Parent Interview: Understanding the Psychosocial Aspects of Hearing Loss

Often, the best resource for understanding a child is the parents as they are truly the experts. Parents have the best knowledge of the factors, which have impacted their family and child since the beginning. Many parents are highly involved with their child and they have made the journey of being Deaf or hard of hearing (Dhh) together. They know their child on intimate levels that no else can understand except a parent. I had the opportunity to interview the mother of a child who is thoughtful, articulate, and open about the entire process. She was a wealth of information that no amount of language samples or short weekly meetings could have given. The mother, who I shall call Danielle, talked candidly about her son, Ben, what they have endured and continue to discover, the types of support involved, and their family life.

The interview was done in two parts by talking one-to-one with the mother, Danielle. The first interview was conducted in their spacious, empty home by the seaside that they are preparing to sell. The second part of the interview was done in the comfort of their lived-in home. The family lives in a quiet cul-de-sac in a neighbourhood on the outskirts of Vancouver. The house is built backed on to the side of a cliff blocking all sounds. It is a large, quiet house with lots of space for the family to live comfortably. The television is only on when they are watching or the children are downstairs playing video games. They have a dog that interestingly enough, only barks when he is playing with Ben. The mother says it’s almost as though the dog understands that her son is hard of hearing.

Their family history all started when Danielle met Martin, the father. She is from Paris and he from a nearby suburb. They met in the marketing department of a major communications company. Everything moved very quickly between them and they decided to start a family. They had their first child, a daughter, Colette who was born in France. They spent 3 years in Belgium before moving to Vancouver. Here, they had their second and last child, Ben. They moved to Dallas, Texas for 5 years where he was diagnosed as hard of hearing. They made their last move as a family back to Vancouver and have lived here for the past 5 years. Danielle and Martin both spoke French at home but they write emails and text on their phones in English. English has been spoken in the home since Ben started speaking to give him as much input as possible. Once they found out he was hard of hearing, she wanted to make herself more available to bring him to appointments. She went back to school to become an interior decorator. This gave her the luxury of working from home allowing her to give Ben the care he needed as well. The daughter is hearing and bilingual in French and English. She is currently in grade 10 at a public secondary school. The two children are presently living with their mother. The father lives elsewhere as the parents have just started the process of divorce. This is undoubtedly yet another difficult time in all of their lives. The family still seems extremely close and involved in both of their kids’ activities.

When asked about her son, Danielle adoringly divulged that he is a very sensitive and curious little boy. He’s aware of peoples’ feelings showing a high emotional intelligence. Since his auditory memory and hearing is not great, he compensates by using his visual sense. The mother says he notices things right away that hearing people may not pick up on right away. Ben shows a strong aptitude for sports. He plays hockey on a local team as well as basketball. Ben has demonstrated musical sensibility since he was young where he used to play the piano and now wants to play the guitar. She notes that he has a good sense of humour. He is courageous as he stands up for other children who are bullied she explained. Danielle notes that he is outgoing and never had problems with communicating in one form or another. Ben is very social and has an active social life. All his friends are hearing although he has met other dhh children in the district through annual events. He has friends come over to his house and goes to others for after school visits and sleep overs on weekends. His friends go watch his hockey games and at the time of the interview, Ben and his friend were out at the golf course nearby collecting golf balls to sell together. Danielle recognizes the importance of his friends as it helps him learn how to socialize properly, it builds his self-esteem, gives him confidence and keeps him from becoming introverted and depressed.

Ben is presently 11 years old but was diagnosed, shortly after he turned 3, with a bilateral moderate to severe sensorineural hearing loss. Before he was diagnosed as hard of hearing, he had many ear infections. Ben underwent at least 4 surgeries: 2 sets of tubes to drain the fluid behind his eardrums, and his tonsils and adenoids were removed due to congestion. His speech therapist found his tongue was tied and so he also had surgery for this. Danielle always suspected that he had a hearing loss since he was a baby. When she was talking to him close with her breath on his skin he would react but from far away when his back was to her he wouldn’t hear. The doctors told her not to worry, as the ear infections would not be permanent. They assured her that he would begin to speak soon. She even had two audiologists who performed audiograms twice. He was cheating in the booth because he knew that they wanted something, he is very visual and understands body language so he was reacting and they were interpreting it as an answer. She did not believe their results were correct and so she demanded an ABR and even offered to pay for this service. The ABR finally gave her the results she had always suspected. They found the ear infections were hiding the hearing loss. Ben is now on his third pair of Phonak BTE hearing aids. At the present, he wears two new Phonak Solana Micro P behind-the-hearing aids and two ML13I FM receivers. He wears them full time and uses his FM system at school and at home as needed.

 When asked how she thinks her son perceives sound through his aids, Danielle admitted to trying them on and said they sounded metallic. She believes he hears lots but has also learned how to cope by understanding body language and other visual cues. On a windy day, she thinks he hears maybe only 50%. She is well aware that he does not hear as a hearing person. There have been many challenges with the amplification equipment. He could not wear the hearing aids when his ears were infected. The shunts in his ear would drip and would damage the molds and tubes. It wouldn’t work properly and would he would get feedback. Ben gets frustrated easily with the feedback from the hearing aids and gets irritated. Luckily, it was usually only one ear at a time that would get infected so he could wear the other one. Also, while playing hockey, the sweat blocks the tubes and stops them from working. It has affected his social life where he has to take off the hearing aids for swimming parties, which reduces his access for language. Ben is aware that he is different because he is the only one in his class that wears hearing aids.

The discussion then moved to whether or not Ben has any other special needs concomitant with his hearing loss. She had admitted that she thought he may have ADHD and so has had lots of psychological assessments. He is very active and has a hard time focusing in school. She researched on the Internet and found an article about cow milk and ear infections. Besides the infections, his stomach was sensitive and often he would vomit. They went to a naturopath to seek out alternatives as she was dissatisfied with the medical model and likes to keep an open-minded about all possible avenues. The first diagnose though was not done properly as the tests were done through a scratch test on his back and she knew it needed to be through blood testing. They said he was not allergic to cow’s milk but when the tests were done properly it was found out he was. Ben was also allergic to soy and wheat. When she stopped giving him milk, he stopped vomiting and the ear infections stopped. She also noticed that when he does not have wheat in his diet, he is able to focus and retain more information. A year later, she reintroduced Ben to cows’ milk; he got an ear infection and vomited right away. It was clear now that milk was the cause of his ear infections. He drinks almond milk now and takes supplements too. This was crucial to his hearing because even when he was wearing hearing aids, the tubes were filling with fluid and it would drain in to his hearing aids causing them to not work. He was unable to wear his hearing aids when his ears were infected although it was usually only one ear so he could still wear the other.

When discussing communication modes, it seems that everyone has a different style while talking to Ben. As a family, they chose to speak English with him as they are all hearing and they live in Canada. His sister, Colette and Ben communicate well with each other. They act like typical brother and sister as they quarrel at times. Danielle says that her daughter was really great to him when he was smaller. She knew his language was not at the level it should be so she would help him. Now that she is a teenager they do not play as much as they do not have so much in common. Colette gets paid to tutor her brother in math and will start tutoring his speech soon. Danielle had noticed that Ben’s pronunciation has degraded. She spoke with his itinerant teacher about her concerns and received some speech activities to do at home. Colette does not have a French accent like her mom so she is able to help more with his enunciation. These sessions work well as they both enjoy their time together too.

When they found out that he was hard of hearing, she had wanted to use American Sign Language (ASL). Ben began learning how to sign in Texas. Danielle would always ask for all his therapists, aides and support workers to use ASL. The Speech Therapist used sign and was also verbal. All of his aide workers would use sign and would also communicate by speaking. His Psychologist also used sign language but does not anymore. Ben is social and can communicate with others well so he does not need sign anymore. He was also taught to read lips but there were challenges like distinguishing between the sounds p/b, t/d, and k/g. When using the phone, he needs to put it on speaker as he has trouble hearing through the earpiece. This is a skill they will continue to work on so he can have private conversations. Text messaging works well for Ben. Still, he incorporates all of his skills to communicate where he listens, speaks, reads body language, and picks up on other visual cues to understand the world around him.

Having a child who is hard of hearing changes the family dynamics in many ways. The impacts on the family can be detrimental if not handled well. Danielle mentions the way it has affected their lives. Even before he was diagnosed, Danielle remembers that he was loud when he was speaking. Ben was very dependent on Danielle for helping him understand and accomplish tasks at home. His sister, Colette was a major support, as she understood what he needed. She was never jealous of her brother and always showed compassion. Homework was taking double the time than her daughters. She had to devote double the time to her son than to her daughter for all the appointments that are linked to the hearing impairment. Jamieson et al. states that in her study, “many parents expressed the need for support for the siblings of their children with hearing loss, whose emotional needs were often overlooked as the parents worked to promote the development of their deaf or hard of hearing child” (2011, p. 124). The parents realized that it was taking time away from her needs and felt guilty for this reason. Mom always takes her out to dinners, lunches and spends lot of mother/daughter time together.

Raising a son who is hard of hearing, the mother lamented, has put stress on the marriage. Yoshinaga-Itano had mentioned in her study, “the ability of each parent to accept and understand hearing loss could impact the marital relationship” (2011, p. 96). The mom mentioned that her husband, Martin has always traveled a lot so he was never too involved. She exposed that Martin has never been there enough for her emotionally. She feels he was not supportive of Ben in the same capacity that she was. Martin has dealt with Ben’s hearing loss in a different way than Danielle. Everyone has their own way of coming to terms with such a complex situation. She thinks he believes that because Ben is wearing hearing aids that he is not hearing impaired. He has always tried to empower Ben by pretending that they are not there. An example is when Danielle asked her husband to tell the hockey coach about Ben’s hearing impairment. Later, Danielle found out that he did not tell the coach. The coach had thought that Ben was acting up because he was not doing what was asked of him and he continued to keep talking when asked to listen. At the beginning, Ben did not want to wear his hearing aids. Martin never pushed him to wear them because it was hard for him to see him like that. There are specific programs in some areas that are designed to involve fathers to interact with their dhh child and Luterman states that there are “families in which the father is distant, which is fairly common, [and these] programs try to strengthen the father-child bond…” (1987, p. 3). Ideally, it takes the whole family to contribute to maintain homeostasis. Luterman goes on to make suggestions for the professional on how “to establish rapport with the father early; to take time to write or leave a note for the father; to make a specific phone call to him; to include the father in regularly scheduled visits; to give the father assignments; and, of course, to reinforce the father for his good work” (1987, p. 3-4).

Other family members had taken the news of Ben’s hearing loss fairly well when they first found out. His sister was 5 years old at the time of his diagnosis. The parents took care to explain what it meant to not hear well. She understood and has stayed positive and helpful ever since. The extended family in France heard the news and was sorry and heartbroken to find out. They were trying to be very supportive and positive for the family. Danielle’s sister was the first to know before the rest of her family and then friends. With her friends, she would share her worries and talk with them about it all the time. Overall, her family and friends have been a great support to her and the family from the beginning.

When asked what her original reaction was to the diagnosis, her face changed and she point blank disclosed that she had cried. Her whole demeanor changed as if she was reliving the time the doctors had told her that her son had a moderate to severe hearing loss. There were many emotions she felt and many questions she wanted answered. These have changed over the course of time. At first, she felt lonely because everyone was telling her not too worry but this was not possible for her. Her feelings of sadness and grief were not being acknowledged or validated by the doctors and her family. Danielle was quite upfront about the grieving process she went through. She clearly stated she was also angry with the audiologists for not finding the hearing loss when she knew there was something wrong. She’s upset that his speech is delayed because he was not diagnosed until after he was 3 years old. It was not mandatory to get a hearing test at birth in 2007 and so he did not have testing at birth. There was no early intervention plan and she is upset that they missed out on time that could have been spent on remediation. She had many worries and questions: was he was ever going to speak? Was his hearing loss progressive? What was his future to be? It is possible that he may lose more of his hearing at puberty? Why was this happening? At the start, she had questions of why this all happened but then realized that she needed to put this energy towards how to make it better. She started to think about solutions. It took her two years to start to deal with her grief. When they moved back to Vancouver, she started to find more answers. There were more resources here with professionals she respected and trusted. When Ben reached school age, she noticed there might be other reasons why his speech was immature and why he had problems in school. She wanted to find out about ADHD or other disabilities right away because she did not want to wait and have a late diagnosis like before.

When asked what some of the biggest challenges she has confronted as a result of having a child with a hearing loss, she empathically spoke directly of her son’s challenges. It was difficult to watch her son’s frustration due to his emotional maturity unable to match his language development. He had a hard time expressing his feelings with his limited language. Instead of trying to speak, he would use physical actions to get attention. With playmates, he would push them and be very physical in his communication. This is quite common as Yoshinaga-Itano claims that Dhh children who possess the “inability to communicate desires and needs can significantly impact the behavior of the child, leading to temper outbursts, tantrums, and aggression… because the child is unable to express how s/he is feeling through words” (2011, p. 99). Ben’s delayed speech has also put him behind in his academics at school. Another challenge they have had to overcome, are the issues of Ben did not wanting to wear his hearing aids. He does not want to be different and as he gets older, he is more aware of his being different. He already asks her if the hearing aids look “cool”. Punch and Hyde explain what has been called “the ‘hearing aid effect’, involving perceptions of stigma associated with wearing hearing aids, have reported that some young adults reject their hearing aids for reasons of cosmetic appearance or peer acceptance” (2011, p. 488). Ben gets sad when he can’t participate in social events and as of lately, he sometimes does not want to. His class was decorating the gym for Halloween but the atmosphere was very difficult to hear in. This frustrates him and in turn frustrates his mom because she does not want him to miss out on activities that everyone else can do.

Overtime, there have been many types of support for Ben and his family from different services and people from emotional to medical. When he was first diagnosed, the parents found lots of information on the Internet. They were living in Texas and had different doctors, ENT specialists, audiologists, and speech therapists for Ben. It was there that she knew he had a hearing loss and had begun to search for any possible information. Before her son’s hearing loss, she had seen other people wearing hearing aids but was young and did not know much about this world. She was quite unhappy with the services in Texas. Her sister’s mother-in-law was in the medical field in France and set up appointments for her to get different opinions. In France, they went to a French therapist to go through the whole diagnosis. This brought another perspective. When the family moved to Vancouver, there were many sources of support and sources available here. Danielle said that they have everything offered here in Vancouver. There is a Hearing Centre in the district that has lots of information. Ben has a speech therapist at school and an itinerant teacher who is a huge support. The itinerant teacher created a team of other specialists who give Occupational, Psychoeducational, and Behavioural assessments and support. She also gives emotional support for the mother who appreciates her expertise and advice. Danielle says that the aides at school have been amazing as they used to sign with Ben but do not anymore since speech is the chosen mode of communication. Now that Ben is more independent, he does not have a full-time aide. The mom also realizes that when he has a job, he will not have an aide beside him. Ben also sees a psychologist, who used to sign with him, bimonthly for the past 3 years but recently only once a month. The Psychologist helps him with his issues of being different and with the behaviours dealing with the hearing loss. Lately, other topics are discussed such as the divorce. Danielle wants the supports lined up, as she knows Ben will have other issues when he starts puberty. Punch and Hyde’s study found that adolescence “was a particularly difficult time for some as they struggled with feeling of self-consciousness…and worries around friendships, dating, and their future place in the world” (2011, p 474).

At the beginning, the most useful information of all was the testing for allergic reactions. This was crucial to his hearing because even when he was wearing hearing aids, the tubes were filling with fluid and it would drain in to his hearing aids causing them to not work. The speech therapy was also a breakthrough because this is when he started talking, communicating, and bonding with his mom. More mature exchanges were happening between them as well as with the other family members and with other people. For her, before the speech therapy, “it was like he was being trapped, a 5 year old with speech of a 2 year old and with the emotional maturity of a 3 year old”. The support of his communication continues to be of utmost importance to her.

The type of emotional support has changed over time and has varied from place to place. Danielle claimed she was depressed at first but eventually came to terms with his hearing loss with the help of professional guidance. When she first found out Ben had a hearing loss, her family was supportive but they lived in France and all conversations were over the telephone. The doctors provided medical advice and gave the family information on where they could find other kinds of assistance. Her best friend in Texas was a major support for her as her friend’s husband, who was a doctor, also happened to develop a hearing loss. Her friend would keep her informed on the services available and where to get them. They would support each other as they were going through a similar process. Her other girlfriends from Texas were there from the start and were a great help while she lived there. When they moved to Vancouver, things were more in place, questions had been answered and she was in a more positive frame of mind. She met other families in similar situations and they were very supportive of one another. Ben didn’t know anyone yet and he was not acting himself. She involved Ben in sports, planned play dates, and made opportunities to socialize with friends. The first Deaf event he attended, the mom had pointed out all the other kids with hearing aids, which helped Ben find his identity. Whether dhh children prefer to assimilate into the hearing world or not, Israelite et al.’s study found “they prefer to rely on each other for meaningful communication, social interaction, and a sense of belonging” (2002, p. 136). This annual event within the school district helped him begin to accept who he was and gave him more confidence in making friends. Further, Israelite et al. notes that “administrators should be encouraged to acknowledge the importance of promoting social interactions among HH students and providing class release time so that they and their specialist teachers can gather with HH peers for special activities and occasional social groupings” (2002, p. 146).

The experience of interviewing the parent of a child that I will work with gave me insight in to the abilities of the child, what goals to aim for while working with the child, where the child is emotionally, what type of support the child and family needs, the ethics and values of the family and the best way to support them.

Ben is fortunate to have a mother who is so dedicated to his well-being. “Parental involvement with their children obviously goes far beyond school involvement and is likely to include the quality and quantity of parent-child communication, parents’ encouragement of their children’s participation in extra-curricular activities, or their ability to encourage children’s friendships” (Antia et al., 2011, p. 151). Ben has an active social life and is involved in many extra-curricular activities. He is lucky to be athletic as this helps him gain the respect of his peers. Being on hockey and basketball teams “extra-curricular activities may also positively influence socialization because they give the deaf students an opportunity to engage with others in mutually interesting activities in which they might shine” (Antia et al., 2011, p. 151). Playing sports and music has helped Ben with his identity construction. Israelite et al. acknowledges, “participation in extracurricular activities is related to higher levels of self-esteem and self-confidence…” (2002, p. 136).

The family also is able to afford the costs of services and specialized equipment that may not be available for funding. Ben goes to a psychologist, naturopath, speech therapist, and other specialists that are not entirely included in his medical or funded through the school district. They have the finances to pay for his hockey gear, hearing aids, dietary supplements, music lessons and the ability to provide transportation to all of his activities. In Jamieson et al.’s study, they found that parents “reported considerable emotional fatigue from trying to sort through complicated funding structures, trying to ascertain their eligibility, and complete the logistics necessary to access support” (2011, p. 119). Even though they have a high socio-economic status, there are funding processes they have to go through and there are high costs involved.

When asked for some advice as a “green” teacher of the deaf and hard of hearing, Danielle offered positive contributions and encouragement that were gladly accepted. After all, she is the expert as she has personally experienced the entire process with her son, knows the different types of supports available, and essentially knows her son best. The first bit of advice she told me, which is probably the best, was to “listen to the parents”. When they suspected Ben of other special needs, their itinerant teacher made sure he was tested right away. She is a firm believer of early diagnosis and intervention and reminded me that if I suspected any other disabilities to assess them early. Friends and family have urged her to write a book about her journey as a parent of a hard of hearing child. I concur, as this would be an accessible resource and support for future parents that will go through similar events. Danielle also urged me to focus on the social and emotional aspects of the job. Ensure that the child is happy and to not let them close up by hosting events where they are social and active. Friendships are important and to work on their socialization skills. She told me to empower them to accept their hearing loss for their self-confidence. Lastly, she told me to follow my instincts, as they will probably be right, as I will have lots of experience. I thanked her for her confidence in me and for the time she spent with me openly discussing her life and her son’s with me. I greatly appreciate the opportunity I was given to speak with her and to understand the challenges and support the family needs on a familial level. I believe this relationship with the family will guide me on how to best support her child.

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