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Respecting Disability While Focusing on Ability:

How to be a Successful DSP

By: **Regis Obijiski**
Perry Samowitz

How does a direct support professional (DSP) find the right balance between understanding and supporting a person's intellectual disability, and encouraging their ability to do things for themselves, while enriching their emotional intelligence, and promoting disability pride?

Recently, Hilda, a person with intellectual and physical disabilities, invited me to her home for dinner. She wanted to show me the progress she was making after a hospital stay as a result of a serious fall. For the thirty years we were friends, she was always comfortable in her own skin and was equally comfortable under everybody else's skin. Social dominance was one of her personality traits in spite of her limitations usually being more obvious to those she tried to control than to herself. In the past few months, she lost much of her usual edginess, and her speech became so slurred that I had to rely on her Direct Support Professional (DSP) to translate. Hilda's words that made no sense to my ears flowed beautifully through Tommie, the DSP: "With a little help from Tommie, I made a really good meatloaf just for us. You better like it." The three of us laughed. Hilda was determined to be a good host and to be herself, and Tommie's keen understanding and skills helped Hilda accomplish that and continue to thrive, even while experiencing physical problems. He helped her to better relate to the feelings of others and only provided support as needed.

Editors: **Dave Hingsburger, M.Ed.**
Angie Nethercott, M.A., RP



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A Balancing Act

In general, DSPs need to understand and respect a person's intellectual disability while supporting the person's dreams, desires and abilities, as well as also helping to enhance skill development. This balancing act is not easy.

What does all this mean to the person with a disability? How does it affect their self-concept? What does it mean for the DSP to respect the disability while focusing on the person's abilities? How does the DSP know when to do something for a person and when to do something with the person? How does the DSP help a person become a productive member of society while helping the person learn to better interact with others?

In the United Kingdom, instead of referring to a developmental disability, professionals use the term learning disability which has a different meaning than in the United States or Canada. We believe the UK description is more easily understood. People with intellectual disabilities are indeed slow learners depending on the person's level of cognitive ability, and also their emotional intelligence. Indeed, it is important to understand a person's zone of learning, how the person understands concepts, words, pictures, etc. Unfortunately, it is common to underestimate an individual person's unique learning abilities and processes. Knowing a person well means paying close attention to what is expressed, the manner in which it is expressed, and how communication is received. A little tweaking of the language, using pictures, non-verbal cues, etc. can make an important positive difference in the quality of social, academic and vocational aspects of a person's life, as well as how they understand themselves and feel about themselves in each of these areas.

The Danger of Generalizations

While there is a wide variance of abilities among people with intellectual disabilities, DSPs and other professionals tend to think that those with greater cognitive abilities are most able to understand their intellectual disability, and its many effects on self-concept. Conversely, it is widely believed that those who need the most amount of support are least likely to understand their intellectual disability and what it means. There is only some truth to these generalizations. Our life experiences reveal that some very smart people have little common sense, a low self-concept, and uncontrollable emotions. We also know people labelled with a low IQ who seem to handle life's unexpected curves with acceptance, evenness and compassion. Emotional intelligence, an important aspect of our common humanities is, in fact, experienced at different levels without respect to levels of cognitive intelligence.

Benny has been a strong self-advocate for most of his adult life, but he admits to feeling wounded and defeated when treated by some people in the community as unworthy or inconvenient. His hurt sometimes turns to anger, and he would lash out about his rights being violated. Wisely, his DSP asked Benny how he would rather be treated; he listened to him, validated his feelings, and suggested that he respond in a way that matched the respect he himself would like to get from people. Now, when Benny senses impatience and rejection about to come his way, he says aloud, "Thank you for having patience with me; sometimes it takes me a little longer to understand certain things, but eventually I get it. I appreciate your time." Benny told his DSP, "It really works. I take a deep breath. I say these words and mean them. The other person seems to relax and ends up treating me nice."

Emotional Intelligence

How does emotional intelligence (EI) play such an important role in how we live our lives? EI is the relative level of ability to observe, understand, and respectfully manage one's feelings in various circumstances. Observing what sparks certain strong feelings (e.g., desire, love, anger, shame, unworthiness, etc.) in ourselves is the first step to self-understanding. All of us need help with this from time to time. Managing those feelings out of self-respect and respect for others is the second and more difficult step for all of us to learn – a DSP and person with a disability alike. It is possible for everyone to improve EI and engage more effectively in our relationships – the context for all human life.

At its root, human dignity is a given. It is not attached to financial worth, one's IQ, physical appearance, or the length of a resume. All people should have pride simply in who they are. In human services, pride comes from understanding and appreciating an intellectual disability as an integral part of a person, and that person should be helped to value and love all parts of themselves. Not being able to discuss an intellectual disability might cause a person to feel ashamed. While having an intellectual disability is only one part of a person, ignoring it can be destructive. Also, each person with an intellectual disability should have the opportunity and encouragement to live a life in a way that they value as long as there is no high probability of harm, abuse or exploitation.

Many years ago, as a supervisor of a group home, I supported a young adult woman with a disability whom I will call Mary. She was a very nice person, well-liked by all and seemed to enjoy her life. One day, a shaken staff alerted me that Mary mentioned that she wanted jump off the roof of the apartment building where she lived. They immediately brought Mary into my office and she said something to me that made me realize that I knew very little about her feelings regarding her intellectual disability. She said that she wanted to hurt herself because her younger sister had gotten into college and she was unable to go to college. Mary felt ashamed of her intellectual disability and thought of herself as not having worth. She was not proud of who she was. A short time later, Mary received a letter saying that her government disability checks might be discontinued. I had to escort Mary to a government hearing in support of her continuing to receive her checks by proving she has a disability. In preparing Mary for the hearing, I was concerned that her listening to proof of her disability would hurt her. We discussed her disability, what it meant, and what she was able to achieve in her life. We won the hearing, and I vividly remember walking with Mary toward the van when she took my arm with her hand and said, "Thank you for treating me like an adult." After, Mary seemed to thrive. She moved into her own apartment and got a job in the World Trade Centers in Manhattan. On 9/11, she walked down over 50 flights of stairs arm in arm with another worker just before the buildings collapsed, and they both survived. While understanding her disability, she utilized her abilities to save herself.

And Finally...

In summary, DSPs need to respect the person they support for who that person is – someone who has an intellectual disability, as well as unexplored abilities. Does the DSP help the person to know that having a disability is not shameful but rather a source of pride? Likewise, a DSP needs to analyze a person's emotional intelligence. Is the person too self-centered and, therefore, has difficulties in forming friendships? Helping the person to understand how to relate to others' feelings and concerns will offer that person a chance for a more enriched social life. Finally, a DSP should always view the person as having a unique set of abilities, able, with varying degrees of support, to have a life where learning and achievement is a life-long process.

About the Authors

Regis Obijiski was the CEO for many years of New Horizons and has worked in the field of developmental disabilities for over four decades. Following his retirement, he initiated and ran a multi-year project for the New York State Office for People with Developmental Disabilities helping to transform the workforce from caregivers to support professional. He recently retired.

Perry Samowitz was the Director of Education and Training at YAI in New York City, working to support people with developmental disabilities for almost four decades. Upon retirement, he joined Regis in the workforce transformation project and is still working on the project.

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