

Physical Disability and Independence

Preface

The following article is based largely on my personal experience with Cerebral Palsy, having lived with it for 37 years, and teaching students that have Cerebral Palsy or other physical disabilities. Its purpose is to call attention to the need of disabled persons to be independent. I hope it is an object analysis of some obstacles a disabled person faces on the road to independence.

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After six years of teaching; dealing with students that have Cerebral Palsy and other disabilities and their parents, I have seen both students that are ready to face the challenges of day to day life and students who are not yet ready. But they have the ability to meet them if given a chance. The key in both circumstances is independence or, to put it another way, the need of these students to become independent and thus enjoy life liberty and the pursuit of happiness.

Let's define the general abilities of these students. They are in the public school system, and meet the requirements of their grade level. Many times, though not always, they have a learning disability, and will, at least, graduate from high school. Many of them will go on to college. Those that do go on to college learn to act for themselves no matter what their disability. What happens when these students go to college? Well, and this sounds almost too simple, they leave home. The safe place where help is available without having to explain what is needed, and where almost everything is done for them. As a result, they become independent; they can, for example, make their own doctors appointments, use public transportation, and deal with people as equals. This is key to personal growth and continued independence.

In many such cases relationships between parents and children change, as their child becomes more independent the parents are less the primary care givers or first line of assistance, and their child uses all the means at his disposal before asking his parents for assistance and not permission. It is at that point, the parents' view of their child changes; they begin to support his independence. This is the best of all possible worlds for these students.

The next best thing for those students who do not go on to college is to find some kind of job training program so they can learn independence and act for themselves. Even if they choose neither college nor work they need some kind of help becoming independent, for it is unlikely they will do it on their own. Having Cerebral Palsy myself, I can state from experience it is very easy to get by doing nothing, and letting parents do it all. Parents want to protect their disabled child from society and make life as easy for them as possible. On the face of it, this seems like a good thing, but there is an underlying problem. All too often, the need of parents to protect their child from emotional pain and frustration becomes overwhelming, and leads to over protection. That is, a disabled child in such a system does not know how to function in society.

In such a system, a disabled child never really becomes an adult, and his relationship with his parents does not change. As he grows he stays within the

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boundaries his parents set for him. While he grows physically, socially he does not, nor does he change the way he does things, for there is no need. There is no need for him to change, for his environment, on the whole, does not change. He ages, friends come and go; but his support system stays, on the whole, the same. His universe is whatever is inside the walls of his home; beyond which he does not travel without one or both of his parents. There are ways he could, but those ways are outside his universe. Thus he does not know they exist or if he does he believes their use is beyond his ability. More often than not, that conclusion is reached on very little or no investigation. The first step if any investigation is undertaken is to ask his parents for permission to look into public transportation and/or a personal attendant. Regardless of his age, 16 or 36, if they say no all inquiry stops dead, for they are the atlas of his world.

From the parents' point of view, there is no need for either public transportation or a personal attendant, and they do not understand why their child would ask for such things when they can provide for him. In fact, the parents may find such questions hurtful, though that was not their child's intent and taken with the overwhelming need to protect their child from emotional pain and frustration which leads to over protection; their response is negative. It is likely their response is based on more emotional than practical factors. He perceives the pain and discomfort such inquiries cause his parents; as the years go by he gets the same type of answer to many such questions. Thus, there is no point in asking them.

As a result, these people do not deal with change, for there is no change in their system, or if there is it comes only from the parents. While it is true that a child with Cerebral Palsy or other disabilities may need special attention and as stated above the child has graduated from high school it follows, then, he has the same needs as any other person; moreover, he understands that he has them. Chief among such needs is independence as much independence as his ability will allow. However, it cannot be assumed that his parents will provide opportunities for him to learn independence. More often than not, his parents only see what he cannot do and what needs to be done for him. Independence is something best left to others. These parents have never had to deal with any kind of teenage rebellion from their son. Thus, the stages of social growth and development are stalled. This is not due to any malevolent design on anyone's part. It is based, largely, on their son's ability, for ability leads to opportunity; however, parental over protection does play a part.

The above is known as a closed system, that is, it responds to exceedingly little change if any at all. The most important thing to the parents and their son is to maintain

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it. That is why he does not ask questions nor take any independent action that could hurt his parents' feelings no matter how much he may want to do so. His parents, on the other hand, may be pained by questions that lead to independence, but, at the same time; they want him to do whatever he can, and they still have the need to over protect their son. This leads to unconscious internal conflict within both parents which is not brought out, for their son does not seek independence. His purpose in the system is, in fact, to avoid conflict.

No one knows him better than his parents, so if he needed a personal attendant, or could use public transportation they would let him. The fact they did not suggests, to him, he is unable. This thought process, while maintaining the system, and acceptable for a teenager, is dangerous for an adult. By its nature it surrenders many basic rights and freedoms, and affects all his relationships outside the system. Those relationships are difficult to maintain due to his stalled social development and fear of change. Thus, while his friends are growing into adults he stays a teenager; giving up the freedom to choose.

What can be done to insure a disabled child attains as much independence as his ability will allow? There is no set of guidelines, but there are some basic methods that any parent can use with any child regardless of his disability.

- ❖ ***Allow the child the freedom to fail.*** People learn more from their failure than they do from their success. If he wants to try something let him who knows what he and his parents may learn. Just because something is easier does not make it desirable.
- ❖ ***Make him and/or let him do all he can for himself.*** He needs to learn how to deal with new situations and people—to speak and act for himself. Thus, the people dealing with him talk to him and not to his parents even though he is in the room.
- ❖ ***Our little boy is an adult.*** At some point he should tell his parent things they do not want to hear on a variety of subjects. As parents they should listen and assist, for he will find a way to do what he wants. Frank and open dialogue is the best way to communicate. There comes a time when his parents just will not be able to stop him. The rights of citizen are his too, and his parents must decide either to help him become independent or fight to keep him dependent. If they choose the latter, and their son fights back they will lose and so will he. Dialogue that leads to compromise is the best way to avoid open warfare.

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- ❖ ***Embrace change.*** Change is the only constant in the universe; therefore, it cannot be stopped. It can, at best, only be slowed. A disabled child must not fear change; he needs to prepare for it in any way he can. He and his parents must be open to different ideas, ask questions, and seek any and all resources outside agencies have to offer.

Above all, it is important to separate physical disability from intellectual ability that is, they are not, and should not be linked. The intellectual ability of a disabled child must be developed to its fullest extent. Neither Cerebral Palsy nor any other physical disability should be a reason for not doing something that is mostly intellectual.