

How the Personal Networks of People with Intellectual Disability can Promote Participation and Engagement

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Introduction:

Families report a lack of responsiveness by formal services to the needs of people with disability. Little is known about how personal networks support the participation, engagement and performance of people with disability (occupational performance).

Objectives:

To explore the ways in which personal networks function to support and develop the meaningful everyday occupational performance of their adult member with intellectual disability.

Methods:

This study is part of a larger ongoing research project that explores the development, maintenance, critical features and function of personal support networks of adults with intellectual disability over a three-year period, using an ethnographic research design. Nine families who are actively supporting the ongoing development and autonomy of an adult member with disability were recruited. Networks include family members, friends and significant community members. Data collection methods include interviews, and participant observations of the daily routines of the people being supported. The Occupational Performance Model (Australia) was used to frame data analysis of the occupational performance of each person with disability. Analysis used open and axial coding and NVivo software.

Results:

Network members described how networks functioned. Choices and needs were identified by the person with a disability or by network members who knew and understood the person well. Patterns of occupations, tasks, sub-tasks and routines were identified and supported by the network members. Component performance was considered. Relationships were identified between informal network planning and relevant community, social, cultural and occupational contexts. Networks sensitively identified what was meaningful to the person with a disability and were responsive in developing innovative strategies of support.

Conclusion:

Informal support networks for adults with disability are able to provide dynamic and sensitive practical support for personally meaningful everyday occupational performance that is embedded in the person's community, social and cultural contexts.

Contribution to the practice/evidence base of occupational therapy:

This study provides detailed information about the significance of informal networks of support in the everyday occupational performance of adult people with disability. This information is central to identifying needs, building networks of support and supporting families to achieve the 'good life' for their person with a disability.