addl Autism & Developmental Disorders Lab

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ENGAGING THE WORLD

Family Quality of Life and ASD Funding in BC: Opportunities for Culturally Responsive Research

Grace Iarocci and Emily Gardiner
Simon Fraser University

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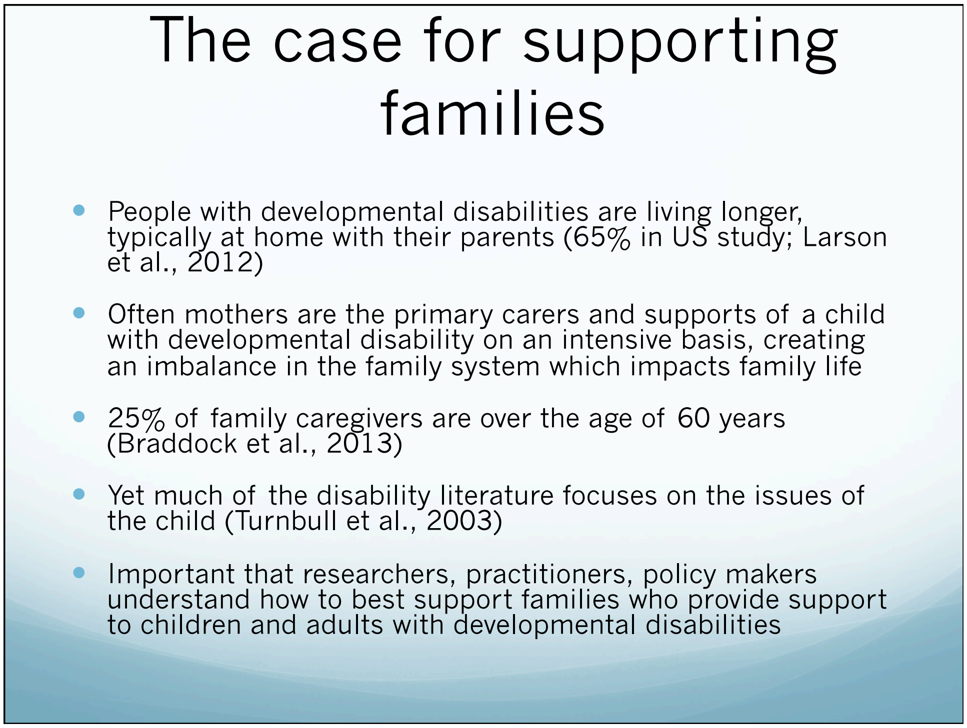
act Autism Community Training



The case for supporting families

- People with developmental disabilities are living longer, typically at home with their parents (65% in US study; Larson et al., 2012)
- Often mothers are the primary carers and supports of a child with developmental disability on an intensive basis, creating an imbalance in the family system which impacts family life
- 25% of family caregivers are over the age of 60 years (Braddock et al., 2013)
- Yet much of the disability literature focuses on the issues of the child (Turnbull et al., 2003)
- Important that researchers, practitioners, policy makers understand how to best support families who provide support to children and adults with developmental disabilities

Family issues that may be common across developmental disabilities

- Developmental disability is unexpected
- No parenting role models or prior knowledge on how to parent a child with DD
- Child is more dependent on family and for longer
- Family is a system and impact is on the whole unit
- Family relies on government, professional services

Family issues that may be unique to ASD

- Social relatedness and connectedness is at the core of the disability
- Genetic risk means that one or more family members are impacted in some way
- Severity of symptoms does not necessarily reflect need
- We know a great deal about the types of service needs, but not how best to tailor services to each family's needs

Family's *subjective* experience varies greatly

- Responses to raising a child with ASD
  - *"Autism has made us realize how precious and great to make each day. We love life."*
  - *"We realized the truth, and by the end of the day we were distraught, because we knew the truth about it. It was actually the worst day of our lives, that was the day we came to terms with the fact that we had this problem."*

(Bayat, 2007, p. 710-711; Midence & O'Neill, 1999, p. 280)

ASD and Service Delivery

- Individuals with ASD may require significant supports across their lifespan
  - Within multiple sectors (e.g., education, medical, social, mental health)
- Responsibility for service coordination rests on the family
- Research highlights the importance of perceived service adequacy for family functioning and quality of life

Quality vs. Quantity

- Families value:
  - Partnership
  - Support
  - Provision of informative, coordinated, and comprehensive care
- Families of children with ASD have unmet service needs
  - Healthcare, family support, referral
  - Less likely to receive coordinated care
  - Less satisfied with child's care

ASD Funding in BC

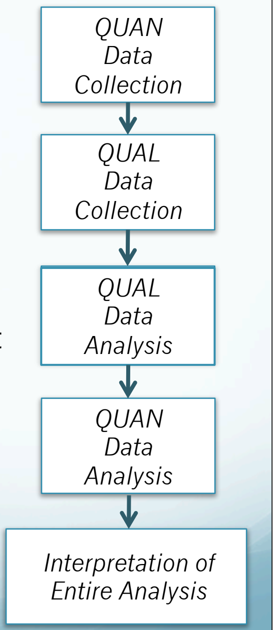
- Autism Funding: Under 6
  - $22,000/year
- Autism Funding: Ages 6-18
  - $6,000/year
    - Professional services
    - Parent and behavioural interventionist training
    - Intervention-related travel, equipment, and materials
- Over 19?
  - Must meet DSM criteria for ID, *or* have an ASD dx *and* significant adaptive functioning limitations to access CLBC funds
    - Residential
    - Community inclusion
    - Family respite
    - Individual and family services

Participant-Directed Service

- Placing decision-making in families' hands aligns with family-centred philosophy
- Families, however, have mixed feelings
  - May perceive lack of structure as overwhelming
  - Others appreciate flexibility and opportunity to customize service
- We are currently 'in the dark' as to the perceptions of families in British Columbia

Current Research

- Mixed-methods approach
  - Variables first explored quantitatively with a large sample (*N* = 160)
  - Qualitative component provided context



QUAN Data Collection

QUAL Data Collection

QUAL Data Analysis

QUAN Data Analysis

Interpretation of Entire Analysis

Study Sequence

Part 1:
N=160

Online Survey

Quantitative

Part 2:
N=15
(12 families)

Follow-up Interview

Qualitative

Participants

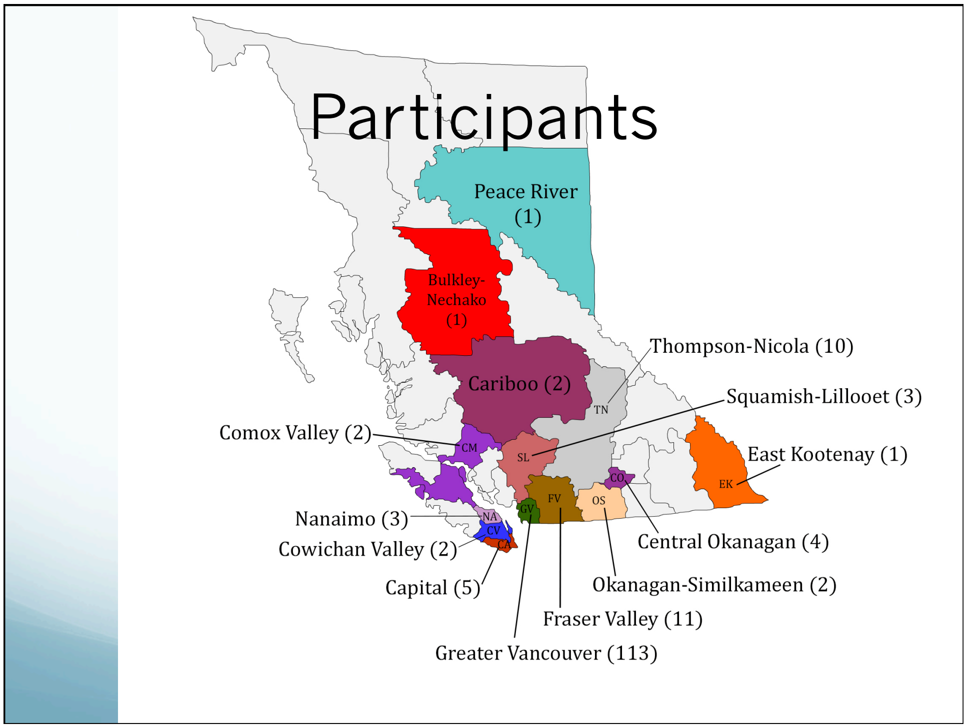
Survey

- *N* = 160 caregivers of children aged 2-35 yrs

Funding Program	n
Autism Funding: Under 6	21
Autism Funding: Ages 6-18	118
19+	21*

**n* = 13 receiving CLBC funds.

- 70.6% from Greater Vancouver



Participants

Family Demographics	**Under 6** *n* **(%)**	**Ages 6-18** *n* **(%)**	**19+ years** *n* **(%)**
Respondent			
% Mother	66.7	89	90.5
Caregiver Age (yrs)			
M (SD)	41.3 (4.7)	44.5 (6.8)	56.0 (6.2)
Family Ethnicity			
Canadian	6 (28.6)	42 (35.6)	7 (33.3)
Asian	2 (9.5)	19 (16.1)	2 (9.5)
European	2 (9.5)	17 (14.4)	5 (23.8)
Multiple	10 (47.6)	38 (32.2)	6 (28.6)
Other	1 (4.8)	2 (1.7)	1 (4.8)
Marital Status			
Married/Common Law	19 (90.5)	90 (76.3)	16 (76.2)
Divorced/Separated	2 (9.5)	19 (16.1)	4 (19.0)
Widowed	0	2 (1.7)	0
Never Married	0	7 (5.9)	1 (4.8)

Child Demographics	**Under 6** *n* **(%)**	**Ages 6-18** *n* **(%)**	**19+ years** *n* **(%)**
Age (yrs) *M* (SD)	4.5 (1.1)	11.7 (3.7)	22.7 (4.0)
Gender Male : Female	19 : 2	103 : 14	16 : 4

Measures

- Satisfaction with Resources and Funds
  - ‘Very Dissatisfied’ to ‘Very Satisfied’
  - Qualitative comments
- FQOL Scale

Parenting

Emotional Well-Being

Family Interaction

Physical/ Material Well-Being

Disability-Related Support

Satisfaction with Resources and Funds

- Overall, 26.3% ‘satisfied’ or ‘very satisfied’ with resources and funds

	Under 6 *n* **(%)**	**Ages 6-18** *n* **(%)**	**19+ years** *n* **(%)**
Families ‘Satisfied’ or ‘Very Satisfied’	9 (42.9)	31 (26.5)	2 (9.5)*

* No respondent ‘Very Satisfied.’

- As funding decreased, so did families’ satisfaction

Qualitative Comments

- **Positive Feedback** (20%)
  - Appreciative of funding program
  - Grateful that it facilitated service access
- **Insufficient Funding** (63.5%)
  - Prevented families from accessing services to desired extent
  - Concerned about future funding decreases (at ages 6 and 19)

> *"We know there are limits to what we can expect, but we also want our child to grow up successfully."*

- **Perceived Limitations** (51%)
  - Complicated and inaccessible
  - Inflexible
  - Burdensome for parents

Funding Program and FQOL

- Significant effect of funding program on FQOL satisfaction ($p < .05$)

- 19+ group significantly less satisfied with Disability-Related Support

Study Sequence

Part 1:
N=160

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Quantitative

Part 2:
N=15
(12 families)

Follow-up Interview

Qualitative

Participants

Interview

- N = 15 (*12 families*)
  - 6 'high FQOL' and 6 'low FQOL' families represented
  - All recipients of *Autism Funding: Ages 6-18* program
  - No intellectual disability (*caregiver report*)
- Selected based on global FQOL Scale item
  "Overall, how satisfied are you with your family's quality of life?"

Interviews

- Conducted in person *(1)*, via telephone *(10)*, or Skype *(1)*
  - FQOL and ASD diagnosis
  - FQOL and service delivery
- 60-90 minutes
- Semi-structured

What are families' perceptions about the impact of the ASD diagnosis on FQOL?

- **Benefits:**
  - New access to support
  - Validation and relief
  - Eased family relations

"Now we're more open . . . it made everyone feel okay to be themselves."

- **Detriments:**
  - Difficulty getting diagnosed (e.g., misdiagnosis)
  - Negative emotional response (e.g., grief, denial)
  - Lack of guidance

"It didn't alleviate any kind of issues that I had, not related to my son . . . there was no holistic view."

- Groups focused equally on benefits and detriments
- 'High' families spoke more about lack of guidance

What are families' perceptions of how FQOL is addressed within service delivery, and how could this be improved?

Community-Based Services

- **Autism Funding Program:** Appreciated, but insufficient and inflexible
  - All reflected on insufficiency
- **Strengths:** Identified information-sharing and partnering as helpful in easing family life demands
  - 'High' families more likely to elaborate with specific examples
- **Gaps:** Felt isolated and unsupported in finding services
  - Groups demonstrated same focus of discussion
  - 'Low' families described "reactive" service system

"The funding is not even close to enough, so then you're in a position where you have to choose major priorities, 'out of all these things that my kid really needs, what does he need most desperately,' and that sucks."

"[It's] the wild wild west, everyone for themselves . . . there is no specialist out there that you can go to who will help you . . . you have to explore which works out for you."

"You get thrown this money, which is great, but what do you do with that? You're turning left or right, you just don't know, there's nobody to walk you through it."

What are families' perceptions of how FQOL is addressed within service delivery, and how could this be improved?

School-Based Services

- **Resources:** Scarcity and lack of transparency around allocation
  - Both groups focused more on scarcity, and less on allocation

> *"I don't know what exists, I have no idea . . . I have to accept what's there, put up with it, otherwise take your child elsewhere."*

- **Partnering:** Reflections on positive experiences, and necessity of a reciprocal relationship
  - 'High' families shared how school was open to partnering
  - 'Low' families did not provide examples of this

> *"It starts at the administration . . . the administration sets the tone and the teaching staff take that tone . . . it's hard to find someone that's that dedicated."*

Discussion

Service Delivery and FQOL

- Service emerged as a significant concern when examined both quantitatively and qualitatively
- Funding program related to FQOL, specifically Disability-Related Support domain
  - Support to accomplish goals at school, work, and home
  - Support to make friends
  - Relationships with service providers
- Lack of guidance emerged as a predominant theme
  - Perception present from initial interactions with service system and beyond

Service Delivery and FQOL

- Diagnostic Experience
  - Caregivers desired better transition support
- Desired greater transparency regarding service options, availability, and quality
- Families perceived a significant mismatch between system that emphasizes family autonomy and actual experience
- Desired greater partnering and information-sharing
- Without support, choice is perceived as burdensome as opposed to empowering

Policy Implications

- Funding services for children with ASD is necessary, though not sufficient to address families' needs
- Service navigator role
- System flexibility and diversity of intervention options
- Post-19 support
  - CLBC adaptive functioning deficit requirement
  - Need for appropriate transition supports
- Family-centred approach

Limitations

- Majority of participants were mothers
- Surveys only available in English
- Majority of participants were from Greater Vancouver
- Participants had high family incomes

- Study is ongoing and efforts to access remote parts of BC are underway

Considering Hard-to-Reach Populations

- Under researched and hard-to-reach populations
  - Size and group boundary unknown (many undiagnosed)
  - Acknowledgement of belonging to the group is threatening (historical, cultural, religious beliefs and practices)
  - Distrustful of non-members (refuse to cooperate)

Hard-to-Reach may be especially vulnerable

- Vulnerable populations may experience inequality in health research and outcomes
- *"those who are not only particularly sensitive to risk factors but also possess multiple cumulative risk factors. They are more likely than others to develop health problems as a result of exposure to risk or have worse outcomes from those health problems than the rest of the population"* (Pacquiao, 2008, p. 190)

Vulnerable Population

- Particular worldview
- Traditions and protocols
- Historical, contemporary, socio-cultural and political realities

Dialogue
&
Negotiation

Researcher(s)

- Possess a sense of humility
- Listen and observe before speaking
- Recognize the expertise of those being researched
- Include their protocols, aspirations, and needs into the research design

(Wilson & Neville, 2009)

How to Reach Hard-to-Reach Populations

- Community-Academic partnerships
- Frontline Service providers
- Advocate members of the community
- Elders/well respected members of the community
- Families who have a network

Culturally Sensitive Approach

- Community-academic cooperation
  - Engagement of group in research planning
  - Community involvement by project staff
  - Community-based organizations as intermediaries
- Cultural adaptation of materials
  - Information/statistics related to specific groups
- Researcher reflection
  - Partnership (joint goals)
  - Participation (meaningful inclusion)
  - Protection (respecting local knowledge, worldviews)
  - Power (give voice, knowledge is powerful)

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THINKING OF THE WORLD

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Autism & Developmental Disorders Lab

How to find us

Website	http://autismlab.psyc.sfu.ca
Email	addl@sfu.ca
Telephone	778-782-6746
Address	8888 University Drive Department of Psychology Simon Fraser University

Thank you!

NeuroDevNet

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