

Start Early, Go Far...
**Observe and learn from the
child.**



**Listen to parents.
Work together**

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Today:



- Definition: Assessment – Ask Families First (2012)~
 - *Start early...*
- Assessment as documentation: Observe and learn from the child
- *Sharing findings from the Case Studies (urban and rural)*
- Assessment as collaboration and consultation: Listen to parents
- *Sharing findings from the MPOC study (parents' access to family-centred early intervention and support services) and from the Linked Disc studies (parents' perceptions of accessing their child's early intervention data)*

*Dedication: In memoriam ~
Karen Brough, Clive Sykes, and
Dr Clyde Hertzman*



- Assessment as the starting point for intervention and follow-up: Considering the unique family contexts
 - *Translating the findings of assessment into recommendation at the program, agency, community and region/provincial levels drawing on research on “urban bias”*
 - Take home points

Introduction: Start early...

Picking up right when we left last year: “Ask Parents First”

as·sess·ment¹

noun \ə-'ses-mənt, a-\

Definition of *ASSESSMENT*

1: the action or an instance of [assessing](#) : [appraisal](#)

2: the amount [assessed](#)

The importance of early screening and assessment

¹ The Merriam-Webster Dictionary
<http://www.merriam-webster.com/dictionary/assessment>

Dana Brynelsen reminded us...

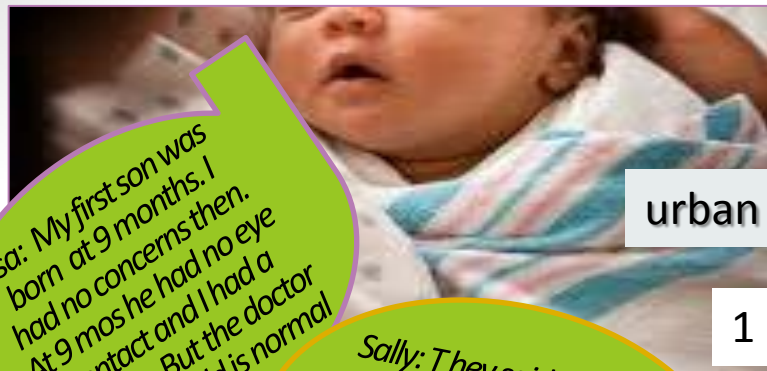


You don't know
what you don't
know!



Assessment as documentation:

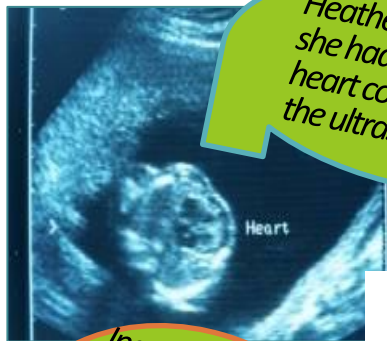
Observe and learn from the child



urban

1

Lisa: My first son was born at 9 months. I had no concerns then. At 9 mos he had no eye contact and I had a concern. But the doctor said my child is normal



2

urban

Heather: We knew she had a congenital heart condition from the ultrasound...

... after she was born we found out she had a rare syndrome



Sally: They said he would not make it. But I had two other children. I just did the same I did for the other two. He adds to our life!

Ingrid: I was there (at the NICU). The doctors and nurses argued all the time... They told us "it could be this, it could be that..."

May: Even now, we still see 7 specialists; and don't know what she has in the end, we said no to Genetics.



rural

3



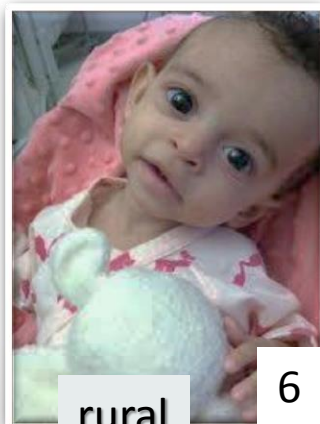
urban

4



urban

5



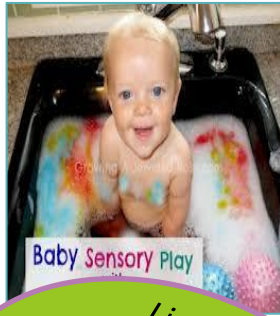
rural

6

Nancy: I knew right away what I had to do (for my child). I am a nurse, and they called me neurotic... Don: I should have listened to her from the get go!

Parents shared similar experiences about when and how they learned about their children's unique needs.

Parents in urban and rural communities: Observing and "knowing," instinctively about their child...



Lisa: The OT helped with Jeff's food sensitivities

1-J

Lisa: The consultant told me my son is "hyperlexic" and I found Reading Rockets, and Samuel Rockets, his first word that was "cat"

Ingrid: At the IDP they asked us what did we need to find about our child. With the IDP we could do our own assessments



Heather: At first I was worried; (about the mess) but then I was fine having the consultant come and be lived-in environment

Jack: [My] child has the potential for 180 problems... physical to psychiatric' ...It's more difficult when you try to make your case and you get patronized...



4

Mai would get Riko to do his physio exercises; he would only do them if his sister was there... Siblings are teachers too



AnaRochaPhotography ©

7

Learning from "daily occurrences" and Family Centred Practices*

Parents and IDP consultants ~assessment "on the go;" home and centre-based interventions that lead to other forms of assessment

Carl Dunst*

Assessment as collaboration and consultation:



Listen to parents~
“*working alliance*”¹

*Making sure parents know what is
the scope of visits/services*

¹Barry Trute and Dianne Hiebert-Murphy

*Not knowing the IDP consultants “scope of practice” what was
the purpose of visits... and frustration over this,
missed opportunities and feelings of lack of trust.
Consultant just copied pages from a book
Shift to quantitative study -*

Asking parents about family centred-services

The MPOC-Parent study

Surveys were distributed (mailed, online) to participant parents living in urban and rural communities in British Columbia.

Purpose: To examine parents' experiences and perceptions of early intervention family centred services received for their children, and to learn in what ways these practices and access to services were related to parents' overall sense of well-being.

- Early intervention and supported child care services received & satisfaction

MPOC Description

- Phase 1: Participants included 29 parents who completed the paper based surveys from families living in small urban, rural and remote communities in BC.

Measures:

- The Measure of Process of Care (MPOC-ID 20)
- Well-being
- Parenting sense of competence
- Family stressors

MPOC Findings (phase 1)

Findings indicate that :

- Higher satisfaction with services received for their child than for their family.

Example item: “Professionals look at the needs of your whole child (e.g., at mental, emotional and social needs) instead of just at physical needs?”

- Spouses and professionals as main sources of support

Example item “Helps you take care of your child”

○ Parents who perceived the services they received as more family centered reported:

- ✓ higher well-being
- ✓ higher sense of parental competence
- ✓ higher satisfaction with services for child and family

Assessment as the starting point for intervention and follow-up:



Considering the unique contexts for families ~ especially those in rural and remote communities

Context: Seasonal Conditions

- **Seasonal weather issues**
 - Snow, fog, ice, avalanches, road closures
 - Danger, as well as delays, uncertainties
 - Periods when travel is not possible
 - Getting stuck away from home
 - Needing vehicles for all weather



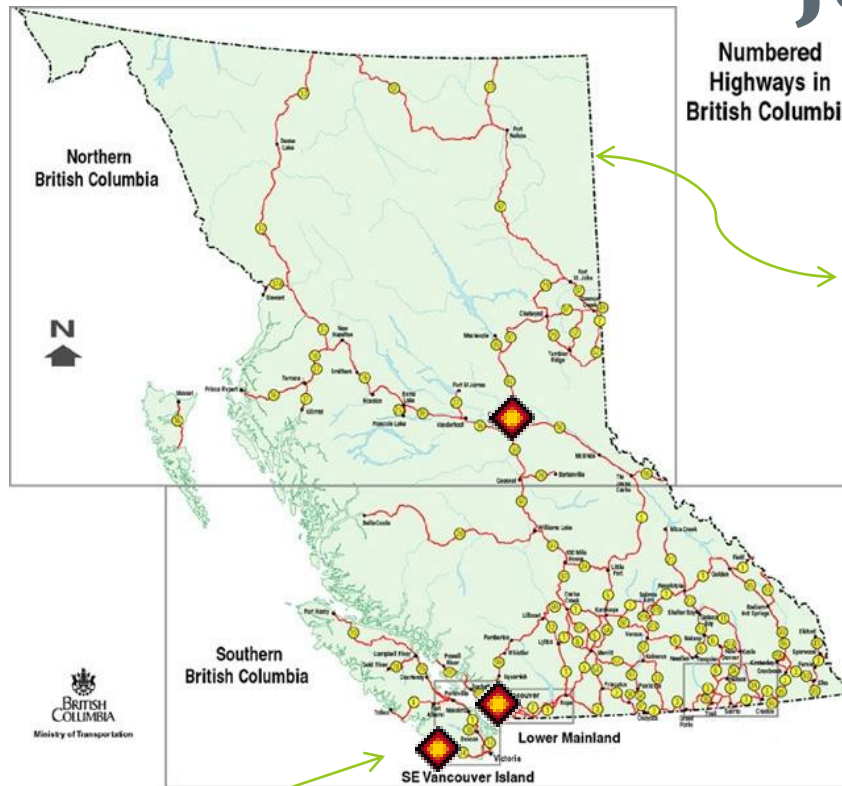
“So I was pregnant, Bill came home, he took the bus home and I had the car and I stayed in Calgary and then all the roads shut down. **Yeah we had avalanches for over a week**, so that was one of the horrific things about not being able to get home and being stuck in a small town.”

Context: Long Difficult Distances



- Unique and beautiful regions
 - coastal communities; mountain valleys and passes; remote communities
- Single roads in and out
- Ferry / plane (dependency and cost)
- Multimodal travel
- Sharing the road with industrial traffic

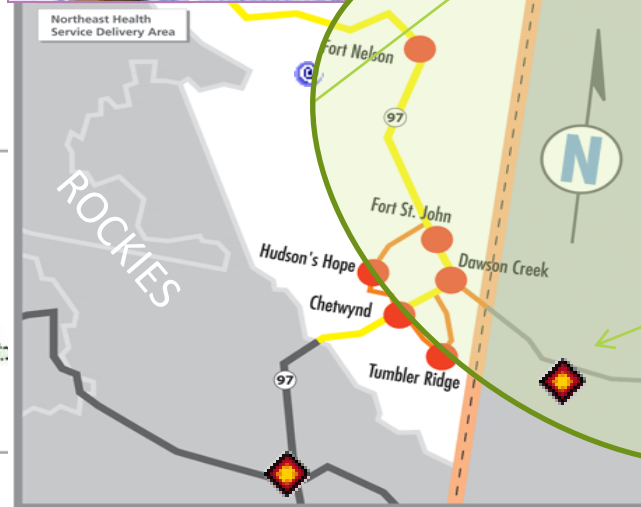
The Challenge of Overlapping Jurisdictions



Numbered
Highways in
British Columbia



Northeast Health
Service Delivery Area



School District
Learning Aid
Local physician

Grand
Prairie, AB
Regional
Hospital

Prince George, BC
Regional Hospital

Vancouver, BC,
Specialized
Surgery

IDP,
Provincial
Manager
in Victoria

Implications for Travel and Preparation

- Travel – not as straight as the crow flies
 - Intermodal travel
 - snowmobile to truck to plane to taxi
 - Scheduling and cost of intermodal
 - Need to plan travel
 - Time - Often requires full day of travel, or overnight travel

“Without any kids you can do it in about 12 hours.. but with kids you have to stop almost every hour, so it’s a two day drive, and you have to get a hotel room in between. And it could be longer if it’s not working out. With two parents you could do it, but with one, it’s too hard...”



Implications: Family needs

- Child care,
- Time off work for travelling person and caretaker
- Impact on siblings
 - Need for community and family supports
- Need to return home soon

Listening to Parents: Urban and Rural Differences

	Urban	Rural
Child has a clear diagnosis and treatment trajectory	Wait lists; falling between the cracks	Long distances; inability to reach specialist services; personal service; one-stop shopping; social integration
Parent is seeking diagnosis or has been referred	Array of specialists available	Not necessarily aware of opportunities; forward references not physically available; part time support engenders delays; recommended supports not available

Parents talk about ~ key agents and who they are in their communities?

Policy Bias: One Size Fits All?

Rural and Urban Differences

- Geography / Weather
- Ignores the significance and far reaching implications of geography/ distances and weather (contextual constraints)
- Assumes all services are equally accessible
- Ignores the existing riches of informal networking
- Lack of consideration for the value of the relational structures.
- Assumes services are co-located or “stacked” on top of each other- navigating jurisdictional divides, similar to services in larger urban areas
- *Ignores geographical challenges and barriers in accessing these services*

“And I think it is actually more beneficial if you don’t fall in the cracks. You don’t fall between because I see so many people; they all have a personal relationship when you see them in the clinic when you get the shots for your kids”



Policy Model Impacts

- Funding allocations based on urban model
 - Per capita models disadvantage small communities
 - Create rural-urban silos of service
 - Ineffective support to address service delivery challenges
- The loss



Not drawing on existing human capital and resources – at the family, community, and professional levels

Take home points: “Daily Occurrences”¹ and “Funds of Knowledge”²

Same, but
different: early
assessment and
intervention DO
make a
difference

- Families with children with special needs love and cherish their children just like any other family, but they anguish about what is next ~ “cycle of disability and anticipation” and “time, timely, and timing” (for accessing and receiving services) were common themes that emerged in the case studies; importance of spousal support (MPOC) in addition to services.

Urban and
rural
contexts
matter
~landscape,
distance,
weather,
and the
economy!

- The urbanistic bias reflects a reality for these parents; it interferes with the possibility of early of assessment and continuity of intervention(s).
 - Consider human capital (KEY AGENTS) and not just population density~ Choice in rural living: networking, personalized, tight-knit community ~ Rural: part-time, short-term professional, long distance to specialists vs. Urban: wait-times, “anonymity,” fragmentation, and long distance to specialists.



Canada



Social Sciences and Humanities
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The End

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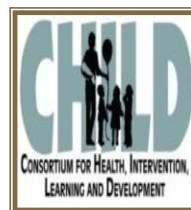
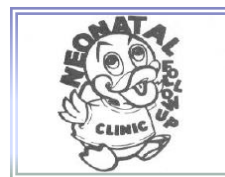
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What else would you like to know ..?

Project and Research Canada Funding Agencies



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- Laurie Ford

Including all Children and Families: Expanding Partnerships



United Way Success By 6* Partners

