

How rights are experienced by people with an intellectual disability and their network members

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Introduction: The United Nations Convention on the Rights of Persons with Disabilities aims "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity". This legally binding protocol has been signed by 139 nations including Australia. It is unclear how the rights framework is understood or experienced by people with disabilities and the members of their informal networks or by paid service providers.

Objectives: To understand and describe how the concept of rights is currently experienced by people with an intellectual disability, their network members and service providers and to examine whether this is consistent with the principles articulated in the convention.

Methods: An ethnographic study of the experiences of people with disabilities in their personal networks is currently being undertaken. Nine people with an intellectual disability were invited to participate in this study along with the members of their personal networks including friends, family and service providers. Information about people's experiences is being collected using in-depth interviews and participant observations and analyzed using open and axial coding and NVivo software.

Results: Preliminary analysis has identified that the topic of rights is contentious. Families, people with disabilities, their allies and service providers are engaged in a number of rights related issues, many of which are a source of conflict. For example, in the provision of services the relationship between rights and risk is not well understood. Families have also described situations where the opportunities and choices supported by formal services have been diminished in the name of rights and families and other personal network members have been excluded from decision making forums using a rights rationale.

Conclusion: The understanding and application of human rights is complex, misunderstood and contentious. This can have an impact on the participation of people with an intellectual disability.

Contribution to the practice/evidence base of occupational therapy: An informed understanding of the implementation of international conventions is a professional responsibility of all therapists working in signatory nations.