Children’s Participation: Recent results from the CFFS & FUNDES-Child

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My Experience

- Occupational Therapy
- Children/youth with disabilities & chronic illness (*Traumatic Brain Injury*)
- Interdisciplinary teams
- Measurement & Intervention Development
- Rehabilitation Outcomes Research
- Qualitative Research
- Consultation / Teaching
Presentation Objectives

1. To provide background to the concept of *participation* and its importance for children & youth

2. To provide an overview of the *Child & Family Follow up Survey (CFFS)* & recent research

3. To provide an overview of the *Functioning Scale of The Disability Evaluation System – Child version (FUNDES-Child)* & recent research
Participation: What it is & why important

• Involvement in life situations

• Multi-dimensional & universal
  • (Coster & Khetani, 2008; Law, 2002)

• Children & youth with disabilities often restricted in participation
  • Affected by child & environmental factors
    • (Bedell, 2009; Law, 2002; King, et al., 2003; Simeonsson, et al., 2001)

• Key aim of rehabilitation, education & community programs (Bedell & Dumas, 2004; Law, 2002)
Participation:

- Enables children to interact, work and live with others and function in society
  - (Law, 2002; Larson, 2000; Mahoney, et al., 2003).

- Associated with enhanced quality of life, social competence and educational success

- Especially activities that promote skill development, and provide a sense of accomplishment and enjoyment
  - (Eccles, et al., 2003; Fletcher, et al., 2003; Mahoney, et al., 2003; Rutter, 1987).
<table>
<thead>
<tr>
<th>ICF DOMAINS</th>
<th>ACTIVITY &amp; PARTICIPATION (SUB-DOMAINS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Learning &amp; Applying knowledge</td>
<td>Purposeful sensory experiences; Basic learning; Applying knowledge</td>
</tr>
<tr>
<td>2. General Tasks &amp; Demands</td>
<td>Undertaking a single task; Undertaking multiple tasks; Carrying out daily routines; Handling stress &amp; other psychological demands</td>
</tr>
<tr>
<td>3. Communication</td>
<td>Communicating-receiving; Communicating-producing (spoken &amp; nonverbal); Conversation &amp; use of communication devices &amp; techniques</td>
</tr>
<tr>
<td>4. Mobility</td>
<td>Changing and maintaining body position; Maintaining a body position; Transferring oneself; Carrying, moving &amp; handling objects; Walking &amp; moving; Moving around using transportation</td>
</tr>
<tr>
<td>5. Self-care</td>
<td>Washing oneself; Caring for body parts (grooming); Toileting; Dressing; Eating; Drinking; Looking after one’s health</td>
</tr>
<tr>
<td>6. Domestic Life</td>
<td>Acquisition of necessities; Household tasks; Caring for household objects and assisting others</td>
</tr>
<tr>
<td>7. Interpersonal Interactions &amp; Relationships</td>
<td>General (basic &amp; complex) interpersonal interactions; Particular interpersonal interactions (Relating with strangers, Informal &amp; formal social relationships, Family relationships, Intimate relationships)</td>
</tr>
<tr>
<td>8. Major Life Areas</td>
<td>Education; Work &amp; employment, Economic life</td>
</tr>
</tbody>
</table>
Social Participation & Participation

- Often used interchangeably

  *Social participation*: “taking part, involvement, engagement, doing or being with others” (Bedell, 2012)

  *Participation* is involvement in activities that can, should or might prefer to be done without others.
What is important to measure?

- **Key themes important to children’s well-being:** 1) essential for survival, 2) supportive of child development, 3) discretionary, & 4) educational (McConachie, et al., 2006)

- **Meaningful & setting-specific goals:** 1) sustenance & physical health, 2) development of skills & capacities, & 3) enjoyment & well-being (Coster & Khetani, 2008)

- **Performance or fulfillment of social or societal roles** (Whiteneck & Dijkers, 2009).

- **Stakeholder needs & goals:** children, families, service providers, program directors, policy makers (Bedell & Coster, 2008; Bedell, Khetani, et al., 2012)
National Survey of Children’s Participation in Taiwan

- Based on United Nations Convention on Human Rights of Persons with Disability (UNCRPD) and the Rights of the Child (UNCRC), participation has been described as the individual’s right to be respected.

- The research of children’s participation in Taiwan began before the new Disability Evaluation System (DES; which was launched in July 2012).

- The DES includes children’s functioning in determining eligibility for social welfare based on the People with Disabilities Rights Protection Act in Taiwan.
Child & Family Follow-up Survey (CFFS)

- Originally developed as parent report measure to monitor needs & outcomes of children & youth with acquired brain injury & their families (Bedell, 2004)

- Informed by the International Classification of Functioning, Disability & Health (ICF, WHO, 2001)

- Now used in multiple settings worldwide with children & youth with other conditions, & for varied purposes and levels of focus (population, program, child/family)


- Translations & cultural modifications:
  - Traditional Chinese (part of the Functioning Scale of the Disability Evaluation System (FUNDES) - Child version (Hwang, et al., 2013)
  - Spanish, Dutch, French, Hebrew, Arabic, German, Swedish, others
Overview of the CFFS (continued)

- **Child & Adolescent Scale of Participation (CASP)**
  - Parent report & youth report versions
  - Extent of participation compared to same age in home, school & community

- **Child & Adolescent Scale of Environment (CASE)**
  - Extent of environmental problems

- **Child & Adolescent Factors Inventory (CAFI):**
  - Extent of impairment

- **Other questions:** Child’s physical & emotional health, ways of communicating & moving around, current services, family needs & quality of life
CASP: Four subsections (20 items)

HOME PARTICIPATION:
1. Social/leisure (family)
2. Social/leisure (friends)
3. Chores/Responsibilities
4. Self-care
5. Mobility
6. Communication

COMMUNITY PARTICIPATION:
7. Social/leisure (friends)
8. Structured activities
9. Mobility
10. Communication

SCHOOL PARTICIPATION
11. Educational activities
12. Social/Leisure (students)
13. Mobility
14. Using educational materials
15. Communication

HOME & COMMUNITY LIVING
16. Household Activities
17. Shopping/Managing Money
18. Managing Daily Schedule
19. Using Transportation
20. Work Activities

*Plus open-ended questions (e.g., strategies, equipment)
Compared to other children your child’s age, what is your child’s current level of participation in the following activities?

- **CASP 4-point rating scale is as follows:**
  - 1 = unable
  - 2 = very limited
  - 3 = somewhat limited
  - 4 = age-expected

- **Not applicable,** other children your child’s age would NOT be expected to participate in the activities

*Higher scores indicate a greater extent of participation*
The Child and Adolescent Factors Inventory (CAFI) 15 Items

1. Paying attention or concentrating
2. Remembering people, places or directions
3. Problem solving or judgment
4. Understanding or learning new things
5. Controlling behaviors, moods or activity level
6. Motivation (lacks interest or initiative)
7. Psychological (e.g., depression or anxiety)
8. Speech
9. Vision
10. Hearing
11. Movement (balance, coordination, muscle tone)
12. Strength or energy level (e.g., weakness or fatigue)
13. Reacting to sensation or stimulation (e.g., over- or under-reaching to sound, light, touch, movement)
14. Physical symptoms (e.g., headaches, dizziness, pain):____
15. Other health and medical conditions: ______________________
The Child and Adolescent Factors Inventory (CAFI)

- Assesses level of impairment and other child personal factors
- Each item or problem is rated on a 3-point scale:
  - 1 = 沒有問題 (no problem)
  - 2 = 有些問題 (little problem)
  - 3 = 嚴重問題 (big problem)

*Higher scores indicate a greater extent of problem.*
Child and Adolescent Scale of Environment (CASE)

- Assesses physical, social and attitudinal environmental barriers

- Adaptation of the CHIEF (initially designed for adults; Whiteneck, et al., 2004)

- Same response options as CAFI (3-points):
  - 1= 沒問題 (no problem)
  - 2= 些許問題 (little problem)
  - 3= 嚴重問題 (big problem)
  
  - There is a “non applicable” response as well

*Higher scores indicate a greater extent of problem.*
Child and Adolescent Scale of Environment (CASE) 18 Items

1. Problem with design and layout of home (Hard to get to places and things, or hard to see or hear important information)
2. Problem with design and layout of buildings and places your child uses in the community or neighbourhood
3. Problem with design and layout of school or work setting (Circle school or work)
4. Lack of support and encouragement for your child in the community or neighbourhood
5. Lack of support and encouragement for your child at school or work (Circle school or work)
6. Problems with people’s attitudes toward your child at school or work (Circle school or work)
7. Problems with people’s attitudes toward your child in the community or neighbourhood
8. Inadequate or lack of assistive devices or equipment
9. Inadequate or lack of assistance from people at home or in the community or neighbourhood
10. Inadequate or lack of assistance from people at school or work (Circle school or work)
11. Inadequate or lack of transportation
12. Inadequate or lack of programmes and services at school
13. Inadequate or lack of programmes and services in the community or neighbourhood
14. Inadequate or lack of family finances
15. Family stress
16. Crime or violence in the community or neighbourhood
17. Problems with government agencies and policies
18. Inadequate or lack of information about your child’s diagnosis or condition or intervention approaches (e.g. educational, rehabilitation or medical)
Recent findings from the CFFS \((n=793)\)

- Age range: 2.5 to 27 years; \textbf{Mean} = 13.5 (SD=3.6); 96% ages 5 to 17.99

- Canada (60%), USA (35.4%), Australia (2.5%), Israel (2.1%)

- Male (55.3%); Female (44.7%)

- Acquired Brain Injury (35.9 %); Cerebral Palsy (18.8%); Developmental / Intellectual Disability (11.9%); No disability (6.7%)
  - Autism Spectrum (4.7%); Learning, attention, communication (4.3%); Spina Bifida (4.4%); Cleft lip/palate (4.2%); Amputee (2.1%); Other (7.1 %)
Home Participation (CASP)

- Social leisure Family: Green (Very limited), Orange (Somewhat limited), Blue (age expected)
- Social leisure friends: Green (Very limited), Orange (Somewhat limited), Blue (age expected)
- Chores: Green (Very limited), Orange (Somewhat limited), Blue (age expected)
- Self-care: Green (Very limited), Orange (Somewhat limited), Blue (age expected)
- Moving about: Green (Very limited), Orange (Somewhat limited), Blue (age expected)
- Communicating: Green (Very limited), Orange (Somewhat limited), Blue (age expected)

Legend:
- Green: Unable
- Orange: Very limited
- Blue: Somewhat limited
- Grey: age expected
School Participation (CASP)

![Bar chart showing school participation levels in various activities.](chart.png)

- **Social leisure**: Unacceptable and unacceptable cases make up a large portion of the chart, indicating significant challenges in social activities.
- **Educational activity**: A mix of unacceptable, very limited, and somewhat limited participation, with unacceptable being the most common.
- **Using materials**: A significant number of cases are unacceptable, with a smaller portion being somewhat limited.
- **Moving around**: Most cases are unacceptable, with a small percentage being somewhat limited.
- **Communicating**: A notable number of cases are unacceptable, with a majority being somewhat limited.

Legend:
- **Unable**: Unacceptable levels of participation.
- **Very limited**: Significant but acceptable levels of participation.
- **Somewhat limited**: Moderate levels of participation.
- **Age expected**: Levels of participation expected within the normal age range.
Home & Community Living Activities (CASP)
## Factors Associated with Participation (CFFS)

<table>
<thead>
<tr>
<th></th>
<th>CAFI</th>
<th>CASE</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>CASP</td>
<td>-.66**</td>
<td>-.57**</td>
<td>.011</td>
</tr>
<tr>
<td>CAFI</td>
<td></td>
<td>.54**</td>
<td>.06*</td>
</tr>
<tr>
<td>CASE</td>
<td></td>
<td></td>
<td>.06</td>
</tr>
</tbody>
</table>

- Child & Adolescent Scale of Participation (CASP); Child & Adolescent Factors Inventory (CAFI); Child & Adolescent Scale of Environment (CASE)
- Pearson Correlation Coefficients (r)
  ** p < .001; * p < .05
## Differences in Participation (Mean CASP Scores)

<table>
<thead>
<tr>
<th>CAFI items</th>
<th>No Problem Mean (SD)</th>
<th>Little Problem Mean (SD)</th>
<th>Big Problem Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cognitive (e.g., problem solving)</strong>*</td>
<td>n=247 91 (13)</td>
<td>n=263 82 (14)</td>
<td>n=191 71 (14)</td>
</tr>
<tr>
<td><strong>Movement (e.g., balance, coordination)</strong>*</td>
<td>n=261 91 (12)</td>
<td>n=259 82 (14)</td>
<td>n=180 70 (15)</td>
</tr>
<tr>
<td><strong>Psychological (e.g., anxiety, depression)</strong>*</td>
<td>n=375 86 (15)</td>
<td>n=229 80 (15)</td>
<td>n=95 73 (15)</td>
</tr>
</tbody>
</table>

*(p < .001)
Recent findings: FUNDES-Child ($n = 18,119$)

- **Age range:** 6-17.99; **Mean** = 12.1 (SD=3.5);
- **Male** (64.6 %); **Female** (35.4%)

<table>
<thead>
<tr>
<th>Diagnoses/ICD-9 codes</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual disability/317-319</td>
<td>10310 (56.9 %)</td>
</tr>
<tr>
<td>Autism/299.01-299.90</td>
<td>4013 (22.1 %)</td>
</tr>
<tr>
<td>Language delay/315.31-315.39, 318.1</td>
<td>801 (4.4 %)</td>
</tr>
<tr>
<td>Cerebral palsy/343.9,</td>
<td>602 (3.3 %)</td>
</tr>
<tr>
<td>Hearing impairment/389</td>
<td>448 (2.5 %)</td>
</tr>
<tr>
<td>Schizophrenia/295.10-295.90</td>
<td>191 (1.1 %)</td>
</tr>
<tr>
<td>Visual impairment</td>
<td>89 (0.5 %)</td>
</tr>
<tr>
<td>CVA</td>
<td>58 (0.3 %)</td>
</tr>
<tr>
<td>Depression/296</td>
<td>31 (0.2 %)</td>
</tr>
<tr>
<td>SCI</td>
<td>20 (0.1 %)</td>
</tr>
</tbody>
</table>
Home Participation (FUNDES-Child)

- 不適用
- 完全協助
- 中度協助
- 監督或輕度協助
- 獨立

图表展示了不同类型的活动的参与度，包括与家人互动、与朋友互动、参与家务责任、自我照顾、在家及庭院移动、在家与其他孩子和大人沟通。
Community Participation (FUNDES-Child)
School Participation (FUNDES-Child)
Home & Community Living Activities (FUNDES-Child)
## Factors Associated with Participation (FUNDES-Child)

<table>
<thead>
<tr>
<th></th>
<th>Body function impairments</th>
<th>Environmental barriers</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participation-Capability restriction</td>
<td>.73***</td>
<td>.37***</td>
<td>-.17***</td>
</tr>
<tr>
<td>Body function impairments</td>
<td></td>
<td>.45***</td>
<td>.08***</td>
</tr>
<tr>
<td>Environmental barriers</td>
<td></td>
<td></td>
<td>.00</td>
</tr>
</tbody>
</table>

Pearson Correlation Coefficients (r)  
*** p < .001
## Differences in Participation (Mean FUNDES-Child Scores)

<table>
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<th>Little Problem Mean (SD)</th>
<th>Big Problem Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cognitive (e.g., problem solving)</strong></td>
<td>n=2416 4.2 (4.2)</td>
<td>n=7569 7.1 (4.3)</td>
<td>n=8132 12.7 (5.9)</td>
</tr>
<tr>
<td><strong>Movement (e.g., balance, coordination)</strong></td>
<td>n=10530 7.3 (5.0)</td>
<td>n=5558 10.4 (5.4)</td>
<td>n=2029 16.0 (6.7)</td>
</tr>
<tr>
<td><strong>Psychological (e.g., anxiety, depression)</strong></td>
<td>n=6978 6.6 (5.1)</td>
<td>n=8019 9.5 (5.2)</td>
<td>n=3120 14.3 (6.4)</td>
</tr>
</tbody>
</table>

*(p < .001)
Summary

- Both the CFFS & FUNDES have evidence of reliability & validity (*responsiveness to change not yet studied*)

- Recent CFFS results are consistent with prior results:
  - children with greater impairment and environmental problems have more restricted participation
  - greater participation restrictions are noted in
    - social leisure with friends (across settings)
    - Structured events in the community
    - Educational activities with others at school
    - All home and community living activities (especially managing daily activity)
  - no clear pattern for sex or age categories

- Recent FUNDES-Child: Results were similar to U.S. data except there was a positive association with participation capability and age in Taiwan.
Implications

- Results provide broad picture of participation patterns & factors affecting participation
  - at the population or societal level
- Results might inform policy & services:
  - Types of participation to target
  - Child & environmental factors that need to be addressed to promote participation
- Foundation for next presentation:
  - how to use the CFFS and FUNDES for goal setting, intervention planning, and program evaluation and improvement
THANK YOU!

ANY QUESTIONS?
References

References

References


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http://sites.tufts.edu/garybedell/
(web-site for additional resources)