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

www.i-can.org.au

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I CAN DO IT!

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WHO ICF
What is the I-CAN?

The Instrument for the Classification and Assessment of Support Needs (I-CAN)

“a support needs assessment designed to assess and guide support delivery for people with a disability including mental illness. It provides a user, client, staff and family friendly holistic assessment, conceptually based upon the internationally recognized WHO ICF framework.”

www.i-can.org.au
What’s so different about assessing support needs instead of assessing functioning, health or adaptive behavior?

The questions we used to ask were:
• Can you count change? Can you climb a ladder?

Now we are asking:
• How much support do you need to go to the shops? If you wanted to climb a ladder, how much support would you need?
A Bit of History

Project in the Australian Capital Territory (ACT) (started in 1998) to develop a resource allocation tool for assessing and classifying support needs of people with an intellectual disability prior to determining funding needs

SCAN

Supports Classification and Assessment of Needs
Our History

• ARC linkage funding over 3 years to develop an instrument to assess & classify support needs
  • administered by the University of Sydney with CDS and Royal Rehabilitation Centre Sydney as industry partners

• Over 5000 participants in trials of first three versions, n = 1012 assessments completed.

• Ongoing revisions based upon:
  • Factor Analysis
  • Validity and reliability studies
  • Feedback (what’s missing?)
  • Ongoing review of the WHO ICF framework (WHO, 2001)
I-CAN v4.2

- Broader conceptualization of support
- Web based assessment
  - e-Health, telemedicine, telepsychology
- Comprehensive Supports Planning and Profiling tool
- Additional online functions include:
  - Upload a photo!
  - Compare scores & track changes over time
  - Custom Summary Report
  - National Minimum Data Set (NMDS) export
  - Excel export (import into SPSS)
  - Cost Estimation Tool
- Community Living e-Health record
Eating & Drinking
- eating
- drinking
- other... please specify

Dressing / Undressing (includes handling zippers, choosing clothes appropriately, footwear)
- dressing / undressing
- make up
- shave
- skin care
- nails
- other... please specify

Hygiene & Grooming
- shower
- bath
- teeth
- hair

I can... Goals... My Support Needs
Bob is independent with most hygiene and grooming activities. Bob is learning to shampoo his hair properly. Our goal is for Bob to be independent in shampooing his hair thoroughly in 2 months. Staff support him with prompts on the weekends only with a showering / shampoo program.

Follow-up?

Toileting
- toileting
- menstrual care
- incontinence
- other... please specify

Medication
- medication management
- other... please specify

Bob requires daily assistance to administer medication from a Webster Pack.
### Background Information

Bob currently lives with three other people in a domestic scale supported living setting at Smith St. Bob has never married or been in a defacto relationship. Bob participates in a recreation program at Angel Care Accommodation Service. His primary source of income is the Disability Support Pension. Bob was born in
First version!
Figure 1b: Difference between assessments dated 11-02-2008 and 30-01-2007

Figure 2: Group comparison of average support needs scores
I-CAN Theoretical Models

Or how to describe humans with boxes and arrows.
Active Support
• World Health Organisation’s (WHO) International Classification of Functioning, Disability & Health (ICF)

• Integration of medical and social models -> Bio-psycho-social
• Person-environment interaction

• Search me online
  – though my webserver seems to keep falling over!
New paradigm vs. Old paradigm

Everyone may have disability
- Continuum
- Multi-dimensional
- Neutral language

Specific impairment groups
- Categorical
- Uni-dimensional
- Pathology language

http://www.icdr.us/ICF07/presentations/Marjorie_Greenberg.ppt
I-CAN is based on the WHO ICF framework

Health Condition (disorder/disease)

Body function&structure (Impairment)

Activities (Limitation)

Participation (Restriction)

Environmental Factors

Personal Factors
Interaction of Concepts

Major depressive disorder (ICD code 296.2)

- Impairment of energy & drive (b130)
- Limitation community life (d910)
- Restriction maintaining a job (d8451)

- Immediate family (e310)
- Personal Factors
The AAIDD 2002 Theoretical Model of Intellectual Disability

- I. Intellectual Abilities
- II. Adaptive Behaviour
- III. Participation, Interactions, Social Roles
- IV. Health & Etiology
- V. Context

Individual Functioning

Supports
## What is Person-Centredness?

<table>
<thead>
<tr>
<th>Rehabilitation Perspective (medico)</th>
<th>Independent Living Perspective (person-centred)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The Problem is:</strong></td>
<td>Impairment / Skill Deficiency</td>
</tr>
<tr>
<td>Located in:</td>
<td>The person</td>
</tr>
<tr>
<td>Solution is:</td>
<td>Professional Intervention</td>
</tr>
<tr>
<td>Person is:</td>
<td>Patient / Client</td>
</tr>
<tr>
<td>Who’s in charge?</td>
<td>Professional</td>
</tr>
<tr>
<td>Outcomes defined by:</td>
<td>Level of functioning</td>
</tr>
</tbody>
</table>

Based on O’Brien & O’Brien (2000)
A Synthesis of Models

I-CAN is based on philosophical, theoretical and practical levels, on the ICF, AAIDD, Active Support, Person-centredness & Strengths-based

- **Active Support** demands a focus on the engagement and empowerment of the person with disability
- **AAIDD 2002** model demands a new conceptualization in the way we conduct assessment, with a focus on support need not deficit or medical diagnosis
- **ICF** demands a holistic health informatics system, based in biopsychosocial philosophy, that considers facilitators and barriers to everyday life
- **Person-centeredness** demands the person with disability is present and drives their assessment wherever possible, with a focus on individualised supports, how I want to be supported
- **Strengths-based** demands a focus on empowerment with the right support, not a mere list of deficits
A Simplified Model?

Person

Disablement

Supports

Environment
The I-CAN Theoretical Model – Mapping it out, v1.03

Person

- Personal Factors
- Physical Health
- Mental Emotional Health
- Behavioural Concerns

Supports

- People (Family, Friends, Community Members, Staff, Health Professionals), Training, Technical Aids, Equipment… Commerce, Industry

Environment

- Activities Participation
- Barriers Limitations Attitudes
- (in) Society Culture
- Built Environment, Natural Environment (pollution)
- Political / Economic
- Family / Friends
- Technological
- Historical
The I-CAN Theoretical Model – ‘People are not boxes, We are all people’ version

- Disablement
  a human condition, not a category

- The Human Experience

- Supports

- Environment

(Person) ————> (the supports continuum) ————> Environment
Person in the centre

Environment

Support

Support

Person
Hmmm a simplified model needs a new name…

“All you need is love” - no no, not technical enough, already copyrighted!

“All you need is support” - no no, not catchy
International Classification of Functioning, Disability and Health

OR

International Classification of People, the Support they Need, and the Environment
ICF and Health Informatics

- Various efforts to integrate ICF, UMLS and SNOMED CT
  - see the Consolidated Health Informatics (CHI) Initiative

- “Mapping … needed from SNOMED CT to ICF … SNOMED CT is still somewhat weak on content coverage in social areas”
  - Donna Pickett, RHIA, MPH, Classifications and Public Health Data Standards, National Center for Health Statistics

- ICF only includes three items which may give an indirect indication of a fulfilling life
  - Prof. Robert Cummins, 2006, leading researcher on Quality of Life and Subjective Well-Being

- Should we be incorporating into codesets?
  - QOL or Subjective Well-being
  - Functional Status Indicators (FSI)
  - Supports / Health Interventions (see the International Classification of Health Interventions (ICHI) – under construction)

- Is it possible to develop a dynamic, web-accessible, practical, holistic, health informatics codeset?
  - That will lead to better outcome measurement at intervention and population levels?
How happy are you?

In comparison to the happy times in your life, how happy were you in the past two weeks?
Research

• On-going development & trial of instrument & process
• Data collected in NSW, ACT, Vic & Qld
• Residential settings, mental health settings, rehabilitation settings, and some day program settings
• Facilitators require training – version 4 allows for auditing of facilitators skills
• Process engaging 5071 participants versions 1-3
• n=1012 complete data sets versions 1-3
• n=170 to date 4\textsuperscript{th} versions
• Studies of reliability, concurrent and predictive validity, practical utility
Reliability Studies

• Internal consistency alpha 0.70 to 0.98 v1-3
• Internal consistency alpha 0.83 to 0.93 v4 except 0.68 for Health & Support Services Domain, due to redesign to allow for specific costs estimation (n=100)
• Inter-rater reliability r = 0.96 to 1.00 v1-3
• Overall agreements r = 0.99 v1-3
• Test-retest reliability r = 0.21 to 0.94 v1-3
  1 year r = 0.21 Physical Health Scale
  r = 0.93 for Mobility Scale
  2 years r = -0.22 Mental Emotional Health
  r = 0.94 Mobility Scale
Participant Evaluations

Positive feedback from:
• People with disabilities
• Trained facilitators
• Family members and advocates

Continued positive feedback with v4
Validity Studies

• I-CAN and Inventory for Client and Agency Planning (ICAP) (Bruininks, Hill, Weatherman & Woodcock, 1986)
  • Moderate and significant correlations with service level score coefficients (-.39 Communication to -.62 Behaviour)

• I-CAN & Quality of Life Questionnaire (QOL-Q) (Schalock & Keith, 1993)
  • Significant correlation between Community Integration/Social Belonging and I-CAN scales of Mental Emotional Health, Communication and Interpersonal Interactions and Relationships
  • Otherwise generally low to moderate correlations

• I-CAN v4 and Service Need Assessment Profile (SNAP) (Gould, 1998)
  • Several strong correlations between, though primarily Health & Well-Being domains, suggests I-CAN more holistic than SNAP
Predictive Validity

Multiple regression analyses of I-CAN scores against

- Day time support hours
- Night support hours
- 24 hour support clock
- Support functions (AAIDD)

Allocation of support hours included up to 40% factors relating to the individual but up to 60% appeared to relate to organizational factors such as policies, staffing, resources
Concurrent / Multiple Ratings...

<table>
<thead>
<tr>
<th>Physical Health</th>
<th>Now</th>
<th>In 12 Months</th>
</tr>
</thead>
<tbody>
<tr>
<td>dementia</td>
<td>Weekly Minor</td>
<td>Daily Extensive</td>
</tr>
</tbody>
</table>

Bob's dementia is progressively deteriorating. It is expected that he will require daily support.

<table>
<thead>
<tr>
<th>Mental and Emotional Health</th>
<th>Now</th>
<th>During Episode</th>
</tr>
</thead>
<tbody>
<tr>
<td>varying mood, depression</td>
<td>Occasional Minor</td>
<td>Daily Extensive</td>
</tr>
</tbody>
</table>

During an episode Bob can become confused, frustrated or very depressed. During these times it is good to...

<table>
<thead>
<tr>
<th>Self Care &amp; Domestic Life</th>
<th>At Home</th>
<th>At Work</th>
</tr>
</thead>
<tbody>
<tr>
<td>shower, teeth</td>
<td>Daily Moderate</td>
<td>Never No Support</td>
</tr>
</tbody>
</table>

In the mornings Bob needs some physical support to shower and brush his teeth. Otherwise Bob is very...

<table>
<thead>
<tr>
<th>Life Long Learning</th>
<th>Informal Supports</th>
<th>Formal Supports</th>
</tr>
</thead>
<tbody>
<tr>
<td>transport</td>
<td>Daily Moderate</td>
<td>Never No Support</td>
</tr>
</tbody>
</table>

Bob is currently driven on most days to and from his recreation program by his brother.
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