"Parent's Perspectives on Accessing Their Child's Early Intervention Program Data"

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What are parents' perspectives on accessing and using their children's early intervention-related information and service records of the program providing services for their child and family? This was an important question that Dr Herbert Chan wanted addressed, following years of research, work and preliminary implementation of the Linked Disc database[1] and a group of researchers at the University of British Columbia's Including All Children and Families-Expanding Partnerships Project.

Dr. Chan and the research team approached parents directly through a series of focus groups. The purpose of the focus groups was to find out from parents how would they like to use online system (secure internet) to access information regarding their child's program records if this were available for them.

Between the summer of 2011 and the fall of 2012, members of the research team conducted 5 focus groups with parents receiving services through one or more of the early intervention/special needs support provincial programs, including Infant Development, Aboriginal Infant Development, Supported Child Development and Aboriginal Supported Child Development Programs of British Columbia. Parents were contacted through their early intervention agencies. Participant parents resided in different urban, smaller urban, and rural communities in the Vancouver-Coastal, Interior and North regions in British Columbia.

We asked parents to reflect and share their thoughts, ideas and opinions on the following questions:

1. What information is important for families to access?

2. In what form would families like the information to be provided?

3. How would families use the information?

3.1. More specifically, would an on-line dialogue between service provider and families be considered an alternative opportunity to access information; for example, by creating an inbox for parent to submit questions?

3.2. In what ways are families' priorities and purpose of accessing information related to their residence location; e.g., living in urban centres, in contrast to living in rural or remote locations?

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[1] Please refer to section 2, Objective 1, in the body of the final report of the Including All Children and Families – Expanding Partnerships Project

Throughout these conversations with parents, participants made evident how well they understand their rights about accessing information about their children and the health and child development early intervention services they receive. Parents know that care providers and service providers are required by law to provide all information they requested.

We identified six major themes in our initial analyses of the data using qualitative content analyses, including "Parent Knowledge," "Lifestyle and Geography," and "Communication." In this summary, we are sharing some of the findings that were grouped under a broad category labelled as "Information," and that reflect what parent participants perceive and experience in terms of different aspects on using, accessing, retrieving, and sharing early intervention-related information about their children's progress (birth to age 12 years):

1. **Assessment -specific information on different types of assessment**. This is the information about child's development such as prescribed daily exercise, therapy and progress. This is often referred to "real time" information. In terms of developmental information, parents appreciate this real time information so that they know what works and how to help their child. This is different from medical information which often has some lag time before information is forwarded to parents.

One parent expressed:

> *"...why are you testing him where he can't be, can't do, why don't you start working with him where is at, work with him with things he can do... and work your way up, and we will get there eventually...that was my frustration, and the little time I get here and there...they are spending time testing him instead of working with him finding where his level should be. . ."*

2. **How to use information** – what participants express as priorities in ways the information needs to be used.
   - *Decision making* – parent's comment on how to use their current information.
   - *Levels of information* – parents wanting to share information among different levels and sources among all service providers
   - *Levels of knowledge and education* – where parents are at in terms of being ready to obtain or receive information.
   - *Progress and fast forward- s*ome parents use the information just to document the progress of their child and how they will pass this on.

One parent clearly shared her experiences in how information can be useful, also for others:

> *". . . It's nice to have the [centre where they receive services] because you get like your speech and your physio, and your doctor's stuff . . . Like if there was one big centre where (one could get access to information like..) 'Sage was diagnosed like with Down's Syndrome, and X, Y, Z date and just kind of like a chronological thing of what is going on in her life and stuff' .for me, and not even for me . . . It's for future stuff; for other kids too, like you know, like they would know what **I 'm** going through with Sage . . . I want it to be an advantage for someone else."*

3. **Opinions access –on-line information**- Participants express their concerns and their favourable opinions about accessing information through Internet or online in different ways. Internet access of online child information similar to EMR (Electronic Medical Records) has not been tested or used in other countries. A few parents indicated that even though they have no concerns using Internet banking, they do have some reservation on the ideas of Internet access of their child's information. The concerns are mostly around privacy, confidentiality and a label of diagnosis that may follow the child to adult's life. Other parents indicated that as long as they knew there was a secure system in place, they would prefer using an online system as they do everything else online (including social media), and they are more confident they will be able to keep all the information in one place, so that it is easy to retrieve at any point in time.

4. **Organization/management of information** -How do participants organize the information they receive; how they would like to follow up with these different sets of information (systems, types). Parents expressed that they are often overwhelmed by the volume and complexity of information given to them. As a result some parents may choose a passive role in terms of information seeking. Therefore it is not surprising to hear that not all parents want to receive all information in one instance. Organization/management of information also relates to how parents are required to give and share information with different service providers such as paediatrician, teacher and child care support worker. They need to collect and organize this information for each of the new care provider.

5. **Overall access to information** –How can participants generally access information?
   - *Computer and internet talk* - Parents' comments about what they know or about what they have heard about using electronic information, accessing computers etc. This relates to the lifestyle and family's residence location. Compared with rural counterparts, families living in urban setting have more experience in using Internet to seek information and to organize information.

One parent expressed her preferences and concerns:

> *"I come from information science. My concern is about the internet health records. How information is going to be protected –and, to pretend that you can ever delete the information is not correct?"*

6. **Information, format and sources-**Comments about the type of information parents' receive currently how and where they receive it from.
   - Verbal information – Parents may receive only verbal comments or information. Distraction from child and environment often leading to missing valuable information.
   - Written information – Parent expressed that it is best to receive organized information and information written in simple language. Otherwise it loses the usefulness of receiving this information.
   - Some parents prefer paper format which tends to be easier to follow as it can leave a "paper trail" of different services and assessment. The disadvantage of a paper format is more time consuming and needs more physical space to store the ever increasing binders and folders of information. Electronic format such as scanned document, name cards of care providers, email correspondences provides easy access and retrieval. One major disadvantage is that there is risk of losing all these electronic files if not backed up properly. It also required some knowledge of computer functionality.

7. **Others**: Information and link to parent support groups allowing parents share helpful information among them. Parents like to be linked to trusted online information about child conditions and diagnosis. Knowing they could be part of a network provided parents with a sense of being listened and kept up to date with new information and advances on certain medical or developmental conditions. One example included a parent who was connected with a group based in east Canada and with contacts in Europe who were researching their child's condition. Not only did the group regularly provided updated medical information to her family doctor and specialist, but they invited parents like her to bring up their comments, experiences and stories and to document their child's progress.

A last quote from a parent reads (names have been changed to protect participant's privacy and confidentiality):

> *". . . For me it is a case of information sharing. We are fortunate in that we get information on Denny's lab results as soon as they get it – he has a file.... She [her doctor] phones me whenever she has the result; she will*

phone me either way (whether there is a change or not) which is great; but again, it would save her time – and it would save mine --if there was a place where I could just log in and were to see 'ok these are the results."

We continue to organize our interpreted findings into additional summaries; academic publications are forthcoming for our study entitled "Parent's Perspectives on Accessing Their Child's Early Intervention Program Data."

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