# Topic 6: Interview with Naleni – Transcript

* [Naleni] My name is Naleni. I'm a mother, I have two sons. My older son is in university. My younger son has cerebral palsy and he went through the school board and now he's in a special program. We have had some good teachers, I would say. What made them good teachers specifically was the way the supported me, personally. I've had times when I had to keep insisting, if my son needed support, but eventually I did get the support. But looking back now I would think it could have have been much better for me and for him. I should say, had I known, because I felt that I had to go with everything the teachers said and everything that I was told, but eventually I learned that that's not how it should have been. I would say some of the teachers were very supportive, but perhaps they weren't aware of my personal feelings as well. But my son had a lot of difficulties, he had a lot of seizures and we had a lot of personal problems at home, like financial problems and he had a lot of appointments. I had to go to everything and attend to everything on my own. Whereby I was told after, that the teachers were in position to help the situation but I wasn't aware of that and I wasn't told that they are able to come to appointments with me. I guess I was supposed to ask, but I didn't know that they would have been that supportive if I had asked. >> [Interviewer] If you knew a parent had a disabled child and they were just starting school, what advice would you give them? >> [Naleni] Well actually, I do know quite a few of them and I'm sorry, the way I say to them is, you have to be really alert, aware, and insist on your rights and you have build relationships with the staff, as well, and you have to let them know where you're coming from, what most of your issues are, how life is with you, and let them get to know you on a personal level almost, so find that they're more supportive when they know what's going on in your life. From a personal experience with Dat, he was in a daycare. And I was told well, that he will be transferred to elementary school and of course, I was devastated because you become complacent, you become used to the daycare. You didn't want them to move because you know, you worry about everything. What's it going to be like? What's the staff going to be like? Are they gonna be able to take care of him? Will they understand his needs? I would say, go into the school. Not just go look at the school, but try to get to know the staff and find out what they offer. Even take your child for a day or two, just to see what it's like and if you feel comfortable, go with it. But don't just take the first offer that you get, because that's what I did. I don't feel that, we were told that it's an integrated program, but I've never really seen him being integrated into, with other classes. But I guess it's called an integrated program because it's situated in the school where there's normal kids, as opposed to my son. I didn't feel that way, no. I don't feel that the school supports that. I feel that they, sort of, because the child has a disability, they look at it as something medical and something to be treated differently, not like, well okay it's a disability, but we'll deal with it. We can deal with this disability by accommodating the student in whatever needs the child has. But for me personally, no, I felt as soon as you enter the system, because your child has disability, he's labeled. That's it, he's segregated. That's how I felt and that's how the program ran all through his time in the school. >> [Interviewer] Did anybody talk to him about his disability in terms of identity in a positive sense of self? >> No, that was not, we have never had those experiences, nobody ever discussed anything, no. We've had a physiotherapist come in or occupational therapist would come. It's always something medical. He did have some attention, but it's always something medical. He is a very social person and he's in a special program which is very, I would say, they offer different opportunities of integration. And he goes out a lot, he goes on a lot of trips. They interact with him on a level, like they would with anyone else. Because I even spoke with one of the staff about a week ago, and I said, just look in his bag, you'll find the money, I sent the money. And she goes, oh no, no, I wouldn't go into his bag. And I thought, oh, okay. That's different as compared to what I've experienced in the school system, that was very respectful. Yeah, that really made me think, 'cause I thought oh, this is different. She's treating him like a real person, right, rather than treating him as someone with a disability. I'd say please, listen to us and try to understand how we feel as mothers, as caretakers. Our lives are different and I know you can't put yourself in our shoes, but you could at least try to understand how we feel and support us in managing with life on the whole rather than segregating us as a family with disabilities. Integrate us as you would with anyone else. Try to meet us on that level where we could communicate. Like if my child was, I can't say not disabled, but at least like you would with any other parents. Yes, to say to the staff, is with the IPRC, I was always told you don't have to come. You don't need, you don't really have to come. It's okay, nothing has changed and we know your child, so it's alright, you just have to, and they forever sent the papers home and I signed the papers because I was totally oblivious to the whole idea. And I thought, okay, well I'll just sign the paper, 'cause this is what my son is. So for years I was told and once I commented. Whenever I went, which might have been three times for his whole school life in the school system, once I commented about, oh, he was enjoying that program, why did you cancel it? And after the meeting was over and I came back to see her again, this was the head teacher, she said to me, oh, I was really taken aback, why did you say that? And I thought, no, I was offended and I was really hurt. And I felt maybe I did say something wrong. As parents, we always wonder if we say something wrong or if we didn't do the right thing, is our child gonna pay the consequences? And because of that, we shut up all the time. We don't say anything because our child, who is totally vulnerable is your hands. So we feel, okay, we're gonna go with what you say because we don't want our child to suffer. And it does happen, so, yeah. For the parents also I would say, just be very alert, be aware, and be fully involved. Communicate if possible on a daily basis, because I did that. We had this communication book and I would go into the school two or three times, just because I worried. Like I said, I don't want to speak up, so I just kept it to myself, but I went in just to see and to make sure. And thankfully, my child is able to communicate verbally, but I've seen many children that aren't able to communicate verbally and I worried about them.
* [Interviewer] Describe your perspective on how disability identity can be constructed in a positive way.
* [Angela] The idea of a disability, it's interesting 'cause in a school board if you want to, not want to, but if there is a quote unquote disability, it usually comes from having an exceptionality on your record so after an IPRC meeting, which is the Identification Placement Review Committee meetings, if a child is going to be given an exceptionality, officially, that would be considered a disability in a sense because that's one way, or the main way, they get certain types of supports. Sometimes though, a disability is often constructed. You can see it just in the way the educator sometimes speak about certain children. So, if they have whether it be physical needs, or emotional needs, or academic needs, oftentimes the word disability is, in my opinion, a very negative word because it's assuming people can't do things and when children have different strengths and different needs, oftentimes when there really is a child who is struggling and they're not being as successful as you know they can be, you can sometimes hear it in the language at the school when they speak about the child, that they're seeing what the child can't do or isn't able to do right now, and they're not looking always at the skills. So, I think that, in and of itself, is again. a conversation to have about thinking a more strengths-based approach in trying to see what children can do and are capable of doing. But yeah, I do think disability more comes from the labels that could be designated by a school or a school board about a child. So, oftentimes though, it's interesting because again, when I think about my role as a consultant or supporting children, I want to support the whole child. But oftentimes, because again, in the school board the role of the consultant is sometimes, it's primarily the academic needs. Oftentimes support staff, like educational assistants, or a SIP support, so you get funding for a particular person to be attached to a child. They are the ones who deal with a lot of the more challenging or more complex cases where children have a whole variety of needs that sometimes need a lot of different types of support. Oftentimes those kind of physical, social, emotional needs get met by support staff. And then the consultant, as a special education teacher, is really supposed to only be focusing on the academic needs. So in that way, different disabilities are viewed in a sense, very differently because the supports that different children with different needs are getting vary based on what your primary area of concern is. If you are a child that the school has flagged to have a concern then the type of support you get could be very different based on your area of need. Whereas in a child care setting, consultants I find, work on all areas. And that is their role so there might be additional staff who later come in, but it's the consultant, I think, in an early childhood setting is usually, their work is a bit more wholistic, whereas, different people in the board are sort of assigned based on the type of need and based on the type of disability they might be designated with. It is very interesting to think about how all the different workers come together because there is a difference. >> [Andrea] It was an very intense and eye-opening experience for one of my placements and I realized that I was way out of my element and that I was never going to and be accepted. I was devastated, I wanted to be involved. But the answer was, I wasn't deaf and I was never gonna be deaf and deaf culture said we use hand signs and we use ALS and until you learn it, I don't have really much to say. On top of which, my child is completely able to speak, but I choose not to and that was something very different. Doesn't everybody want to speak? Doesn't everybody want to be like everyone else? And the answer was, absolutely not and the pride that you find and come up against was something that I had to embrace very quickly. As well as, cerebral palsy at the large hospital in midtown Toronto where I was with people who had a diagnosis of cerebral palsy but also blatantly, outwardly, and I was very cautious to be very tempered about the language that I used and anything about the way the body movements were, and they very quickly, at the ages of 17, 18, 19 razzed each other about and each other between them, about the way that their bodies moved, or didn't move and called themselves terms that I still today, am very uncomfortable with. So I realized there is a strong dynamic and pride that goes along with using the terms and diagnoses and understand who it is that is your dealing and working with and be respectful of those limits and boundaries, but also accepting of anything that comes with kin and kinship.