



16th Annual HISA Health Informatics Conference: The Person in the Centre

The I-CAN:

Using e-Health to get People the Support they Need

www.i-can.org.au

I-CAN Needs Summary

Name: Cynthia 'De-identified' Smith
Address: 21 Smith St, Smithville 2164
Email: cynthia@hotmail.com
Mobile Phone: 0424 727 567
DOB: 24-05-1978
Age: 29 years
Date of Interview: 29-01-2008
Participants: Cynthia, John (boyfriend), Emily (Nursing staff)
Facilitator: Bruce O'Bruce

Needs Summary Only
 Please note that this is an abbreviated summary only of the I-CAN Individual Support Needs Report. For additional background information or greater detail please review the full I-CAN Individual Support Needs Report.

About Me
 Until recently Cynthia worked as a PA for Government officials. She would like to return to work once she has adjusted to her new life circumstances. Cynthia loves television dramas and Bridget Jones diary, reading a good book, spending time with her boyfriend and family.

Current Life Situation
 Cynthia was employed by the Government until her recent car accident where she endured a spinal injury. She now has paraplegia at C5. Cynthia is currently staying in the rehab unit although is due to be discharged in one to two weeks.

Figure 1: Highest and Average Support Intensity

Support Intensity	Physical Needs	Mental & Emotional Needs	Behaviour	General Tasks	Communication	Self Care	Mobility	Relationships	Life Living Learning	Community
Highest	3	3	0	0	0	0	0	0	0	0
Average	5	7	1	1	1	1	1	1	1	1

- Samuel Arnold
- Vivienne Riches
- Trevor Parmenter
- Roger Stancliffe

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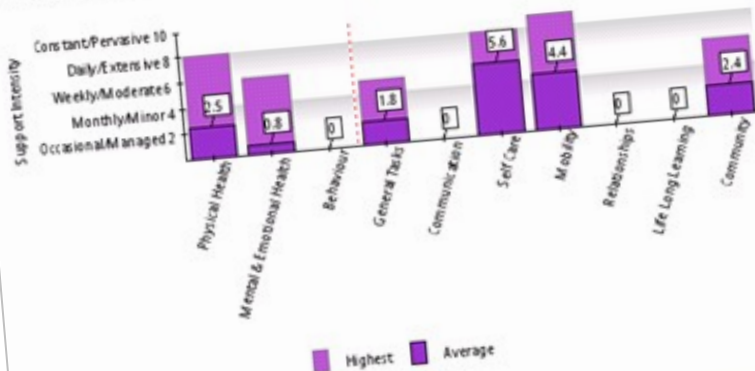


Figure 1: Highest and Average Support Intensity

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Samuel Arnold

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Roger Stancliffe



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Acknowledgements



Aussies: Vivienne Riches, Trevor Parmenter, Samuel Arnold, Roger Stancliffe, Gwynnyth Llewellyn, Keith McVilly, Jeffrey Chan, Gabrielle Hindmarsh, Julie Pryor, Tony Harman (and **many** others)



POMs: Helen Sanderson, Michael Smull, Edwin Jones, David Felce, Sandy Toogood, Jim Mansell and colleagues



Yanks: John O'Brien, Marc Gold, AAIDD



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.”

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Support Needs Assessment

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?

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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



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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)

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- 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

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 Address: 21 South St, Smithville 2164
 Email: cynthad@npsa.com
 Mobile Phone: 0124 227 567
 DOB: 24-05-1978
 Age: 29 years
 Date of Interview: 19-12-2007
 Date Revisited: 12-02-2008
 Participants: Cynthia, John (boyfriend), Emily (nursing staff)
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Figure 1: Highest and Average Support Intensity

Category	Highest Intensity	Average Intensity
Personal Care	3	2
Medical & Therapeutic	3	2
Activities	3	2
Community	3	2
Education	3	2
Employment	3	2
Relationships	3	2
Life Long Learning	3	2
Domestic	3	2

• Community Living e-Health record

Eating & Drinking eating drinking other... please specify

Hygiene & Grooming dressing / undressing (includes handling zippers, choosing clothes appropriately, footwear) shower bath teeth hair make up shave skin care nails other... please specify F: 3.Weekly L: 3.Moderate

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 F: 4.Daily L: 4.Extensive

I can...

Bob requires daily assistance to administer medication from a Webster Pack

Living Arrangements	<input type="checkbox"/> Lives alone	Or Lives With:	<input checked="" type="checkbox"/> others
	<input type="checkbox"/> spouse / partner	<input type="checkbox"/> dependent children	
	<input type="checkbox"/> parents	<input type="checkbox"/> brothers	<input type="checkbox"/> sisters
	<input type="checkbox"/> grandparents	<input type="checkbox"/> relatives	
Residential Setting Type	<input type="text" value="Domestic scale supported living facility"/>		
Name of residence	<input type="text" value="Smith St"/>		

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

v4.2 Domains

About Me, My Dreams & Aspirations,
Current Life Situation, Support Network

Health & Well Being

Physical Health

Mental & Emotional Health

Behaviour

Health & Support Services

Activities & Participation

Applying Knowledge, General Tasks &
Demands

Communication

Self-care & Domestic Life

Mobility

Interpersonal Interactions & Relationships

Life Long Learning

Community, Social & Civic Life

My Goals



Direct Support Staff (Shift Work)						
NSW SACS Employees (State) Award 12/8/06, HSU Residential Care Assistant						
POSITION	YR	Hours	BASE	ONCOST	TOTAL	PERCENT
CSW	Grade 1 Yr 1		14.72	3.68	-	100%
CSW	Grade 1 Yr 2		15.28	3.82	-	100%
CSW	Grade 1 Yr 3		15.84	3.96	-	100%

I-CAN Cost Estimation			
1	Last updated 17/6/08		
2			
3			
4	Date of estimation	18-06-2008 11:59pm	
5	People included in estimation	Test Guy	
6			
7	Shift work on-costs	25.00%	
8	Non-shift work on-costs	20.00%	
9			
10	Total for Health Professionals	\$0.00	per week
11	Total for Allied Health	\$51.25	per week
12	Total for Support Staff and Services	\$962.05	per week
13			
14			
15	Combined Total for Wages	\$1,013.30	per week
16		\$52,691.80	per year
17			
18			
19	+ Administration costs	12.50%	of total wages
20			
21	+ Transport or Vehicle costs	\$0.00	per week
22	+ Other costs	\$0.00	per week
23			
24			
25	Total Cost Estimate	\$1,139.97	per week
26		\$4,559.87	per month
27		\$59,278.28	per year

First version!

Track Changes

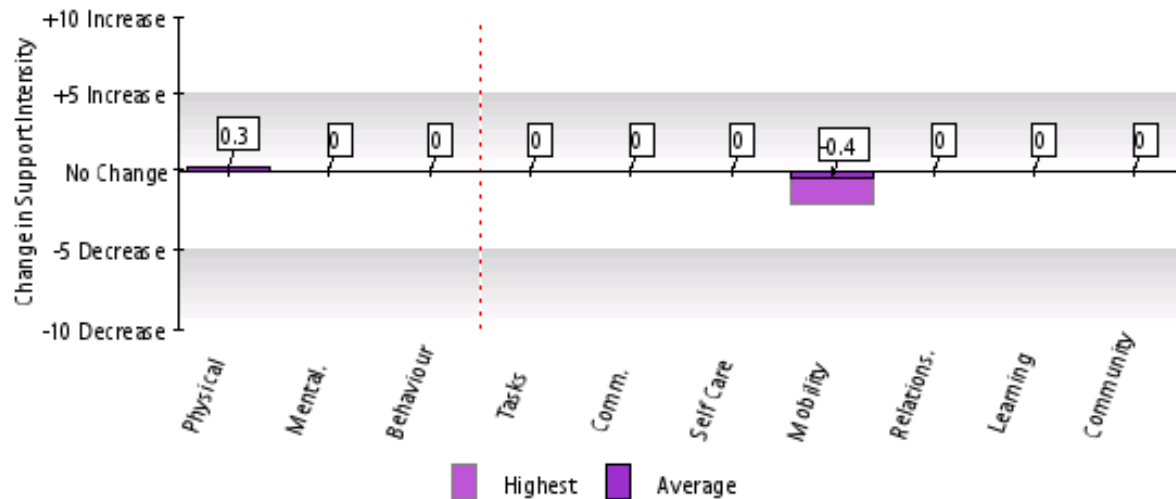
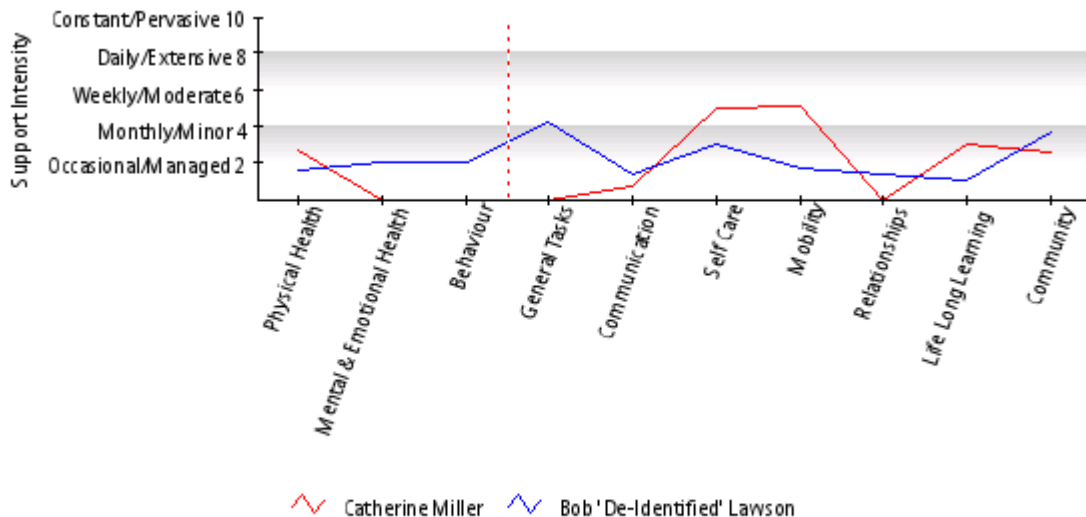


Figure 1b: Difference between assessments dated 11-02-2008 and 30-01-2007



Compare Needs

Figure 2: Group comparison of average support needs scores



I-CAN Theoretical Models

Or how to describe humans with
boxes and arrows.

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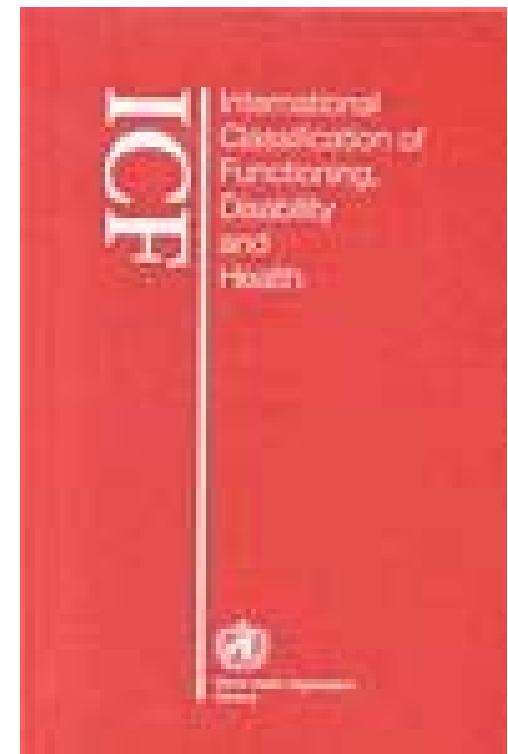


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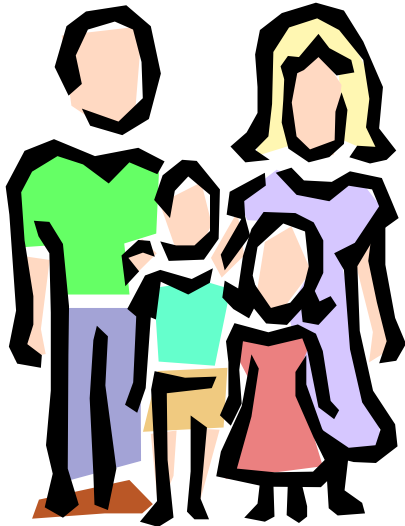
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International Classification of Functioning, Disability and Health

- 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

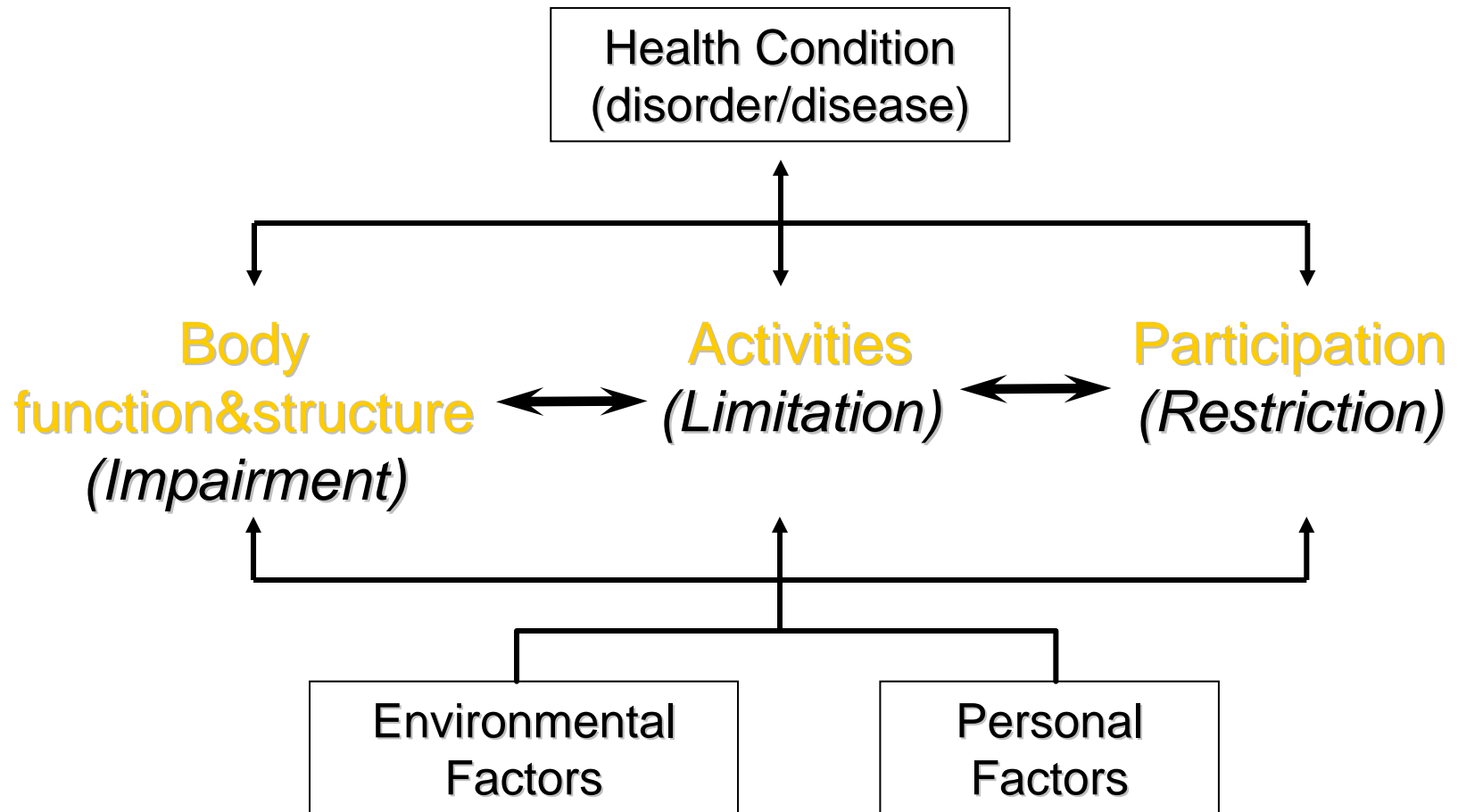


Everyone may have disability
Continuum
Multi-dimensional
Neutral language

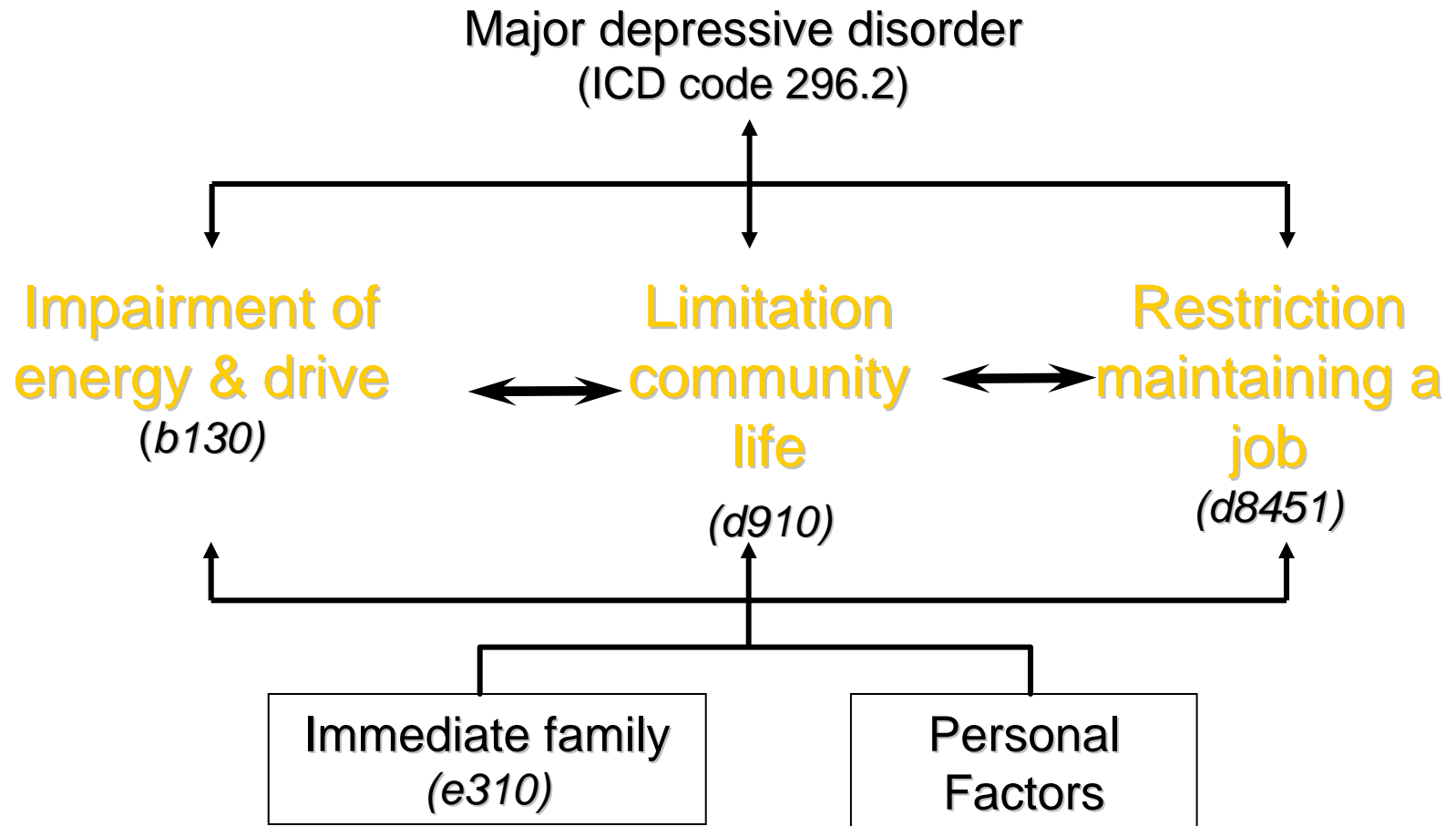


Specific impairment groups
Categorical
Uni-dimensional
Pathology language

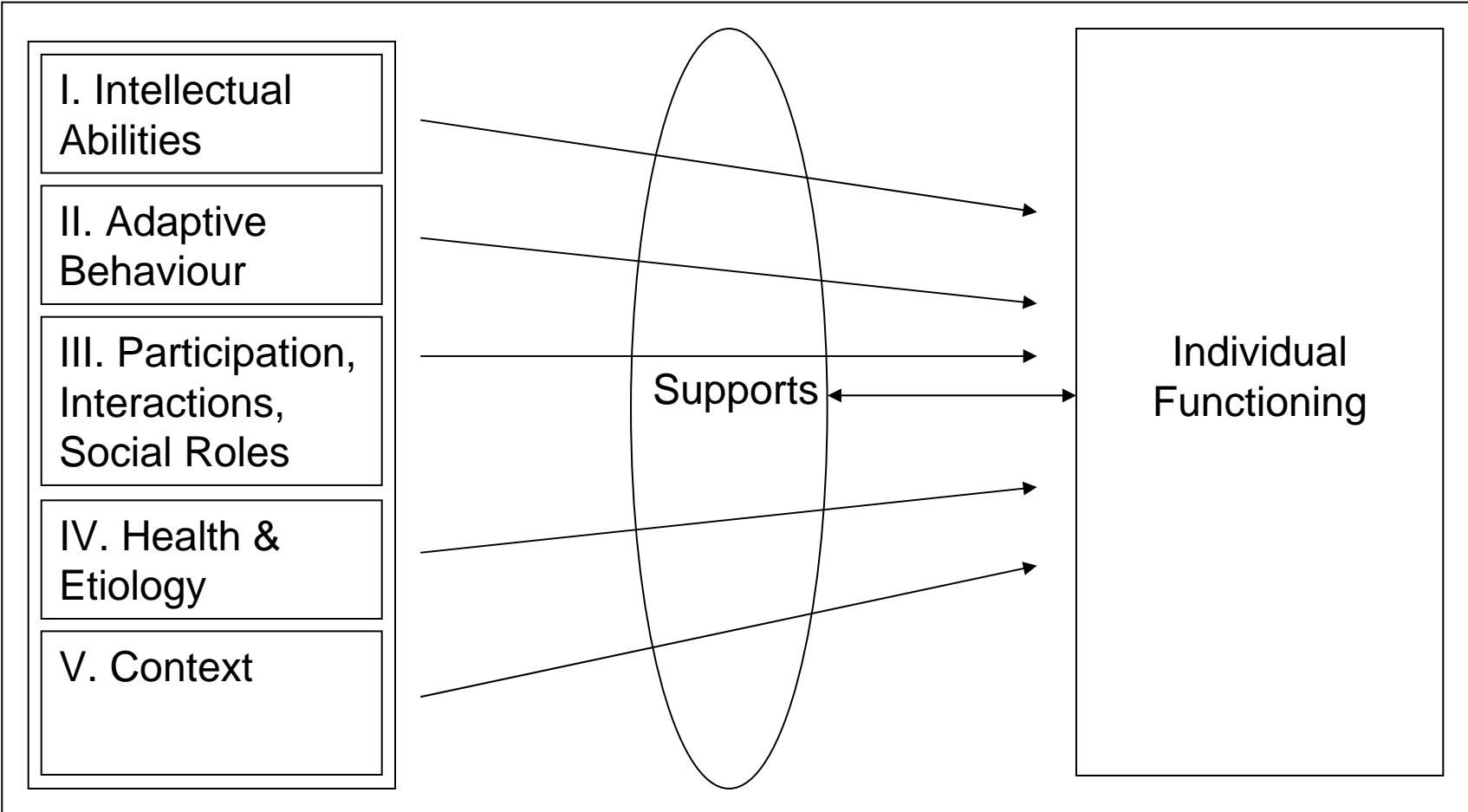
I-CAN is based on the WHO ICF framework



Interaction of Concepts



The AAIDD 2002 Theoretical Model of Intellectual Disability



What is Person-Centredness?

Rehabilitation Perspective

(medico)

Independent Living Perspective

(person-centred)

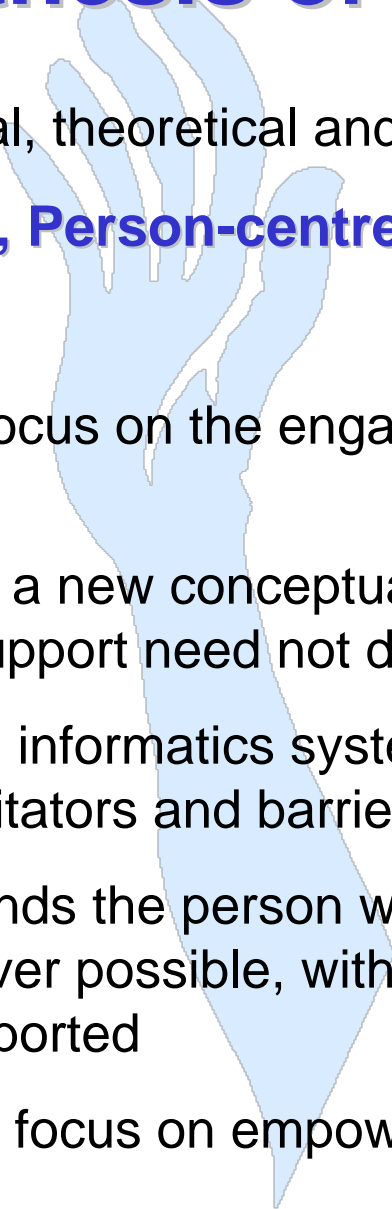
The Problem is:	Impairment / Skill Deficiency	Dependence on professionals and others who take control of your life
Located in:	The person	In the environment and services
Solution is:	Professional Intervention	Removal of barriers, advocacy, self-control
Person is:	Patient / Client	Person / Citizen
Who's in charge?	Professional	Person
Outcomes defined by:	Level of functioning	Living independently and being in control of my life

A Synthesis of Models

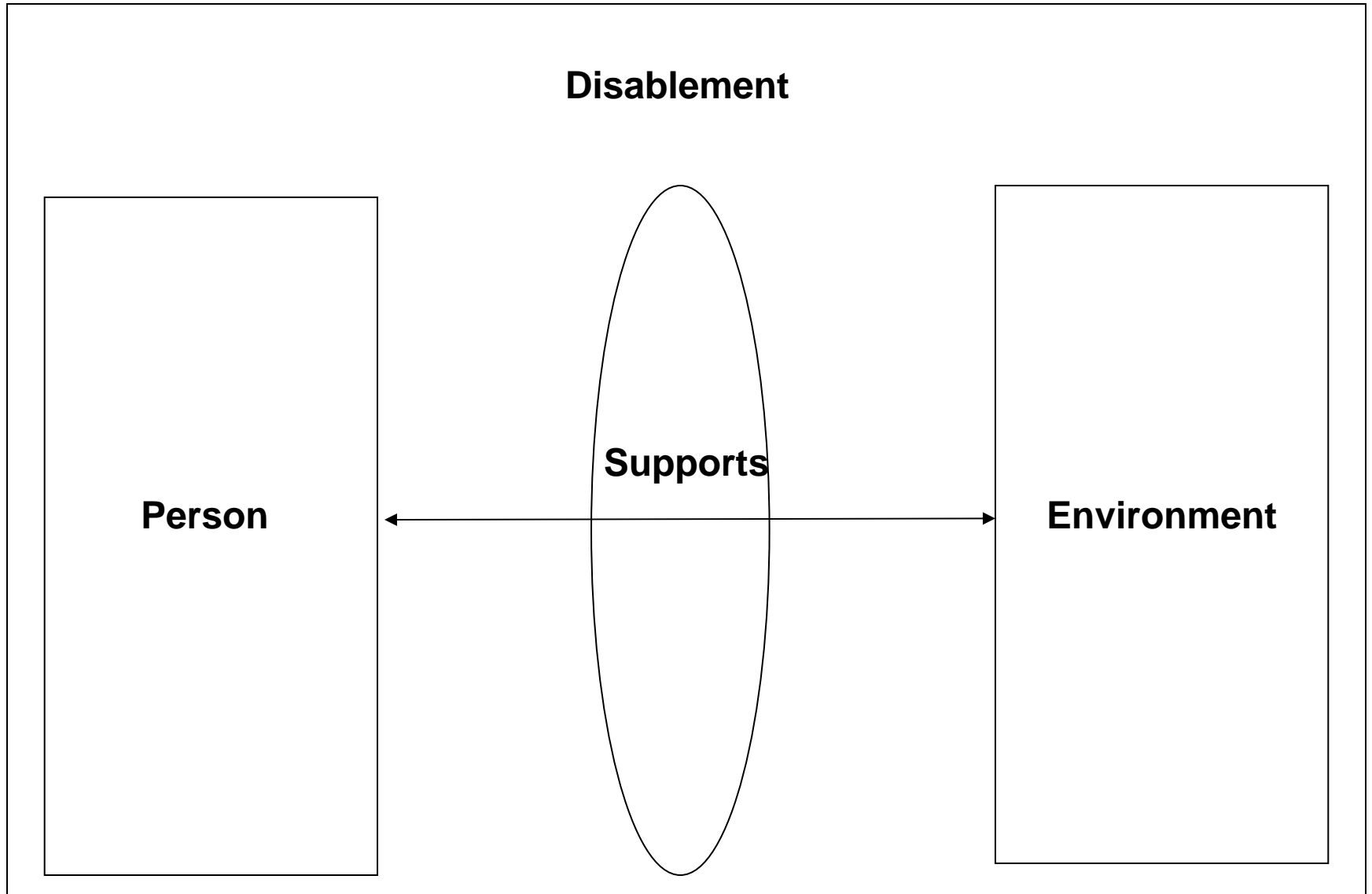
I-CAN is based on philosophical, theoretical and practical levels, on the

ICF, AAIDD, Active Support, Person-centredness & Strengths-based

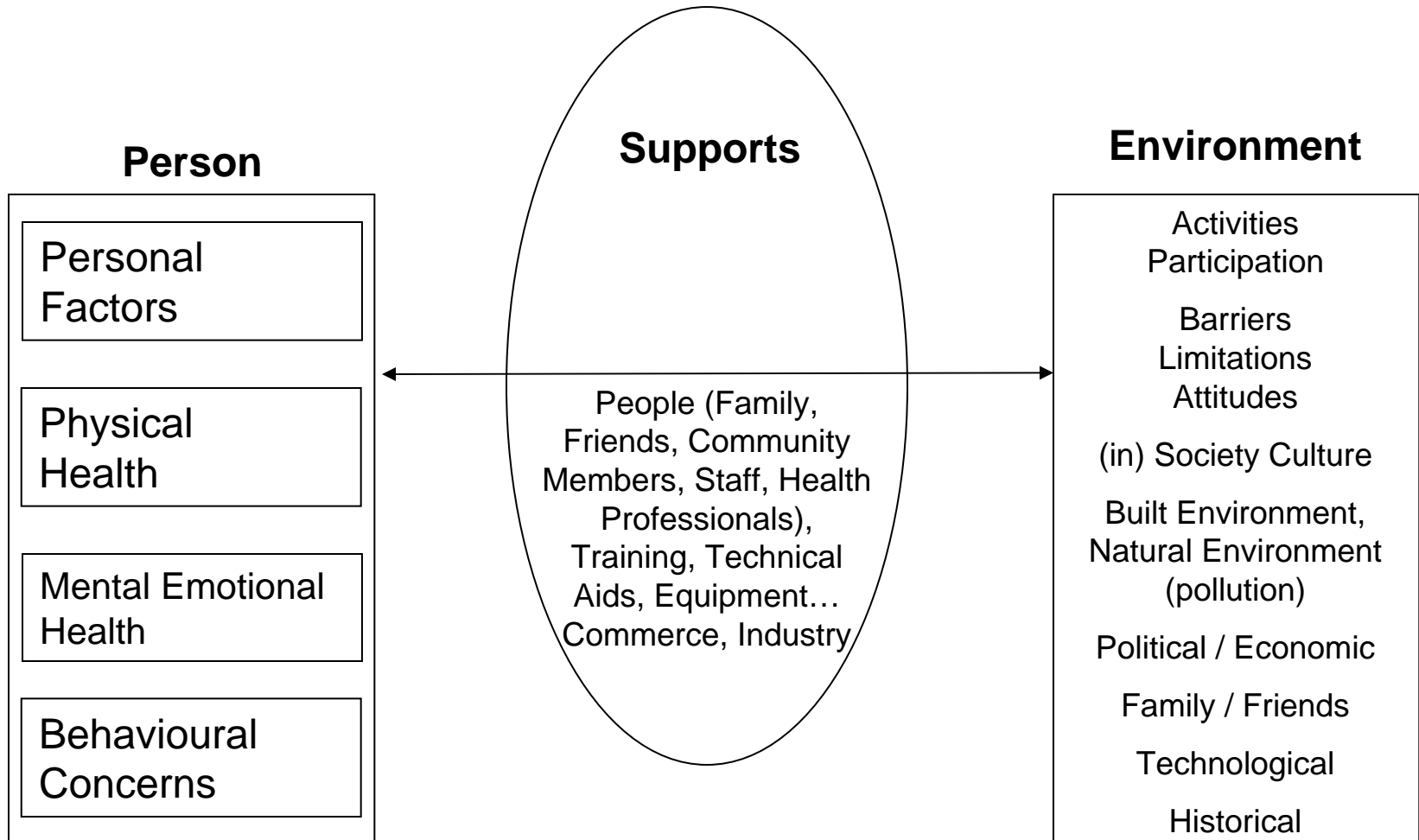
- **Active Support** demands a focus on the engagement and empowerment of the person with disability
- **AAIDD 2002** model demands a new conceptualization in the way we conduct assessment, with a focus on support need not deficit or medical diagnosis
- **ICF** demands a holistic health informatics system, 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?



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



The I-CAN Theoretical Model –

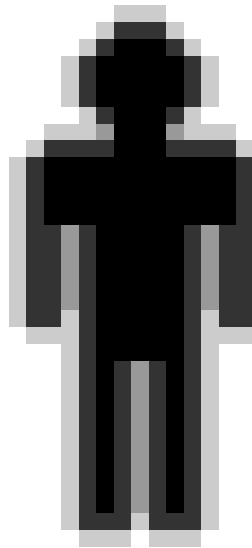
‘People are not boxes, We are all people’ version

~~Disablement~~

a human condition, not a category

The Human Experience

Person



Supports

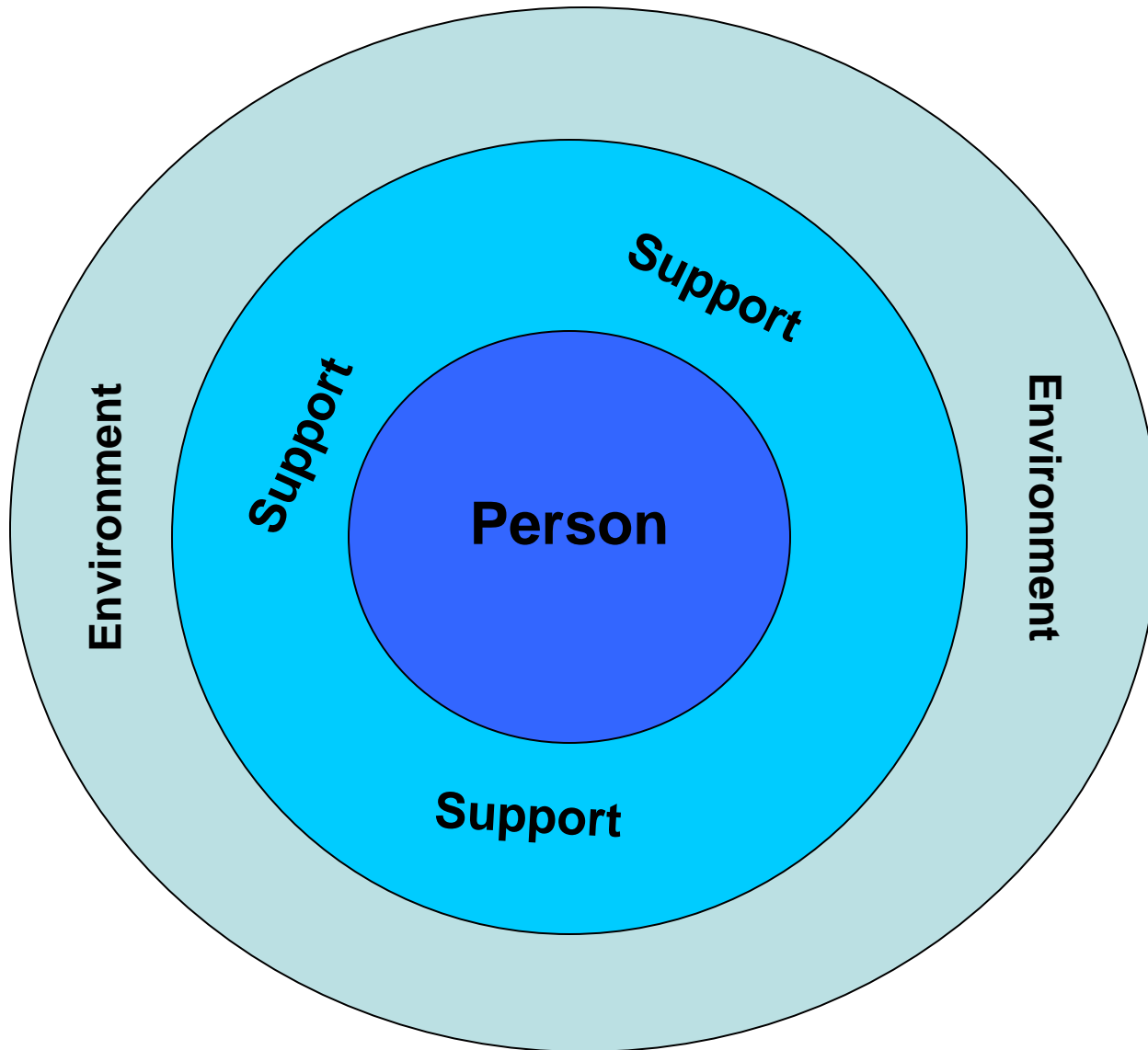


Environment



← (the supports continuum) →

Person in the centre





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

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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

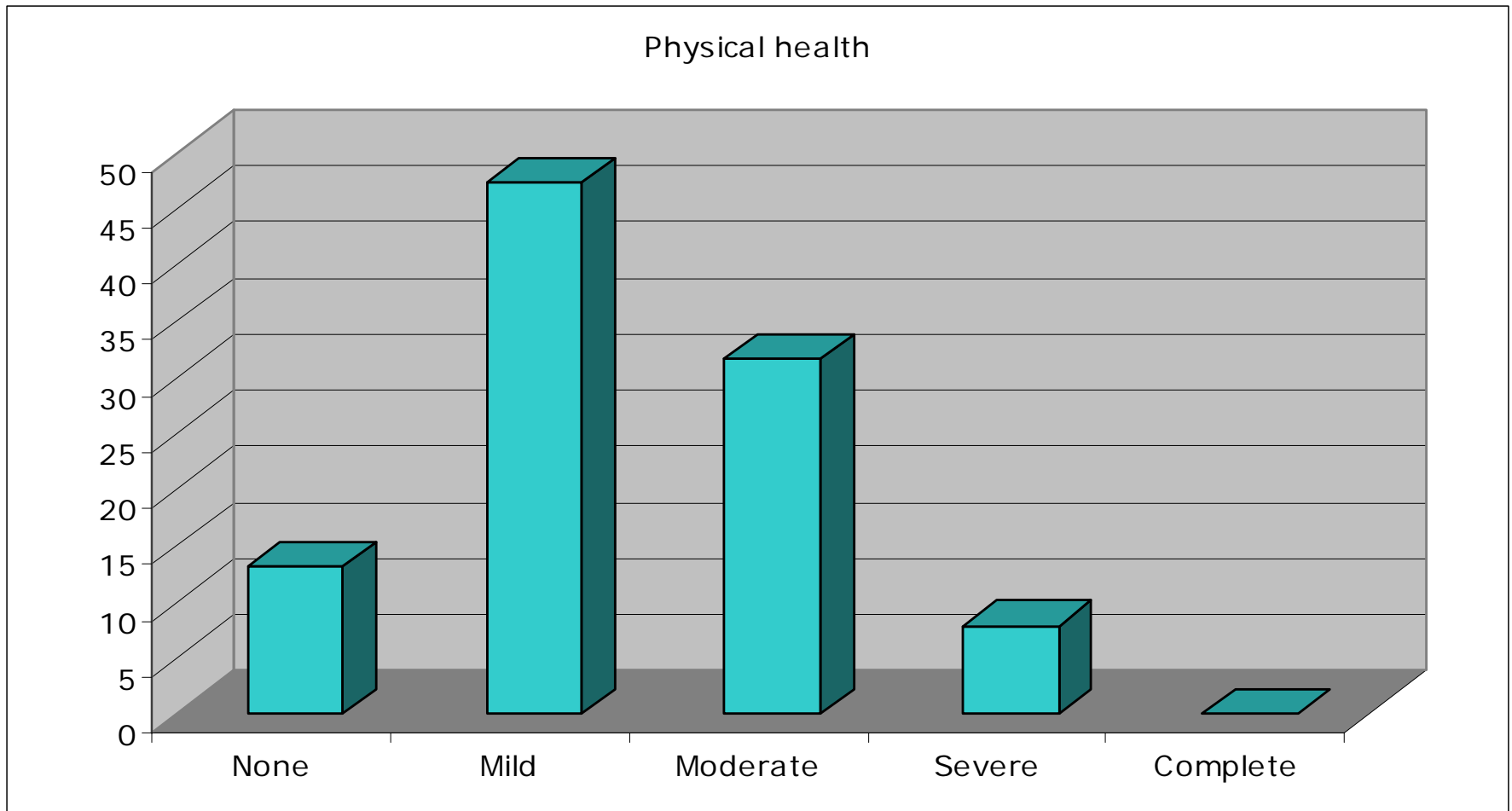
- On-going development & trial of instrument & process
- Data collected in NSW, ACT, Vic & Qld
- Residential settings, mental health settings, rehabilitation settings, and some day program settings
- Facilitators require training – version 4 allows for auditing of facilitators skills
- Process engaging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

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Physical Health Support Bands





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

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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

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Concurrent / Multiple Ratings...

Physical Health	Now	In 12 Months
dementia	Weekly Minor	Daily Extensive
Bob's dementia is progressively deteriorating. It is expected that he will require daily support,		

Mental and Emotional Health	Now	During Episode
varying mood, depression	Occasional Minor	Daily Extensive
During an episode Bob can become confused, frustrated or very depressed. During these times it is good to		

Self Care & Domestic Life	At Home	At Work
shower, teeth	Daily Moderate	Never No Support
In the mornings Bob needs some physical support to shower and brush his teeth. Otherwise Bob is very		

Life Long Learning	Informal Supports	Formal Supports
transport	Daily Moderate	Never No Support
Bob is currently driven on most days to and from his recreation program by his brother		



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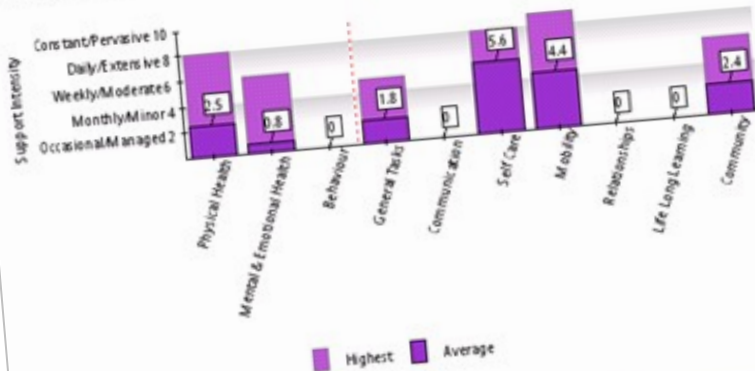


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