechanical restraint, seclusion) is associated with being cared for in institutions rather than ordinary homes and communities. Therefore, research, policy and practice that support reducing restrictive approaches are likely to support community living. We present research on the relationship between legal approaches, frontline leadership, professional views and direct staff practice and reduction in restrictive practices. **Rationale:** Many countries have a policy framework which promotes supporting people with intellectual disabilities to live in ordinary homes and communities. However, evidence of continuing institutionalised, abusive and restrictive care continues to emerge. Legal and policy initiatives appear to have mixed influence upon frontline practice. Scientific approaches may be enhanced with contributions from different cultures and nations. In addition, scientific focus upon the implementation of policy and research into practice is central for intellectual disability and the area of restrictive practice brings together the themes of policy, research and practice with clarity and importance. We hope to develop potential for international collaboration and comparative research focussed upon policy and practice in reducing restrictive approaches and improving inclusion of people with the most complex needs in ordinary communities.

Close collaborations with and within practice

P. Embregts (p.j.c.m.embregts@uvt.nl) **& W. van Oorsouw**
Tranzo Scientific Center for Care and Welfare, Tilburg University, The Netherlands

Purpose: The Academic Collaborative Center for Living with an Intellectual Disability, aims to build a bridge between science and practice. In this roundtable session we will explain the goals and structure of the Centre and present examples of research that successfully included the perspectives of clients, relatives and professionals. **Rationale:** Research themes are based on common needs of our partners (seven Dutch-health-care organisations, Tilburg University, and an advocacy organisation for people with intellectual disability). Partners share knowledge, research-based products and provide opportunities for data collection. It is possible to include the perspectives of clients, relatives and professionals more than had previously been done. For example, we analysed health-care questions, clients and relatives participated in focus groups, conducted interviews about experiences, opinions and perceptions, and included them as co-researchers. Also we conducted studies that investigated perceptions of care-staff to find out what they considered important aspects in the relationship with their clients. Together, partners in the Academic Collaborative Center identify relevant research questions and search for answers. The relationships between clients, relatives and professionals have become the essence of our research programmes. Development and implementation of knowledge generated by these projects might be more likely to succeed due to shared ownership.

Pushing the frontiers of knowledge in the field of parents and parenting with intellectual disability [1]: 'there is nothing so practical as a good theory'

D. McConnell (david.mcconnell@ualberta.ca), **M. Feldman, P. Granqvist, H. Sigurjonsdottir, L. Pacheco, G. Llewellyn & R. Mildon**
International panel

Purpose: In this, the first of two roundtable discussions concerned with 'pushing the frontiers of knowledge', an international panel will 'think theoretically' about parents and parenting with intellectual disability. **Rationale:** The jumping-off point for the discussion is Kurt Lewin's epigram, 'there is nothing so practical as a good theory'. Panelists will present their perspectives on whether, and if so how theory matters, both to research and practice. Then utilising data from their research, the panelists will discuss the potential value and applications of various psychological and sociocultural theories, that is, to advance understanding of the diverse capabilities and support needs of parents with intellectual disability and their children. 'Theories' to be introduced into the discussion include Applied Behaviour Analysis (concerned with how people learn), Attachment theory (concerned with the importance of early psychological bonds), Social-ecological theory (concerned with the dynamic interrelations between person and environment), Intersectionality theory (concerned with the formation of social identity), and knowledge exchange and implementation theory (concerned with the spread and uptake of new ideas). The discussion will foster understanding of some of the big ideas driving research and innovation in the field.

Pushing the frontiers of knowledge in the field of parents and parenting with intellectual disability [2]: utilising population-based and administrative data to push the frontiers of knowledge

D. McConnell (david.mcconnell@ualberta.ca), **E. Emerson, G. Llewellyn, B. Horglund, T. Laliberte, G. Hindmarsh, L. Hahn, M. Aunos & N. Wing Man**
International panel

Purpose: In this, the second of two roundtable discussions, an international panel will present findings from studies that have utilised (or are utilising) population-based and/or administrative data to push the frontiers of knowledge in the field of parents and parenting with intellectual disability. **Rationale:** Presentations will include data on the prevalence, health and wellbeing of parents with intellectual disabilities and their children. The panelists will discuss the knowledge-creating potential of secondary data analysis; the limitations of secondary data analysis (e.g., with respect to the types of questions one may ask); and, the need for a variety of 'old' and new or innovative research methods to push the frontiers of knowledge. The Roundtable will conclude with an open discussion for the purposes of identifying directions for future research and strategies to promote knowledge exchange and implementation.

A framework for an integrated process for improving quality of life

A. Schippers (alice.schippers@tiscali.nl)**, I. Brown, M.A. Verdugo, D. Roth & L. Croce**
The Netherlands

Purpose: This Roundtable presents a conceptual framework for integrating quality of life at the policy, practice, and personal levels, and for recording overall outcomes. It also demonstrates application of the framework through two case examples. **Rationale:** Quality of life for individuals and families is best realized if policy and practice are integrated with one another, and also with interventions at the personal level. In 2012, Schalock and Verdugo introduced a method for integrating the former, and Schippers, Zuna, and Brown recently addressed the latter by adding a third level: individual- and family-level living. Also, indicators of quality of life outcomes were added to the framework; these are considered to be the focus in which we are ultimately interested. Published literature has called for applying quality of life conceptual work to practical experience; in response, this workshop illustrates, through two case examples, how the integrated framework is being applied in services in two countries. Factors that facilitate and detract from such application are identified and discussed in relation to the major philosophical views of our field. This workshop presents an integrated conceptual framework for applying quality of life effectively. Two presenters illustrate how the framework works in practical situations.

Theme: Participation Over the Lifespan

Grounding people in their own reality

J. Clapton (j.clapton@griffith.edu.au)**, M. Redley, K. Scior, D. Charnock & J. Clegg**
Griffith University, Brisbane, Qld, Australia

Purpose: Expanding ethical practice by exploring difference. **Rationale:** Inclusion usually involves PwID speaking in public or co-chairing committees, yet despite following best communication a 'parliament' rarely enabled PwID to speak. Marcus Redley reflects upon the minimal interest this research generated: what has changed in going from excluding PwIDs to making inclusion mandatory? Katrina Scior examines the poor fit of policy for many people from non-Western backgrounds, arguing for close attention to culture and religion in negotiating differences. David Charnock reveals different public & private staff views of the lives of men wID, arguing that discourses of normalcy and thwarted ambition are problematic: more honesty is needed. Jennifer Clegg considers denial of the situation of PwID with mental health problems, which feeds underestimation of difficulties experienced by formal & informal carers. So we shall discuss: If expecting PwID to fit into situations designed for others is colonializing, whose space is being colonised and what is the nature of that space? How might the perspectives of PwID in different situations be better understood and incorporated? Could Braidotti's triple shift from liberal individualism to Deleuzean pluralism (ie from individual achievements to enduring positive relationships, from negative judgement to affirmative living, from moral rules to practical action) refresh inclusion?