

Parent Feedback Project Results

December 2016



inclusionBC



BCACDI
The BC Association for Child Development and Intervention



FAMILY SUPPORT
Institute of **BC**
families supporting families



The Family Support Institute, BC Association for Child Development and Intervention, and Inclusion BC all play a role in support and advocacy for families who have children and youth with developmental delay or at risk of developmental delay. Over the past several years these organizations have had a significant increase in the number of calls from families seeking advocacy and assistance due to an inability to access programs and services to help their children. To further explore this trend, these three organizations engaged in a collaborative information gathering exercise to reach out to parents across BC to get their feedback regarding the state of early intervention services in this Province.

Methodology

The target audience for feedback was parents who had accessed, were currently involved with, or waiting to access early intervention services and supports for their child/youth. Two methods were utilized to gather information: focus group discussions, and an online survey. There were six focus groups held across BC with a total of 35 participants, and an online survey that had 300 respondents. Resource parents from the Family Support Institute facilitated the focus groups using a set of questions to stimulate discussion. These questions are available in Appendix A. The online survey was distributed through the networks of all 3 participating organizations. Survey questions and results (excluding test responses due to length) are available in Appendix B. Appendix C contains a summary of the text responses from the online survey.

Results

Both the focus groups and the online survey had a good distribution of participation across the Province. Participants identified many of the Government funded programs available to support families and children and youth, with early intervention therapies (Occupational Therapy, Physiotherapy, Speech Language Pathology) most commonly identified. Parent satisfaction with these programs and services is quite high, with the survey demonstrating 73% of respondents reporting 'moderately' or 'very satisfied.'

Three key themes emerged from both the focus group discussion and online survey results: Wait times, parent/family support, and a lack of information regarding what's available.

Wait Times

Wait times were a big theme in both focus group discussions and online survey results when parents described barriers to access and how the current state could be improved. Clearly, wait times for supports and services are impacting the ability for families to receive the assistance from Government programs that will support them through this critical period in their children's lives. The majority of survey respondents, approximately 64%, had to wait more than 3 months to access a program/service. 20% of respondents waited more than 6 months and 10% more than one year. The wait times for speech-language pathology and for respite services are particularly lengthy, with many families waiting more than 2 years for these services. In some cases, families never received the service they were referred for due to the excessive wait. Many families ended up paying to access services in the private sector.

Quotes from families:

"Everything except IDP have had lengthy waitlists. We have been on a respite waitlist for my daughter for 2 years. Was on it for our son at least 2 years, and only ended up getting it because I ended up going in for brain surgeries and our social worker at the time was extremely helpful."

"Yes we were waitlisted for over 8 months for SCD before we got partial services and well over a year before we got the full support needed. During the waiting period I advocated and my MLA brought up this matter in the legislature in 2013. We paid out of pocket for extra support until we qualified for funding, and went into some debt as a result."

"Never did get to see a therapist – was referred for OT and SLP"

"Paid out of pocket for supported child care"

"....never actually received services other than waitlist consultation."

Parent/Family Support

The lack of parent/family support, including respite services, was another theme that emerged from the data. It was clear that many families would have benefitted from some form of support or guidance while caring for their child, and access to respite. In many cases these services weren't available, families didn't know how to access them, or the wait times were so long it was a barrier to access.

Quotes from families:

"I wish I had a personal guide through all of this special needs parenting. I feel so alone I wish there was someone I could talk to every week who could tell me what to do"

"There needs to be more networking opportunities for parents to get together. This means providing daycare so parents can actually meet with other parents. Additionally, there needs to be advocates, locally and provincially, that help parents with the IEP and school process. These advocates have to be independent of the school system and readily available to come into IEP or other school meetings"

"Some kind of social worker or family support. Someone to assist us in parenting a complex child and someone who could assist us in accessing financial supports. One of the most important things is reduce barriers to financial support application/access"

"Support for children and parents to network and support them emotionally, socially, as well as educated them to the options that are out there"

General lack of knowledge regarding what's available

Parents shared the challenges they had in discovering the services available to them, and the difficulties navigating what is a complex system of multiple programs and services funded by multiple Ministries. Poor communication and collaboration between the various service providers and Ministries was also a factor. Word of mouth was one of the most relied upon mediums for learning about services and supports that could help, and only 54% of survey respondents were 'moderately aware' to 'well aware' of what was available. 15% of survey respondents were 'not aware at all' of the Government programs and services to support children and families.

Recommendations

Decrease wait times

Many of the programs and services identified by parents in both the focus groups and survey have not had an increase in funding for more than 7 years. The agencies delivering these services have seen increases in operational costs, increasing service demands in their communities, and increased complexity in the families they are trying to support. Yet their contracts with Government to deliver these services have had essentially frozen funding since 2008/09. These agencies have been innovative and become as efficient as possible as they struggle to meet the needs of their communities, but the result has been a watering down of service and increase in wait times. Government needs to increase the base contract funding for the valuable programs and services they contract with agencies to provide, so that agencies can implement effective strategies to improve access and decrease wait times.

Parent/Child Support

Parents and families in many cases are looking for more support. Prior to funding freezes many agencies had Family Support Workers that would do this; however, the majority have lost that position due to budget shortfalls. The Ministry of Children and Family Development has social workers to

assist families; however, they are almost always 'off site' from where services are delivered, and some families are tentative to work with MCFD due to the primary child protection role of this Ministry. This sector would benefit from dedicated funding for trained family support worker role located where the services and supports are housed (i.e. – at the agency responsible for delivering that program).

General lack of knowledge regarding what's available

The system in BC supporting children and youth and families is multi-Ministry and very complex. There are many programs delivered by a variety of agencies that have a positive impact on families lives when they have the opportunity to access them. The general public is well aware of where to go if in need of emergency care (i.e. – hospital), where to access education (i.e. – schools), but little to no knowledge of how to access programs and services to support their family and their child's development. This needs to change.

The BC Government has taken strides in this area through their development and branding of Early Years Centres in many communities across the Province. This work has real potential to create broader general awareness of early intervention services and supports, provided Early Years Centres have adequate funding to establish their presence. However, awareness itself is meaningless if the issue of wait times to access these programs and services isn't addressed.

Conclusion

The three themes emerging from this data collection are very concerning. Families raising children and youth with developmental disabilities are among the Province's most vulnerable. Research demonstrates the positive trajectory that can result in these families lives when they have access to programs and services to help them build capacity and reach their full developmental potential. This data collection demonstrates that many families in BC that would benefit from such services are not well informed of what's available, don't have the support they need to assist them through the process, and once referred are waiting far too long for access. This is unacceptable. Our 3

organizations encourage Government to strongly consider the recommendations outlined in this document, and we look forward collaborating with Government to ensure they are effectively implemented.



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Appendix A

Focus Group Questions to Stimulate Discussion

1. What types of supports and/or services would assist you in supporting your child's development?
2. What services/supports are you aware of that are offered in your community?
3. What types of supports and/or services have benefitted your child's development?
4. What are the barriers to you being able to access any supports/services
5. How do you think the current system can be improved?

Appendix B

Online Survey Questions

1. What region of BC do you live in?
2. Have you accessed any services for your child in your community? If so, what were they?
3. Did you have to wait for those services? If so, how long? What did you do during that wait time?
4. How aware were you of such services being available?
5. How did you learn about these programs?
6. How satisfied were you with the supports and services you were able to access?
7. Are there any supports/services missing? Any areas of support or type of service not available in your community that would have helped?
8. What barriers impacted your ability to access supports and services?
9. How do you think the current system can be improved?

Provide any other comments you have regarding services for children and youth with special needs

Survey Responses

What region of BC do you live in?

Response	Chart	Percentage	Count
Vancouver Island		16.1%	48
Northern (Quesnel and North)		17.1%	51
Interior (South of Quesnel, Kootenays, Thompson-Okanagan)		32.8%	98
Lower Mainland (Vancouver/Fraser Valley)		34.1%	102
		Total Responses	299

Question 1 - Have you accessed any services for your child in your community? If so, what were they? (choose all that apply)

Response	Chart	Percentage	Count
At-Home Program - Respite		17.2%	51
At-Home Program - School Age Extended Therapies		13.2%	39
Infant Development Program		53.0%	157
Aboriginal Infant Development Program		3.7%	11
Early Intervention Therapies (OT, PT, or SLP)		67.9%	201
Supported Child Development		47.3%	140
Aboriginal Supported Child Development		3.0%	9
Family Resource Programs		22.3%	66
Parent Child Mother Goose		22.0%	65
Other, please specify...		23.3%	69
		Total Responses	296

Question 2 - Did you have to wait for those services? If so, how long? What did you do during that wait time?

Response	Chart	Percentage	Count
Less than 3 months		35.8%	103
3 - 6 months		16.7%	48
6 - 12 months		13.2%	38
Over one year		9.7%	28
Additional information here:		24.7%	71
		Total Responses	288

Question 3 - How aware were you of such services being available?

Response	Chart	Percentage	Count
Very Aware		22.4%	67
Moderately Aware		30.1%	90
Somewhat Aware		18.1%	54
Mildly Aware		15.7%	47
Not Aware at all		13.7%	41
		Total Responses	299

Question 4 - How did you learn about these programs?

The 285 response(s) to this question can be found in the appendix.

Question 5 - How satisfied were you with the supports and services you were able to access?

Response	Chart	Percentage	Count
Very satisfied		45.9%	135
Moderately satisfied		26.5%	78
Somewhat satisfied		14.6%	43
Mildly satisfied		8.5%	25

Not satisfied at all

	4.4%	13
	Total Responses	294

Question 6 - Are there any supports/services missing? Any areas of support or type of service not available in your community that would have helped?

The 190 response(s) to this question can be found in the appendix.

Question 7 - What barriers impacted your ability to access supports and services?

The 215 response(s) to this question can be found in the appendix.

Question 8 - How do you think the current system can be improved?

The 214 response(s) to this question can be found in the appendix.

Question 9 - Provide any other comments you have regarding services for children and youth with special needs:

The 138 response(s) to this question can be found in the appendix.

Question 10 - If you are interested in learning more about parent driven advocacy opportunities please provide your name and contact information (optional!)

The 74 response(s) to this question can be found in the appendix.

Appendix D

Summary of text responses to survey

The amount of additional text data from participants was quite high and the report containing it all is 48 pages in length. Thus the text responses have been summarized to a briefer format in this Appendix

Q#1 – Services accessed

Majority of responses for services typically accessed by families with children demonstrating or at risk of a developmental delay. Infant Development, Supported Child Development, and Early Intervention Therapies. Also a significant number of respondents accessing At-Home Program respite services, parent-child mother goose, and family resource programs.

Q#2 – Wait times

Majority of respondents, approximately 64%, had to wait more than 3 months to access a program/service. 20% of respondents waited more than 6 months and 10% more than one year. The wait times for speech-language pathology and for respite services are particularly lengthy, with many families waiting more than 2 years for these services. In some cases, families never received the service they were referred for due to the excessive wait. Many families ended up paying to access services in the private sector.

Quotes from families:

"Everything except IDP have had lengthy waitlists. We have been on a respite waitlist for my daughter for 2 years. Was on it for our son at least 2 years, and only ended up getting it because I ended up going in for brain surgeries and our social worker at the time was extremely helpful."

"Yes we were waitlisted for over 8 months for SCD before we got partial services and well over a year before we got the full support needed. During the waiting period I advocated and my MLA brought up this matter in the legislature in 2013. We paid out of pocket for extra support until we qualified for funding, and went into some debt as a result."

*"Never did get to see a therapist
– was referred for OT and SLP"*

*"Paid out of pocket for
supported child care"*

"....never actually received services other than waitlist consultation."

Q#3 – How aware were you of these services being available

Approximately 54% moderately to very aware of such services being available to help support their child. 15% not aware at all.

Q#4 – How did you learn about these programs?

Respondents were asked to list how they learned of the programs and services that could support their child. The most common response was from via the hospital/physician/paediatrician, followed by other parents/word of mouth, public health nurses, self-research online, and schools.

Q #5 – How satisfied were you with the services and supports you were able to access?

More than 73% of respondents moderately to very satisfied with the services and supports they were able to access, with 'very satisfied' being the most common response at 48%. However, some of the struggles regarding frequency of service once programs were accessed became apparent in the comments for this question:

"Our OT in that area was phenomenal. However, she was so overworked she only got to see us for an hour every 4 months or so. She had 165 kids on her caseload at that time"

"They are great services, and we really liked all of them. But the problem is the wait to start them, and then the amount of time we actually accessed the services. You are lucky to get service once a month, if that"

"Too few one on one hours"

"We couldn't access the services enough for what was needed"

Q #6 – Any services or supports missing? Any area of support or type of service not available in your community that would have helped?

The most common responses to this question were services for older children, respite services, access to family/parent support, and recreation/leisure opportunities for children with developmental delay. Many families also shared the financial impact of traveling to Vancouver for specialist appointments, accessing private services, etc., and how access to funding to mitigate some of these costs would have been helpful.

Some of the responses from parents:

"Supported Child Development program needs an increase in funding to meet the support needs of the children in our region. Children should not have to wait for services in the early years and some children require support in day care so families can work and contribute to the economy"

"I wish I had a personal guide through all of this special needs parenting. I feel so alone I wish there was someone I could talk to every week who could tell me what to do"

"Support and services for Kindergarten holdbacks"

"There needs to be more networking opportunities for parents to get together. This means providing daycare so parents can actually meet with other parents. Additionally, there needs to be advocates, locally and provincially, that help parents with the IEP and school process. These advocates have to be independent of the school system and readily available to come into IEP or other school meetings"

"Some kind of social worker or family support. Someone to assist us in parenting a complex child and someone who could assist us in accessing financial supports. One of the most important things is reduce barriers to financial support application/access"

"Support for children and parents to network and support them emotionally, socially, as well as educated them to the options that are out there"

Q #7 – What barriers impacted your ability to access supports and services?

The overwhelming response to this question was waitlists. Parent work schedules, transportation issues, lack of home based services, and a lack of professionals were also common responses. Several respondents also indicated the barrier of a general lack of awareness regarding services and supports that could help their child.

Some examples:

"Days of availability, travel and work schedule"

"No barriers other than the ridiculous waitlists"

"Transportation. Also the limitations of the programs. SCD in my region does not provide support to 3 year olds or Kindergarten holdbacks. Only 4 year olds can receive a support worker"

"Knowing what's available and what he qualifies for without At-Home"

"Lack of information. Lack of knowledgeable support people to help us navigate the system. Sometimes finances so that we could access paid supports. Long waitlists"

"Lack of therapists to provide the services needed. Complex families/children pop up all the time and you end up getting bumped down the list"

Q #8 – How do you think the current system could be improved?

Responses to this question focused on the need to increase the number of staff working in the sector and to decrease wait times. Themes from prior questions such as respite and support for parents were also prevalent.

Excerpts from parents:

"Obviously increased budgets; as well as maybe adjusting the disbursement of funds within the programs. I believe that providing more funding can clearly lead to more staff and ability to offer services to more clients"

"Parent packages with information including identification of resources should be given to women at the time of their child's birth to help awareness and resource access"

"Increase funding so children get the services they require early on. When children sit on a waitlist during the most crucial period of brain development society ends up paying for it later on. A child's developmental trajectory can change dramatically if provided with early intervention and support"

"More equitable funding model for kids with moderate disabilities or medically complex kids. Not just for Autism and severe multiple disability kids"

"...quality inclusive preschool should be available to all children with significant developmental disabilities"

"Establishing a clear boundary between mental health and child protection services; ensuring that child and youth mental health services are made available without child welfare involvement"

"Shorter waitlists, readily available information on services, navigators to assist on a personal level, family workers to support families in crisis"

"More help for parents. We are exhausted. We have other children to deal with too. Some of us don't have family in town. We are tired and need help and support so we don't feel so alone. We need to know what's next for our kids. What will happen once the services end? Will there be any help in school? What services are there for them when we are older? Will we have to go private and try to come up with the money?"

Q#9 –Provide any further comments you may have regarding services for children and youth with special needs

Responses to this questions were again dominated by previous themes of excessive wait times, poor frequency of service, and lack of information/awareness of what's available. Respondents also took the time to praise the quality of the programs, services and clinicians once they had the opportunity to access them.

Some other comments from respondents:

"Helping parents learn how to set goals for their children. Helping families create their own plan for their children. Most families don't know the ins and outs of child development, and would likely appreciate some guidance for what they should shoot for"

"I would love to see a handbook that explains all services.....This resource should include all government administered programs as well as all other supports and services. Parents should be recruited to help build and design this so it reflects the needs of the families"

"IDP is fabulous and available regardless of severity. This needs to be extended through preschool age, or expanding the preschool program so our moderate kids are not cut off support at age 3 until Kindergarten"