

Evaluating the validity and responsiveness of the **FOCUS: Focus on the Outcomes of Communication Under Six.**



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WORKSHOP

**A Health Services Research Agenda: Building
Capacity within the Maternal, Child, & Youth Sector**

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Sheraton Gateway Hotel, Toronto, Ontario

Project Overview: BACKGROUND

- Speech-Language Pathologists need outcome measures to:
 - Determine clinically important change.
 - Improve treatment services in an evidence-based manner.
 - Determine optimal length for treatment.
 - Select the best treatment model for each child.

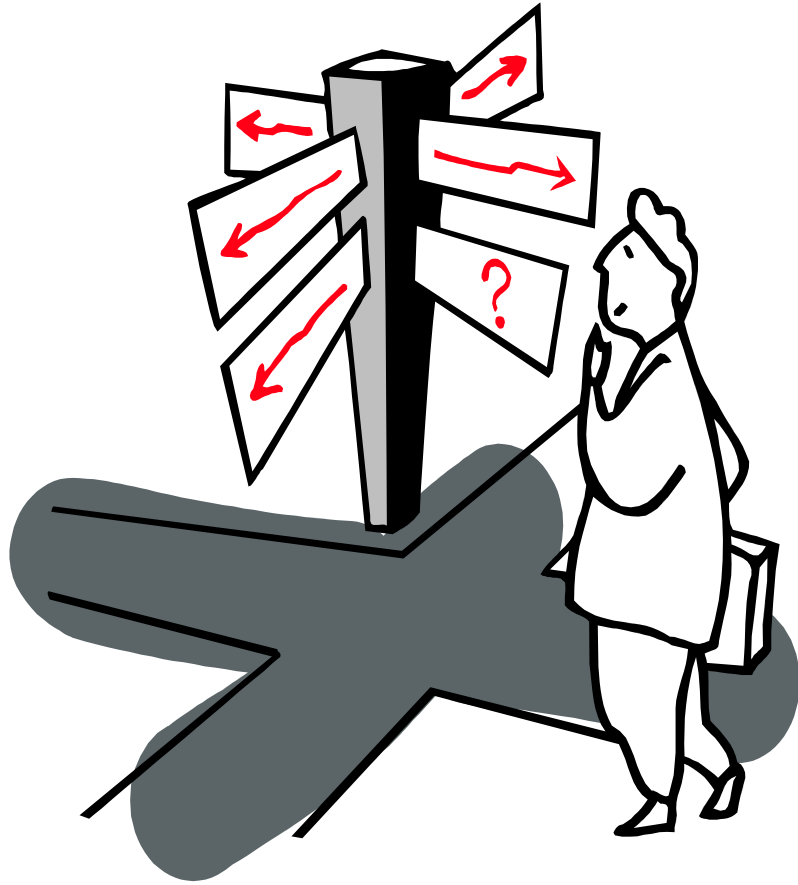
Project Overview: BACKGROUND:

- In 1998, Bloorview Kids Rehab wanted a outcome measure for their speech-language pathology services.
 - Lit. search revealed only two outcome measures
 - Neither measure had data to prove they worked.

- Completed a 2-year study with 6 organizations in Ontario to evaluate one of the measures.

- Results showed that the measure was NOT responsive to treatment changes.

Project Overview: We are at a crossroad!



- We had data describing the changes observed by parents and clinicians after therapy.
- Should we create a new outcome measure?

Project Overview: Develop a NEW Outcome measure!



To develop a valid,
reliable and
responsive
outcome measure
that captures 'real
world' changes
following speech
and language
treatment.

Project Overview: Developing the FOCUS

Method: Six Linked Steps

1. Analyze our data from parents and clinicians to create items.
2. Test the measure with clinicians and families.
3. Revise the measure.
4. Test the revised measure again.
5. Revise measure a second time.
6. Test final measure and establish its reliability.

Project Overview: Developing the FOCUS

- 420 questionnaires from parents and clinicians describing the changes they observed in their child during speech-language therapy.
- 3 researchers completed a content analysis to find recurring categories of change.
- Changes were noted in communication skills
- Changes also noted in 'real world' skills:
 - attention,
 - confidence,
 - socialization with peers
 - participation in community activities.

Project Overview: Developing the FOCUS

- ❑ Comments reflected the ICF and the newer version the ICF-CY frameworks.
- ❑ Adopt the ICF framework to measure 'real world' changes.
- ❑ FOCUS items developed from categories cited by >10% of parents & clinicians.
- ❑ Resulted in 200 items → reduced to 103.
- ❑ Items used parents own wording.

Project Overview: Sample FOCUS Item

My child makes friends easily.

Not at all like my child	A little like my child	Some what like my child	A fair bit like my child	Quite a bit like my child	Very much like my child	Exactly like my child
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Project Overview: Sample FOCUS Item

My child will ask for things from other children.

Can not do at all	Can do with a great deal of help	Can do with a lot of help	Can do with a bit of help	Sometimes does without help	Often does without help	Can always do without help
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Project Overview: Developing the FOCUS

- Criterion referenced measure.
- Take a 'snapshot' of child at beginning and end of treatment and use the changes in the scores to measure change.

- Child's performance is judged according to pre-stated criterion.
 - My child's speech is clear
 - Exactly like my child → Not at all like my child.

Project Overview: Developing the FOCUS

- ❑ FOCUS tested with 165 families and their clinicians.
- ❑ Revised after each testing phase.
- ❑ Reduced from 103 to 50 items.
- ❑ Takes 10 minutes to complete.
- ❑ High internal consistency! ($\alpha = .96$)
- ❑ Parent test-retest reliability is very high. ($r > .95$)
- ❑ Clinician test-retest reliability acceptable. ($r > .7$)

Project Overview: Current Project



Evaluating the Validity and Responsiveness of the FOCUS

Funding:
Canadian Institutes for Health
Research
CIHR Partnerships for Child and
Youth Health Indicators

Project Overview: 7 Partner Sites across Canada

- ❑ BC Center for Ability, BC
- ❑ Calgary Health Region, AB
- ❑ Waterloo Preschool Speech & Language Program, ON
- ❑ Technology Access Clinic, Hamilton, ON
- ❑ First Words Preschool Program, Hamilton, ON
- ❑ Bloorview Kids Rehab, Toronto, ON
- ❑ Nova Scotia Hearing and Speech Centres, NS

Project Overview: Construct Validity

1. The FOCUS should measure more change during treatment than in the wait list interval.
2. FOCUS change scores should moderately correlate with related measures (PEDS-QL; ASQ-SE; VABS).

Project Overview: Construct Validity

3. FOCUS change scores should correlate with parents' and clinicians' ratings of change.

4. FOCUS change scores should correlate with changes in speech and language skills.
[blind raters]
 - Developmental Sentence Scoring
 - Children's Speech Intelligibility Measure
 - Percent Consonants Produced

Project Overview: Where are we now?



Project Overview: Developing the FOCUS

- Currently in data collection phase of the study.
- Initial data received for 130 participants.
[Goal = 250]

Delays in data collection due to:

- Delays in obtaining ethics clearances
- Recession/layoffs for SLPs
- Fewer clients in treatment → slower data collection.

Project Overview: Developing the FOCUS

- Partner sites report that additional participants have been recruited.
- 45 participants have completed the study.
- Decision-Maker partner (MCYS) facilitated contacts with two new partner organizations to help with data collection.

Project Overview:

- Participants range in age from 10 months to 5 yrs 3 months with a variety of communication disorders.
- Mean age = 2 yrs 8 months.
- Two-thirds of participants are male.
- 76% of children have severe communication disorders.

Achievements / Milestones: FOCUS & PEDS-QL (N=26)

- ❑ FOCUS significantly correlated with PEDS-QL
 - end of treatment FOCUS scores & PedsQL total scores ($r = .466, p = .029$)
- ❑ Children who made the most change as measured by the FOCUS had higher PedsQL scores ($r = .488, p = .04, n = 18$)
- ❑ The children who had better communication skills and those who made the most positive changes as measured by FOCUS had higher health-related quality of life scores.

Achievements / Milestones: Reliability

- Clinician Inter-Rater Reliability
 - Two clinicians scored the FOCUS within 8 days.
 - Both clinicians had seen the child clinically and obtained input from parents and teachers.
 - Inter-rater reliability was $r = .96$
- Test – Retest Reliability
 - Parents ($r > .95$)
 - Clinicians ($r > .90$)

Achievements / Milestones: MCYS

- Ms. Claire MacLean from Ontario Ministry of Children and Youth Services, Speech and Language Services is a Decision-Maker Partner for this project.
- MCYS interested in FOCUS' potential to collect province-wide outcome data for the province-wide Preschool Speech and Language Services.
- No final decision can be made until FOCUS' validity and responsiveness have been established.
- Potential to sign a data sharing agreement.

Achievements / Milestones: FOCUS influences clinical Practice!

- Clinicians' say:
 - FOCUS helps them learn more about the child's communication skills in real life.
 - They are setting more 'participation' level goals. (e.g., talk more with other children)
 - FOCUS facilitates parent involvement in the child's treatment.
- Parents' say:
 - FOCUS helps them understand the role of speech-language pathology and how therapy will help their child.

Achievements / Milestones: FOCUS becoming recognized internationally!

- ❑ FOCUS has been translated into French (FOCUS-F)
- ❑ FOCUS is being used in England (research project)
- ❑ Possible research partner in Australia.
- ❑ Invited to present at an ICF symposium at the International Association of Logopedics and Phoniatics Congress, Athens, Greece 2010.

Key KT Challenges

- Clinicians want to use the FOCUS now!
- Clinicians see that the FOCUS supports the effectiveness of therapy.
- Don't want to wait until reliability, validity and responsiveness have been established.
 - There is a lack of understanding that an outcome measure must have demonstrated psychometric properties.

Key KT Challenges

- Research process seems very slow to clinicians.
- Some KT activities need to wait until validity is established.
- CASLPA to develop a Position Statement to support use and development of SLP outcome measures.
- Member of the CASLPA committee

Key KT Challenges:

- ❑ Design a website for world-wide distribution of the FOCUS (at no charge).
- ❑ Write a manual to accompany the measure.
- ❑ Develop scoring protocol.
- ❑ The above steps require additional funding to hire required expertise.

Key KT Challenges

FOCUS 'launch' workshop for key representatives of:

- Regulatory colleges
 - Professional associations
 - Provincial Government Representatives
 - Speech-Language Pathology University Training Program personnel.
- Additional KT funding would facilitate this broader-based dissemination plan.

Next Steps: Operationalize KT Plan

- Journals/ Conferences ✓
- Partner organizations disseminate locally ✓
- Newsletter Updates for Interested Parties ✓
- Expand International partnerships ✓
- Completing a Systematic review of SLP outcome measures for children ✓
- Website
- Manual
- FOCUS launch
- Disseminate to relevant parent groups

Next Steps: Research Plans

- Additional validity studies with specific populations.
 - Children with Autism
 - Children with Cochlear Implants
- Possibly use province-wide FOCUS data.
- Develop complementary measures
 - 'Wee' FOCUS
 - Elementary/School-age FOCUS
- Treatment efficacy studies.

Acknowledgements



A special thank you to all of the families and clinicians who have participated in the FOCUS' development.