I-CAN: A New Instrument to Classify Support Needs for People with Disability: Part I

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Background The supports paradigm has shifted focus from assessing competence and deficits among people with disabilities to identifying supports needed to live meaningful and productive lives in inclusive settings. Consequently, a rigorous and robust system is required that is capable of accurately determining the type and intensity of support needed and of allocating resources accordingly. The aim of the present study was to develop such a system to identify and classify support needs of people with disabilities based on the conceptual framework of the *International Classification of Functioning, Disability and Health* (ICF) [WHO, *The International Classification of Functioning, Disability and Health (ICF)*, Author, Geneva, 2001], and the supports concept [*Mental Retardation: Definition, Classification and Systems of Support*, 9th edn (1992), 10th edn (2002), American Association on Mental Retardation, Washington, DC].
Method A total of 1012 individuals with disabilities who were supported by accommodation and day programme organizations across the eastern states of Australia were assessed. The instrument was used in a team setting involving the person, their family and friends and staff as appropriate. *Version 1* was administered with 595 people with disability. This version was refined according to qualitative and quantitative analyses. Another 342 individuals were assessed using *Version 2*, resulting in a combined data set for 936 individuals. *Version 3* was then trialled with a further 76 individuals with disabilities.
Results Ten domain scales in Health and Well Being (HWB) and Activities and Participation (A&P) were explored and refined. The scales effectively discriminated a range of intensities of support for people with various disabilities, with the highest support needs generally recorded by individuals with multiple disabilities who were ageing. The instrument can be used to develop a profile of needed supports across the domain scales. These measure current and predicted support needs, and contribute to future planning. The team approach proved beneficial in this regard.
Conclusions The *I-CAN* is a useful instrument for effectively assessing the support needs of people with a disability using a person centred approach. It is effective in identifying support needs across health and well-being areas, and activities of daily living.

Keywords: assessment instrument, classification, disability, ICF, support

Introduction

Disability is no longer regarded as a trait of the individual or as an outcome of underlying pathology. The recent determination by the World Health Organization's *International Classification of Functioning, Disability and Health* (ICF) (World Health Organization (WHO) 2001) reinforces the concept of 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 they may have in carrying these out); and environmental and personal factors (restrictions on participating in the community such as 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.

Further, many now contend that it is the provision of relevant and effective supports that can improve

everyday life functioning and further empower individuals with disability to live the life they choose. Indeed, a 'systems of supports' approach is now advocated by the American Association on Intellectual and Developmental Disability (AAIDD),[1] based on the premise that the judicious application of appropriate supports can improve functional capabilities of individuals with intellectual disability, thereby enhancing a person's independence/interdependence, productivity, community integration and satisfaction (Luckasson *et al.* 1992, 2002).

The concept of supports was first adopted by the AAIDD in its 1992 definition and classification of persons with an intellectual disability (Luckasson *et al.* 1992). While the definition of intellectual disability remained unchanged, controversially, one significant variation introduced was a change in the classification system from one based on level of severity of intellectual functioning according to numerical IQ scores to one based on intensities of supports. Following the diagnosis of mental retardation/intellectual disability, the development of a supports profile for supports planning was also recommended.

In 2002, the 10th AAIDD manual retained the concept of supports as an integral component of the system and as relevant for both classification and planning of supports functions. Further, in line with the ICF (WHO 1997, 2001) the AAIDD conceptualized disability as 'a significant problem in functioning … characterized by … marked and severe problems in the capacity to perform (''impairment''), the ability to perform (''activity limitations''), and the opportunity to function (''participation restrictions'')' (Luckasson *et al.* 2002, p. 16).

The changing conceptualization of intellectual disability from a solely biological to a functional base and the introduction of the supports system has not been without its critics (Baumeister 2006; Jacobson & Mulick 2006). Baumeister (2006) for example, questioned the AAIDD formulation in terms of its supposed originality and effectiveness, and an inherent dangerous assumption that supports can 'cure mental retardation'. He also questioned the ability of the supports system to answer real and pressing scientific and ethical questions such as those relating to the 'new eugenics' of human genetics and the best allocation of finite resources.

Nevertheless, the bio-psycho-social model of disability has been widely accepted and organizations that provide services to people with disabilities have been quick to adopt the supports system as a basis for planning and reimbursement systems. Indeed, conceptual and practical interest in the supports paradigm is gaining wide acceptance across families; and education, rehabilitation, medicine, social services and community living professionals worldwide (Schalock 2001; Luckasson *et al.* 2002).

Another criticism levelled at the system of supports is that it cannot be subjected to experimental research (Baumeister 2006). However, research into the Active Support model contradicts this, and demonstrates that changes in support can directly influence outcomes. The Active Support model originated as a response to the fact that, despite the move from institutional living to community living, people with severe disability in particular often continued to experience low levels of participation in meaningful activity (Emerson & Hatton 1996; Jones *et al.* 1999; Stancliffe *et al.* 2001; Felce *et al.* 2002). This was seen as both unjust and unnatural, and it was also recognized that many serious problems can be associated with under activity and passivity, including increased challenging behaviour, physical health problems and depression. Consequently, Active Support involves training staff in specific skills and organizational procedures that focus their work on the direct support of client participation in meaningful activity (i.e. staff doing *with* rather than *for* individuals).

Several studies in the United Kingdom and Australia have now demonstrated that relevant and appropriate support using the Active Support model has resulted in significant increases in participation in domestic, community and social life for many individuals with disability (Jones *et al.* 1999, 2001; Felce *et al.* 2000; Mansell *et al.* 2003; Bradshaw *et al.* 2004; Stancliffe *et al.* 2007). Moreover, although organizational training costs were incurred, these results were associated with changes in the way staff provided supports to individuals within existing staffing structures, rather than requiring additional staffing. This is a critical issue, since the assumption is often made that assessing support needs will itself create more demand for services and resources.

While the aim of a supports system is the provision of adequate and relevant natural and paid supports to assist people with all types and levels of disability to more actively participate in their communities and live more satisfying and fulfilling lives, based on their needs, aspirations and desires, a significant challenge is the actual identification and assessment of support needs. A profile of needed supports is required that addresses psychological, emotional, health and physical strengths and weaknesses in the context of environmental factors.

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[1]Formerly the American Association on Mental Retardation (AAMR), now the American Association on Intellectual and Developmental Disability (AAIDD).

At the same time, a system is also required that will effectively and efficiently allocate scarce resources to the rapidly increasing proportion of the population with a disability (AIHW 1997a; Schalock 1999; Thompson *et al.* 2002a; Guscia *et al.* 2006), based on what people with disabilities need rather than on what particular programmes choose to provide (Wade & de Jong 2000; Thompson *et al.* 2002b).

A recent review by the Australian Institute of Health and Welfare (AIHW) found there was little uniform use of assessment instruments or procedures across Australia or even within jurisdictions for the management and assessment of support needs of people with disability (AIHW 2002). Consequently, a range of different support need assessment instruments and procedures were being developed and employed, with variable results.

Some in the disability sector use a traditional approach to determine support needs by assessing adaptive behaviour, with more recently, a measure of functional performance included (Vertongen *et al.* 1998; Young *et al.* 1998). However, most instruments for the assessment of adaptive behaviour have been designed for use with particular disability types (e.g. spinal injury, Acquired Brain Injury (ABI)) or at different ages (children, the elderly) or with different levels of impairment (mild, moderate or severe). Instruments designed to assess function in daily living activities (e.g. personal care, mobility, communication) rely on observed or reported performance without accounting for behavioural or situational influences that may have a marked effect on functional performance. Typically, such assessments pay little, if any, attention to assessing support needed for physical health and/or emotional health and well-being. Further, there are different purposes for scales, with adaptive behaviour scales essentially used for diagnosing the condition of intellectual disability, whereas measures of support needs are critical for developing individualized support plans (Thompson *et al.* 2004).

A *Supports Intensity Scale* (SIS), developed by the AAIDD (Thompson *et al.* 2002a) appears promising, but initial attempts to administer this scale in Australia have proven difficult, as raters have encountered problems making ratings 'if necessary by an ''educated guess'' …without regard to the services or supports currently provided or available' (Guscia *et al.* 2005, p. 154).

Consequently, a scientifically valid and reliable instrument is urgently required that is capable of accurately determining the type and intensity of support needs across all relevant domains; that is easy to administer; and, that can ensure equitable resource allocation that

permits people with disabilities to pursue their personal goals and chosen life activities.

Initial work undertaken in the late 1990s by the Centre for Developmental Disability Studies (CDDS) and the Australian Capital Territory (ACT) Community Care Disability Programme developed an assessment process to measure and classify the support needs of individuals with an intellectual disability in community-based accommodation and respite care programmes. This resulted in an initial instrument comprising qualitative and quantitative data, designed to measure comprehensively support requirements in the domains of physical assistance, adaptive skills, communication and social skills, as well as health care needs, behaviour and risk (Riches *et al.* 2000; Riches 2003).

This project used a multi-dimensional rather than uni-dimensional scoring system to enable the diversity of support needs among people with disabilities to be assessed (Boake & High 1996; Riches *et al.* 2000). The measurements used in the domains yielding quantitative analyses were based upon the AAIDD supports-outcome model with its four levels of supports intensities that take account of time duration, time frequency, the settings in which the supports are needed, the resources required for the supports and the degree of intrusiveness required (Luckasson *et al.* 1996; Schalock 1997; Luckasson & Reeve 2001).

Building on this initial work, a collaborative project was developed between The University of Sydney and Industry Partners, the Royal Rehabilitation Centre Sydney (RRCS), and the CDDS. This research was supported by a grant from the Australian Research Council Linkage Grant Scheme 2002–2004. The project aim was to develop an innovative, rigorous and robust system of identifying and classifying support needs of people with disabilities, based on the conceptual framework promulgated by the World Health Organization through the ICF (World Health Organization (WHO) 2001).

This article (Part I) reports on the development and application of an instrument, the *I-CAN*, across disability types, while the following article (Part II) reports studies on the reliability, validity and practical utility of the instrument.

Methods

Participants

Sixteen organizations that support individuals with disabilities in residential and some day programme settings participated in the research in line with The University

of Sydney ethics protocols and procedures. These orga-
nizations were geographically located in metropolitan,
urban and some rural and remote areas across the east-
ern states of Australia. Overall, assessments were under-
taken with and on behalf of a total of 1012 individuals
with disabilities. This assessment process involved 5071
individuals, comprising 3093 staff from disability orga-
nizations, 1012 trained facilitators, 532 persons with a
disability, 339 parent/s, relatives or guardians, 23 advo-
cates, and 72 others such as friends.

Sample demographics are reported in Table 1. Ages
ranged from 17 to 77 years, with the average age being
41 years, and the standard deviation 10 years. To enable
the analyses of any differences in support requirements
due to increasing age, ages were grouped according to
the Australian Prime Minister's Science, Engineering
and Innovation Council (PMSEIC 2003) groupings. Only
2.3% of the sample was aged 65 years or older.

Disability was recorded in line with the Minimum
Data Set used by the Australian Bureau of Statistics
(ABS) and the AIHW (AIHW 1997b). The primary dis-
ability for the majority of the sample was intellectual
($n = 848$ or 84%). The group labeled Other consisted of
individuals whose primary disability was other than
intellectual disability. Additionally, many individuals
(72%) had two or more disabilities, such that seven
major disability groupings were identified and used for
further analyses. The number and percentage of partici-
pants assessed in each disability group are presented in
Table 2 according to instrument version.

Table 1 Sample demographics

	Version 1	Version 2	Version 3	Total N = 1012
	n (%)	n (%)	n (%)	n (%)
Gender (N = 1011)[1]				
Male	356 (59.8)	183 (53.8)	46 (60.5)	584 (57.8)
Female	239 (40.2)	157 (46.2)	30 (39.5)	427 (42.2)
Total	595 (100.0)	340[1] (100.0)	76 (100.0)	1011[1] (100.0)
PMSEIC[2] age groups (N = 1012)				
24 and under	25 (4.2)	23 (6.7)	3 (3.9)	51 (5.0)
25–44 years	365 (61.3)	206 (60.4)	29 (38.2)	600 (59.3)
45–64 years	195 (32.8)	103 (30.4)	40 (52.6)	338 (33.4)
65–79 years	10 (1.7)	9 (2.6)	4 (5.3)	23 (2.3)
Total	595 (100.0)	341 (100.0)	76 (100.0)	1012 (100.0)

[1]One case missing data.
[2]Prime Minister's Science, Engineering and Innovation Council
(PMSEIC) (2003).

Table 2 Disability groupings by instrument version

Disability groups	Version 1–2 n (%)	Version 3 n (%)
Multiple disabilities	269 (28.7)	21 (27.6)
Intellectual only (ID)	221 (23.6)	11 (14.5)
Intellectual disability & neurological	148 (15.8)	8 (10.5)
Other	110 (11.8)	17 (22.4)
Intellectual disability & mental illness	71 (7.6)	7 (9.2)
Intellectual disability & sensory	66 (7.1)	7 (9.2)
Intellectual disability & physical	51 (5.4)	5 (6.6)
Total	936 (100.0)	76 (100.0)

Typically, residential settings consisted of supported
accommodation facilities housing more than six individ-
uals (63%) and domestic scale supported living facilities
for between two and six people (28%). A small number
lived alone (4%) or with family (4%) and two were from
Aboriginal communities. Several individuals were in an
aged care facility, a psychiatric facility or a hospital
(1%).

Measure and procedure

The I-CAN instrument contains items in ten domain
scales: four domains covering Health and Well Being
(HWB) and six domains covering Activities and Partici-
pation (A&P). Each item is rated for support according
to both frequency (from 0 = never through 5 = constant
support throughout the day) and level of support (from
0 = none through 5 = total/physical assistance from one
or two people). Other quantitative data collected
included disability and demographic data. Qualitative
data included health conditions and behaviours requir-
ing support, reasons for change in support needs, pref-
erences and feedback about the instrument and the
assessment process (Llewellyn *et al*. 2005).

A member of the research team trained nominated
staff from participating disability organizations to act as
facilitators in the assessment process. Facilitators
arranged and facilitated meetings with relevant stake-
holders, including the designated person with disability
wherever possible, and completed the I-CAN instrument
and an evaluation form based on group responses.

The first step involved analysis of data from the initial
version of the instrument, *Version 1* ($n = 595$), that was
developed for people with intellectual disability and tri-
aled in residential and respite settings (Riches 2003) and
a large residential/institutional setting due for closure.

Activity and Participation domain scales data were subjected to factor analysis using a Principal Axis Factoring rotation method: Varimax with Kaiser Normalization. Results from these analyses, as well as feedback from consumers, resulted in a modified instrument *Version 2*. Other changes were made based on qualitative data analyses and stakeholder feedback, particularly in the behavioural and health areas.

Version 2 was then trialled across organizations supporting people with a range of disabilities ($n = 341$). Data that were common across versions were combined, resulting in some combined data ($n = 936$). Additional qualitative data collected in *Version 2* were subjected to qualitative analyses according to themes. These results were examined together with feedback from a reference group consisting of consumers, advocates, parents and specialists in the disability field. Further reference to and alignment with the ICF classification system and codes (World Health Organization (WHO) 2001) resulted in a further revision (*Version 3*) that was more aligned to the terminology and classifications contained in the ICF Part 1 Functioning and Disability. *Version 3* of the instrument was then trialed with a further 76 individuals with disabilities.

Feedback was sought from all participants on the comprehensiveness, accuracy and helpfulness of the instrument in identifying relevant support needs. Qualitative responses were also recorded for 149 individuals with disability who were interviewed privately by the facilitator regarding specific supports required during the trial of *Version 2*.

All data were entered into excel spreadsheets and imported into spss for Windows 10.0 and later updated to Version 12.0 (SPSS 2003). Following data checks, data from the various versions were combined wherever possible, and analysed in a number of ways. Items within scales were added together to form four HWB domain scales and six A&P domain scales. Each domain scale was adjusted to range from 0 to 100. Domain scales were subjected to exploratory analysis and scale reliability techniques, with reliability coefficients using Cronbach's alpha computed to assess the internal consistency of items comprising each sub-scale. Analyses of variance were conducted using the independent variables of gender, age, and disability grouping. As disability group sizes were unequal, Levene's test for homogeneity of variances was applied and when this was not significant ($P > 0.05$) the F probability was set at $P = 0.05$. However, when the assumption of homogeneity of variance was violated ($P < 0.05$) the F-probability value was set at $P < 0.001$ to reduce the effects of Type I error. *Post-hoc*

comparisons were run using the Tamhane *t*-test or the Tukey HSD *t*-test for unequal variances in the case of the unequal disability groupings.

Results

The statistical properties of the 10 I-CAN domain scales, plus the HWB Total and the A&P Total for the various versions are reported in Table 3. Domain internal scale reliability coefficients for Version 3 were moderate to high and ranged from alpha 0.70–0.98, indicating that each item made a significant contribution to its scale and to the reliability of the HWB and A&P Totals.

Health and well-being domains

Versions 1–2 ($n = 936$) required participants to record all medical conditions that resulted in support requirements and to rate the overall frequency and level of

Table 3 Domain scales and statistical properties

Domain scale	Version	Mean	SD	Mdn	Range	Alpha
Medical conditions	v1	5.4	6.0	6.0	0–41	0.74
Medical and epilepsy	v2	6.8	6.7	7.0	0–47	0.60
Physical health	v3	22.9	17.3	20.0	0–76	0.83
Psychiatric conditions	v1–2	1.0	2.4	0.0	0–10	0.57
Mental emotional health	v3	18.4	13.9	15.0	0–53	0.84
Behaviour	v2	7.2	8.9	3.5	0–39	0.70
	v3	16.7	14.1	11.7	0–57	0.77
Health services	v2	11.7	10.6	9.0	0–46	0.87
	v3	16.7	7.2	16.8	0–33	0.70
HWB Total	v1–2	9.2	8.1	8.0	0–62	0.84
	v3	18.5	9.4	16.7	0–43	0.90
AKGT & demands	v1–2	54.3	24.2	60.0	0–86	0.87
	v3	27.7	24.7	23.6	0–85	0.95
Communication	v1–2	31.1	17.7	31.1	0–67	0.92
	v3	21.5	23.0	15.3	0–83	0.96
Mobility	v1–2	26.5	25.2	16.7	0–95	0.92
	v3	19.9	26.5	8.9	0–90	0.96
Self-care & domestic life	v1–2	58.3	25.5	66.7	0–99	0.95
	v3	38.5	27.0	37.1	0–85	0.97
Interpersonal interactions & relationships	v1–2	36.7	19.9	36.7	0–67	0.94
	v3	24.7	23.5	21.5	0–82	0.95
Community social & civic life	v1–2	70.2	25.4	80.0	0–100	0.90
	v3	37.1	23.8	38.6	0–82	0.94
A&P Total	v1–2	46.2	18.3	47.7	1–80	0.97
	v3	28.2	18.9	26.3	0–77	0.98

support required. Epilepsy data were collected separately. Overall, 38% of persons with disability assessed had no medical support needs, 59% had at least one medical condition requiring varying levels of support from intermittent through occasional to daily, and 3% had multiple conditions that required total support (daily support with physical assistance from one or two carers). Additionally, 28% of the sample required varying levels of support due to seizures or epilepsy conditions.

Qualitative analyses were conducted on a set of data from nine organizations (n = 719), enabling type of medical and physical health conditions (excluding epilepsy) to be grouped along functional lines using descriptors found in ICF (WHO 2001). These categories were then applied to the medical conditions recorded for *Version 2* (n = 341). Intensity of support (frequency and level) needed for a range of conditions was identified, with support most often required in the categories of skin problems (17%), eating, drinking or swallowing problems (12%) through to conditions such as heart problems (7%) and cancer (2%). Additionally, progressive degenerative conditions were present for 15.6% of the sample.

Analysis of variance tests (Table 4) conducted for Medical Support Needs (*Version 1–2*, n = 936) across gender, age and the seven selected disability groups revealed significant differences according to increasing age $F_{(3,932)} = 4.84$, $P = 0.002$ but not gender $F_{(1,933)} = 3.55$, $P = 0.06$. Type of disability was also significant $F_{(6,929)} = 5.17$, $P < 0.001$ with highest mean scores (M) and therefore higher support needs registered by individuals who had both an intellectual and physical disability (M = 6.9, SD = 5.82) and the 'Other' group which consisted of individuals with physical disability and Acquired Brain Injury (ABI) as the primary disability (M = 6.7, SD = 7.59). Significantly lower mean scores signifying lower support needs were gained by individuals with intellectual disability only (M = 3.8, SD = 5.09).

Further analyses of the Physical Health Domain were conducted and categories were further aligned with the ICF body structures and/or body function domain categories, with epilepsy data included under the nervous system category (World Health Organization (WHO) 2001). However, there was no advantage in distinguishing between support needed for body functions (such as voice and speech functions that identifies articulation functions etc.) as opposed to body structures (such as structure of the mouth in voice and speech structures). Consequently, for the purposes of assessing support

Table 4 ANOVA results across HWB domain scales

Domain	Variable	Version	N	F	df	P
Medical and physical health conditions	Age	1–2	936	4.84	3,932	0.002*
		3	76	2.71	3,72	0.05*
	Gender	1–2	935	3.55	1,933	0.06
		3	76	8.96	1,74	0.004**
	Disability	1–2	936	5.17	6,929	0.000**
		3	76	1.54	6,69	0.18
Mental-emotional	Age	1–2	935	0.94	3,932	0.421
		3	76	5.87	1,74	0.02*
	Gender	1–2	936	0.35	1.933	0.56
		3	76	1.33	3,72	27
	Disability	1–2	936	32.85	6,929	0.000**
		3	76	2.95	6,69	0.01**
Behaviour	Age	2	334	3.04	3,330	0.03*
		3	76	2.84	3,72	0.04*
	Gender	2	334	0.09	1,331	0.77
		3	76	6.26	1,74	0.01**
	Disability	2	334	3.34	6,327	0.01**
		3	76	1.57	6,69	0.17
Health well-being total	Age	1–2	936	1.12	3,932	0.34
		3	76	0.98	3,72	0.41
	Gender	1–2	935	6.15	1,933	0.01**
		3	76	10.17	1,74	0.002**
	Disability	1–2	936	21.03	6,929	0.000**
		3	76	0.82	6,69	0.56

*$P < 0.05$; **$P < 0.01$.

needs, body function and body structures were combined, and this resulted in nine categories in the Physical Health domain. The sample then assessed using *Version 3* (n = 76) recorded a range of support needs across all listed physical health categories, with the categories most commonly requiring support pertaining to digestive, metabolic and endocrine systems and skin, nail and hair conditions (including ulcers, skin integrity and pressure sores). Increasing age was again found to be significantly associated with higher physical health support scores, as individuals aged 25–44 years gained a mean of 21.1, those aged 45–64 gained a mean of 24.1, while the mean for those over 65 years was 36.7 [$F_{(3,72)} = 2.71$, $P = 0.05$]. However, on this smaller sample where group sizes were problematic, there was no significant difference according to disability groupings [$F_{(3,72)} = 1.54$, $P = 0.18$] (Table 4).

The Mental Emotional Health domain was originally designed to measure support for diagnosed mental illness, but was revised following qualitative analyses, to cover functional mental and emotional health support categories. Consequently, many support needs including

emotional outbursts, concentration difficulties, eating and sleep disorders and sexuality issues not previously accounted for in the first version were subsequently captured. Results indicated that the scale was able to distinguish a range of supports needed, and individuals who had both an intellectual disability and a diagnosed mental illness registered highest support needs on this scale [V1–2: $F_{(6,929)} = 32.85$, $P < 0.001$; *Version 3* $F_{(6,69)} = 2.95$, $P = 0.01$].

In the behaviour domain, frequency and severity of the primary behaviour problem were initially rated according to eight categories similar to those used in the *Inventory for Client and Agency Planning (ICAP)* (Bruininks *et al.* 1986). This scale was developed for people with intellectual disability, and relevance across other disability types was uncertain. In *Version 2* ($n = 341$), respondents were required to record all known behaviour problems that had occurred over the last 12 months and the intensity of support required, as well as any behavioural concerns or risks anticipated over the next 12 months and the intensity of support expected to be required. Emotional issues were relocated to the Mental-Emotional Health domain. A qualitative analysis of all recorded known and probable behaviours identified five major behavioural categories for which a substantial proportion of the sample required varying levels of support: (1) hurtful to self = 21%, (2) socially excluding behaviour = 37%, (3) self-advocacy and protection = 28%, (4) damage to property = 21% and (5) hurtful to others = 24%.

Overall, higher known behavioural support scores were found among those who had an intellectual disability and mental illness or an intellectual disability and a neurological disability [*Version 2*: $F_{(6,327)} = 3.34$, $P = 0.01$]. Significant differences were also evident with younger persons recording higher behavioural support scores than older people [*Version 2*, $F_{(3,330)} = 3.04$, $P = 0.03$; *Version 3*, $F_{(3,72)} = 2.84$, $P = 0.04$].

Generally, there was little difference between ratings given to known behaviour as distinct from probable or risk behaviour for the majority of the sample. However, where changes in support intensity were predicted for the next 12 month period, these were considered significant and reflected both increases and decreases in support, occasioned by changes in medical conditions (23%), changes in accommodation (18%), the illness or death of a significant other (18%), staffing changes (15%), and changes in daily routine or activities (7%).

The Health Services Domain Scale gathers information on the frequency and level of support required to access health care professionals. Responses to this scale indi-

cated many people with disability require a range of supports including help with transportation and communication to access medical and allied health professionals.

The HWB Total score (*Version 1–2*, $n = 936$) initially excluded the health services domain but this was included in the later *Version 3* ($n = 76$). Analysis of variance results indicated that significantly higher support needs on the HWB Total (*Version 1–2*) were recorded by those who had multiple disabilities (M = 12.2), Intellectual Disability and Mental Illness (M = 11.9) and Other disabilities (M = 10.7), while lower support needs were recorded by those who had intellectual disability only (M = 5.0) or intellectual disability and sensory disability (M = 7.3) $F_{(6,929)} = 21.03$, $P < 0.001$. No significant differences were apparent according to age or disability on *Version 3*, although the trend was for the highest scores to be gained by individuals with two or more disabilities.

The internal consistency of each of the HWB domain scales was acceptable, and each domain scale contributed to the HWB Total [*Version 1–2* alpha = 0.84; *Version 3* alpha = 0.90]. All domain scales also correlated positively and significantly with the HWB Total on *Version 3*, ranging from $r = 0.74$ with the Health Services Scale to $r = 0.81$ with the Mental Emotional Health Scale.

Activity and participation domains

Initial items in the Activity and Participation (A&P) scales came from a pool of adaptive behaviour, communication and physical activity items used in the first version of the instrument. Factor analyses resulted in six groupings which were aligned where practical, with ICF domains.

For the first domain entitled Applying Knowledge and General Tasks (AKGT), factor analysis indicated one predominant factor, although Principal Axis Factoring extracted two factors with eigenvalues greater than 1, accounting for 67% of the variance (See Table 5). The first involved memory, decision making, problem solving, applying knowledge to tell time, and recognising danger, while the second factor consisted of undertaking instructions, learning new routines, responding to common signs and understanding consequences.

In the Communication domain, three factors were identified among the original 30 scale items that explained 65% of the variance. The first factor involved the ability to communicate ideas and opinions in speech or writing, to engage in conversation, recount daily events and stay on the topic. The second factor involved

Table 5 Rotated factor matrix AKGT scale

Items	Factor 1	Factor 2
Memory	0.733	0.296
Problem solving, decision making	0.759	0.301
Tells time correctly & uses for specific purpose	0.715	0.288
Shows awareness & care re danger home & community	0.734	0.279
Understands instructions directions 3 or more parts	0.260	0.828
Understands familiar routines	0.376	0.303
Understands new routines	0.301	0.688
Responds to common signs	0.382	0.664
Understands consequences	0.311	0.764

basic communication skills such as gaining attention, making needs and wants known, asking and answering simple questions and responding to instructions. The third factor revolved around interpersonal and social interactions. This third factor was removed to become the basis for an Interpersonal Interactions and Relationships Scale (IIR), while items identified in the first two factors became the basis for the Communication Scale.

Factor analysis of the original physical assistance/mobility domain that included items regarding support for transfers and lifting, use of arms/hands and toileting revealed good communality of all items, explaining 69% of the variance. However, bowel and bladder management were extracted as a second factor. These items were moved to the self-care and domestic life domain, leaving mobility items and transfer and lifting items in the new mobility domain. Two additional items concerning transport support needs were also included in the revised *Version 2* Mobility Scale.

In the areas of self-care and domestic life, three factors with eigenvalues greater than 1 accounted for 77% of the variance. Two of these factors comprised items regarding self-care (dressing, bathing, hygiene, grooming, toileting) and basic domestic skills (simple cooking, cleaning and using household appliances). These items were used as the basis for the Self Care and Domestic Life (SCDL) Scale. A third factor concerned economic activity (counting change, making minor purchases, banking and budgeting) as well as danger awareness and other community access skills such as crossing roads, making appointments, and engaging in leisure and recreation. These items were used to create a new Community Social and Civic Life (CSCL) Scale. The distribution of this scale for *Version 1–2* was negatively

skewed and indicated a possible ceiling effect in operation. Additional ICF items relating to spirituality and political life and citizenship not previously included but identified through stakeholder feedback, were added to extend this domain for *Version 3*.

The A&P Total Score was found to be relatively normally distributed across the larger sample (*Version 1–2*) but positively skewed for the sample that used *Version 3*. Analysis of variance conducted on the A&P Total Scale ($n = 936$) found no difference according to age [$F(3,932) = 1.98$, $P = 0.12$], but significant differences according to gender [$F(1,933) = 8.42$, $P < 0.01$] and selected disability groups [$F(6,905) = 22.50$, $P < 0.001$]. Females in this sample (M = 48.2, SD = 18.2) registered significantly higher support need scores than males (M = 44.2, SD = 18.3). Post-hoc comparisons using the Tamhane *t*-test identified significantly higher support need scores among individuals who had multiple disabilities (M = 52.7, SD = 17.5) and those with both an intellectual disability and either a neurological condition (M = 51.9), a physical disability (M = 50.8) or a sensory disability (M = 46.8), but lowest scores among those with intellectual an disability only (M = 40.4). However, no significant differences were registered on the smaller sample that completed *Version 3*.

Correlation coefficients between the A&P Total and the six A&P domain scales were all significant and positive for *Version 2* ($r = 0.72$ to $r = 0.94$, $P < 0.05$) and for the majority of scales in *Version 3* ($r = -0.002$ to $r = 0.87$). The highest groupings were among the domains of AKGT, Communication, IIR and CSCL. The major difference was the Mobility domain scale on *Version 3* (for details see Table 6).

A large proportion of the sample who completed *Versions 1–2* and who lived in large residential settings were found to have significantly higher support needs across all the A&P Domain Scales and the A&P Total (M = 49.9, SD = 16.1, $t(909) = -9.32$, $P < 0.001$) than individuals who lived in smaller domestic settings (M = 37.9, SD = 19.4). This finding was not repeated in the sample that completed *Version 3*, as the majority in this sample lived in smaller domestic scale accommodation settings.

The average time taken to complete the assessment for *Version 2* was 100 minutes (SD = 42 min, range = 30–300 min). The extremely lengthy times involved several individuals who had physical disability and communication (AAC) requirements, and a person who was deaf. These individuals required breaks during the assessment as well as extra time to communicate their ideas and requirements. Additional time was also taken

Table 6 Relationship between A&P scales and A&P Total *Version 3*

Scale	Applying Knowledge & General Tasks	Communication	Mobility	Self-Care & Domestic Life	Interpersonal Interactions & Relationships	Community Social & Civic Life
AKGT	1.000					
Communication	0.799**	1.000				
Mobility	0.032	−0.002	1.000			
SCDL	0.517**	0.408**	0.652**	1.000		
IIR	0.807**	0.776**	0.093	0.457**	1.000	
CSCL	0.702**	0.639**	0.288*	0.714**	0.672**	1.000
A&P TOTAL	0.827**	0.770**	0.477**	0.833**	0.814**	0.871**

*Correlation significant at the 0.05 level (two-tailed).
**Correlation significant at the 0.01 level (two-tailed).

to rate support hours received using AAIDD categories (Luckasson *et al.* 2002) as well as a 24 h clock rating of support hours. These features were not included in *Version 3*, which was also further shortened and simplified in terms of scoring. Consequently the time taken for administration of *Version 3* was reduced to a range from 30–60 min.

Participant feedback resulted in several items being revised slightly to avoid ambiguity, and several issues were identified as not covered sufficiently in the instrument: ageing and respite concerns, ageing parents, support for holidays, lack of recognition of support given by family and insufficient focus on the needs of people living with family members. Some difficulty was also reported around the calculation of paid support hours and the support diary – the results of which are detailed in Part II.

Most of the 149 participants with disability who were interviewed by facilitators reported they were happy with the support currently received or had nothing further to add. Many of these individuals responded according to basic support needs for daily life, but others spoke more of their hopes, dreams and aspirations, and the support they required to achieve these. Specific support areas nominated of greatest concern were categorized and summarized in Table 7. It is noteworthy that 16% of these involved the interpersonal interactions and relationships category and pertained to specific relationships, including support for intimate and sexual relationships, and support to manage difficult relationships with fellow residents. Not surprisingly, some responded that they wished to change the people they lived with, or to change house, or live on their own. Some were concerned about staff, or staffing hours, and some wanted to be able to choose their own staff.

Table 7 Support desired by people with disability (*n* = 149)

Category	n (%)
Nil additional support	26 (17.4)
Interpersonal interactions & relationships	24 (16.1)
Recreation and leisure & holidays	22 (14.8)
Personnel to assist in daily living	22 (14.8)
Daily living equipment/resources/finances	14 (9.4)
Learning	10 (6.7)
Change of residence	8 (5.4)
Therapy/intervention	8 (5.4)
Staffing	6 (4.0)
Home/room maintenance	5 (3.4)
Employment	4 (2.7)
Total	149 (100.0)

Discussion

Across the 10 I-CAN scales, alignment was made as closely as possible to the domains used in the ICF framework (World Health Organization (WHO) 2001). However, this was not always feasible, especially in some HWB scales.

Several revisions were made to the Physical Health Domain, particularly the development of categories based on the analyses of qualitative data collected in *Version 2* that were aligned with the combined chapters of body functions and body structures from the ICF. Results obtained on this revised physical health domain *Version 3* demonstrated it was possible to assess support needed across these categories, and that differing levels of supports intensity could be ascertained. The analysis of variance results using the selected disability groupings also provided confirmation that the scale was sensitive in distinguishing a range of medical and

neurological support needs that correlated positively and significantly with physical and neurological disability data.

Regardless of the fact that the majority of people with disability assessed had an intellectual disability, a significant proportion of those sampled (72%) required support in the physical health domain, and 25% of the total sample were found to require some support for epilepsy or seizure conditions. These findings are in keeping with research evidence about the significant and often chronic and complex health care needs in this population that have often gone under-diagnosed and under-treated (Beange & Bauman 1990; Wilson & Haire 1990; Beange *et al.* 1995; Lennox & Kerr 1997; Centre for Developmental Disability Studies 2006).

The trend for higher physical support to be required with increasing age was evident across all samples. Typically, age was associated with an increased number of physical health conditions that required a greater level of support. Additionally, individuals scoring at the upper end of the scale recorded multiple difficulties. For example, an individual with an intellectual disability who gained a very high physical health intensity score recorded a range of support needs related to circulation problems, instability, incontinence and bowel issues, daily monitoring of weight and food intake, an eye infection, dry skin, and possible dementia. Documentation about the type of health conditions and/or concerns and the actual support required can be critical for individual planning and follow up purposes, and provides an important adjunct to the quantitative data recorded in the I-CAN domain scores.

Inclusion of the Mental and Emotional Health, Behaviour and the Health Services domain scales was considered critical in a support needs assessment instrument to be used across disability types, since these support areas are critical and can consume a significant amount of time and resources for families and agencies alike. The majority of categories in these HWB domains were derived from analyses of qualitative data from *Version 2*, although several categories in the Mental and Emotional Health domain align with ICF Chapter 1 Mental Functions (World Health Organization (WHO) 2001).

Typically, people with intellectual disability have a higher prevalence of psychiatric disorders such as depression, schizophrenia, and anxiety than others in the population (Borthwick-Duffy 1994; Moss *et al.* 2000; Deb *et al.* 2001a; b; Emerson 2001, 2003; Holland & Jacobson 2001; Einfeld *et al.* 2006). However, cognitive and communication difficulties mean they may present in an atypical manner (Bernet & Dulcan 1999; Emerson 2001;

Holland & Jacobson 2001) while diagnostic overshadowing often means these issues may be overlooked (Reiss *et al.* 1982; Reiss 1990; Prosser *et al.* 1998). The move from solely diagnostic based mental health categories that required a psychiatric diagnosis, to the use of functional mental and emotional health categories, enabled teams to rate support needs in these areas realistically, and thereby avoid such problems.

Consequently, the revised Mental Emotional Health scale enabled many support needs including emotional outbursts, concentration, eating and sleep disorders and sexual issues not previously accounted for to be captured: such that the proportion for whom support was registered in this domain rose substantially from 18 to 88%. Generally, individuals who had an intellectual disability and a diagnosed mental illness registered higher support needs on *Version 2*. In the smaller sample that completed *Version 3*, highest scores were gained by individuals who had an intellectual disability and either a physical disability or a mental illness. As would be expected, for those with episodic conditions, a substantial rise in intensity of support was recorded for episodes when the individual was unwell, but amount of time unwell was very individual and bears further investigation. Only a small number of people whose only or major disability was mental illness participated in the assessment process, and it is not known whether the assessment process itself is appropriate for this group. The extent to which the scale reflects their support needs therefore requires further study.

Higher behaviour domain support scores were found among those who had an intellectual disability and mental illness or an intellectual disability and a neurological disability. This was consistent with other research evidence that has demonstrated a high incidence of behavioural problems among those with intellectual disability and additional difficulties such as sensory impairments, communication problems, poor social skills and other mental health disorders (Deb *et al.* 2001b; Emerson 2001). Significant differences were also evident according to age, with younger persons recording higher behaviour support needs than older people. The fact that the highest behaviour support needs were recorded in the categories of socially excluding/disruptive behaviour and self-advocacy and protection (*Version*s *2 & 3*) may also reflect the high percentage of adults in the sample who had an intellectual disability.

Relatively small differences were found between known behaviour support needs (past 12 months) and probable (next 12 months) behaviour support needs for the majority of the sample, with correlations all positive

and significant. However, those cases that did record anticipated changes had valid and explicit reasons for recording either increased or decreased variation in support requirements. Further, users reported there were definite advantages in being able to make ratings for the current situation or environment as well as to provide an alternate rating for a projected change in situation, circumstances or environment, which would require more or less support. Obviously, the need for sensitivity to changing needs and ability to flag and ensure flexibility in support resource allocation based on such change is an essential feature of a useful support needs instrument. Consequently, this feature of the instrument has been retained as an optional facility and expanded, such that all domains can be rated for the current as well as any projected change in environment or situation.

The instrument demonstrated that it was possible to gather information about the type of health professionals visited, and the frequency and level of support required to access these services. This information can be critical for organizations that employ paid carers to provide this support, although natural supports including volunteers, family and friends can also be used.

Inter-correlations between the HWB Total and the HWB domain scales were all positive and significant, and the adjusted domain scores and the overall HWB Total were all effective in discriminating frequency and level of support across the sample. However, differing patterns were discernible according to disability type such that the use of the multi-dimensional domain scales is recommended as they give far richer information than a single HWB Total score.

The ICF provides a single list of A&P domains, or life areas, with options for use. An activity (A) is defined as the execution of a task or action by an individual, and activity limitations are therefore difficulties an individual may have in executing activities. Participation (P) is defined as involvement in a life situation, and participation restrictions as problems an individual may experience in the involvement of life situations. No consensus has been reached over the differences between activities and participation, and in line with other Australian developers using the ICF (AIHW 2003), the project team determined to use all domains as both A&P rather than attempt to separate these out across different fields. Supports in this context constitute those resources (human and otherwise) that are required to enable a person to overcome activity limitations and/or participation restrictions.

Although the ICF has nine chapters covering both A&P, only six domain scales were developed for the purposes of the support needs instrument, based on factor analysis results and practical utility. This meant several ICF chapters were amalgamated, for example Learning and Applying Knowledge was combined with General Tasks and Demands, and Self Care with Domestic Life. Another chapter covers Major Life Areas that includes education, work and economic life. Since the instrument was developed and tested among individuals in residential settings, insufficient information was available regarding education, work and employment so this domain was not included at this point, although plans are to develop this at a later stage. Several items regarding economic life were placed in the CSCL domain.

A wide range of scores was gained on each of the A&P domain scales, indicating each domain scale was sensitive to measuring differences in support according to intensity data. Further, distributions gained on the A&P Domain Scales and the A&P Total Scale indicate that the instrument is capable of distinguishing levels of support in each domain, from no support required through to complete support. Correlations between the six A&P Domain Scales and the A&P Total Scale were significant and positive. Several patterns were evident across the scales related to disability type, indicating that the specific scales measure different although at times related concepts, that could be masked by use of the A&P Total Score alone. Consequently, the importance of a supports profile was ratified.

The presence of two or more disabilities was usually associated with increased support requirements. Individuals who had multiple disabilities or intellectual disability in addition to a neurological disability, a sensory or a physical disability registered higher support needs on the A&P Total Scale. They also registered higher support in the domains of AKGT, Communication, SCDL and CSCL. Highest support needs on the Mobility Scale were registered by individuals who had both an intellectual and a physical disability; those with multiple disabilities; and those in the Other disability group, that included a number of individuals whose primary disability was physical or ABI. Mobility support scores were also found to rise with age. Individuals who had an intellectual disability only, or who were in the Other disability group registered lower support needs across most A&P Domain Scales and the A&P Total.

It was not surprising that a large proportion of the sample who lived in large residential settings registered higher support needs across all the A&P Domain Scales and the A&P Total than individuals who lived in smaller domestic settings; as larger more institutional

type settings often foster dependence or fail to provide opportunities to gain competence across many A&P domains. However, such findings highlight the importance of studying the influence of environment on support needs. While the I-CAN was developed to enable several ratings to be made, one for the current and another for a future or other environment, this aspect has not been investigated fully to date and requires further investigation.

Theoretically, a trained assessor alone could complete the instrument. Nevertheless, the assessment process that involved trained facilitators who coordinated and involved all relevant stakeholders, including the person with disability to whatever extent possible, was considered critical for gaining accurate and reliable information, taking account of whole of life issues. Individuals with disabilities and their families, advocates and caregivers are familiar with this process through participation in individual future and lifestyle planning meetings and were supportive of applying this team approach to supports assessment. Ideally, such assessment could link with and guide future planning, especially as the instrument enables specific notes to be recorded and reported about type of support needed on specific HWB and A&P domain scales, and follow up needs, that can be used for individual planning purposes. Furthermore, open ended questions allowed many individuals with disability the opportunity to express more personal desires, suggesting this may be an essential feature for some with regard to person centred planning.

Notwithstanding the generally positive evaluation of the instrument, there were several issues requiring further consideration. First, the absence of focus on lifestyle choices was apparent for some participants. The instrument is lacking in this area, for example, as noted in education and employment areas. It appears also that facilitators did not stress lifestyle choices, but focused more on level of support need relative to the support currently received by the person. This also raises the question of whether the participant's and facilitator's perspectives on possible support were limited by the known constraints on funding to support desired choices. Other areas raised included the differentiation between non-negotiable and negotiable support needs, the need to focus on lifestyle choices and a fulfilling life as distinct from survival needs.

Conclusion

The I-CAN provides a useful and practical instrument for assessing the support needs of people with disabili-

ties using a process that involves the person, their family and friends and staff as appropriate. The I-CAN is mapped to the conceptual domains of the ICF to facilitate greater awareness and understanding of the need for support to enhance the participation of people with disability in their communities.

This research and development project highlights the urgent need for further research to include additional sections covering education and employment, and to investigate the apparently strong influence of the environment in determining support provided irrespective of empirically identified individual need. The instrument is lacking in this area and warrants further investigation into perception of need for support related to the individual's current environment against their capacity, goals or desire for participation. In line with the above, it would also be helpful to investigate the usefulness of the I-CAN with other groups including older people (with identified disabilities and non-disabled), younger people (and particularly those living in restricted environments such as nursing homes and juvenile justice institutions) and people with a disability who are incarcerated or on parole.

Acknowledgments

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