CHALLENGES OF CHILDREN WITH PHYSICAL DISABILITIES

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Take yourself back to a time when you had no real academic worries, recess was the most important part of the day, and you could not wait for snack time. Can you imagine never being able to play on the monkey bars or tire swing at recess? Or always being picked last in gym class because you weren't "good enough"? Or maybe even never being able to participate in gym class at all? These are just a few issues for children with disabilities. Being a child with a disability is the hardest thing in the whole world because they do not understand why everyone else is "normal" and they aren't. They know that their physical disability limits them to certain activities, but the exact reasoning for that, in their young minds, is unclear, as well. All they know is that they are different and those differences limit them greatly in their everyday lives and activities. Children with physical disabilities are limited in almost all aspects of their lives in one way or another. This creates tremendous confusion and frustration for those children.

The question that I wish to further explore is "What challenges do individuals with physical disabilities encounter in childhood?" My interest in this topic stems from personal experience with my own physical disability that I have suffered with throughout my life. I was born with bilateral club feet, which means that both feet, at birth, were turned completely outwards, and arthrogryposis, which is a stiffening and permanent locking of all the joints in one's body. I have had nineteen surgeries, to date, because of my disability. It affects my life on a daily basis, both physically and emotionally. It is not easy to live with a physical disabilities or show a high enough level of compassion for people suffering from a disability. The issues of the question that I will specifically look at include inclusive classrooms, children internalizing their anger, frustration, and confusion, and parents' depressive symptoms when they have a child with a physical disability and the toll that it takes on their child.

The first article that I will discuss deals specifically with the topic of inclusive classrooms and the challenges that children face when included in them. Inclusive classrooms are classrooms where children with and without disabilities are educated together, with extra support provided for the child with a disability. A young boy named Kevin is the main subject of this article. He suffers from a physical disability and is placed in an inclusive classroom. He is fully mobile with the help of a walker. According to Sonja de Groot (2005), children, like Kevin, who are placed in this setting tend to be rejected or neglected more than their typically developing peers and are involved more with the adults in the classroom than with their peers. It is not healthy for children at that age to socialize more with the adults in the classroom than with their peers. Children at a young age need friends to invite to birthday parties and other outside events. Having friends makes children feel special, accepted, and above all, normal. No child likes to think that there is something wrong with them that makes other children not want to play with them. These children are most often rejected due to the fact that they cannot socialize in a physical way (running, climbing, jumping, skipping, hopping), which is customary to most schoolaged children. In typically developing young children, the rate of rejection by other children is about 10% (Sonja de Groot, 2005). However, the rate of rejection goes up to 33% for children who are labeled

as special needs students (Sonja de Groot, 2005). People, as a whole, become nervous around others with a physical disability. They do not know exactly how to handle it and instead of trying to make friends, they stay away altogether. That is one of the worst things someone could do whether they are a child doing it or an adult. This article documents that adult assistance and curriculum activities both play an important role in either facilitating or constraining social interaction with peers (Sonja de Groot, 2005). Children who are limited to table activities socialize much less with their peers for two reasons. The first reason is that most children want to be moving around as much as possible and for children with physical disabilities, that is not an option. The second reason is that even if the child with the physical disability got another child to sit and play with him/her that would only last a short amount of time before that child became bored with the sedentary activity. The positive side of the child playing with his/her peers is that in doing so, they are more independent. They choose what to play and with whom. In this article, the teacher reported that "Kevin did so much better in class without the assistant, Katie, present" (Sonja de Groot, 2005). She always pays special attention to Kevin and keeps him safe while in the classroom. In doing this, Katie, in a way, takes away much of his freedom and independence. According to Sonja de Groot (2005), when Katie was gone, Kevin spoke more often and in complete sentences. He played in what the teacher called the "dramatic play area", maneuvered his walker around all sorts of obstacles, and even took a few steps without it, which is a huge accomplishment for him. When Katie is there, his conversations are monitored by her, which makes him speak much more infrequently and without as many words. She makes sure that all of his activities can be done on a table-like playing with mini farm animals- and with children that would sit with Kevin rather than let him try to move around. Though Katie is a good protector, she holds Kevin back from doing all of those things and many more. The teacher reported that Kevin was much happier and more proud of him self after seeing what he could accomplish on his own (Sonja de Groot, 2005).

Personally, I think that assistants are needed at schools to help monitor the children and their activities, especially in inclusive classrooms. Certainly one teacher for twenty to thirty students is too much and can become overwhelming very quickly, therefore, an assistant is beneficial to everyone involved. However, after reading this article, I also believe that there is such a thing as too much helping and monitoring, especially for children with disabilities. Someday these children with disabilities are going to be adults with disabilities and once they are adults, there are going to be a lot less people around to help and support them and everything they do. Reading further, the article went on to say that when Kevin tried to spread peanut butter on bread for his lunch, Katie took it away from him and did it herself. Then after Kevin ate, he had to wash his hands and rather than stand him up and help him walk with his walker or help him take small steps, she sort of dragged him along so his feet swept the ground (Sonja de Groot, 2005). After reading this article, one can see how desperate Kevin was to be independent and help himself. As his teacher said, "He takes almost every chance he gets to try to gain some independence and tries to do things on his own (Sonja de Groot, 2005)".

This particular scenario relates so much to my own story in every way possible. When I was born, I was immediately put into corrective casts and they did not come off until I was four years old. During that time, my mother was advised by my doctor not to baby me or treat me as if I even had a disability because he was sure that treating me that way "Would be most beneficial to me in the long run." I ran around outside with my casts, danced with them on, and never really gave much thought to why they were there. I was just focused on being a happy kid and having as much fun as possible, regardless of my situation. Even now, I go to the gym daily, participate in various athletic activities, and am in good shape. Too many people with my disability were babied as children and to this day, either rely on wheelchairs to get around or rely fully on their parents to do everything for them. Due to my doctor's

excellent advice and my mother's will to push me to the next level in the hardest of times, I am a successful college student who has not let her disability affect her life or freedom at all.

The second issue that I would like to discuss is children internalizing the anger or frustration that they experience with a disability. People do not understand how much emotions such as anger and frustration are linked to disabilities. It is the most frustrating thing in the entire world to not be able to do certain things that you want to do or, even worse, watch others freely do what you cannot on a daily basis. This pent up frustration eventually leads to anger and the child wanting so desperately to take that anger out on someone, something, anyone or anything that is around. This, in turn, leads to children acting out in class or other places. People wonder why they act out, but according to Granlund and Welunder (2007), about 56% of children with a disability who act out are acting out in some way that is related to their disability. That is a high number-more than half of the cases act out for that reason, alone. In my opinion, that is a very compelling statistic because I have been in that position before and have acted out because of my disability, too. Sometimes, as the article says, you just cannot help it when you're in the heat of the moment and you're just so sad, frustrated, and dejected. Reading this article takes me back to the mall just this past summer. I was with my mom who was so excited that she finally found me the "perfect pair of jeans". She could not wait to show them to me. I went into the fitting room and as I pulled them up, I was amazed at how perfect they really were- until I saw the bottom of them. The bottoms of pants are the most important part for me. They need to be wide leg pants (when I say wide, I mean extra, extra wide) or else I cannot wear them because of my shoe issue. As I said before, my joints are all frozen in place, which includes my ankles. This means that all of those cute shoes with high heels that you see girls wearing to proms and fancy occasions are off limits to me. If they have a heel, they will not work for me. The shoes that I can wear must be mostly flat on the inside. This problem limits me to chunky platform shoes, which are not the most stylish in today's fashion world. As you can see, a day of shopping for me is somewhat torturous. If the pants are good, the shoes are not and if the shoes are good, the pants are not. It is a vicious cycle. I cannot win. So, after seeing the bottom of the pants that my mom picked out for me, I cried. It was the tenth pair of pants that I had tried that day that did not work for the same reason, time and time again. I had had enough and stormed out of the store. I wanted to leave the mall and go home. I was so angry the whole car ride home and questioned why my mom even had me in the first place. My level of frustration with this issue is as high as it can get. My mom tried to calm me and make me feel better, but nothing worked. That was one time when I was desperate to get away from my disability. I wanted to walk away and be rid of it, even if it was for just a moment, but I couldn't. In this respect, my disability has robbed me of a large piece of my own precious feminism.

Furthermore, pent up anger can lead to stress and stress can be extremely detrimental to one's health. According to Holtz & Tessman (2006), stress can cause anything from muscle spasms and anxiety disorders to high blood pressure and even eating disorders or depression. Though stress seems so minor, it is nothing a person would want to test because stress, unfortunately, is something that can creep in and then begin to affect every part of one's body. Approximately 74% of people with physical disabilities have higher stress levels than the average person (Holtz & Tessman, 2006). Whether the stress levels of these people are much higher is unknown, but studies have proven that they are, in fact, higher.

The third issue I would like to discuss is parents' depressive symptoms when they have a child with a physical disability and the toll that it takes on their child. First, research has demonstrated that the functioning of parents is related highly to the emotional and behavioral functioning of children and adolescents (Holtz & Tessman, 2006). For example, according to Holtz & Tessman (2006), it is

suggested that the stress of dealing with a chronic illness or disability is a primary risk factor for the development of psychosocial problems in both affected children, as well as, their family members. These stresses may be the result of actual disease parameters, such as illness or disability severity, cognitive intellect, or the functional limitations imposed on children. A study (Holtz & Tessman, 2006) conducted in Bangladesh found that a high proportion of mothers of children with cerebral palsy (41.8%) were suffering from stress. Behavioral issues in these children were found to be the strongest predictor of maternal stress. It was found that mothers of children with a chronic illness or disability (Holtz & Tessman, 2006). Yet another study (Govindshenoy & Spencer, 2007) showed that in families with even mildly impaired children parenting stress was relatively high compared to other families without this added stressor.

I strongly believe that personal reflections have much to offer a paper like this– a paper that takes a seemingly regular topic and twists it to clearly convey a hardship while incorporating certain educational aspects within it, as well. That is why I had a woman who has successfully raised a child with a physical disability write a personal reflection and submit it to me to put in this paper. Because I have included so many of my own reflections and stories, I saw it fitting to make the woman who wrote this reflection be my own mother, Tracey Taverna. She is the only other person in the entire world who knows and shares the pain of all that I have endured over the course of my life. This is what she said:

"It is my honor to have been asked to write my perspective, as a parent, on raising a child with a physical disability. The child I am writing about just happens to have authored this paper, my daughter, Jillian. She was born with a congenital birth defect known as Distal Arthrogryposis, defined as a "congenital defect of the limbs characterized by contractures of joints". Since birth, Jill has undergone a total of nineteen (19) corrective surgeries to both feet and knees.

When Jill was born, I was notified immediately that she would be transferred to another hospital within a few days due to complications surrounding her medical condition. The stress level was significantly raised for me, of course, but it was as if I was transformed from a new mother to a lion protecting her cub. I found strength I didn't know I had and set course with much determination. I was told by doctors in the months to follow that Jillian had a very tough road ahead, which was appropriately stated. At the same time, I was advised by her surgeon (who I had come to know and trust) that "the best thing I could do for Jillian was to be sure she received a good education" - that she would need it to get by in her adult life. This struck me as odd because she was only a baby! But, better advice was never given and made me realize the seriousness of her condition and that her disability would indeed hinder her throughout her life. To this day I am grateful for this advice.

We spent countless hours, days and weeks in hospitals prepping or recovering from surgeries. These were the hardest days for me. It is without a doubt the hardest thing to endure to see your child put to sleep with several doctors standing overhead while one places a mask over her mouth and nose, or in pre-op being pinned down to a table with arm and leg weights in order to keep her from moving to get an accurate x-ray - and just knowing that she has no idea why you, her all-loving mother, are allowing this to happen. I compared it, in a way, to child abuse - not in the typical way we are used to hearing about it, but I was so worried that it may carry the same long-term effects of any traumatic event on a child and how she would process this. This made my job tougher in not only getting her through the surgery and back to her healthy, smiling, self, but the psychological effects in later years it might be having became a whole other concern to me, as well.

Raising a physically challenged child made me much more aware of what is taken for granted in life. I would look at other children running in a playground while my child was growing up in casts, leg

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braces, and, at times, confined to a wheelchair following surgery. This broke my heart and made me so sad-possibly the saddest (and most empathetic) that I have ever been. I read a poem once about a disabled child on a playground from a parent's perspective. It hit home and I cried my heart out. It spoke about how it could be such a scary place and I related all too well. When other mothers were signing their children up for dance, we wouldn't go. I got brave and signed Jill up for T-ball when she was five. It was very exciting and she was able to wear a uniform and go out and play because she was finally free from her leg braces and casts. I was overjoyed until I overheard a coach say "what are we going to do with her, she can't run? It was the cruelest comment I, personally, have ever heard. I expected this from other children, but not from an adult. I was so hurt that I never went back - I just accepted that there would be certain places we wouldn't be as welcome as others.

Jillian's disability was devastating in many ways and I became a constant worrier. Mostly, I worried that she would fall and hurt herself because her balance was not good. I became the most overprotective mother I knew and MY friends would chide me for this and say oh let her go - you are too protective of her. I thought to myself how little I thought they knew, because I knew she needed more protection than other kids because of her disability. I worried about her being accepted by friends and classmates, too. Her pain was my pain. It was as if when she made friends, I made friends, and when she was teased, so was I. I wondered would kids make fun of her? Was I even capable of instilling in her the kind of confidence I knew she would need to hold her own in life?

Those were the tough times for me, but it didn't compare with what Jillian faced. What's worse than being made fun of for something you have no control over? As the parent, I had to endure the hurt right along with her. I was the one who she looked to for consolation when I felt like crying right along with her. But I am a role model and learned to be strong in the hope that she would learn strength, too.

The teenage years were the toughest and she was never more aware of her disability than at that time and hated everyone for it. Me, most of all. I had been a "friend" to Jill all of her life - even more so than some parents because of what she endured. I felt a lot of compassion for her - I would have cut off my right arm for her - we loved each other, but at no other time in her life did I determine that if she was going to get anywhere I had to stop coddling her - I had to take on the "bad guy" role. It was new to me and I didn't like it. I was used to being the good, nurturing mother - there for her, helping her at every turn. But I didn't like what I was seeing in her either, so I changed and it took battle after battle to coax her to make necessary changes. I felt completely duped because I was, after all, the one who sacrificed so much for her only to end up the one she hated! I hoped it was a passing stage but it sure didn't feel like it. It seemed endless and became depressing. I had always been upbeat and had overcome every obstacle when it came to raising her, but now it seemed as if it had all been for naught. I was physically and emotionally exhausted from all we had been through and it was clear she was not going to give me a break. It took years of not being her friend for her to come around.

She went away to college and did a lot of growing up. She is, once again, back to being my best friend. She is 22 years old at the time of this writing, and what she has taught me seems to me to far outweigh what I have taught her. She didn't give up and neither did I."

My mother's reflection was so interesting to read. Now, I am eager to find out what every mother's thoughts about raising a child with a disability are. That is why I have decided to include one more personal reflection written by a woman named Silvia Lawniczak who wanted to share her feelings with all who are interested in reading about raising a child with a physical disability. It reads:

"On most days, the furthest thing from my mind is my child being different from any other. We laugh, play together, even bandage changes are so routine it feels like a 'normal' thing to do. I don't have any other children, so I don't have anybody to compare him to on a daily basis, and that might very well

be a blessing. I don't sit there feeling sorry for myself, or feel sorry for Nicky that much, if at all. We just live and take care of what needs to be done."

That all changes, however, once we go out in public. The stares, the questions, seeing other kids my son's age do things Nicky will never be able to do, can truly be heartbreaking. I often worry about Nicky's mental state seeing other kids do things he cannot do, and that is why I try my best to get him to spend some time with children like him. I also try to help him do the things he cannot do and do them in a creative way. Like holding him in my lap to go on a swing, or down the slide.

The questions and reactions I get from people are varied. There are those who just ask 'What happened', and after I offer my initial brief explanation they walk away (yes, they walk away!). Then there are those people who truly seem concerned and ask a million questions. I like these people, but there are only a few of them out there. I even had some wonderful souls who start crying, WOW. Then there are those people who think are out of earshot but aren't, who comment or try to explain to their children what is 'wrong' with Nicky... and they always without fail get it wrong. They will say 'he got burned in a fire', or 'he was in an accident' or things of sort. Others tell me about their cousin or aunt with a skin disorder (usually eczema or similar) or think they know what it is, but it's never the case. Any skin disorder pales compared to EB, so I know they don't understand how badly Nicky is affected. To most others I hand out a card that explains what Nicky has in simple terms, and that has worked best because it has links to websites to get more info.

The stares sometimes are the cruelest things. Admittedly, I have gotten used to having my child stared at, and I know that is true because when there are other people with us they comment constantly on this person or that person staring that I did not even notice. There are also different kinds of staring. There is the staring out of curiosity that ends just as quickly as it started. Then there is the persistent stare-the one that follows you for a whole minute or five! Then there is the 'yuk' stare (my personal peeve), the 'poor baby' stare, but my favorite is the stare with a smile... but my child rarely gets those, unfortunately.

I realize that people are curious and notice things that are different than what our society feels is 'normal'. Picking out what's different is a skill children learn at a young age, perhaps it's a skill that is part of being human, and that enables us to pick the freshest fruit to eat or avoid illness or an accident. Nicky's only difference though, it's on the outside. His skin may be damaged, and he might have tons of wounds and limitations, but inside, he's as whole as any of us. Perhaps more. He has a keen sense of love and his ability to love and even forgive me, or anyone, for anything, is beyond measure. He is without a doubt the happiest child anyone has ever seen. Even after an excruciating bandage change full of blood and needles he's so happy it's over he comes over for a hug and starts singing, and that smile... boy, that just melts my heart.

My child's disability is only part of who he is, but because his disability is so incredibly visible, I feel too many people tend to concentrate on that alone, and that is very sad. What a world this would be if people would only be judged by their insides..."

These two reflections amazed me. They were written at two different times by two different women, but basically convey the same messages- their hearts break for their children, people can be so unbelievably cruel to others with physical disabilities, and what was most surprising to both women was that some adults acted with less sensitivity to their children's situation than a child who didn't understand the situation or even know better would have acted. That is the most heartbreaking fact of all. After skimming the second reflection, I thought that it would absolutely back up the first one, but I can't believe how much it really does. It is as if these two women brainstormed together and then went and wrote two different reflections, which is fascinating to see.

Lastly, as one can see from these heartfelt reflections, children are their parents' whole world. They are the first thing they think about when they wake up in the morning and the last thing that they think about when they go to bed at night. When something is wrong with their child, their world is turned upside down, especially when what is wrong with their child is permanent. It is so unbelievably unfair that parents must go through this right along with their children. In most cases, they didn't choose that life for their child or for themselves. Raising a child with a disability is very stressful for a mother and can, at times, be depressing. The question imprinted on my mind is why do any parents have to go through this pain and sadness at all? Why are some babies born with problems that others are not born with? Is it about fairness? Is it about fate? We will never know.

The theory that I feel applies most to my topic is symbolic interaction theory. According to Rogers & Lieberman (2006), symbolic interaction theory refers to the unique ways in which people and systems interact and communicate with one another, as well as the essence and characteristics of that interaction and communication. An important tenet of this theory is that we all attach meaning to our communications with others within the context in which the interaction takes place (Rogers & Lieberman, 2006). Even though several people might experience an interaction in the same place and time, we might interpret that action very differently, depending on the meaning we place on it. This theory maintains that we are not just passive receivers of information, rather we filter and interpret the information based on our culture, cognitions, experiences, and so on, and we respond to this information based on how we interpret it (Rogers & Lieberman, 2006). There are three main premises to this theory. They include: 1.) That we act on our world based on the meanings that we attach to our experiences, 2.) The meanings are affected by our interpretations of our interactions. Therefore, our experiences, interactions, and interpretations of our experiences and interactions constitute an ongoing dynamic process (Rogers & Lieberman, 2006).

Symbolic interaction theory is a theory that one could absolutely apply when talking about children with physical disabilities because a child with a physical disability is constantly attaching meaning to experiences and conversations with certain people and vice versa. A child with a disability grows up in a world where every little thing that they experience is different than it would be for a child without a disability, therefore, making each of their experiences not only unique, but also memorable, whether it is a positive or negative memory. They always attach meaning within the context of certain situations because it is beneficial to their lives, which are often so much different than those who do not have a physical disability. In doing this, it is as if they are bookmarking certain negative or positive events so they will know what to expect in the future. For example, many children do not terribly mind semi-loud noises around them. When I was a child, and even now, the minute I hear a loud noise, I become nervous and cover my ears with my hands. I, then, try to get away from that noise, even if that means running away and maybe making me look stupid in front of others. That does not matter to me though, because unlike other children and adults, I associate loud noises with the hundreds of cast changes that I had as a baby. The loud noise of the technicians drilling at my casts is something that I will never forget. I would struggle to get away, but that would only cause them to hold me down with greater force. Loud noises, to me, equal unwanted force, which I may have viewed at the time as a semi-abusive situation. This is the meaning that I have attached to that particular experience. As for the communication aspect of this theory, when someone tells me that someone is going in for surgery my immediate thought is "What will they think or what will happen when they wake up during their operation?" Most people would not even begin to think about this because they have never had many surgeries or even woken up during one. One of my earliest childhood memories is of waking up during one of my operations. I

opened my eyes and everything was bright and white, there were people huddled around me like a football game, and finally, someone came back with a funny smelling mask and I was asleep again. Again, I attached meaning to what was communicated because of my own experiences. An even subtler example of the communication aspect of this theory is when someone near me says "Oh so and so hurt their knee." I get goose bumps that cover my entire body when I hear about knee injuries. I cringe and cannot control my facial muscles because a knee injury, in my mind, is a knee dislocation, which is one of the most horrible pains I can imagine. All I can feel is my knee bending, tearing, and finally snapping like the stem of a flower just like my knees have done so many times in the past. Again though, this is all based off of my own experience. The last example that clearly illustrates this aspect of this particular theory is when most children see a wheelchair they want to play on it or ride on it because it looks like fun. I know better. To me, a wheelchair is for medical use only. Since I was little, the minute I was discharged from the hospital, I would go home in a wheelchair. I do not see them as toys like so many other children do because of my lengthy experience with them. Therefore, the way I think and feel about certain actions, words, and objects have been taken directly from the context of the initial occurrence of certain situations and encoded within my mind to foreshadow either good or bad results.

Thirdly, interaction with others is a part of this theory, as well. To many children doctors are scary, impatient, and give you shots. My experience, on the other hand, is that, yes, they are scary, but not so much impatient, because the nurses are the ones that usually deal with any problematic children before the doctor even gets into the room, and not only does the doctor give you a shot, but he takes out bones and cuts you open, too. This was my experience with doctors. They were always so caring and kind to me and I know their role so well because I have seen them in action plenty of times. Other children might be confused by the differing roles of the doctors and nurses, but I know better because of my lengthy experiences and interactions with them. I also view doctors as performing much more invasive tasks like performing operations instead of simply giving a check-up because that is what I know and have seen most often in the past. As symbolic interaction theory states, all of my little "worlds" have processed one another and have come together in such a way that produces many different reactions to certain stimuli.

It is amazing to see how well symbolic interaction theory fits in with my paper topic. It is almost as if we are conditioned or preprogrammed at birth as to how we will react to certain things throughout our lives. The conditions that we are given at birth set the stage for the rest of our lives and all the experiences to come.

Though I have lived with a disability for twenty two years, this assignment and the research that has come up while doing it, has taught me a couple new things and reinforced certain things that I already knew. First, I never realized how essential it is to give a child with a physical disability their independence at such an early age. I always knew it was a positive thing to do, but I never realized that it can truly set the pace of activity for them for the rest of their lives. Like others, if I saw a child with a disability, I would want to pamper them and do everything for them. I also did not realize that doing everything for a child with a physical disability is so frustrating to them, as well. Too often, adults look at children as helpless creatures that need everything to be done for them, but that is not the case. In fact, this assignment has taught me that it actually hinders the development of certain social and academic skills. That is fascinating to me. I have also learned that people with disabilities have a higher stress level than those without a disability. That makes perfect sense when you think about it, but is not something that someone would know otherwise if they were not taught it.

I will absolutely use this learning when dealing with anyone with a physical disability in the future. Whether I pursue the field of psychology or social work, I will most likely run into people who have physical disabilities and after having done this assignment, I will have a better understanding of their attitudes toward their disability and the mindset that they have at that particular stage in their life.

In conclusion, these articles were very informative and interesting to read, but there are a few questions that I am left with. The first is what are the various coping techniques that children use when they become angry or frustrated with their disability? The second is how do you deal most effectively with a child who is frustrated and angry about having a physical disability? Is there any one specific/best way to deal with it or is it situational? And lastly, how can we better prepare or help parents who have or are expecting a child with a physical disability?

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