

The Experience of Support in the Personal Networks of People with Intellectual Disability

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Introduction:

Personal support networks are strongly linked to positive health and wellbeing for the person at the centre of each network. Network members feel their contribution is disregarded by service providers.

Objectives:

To explore how relationships between members of personal networks supporting adults with intellectual disability contribute to support outcomes.

Methods:

This study is part of a larger ongoing research project investigating the development, maintenance, critical features and function of the personal support networks of adults with intellectual disability over a three-year period using an ethnographic research design. Nine families actively supporting the ongoing development and autonomy of an adult member with disability were recruited. Data collection methods include interviews, and participant observations of the daily routines of the people being supported. Data analysis for this study considered how people in the networks, including the person being supported, related and responded to each other in terms of the support being offered. Analysis used open and axial coding and NVivo software.

Results:

Network members set goals intended to promote the autonomy, community participation and wellbeing of the individual being supported. Strategies were developed and implemented. Network members had an ongoing, personal and committed relationship with the person they were supporting, which meant they were sensitive and accurate in interpreting verbal statements, body language and behaviours. This allowed the person being supported to guide the network by his or her responses and behaviour in relation to strategy implementation. Where strategies were not successful, network members were often able to identify how to reframe their approach. In this way, a high degree of reciprocity was identified within support networks.

Conclusions:

Members of the personal support networks in this study depend upon the person they are supporting to develop and 'fine tune' strategies that will produce successful outcomes. Because they know the person well, and have a respectful, affirming relationship, they are often able to effectively implement, evaluate and modify their support strategies.

Contribution to the practice/evidence base of occupational therapy:

Personal networks can help occupational therapists to identify and address occupational performance issues, assist in identifying choices and needs, inform about aspects of occupational context and guide support.