ICF Implementation Approaches for AAC Worldwide

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Murphy, J. and Boa, S. Using the WHO-ICF with Talking Mats as a goal setting tool.


Granlund, M., and Pless, M. Implementation of the International Classification of Functioning, Disability and Health (ICF/ICF-CY) and how this relates to Augmentative and Alternative Communication.

Simeonsson, R., Bjork-Akesson, E. and Lollar, D. Communication, disability and the ICF-CY.
PROBLEM: Knowledge of health condition alone does not predict child’s functional communication

- Individuals with CCN may have difficulty communicating related to a variety of different health conditions

- Identifying the health condition alone may not suggest the appropriate intervention

- The individual’s functional capacity in different environments + knowledge of the health condition suggests appropriate interventions
A Solution: The ICF and ICF-CY

- ICF: International Classification of Functioning, Disability and Health (Child & Youth version)
- Developed by the World Health Organization (WHO) to complement the ICD (International Classification of Disease)
- Designed to describe the functional status of individuals in a standardized manner
Why use the ICF-CY?

- Provides a systematic coding scheme to describe a child’s function and intervention needs.
- Complements ICD diagnostic coding, focusing on function, instead of etiology or diagnosis.
- Establishes a common language for professionals, PWD, family members & the public worldwide that can be used across education, medical and social services.
- Provides a scientific basis for understanding and studying health status and outcomes.
An Example: Complex communication needs of one child with Down Syndrome

- Participation: D7504.2--Informal relationships with peers: Moderate difficulty
- Participation D820.3--School education: Severe difficulty
- Body Function B320.4--Articulation: Complete impairment
- Body Structure S3203.3--Tongue: Severe impairment
- Activity D330.3 Speaking--Severe difficulty
- Activity D3501.3 Sustaining a conversation--Severe difficulty
- Environment E420.+2--Friends: Moderate facilitator
The ICF-CY and AAC

The ICF-CY works especially well for AAC learners, because it separates speech functions from communication functions.

Communication ≠ Speech
Using the ICF-CY as an Organizational Framework to Improve Communication Goals for AAC Users

- **Population**: School-aged children (in U.S.) who use AAC or are candidates for AAC
- **Goal 1**: Develop and evaluate the ICF-CY for AAC Profile to describe communication strengths and needs of children who use AAC
- **Goal 2**: Use the ICF-CY for AAC Profile to guide communication goal development

C. Rowland, M. Fried-Oken, D. Lollar, SAM Steiner
From WHO document to ICF-CY for AAC Profile

Published manual of codes

On-line interactive ICF-CY for AAC Profile
Two-part ICF-CY for AAC Profile

- **Survey**: identify participation restrictions, communication limitations, functional reasons for them, and environmental facilitators and barriers

- **Report**: prioritize identified items to facilitate IEP goal development process
The ICF-CY for AAC is a Code Set

Four categories:
1. Restrictions in Participation caused by communication limitations
2. Communication Limitations
3. Functional Impairments that limit communication
4. Environmental Factors that serve as barriers or facilitators for communication
Participation Restrictions:
Rate the degree of participation restriction caused by communication limitations in:

• School-related Activities
• Interpersonal Relationships
Communication Limitations:

Rate limitations in:

- Receptive Language and Literacy
- Expressive Language and Literacy
- Functions of Communication
- Rules of Social Interaction in Conversation
- AAC: Receptive Communication
- AAC: Expressive Modes and Strategies
- AAC: Motor Access
Body Functions:

Rate impairments that limit communication...

- Hearing
- Vision
- Touch
- Oral Motor
- Respiratory
- Intellectual
- Gross and Fine Motor
Environmental Barriers

Rate environmental factors that impede or support the student’s communication...

• Physical Environment
• Assistive Technology
• People
• Services and Policies
Download the ICF-CY for AAC Code Set:

www.icfcy.org/aac

Using the ICF-CY to Generate Communication Goals For Non-Speaking Children
C. Rowland, M Fried-Oken, S. Steiner, R. Phelps, C. Gibbons, M. Granlund, H. Feldman, D. Lollar

ICFAAC@ohsu.edu

Proposed Core Set for Augmentative and Alternative Communication Users

<table>
<thead>
<tr>
<th>COMMUNICATION LIMITATIONS</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Does the child experience difficulties in terms of RECEPTIVE COMMUNICATION MODES, SYNTAX, and SEMANTICS (understanding communication directed toward him/her)?</td>
<td></td>
</tr>
<tr>
<td>Focusing attention on human touch, face and/or voice</td>
<td>d 1600</td>
</tr>
<tr>
<td>Responding to the human voice at a very basic level</td>
<td>d 3100</td>
</tr>
<tr>
<td>Comprehending the meaning of single spoken words</td>
<td>d 3100a</td>
</tr>
<tr>
<td>Comprehending the meaning of 2-3 word/symbol phrases</td>
<td>d 3101</td>
</tr>
<tr>
<td>Comprehending the meaning of sentences and sets of sentences accurately</td>
<td>d 3102</td>
</tr>
<tr>
<td>Comprehending the meaning of body gestures (facial expressions, posture, hand gestures, movements)</td>
<td>d 3150</td>
</tr>
<tr>
<td>Comprehending the meaning of drawings and photographs used to communicate</td>
<td>d 3152</td>
</tr>
<tr>
<td>Comprehending the meaning of sign language</td>
<td>d 3170d</td>
</tr>
<tr>
<td>Comprehending the meaning of other signs and symbols (such as Braille, Blissymbols, 3-dimensional symbols, etc.)</td>
<td>d 3152a</td>
</tr>
<tr>
<td>Comprehending the meaning of written language</td>
<td>d 325</td>
</tr>
<tr>
<td>Comprehending the meaning of a narrative that conveys a cohesive topic</td>
<td>d 3102a</td>
</tr>
<tr>
<td>Does the child experience difficulties in EXPRESSIVE COMMUNICATION MODES, SYNTAX, and SEMANTICS (communicating with other people)?</td>
<td></td>
</tr>
<tr>
<td>Using body language, facial expressions and gestures to communicate</td>
<td>d 3550</td>
</tr>
<tr>
<td>Using eye gaze to communicate</td>
<td>d 3350a</td>
</tr>
<tr>
<td>Using signs and symbols (such as Blissymbols, icons) to communicate</td>
<td>d 3351</td>
</tr>
<tr>
<td>Using drawings, pictures or photographs to communicate</td>
<td>d 3352</td>
</tr>
<tr>
<td>Using 3-dimensional objects/representations to communicate</td>
<td>d 3352a</td>
</tr>
<tr>
<td>Using manual sign language to communicate</td>
<td>d 340</td>
</tr>
<tr>
<td>Writing messages to communicate</td>
<td>d 345</td>
</tr>
<tr>
<td>Using correct spelling conventions</td>
<td>d 345a</td>
</tr>
<tr>
<td>Using Braille to communicate</td>
<td>d 3602a</td>
</tr>
<tr>
<td>Using communication devices and technologies</td>
<td>d 360</td>
</tr>
<tr>
<td>Using intelligible speech to communicate</td>
<td>d 330</td>
</tr>
<tr>
<td>Combining words or symbols into 2-3 word or symbol phrases</td>
<td></td>
</tr>
<tr>
<td>Using correct word or symbol order for communication function</td>
<td></td>
</tr>
<tr>
<td>Using sentences and sets of sentences appropriately</td>
<td></td>
</tr>
<tr>
<td>Combining sentences to convey a cohesive topic</td>
<td></td>
</tr>
<tr>
<td>Using vocabulary appropriate to the situation</td>
<td></td>
</tr>
</tbody>
</table>
What is the relationship between items prioritized on ICF-CY for AAC and goals on pre-existing IEPs?

- N = 43 SLPs and Special Educators, from 17 states
- Work settings: Elementary (28%), Secondary (23%), Combined (35%), Other (14%)
- Knowledge of AAC: Expert/Great deal (33%), Moderate (58%), Little (7%)
- Mean # communication-related IEP goals and objectives per IEP = 11
## Participation Items

<table>
<thead>
<tr>
<th>Section</th>
<th>Most common score for these items</th>
<th>Mean % of participants who gave <strong>High Priority score</strong> to these items</th>
<th>% IEP objectives that address these items</th>
</tr>
</thead>
<tbody>
<tr>
<td>School-related Activities</td>
<td>Severe restriction</td>
<td>13%</td>
<td>7%</td>
</tr>
<tr>
<td>Interpersonal Interaction/Relationships</td>
<td>Severe restriction</td>
<td>13%</td>
<td>1%</td>
</tr>
</tbody>
</table>
## Impairments in Body Functions Items

<table>
<thead>
<tr>
<th>Section</th>
<th>Most common score for these items</th>
<th>Mean % of participants who gave <strong>High Priority</strong> score to these items</th>
<th>% IEP objectives that address these items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body Functions</td>
<td>No impairment</td>
<td>9%</td>
<td>1%</td>
</tr>
</tbody>
</table>
## Environment Items

<table>
<thead>
<tr>
<th>Section</th>
<th>Most common score for these items</th>
<th>Mean % of participants who gave <strong>High Priority</strong> score to these items</th>
<th>% IEP objectives that address these items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Environment</td>
<td>Facilitator</td>
<td>6%</td>
<td>1%</td>
</tr>
<tr>
<td>Assistive Technology</td>
<td>Facilitator</td>
<td>13%</td>
<td>6%</td>
</tr>
<tr>
<td>People</td>
<td>Facilitator</td>
<td>11%</td>
<td>0%</td>
</tr>
<tr>
<td>Services + Policies</td>
<td>Facilitator</td>
<td>13%</td>
<td>9%</td>
</tr>
</tbody>
</table>
## Communication Limitations Items

<table>
<thead>
<tr>
<th>Section</th>
<th>Most common score for these items</th>
<th>Mean % of participants who gave <strong>High Priority</strong> score to these items</th>
<th>% IEP objectives that address these items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Receptive Language + Literacy</td>
<td>Severe limitation</td>
<td>11%</td>
<td>23%</td>
</tr>
<tr>
<td>Expressive Language + Literacy</td>
<td>Complete limitation</td>
<td>13%</td>
<td>24%</td>
</tr>
<tr>
<td>Functions of Communication</td>
<td>Complete limitation</td>
<td>12%</td>
<td>27%</td>
</tr>
<tr>
<td>AAC Expressive Modes + Strategies</td>
<td>Mild limitation</td>
<td>16%</td>
<td>39%</td>
</tr>
<tr>
<td>Rules of Social Interaction/Conversation</td>
<td>Complete limitation</td>
<td>14%</td>
<td>4%</td>
</tr>
<tr>
<td>AAC Receptive Strategies</td>
<td>Mild limitation</td>
<td>12%</td>
<td>4%</td>
</tr>
<tr>
<td>AAC Motor Access</td>
<td>No limitation</td>
<td>7%</td>
<td>0%</td>
</tr>
</tbody>
</table>
Summary of Results

• For 10/14 sections on the *ICF-CY for AAC Profile*, participants were more likely to rate items as High Priority than to address them in IEP goals/objectives.

• For 4 sections related to Communication Limitations, however, the reverse was true: that is, participants were more likely to address such items in IEP goals/objectives than to rate them as High Priority on the *ICF-CY for AAC Profile*. 
Possible Explanations

Some sections contain items that are:

• not normally considered at all in terms of intervention (e.g., Participation, Environment)
• not considered amenable to change (e.g., Body Functions)
• rarely addressed in IEPs (e.g., AAC Receptive)
• considered too sensitive to address (e.g., People)
• traditionally addressed and present in pre-packaged goal sets (e.g., Expressive/Receptive Language/Literacy)

Some IEPs did not include supplemental services
Next: Does the ICF-CY for AAC Profile Influence Development of Subsequent IEP goals?

- New study underway now: SLPs or Special Educators
- Money incentive
- Participants needed!!
Contact Us at icfaac@ohsu.edu

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Charity Rowland, PI
Using the WHO-ICF with Talking Mats® as a goal setting tool

Joan Murphy and Sally Boa
Talking Mats Limited, Scotland

www.talkingmats.com

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Goal setting background

• Community rehabilitation team
• Adults with long term conditions
• Active participants in the rehab process
  – Identify their own goals
  – Indicate changing priorities
  – Track their progress

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Talking Mats Framework

• Research evidence-based communication framework
• Supports people to understand, organise their thoughts and then express their views
• Diverse specialist areas
• Used worldwide
WHO-ICF

• Variety of topics
• Time for organisation
• Structured hierarchy

International Classification of Functioning, Disability and Health (ICF)
World Health Organization 2001
Interactions between the components of ICF in graphic symbol format
WHO-ICF framework
(http://www.who.int/classifications/icf/en/)

Activities and Participation

1 Learning & Applying Knowledge
2 General Tasks and Demands
3 Communication
4 Movement
5 Self Care
6 Domestic Life Areas
7 Interpersonal Interactions
8 Major Life Areas
9 Community, Social & Civic Life

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Examples of Options
in Activities and Participation

- **communication**
  - e.g. understanding
  - writing
  - communication with group

- **mobility**
  - e.g. walking
  - using transport
  - lifting

- **self care**
  - e.g. washing
  - dressing
  - exercise

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Ian using Talking Mats with WHO-ICF
Conclusion

Using the WHO-ICF together with Talking Mats allows people with communication difficulties to be actively involved in identifying, setting and reviewing their own goals.
References

Contact

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www.talkingmats.com
Social networks and self-determination of children with complex communication needs, physical disabilities and typical peers

Pammi Raghavendra, Ph.D.
Disability & Community Inclusion
Flinders University
Adelaide
Australia

Cathy Olsson\textsuperscript{2}, Rachael McInerney\textsuperscript{3}, Tim Connell\textsuperscript{2}, Alison Lane\textsuperscript{4}
Department for Communities & Social Inclusion- Disability Services SA\textsuperscript{2}, Novita Children’s Services\textsuperscript{3}, The Ohio State University\textsuperscript{4}

Funded by: Channel 7 Children’s Research Foundation, SA
Aims

1. To develop a comprehensive, multi-dimensional description of the participation of children with physical disabilities and complex communication needs.

2. To examine the association of key functional abilities with aspects of participation:
   - Communication and physical ability
   - Time use
   - Social networks (parent and school staff)
   - School participation
   - Participation in activities
   - Level of self-determination
The ICF (WHO, 2001)

Health condition (disorder or disease)

Body functions & structures
- Social Networks
- GMFCS Level

Activities
- MARCA

Participation
- ACTIVITY PARTICIPATION
- SCHOOL PARTICIPATION

Environmental factors
- Social Networks

Personal factors
- AIR Self-determination Scale
Self-determination

• Important personal factor for overall health and wellbeing

• A self-determined person:
  – Knows and can express their own needs, interest and abilities
  – Set appropriate goals and expectations for themselves
  – Make choices and act on their goals

(Wolman et al., 1994).
Importance of self-determination

- Opportunities to make choices reductions in problem behaviour (Shogren et al., 2004, cited in McNaughton et al., 2010)

- More self-determined students with disabilities lived independently, employed and earned higher wages (Wehmeyer et al., 1997; 2003, cited in McNaughton et al., 2010)

- Young adults who use AAC with highest levels of self-determination also scored highest on quality of life (Lund & Light, 2006)
## Participants

<table>
<thead>
<tr>
<th>GROUP</th>
<th>NO</th>
<th>MEAN AGE (SD)</th>
<th>GENDER</th>
<th>DIAGNOSIS</th>
<th>GMFCS</th>
<th>CFCS</th>
<th>TYPE OF SCHOOL</th>
</tr>
</thead>
<tbody>
<tr>
<td>I Physical disability &amp; CCN</td>
<td>14</td>
<td>12;5 years, (1.74)</td>
<td>8 males 6 females</td>
<td>CP = 12</td>
<td>Level I = 1</td>
<td>Level I = 0</td>
<td>Level I = 0</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Quadriplegia = 1</td>
<td>Level II = 2</td>
<td>Level II = 1</td>
<td>Level III = 4</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>Syndrome = 1</td>
<td>Level III = 3</td>
<td>Level III = 4</td>
<td>Level IV = 8</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Level IV = 5</td>
<td>Level IV = 8</td>
<td>Level V = 1</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Level V = 3</td>
<td>Level V = 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>II Physical disability</td>
<td>11</td>
<td>12;7 years, (1.55)</td>
<td>7 males 4 females</td>
<td>CP = 10</td>
<td>Level I = 11</td>
<td>Level I = 11</td>
<td>Level II = 0</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Spina Bifida = 1</td>
<td>Level II = 3</td>
<td>Level III = 0</td>
<td>Level IV = 4</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Level III = 3</td>
<td>Level IV = 0</td>
<td>Level V = 0</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Level IV = 4</td>
<td>Level V = 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>III No disability</td>
<td>14</td>
<td>12;5 Years (1.74)</td>
<td>8 males 6 females</td>
<td>No disability</td>
<td>N/A</td>
<td>N/A</td>
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</tbody>
</table>
AIR Self-determination
Wolman, Campeau, DuBois, Mithaug & Stolarski (1994)

- Easy to use questionnaire
- School age students: 5-21 years
- Capacity: knowledge, abilities, perceptions
- Opportunities: school and home
- Thinking, Doing and Adjusting - 2 items
- Total 30 items
AIR Self-determination
Wolman, Campeau, DuBois, Mithaug & Stolarski (1994)

- Educator form
- Student form – ability to read and comprehension skills
- Parent form
- Research form
- Headings and questions slightly different for students
I know what I need, what I like, and what I’m good at:

1 = Never,
2 = almost never,
3 = sometimes,
4 = almost always,
5 = always

People at school listen to me when I talk about what I want, what I need, or what I am good at
AIR Self-determination
Wolman, Campeau, DuBois, Mithaug & Stolarski (1994)

The AIR Self-Determination Profile
Educator Form

Items

Think Do Adjust
1-2 3-4 5-6

Think Do Adjust
1-2 3-4 5-6

Think Do Adjust
1-2 3-4 5-6

Think Do Adjust
1-2 3-4 5-6

150
140
130
120
110
100
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%

Total
8 5 3
Knowledge
16

6 5 3
Ability
14

5 6 4
Perception
15

4 4 2
Opportunity at School
11

4 2 3
Opportunity at Home
10

45
Capacity

21
Opportunity

66
Level of Self Determination

(Write sum in box and mark in column.)

Student name: Pat Reed
Date: 1/19/95
Social Networks
(Blackstone & Hunt Berg, 2003)

Circle 1 = life partners
Circle 2 = good friends
Circle 3 = acquaintances
Circle 4 = paid partners
Circle 5 = unfamiliar partners
## Levels of Self-determination

<table>
<thead>
<tr>
<th>Group</th>
<th>Number of Participants</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group CCN</td>
<td>7</td>
<td>88.71</td>
<td>8.14</td>
</tr>
<tr>
<td>Group PD</td>
<td>10</td>
<td>71.62</td>
<td>13.41</td>
</tr>
<tr>
<td>Group TD</td>
<td>14</td>
<td>80.26</td>
<td>6.08</td>
</tr>
</tbody>
</table>
Results

Social Networks: Mean number of communication partners

<table>
<thead>
<tr>
<th>Group</th>
<th>Home</th>
<th>School</th>
</tr>
</thead>
<tbody>
<tr>
<td>CCN</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TD</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

CCP1: Group CCN, Group PD, Group TD
CCP2: Group CCN, Group PD, Group TD
CCP3: Group CCN, Group PD, Group TD
CCP4: Group CCN, Group PD, Group TD
Key outcomes

- The ICF and ICF-CY provide a good framework for research
- Important to measure personal factors such as self-determination
- Need to obtain information from the child/adolescent with disability, parents, & teachers
- Families and professionals have a responsibility to build capacity and provide opportunities to facilitate self-determination
- Social networks must be enhanced for Group CCN and PD; opportunities for more involvement in variety of activities
References


• McNaughton, D., & Kennedy, P. (2010). Supporting successful transitions to adult life for individuals who use AAC. In McNaughton, D., & Beukelman, D. (Eds.). *Transition Strategies for Adolescents & Young Adults who use AAC*. (pp.3-17). Paul H. Brookes: Baltimore, MD