



# DREAM BIG

With a Parachute On

*by Kristen Bansal*

Dream Big – with a parachute on!

When people hear that someone like myself has a chronic condition, I believe they automatically think that I am unable to accomplish much. Yes, it is true; I must confess I was born with cerebral palsy (CP). The next question I'm asked is, "What do I do? Do you work at an office?" I am a licensed psychologist and I love helping people and their families who have disabilities. The next statements are puzzling to me. "Oh, you are a psychologist - that means you went to college." "Yes," I say, "Twice." People at this point either smile and don't ask any more questions or on occasion, they are brave enough to ask me how I was able to do such a task. I simply reply, "With God's help and a lot of dedication." But I also believed that I wanted and possessed the abilities to achieve the goal of becoming a psychologist, and it all began because I set standards for myself that went against the "status quo." I believed I could do more than what most people thought I could do. My belief, to set reasonable and attainable goals for myself is why I wanted to write this short book.

Who am I and why am I qualified to write on such a subject? I am an adult living my life, trying my best to leave a positive mark in the world. I have had many years of attempting to find my way in a world which I have come to realize fails to consider the challenges and point of view of the disabled population.

Let me first say if you are a parent reading this because your son or daughter was newly diagnosed with a disability or chronic illness I am truly sorry. Your life is going to be much more different than you probably expected. But it is certainly not over. You are the most influential person in your child's life and feeling sorry for yourself or them is not going to help. That said, it is OK to grieve and mourn the loss of not having a "normal" child. I always recommend this because it is a necessary first step to accepting the role and responsibility of caregiving. Secondly, educate yourself on your child's diagnosis. This may be scary and awkward but knowledge makes you informed and therefore allows you to make wise choices.

If you happen to be a person living with a disability you know what your life is like and hopefully are able to help others understand how your life is different. If you are a friend of a person who has a disability please don't underestimate your role in your friend's life. If you are simply a person who saw this and thought this is something worth reading, thank you. Hopefully it will allow you to think about aspects of life in new ways.

Since I am most familiar with CP, I will use personal examples. What is cerebral palsy (CP)? It is a neurological condition, meaning that it affects the brain. The brain is obviously really complex and often times CP is a result of a lack of blood or oxygen to the brain. This can either happen in utero or during the birthing process. It is a condition and therefore is not contagious. CP is on

a continuum. Depending on how much blood or oxygen was lost and the length of time they were lost will determine the severity of the condition.

It should also be said that while there are many common aspects of people with CP, it is rare to find two cases of CP exactly alike. Some children may not be able to talk, walk, eat, or play like other children; any of these actions can be mildly, moderately, or severely affected. One child could have problems saying certain sounds, while another child may have no speech problems but not able to walk. Some children have no problem with speech; yet their fine motor skills may be affected, making handwriting or tying shoes difficult. Still there are other children who will be in a wheelchair and have virtually every part of their body affected. According to Cerebral Palsy Alliance 1 in 5 children may also have moderate to severe intellectual disability (<http://www.cerebralpalsy.org>). The most common form of CP is the spastic type. Simply stated the spasticity makes it hard for muscles to relax. Because of the spasticity people with CP often appear stiff no matter what part of their body is affected. Movements are often slower and or more labored.

I have a mild case of CP. My limitations affect all four limbs and as mentioned earlier, I walk with forearm crutches, and use a wheelchair for long distances. My intellectual abilities are normal, however, I did have to work hard for a number of years to talk clearly, write, and also type. I can take care of myself on a daily basis. Depending on the task or when my environment changes, I do sometimes need assistance. You may be reading this thinking I am glad to hear her story, but what does this have to do with me? People all around us are affected with disabilities and we need to educate ourselves to understand their struggles. The fact is that there are a number of physical disabilities and they all differ in severity and how it affects the body. There are a number of foundational struggles and challenges that we all must overcome based on our ability level. I have said this before and you will probably hear it from me again, living with a disability is not always fun, but that does not mean it has to be negative. Just because you cannot do something today that does not necessarily mean it will be that way forever.

The best way to change a current situation is to change the way you view it. I have worked with people long enough to know that without believing in yourself or your child nothing will happen. The other most important aspect is to set clear and reasonable expectations. This advice is mainly written with parents in mind, because they are forming and influencing young lives; however, the principles discussed can be implemented to any age or abilities. So if I use the word child, it can easily be applied to a teen or adult with some minor modifications.

When having a child with a disability and you know that there will be some limitations what do you do? In my experience you still “Dream Big.” When kids are very young, say ages 2 to 5 years old, parents are the primary influence on their lives. Just because you get a diagnosis of CP or

some other disability does not mean you should lower your expectations. Expectations are what will drive your child to be successful. An expectation is a belief or a feeling that something will happen. You as the parent have to visualize success. Believe that success can and will occur. Now I am not saying that I want you to have a “pie in the sky” mentality. I am saying to set small reasonable goals and even small accomplishments are success.

In my case I have a twin sister. My parent’s house rules and consequences applied to both of us. I was unable to walk independently so I did use adaptive equipment. I also went to therapy to help strengthen my muscles and I moved slower, so my family allowed me extra time. But it was not until age 5 or 6 that I even thought to ask why I couldn’t move like the other kids. My mom told me that I had CP and that tasks took me longer to do. She never told me I could not do something and both of my parents encouraged me to explore my own unique interests. I just naturally did the things I could physically do. If I could not do something they either encouraged me to try or let me be involved as much as possible, such as watching and encouraging others.

How do you evaluate if your child is ready to learn a new task? First, talk to professionals that know the medical condition of your child. We will talk about working with professionals a little later. For the purpose of deciding if a child has the capability of learning a new task, it is always a good idea to ask people who work with the child. If the child is older and is able to contribute to the discussion then let the child help set goals for themselves in order to have some ownership in the process. Children are just like adults in a lot of ways. They do not always like to be told what and how to do things. Any parent with children can probably attest to that. I believe this can even be truer with children with physical limitations, because they require a great deal of help. Sometimes as the child gets older his/her opinion is not always considered.

That said it is also a possibility that a child might use his/her limitations as an excuse not to try new tasks or be as independent as possible. This is particularly true with the primary care giver or moms and dads. Here are some guidelines to look for or consider when deciding if your child is able to do something by themselves.

1. Can the child do this task consistently or only when they think you will be there to do it with them or for them?
2. Does the child do the task in certain environments such as at school with teachers, but not with you at home?
3. Is your child able to do this in the presence of friends/peers or other adults?

Some additional questions might include:

4. How much energy does it take? Does the child get or act tired? It is important to evaluate the actions that put your child in a good mood.

5. Does your child feel confident to complete this task?

The last two questions mentioned above are different than the first three. The first three are asking if the child is able to complete the task or tasks. The last two questions are more or less asking about how the child feels about doing the task. In my opinion both are important. I point this out because if your child is not confident or having to expel a great deal of energy trying to complete the task there are things that can be done without abandoning the task completely. Also as a child gains confidence he will gain momentum and will hopefully learn more things that will lead to greater independence.

To help instill confidence, parents and caregivers need to understand kids with physical limitations and more specifically CP, no matter how involved the physical limitation is. Children and even some teens and adults with CP have difficulties with their body or movements. This is due to a couple of things. One is how people with CP perceive their bodies in space. The way the brain processes the body in relationship to objects and people can be altered. Secondly, spasticity can be a factor. Children and adults with CP often have a hard time getting muscles to relax. Many times some muscles stay contracted for long periods of time. Because of these two factors learning new tasks and/or learning how to move in new and different ways can cause a certain level of stress and anxiety. When considering their limitations and the fears of such things as falling or failure to learn new things, some fear and anxiety are completely understandable.

Children with CP function best when their environment remains the same. For example, having the furniture in the same place in their bedroom or having objects that they use often kept in the same spot. When going through a daily task it is helpful to have repetition (practice the task over and over again). When helping children with CP it is extremely important to remain patient and to practice tasks in order to give children plenty of time to feel confident. I have discussed this point with parents in the past. Most of the time parents agree with me. However, they seem surprised with the amount of time it takes for their children to gain confidence. I gently remind them the body works differently with CP.

Now let's take a moment to consider something. Take your arm, either arm and flex your bicep muscle. For the next ten minutes get up from the couch or computer and walk around while continuing to keep your bicep flexed. After ten minutes relax and continue reading. How does your bicep muscle feel, tired or weak maybe? Think about the extra energy required to keep your bicep flexed for just ten minutes now that you get to enjoy the pleasure of being able to relax your arm. The truth is that this pain or weakness plus more is how your child feels with CP.

Parents must realize that when helping young children gain their own independence the child thinks only about the present. They naturally look to a parent or caregiver as someone who cares for them. Children assume that parents will always do this. Therefore, children might not see the need to be independent especially when given a new or different task. When children are young, between the ages of 3 to 5, they are often concerned with exploring their world and making friends. But at this age, the child views her/his parents as always being there and always caring for them. A young child may not see the point of learning a new task. It is important that parents consider this when discussing and encouraging kids of this age. Use a lot of encouragement when setting goals for them. You can say things like, "You can do it," or "let's try this or that." At this age you probably don't want to discuss the fact that when they get older you might not be there to help them with this task. This could cause anxiety in your child.

As children grow and begin school "able-bodied" children begin to learn basic academics. Teachers therefore play an important role. Hopefully your child's teacher will understand your child's limitations and try to identify strengths to build his/her confidence. Parents should be very active in developing a plan with professionals. As a parent, you should be aware that there are many different types of professional people available to help you and your child reach his/her full potential. I always recommend consulting with professionals. Therapists, doctors, and teachers can all provide information as to goals and appropriate expectations for your child. Whenever possible you should look for a primary care physician who is dedicated to working with you. It is important to have the primary care doctor keep track of your child's progress and keep track of what specialists your child has seen as well as the results of therapists and treatments.

What makes professionals worthy of their titles? Simply put professionals have education and experience with working with children and adults with the same medical diagnosis. Professionals have information that should be used as guidelines in the decision making process. The more they work with your child the more trust a parent can have.

When I was young my parents and I remember working with a number of professional people. Some professionals had a better grasp of what I would be able to achieve than others did. For example, my parents were told I should be able to walk independently, yet I was not able to achieve this. Others told my parents that special education was the best place for me. Yet after 2 years I was bored and wondered why we would do the "same things" in school every day.

It is when a child enters school around the age of 5 or 6 that they really begin to notice that they are different. They will probably start asking questions about their limitations and why they are not like other kids they know. This is why it is crucial to tell kids that they are important because of who they are for their personalities. Yes, there may be times when they struggle. If the child has a good sense of who he/she is based on the parent's encouragement,

they will begin to internalize this and hopefully realize that their worth has nothing to do with their limitations.

When kids become teenagers they are normally really excited because they become more independent. However, it is often a really stressful time in many ways for a child with a disability. They often find independence something that they want but have trouble achieving. Children may need the help of others they have come to trust to determine future goals. This will depend solely on the child's abilities and interests. When children become teens they still look to adults for guidance. Disabled teens still deserve to "Dream Big." The only difference is that they need to own their decisions.

When I think of "Dreaming Big," I believe the world is an open door. Possibilities of success are everywhere. Abilities are always emphasized. This should be the goal of every parent to encourage teens to "Dream Big" and pursue their dreams and desires. The only difference with a disabled teen is that they must have dreams grounded in the reality of their abilities. Someday it is my dream to jump out of an airplane and enjoy the thrill of skydiving. The sky is so vast, bright, and beautiful that it is so free and unencumbered that anything is possible. However, for me to do this I have to prepare my body for such a jump. I also need to have the right equipment, like a parachute. But the reality is if I am going to "Dream Big" I must do it with a parachute on. Why? Because I must be grounded in my abilities.

I truly believe that children with disabilities want to function as well as they can. No one really enjoys not being able to do things for themselves. Also children with or without a disability will often time misbehave. Kids will be kids whether they have a disability or not. Sometimes children will use their limitations to try to upset their parents by refusing to do something or take an extra-long time to do something. At this point it is easy to determine if the child is being defiant. Therefore, it is important when we are discussing raising children and teaching them to "Dream Big" to be aware of their abilities. It is also recommended that they have consequences for being defiant.

I want to clarify what I am saying. When you know for certain that a child is able to do a task and is just choosing not to, a consequence is needed. Consequences are used when you want to stop a behavior. For example, because a child chooses not to pick up their toys, they may have the consequence of not being able to watch television or something else they really like to do. Consequences are a good thing when you want to extinguish a behavior. The consequence should always be something the child enjoys doing so they feel a loss when they are not able to do or participate in the activity.

When you are trying to increase behavior and confidence there should never be a consequence because that will end the child's ability to learn new things rather than leading them to trying.

When you want or need to increase a behavior a reward should be given. A reward should also be something the child likes to obtain or do. For example, if your child brushes his teeth by 9:00 he/she can watch their favorite television show. A reward gives an incentive to do something even if it is hard. Adults like rewards as well, such as a paycheck. Tell the child exactly what needs to be done to earn the reward. Be very specific. It is also OK to have a child earn a reward over a period of time (a week or two). Over time you can phase out the reward or choose to work on a different task.

Everyone enjoys a reward. This method works extremely well no matter what a person's age. The only thing to be mindful of is that the type or quality of the reward changes due to age, interests, and maturity. For example, a young child is normally content with earning a sticker while most teens are a lot more concerned with their cellphone and their social lives however that may look. Rewards are encouragement and should be used to increase behavior. Rewards can work to allow people with disabilities and their caregivers to achieve goals.

In addition to offering rewards which build a child's self-confidence I believe there are some "accidental pitfalls" that parents mistakenly fall into. These pitfalls in turn can lead to parents inadvertently destroying the child's view of him or herself. I believe that if you are reading this you are doing so to gain information. I also believe for the majority of parents they would never want to do something to hurt their child. Therefore, just hear me out. As I previously discussed with Cerebral Palsy and other conditions, the body and brain require people to use more energy. Therefore, using the term lazy or saying, "Stop being lazy," is not a good idea. Just turn the sentence around by saying, "I know you are capable and I know you are strong, so you can do what I am asking of you." Another "accidental pitfall" that parents sometimes fall into is constructive criticism. While it is always good to offer ideas about ways to make a task easier, be careful not to criticize, which can lead to hurt, rebellion, and the lack of initiative to try again. It is important to encourage kids to think differently and to use their abilities that they possess to get the task done. Try to encourage while minimizing criticism. The last "accidental pitfall" might seem harsh and unloving and I think that every parent must look at their own situation and evaluate this for themselves. As a parent you want to allow your child to be as independent as possible. One of the ways to sabotage this is by doing too much for them when they are able to do it for themselves. When children and teens know that you as the parent are going to solve their problem, you run the risk of them becoming dependent on you or someone else. If their abilities are such that they truly need your help, then by all means give it regularly. However, when too much help is given it can lessen the message that you are working so hard to instill. Sometimes more patience may be needed as you know that if you step in and help it would save you time and their effort. "Accidental pitfalls" happen because parents and caregivers mean well. Just be cautious of the underlying message you may be sending.



The role of parent or caretaker is not an easy one when it comes to caring for someone with physical challenges. You know as well as I do that many disabilities are on a continuum. Because this is often the case it is really difficult to say for certain what any one individual is able to accomplish. That is where you come in. When I talk to parents and or caregivers they always amaze me not only for what they do on a daily basis but also because they instinctively know the abilities of the person they are caring for. While this book was intended to present some guidelines it is also just as important to not dismiss your role. You as the parent see and know what your child can do. Every day you see the struggles and the victories your child achieves. Please don't let anything you read or anything someone suggests to you to cause you to put aside what you know to be in the best interest of the child. When discussing what is best your child deserves your opinion to count. You need to be the voice for your child and as they grow encourage them to find their own voice. Talk and evaluate with them what is reasonable. We all need to work together and educate one another as to what is best. Disabled people need good support around them. It allows them to have access to a large number of people that believe in them and therefore, their confidence will grow. Then ... they can truly "Dream Big" with a parachute.