

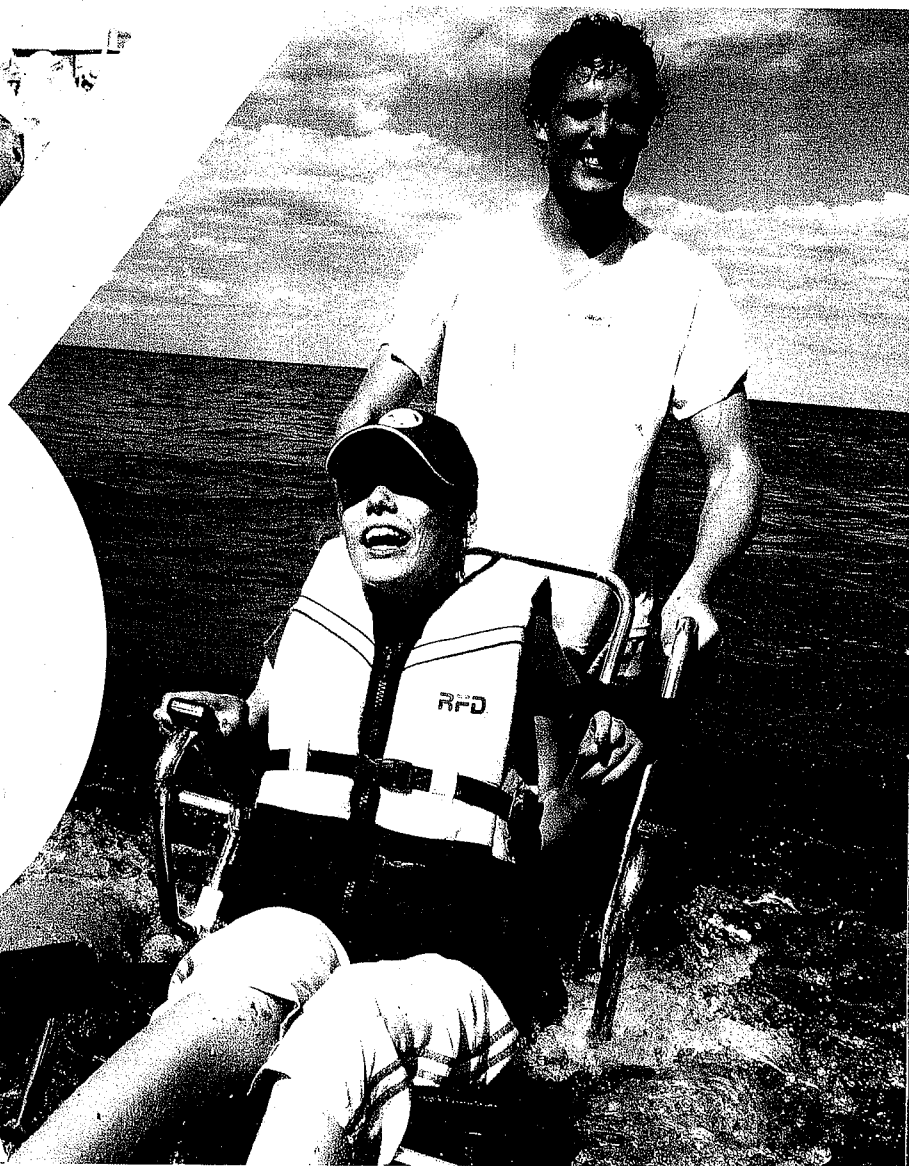
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PROGRAM AND
ABSTRACTS



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Quality of life measurement for people with intellectual disabilities: a systematic review of available instruments

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Quality based reform requires accountability and frameworks that include reporting mechanisms to monitor service effectiveness and congruence with consumer needs. Routine outcome measurement systems which measure the degree to which service provision meets goals articulated in Person Centred Plans (PCPs) or Positive Behaviour Support Plans (PBSPs) is crucial. The construct of quality of life (QoL) has been proposed as a method to assess service outcomes for people utilising disability services. Psychometrically robust and culturally sensitive tools which capture the subjective experience of people with intellectual disability, including those who exhibit challenging behaviour are important. We conducted a systematic review of available QoL measures for people with intellectual disability to identify measures that are psychometrically sound and suitable for routine use as a service evaluation tool. A systematic search of the disability literature was conducted. Twenty four instruments were identified and evaluated against a set of psychometric and measurement criteria. Six identified instruments were deemed psychometrically sound on the current available information. No instruments were found that specifically assess QoL for people with intellectual disability who exhibit challenging behaviour. In conclusion, more validation research is needed for existing QoL measures and more instruments that measure QoL for people with intellectual disability need to be developed and rigorously validated. This is especially the case for high needs disability populations including people who exhibit challenging behaviour or have severe to profound intellectual disability.

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Application of quality of life instruments in routine service evaluation for individuals with severe to profound intellectual disability.

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This study discusses the application and limitations of Quality of Life (QoL) assessment tools for individuals with severe to profound intellectual disability in residential settings. A QoL questionnaire and checklist were selected from a systematic review of Quality of Life instruments. Participants in the Positive Behaviour Intervention Study were asked to complete the Schalock Quality of Life Questionnaire (Schalock & Keith, 1993) and the Guernsey Community Participation and Leisure index (Baker, 2000) to assess QoL changes resulting from interventions implemented within the study. Due to the limited communication skills of the participants, two support workers provided responses on behalf of the individual. Preliminary findings indicated significant variability in the responses provided. This was problematic as the QoL measurement tools were unable to accurately reflect the differing proxy responses. The evidence indicated that other measures are required to monitor outcomes. The Residential Outcomes System (ROS; (Newton, Anderson et al., 1996); was adopted to assess a limited range of QoL domains. The ROS aims to improve lifestyle outcomes through increasing a person's participation in their preferred activities. It employs direct observation and staff interview measures followed by positive programming changes linked to the results of the assessments. The results of this study and the incorporation of the ROS in routine consumer outcomes evaluation will be discussed.