

10.7 Classification of support and need

Prof Trevor R. Parmenter,* Director, Centre for Developmental Disability Studies

Prof Gwynnyth Llewellyn, School of Occupation and Leisure Sciences, The University of Sydney

Mr Jeff Chan, Director, Community Integration Program, Royal Rehabilitation Centre Sydney

Dr Vivienne Riches,* Senior Research Fellow, Centre for Developmental Disability Studies

* Address for correspondence: trevorp@med.usyd.edu.au vriches@med.usyd.edu.au

Supports Classification and Assessment of Needs Instrument

Work is currently under way on a project to develop a new system for classifying and assessing the support needs of people with disabilities. This is a collaborative project between The University of Sydney, the Royal Rehabilitation Centre Sydney (RRCS) and the Centre for Developmental Disability Studies (CDDS). It is a 3-year project (2002–04), with funding provided through a competitive Australian Research Council grant, with contributions from industry partners RRCS and CDDS.

Rationale

People with a disability (and their families and advocates) now expect to take part in ordinary everyday activities such as leaving home, moving house, joining and retiring from the workforce, developing relationships and raising a family. Providing support to enable people with a disability to live and work within the community is now an accepted part of Australian life. Varying types and intensities of support may be needed for some or all of these activities. In the face of a marked population increase of people with a disability (on average 14% annually or seven times the population growth over the past 5 years) a scientifically sound valid, and reliable needs assessment and support planning system is urgently needed.

All jurisdictions in Australia are grappling with the need to provide rational allocation of limited resources based on support needs, in an era of growing demand for services. Moreover, there is ample evidence in Australian and international literature that a better system is required for assessing the support needs of people with a wide range of disabilities and to translate those needs into responsive and individualised service delivery (e.g. Schalock 1999). Providing such services with the available resources is a significant government challenge. Already 42% of people needing support are receiving

some form of assistance from formal service agencies (ABS 1999). Existing demand (at least 58% of those needing support on 1998 figures) and growing demand (estimated at around 3% per year with the ageing of the population) indicates that a more effective and empirically sound system is required to ensure the resources available reach those most in need in the Australian population.

The support needs classification and assessment system

The project is developing an innovative, rigorous and robust system of identifying and classifying support needs based on the conceptual framework of the ICF (WHO 2001). In line with this framework, the project conceptualises disability as a dynamic state typically incurring restricted function due to:

- the interaction of the person (their health condition including impairment)
- the activities they desire to do (and any difficulties in carrying these out)
- environmental and personal factors (restrictions on participating in the community, e.g. physical access, discriminatory attitudes, particular background of an individual's life and living).

Hence, an individual's functioning in everyday life is the result of a complex relationship between these three components.

The aim of this new system for support needs assessment and classification is to reliably identify the type and intensities of support needed, taking into account the complex interactions that characterise disability (WHO 2001). A valid system will overcome the limitations of existing instruments that either overestimate (lack of sensitivity) or underestimate (lack of specificity) the support needs of people with a wide range of disabilities in varying situations. The system comprises:

- procedures to involve the person with a disability and those most familiar with the person in identifying and assessing needs
- reliable methods of observing and assessing support needs in situ
- valid measures to identify support needs in a range of life activities, and which take into account the interactive effects of health condition (and impairment), desired activity and context (including environmental and personal factors).

The system is unique in that the person with a disability and people relevant to that person (i.e. the person themselves, parent/s or carer/s, advocate, and key service providers) complete the assessment together in the person's living environment. They are able to consider the person's hopes, dreams, likes and dislikes, as well as the difficulties and barriers he or she experiences in attempting to fulfil personal goals. This contrasts with the current situation where assessment is typically done 'to' or 'on behalf of' people with disabilities by (well-meaning) professionals often in unfamiliar settings (consulting room or institutional environment) without the benefit of information from those closest to the person with a disability.

A trained facilitator guides the assessment meeting(s) to identify personal goals and activities (such as where and how the person wishes to live, work and spend their

time) and what is required to achieve these in the most effective and practical way. The facilitator's role is to encourage differing views to be openly debated in order to develop an action plan that is responsive to the individual's preferences, and that is constructive, achievable, and acceptable to all. This assessment process may last up to 2 hours or require an additional meeting to achieve an agreed record of the individual's personal goals and the type and amount of support required to achieve these on a daily basis in activities and participation domains such as self-care, domestic life, mobility and transport, communication, interpersonal interactions and relationships, health management, emotional and behavioural management and home and community living.

Application of the concept of support has been further guided by the conceptual model of support in the Mental Retardation Definition, Classification and Systems of Support, 9th and 10th editions (AAMR 1992, 2002). This support outcomes model directly links support resources (including the person with a disability and others, technology and services) with the functions of support (e.g. receiving assistance with finances or work, or with home living activities, friendship, instruction) and, the intensities of the support required. Intensities of support considers time duration, time frequency and intrusiveness measures, and allows assessment of whether support is only required occasionally (intermittent); is time- or occasion- specific (limited); is needed over an extended period (extensive); or is of a frequent, intensive and possibly life-sustaining nature (pervasive). This model is based on a 'best fit' assumption; that is, a match between the supports needed and the type and intensity of the support provided results in desired outcomes such as achieving personal goals in key life activities, increased personal satisfaction and enhanced quality of life. A multi-dimensional scoring system is used for key activity and participation domains, with the level of intensity of support needs identified using the categories intermittent, limited, extensive and pervasive.

The system has been trialled extensively for people with an intellectual disability in residential environments. Currently, work is being undertaken to trial the system among individuals from a range of disability types and across diverse environments.

Expected outcomes

The proposed project will demonstrate:

- the multidimensional and dynamic nature of the support needs of people with disabilities
- the reliability and validity of the proposed support needs assessment and classification system across a wide range of disabilities
- the training and protocols required to ensure proposed system is reliably implemented in diverse settings
- ways that the proposed system can be directly linked with service planning and resource allocation.