

Self-Determination

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I really started to learn about self-determination when I went into an institution when I was five years old. I am one of four children and I lived in three different New York State institutions for a total of 15 years. In the institutions, I had to learn to speak for myself and the other residents because of the attitudes of the staff who worked there. Very early on, watching how people were treated, I decided that I would have to learn to advocate on my own behalf. It was hard at first because I didn't have to do that until that point. Living in the institution is a totally different world than living at home.

The meaning of self-determination has changed for me over the years. When I was in the institutions, I had to make sure I got the basic care I needed, like my personal hygiene and three meals a day, so that was what self-determination meant at that time. There, the caregivers seemed to think people didn't know what they wanted or how they wanted it done. Now, self-determination means running my own life and directing my personal care assistants on how best to assist me in my personal care. Now, people treat me like a human being who knows what I want and who needs support to live my life. They ask me what I want and how I want it done. They also ask me what is the easiest way to get things done, so that I feel comfortable and they feel comfortable as well. So self-determination doesn't mean you have to do everything yourself, but it does mean you have to be in charge of your life to the fullest extent that you possibly can be.

It may seem like some people can't understand how to make decisions for themselves. I think that is because they have never had the opportunity to learn how to do it. If you've always been sheltered in terms of life experiences, you may not know enough to make the right choices about your life. If you've been told for years that you don't have the right to make choices, you will start to believe what you are told. It has to be confusing to people who have been told for years that they don't have these rights, and who are now told that they do. For example, when I first moved out of the institution and into a supported apartment setting, they told us we had the right to make choices. One of my roommates asked, "What's choices?" It's a shame but that's how it was. When you live under an agency or an institution, they tend to think they know what you need without bothering to include you. And this is why so many people with disabilities feel that they can't make choices, because every time they voice their opinions, the staff or the agency or their parents disregard what they have to say and go ahead and do what they want to do rather than what the person wants.

What I consider to be self-determination for people with disabilities is to work collectively, with the person with the disability at the top. The person's family members, friends, agency staff, and anyone else the person wants involved become the collective, along with the person themselves. They make the decisions together, with the person at the top, doing it with the person instead of having it all set up beforehand. Self-determination is not having everything

done for you because then you're not learning to do it for yourself. We have to be allowed to learn about life, make mistakes, and fall on our faces if need be. For example, I made a decision a couple of years ago to move to Georgia with my roommates. That didn't work out at all, and I felt like I had fallen flat on my face. But it really made me stop and realize that what I had before was better than I had thought it was, and I was fortunate to be able to come back and make a new life for myself. When I came back, I looked at things in a totally different light, and because of that my life is a lot better than before I left. One thing I learned is that you can't be afraid to ask for help when you need it. Asking for help is self-determination, too.

It is not self-determination when everybody makes your decisions for you, tells you where you are going to live, what house you can live in, what neighborhood you can live in, what clothes you should wear, what food you can eat, how much money you can spend and what you should buy. Why do people without disabilities feel that they have the right to become independent and self-determining but people with disabilities don't have that right? By not letting someone take a chance and experience life, professionals and parents make the biggest mistake they can make, because before a person becomes self-determining they've got to go through some trials and tribulations of just life itself like anybody else. Instead of doing everything for us and protecting us from life, people should just be available if and when we need help. And they shouldn't discard us if we don't want to take their suggestions, because we can't set up our lives like they set theirs up.

What people need to realize is that self-determination can be different things to different people. All people should have the opportunity to be self-determining, based on what that means for them. They might need some guidance, they might need some help, but that doesn't mean they ought to be shut out of opportunities to have their life. Everybody needs some support at one time or another, I don't care who you are. What's important is to focus on what you can do, what you are good at and like to do. When you are getting supported, you have to take the initiative to tell other people what you want, what you need, and the supports you will need to live the way you want.

The Center on Human Policy has available a variety of reports and resources on community integration. For a list, please write to :

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