



Family-Centered Services versus Family-Centered Systems: The Relationship Between ASD Services and Mothers' Wellbeing

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Going to present some data that is drawn from a larger, province-wide, mixed-methods study that my colleagues and I conducted in Alberta a couple of years ago. This project, and these data, were part of my post-doctoral work.

- Mothers of children with ASD are at increased risk of stress, depression, low parenting satisfaction, and poor family QoL
- A lack of formal support & services not problematic
 - Although many families want more access to respite care services.
- In Alberta, families typically have multiple professionals and agencies across multiple service sectors involved in their lives.
- *Can the involvement of so many agencies/professionals be overwhelming and disruptive, contributing to poorer outcomes?*

Compared with general population, and families with children with other neurodevelopmental disorders.

*Our data is specific to families of children with ASD, and there may be some differences with these families compared to other families, but I suspect that our findings would generalize well to other families who are involved with formal service systems.

There is a relatively substantial body of work that looks at the effects of the lived-experience of raising a child with ASD on maternal wellbeing, but not specifically looking at how services, intended to help families, might influence wellbeing.

- To investigate the relationship between services and well-being among mothers' of children with ASD

Hypotheses

- (1) higher number, frequency and discontinuity of services would be associated with decreased maternal wellbeing;
- (2) increased perceptions of family-centered care would be associated with improved maternal wellbeing;
- (3) services provided in the families home, as opposed to the family travelling to access services, would decrease mother's stress.

- Mothers (n=139) with a child with ASD completed a comprehensive questionnaire addressing:

Child & family demographics

Formal supports & services received

- Education & Rehab Services Questionnaire (Remple, Rogers & Manjemer, 2010)

Service fragmentation/continuity of services

- 15-item "system fragmentation" subscale of the Alberta Continuity of Services Scale for Mental Health (Adair et al., 2002; adapted with permission)

Responsiveness (FCC from professionals)

- MPOC-20 (King, Rosenbaum, King, 2004)

Maternal wellbeing

- Perceived Stress Scale (PSS-4, Cohen et al, 1983)
- Parenting Sense of Competence Scale (Gibaud-Wallston & Wandersman, 1978)

Participants recruited in such a way that we accessed families who did and did not want and/or receive formal services;

**CFA:
Wellbeing**



Model fit indices: χ^2 goodness-of-fit = 87.39, DF=62, p = .02, CMIN/DF = 1.41, CFI = .94, TLI = .93, RMSEA90 = .025-.086

There is no agreed-upon definition of what comprises psychological wellbeing, and no gold-standard instrument for measuring psychological wellbeing. We subscribed to the definition that is about 'lives going well. The combination of feeling good and functioning effectively' (Winefield and colleagues, 2012). We derived our measure from two widely used scales, and used CFA to first validate and then derive measures of the construct.

Wellbeing: Example Items

- I honestly believe I have all the skills necessary to be a good mother to my child.
- Sometimes when I am supposed to be in control, I feel more like the one being manipulated

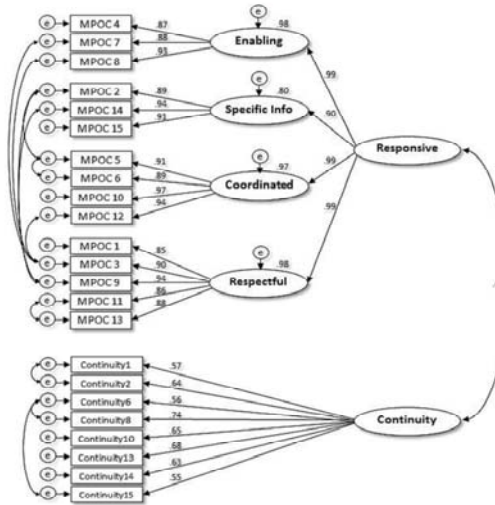
In the last month...

- ...how often have you felt confident about your ability to handle your personal problems?
- ...how often have you felt difficulties were piling up so high that you could not overcome them?

First ones: PSOC

Last 2: PSS

CFA: Continuity & Responsiveness



Model fit indices: χ^2 goodness-of-fit = 322.86, DF=214, $p < .001$, CMIN/DF = 1.51, CFI = .96, TLI = .96, RMSEA90 = .051-.080

Continuity: Example Items

- I've had to repeat my child's history every time we need help
- I have to deal with a confusing number of agencies and programs
- There don't seem to be links from one service to the next
- There is no single place to find out about all services available

Responsiveness: Example Items

The people who work with your child...

- ...fully explain treatment choices to you
- ...look at the needs of your “whole” needs of my child
- ...make sure that at least one team member is someone who works with you and your family over a long period

Child's age (years)	Mean (SD), Range	10.4 (5.7), 2-29
Child's language	Non-verbal/single words	29%
	Sentences, not conversational	24%
	Conversational	47%
Child's intellectual ability	No impairment	37%
	Mild delay	20%
	Moderate/severe delay	43%
Has disruptive behaviours		74%
Mother's age (years)	Mean (SD), Range	41.2 (7.2), 26-63
Single mothers		18%
# Siblings		1 (0-7)
Mother's education	No post-secondary	12%
	Some college/university	24%
	Completed college/university	64%
Household income	< \$45,000	9%
	\$45,000-\$75,000	22%
	\$75,000-\$120,000	43%
	\$120,000+	26%
Lives urban/suburban		92%
Speaks English as primary language at home		86%

Total # professions involved	
	Mode = 3
	Range: 0-8
Frequency of contact with professionals	
	None: 14%
	6 months+: 10%
	3 mo: 6%
	1-2x/mo: 26%
	1x/wk+: 35%

Diversity in most descriptive and demographic variables (child's age, mother's age, urban/rural, severity of various symptoms, etc.).

Relatively high SES, but typical of Alberta at that time.

Our sample was biased towards mothers with higher-than-average educational attainment, typical of research samples.

Very limited representation of families for whom English was not their self-identified first language (few immigrant families)

Regression Models

Variable		Model 1		Model 2	
		B		B	90% CI
<i>Services</i>	(Constant)	0.25		-0.57	[-1.29, 0.16]
	Multiplicity	-0.20**		-0.15**	[-0.23, -0.07]
	Continuity	0.28**		0.28*	[0.09, 0.46]
	Frequency	0.03		0.03	[-0.06, 0.13]
	Responsiveness	-0.03		-0.01	[-0.10, 0.07]
	Home-based	-0.16		-0.15	[-0.38, 0.08]
	Rehab: OT/SLP	0.38*		0.54**	[0.21, 0.86]
<i>Mother-household</i>	Behaviour-support	0.09		-0.13	[-0.40, 0.14]
	Co-parenting			-0.03	[-0.28, 0.23]
	No. of other children			0.09	[-0.01, 0.19]
	Educational attainment			-0.04	[-0.11, 0.04]
	Employment status			-0.03	[-0.15, 0.10]
	Household income			0.08**	[0.03, 0.12]
<i>Child characteristics</i>	Child age			0.04*	[0.12, 0.06]
	Intellectual ability			0.04	[-0.09, 0.16]
	Disruptive behavior			-0.03	[-0.27, 0.20]
	Language skills			-0.04	[-0.14, 0.07]
	R ²			0.256	0.370
	F			5.46***	3.74**

* p < .05, ** p < .01

Service variables alone explained about 26% of the variance in maternal psychological wellbeing. Adding mother-household and child variables to the model explained an additional 11% of the variance.

Hypothesis 1: higher number, frequency and discontinuity of services would be associated with decreased maternal wellbeing;

partially supported – maternal wellbeing was positively associated with continuity of services and negatively associated with multiplicity, but no statistically significant association b/w maternal wellbeing and frequency of contact.

Hypothesis 2: increased perceptions of family-centered care would be associated with improved maternal wellbeing; **not supported**

Hypothesis 3: services provided in the families home, as opposed to the family travelling to access services, would decrease mother's stress. **not supported**

Notably, controlling for maternal-household and child characteristics did not results in any substantial changes in the observed relationships between these service variables and maternal wellbeing. Consistent with previous research – maternal wellbeing was positively associated with child age and household income.

However, maternal wellbeing was not associated with child intellectual or language level, or disruptive behaviour.

Take home interpretation: Continuity of services and #professionals involved, but not frequency of contact with any one professional, or perceptions of family-centeredness, predicted maternal well-being.

Conclusions

- Systemic, not practitioner-level or child variables (e.g., IQ and language ability), predicted maternal wellbeing.
- Findings reinforce the negative influence of systems-level challenges, *especially fragmentation of services*, on maternal well-being, despite positive front-line services and differences in child and family characteristics.

Wellbeing among mothers of children diagnosed with ASD vary more as a function of service system variables (or rather, mothers' experience of the service system) than practitioner-level or child-level variables.

Practice & Policy Implications



The theme of this meeting is “across disciplines, jurisdictions, and generations”, and our findings have relevance to this.

First – the assumption that ‘more is better’ is not supported when it comes to full, multidisciplinary teams and different teams across sectors, for example home and school-based services. Our findings suggests that mothers may not be burdened by regular involvement with professionals, as long as the total number of professionals is limited.

So, key team members with direct contact based on individual needs might foster improved maternal wellbeing, rather than individuals/co-visits with a variety of multi-disciplinary professionals. May have policy implications in jurisdictions that require children and families to demonstrate need across a variety of areas (demonstrating the need for multi-disciplinary teams) – maybe very targeted needs should be considered.

Second, related to the bigger picture overall, the common presumption is that involvement with professional services will alleviate stress and ‘make things better’ is not always supported. We all know that silo’d service systems is a problem, but our findings reinforce just how taxing systemic issues can be for parents, even in the context of other really positive services. Reducing silos is often motivated by financial and personal resources, but parents wellbeing should also be a strong motivator.

Thanks for listening!

Thank you to the families
who took time out of their full lives
to participate in this research.

Zero-Order Correlations: Maternal Well-being and Service Characteristics

	1	2	3	4	5	6	7	Mean (SD) or %
1. Wellbeing	1.00							0.00 (0.68)
2. Multiplicity	-.324**							2.76 (1.87)
3. Frequency	-.041	.553**						2.70 (1.41)
4. Continuity	.228**	.197*	.233*					0.00 (0.64)
5. Responsiveness	.038	.177	.161	.495**				0.00 (1.28)
6. Receives home-based services	-.204*	.505**	.436**	.115	.091			48
7. Receives OT/SP	.019	.627**	.652**	.303**	.192*	.412**		66
8. Receives behavior support	-.115	.632**	.339**	.252**	.073	.461**	.518**	48