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Journal of Intellectual Disability Research

The Foremost International Journal on Intellectual Disability

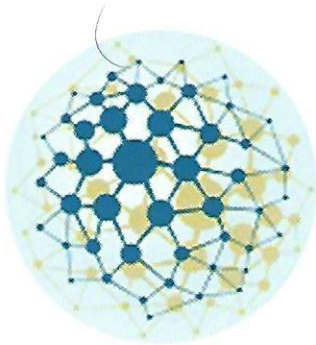
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Policy and Practice**

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produced notable advances will be included. Such reviews will normally be by invitation. Anyone expert in his/her particular field wishing to submit an uninvited review is advised to seek prior guidance from the Editor. The Journal also includes brief reports, occasional letters, and an 'Hypothesis' section (see instruction for contributors, inside back page). All papers are assessed by expert referees. Lay abstracts from the journal can be accessed via <http://www.ldrg.org.uk/jidr>.

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Comparing staff and self-reports of complicated grief symptoms in adults with intellectual disabilities

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Aim: While previous studies have shown a significant association between parental bereavement and the development of psychopathology in people with intellectual disabilities (ID), little work has been done to accurately assess symptoms of grief, specifically symptoms of complicated grief in this population. Complicated grief has been detailed in the recent publication of DSM 5. This study aims to compare self and proxy reports of the symptoms of complicated grief. **Method:** A Bereavement History Questionnaire and the Complicated Grief Questionnaire-Intellectual Disability (CGQ-ID) were administered directly to a group of people with mild or moderate ID, who had experienced a parental bereavement within the previous two years of the research interview. Care staff also completed a proxy symptom report. **Results:** Data have been collected from 30 adults with ID. Comparative analysis highlighted very few correlations between staff and service user reports, with trends in the data suggesting service users had higher reports of symptoms. **Conclusions:** Adults with ID may be reporting higher level of symptoms of complicated grief compared to proxy reports. Complicated grief may be an under-reported cause of distress in adults with ID.

Family perspectives on the experience of parental bereavement among adults with intellectual disabilities

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Aim: This research explores families' perspectives of the experiences of parental bereavement for a family member with an intellectual disability (ID). **Method:** Qualitative interviews were conducted with five participants (four females, one male). The family had experienced the death of a parent in the previous 6 to 24 months. Braun and Clarke's (2006) framework was used to analyse the data. **Results:** Experiences of supporting the family member with ID after the death were varied. Families regularly reported normal grief reactions, including crying and missing the deceased. However some responses were more atypical, with one family member with ID appearing to enter a manic episode, and another showing a delayed response to the bereavement. All family members with ID attended the funeral and all families encouraged openness with the member with ID around the topics of illness and death. **Conclusions:** Families are well positioned to report on the bereavement experiences of members with ID. This research concludes that families recommend a policy of openness and inclusion of members with ID in the bereavement experience. More research needs to be conducted on how families with members with ID can be supported pre and post bereavement.

Exploring organisational perspectives on the provision of respite services for people with intellectual disabilities in Ireland

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Aim: To gain an understanding of service perspectives on respite care for people with intellectual disabilities (ID) in Ireland. Specific objectives include; generate an understanding of what providers consider respite to be; establish the extent to which current care reflects models identified in the literature; and capture innovative respite practices currently available. **Method:** The study used an online mixed method

survey to gather information from organisations offering respite care to people with ID. A sampling frame of suitable organisations was generated and 45 responses were received. **Results:** Responses were received from statutory services (n=11), voluntary agencies (n=21) and other organisations from across the country. Common forms of respite reported were planned respite (n=22) and crisis respite (n=19). A large majority of organisations (n=26) reported that they were not currently able to fully cater to the demand for respite but a minority (n=7) reported they were developing new models of respite. **Conclusions:** The survey findings provide significant insight into organisational perspectives on respite care, suggesting a high level of unmet need though little discussion of engagement with innovative practices.

Evidence and perspectives from Spain: Findings from research on the Spanish translation of the SIS-A and SIS-C

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Aim: The assessment of support needs has gathered much attention over the last few years in the field of intellectual disabilities, becoming a key aspect for the implementation of individualised support plans. This work is aimed to present findings from research on the Spanish adaptation of the Support Intensity Scale for Adults (SIS-A) and for Children (SIS-C) in Spain. **Method:** The SIS-C adaptation process (n=814; aged 5-16) was linked to the SIS-A previously conducted (n=885; 16-64 years old). Some extra analyses were also included considering item response theory and comparisons with the ordinary support needs of students without disabilities. **Results:** Both SIS-A and SIS-C obtained a Cronbach's alpha > .99; test-retest reliability > .94 and inter-rater reliability > .80. The confirmatory factor analysis showed proof of validity based on the correlational structure of the scale. Some minor problems in the SIS-C discriminant validity were found. **Conclusions:** Given the lack of instruments to assess support needs in Spain, SIS-A and SIS-C are promising and powerful tools to facilitate the implementation of individualised support plans. However, more research is needed.

An evidence-resistant strain of disablism: Parents and parenting with intellectual impairment

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Aim: The brutal reality is that many parents with intellectual impairment will have their child taken from them by child welfare services. This, despite evidence accumulating since the early 1900s, which shows that most parents with intellectual impairment can meet the needs of their children with appropriate supports. **Method:** In this paper we revisit some of the earliest (and perhaps forgotten) studies related to parents and parenting with intellectual impairment. In addition, we examine discourse in the media using press clippings dating back 100 years. Using these early studies and media portrayals of parents and parenting with intellectual impairment as our reference point we reflect on the progress, and lack thereof, that has been made in research, policy and practice in this field. **Results:** Although significant progress has been made in some areas, parents with intellectual impairment are subject to an evidence-resistant strain of disablism. **Conclusions:** What is the remedy for this disablism? We suggest that intentional (rather than the traditionally passive) knowledge translation strategies are needed to overcome the systemic discrimination that disables parents with intellectual impairment.

Self-perceptions of people with intellectual disabilities about their quality of life: A preliminary analysis of the dimensions of self-determination and rights

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Aim: We hypothesised that people with intellectual disabilities (ID) have low scores on self-determination and rights due to the lack of attention to their felt needs. Our goal was to describe the perceptions of adults with Down syndrome (DS) regarding their rights and opportunities for self-determination. **Method:** Four adults with DS were interviewed using the INICO-FEAPS Scale Quality of Life (Schalock & Verdugo, 2013). We used the ATLAS T 7 software to analyse the transcripts of the four interviews. This analysis consisted of a cyclical process of three activities: data reduction, interpretation and removing emerging reflections. **Results:** The adults interviewed perceive that others tell them what to do. They report that environments make it difficult for them to have opportunities to decide for themselves. As for the dimension of rights, they constantly refer to the right to freedom and mutual respect. **Conclusions:** It is important to address self-perceptions to identify the felt needs without interference from third parties. In general, while recognizing the existence of rights, adults with ID may not perceive that they have rights.

Constructing and evaluating the Grief-Cube: A tool to provide grief support for people with ID

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Aim: Researchers have acknowledged that adequate grief support enhances the quality of life of people with intellectual disabilities (ID). The aim of this research is to construct and evaluate a tool that enables staff to support people with ID during a grief process. **Method:** Based on current research and theories of grief and loss in the general population and in people with ID, a tool was designed called the Grief-Cube. The Grief-Cube covers six dimensions of the grief process and grief support. The comprehensibility and usability of the tool was assessed in two focus groups consisting of four professionals each. An advisory group consisting of professionals, people with ID and their relatives discussed the tool and its content. **Results:** The participants found the Grief-Cube to be an appropriate and accessible tool for learning more about grief and grief support of people with ID. **Conclusions:** The Grief-Cube is a potentially suitable tool for staff members to provide high quality grief support. In the next phase, the optimal way of use will be studied and its consequences evaluated.

Self-determination in adolescents with intellectual disabilities: A confirmatory factor analysis of the ARC-INICO scale

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Aim: The aim of this study is to analyse the internal structure of a new assessment tool developed in Spain (ARC-INICO Scale) to assess self-determination in adolescents with intellectual disabilities (ID) according to the Functional Self-determination Model. Self-determination is considered a right frequently demanded by people with ID; however, there are few tools to assess and promote self-determination. **Method:** The process of developing and validating this new instrument has been completed after an exhaustive review procedure and with

the collaboration of different entities, professionals, and users. The sample of validation consisted of 279 young people with ID (aged between 11 and 19 years). **Results:** The Scale and its four sections (autonomy, self-regulation, empowerment and self-realisation) are reliable. Confirmatory factor analysis shows proof of validity based on the internal structure of the Scale, and confirms the correct fit of the proposed hierarchical structure. **Conclusions:** This tool provides reliable and valid information about self-determination and its domains. Its use may be useful in designing intervention strategies to improve self-determined behaviours and promote transition to adulthood.

Identifying people with intellectual disabilities who may need palliative care: The development of a tool for practice

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Aim: Healthcare professionals are in need of support in identifying people with intellectual disabilities (ID) who may need palliative care. We aimed to develop a tool for this purpose. **Method:** With a survey for physicians about their last patient with ID with a non-sudden death and interviews with professionals regarding identifying palliative care needs, we were able to generate relevant items for the tool. These were subsequently prioritised in focus groups. The resulting preliminary tool was tested in a prospective follow-up study among 185 Dutch people with ID. At baseline, 5 and 10 months, professionals completed the tool and provided information on relevant health parameters. **Results:** The preliminary tool includes 39 questions, which can be answered either by the physician or by the professional caregiver with 'yes', 'no', or 'don't know'. Preliminary results from the follow-up study suggest that the tool is considered feasible. People who died during follow-up had a higher score on the tool at baseline. **Conclusions:** The tool generates important information that may help professionals to identify and discuss those people with ID that may benefit from palliative care.

Patient and illness characteristics related to whether or not people with intellectual disabilities will die

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Aim: Mortality in people with intellectual disabilities (ID) is an important domain receiving increasing attention in research and practice. We explored which patient and illness characteristics are related to whether or not people with ID will die. **Method:** We followed 185 Dutch people with ID for 12 months. They were included if their principal physician indicated they would not be surprised if they died in the next year. Patient and illness characteristics were collected through surveys from physicians and professional caregivers, and by review of medical records. **Results:** After 12 months, 20% of the people had died. Preliminary results suggest that these people had a lower quality of life at baseline and had shown a greater overall decline in the past months. Furthermore, these people were more dependent in activities of daily living and were more often in need of symptom management (e.g., fatigue, dysphagia and dyspnoea). **Conclusions:** The results generate important information in the understanding of mortality of people with ID. Early awareness of people with ID nearing end-of-life helps to attain the highest quality of death and dying.