The I-CAN: Using e-Health to get People the Support they Need

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Abstract

Background: The I-CAN is a comprehensive, reliable and valid system of identifying and classifying support needs of people with disabilities based on the conceptual framework of the International Classification of Functioning, Disability and Health (ICF) [1] and the American Association on Intellectual and Developmental Disability (AAIDD) supports concept [2,3]. Originally developed for people with Developmental Disability, the I-CAN's application of internet technologies is currently being trialled in Mental Health, Rehabilitation Medicine and other disciplines. Conceptual underpinnings, research and implementation to date are summarized.

Method: ICF based domains covering Health & Well Being and Activities & Participation have been refined over several versions. A total of 1012 individuals with disabilities across the eastern states of Australia were assessed using the first three versions, and 193 with the fourth versions. Studies investigated reliability, concurrent and predictive validity and user satisfaction. A fourth internet-based version has been implemented and is under continuing investigation and refinement.

Results: The I-CAN instrument demonstrated good reliability and validity in studies to date. Domain scales effectively discriminated a range of intensities of support for people with various disabilities, with highest support needs generally recorded by individuals with multiple disabilities and ageing issues. Correlations between I-CAN and adaptive behaviour scales were mixed. The I-CAN scales measure individual support needs. However, regression analysis suggests that staffing and other organizational factors play a significant role in resource allocation apart from individual support need. There was general satisfaction with the assessment process from stakeholders and participants groups. Several brief case examples shall be presented.

Conclusions: The I-CAN provides a reliable and valid tool for assessing and reporting on the support needs of people with disabilities using a process that involves the person, their family, friends and staff as appropriate. Several possibilities exist for this unique tool and the application of the ICF framework to e-health.

Keywords: ICF, Disability Evaluation, Diagnostic Techniques and Procedures, People with Disability, Electronic Health Records, Classification

1. Introduction

The Instrument for the Classification and Assessment of Support Needs (I-CAN) [4] is an assessment and supports planning system developed for people with disabilities based on the conceptual framework of

the International Classification of Functioning, Disability and Health (ICF) [1].

The ICF [1], published by the World Health Organisation (WHO), is a framework and code set which aims to classify health and disability at individual and population levels. The ICF is a member of the WHO Family of International Classifications (WHO-FIC), of which the International Statistical Classification of Diseases and Related Health Problems, 10th revision, Australian Modification (ICD-10-AM) [5] is also a member. Whereas the ICD-10-AM classifies diseases as causes of death, the ICF classifies health. The ICF complements the ICD-10-AM, and together they provide a holistic method to classify population health and review the impact the environment plays in health outcomes.

Key aspects of the ICF's model of disability are its move away from traditional medical models towards a biopsychosocial framework. The ICF conceptualises disability as something that does not simply reside within the person; instead disablement comes about through an interaction between the person and their environment. The ICF conceptual framework, as shown in Figure 1, outlines a complex interaction between a health condition or disorder, which will impact on a person's body function and structure. This will in turn impact upon the person's level of activity limitation or participation restriction, moderated by the environment and personal factors.
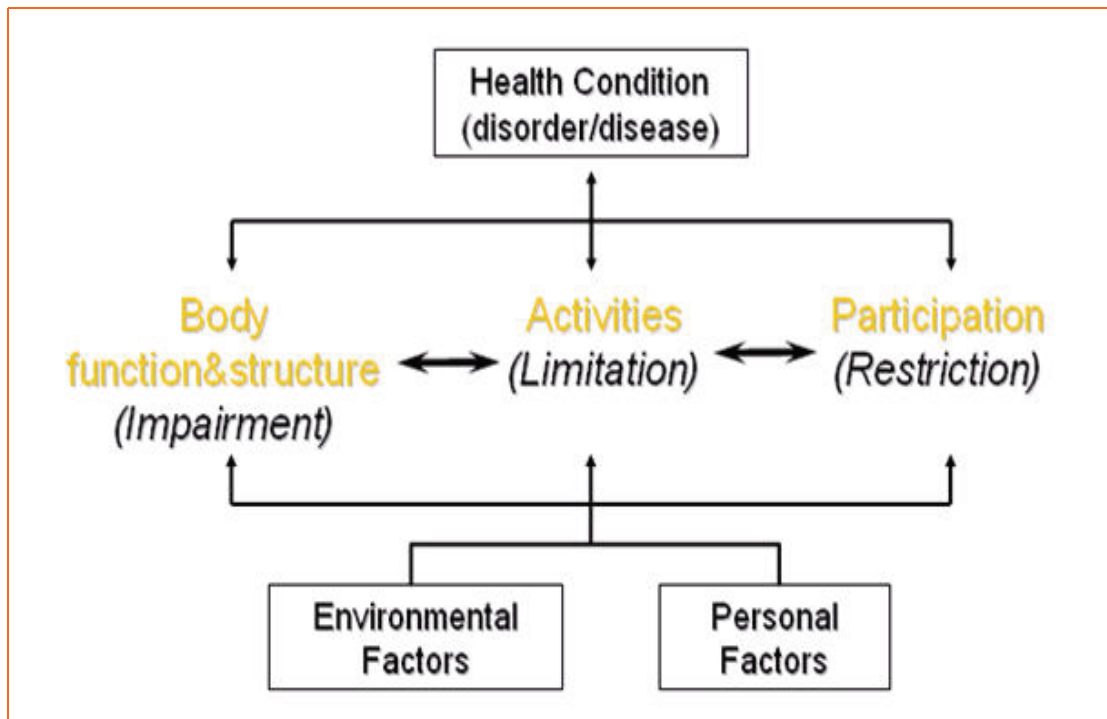

Figure **1**: The ICF Model of Human Functioning and Disability

Despite the broad, detailed and holistic nature of the ICF code set it has not been without criticism. Cummins [6], a leading researcher on Quality of Life and Subjective Well-Being, notes that the ICF only includes three items which may give an indirect indication of a fulfilling life. This raises questions regarding the ICF's applicability as a basis for outcomes measurement. The ICF's most significant improvement on previous classifications is the inclusion of environmental factors, however further work is required to delineate and test these factors [7]. The ICF places mental and emotional health needs on the same level as physical health needs, recognising the burden depression is having on society [8], however it does not provide a code set to record specific mental illnesses. Some of these identified issues have been incorporated into the domain structure of the I-CAN, as shown in Figure 2.

Figure **2**: The I-CAN v4.2 domain structure

The I-CAN is also conceptually based on the 1992 and 2002 AAIDD supports concept [2,3]. The 2002 theoretical model put forward by the AAIDD is shown in Figure 3. A key concept within this model is that a person's level of individual functioning is moderated by the supports that are built around the person. The ICF and other commonly employed classifications and measures used to plan supports and measure health outcomes, such as the Functional Independence Measure (FIM) [9], are measures of functioning or deficit, that is, what a person does not have the abilities to do. However, the I-CAN is a support needs assessment that directly measures the frequency and level of support that the person requires. The I-CAN's focus is on the empowerment of the individual. Support needs measures are developed on the assumption that a direct measure of support need will be "more useful for planning teams and those in systems-level supports management" [10].
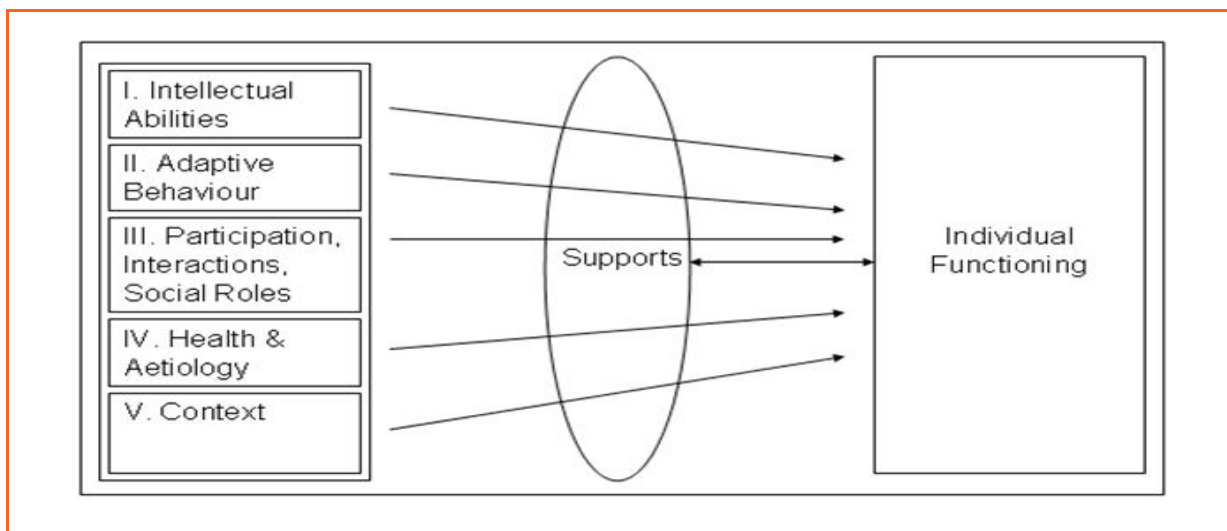

Figure **3**: The AAIDD 2002 Theoretical Model of Intellectual Disability

Working with the ICF and AAIDD frameworks has led the I-CAN authors to conceptualise a new framework that focuses on the Person, Supports and the Environment, as shown in Figure 4. This model is person-centred in the sense that a person interacts with their environment through supports, including human relationships and technology. A non-specific distinction between people,

supports and the environment captures the notions of supportive relationships, supportive environments, and dynamic interaction. This theoretical framework may be employed by a possible fifth version of the I-CAN and could have applicability elsewhere within health.
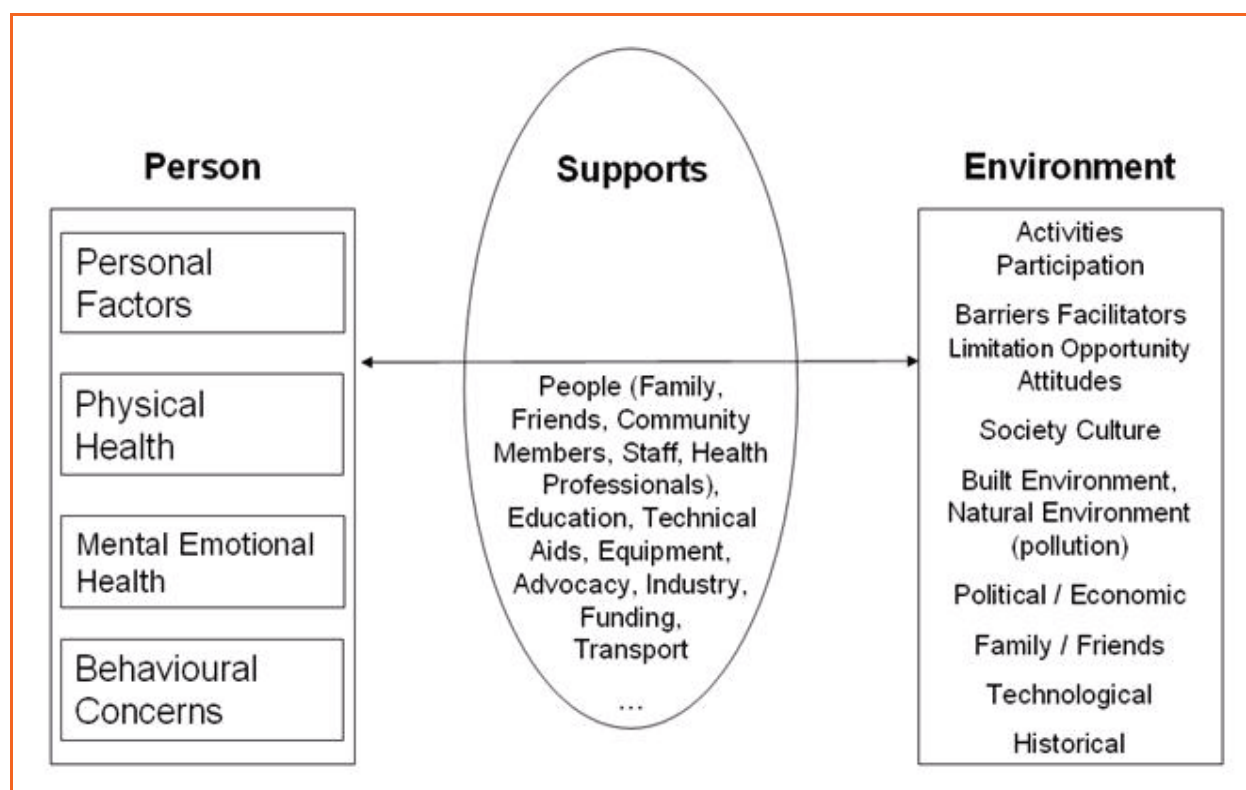

Figure **4**: The I-CAN proposed Theoretical Model of People, the Support they Need, and the Environment v1.04

The I-CAN has been under development since 1998, over several versions, with versions 4 to 4.2 incorporating Information and Communication Technologies (ICT). The following sections will attempt to summarize studies to date and proposed future studies. Validity and reliability results summarized are reported more comprehensively in the original reports [11 -13].

2. Participants

1012 assessments were completed during trials of the first three versions, the majority of participants were people with intellectual disability or people with multiple disabilities. As the I-CAN is completed through a group interview process, 5071 people participated in these trials.

Currently people are being recruited and data gathered using versions 4 to 4.2 (n=193); including people with intellectual disability, mental illness, traumatic brain injury or spinal cord injury. The majority of these people receive support from disability, mental health or rehabilitation services located in the eastern states of Australia.

3. Method

The instrument has been under ongoing revision according to (a) qualitative feedback from an advisory group and stakeholders, (b) analyses of results, and (c) further alignment with the ICF classification system. Studies for versions 1-3 were conducted to assess internal consistency of scales (n=23), test-retest reliability (n=30), inter-rater reliability (n=14), and concurrent validity in comparison with the Inventory for Client and Agency Planning (ICAP) [14] (n=30) and the Quality of Life Questionnaire (QOL-Q) [15] (n=29). Predictive validity (n=1009) compared assessment results with number of hours of day and night support. Practical utility was ascertained through telephone interviews (n=22) and face-to-face interviews (n=17).

It is planned to repeat these studies using data gathered from version 4 onwards, and to generate normative scales. Concurrent validity may also be measured in comparison to tools such as the FIM or Barthel Index [16]. Practical utility studies will take into consideration the incorporation of

4. ICT.Results

Internal consistency was in the moderate to high range with alpha scores for the overall Health & Well-Being (HWB) domains at 0.84 for

versions 1-2 and 0.90 for version 3; the overall alpha scores for the Activities & Participations (A&P) domains at 0.97 for versions 1-2 and 0.98 for version 3. An initial subsample (n=100) of version 4.1 data showed internal consistency for individual domains ranging from 0.83 to 0.93, excluding the Health & Support Services domain with 0.68 due to it's redesign to allow for staffing cost estimates.

Test-retest reliability, measured at one and two years, ranged from -.22 to .51 across domains. Although these generally low and non significant results could indicate poor reliability, alternatively they may indicate sensitivity to real change, as a number of physical and mental health changes were reported for participants that explained both increases and decreases in support over time. Version 4.1 onwards includes an item asking if any major changes in level of support need have occurred for use when measuring test-retest reliability.

Inter-rater reliability was extremely high ranging from 0.96 to 1.00. This result may be attributed to the group-interview assessment process itself, led by trained facilitators, with the independent researcher present at the interview

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Concurrent validity studies showed several significant correlations between domains of the I-CAN and ICAP combined service level score and the ICAP Social and Communication, Community Living and Broad Independence adaptive behaviour scales and the Internalized, Externalized and General maladaptive behaviour indexes. Several significant correlations were found between domains of the I-CAN and the QOL-Q Empowerment domain and to a lesser extent the QOL-Q Social living domain.

Predictive validity was measured using multiple regression with day-time support hours as the dependant variable. Three of the A&P domains were able to explain 40% of the variance of daytime support hours.

Although encouraging in term of the I-CAN's predictive validity, this result also suggests that that an important factor in retrospectively predicting individual funding allocations may be organisational structure or residential setting, as has been found by other researchers [10].

Two practical utility studies resulted in the majority of people surveyed across both studies giving positive feedback. Of 39 people interviewed either face-to-face or via telephone, only three people gave negative feedback. Feedback forms completed by participants and trainee facilitators of fourth versions have been mostly positive, with suggestions incorporated into on-going enhancements of the tool.

ICT is used to score, report on and database assessment results. Using ICT within the fourth versions offers many new possibilities as exemplified by the following case studies.

Completing a series of assessments across an institutional setting, the collated data outputted into MS Excel were able to clearly identify one person whose low level of support need raised serious questions regarding his current residential placement. These data were also useful to propose possible resident groupings as these people moved into smaller community housing, by identifying people with similar needs. However, it was noted that resident groupings can not be based on assessment results alone and require clinical judgement, input from the person and their family. Ideally, the person with disability would have a higher level of choice.

As data were being collected for people with intellectual disability living in community homes, individual reports being reviewed by a psychologist in a remote location noted several people were being recorded with a diagnosis of autism. On enquiry it was identified in fact that these people had received misdiagnosis from the local General Practitioner, who was not qualified to diagnose the dis-

order. Incorporated in the diagnosis recording section of the I-CAN is a checkbox for "query only". It was suggested in future that this checkbox be utilised unless a firm diagnosis is given by a qualified professional. A "query only" checkbox may also be a useful addition to other health recording systems.

Positive feedback has been received regarding the use of the I-CAN within transdisciplinary teams. This is likely due to the holistic nature of the ICF, and the I-CAN's ability to record input from various team members into the one centralised report, and to reference any specific care plans that have been developed by team members.

5. Discussion

Statistical results to date and feedback from implementation of the fourth versions have been encouraging. The I-CAN's focus on the support the person needs, and their central involvement in the assessment and planning process, leads to the development of a person-centred individual support needs report. The comprehensive support needs planning and reporting functionality of the fourth version of the I-CAN was only made possible through the incorporation of ICT. Basing the fourth version on a web-enabled database using a Linux Apache Mysql PHP (LAMP) web server allowed for the collection of a much larger dataset, including extensive qualitative as well as quantitative data. The online system allows pop-up help and suggestions to be given to assessment facilitators during the group-interview assessment process. Generating paragraphs and sentences using templates with some embedded logic allows for numerical data values to be outputted into a clinician and person friendly format. A pen and paper data collection form has been developed to allow assessment in clinical settings where internet access is not readily available or the interview facilitator does not have adequate computer skills.

Although hand scoring would still be possible, though highly laborious, the employment of a web-based database saves considerable clinician time that is usually spent scoring and reporting on assessment results. Screenshots of a generated individual support needs report are available on the I-CAN website.

Utilising ICT in the scoring and reporting of assessment results also opens up many other possibilities; such as telepsychology, linking with other databases - the I-CAN has been linked to the National Minimum Data Set (NMDS) [17], outputting data in different formats such as MS Excel spreadsheets, costing of supports delivery, online comparison tools, customised report formats and attachment of the person's photo to their person-centred individual support needs report. ICT could allow for further multimedia and Alternative and Augmentative Communication (AAC) supports to be incorporated into the assessment process.

A web-enabled server-side database as opposed to a client-side database offers advantages such as ease of access and reduction in compatibility issues. Most professionals and support services have access to internet browser enabled computers and some additional work on the server-side software ensures that the database is accessible from most popular browsers. Disadvantages focus on questions of security and privacy. Some government bodies have resisted the uptake of the I-CAN tool due to policy that limits the use of internet technologies. Whilst industry standard security protocols and encryption are in place, no guarantee can be made that any internet enabled database is 100% secure. An important part of the I-CAN assessment process is the gathering of consent. An easy English consent form informs the person that their personal details will be stored in a password-protected internet database following the group-interview assessment process. The incorporation of internet technologies

has greatly improved on the versatility of the assessment, and it is aimed that further practical utility studies will reflect on these enhancements.

The ICF provides a useful framework for health data recording. Despite its outlined limitations it may have further utility within other e-health applications, particularly if augmented with the Theoretical Model of People, the Support they Need, and the Environment as shown in Figure 4. It is important for any assessment or health recording system to consider the person's biopsychosocial needs and the environment within which they live, and to move beyond a focus on medical needs alone.

Acknowledgements

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