

Child & Family Follow-up Survey (*CFFS*)

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My Experience

- Academic and professional education
- Occupational Therapy
- Children/youth with disabilities & chronic illness (*Traumatic Brain Injury*)
- Interdisciplinary teams
- Measurement & Intervention Development
- Rehabilitation Outcomes Research
- Qualitative Research (*strategies to support participation*)
- Consultation / Teaching

Presentation Objectives

1. To briefly describe the CFFS and how it has been used by others
2. To highlight psychometric findings from two recent studies:
 - Comparing Youth and Parent report versions of the Child and Adolescent Scale of participation (CASP)
 - Further validation of the Child and Adolescent Scale of Environment (CASE)
3. To describe limitations and future directions

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
- 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 (CFFS or separate measures) with some 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 in progress

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

Two Recent Studies (*Same Sample*):

Comparing Youth & parent report CASP

Further Validation of the CASE

- 430 youth with chronic conditions (*8 rehabilitation centres, Ontario, Canada*)
- Youth mean age was **14 years** (SD=2.2); **55%** were male
- **35%** had cerebral palsy, **14%** acquired brain injury, **9%** autism spectrum disorder, **8%** spina bifida, **8%** cleft lip /palate, **8%** developmental delay, **4%** amputation, **3%** communication disorders, & **13%** Other Condition
- Parents' mean age was **45 years** (SD=6.5); **88%** were femaleese studies when
- **English spoken in 90% of families' homes**, French in 2%, Others in 8%

(McDougall, Bedell & Wright, 2013; Bedell & McDougall, 2013)

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

***Plus open-ended questions
(e.g., strategies, equipment)**

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

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=無法參與活動
 - 2=參與程度非常侷限
 - 3=參與程度部分侷限
 - 4=參與程度與其年齡相符
- **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*

CASP: Prior psychometric findings

- **Test-Retest Reliability:** ICC = 0.94 (*parent version only; Bedell,2004*)
- **Responsiveness to change** – not yet examined
- **Convergent Validity:** **Higher CASP** scores (greater extent of participation) significantly associated with:
 - **Higher Pediatric Evaluation of Disability Inventory (PEDI)** scores (*greater functional skills*)
 - **Lower CAFI** scores (*lesser extent of impairment*)
 - **Lower CASE** scores(*lesser extent of environment problems*)

(Bedell, 2004; 2009).

CASP: Discriminant Validity

- Typically developing children had significantly higher scores (parent version) than children with TBI and other disabling conditions (Bedell, 2009).
- Significant differences in CASP scores existed for disability groups ($p < 0.0001$), but **NOT for age** ($p < 0.81$) **or sex** ($p < 0.12$)
 - Youth with cerebral palsy had significantly lower scores than those with amputation ($p < 0.01$)
 - Youth with autism had significantly lower scores than those with communication disorders/cleft lip or palate ($p < 0.01$) & those with amputation ($p < 0.0001$)

(McDougall, Bedell, & Wright, et al, 2013)

CASP: Internal Structure

(Factor analyses: Youth & Parent Versions)

- Three conceptually similar factors were identified in both versions contributing 44% of variance (*youth*) & 65% (*parent*):
 1. **Social, leisure & communication** (17% & 22% respectively)
 2. **Advanced daily activities** (14% & 17% respectively)
 3. **Basic daily activities/mobility** (13% & 26% respectively)

(McDougall, Bedell & Wright, 2013)

Internal Consistency: CASP Total & Factor Subscale Scores (McDougall et al., 2013)

(Cronbach's α was high^{*}, moderately high[†], moderate[‡])

CASP Total & Subscale Scores	Youth	Parent
CASP total score	0.87 [*]	0.95 [*]
Social, leisure & communication	0.80 [†]	0.90 [*]
Advanced daily activities	0.67 [‡]	0.86 [*]
Basic daily activities & mobility	0.74 [‡]	0.89 [*]

Comparison of Youth & Parent Scores

• CASP Total & Subscale Scores	Youth <i>Mean (SD)</i>	Parent <i>Mean (SD)</i>	<i>t</i> *	<i>ICC</i> **
• CASP total score	69.5 (8.2)	63.5 (12.8)	10.93	0.70
• Social, leisure, communication	27.6 (4.1)	25.9 (5.2)	7.26	0.65
• Advanced daily activities	21.1 (2.8)	18.6 (4.5)	12.52	0.59
• Basic daily activities mobility	20.7 (3.0)	19.2 (4.3)	9.00	0.74

*significant score differences($p < 0.0001$); ** moderately high correlations (McDougall, Bedell & Wright, 2013)

Discussion: CASP Findings

- Evidence of internal consistency & structure for youth-report & parent-report
- 3-factor scale solution virtually same for youth & parent versions & prior results (*Bedell, 2009*)
- Youth & parent scores moderately to highly correlated & significantly different - each provides understanding of youth's participation
- Results reflect other studies' results that youth with chronic conditions / disabilities report higher scores than parents related to quality of life measures (Upton, et al., 2008)
- Both versions appear to discriminate among groups of youth with different conditions and type/severity of impairment

CASP limitations & future work

- **Prior work lacked controlled data collection**
 - Combined different formats of administration; Missing data; Combination of small size samples of convenience
- **CASP measuring both activity & participation**
- **Might not be responsive to change over time:**
 - Due to comparison to others of same age
 - Due to Broad versus Discrete activities
 - Possibly add more response options (*4 to 6 point scale*)?

Further psychometric & utility testing needed

(with larger, more diverse & representative samples):

Reliability, validity, responsiveness (*underway*); use in intervention planning; which scores to use for different stakeholder purposes?

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.*

CAFI: Prior Psychometric findings

- **Reliability**

- *Internal Consistency*: Cronbach's alpha = .96 to .98
Test-Retest: Intra-class correlation coefficient = .94

- **Responsiveness to change** – not yet examined

- **Convergent Validity: Higher CAFI** scores (greater impairment) significantly associated with:

- **Lower PEDI** scores (*more limited functional skills*)
- **Lower CASP** scores (*lesser extent of participation*)
- **Higher CASE** (*greater extent of environment problems*)

(Bedell, 2004; 2009)

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)

CASE: Prior Psychometric findings

- **Test-re-test:** Intra-class correlation coefficient = .75 and Spearman's Rho coefficient = .78
- **Responsiveness to Change** – not examined
- **Convergent Validity:** **Higher CASE** scores (*greater extent of environmental problems*) significantly associated with:
 - **Lower CASP** (*lesser extent of participation*)
 - **Lower PEDI** scores (more limited functional skills)
 - **Higher CAFI** scores (*greater extent of impairment*)

(Bedell, 2004; Bedell et al., 2004).

CASE: Internal structure & consistency

(Bedell & McDougall, 2013)

CASE Total & Factor Scales	Variance Explained	Cronbach's Alpha
Total CASE (<i>18 items</i>)	55.02%	0.89
1. Community / home Resources (<i>9 items</i>)	21.87%	0.85
2. School Resources (<i>4 items</i>)	18.64%	0.85
3. Physical design / access (<i>5 items</i>)	14.51%	0.79

CASE: Discriminant Validity

- No significant score differences for **age** ($p=0.68$) or **sex** ($p=0.15$)
- Significant score differences ($p\leq 0.004$) for **cognitive, physical & psychological impairment severity**, but not for CASE Physical Design/Access factor score related to cognitive ($p=0.153$) & psychological ($p=0.019$) impairment
- Significant score differences for **condition/diagnosis** ($p\leq 0.001$), but NOT for School Resources Factor Subscore ($p=0.037$)
- Youth with cleft lip / palate & amputation had lower CASE scores than youth with Cerebral Palsy, Autism Spectrum Disorder, Spina Bifida & Developmental Delay

(Bedell & McDougall, 2013)

Convergent: Validity (CASE, CAFI, CASP)

(Bedell & McDougall, 2013)

CASE & Factor subscale Scores	CAFI	CASP: Total Score	CASP: Social, Leisure	CASP: Advance Daily Living	CASP Basic Daily / Mobility
CASE: Total	0.52	- 0.61	- 0.54	- 0.57	- 0.55
CASE: Community, Home Resources	0.56	- 0.62	- 0.57	- 0.60	- 0.51
CASE: School Resources	0.37	- 0.37	- 0.36	- 0.37	- 0.26
CASE: Physical Design, Access	0.28	- 0.45	- 0.31	- 0.37	- 0.58

Discussion: CASE key findings

- 3-factor solution similar to prior 4-factor solution with large proportion of variance explained (Khetani, et al., 2014)
- 3 factor subscales had moderate to high internal consistency (*possibly 3 good estimates of dimensions*)
- Youth with higher CASE scores had lower CASP scores & higher CAFI scores (*convergent validity evidence, similar to prior results*)
- Scores discriminate for condition & impairment type / severity & NOT for age or sex.
 - Youth expected to have greater physical & social environmental problems had higher CASE scores

CASE: Limitations & Future Work

- **Prior work lacked controlled data collection:**
 - Combined different formats of administration; Missing data; Combination of small size samples of convenience
- **Only parent report (*youth version being explored*)**
- **Only focused on problems / barriers (not supports)**
- **Might not be responsive to change over time:**
 - Due to Broad versus discrete items
 - Possibly add more response options (*from 3 to 5 points*)?

Further psychometric & utility testing needed:
(*with larger, more diverse & representative samples*):

-Reliability, validity, responsiveness; use in intervention planning; which scores to use for different stakeholder purposes

THANK YOU!

ANY QUESTIONS?

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