

## The Personal Support Networks of People with Intellectual Disability

Anne M. Hillman<sup>1</sup>, Michelle Donnelly<sup>1</sup>, Louise Whitaker<sup>1</sup>, Marie Knox<sup>2</sup>, Roger Stancliffe<sup>1</sup>, Trevor Parmenter<sup>1</sup>

<sup>1</sup>The University of Sydney, Sydney, NSW, Australia, <sup>2</sup>Queensland University of Technology, Brisbane, QLD, Australia

### Introduction:

Informal support networks for people with disability are not well understood, yet personal support networks provide invaluable practical support, reciprocity and safeguards. They are strongly linked to positive health and wellbeing for the person at the centre of each network.

### Objectives:

To explore the development, maintenance, critical features and function of the personal support networks of adults with intellectual disability over a three-year period.

### Methods:

The study is ongoing. An ethnographic research design supports our investigation of the unique, subjective realities of those involved with the networks. We recruited nine families actively supporting the ongoing development and autonomy of an adult family member with disability. Networks include family members, friends and significant community members. Data collection methods include interviews and participant observations of the daily routines of the people at the centre of each network and of network meetings. Data analysis involves open and axial coding and NVivo software.

### Results:

The personal support networks in this study are diverse, utilising a wide range of skills, resources, and reasoning frameworks, making it difficult to compare specific successful strategies between networks. However, each network is dynamic and responsive to the needs of the person at its centre, with positive achievements over time. Critical events or experiences have contributed to network development. For the person with a disability, networks are a source of friendship, ideas, safeguards, priorities, inspirations, and opportunities. Networks focus on important issues such as realising employment opportunities, developing accommodation options, establishing a new home, creating leisure opportunities, and facilitating new friendships.

### Conclusion:

Because network members know and are committed to the person with disability and can provide major ongoing support for his/her wellbeing and social participation they are highly responsive to the person's needs.

### Contribution to the practice/evidence base of occupational therapy:

Personal networks of support can identify in fine detail the support needs of the person with disability. They highlight the importance of a family-centred approach by support services.