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**Caring for Persons with Intellectual and
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Ethical and Religious Perspectives

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Inside Out not Outside In – A Change of Attitude for All

**A Self Advocate’s Vision for Those with Intellectual and Developmental
Disabilities**

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Abstract

A person with intellectual and developmental disabilities reflects on his own experiences with himself and others.

Keywords: developmental disability, intellectual disability, treatment by others

Introduction

I want to share my life experiences with you and help you understand how my learning and developmental disability has shaped my life. These are the thoughts and feelings I have *inside*. I would like you to understand how people's perceptions and attitudes about this disability can be positive and negative. These are the thoughts and feelings *outside* of me which belong to other people. Sometimes these beliefs and attitudes do not help me and often they are not how I think and feel.

I am now going to describe who I think I am, what I would like to do with my life, what help I need to live happily, and what changes need to be made to help me and others like me succeed. For you to understand the "inside out of me" and the "outside in of me" I am also going to tell you how others often describe me, what they think my future will be, what my society thinks I need, and what currently happens to me in my life.

When I finish sharing my thoughts with you, I want you to check your own feelings and find out if you view people like me with intellectual and developmental disability from the "outside in" or from the "inside out." I am hoping that you can always understand and know the "inside out." That would make a big difference to me and many others like me.

Who I Am

I am a single Canadian man, 38 years old. My closest family members are my mother and father, two older sisters, a brother-in-law, and my little niece. I have many aunts, uncles, and cousins in Canada, the U.S., Ireland, and the Middle East. I have been able to travel to see many of them. I live in my own apartment in my parents' home and I have a part time job. I work at a movie theatre as an usher and I emcee the World Wrestling Entertainment Pay-per-View events there. I am a keen cyclist, an avid bowler, and was on the winning team last year! I am actively involved in my local Community Living Organization and have emceed some of their annual events.

I am learning to be a self-advocate. I sit on the Community Transitions Network in my City; this helps find opportunities for young people with disabilities who are leaving school and educates their families about community resources. For the last six months I have been training to be an interviewer for a research project led by researchers from McMaster and Ryerson Universities, here in Canada. The topic of the research is *Reimagining Parent Possibilities: Developmental disability, support and the lived experience and expectations of parenting*.

I like to go out socially – I enjoy playing videogames and I like to babysit my niece. My cooking skills are still limited – due to lack of practice! If you met me you would appreciate my sense of humor, and I hope you would recognize my impersonations of famous people.

How Others Describe Me

First, I will tell you the negative opinions I receive. Some people describe me as a retarded single male with juvenile diabetes, scoliosis, and severe acne, who has particular difficulty with organizational tasks, coordination, and math skills and difficulty finishing work on time. They say that I have limited potential to find full time employment. As a child, I was considered unteachable by one grade school teacher. Other people laugh at me

because I still need support from my parents. Some do not appreciate my frustrations when I do not always understand what is being said to me.

Now let me give you the positive opinions. Others find me kind, humorous, fun to be with, a good friend, and a hard worker. My friends trust me and know me to be responsible, reliable, and loyal. I manage my diabetes independently along with my health care team.

What I Would Like to Do with My Life

I would love to have a girl friend and a family of my own someday. I would like to be able to use my community college training to find more interesting, permanent, and better paying employment. I would like to have my own apartment away from my parents' home and improve my independent living skills. I would like to be able to stop worrying about my future, especially what will happen to me if my parents pass away. I want to develop advocacy skills as I want to break down the barriers in society so people with special needs can have a rewarding life. I want to make sure I continue to control my diabetes so that I do not experience complications. As I love travelling, I will take any opportunity to visit other places and countries.

What Others Think My Future Will Be

I have been told to be happy with what I have and accept my disabilities and that I am not clever enough to get full time work. I am told to stop worrying about my future and that it is okay to depend on my parents. Very few people see a different future for me; they always stress my limitations and not my potential or dreams. I am always reminded that there are limited opportunities for people like me with developmental disabilities. I struggle to show them that I have many abilities and am no different in my expectations of life than a man of my own age without developmental disability.

What Help Do I Need to Live Happily

I am trained to be a personal support worker and was told I have special skills with people who have severe behavioral problems. I would appreciate if employers were prepared to provide more support for me as I start a job and that a job coach was available during the orientation time in a new position. As work situations are always changing, I would like to know that job coaching was available on request and not for only a short period at the start of my first employment. In Canada I receive a disability pension for which I am very grateful, but staying within its funding rules will always keep me in poverty and unable to live independently of my parents. This is because I am not able to keep all of my small wages; there is a draw back if I go over a certain limit. The amount allowed is not enough to live on. I see these rules as punishing me for my disability and trying to work hard. I believe that if there had been better inclusion and social integration in my school life, everyone would have benefitted. Now I would like to see that our governments award employers for supporting persons with disabilities get job opportunities. Although I know that my family members will continue to support me when my parents pass away, I wish that we had more community support workers and public housing policy that ensured that I would have a safe affordable place to live.

People Who have Made a Difference in My Life

I would like to tell you about some of the people, apart from my family, who helped me to become the person I want to be and who always saw the “inside me.” I do not know how they came to be that way, but I can tell you how they treated me and how they made a difference in my life.

My best friend always treated me like everyone else; he included me in all his activities, we shared a sense of humor and we have stayed close friends for 26 years. I was part of his wedding party and have always felt welcomed by his family. I had a very special teacher at vocational school who believed in my potential and helped me discover that I could learn to read and write. She insisted I work hard but helped me at every step along the way. She helped me feel proud and successful and I learned that if I worked at something it was possible to learn more. She never gave up on me!

One of the patients I helped at a nursing home had severe behavioral problems. I learned to calm him down because he taught me that difficulties with or lack of communication makes people very frustrated and that we have to understand what somebody else is experiencing.

I have also helped “a little person” (someone with dwarfism). At first I was his special needs worker but now he and I are firm friends. I have learned to appreciate his strength in facing many more challenges than I have met and to endure his developing blindness. I respect his lively spirit and optimistic personality.

I am very grateful to my employment counselor who actually stayed with me as I tried out a job placement. This gave me confidence and made me feel comfortable in a new work place. One woman in particular had confidence in me and recruited me as a member of the Community Transition Network in our Hamilton Community. She saw my potential and created an opportunity for me to participate and contribute information about my relevant life experiences. She enabled me to give back to my community.

What You can Do to Help People with Intellectual and Developmental Disabilities

When I was young my special heroes included Batman. Batman used his brain and gadgets to solve problems and believed that it was not enough to think about something; it was the actions you took that defined you. R2D2 from “Starwars,” who, although he is small, helps when needed and saves the day; Hulk Hogan, who told me to believe in myself to overcome life’s obstacles; and John Cena, who told me never to give up and always be prepared to fight for success. I know that people like me need help along the way.

Here are some of the actions that really make a difference:

- Treat me like an equal, include me and ask for and value my opinions.
- Give me the time to put these together and express them.
- If I have difficulty understanding you, be patient and find a way for us to communicate more successfully.
- Respect and recognize my skills.

- Help me to succeed as best I can.
- Do not talk about me behind my back. I like to laugh with you but not to be laughed at.
- Please do not describe me as a disability, I have a name and am more than your label.
- I have many medical problems but I do not appreciate being told that they cannot be helped simply because I also have a developmental disability.
- Some physicians give up on people like me. This is not helpful. Understand that I have dreams and hopes; please help me to make them a reality.

If we all work together on this advice, then I know that the *inside out* of people will be appreciated and the *outside in* perspective will fade away.