

A comparison of the WeeFIM and PEDI questionnaires for measuring change in functional status of young children with cerebral palsy or developmental delay

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Other partners: CRRN, Bloorview Research Institute and Bloorview Kids Rehab

WORKSHOP

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

**February 18th and 19th, 2010
Sheraton Gateway Hotel, Toronto, Ontario**

Project Overview

- Maximization of a young child's potential in functional abilities (i.e., skills and independence in self-care, mobility, speech/language, cognition, play skills and social function) is of priority to families and service providers.
- Recognized barriers to the establishment of outcome indicators in pediatric rehabilitation are the diversity of measures in use within/across the various areas of the ICF, the continual emergence of new measures, and lack of consensus across clinicians and facilities as to which one(s) to use at a systems level.

Origins of this project

From previous outcomes indicators initiatives with the Ontario Ministry of Children and Youth Services (MCYS)

- Extensive outcomes project with *CanChild* and MCYS
- Then a smaller outcomes project funded by MCYS with Bloorview Kids Rehab and Ontario Association of Children's Rehabilitation Centres (OACRS) to find out what approaches clinicians were taking to outcome measurement (2006)
- Our work confirmed a lack of use of standardized measures and lack of a co-ordinated approach to measurement across OACRS centres

The dilemma

- In 2007, MCYS suggested using the WeeFIM Instrument across OACRS centres to permit a system-wide evaluation functional ability outcomes
- OACRS centres very apprehensive about use of this **minimum data set** measure – would it detect the changes that occur in association with services offered?
- Perhaps a more **detailed measure like the PEDI** would be more sensitive to important clinical changes?
- BUT ...Clinicians and managers' concerns: While the PEDI is comprehensive, is the outcome information gained worth the time needed to administer it?

Project Overview

- The WeeFIM ® Instrument and Pediatric Evaluation of Disability Inventory (PEDI) and the are well-known, non-categorical measures of ‘activity’ recommended in the published literature for standardized evaluation of outcome related functional abilities with children with CP or other developmental delay (DD).
- Both are parent-report measures that cover functional abilities in the domains (subscales) of *Self-care*, *Mobility* and *Social function/Cognition* (including speech and language skills).



Project Goals (with MCYS and OACRS)

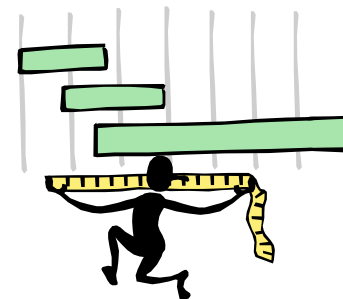
The primary goals of our project are:

- i) to conduct a first-ever parallel evaluation of the ability of the WeeFIM and PEDI to detect change, and
- ii) to determine magnitudes of change that are considered clinically important in the context of functionally-based rehabilitation interventions.

Provide benchmarks for evaluation of changes in functional ability

ENROLMENT ACROSS 9 CENTRES (6 in Ontario, Edmonton, Winnipeg, Saskatoon)

- 150 - 175 children with CP, developmental delay, or autism spectrum disorder
- Parents of children ages 18 m to 7 y
- Baseline and follow-up interview 2 to 6 m later



PEDI Functional Skills (Part I by parent on own)

- maximum data set

G) HANDWASHING



	Unable	Capable
29. Holds hands out to be washed	<input type="checkbox"/>	<input type="checkbox"/>
30. Rubs hands together to clean	<input type="checkbox"/>	<input type="checkbox"/>
31. Turns water on and off, obtains soap	<input type="checkbox"/>	<input type="checkbox"/>
32. Washes hands thoroughly	<input type="checkbox"/>	<input type="checkbox"/>
33. Dries hands thoroughly	<input type="checkbox"/>	<input type="checkbox"/>

H) WASHING BODY AND FACE



	Unable	Capable
34. Tries to wash parts of body	<input type="checkbox"/>	<input type="checkbox"/>
35. Washes body thoroughly, not including face	<input type="checkbox"/>	<input type="checkbox"/>
36. Obtains soap (and soaps washcloth if used)	<input type="checkbox"/>	<input type="checkbox"/>
37. Dries body thoroughly	<input type="checkbox"/>	<input type="checkbox"/>
38. Washes and dries face thoroughly	<input type="checkbox"/>	<input type="checkbox"/>

PEDI Caregiver Assistance (Part II – with interviewer)

PART 1: SELF CARE	5 Independent	4 Supervision	3 Minimal	2 Moderate	1 Maximal	0 Total
Eating: eating and drinking regular meal; do not include cutting steak, opening containers or serving food from serving dishes						
Grooming: brushing teeth, brushing or combing hair and caring for nose						
Bathing: washing and drying face and hands, taking a bath or shower; do not include getting in and out of a tub or shower, water preparation or washing back or hair						
Dressing Upper Body: all indoor clothes, not including back fasteners; include help putting on or taking off splint or artificial limb; do not include getting clothes from closet or drawers						
Dressing Lower Body: all indoor clothes; include putting on or taking off brace or artificial limb; do not include getting clothes from closet or drawers						
Toileting: clothes, toilet management or external device use, and hygiene; do not include toilet transfers, monitoring schedule or cleaning up after accidents						
Bladder Management: control of bladder day and night, clean-up after accidents, monitoring schedule						
Bowel Management: control of bowel day and night, clean-up after accidents, monitoring schedule						

WeeFIM® Instrument Rating Form (parent interview)

- 'minimum data set'

WeeFIM[®] Rating Levels

No Helper:

- 7 **Complete Independence** (no device, timely, safely)
- 6 **Modified Independence** (device, not timely, or not safely)

Helper – Modified Dependence

- 5 **Supervision** (subject performs 100% of the effort)
- 4 **Minimal Assistance** (subject performs 75% or more of the effort)
- 3 **Moderate Assistance** (subject performs 50% to 74% of the effort)

Helper – Complete Dependence

- 2 **Maximal Assistance** (subject performs 25% to 49% of the effort)
- 1 **Total Assistance or Not Testable** (subject performs less than 25% of the effort)

Mobility

i) Chair, Wheelchair _____

j) Toilet _____

k) Tub, Shower _____

l) Of the following three methods, score each method that is used. Mark an asterisk (*) next to the most frequently used method:

i. Walk _____

ii. Wheelchair _____

iii. Crawl _____

m) Stairs _____

Cognition

n) Comprehension _____

o) Expression _____

p) Social Interaction _____

q) Problem Solving _____

r) Memory _____

The PEDI-Computer Adaptive Test or PEDI-CAT



- Created by the PEDI's developers for the Self-care and Mobility FS domains
- a reduced item-presentation algorithm based on respondent's previous answer(s)
- Requires administration of no more than 15-items for each of the Self-care and Mobility subscales
- Available to use specially from its developer, Dr Steven Haley, for use in our study
- **Our question: Is it sufficiently sensitive to change to make it a substitute for the whole PEDI? ... VERY TIMELY QUESTION**

P1

Slide 10

P1

Not sure if this is actually true - in the PEDI-CAT manual, one of the screen shots shows mobility had 17 items in the summary...

Patricia, 7/7/2008

PEDI Computer Adapted Testing (CAT)

Pediatric Function Outcome Assessment v2.40


Before we begin, please answer the questions about your child.


REMINDER:
If you can count on your child doing the activity most of the time, choose Capable.
if you mostly do the activity for the child, or it is too difficult for your child to perform or attempt, choose Unable.

Is your child able to:

Use a fork well when eating?	<input checked="" type="radio"/> Capable	<input type="radio"/> Unable
Put on his/her own shirt, dress or sweater?	<input checked="" type="radio"/> Capable	<input type="radio"/> Unable
Tie his/ her own shoelaces?	<input checked="" type="radio"/> Capable	<input type="radio"/> Unable
Sit unsupported on a chair or bench?	<input checked="" type="radio"/> Capable	<input type="radio"/> Unable
Walk up an entire flight of stairs?	<input type="radio"/> Capable	<input checked="" type="radio"/> Unable
Hop in place on one foot 10 times?	<input checked="" type="radio"/> Capable	<input type="radio"/> Unable

Next

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Interpretation of change scores on the measures: Rating of Change by parent and clinician(s) (anticipated and actual)

- **BASELINE:** Amount of change expected in ability of child to perform specified tasks after treatment?
- **FOLLOWUP:** Ability of child to perform compared to the last time we spoke? (Review child's goals from clinicians)



-7	A very great deal worse
-6	A great deal worse
-5	A good deal worse
-4	Moderately worse
-3	Somewhat worse
-2	A little worse
-1	Almost the same, hardly any worse at all
0	SAME (NO CHANGE)
+1	Almost the same, hardly any better at all
+2	A little better
+3	Somewhat better
+4	Moderately better
+5	A good deal better
+6	A great deal better
+7	A very great deal better

Achievements / Milestones

- Excellent progress with study interviews:
n = 95 baseline assessments and 50 of these have follow-up assessments completed – aiming for 150 to 175 interviews in total
- Less than 2% drop-out rate at follow-up - speaks of perceived value of the PEDI and WeeFIM interviews to the parents
- Diversity of PEDI and WeeFIM scores represented across the sample in each of their subscales – NO evidence of any ceiling effect
- We also have a sample of children who are making change as judged by parents and service providers (goal forms and rating of change scales)

Achievements / Milestones

- Learning some interesting/unexpected things about the PEDI CAT and its clinical utility
- Our interviewers have been involved in guiding other researchers in their use of the PEDI (Ryan et al)
- Two of our out-of-province centres have shown strong interest in the PEDI and WeeFIM – will be ideal centres for initial roll-out and testing of clinical guidelines for use

Achievements / Milestones

- Spin-off projects that relate to KT
 - i) Training materials
 - developed for interviewer training workshop (2008)
 - enhanced parent interview materials for PEDI (2008/09) developed by OT MSc student – prototype for the WeeFIM as well
 - ii) What are parents` views about completing the PEDI
 - OT graduate student project (Spring/Summer 2010)
 - in direct response to parents` comments about the PEDI and WeeFIM interviews.

Next Steps

- Complete enrolment and follow-up assessments – strive to find more children with CP (right now 25% fewer than children with DD)
- Data analysis/reports – establish benchmarks for change
- Summer/Fall 2010 policy work with MCYS (environmental scan) ...
- Workshop on use of the PEDI and WeeFIM clinically at OACRS conference November 2010, Toronto – making plans now for this
- Presentation of results at American Academy of Cerebral Palsy and Developmental Medicine conference 2011 and World Physio Congress 2011

KT Plan

- MCYS, OACRS and the investigative team will **jointly co-ordinate** the design, development, and establishment of the functional outcome indicator education/implementation strategy to be used across the CTCs in Ontario.
- Within 3 months of the end of this project we will have developed a clearly-defined plan for roll-out, implementation and evaluation of the selected outcome indicator(s) (assuming the PEDI, PEDI-CAT or WeeFIM prove(s) to be acceptable as an outcome indicator.)

KT Plan ...

- Funding commitment from Bloorview Kids Rehab for a 'knowledge broker/ translational scientist' to pilot test a strategic plan (as developed by the investigators and Policy Steering Committee) for the clinical introduction of the chosen functional outcome indicator(s) at the completion of the study. This pilot-testing of a KT process is critical for subsequent widespread adoption.
- Additional funding will be sought to evaluate the effectiveness and impact of selected outcome indicator(s) use across the CN-CYR network of children treatment centres in Canada and possibly further afield.

Key KT Challenges

The time issue (speed is of the essence):

- Changing partners mid-dance: MCYS and OACRS
- Shifting sands: new outcome measures in our midst and others on the horizon (Haley et al., 2010) – the appeal of the ‘new’
- Budget cut-backs within OACRS centres - ? support of time for outcome measurement – regardless, it is always tough to introduce new clinical requirements (resistance to change)
- Changing involvement overall/directions of MCYS for outcome indicator initiatives – concern about a disconnect

Key KT Challenges ...

- Bringing the measures up to date in terms of presentation format to take advantage of new electronic technologies (PEDI and WeeFIM currently done as paper forms)
- How do we go about making recommendations/changes to administration processes measures that are owned by others (WeeFIM and PEDI)?



