Critical Social Futures: Querying Systems of Disability Support

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University of NSW, Kensington

Querying Support and Support Needs: Individualising the Supports Paradigm

Samuel Arnold
Vivienne Riches
Roger Stancliffe
How happy are you?

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

5  Very Happy
4  Happy
3  A Little Happy
2  A Little Unhappy
1  Unhappy
0  Very Unhappy

Proxy Respondent
How healthy do you feel?

In comparison to the times in your life when you felt healthiest, how healthy have you felt in the past two weeks?

5 Very Healthy
4 Healthy
3 A Little Healthy
2 A Little Sick
1 Sick
0 Very Sick
Support needs mentioned 220 times

Support needs defined 0 times
Querying Support and Support Needs: Individualising the Supports Paradigm

• AAIDD “Supports Paradigm” & ‘normative’ definition of support needs

• Brief introduction to the I-CAN

• “People-Supports-Environment” model & ‘valued life’ definition of support needs

• I-CAN evidence that support needs should be considered as multi-dimensional

• NDIS vs. data-based approaches to resource allocation
The “Supports Paradigm”

The supports paradigm “shifts the focus from caregiving to investing time in creating and nurturing support networks;” (Thompson et al., 2004, p. 5)

“The New Supports Paradigm suggests that individuals should first, without restriction, define the lifestyles they prefer and the environments they want to access” (Buttsworth, 2002, p. 85)
The AAIDD 2002 Theoretical Model of Intellectual Disability
The supports paradigm “shifts the focus from caregiving to investing time in creating and nurturing support networks; thus, this paradigm shift redefines, but does not eliminate the role of paid staff” (Thompson et al., 2004, p. 5)

“The New Supports Paradigm suggests that individuals should first, without restriction, define the lifestyles they prefer and the environments they want to access. Their goals and priorities then become the basis for intensity and types of support they need to succeed in those environments” (Buttsworth, 2002, p. 85)
Five component support needs assessment and planning process. Reproduced from Thompson, Wehmeyer & Hughes, 2010, p. 173.
<table>
<thead>
<tr>
<th>Model</th>
<th>AAIDDD Supports Paradigm</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normalisation</td>
<td>✔</td>
</tr>
<tr>
<td>Social Role Valorisation</td>
<td>SRV</td>
</tr>
<tr>
<td>Person-Centredness</td>
<td>Centredness Yes ✔ Planning not quite ✗</td>
</tr>
<tr>
<td>Social Model of Disability</td>
<td>Strong social model focus on societal change ✗ Supports paradigm discourse focused on <em>individualised</em> supports, available support needs assessment do not measure ‘social change needs’ ✗</td>
</tr>
<tr>
<td>International Classification of Functioning (ICF)</td>
<td>Supports are implied within the environment component of ICF. ≙ (Supports central in AAIDDD model) Person-Environment interaction ≙ (standardised environment) Universal model not specific to people with disability. ✗</td>
</tr>
<tr>
<td>United Nations CRPD</td>
<td>Rights basis for entitlement to individualised supports. Provides some normative standard of reasonable and necessary ≙ America hasn’t ratified</td>
</tr>
</tbody>
</table>
Definition of Support Needs

“a psychological construct referring to the pattern and intensity of supports necessary for a person to participate in activities linked with normative human functioning” (Thompson et al., 2009, p. 135)
Definition of Supports

In 2002 the concept was redefined as “Supports are resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and that enhance individual functioning.” (Luckasson et al., 2002, p. 151)
I-CAN v5
www.i-can.org.au
I CAN DO IT!
Samuel Arnold
Vivienne Riches
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 support services and family friendly holistic assessment, conceptually based upon the internationally recognized WHO ICF framework.”
QOL

How Happy & Healthy?

About me, long term goals?

I Can contribute

Supports needed

QOL
I Can Contribute

Ally’s I Can Contribute Statement:

“I give to Médecins Sans Frontières every month. I work in an industry that is focused on helping people. I try to smile a lot and at other people, and when I meet someone new I am always willing to listen. I do a good job looking after our dog Lady, and looking after my husband. I only buy cage free and free range chicken.”
Bob can do many hygiene and grooming activities independently. 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. Bob gets support to shave every second day. He can put the toothpaste and staff will brush his teeth, and need to be gentle on the right side where his teeth are sore - he has seen the dentist and was prescribed a special toothpaste.

**Domestic Life**

**Shopping**

Bob likes to go on the weekly grocery shopping, and will help choose meals from the easy recipe book to make up the shopping list. Bob likes to put things in the trolley, and Graham usually comes along and pushes the trolley. Bob likes to hand over the money at the counter and say hello to the shop staff.

**Cooking**

Bob loves to cook from the easy recipe book, with support to read the recipe, and complete some steps such as handling hot pots and pans. With verbal prompting he can get ingredients from the cupboard, chop carrots, stir the pot, keep an eye on sausages etc. Usually other housemates can help carry things to the table. At the moment Tuesday and Thursday is Bob's cooking nights, with Friday pizza night.
I-CAN v5 Domains

Introductions
- About Me
- Long Term Goals, Dreams & Aspirations

Activities & Participation
- Mobility
- Self Care
- Domestic Life
- Community, Social & Civic Life
- Communication
- Learning & Applying Knowledge
- Life Long Learning
- Interpersonal Interactions & Relationships

Health & Well-Being
- Behaviour of Concern
- Mental & Emotional Health
- Physical Health

My Goals

Circle of Support & Support Services
**Frequency of Support**

**Never**  no support required  
**Occasionally** support required less then once a month  
**Monthly** support required 1-3 times a month  
**Weekly** support required 1-6 times a week  
**Daily** support required once, twice or a few times in a 24 hour period  
**Constant** support required a number of times or consistently throughout the day

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**Level of Support**

**N/A**
This health need or activity does not need to be rated as a support need.

**Independent**
Person does not need any support.

This health need or activity limitation is managed through any of the following:

- the independent use of aids or equipment, eg. independently using a wheelchair, a text to speech device, glasses, a hearing aid or a calculator.
- a simple strategy, eg. using a diary for reminders.
- purchase of a product, eg. special equipment, independently using continence aids, or a self-soothing strategy such as a buying a herbal tea or movie ticket.
- simple medication administration, eg. medication from a Webster Pak.
- occasional visits with health professionals eg. visits to the local doctor or dentist.

Alternatively, this task is completed by a charitable or low cost service, e.g. volunteer home visiting.

**Minor**
Person may need brief or minor support from another person, e.g. applying a simple bandage or cream, giving a brief prompt or word of reassurance, minor setup or occasional supervision or mentoring, monitoring for signs of discomfort, or brief physical assistance for a minor aspect of the task. Alternatively, this task is completed for five or more people.

**Moderate**
Person may need a series of prompts or instructions, reassurance or emotional support or more regular supervision, speaking on the person’s behalf to enable successful communication, or physical assistance for some aspects of the task. Alternatively, this task is completed for 2 to 4 people.

**Extensive**
Person needs extensive physical assistance for the majority of or for the entire task, such as hand over hand guidance, extensive emotional support, intensive support for a complex communication system or close supervision or monitoring. Alternatively, this task is completed for the person.

**Pervasive**
Person requires the direct support of two or more people due to this health need or to complete this activity.
• For example:
  – **Is this a met need?**
    - Yes, no, partially, over supported
  – **Source of support?**
    - Funded, Informal, Other Formal OR
    - ADHC, LifetimeCare, Family, Other
  – **Improvement since last assessment?**
    - Improvement, no, no change
  – **Support with or for?**
    – Other possibilities…
Support Needs Prediction Algorithms

Individual Funding Need Estimate: $53,473 (+- $14K).

This funding need estimate is based on 161 Australians with disability who were in receipt of an individualised funding allocation in 2010. It may underestimate need for people in supported living arrangements, or people with complex health or behavioural support needs. Please see the I-CAN manual for further details.
Querying Support and Support Needs: Individualising the Supports Paradigm

- AAIDD “Supports Paradigm” & ‘normative’ definition of support needs
- Brief introduction to the I-CAN
- “People-Supports-Environment” model & ‘valued life’ definition support needs
- I-CAN evidence that support needs should be considered as multi-dimensional
- NDIS vs. data-based approaches to resource allocation
The Amount of Support we Need

How old we are and what’s going on in our life

The Supports Continuum

Rug rat

Midlife Crisis

Car Accident

Here comes dementia
The person, surrounded by a circle of supports, interacts with their environment.
Figure 7: The I-CAN Theoretical Model of People, the Support they Need, and the Environment v1.04, reproduced from Arnold, Riches, Parmenter & Stancliffe (2009).
Figure 7: The I-CAN Theoretical Model of People, the Support they Need, and the Environment v1.04, reproduced from Arnold, Riches, Parmenter & Stancliffe (2009).
Defining Supports

“Supports are **resources and strategies** that aim to **promote the development, education, interests, and personal well-being** of a person and that **enhance individual functioning**.” (Luckasson et al., 2002, p. 151)

“Supports are **people, resources, tools, equipment, education or strategies** that **enable a person to interact with their environment** and **pursue a valued life**.” (Arnold, n.d., p. 12)
Defining Support Needs

“a psychological construct referring to the **pattern and intensity** of supports **necessary** for a person to participate in **activities linked with normative human functioning**” (Thompson et al., 2009, p. 135)

“a psychological construct referring to the **frequencies, types and overall amounts** of supports that are **reasonable and necessary** for a person to **pursue a chosen life of quality**.”
Mom? What is... Normal?

It's just a setting on the dryer, honey.
Conceptualising Support Needs

“How much support would you need to fully engage in all aspects of this activity to a contemporary community standard?” even if the person “does not” and “has no intention of doing” the activity

“How frequently, and what level of support, does this person need from another person, in order to complete this activity, or because of this health need, in supporting them to have a life of quality of their choosing?”
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Sample

• 163 Aussies

• Individual Funding package determined via a person centred planning process
<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>Frequency %</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>89</td>
<td>54.6</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>74</td>
<td>45.4</td>
<td></td>
</tr>
<tr>
<td>Age Groups</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. 0 - 14 years 11 months</td>
<td>20</td>
<td>12.3</td>
<td></td>
</tr>
<tr>
<td>2. 15 - 34 years 11 months</td>
<td>48</td>
<td>29.4</td>
<td></td>
</tr>
<tr>
<td>3. 35 - 54 years 11 months</td>
<td>65</td>
<td>39.9</td>
<td></td>
</tr>
<tr>
<td>4. 55 years +</td>
<td>30</td>
<td>18.4</td>
<td></td>
</tr>
<tr>
<td>Primary Disability</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neurological</td>
<td>31</td>
<td>19.0</td>
<td></td>
</tr>
<tr>
<td>Physical (50) and sensory (2)</td>
<td>52</td>
<td>31.9</td>
<td></td>
</tr>
<tr>
<td>ABI</td>
<td>21</td>
<td>12.9</td>
<td></td>
</tr>
<tr>
<td>Intellectual</td>
<td>59</td>
<td>36.2</td>
<td></td>
</tr>
<tr>
<td>Living Arrangements</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Lives Alone</td>
<td>45</td>
<td>27.6</td>
<td></td>
</tr>
<tr>
<td>2. With Others</td>
<td>21</td>
<td>12.9</td>
<td></td>
</tr>
<tr>
<td>3. With Family</td>
<td>97</td>
<td>59.5</td>
<td></td>
</tr>
<tr>
<td>Geographic remoteness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Accessible</td>
<td>23</td>
<td>14.1</td>
<td></td>
</tr>
<tr>
<td>2. Highly Accessible</td>
<td>140</td>
<td>85.9</td>
<td></td>
</tr>
<tr>
<td>Annual Individual Funding level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. $0-19,999</td>
<td>61</td>
<td>37.4</td>
<td></td>
</tr>
<tr>
<td>2. $20-44,999</td>
<td>46</td>
<td>28.2</td>
<td></td>
</tr>
<tr>
<td>3. $45-90,000+</td>
<td>56</td>
<td>34.4</td>
<td></td>
</tr>
</tbody>
</table>
Method

- Assessments with both ICAP and I-CAN Brief Research Version

- Block regressions and stepwise regressions
Adding the ICAP doesn’t add anything

Enter method, summary scores
• Demographics
• I-CAN
  – H&WB, I-CAN A&P
• ICAP
  – Broad Independence, ICAP Maladaptive Index

Block 1 – Demographics: $R^2 = .11$
Block 2 – Demographics + I-CAN: $R^2 = .23$
Block 3 – Demographics + I-CAN + ICAP: $R^2 = .23$
Only ICAP domain scores

Enter method

- Demographics
- ICAP
  - Motor Skills, Social & Communication Skills, Personal Living Skills, Community Living Skills, ICAP Maladaptive Index

Block 1 – Demographics: $R^2 = .11$
Block 2 – Demographics + ICAP: $R^2 = .22$
Only I-CAN domain scores

Enter method
- Demographics
- I-CAN
  - Physical Health, Mental & Emotional Health, Behavior of Concern, Major Life Areas, Mobility, Communication, Self Care, Domestic Life, Community Social & Civic Life, Learning & Applying Knowledge, General Tasks & Demands, and Interpersonal Interactions & Relationships

Block 1 – Demographics: $R^2 = .11$
Block 2 – Demographics + I-CAN: $R^2 = .35$
Summarising

• Adding ICAP domains didn’t explain any more variance.

• Using ICAP $R^2 = .22$

• Using I-CAN $R^2 = .35$

• Support needs (measured by I-CAN) predicts funding need (allocated using PCP) better than adaptive behaviour (measured by ICAP)
Using Stepwise Regression & ‘Funding Needed’ items

Do you need support to get dressed?
Can your informal supports assist you to do this, or do you need funded supports?

• $R^2 = .87$
\[ R^2 = 0.87 \]

No “Bootstrapping”
Article to come

- Full details to come in AJIDD
- Limitations
- Good reliability

- Help independently verify our findings!
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Resource allocation

- Currently appears to be an ‘Individual Planning and Clinical Judgment’ approach
  - Potential lack of equity, transparency and defensibility
  - Inability to benchmark reasonable package sizes
  - Limited cost control, potential for cost-blowouts
  - Potential reliance on skill of case manager
  - Could lead to jurisdictional differences
Data-based approach to individual funding resource allocation

• Support needs assessment designed on the principle that individual funding needs to be based on levels of support need to be equitable
• Data-based approaches a legislated requirement in the US
• Potentially more defensible, transparent and equitable
• Can allow sliding scale allocations, and creative, person centered approaches to use of resources
Dali Lama Supports ICAN

"I can imagine a world without nuclear weapons, and I support ICAN."

The Dalai Lama
I CAN DO IT!

Samuel Arnold
Vivienne Riches
Trevor Parmenter
Roger Stancliffe
Gwynnyth Llewellyn
Jeff Chan
Gabrielle Hindmarsh
When everyone else says you can't, determination says, "YES YOU CAN."

Robert Thensel
longest non stop wheelie in a wheelchair
Founder of Beyond Limitations Week

www.i-can.org.au
cds.med.usyd.edu.au