

“The Benefits and Challenges for Parent Living in Rural or Remote BC with a Child with a Disability or Developmental Delay”

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“What are the experiences of parents living in rural and remote BC raising a child with disabilities or developmental delays?” was the question examined in a recent study completed at the University of British Columbia (2011). Eight parents living in 4 rural communities in BC were interviewed in their homes on two separate occasions to explore this question in more depth.

Not only was the parenting experience of raising a child with a disability explored but this experience was also explored within the context or “culture” of a rural or remote community. Most research is done within a geo-ethnocentric approach where living in rural and remote communities is often reported as a more negative experience than living in an urban setting. Also research on the experience of parenting a child with a diagnosed disability or developmental delay is often viewed as negative due to the perceived high stressors these families face and their possible need for specialized services. It was very important for this researcher to document through the voice of parents a more comprehensive picture of the parent’s lived experiences.

Who participated¹:

Nancy and Don are married to each other. Nancy is 32 and Don is 31. Both Don and Nancy have University degrees, Don is self-employed and Nancy works part-time. Erica, their two year old daughter, loves TV and blueberries, has developmental delays and was recently diagnosed with a rare genetic condition.

Sally is married and works full time and lives on a farm. She has a university degree and is 36 years old. Her son Jack is 21/2 years old, he loves playing hockey with his two older brothers, is a Canucks fan and was prenatally diagnosed with a rare genetic condition.

Wilma is a stay at home Mom with 4 children and is married. With some college education, she works part-time in the local school. Beth is the youngest child in the family, loves to keep up with her older brothers and sister and has motor delays.

Cindy is 29 years old, married with 2 children. She completed high school and is looking for part time work in her community. Susy, her 2 year old daughter is the youngest in the family, loves to play at the park and has motor delays.

Ally is 37 and married. She has some college courses and is now staying at home full time with the recent arrival of a baby sister for her 4 year old son Adam. Adam loves his preschool, loves to ski and was prenatally diagnosed with a disability.

Tala is 35 years old, married and is a full time homemaker. Her daughter and only child, loves her playschool and her new IPAD, she has undiagnosed global delays.

Betty is also at home full time taking care of her family and a new baby girl. Betty, is 41 and lives with her partner, her two older children as well as her daughter Kelly who is 3 years old. Kelly loves books, doing dishes, copying anything her older brother and sister do and she has developmental delays.

What parents had to say:

In the findings, three broad themes emerged entitled “community experiences,” “parenting experiences,” and “family experiences.” Each theme comprised subthemes, some of which are discussed below:

“Community experiences” included these subthemes:	“Parenting experiences” included these subthemes:	“Family experiences” included these subthemes:
<ul style="list-style-type: none"> • Is it rural or is it remote? • What is community lifestyle • The importance of relationships 	<ul style="list-style-type: none"> • Challenges with delivery • Parent experience is different if my child has a diagnosed disability versus a developmental delay • This was an intensely emotional experience • There is always the unknown that lies ahead • How do I understand disability 	<ul style="list-style-type: none"> • Travel issues: <ul style="list-style-type: none"> High costs of travel Frequency of travel Travel with young children or medically fragile children • Separation from other family members • Relationship with local service providers and service providers outside of community. • This has changed me.

Rural or remote? Parents most often defined their community as ‘small town’ and half the parent’s considered their community to be rural and half considered their community to be remote. Rural and remote mean different things to different people. All agreed that living in a small town this provided them with close proximity to services such as getting the mail, groceries and access to the Dr’s office. Everything was “5 minutes away”. They also valued the outdoor and recreational opportunities in their community, some came to the community because of this but most enjoyed camping, hiking along the river, skiing and time in nature. For one parent, living in a small town was a little too quiet for her and she would rather spend her time in a larger center, shopping in a mall.

Importance of relationships: Small town also meant that people knew each other, that you got to know your neighbor and you could count on people if you broke down on the highway. One parent described this as creating a sense of “safety” The importance of relationships also was obvious in the relationship with service providers, parents commented that they liked seeing their doctor on the ski hill, or having their children in the same school as public health nurse, it made the service provider or medical professional seem more accessible and “human”. A couple parents also commented that this close interpersonal network protected them

from “falling through the cracks” or not getting services which they speculated might happen if they lived in a larger urban center.

Delivery: A surprising finding was that none of the parents delivered their baby in their home community. For some parents this was planned because of pre-natal diagnosis or due to premature delivery, but for the rest of the parents, delivering in rural communities is not an option.

Emotional Experience: Consistent with most of the literature on raising a child with a disability or developmental delay there are many challenges regardless of where you live. These parents experienced extremely emotionally difficult times either with obtaining a diagnosis or pursuing a diagnosis. It was difficult to hear the diagnosis and undergo some of the medical testing or procedures they or their child had to endure. One parent felt it was a struggle to get information about diagnosis, she did not feel supported in her community, and thought she was seen as “just a neurotic mother”. These difficult experiences created depression for several of the parents, both mothers and fathers.

Travel issues: While living in a rural or remote community was seen as beneficial for most of the parents, one of the additional challenges about raising a child with a disability or developmental delay in a rural area was the additional burden of travel and the costs and issues related to travel.

1. Families often needed a better more reliable vehicle.
2. Winter roads can be uncertain and even perilous
3. Parents had the additional costs of travel to an urban center for medical care,
4. Travel with a young child or medically fragile child is more stressful and takes longer.
5. Frequent stops are required with young children or for medical care.
6. Parents (often the mother) reported being away spouse and other children for long periods of time with no contact
7. This prolonged separation caused some separation anxiety for the remaining children at home.
8. Some families had to declare bankruptcy – taking time off work was not an option.
9. Funding structures do not adequately cover all the ‘away from home’ challenges these parents experienced.

Relationship with service provider: As interpersonal relationships play a key role in small town living, this also was consistent with the importance of the role of the primary early intervention service provider. In this study this was the Infant Development Consultant. Some parents described this person as “a friend”, someone who if they needed anything they just needed to talk to the consultant. This person linked them with all the necessary services both

within community and outside of community. For one parent the primary source of support was the Friendship center. One parent, did not get what she needed from her consultant, and stated that while the consultant, “was a nice person” she did not really know her scope of practice or what she was doing and the parent got most of her information from the website and her own advocacy work.

This has changed me: The parents in this study expressed that they felt more compassionate and understanding of other parents raising children with disabilities and it also made them stronger advocates for themselves and for their child.

Many thanks for the parents who willingly shared their time and stories to bring further insight into the experiences of parents living in rural and remote BC raising a child with disabilities or developmental delay.

To read the full study please go to
<https://circle.ubc.ca/browse?value=Stewart%2C+Mary&type=author>

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