

Family Wisdom

**Measuring Family-Centred Service in
Early Intervention:
Is the MPOC-20 Reliable and Valid?**

Heather Boyd, M.Sc (cand.),
McMaster University
SpecialLinks Conference,
August 22, 2008
Winnipeg, Manitoba



A brief history of family-centred care:

1960s and 70s

- child-focused, deficit-oriented
- professional-focused
- paternalistic

1970s

- Carl Rogers, psychologist, introduced the idea of 'patient-centred care'
- from this emerges the idea of family-centred care in paediatrics and Early Intervention

1986

- U.S. legislation (later called Part H of I.D.E.A. –Individuals with Disabilities Education Act) mandated family-centred care and family outcomes in Early Intervention



Family-Centred Care: Everybody's talking about it!



....but are we actually practicing it?

Purpose

- To evaluate the utility of the Measure of Processes of Care (MPOC-20), a parent-completed measure of family-centred service in Infant and Child Development Programs

What can we cover in the next hour?

Part I: THE BASICS

- What is family-centred care?
- Why is it important?
- How can we measure it?

Part II: THE STUDY

- What was done?
- What were the results?
 - Who?
 - How many?
 - How high?
 - How wide?
 - How useful?

Part III: WHAT NEXT?

Is Family-Centred Service a Sound Bite?

- Do we walk the talk?
- How do we know?
- How can we measure something that is so abstract?
- How do we make sure that it does not become a 'sound bite' (Brinker, 1992)

From Medical Model to Family-Centred

Professionals are the experts and know what's "best"



Parents know their children best and want what's best for them

Professionals make decisions/choose goals →

Parents and service providers collaborate

We need to measure progress objectively – parents can't be objective →

Parents' perceptions reflect their day to day reality, values, fears, and dreams

Family-Centred Service (FCS)

- A model of service delivery that focuses on the relationship between the family and the service provider
- Based on trust, communication, respect, and shared decision-making
- Empowers and strengthens a family's capacity to promote a child's health and well-being
- Considered best practice but inadequately evaluated at present

Paradigms for Approaching our Relationships with Families

<u>Paradigm</u>	<u>Outcomes</u>
Family-focused	-- family outcomes
Child-focused	-- child outcomes
Family-centred	-- family-driven outcomes (child + family outcomes)

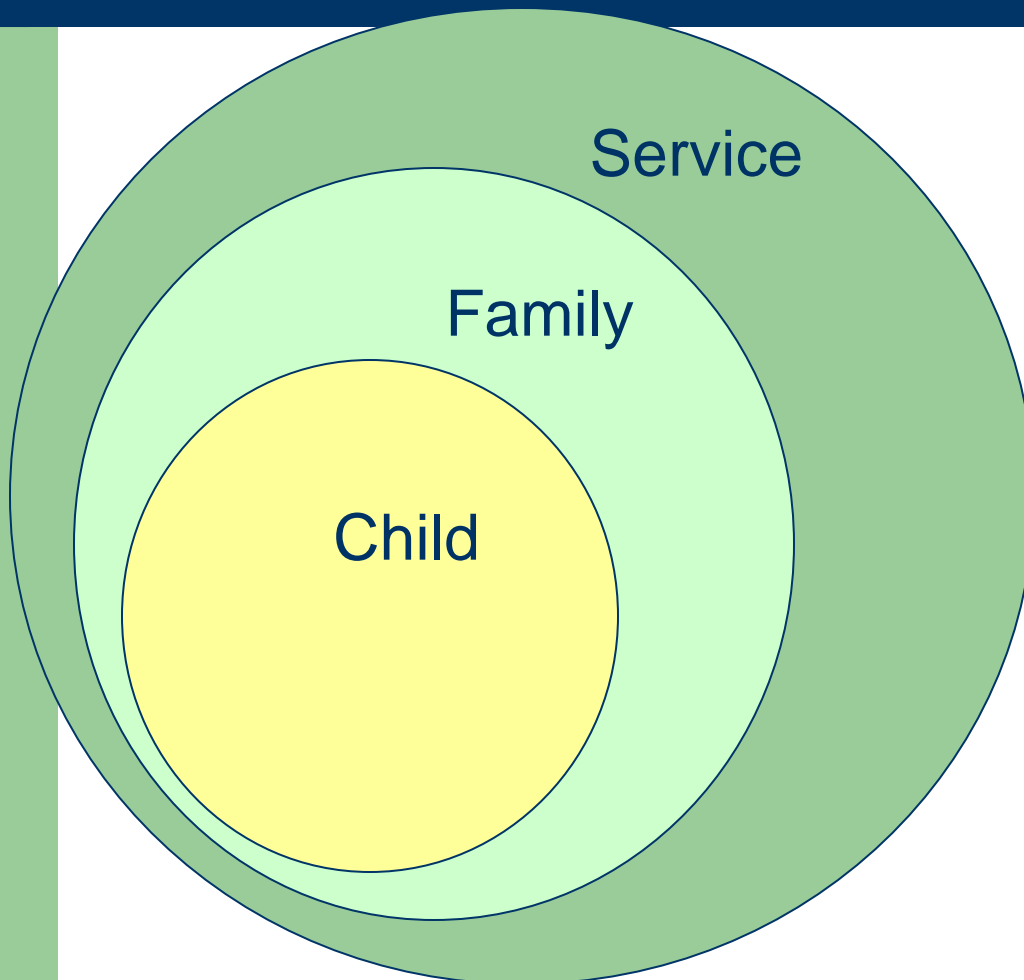
Child versus Family Outcomes

- Where is most of our measurable change happening?
 - Child outcomes now?
 - Child outcomes in the future?
 - Parent well-being
 - Family functioning, coping, and use of resources
 - or is it service → family functioning → child outcomes?
- How do we measure what is happening?
 - Parent report/ parent perception

The Family's Perspective

“When the client’s perspective is not taken into account, the evaluation of services is incomplete and biased” (Larsen et al., 1979).

Ecological Theory: Development in “Context”



- To understand child development, we must look at it in “context”
- This context acknowledges that the family is the primary influence on a child
- People and settings outside of the family can have a significant impact on a child’s outcomes
- School, day care, and Infant Development Programs are part of this ecological context

Bronfenbrenner, 1979

Why Measure FCS?

- Evidence-based practice

FCS has been related to:

- Parent well-being
- Parent satisfaction

We also know that:

- Parent well-being influences a child's outcomes
- Parent well-being is influenced by child behaviour and by supports in the social environment: relationships are not 'one-way'

- Best practice guidelines (e.g., www.oaicd.ca) and policy and procedure manuals (e.g., BC Infant Development)
- We can't improve what we don't measure

Family-Centred Framework

- Key assumptions of FCS (Rosenbaum et al., 1998)
 - Families are different and unique
 - Parents know their children best and want what's best for their children
 - Child development occurs within a supportive family and community context: The child is affected by the stress and coping of other family members.
- This framework also outlines the principles and the behaviours that reflect family-centred service

If we're measuring HOW, we still have to measure WHAT.

- Turning the intangible into the measurable
- Observable, measurable behaviours
- Based on parent perception of what is happening
- MPOC-20 questionnaire is based on Rosenbaum et al's framework, on research, and on input from parents of children with physical disabilities receiving service from Children's Rehabilitation Centres in Ontario

What is the MPOC-20?

- 20 item measure with 5 scales
 1. Enabling and Partnership (EP) – 3 items
 2. Providing General Information (GI) – 5 items
 3. Providing Specific Information (SI) – 3 items
 4. Coordinated and Comprehensive Care (CCC) – 4 items
 5. Respectful and Supportive Care (RSC) – 5 items
- 7-point scale
 - Not at all (1) ...To a very great extent (7)
 - Not Applicable (0)

Scale 1: Enabling Partnership

- TO WHAT EXTENT DO THE **PEOPLE** WHO WORK WITH YOUR CHILD...
- 4. ... let you choose when to receive information and the type of information you want?
- 7. ... fully explain service choices to you?
- 8. ... provide opportunities for you to make decisions about the type of service you receive?

Scale 2: Providing General Information

- TO WHAT EXTENT DOES THE **ORGANIZATION** WHERE YOU RECEIVE SERVICES:
 - 16. ... give you information about the types of services offered at the organization or in your community?
 - 17. ... have information available about your child's developmental issue (e.g., its causes, how it progresses, future outlook)?
 - 18. ... provide opportunities for the entire family to obtain information?
 - 19. ... have information available to you in various forms, such as a booklet, kit, video, etc.?
 - 20. ... provide advice on how to get information or to contact other parents (e.g., organization's parent resource library)?

Scale 3: Providing Specific Information

- TO WHAT EXTENT DO THE **PEOPLE** WHO WORK WITH YOUR CHILD...
- 2. ... provide you with written information about what your child is doing developmentally?
- 14. ... provide you with written information about your child's progress?
- 15. ... tell you about the results from assessments?

Scale 4: Respectful and Supportive Care

- TO WHAT EXTENT DO THE **PEOPLE** WHO WORK WITH YOUR CHILD...
- 5. ...look at the needs of your whole child (e.g., at mental, emotional, and social needs) instead of just at physical needs?
- 6. ...make sure that at least one team member is someone who works with you and your family over a long period of time?
- 10. ...plan together so they are all working in the same direction?
- 12. ...give you information about your child that is consistent from person to person?

Scale 5: Comprehensive and Coordinated Care

- TO WHAT EXTENT DO THE **PEOPLE** WHO WORK WITH YOUR CHILD...
 1. ...help you to feel competent as a parent?
 3. ...provide a caring atmosphere rather than just give you information?
 9. ... provide enough time to talk so you don't feel rushed?
 11. ...treat you as an equal rather than just as the parent of a child on their caseload (e.g., by not referring to you as "Mom" or "Dad")?
 13. ...treat you as an individual rather than as a "typical" parent of a child with a developmental risk?

Methods

- Minor modifications to the MPOC-20
 - To reflect the language and setting of Infant Development (e.g. focusing on development, not necessarily physical disabilities).
- Mailed survey
 - Children < 36 months old
 - > 6 months of service
 - Random selection: programs were English, and did not focus exclusively psychosocial risk factors (e.g. drug use)
- Parents received MPOC-20, as well as a satisfaction measure, and a parenting stress measure

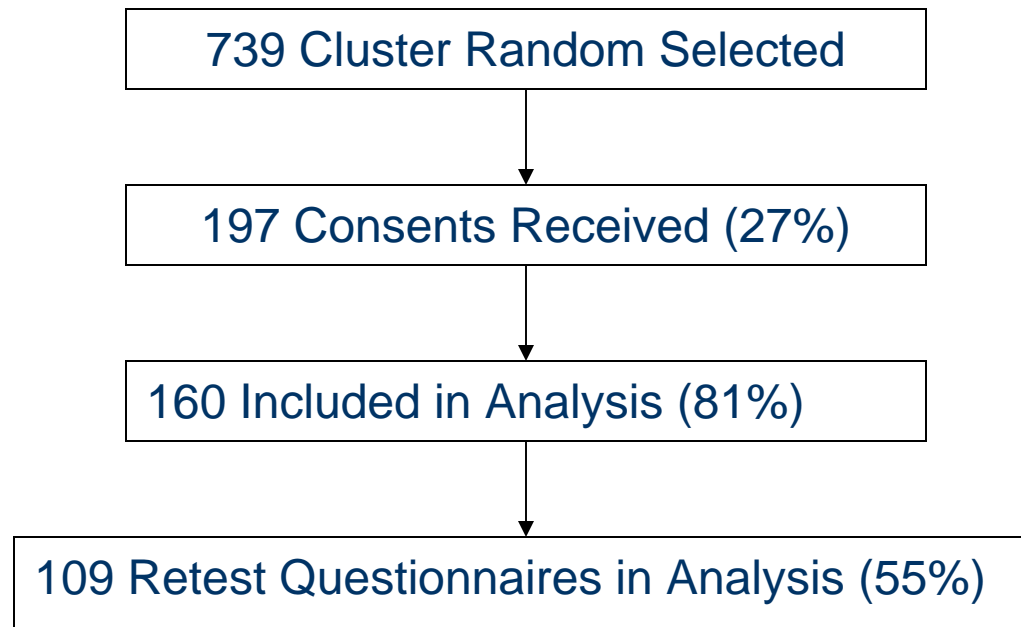
Methods –To test validity...

- Satisfaction
 - Client Satisfaction Questionnaire (CSQ, [Larsen et al., 1979])
 - 8 items, 4 point scale, total score
- Parenting Stress:
 - Parenting Stress Index (PSI/SF, [Abidin, 1995])
 - Measures the stress associated with the role of parenting 36 items, 5 point scale, total score

Results: Programs

- 14 of 49 eligible programs in Ontario
- Number of staff: 1 to 78 service providers
- Caseload size: 13 to 1150 children

Results: Response Rate



Results: Participants

- Children receiving service:
 - 62% male
 - Mean age of 25 months (S.D. 8 months)
- Respondents:
 - Biological mother: 83%
 - English: 93%
 - Education level of at least some university: 44%
- Families:
 - Two-parent family: 86%
 - Income >\$90,000: 38%

Reliability



- Discriminating between:
 - Parent experiences
 - Programs
- Reliability: does the measure elicit different ratings? (the broken thermometer)
 - Same temperature every day?
 - Variety of responses?
 - We're testing the *questionnaire*, not the program

Reliability: The “Universe” of Possibilities

- What are all of the factors that could be affecting a parent’s rating?
 - Timing: *when* we ask them
 - Timing: *how long* they have been in service
 - Question: *what* question we ask them to answer
 - Who: *which* parent we ask
 - Where: what program that parent is from
 - Who is their service provider?
 - Family circumstances: depression, poverty, education, etc.

Reliability

- If we want to be able to distinguish between different parents' experiences, we want *most* of the differences in scores to be between *PARENTS*
- Everything else (items, times, programs, etc.) is just noise
- Include as many factors as you can so that you can understand the questionnaire better
- Included in this study: Program, Family, Item, Time

Results: Family-Level Reliability

- Internal consistency, Test-retest reliability, and overall reliability
- The calculations used Generalizability Theory (G theory)
 - G theory is a more flexible (but also more complex) approach to reliability that lets you tailor reliability to exactly how you plan on using the measure
 - The results, however, are sometimes a little bit lower than you would expect to get if you used the exact same data but used the more traditional Classical Test Theory.
- Results suggest good reliability at the family-level (distinguishing between individual family's experiences of family-centred service).
- Full results will be available in:

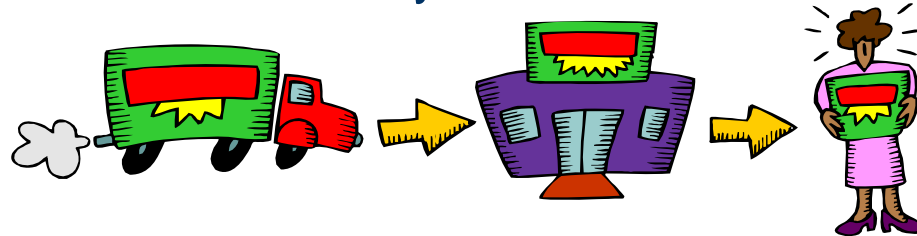
Boyd, H. (2008). *Reliability and validity of the Measure of Processes of Care (MPOC-20) in Infant and Child Development Programs in Ontario*. Unpublished master's thesis, McMaster University.

Results: Program-Level Reliability

- Reliability was also calculated to test the MPOC-20's ability to distinguish between different programs
- With the exception of adequate internal consistency for “Providing Specific Information” and “Providing General Information”, the MPOC-20 was not very reliable at the program level.
- These results reinforce the original intent of the MPOC-20 (to determine individual perceptions of care) and the family-level reliability results.

Validity

- Are we measuring what we think we're measuring?
 - The *Process* of family-centred service delivery



- Processes of Care → Outcomes (Donabedian, 1988)
- What is family-centred service related to?
 - Satisfaction
 - Parent well-being

Validity –Correlation with Satisfaction

- If we already know that family-centred service is related to satisfaction, then scores on the MPOC-20 should relate to scores on the CSQ
- Client Satisfaction Questionnaire (CSQ, [Larsen et al., 1979])
- Results showed that:
 - ↑ MPOC-20 Scores = ↑ CSQ total score
= indication of validity

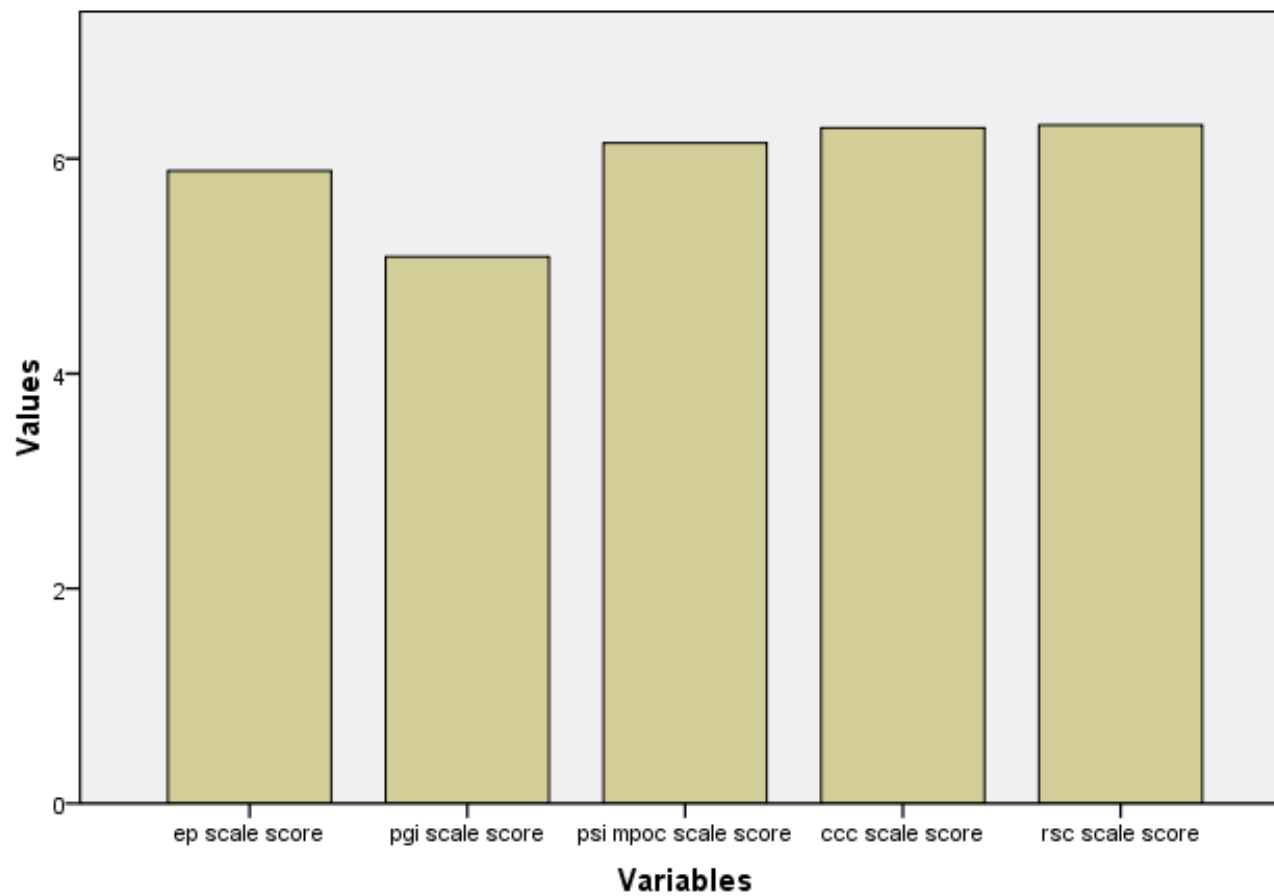
Construct Validity –Parenting Stress

- If we already know that family-centred service is linked with better parent well-being, then MPOC-20 scores should go up as parenting stress scores go down
- Parenting Stress Index (PSI/SF, [Abidin, 1995])
- Results showed that:
 - ↑ MPOC-20 Scores = ↓ Total Stress on PSI

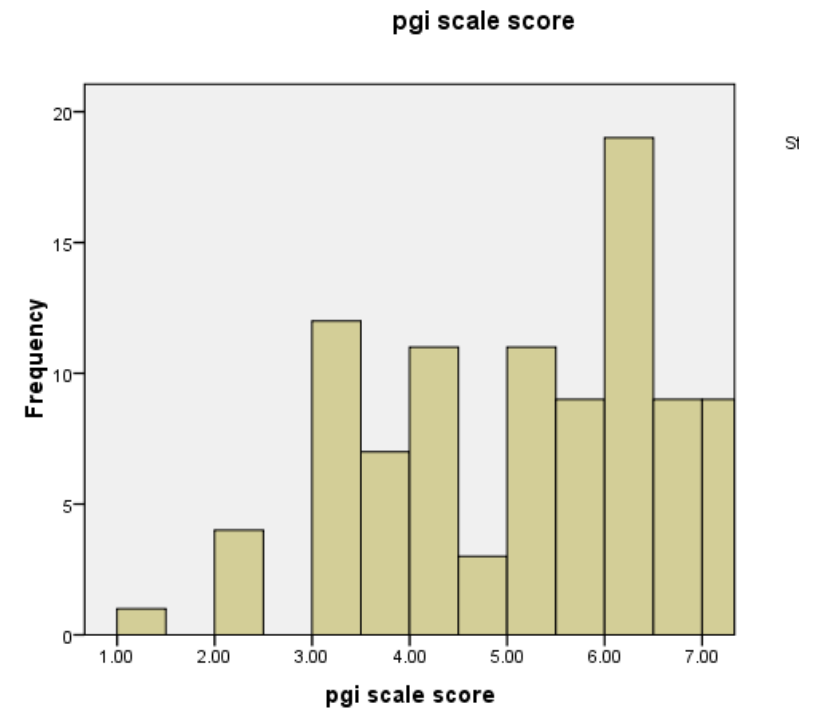
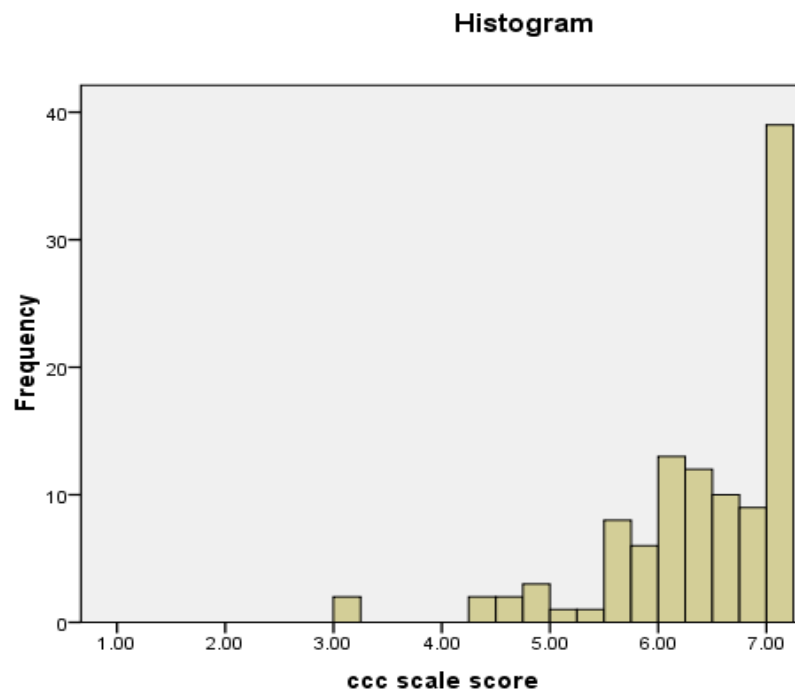
but only for two scales (Providing General Information and Providing Specific Information). The other three scales were either not related to parenting stress or were not statistically significant

How High?

Descriptive Statistics



How Wide?



How Many “Not Applicable” Responses?

- Most parents rated each item on the 20-item questionnaire
- However, there were some items that had ‘relatively high’ numbers of people (e.g. between 10 and 20 parents out of the total 160 who completed the MPOC-20) selecting ‘not applicable’.
- What does this mean? Is the item not relevant to *every* family (this might be OK)? Or is this telling us that the item really is not relevant to Infant Development in general? Is the wording awkward or misleading?
- More research may help us find out.

Conclusions

- MPOC-20 demonstrated adequate reliability and validity at the family level in this study
- Recommended for use in Infant and Child Development Programs for program evaluation and quality improvement initiatives within programs
- Other applications include settings in which the primary reason for involvement is related to the child (versus family and psychosocial issues as the primary concern)
- Utility of the MPOC-20 may improve with further modifications

Future Directions

- Refine the MPOC-20 and Test modifications
 - Explore high rates of “not applicable”, particularly the GI Scale
 - Parent feedback
 - Collect data from program evaluations to re-evaluate the measure
- Improve representativeness
 - Northern Ontario communities and First Nations Programs
- Use in program evaluation

Valuing Family-Centred Service

“...the ultimate and most appropriate judges of the level and quality of family-centredness are the families themselves” (Petr & Allen, 1997, p. 197).

If we truly value family-centredness, and we believe it is the best way to provide service, then we need to show that we are being family-centred. To do this we need to begin with a reliable and valid way of measuring it, and we need to ask parents to tell us how we are doing. The MPOC-20 is one questionnaire that could help us do this.

Participating Programs

- ICDS Dufferin
- ICDS Durham
- Infant and Child Development Program Brockville
- Infant Development –Haliburton County
- Trellis Infant Development Program -Guelph
- Haldimand-Norfolk REACH Infant & Child Development Program
- ICDS Halton
- Infant Development Program -Kingston
- ICDS Muskoka/Parry Sound
- IEPTP Niagara
- Infant Development Service (Ottawa Children's Treatment Centre)
- ICDS Peel
- Infant Development Program –Centennial Infant and Child Centre (Toronto)
- ICDS Wellington
- Children First (Windsor)



Acknowledgements

- Many thanks to my thesis committee for their support
 - Dr. P. Rosenbaum
 - Dr. D. Cameron
 - Dr. H. Shannon
 - Dr. S. Wilkins
- Financial support
 - *CanChild* Centre for Childhood Disability Research
 - Sick Kids CYHN/COTF Masters Award
 - Basmajian Travel Award



LA FONDATION
CANADIENNE
D'ERGOTHÉRAPIE

Doter le savoir et la recherche



CANADIAN
OCCUPATIONAL
THERAPY FOUNDATION

To fund scholarship and research



Key References

- Abidin, R. R. (1995). *Parenting stress index: Professional manual* (3rd ed.). Odessa, Florida: Psychological Assessment Resources, Inc.
- Brinker, R.P. (1992). Family involvement in early intervention: Accepting the unchangeable, changing the changeable, and knowing the difference. *Topics in Early Childhood Special Education*, 12(3), 307 -332.
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Massachusetts: Harvard University Press.
- Donabedian, A. (1988). The quality of care. how can it be assessed? *Journal of the American Medical Association*, 260(12), 1743-1748.
- King, S. M., King, G. A., & Rosenbaum, P. L. (2004). Evaluating health service delivery to children with chronic conditions and their families: Development of a refined measure of processes of care (MPOC-20). *Children's Health Care*, 33(1), 35-57.
- Larsen, D. L., Attkisson, C. C., Hargreaves, W. A., & Nguyen, T. D. (1979). Assessment of Client/Patient satisfaction: Development of a general scale. *Evaluation and Program Planning*, 2, 197-207.
- Petr, L. & Allen, R. (1997). Family-centred professional behavior: Frequency and importance to parents. *Journal of Emotional and Behavioral Disorders*, 5(4), 196-204.
- Rosenbaum, P. L., King, S. M., Law, M., King, G. A., & Evans, J. (1998). Family-centred service: A conceptual framework and research review. *Physical and Occupational Therapy in Pediatrics*, 18(1), 1-20.
- Shelton, T. L., & Stepanek, J. (1994). *Family-centered care for children needing specialized health and development services* (3rd ed.), Bethesda, MD: Association for the Care of Children's Health.
- Streiner, D. L., & Norman, G. R. (2003). *Health measurement scales: A practical guide to their development and use* (3rd ed.). New York: Oxford University Press.

Other key references (warning: may cause number-phobia and statistics anxiety!):

- Brennan, R. L. (2001). *Generalizability theory*. New York: Springer-Verlag.
- Shavelson, R. J., & Webb, N. M. (1991). *Generalizability theory: A primer*. California: Sage.

Other references

Original MPOC Manual (and other resources on FCS)

CanChild Centre for Childhood Disability Research, McMaster University, www.canchild.ca

-Use search words MPOC or family-centred service or go to <http://www.canchild.ca/Default.aspx?tabid=200>

Exciting Reading that is loosely related --Social Model of Disability

Colver, A. (2005). A shared framework and language for childhood disability. *Developmental Medicine & Child Neurology*, 47(11), 780-784.

Whalley Hammell, K. (2006). *Perspectives on disability and rehabilitation: Contesting assumptions; Challenging practice*. Elsevier, Philadelphia.

Full results will be available in:

Boyd, H.R. (2008). *Reliability and validity of the Measure of Processes of Care (MPOC-20) in Infant and Child Development Programs in Ontario*. Unpublished master's thesis, McMaster University, Hamilton, Ontario, Canada.

If you have trouble finding or accessing any of the above references, feel free to contact me and I may be able to help.

boydhr@mcmaster.ca or

hrboyd@gmail.com