
CENTER FOR DISABILITIES AND DEVELOPMENT

Possibilities in Education and Training

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Communication Training Opens New Windows to the World for Rock Valley Resident

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“I wanted to be able to talk to my brother.”

That was Deb Rensink’s wish. Her brother, Randy Mouw, has lived with deaf-blindness for most of his life. Thanks to a natural disaster, forward-thinking people, a spirit of cooperation, and Randy’s determination, Deb’s wish is coming true.

Randy began living at Westview, a six-person Hope Haven Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/ID) in 1991. Westview flooded in 2014, forcing residents to move to a series of makeshift living environments until suitable arrangements could be made. Randy eventually moved to a house which he shares with three roommates.

“The transition took its toll on Randy,” explained Hope Haven Community Living Manager Kimber Patterson. “Staff became very protective during the series of moves, and that tendency continued once Randy moved in to his permanent home. As a result, he was not encouraged to explore and familiarize himself with his new environment. Randy became further isolated because staff no longer used the signs which he depended upon for communication.”

The transition triggered a series of events which ultimately led to new opportunities for Randy to interact with the world around him. First, it opened the door for Randy to become eligible for Money Follows the Person (MFP), a program which provides one year of intensive supports to Medicaid recipients on select waivers wishing to relocate from congregate facilities to community-based settings. Shortly after he entered the program, Randy’s MFP Transition Specialist, Sherry Stowe,

observed a communications training in Randy's new home provided by staff of the New York-based Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC). At about that same time, a nurse working in Randy's home informed Rensink that Randy was vocalizing at night and not sleeping.

"She wanted to give him a sleeping med," Rensink told me. "I didn't like that because I didn't want him walking around in a fog. I reached out to Sherry to discuss options."

"I told Deb about the training which I'd observed and a follow-up conversation with HKNC regional representative Beth Jordan about a week-long "immersion training" offered at HKNC headquarters," explained Stowe. "She was very receptive to the idea, so we began the planning process."

Though there were "bumps in the road," Rensink and Stowe persevered. In September, 2016, Randy and his support team traveled to New York to participate in the training.

"It was very intense, and highly successful," commented Patterson. "By noon of the first day, Randy was lifting his hands up to accept signs. He quickly learned practical signs such as names of individuals close to him, allowing him to know with whom he's communicating. It was rewarding to watch him unfold before our very eyes."

"The immersion training helped us reshape the way we think about Randy," Patterson continued. "On the very first day at breakfast, they asked, 'How does Randy communicate?' We told them, 'Staff does that for him.' We learned throughout the week that it's Randy's job to communicate and our job to understand what he's telling us. We realize now that when he vocalizes, he wants someone to engage with him. If he hits a pillow or rocks back and forth, we do that with him so that he knows someone is with him. We've gone from seeing him as a "grumpy old man" to a social guy."



Deb is enjoying communication with Randy in very practical ways. "He knows me now!" she says with excitement. "He's much more relaxed and trusting in social situations. In the past, he was very protective of his food. Now, I can sign things like 'my plate,' 'your plate,' or 'food is coming.'"

"As a transition specialist, it was great to see everything come together," commented Stowe. "It was a big deal for Hope haven to send two staff members to New York. Multiple funding sources, including the Conner Training Connection, the Iowa Department for the Blind, and Randy himself partnered to make it happen."

Patterson and Rensink succinctly summed up the events and benefits reaped from the past three years. "It (the immersion training) was the opportunity of a lifetime for both Randy and me," says Patterson. Adds Rensink, "I can communicate with my brother!"

The Disability Resource Library ... Empowerment Rules!

High school transition that works! Lessons learned from Project SEARCH. Daston, Maryellen. Baltimore, MD: Paul H. Brookes Publishing Co. (2012).

Project SEARCH is a school-to-work program based on total workplace immersion of one year's duration. It is for high school graduates with intellectual and developmental disabilities. During the SEARCH year, participants engage in classroom instruction, career exploration, and on-the-job training and support. With hundreds of sites now participating around the world, the authors quote a 70% positive employment rate.

Prosody intervention for high-functioning adolescents and adults with autism spectrum disorder: Enhancing communication and social engagement through voice, rhythm, and pitch. Dunn, Michelle A. London; Philadelphia, PA: Jessica Kingsley Publishers. (2017).

Communication is part and parcel of modern life. Prosody is that element of speech that gives your voice appeal and intelligibility to other listeners. Laconic, somnolent, or piercing voices won't win you any fans, but your voice can be modulated with practice. This book presents the anatomical dimensions of voice, and the tools for assessment and training that are available to an individual.

The PEERS curriculum for school based professionals: Social skills training for adolescents with autism spectrum disorder. Laugeson, Elizabeth A. New York, NY: Routledge. (2014).

The PEERS program is a highly recommended evidence-based curriculum to help American school systems work with young people on the spectrum in age-based groups to establish friendships and collaboration.

Functional communication training for problem behavior. Reichle, Joe & Wacker, David P. New York, NY: London: Guilford Press.

Problem behavior, taken to the extreme, requires a systematic plan of action. This book is all about teaching socially acceptable behavior to those individuals who misbehave or self-injure themselves by giving them a carefully constructed voice through choice.

Standing together and finding a voice apart: Advocating for intellectual disability rights. Rich, A. Washington, DC: AAIDD. (2015).

“Systematic advocacy explained in three parts: 1) Advocacy theory and social movements; 2) What unites IDD rights advocates and the differences across social and professional roles and identities; and 3) how advocates and social movement actors live advocacy, and how they go about making change by acquiring and using power.” –chapter 2

The capacity contract: Intellectual disability and the question of citizenship. Simpican, Stacy Clifford. Minneapolis, MN; London: University of Minnesota Press. (2015).

“Taking seriously democratic promises of equality and inclusion, The Capacity Contract rejects conceptions of political citizenship that privilege cognitive capacity and, instead, centers such citizenship on action that is accessible to all people.” --cover

*“Speech has power and few men realize that words do not fade,
what starts out as a sound ends in a deed.”*

- Rabbi Abraham Herschel

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