

Social Work Today
Person-Centered Thinking in Developmental
Disabilities — Dreaming Possible Dreams

By Lynn K. Jones, DSW

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People with developmental disabilities dare to dream outside the box of standard social services options with the guidance of astute, creative professionals, family, and community.

“I have a dream today...” intoned Martin Luther King, Jr., as he painted his vision for America’s future. From that moment, America was changed. The power of that dream publicly shared with a crowd on the Washington Mall continues to be felt 40 years later, reverberating through the message of hope that set the tone of Barack Obama’s election.

Trying to understand the dreams that people have for their lives is not foreign territory for most of us; as children, we were encouraged to dream. What child wasn’t asked the question “What do you want to be when you grow up?”

But dreams are still denied to some groups of Americans. Rarely have people asked those with developmental disabilities what dreams they’ve had for their lives. Their futures, limited by the reality of their disabilities, have been about finding suitable options within the social service system. For many, these options have been based on what is available among institutions and group homes, sheltered workshops, and day programs, not on their dreams. Instead of being encouraged to dream about their futures, they have been forced to grapple with the realities of their disability and how it defines their lives.

Susan L. Parish, PhD, MSW, an assistant professor at the University of North Carolina at Chapel Hill and director of the Developmental Disabilities Training Institute at the University of North Carolina, explains it this way: "Honoring the desires of the individual and his or her family is a vastly different proposition from putting a person into a residential facility and then giving them whatever that facility offers. In some facilities, if occupational or speech therapy is offered, then the person will automatically get that. That is a different approach from saying, 'Well, here is an individual, and what is it that they want to achieve with their life? What can we scaffold around them to help them to achieve their desires?'"

An Appreciative Perspective

Shifting thinking about people with developmental disabilities from their deficits to appreciating what they have is at the core of person-centered thinking and akin to social work's strengths-based approach.

Angela Amado, PhD, has been working on implementing person-centered approaches for people with developmental disabilities for the last 20 years. She explains how a person-centered approach differs from the familiar systems-centered approach: "In a system-centered approach you see someone as a client and focus on their deficits and their needs, which lead you to certain conclusions as to what kind of treatment the client needs or what kind of support the client needs. In a person-centered approach, we see someone as a person first, not someone who is defined by their disability. By understanding who this person is, we see the person in terms of the person's capacities; we appreciate the person for what the person can do, for the gifts the person has, and how the person can contribute to others. This shifts thinking to how can we help the person have as normal a life as possible.

This does not mean ignoring the disability but rather supporting it in as normal a way as possible. The focus is on supporting the personhood as much as possible.”

Stephanie Beck, MSW, LCSW, is a clinical director in North Carolina who works from a person-centered perspective and explains how supporting personhood alters the focus of social workers: “The individual has the right, and we have the responsibility. You talk to people who just want to go to school or just have guitar lessons. Our responsibility as social workers is to identify the steps to achieve what they want. It is like an onion. We have to peel the layers away to see what the steps are. All the steps are the barriers that have prevented the individual from achieving their dream.”

Dreaming the Possible Dream

How does one begin to find out another’s dreams, especially someone who has been bombarded with the message that dreams are limited by a disability? Amado says it is not easy. “Some people with developmental disabilities don’t talk; some just say what they think is available in the services system,” she explains. “I met a woman once who lived in a facility with 24 beds. I asked her, ‘What do you see as your future?’ She responded, ‘Well, first I’m going to a waiver home then independent living.’ She had all the system categories down. That was what she had learned. But it wasn’t her dream. If you separated out what was offered to her in the system, what she really wanted was to live in her own apartment and get married.”

Helping people with a developmental disability dream involves being an astute listener. “You have to see underneath the first thing people say; you have to listen for the unsaid,” explains Amado.

Some social workers who are helping people with developmental disabilities to dream begin by taking all the traditional service options off the table. This forces the person to think about what else may be in their future beyond the service system.

Expanding the Possibilities

“Our understanding of what is possible for people with a developmental disability keeps expanding,” explains Amado.

Sue Harding is an example of a woman who has been helped to dream about a life that few would have thought possible for someone with a developmental disability. Patti Scott, the CEO of an organization in New Jersey that supports people “to live the life they want to live,” helped Harding figure it out. Scott explains: “I first met Sue in 1998. She was living with her parents. We spent a number of months planning for what she wanted her life to look like. Because of her disability, she needed help with some basic self-care and in tasks like cooking. We put together a plan where she would move out of her parents’ home and would live with someone who did not have a disability and could help her in the ways that she needed help. We were all set to submit her plan to the state when she called and said, ‘I have decided I want to be a nun. Don’t tell my parents.’ She had done some paid work with the Sisters of Mercy, and it turned out she had been secretly dreaming about being a nun since she was 8 years old.”

Sometimes articulating the dream is the first step in making it happen. When Scott and Harding asked the sisters whether Harding could join their community, the idea seemed out of the question at first, but they figured out a way. Today, Harding has been an “associate” in the Sisters of Mercy community for the last 10 years. As part of her duties, she attends associate

conferences, does some computer work for the community, coordinates volunteers, and answers the phones. "I may not officially be a nun, but I pray with the sisters, and I had a private ceremony with God. I do everything with the sisters," Harding says.

Scott says that Harding has a "reciprocal relationship" with the sisters. With the supports that she has developed through the Sisters of Mercy community, the staff support that she needed dramatically diminished. In fact, she hasn't needed any extra support for the last three years. She has developed a rich social life, including singing around the state with several sisters in a group they formed called Tender Mercy.

Actualizing New Futures

Actualizing the dreams of people with developmental disabilities involves including the people who love them, care about them, and have been a part of their lives in some way. In Harding's situation, these people included the Sisters of Mercy and her parents. Initially, she hadn't wanted to tell her parents about this dream. When they learned of her dream, however, they supported her.

"A group of committed people come together to create a life of meaning and purpose on behalf of the individual with a developmental disability. If the people care about the person, they generally are willing to think more," explains Amado.

Amado helped the mother of the 24-year-old woman, who could only dream about going to a waiver home, gather all the people who loved her daughter. This included her daughter's "babysitter" from her teenage years. During the meeting, Amado determined that the woman had been the happiest when she had a relationship with her babysitter, who really loved her. "We

found this out by asking questions of the group: ‘When was she the happiest in her life? When did she flourish the most?’” Amado explains.

The meeting resulted in an arrangement for the woman to move in with her beloved babysitter, her husband, and their new baby. The money that would have been spent paying for a caretaker went instead to the babysitter, allowing her to be able to stay home and take care of the family’s new baby instead of going back to work. It was a win-win situation for everyone.

Systems Transformation

Person-centered thinking is transforming whole systems of care and organizations that serve people with developmental disabilities.

The Tri-Counties Regional Center in southern California is responsible for developing plans and providing services for more than 10,000 people with developmental disabilities within its three-county service area. The center is an example of an organization that has been transformed by creating “a person-centered thinking culture.”

Omar Noorzad, PhD, the center’s executive director, explains that they are committed to doing more than just consistently and successfully meeting basic assurances—the clear, nonnegotiable requirements that keep people safe, healthy, and protect their basic rights. “We need to also have the skills, actions, and practices that will support the vision of the future for each person that we serve,” he says. “This entails changing from a consumer mindset to an informed and active citizen mindset. Increasingly, people tell us what they expect: It is that meaningful and individualized results are paramount. Person-centered thinking is essential to achieving these outcomes.”

To see people with developmental disabilities as informed and active citizens rather than consumers of services is a dramatically different view. Just as King dreamed of a future when black children would not be judged by the color of their skin, today a new future is being constructed for people with disabilities to dream possible dreams.

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Key Values and Principles of a Person-Centered System

A person-centered system involves person-centered thinking, planning, and organizations. These guiding principles apply to the system serving all people who need long-term services and supports, and their families. A person-centered system acknowledges the role of families or guardians in planning for children/youth and for adults who need assistance in making informed choices.

To be person-centered means the following:

- treating individuals and family members with dignity and respect;
- helping individuals and families become empowered to set and reach their personal goals;
- recognizing the right of individuals to make informed choices, and take responsibility for those choices and related risks;
- building on the strengths, gifts, talents, skills, and contributions of the individual and those who know and care about the individual;

- fostering community connections in which individuals can develop relationships, learn, work and produce income, actively participate in community life, and achieve their full potential;
- promising to listen and act on what the individual communicates;
- pledging to be honest when trying to balance what is important to and for the person;
- seeking to understand individuals in the context of their age, gender, culture, ethnicity, belief system, social and income status, education, family, and any other factors that make them unique;
- acknowledging and valuing families and supporting their efforts to assist family members;
- recognizing and supporting mutually respectful partnerships among individuals, their families, communities, providers, and professionals;
- advocating for laws, rules, and procedures for providing services, treatment, and support that meet an individual's needs and honor personal goals; and
- endorsing responsible use of public resources to assure that qualified individuals are served fairly and according to need.

— As adopted by the North Carolina Department of Health and Human Services Long-Term Services and Supports Cabinet