

## Envisioning the Future of Supports for People with Disabilities

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How often we wish for the kind of wisdom a crystal ball would offer. Wouldn't life be easier if we knew on the first date where this relationship would lead, could predict our grade before we signed up for the course, or see our children happily established in their adulthoods? What if we could see what the world of supports for adults with intellectual and developmental disabilities would look like a dozen years from now?

One of the things I love about working in this field is that I feel a sense of discomfort when I think about all the well-intentioned work I have done over the years. It's good to be uncomfortable? It can be -- in this case it means that things are constantly changing; it means we are learning from people with disabilities and their families how to do better with them, for them, and for our communities.

So, why do I cringe when I look back at my early work in support of people with disabilities? While I wasn't doing anything awful in the first years of my career, nor did I offer the kinds of supports I would be proud to bring to people today. My first job in the field was as a direct support person in a group home for ten men with intellectual disabilities. Together, we had a great time – we cooked big meals, explored our town and went on trips to baseball games, county fairs, and on just about every imaginable kind of adventure. We all learned some important things in the process. The downside was that the power differences between the “staff” and “clients” were well accepted. We had a lot of fun together but clearly then, staff were in charge. **We** were the teachers – **they** were the learners. I soon learned how often those roles were reversed and the importance of people with disabilities being in charge of their own lives.

Toward the end of my time at the group home, I returned from a vacation to London, bringing back a small gift for each of the men who lived in the home. I showed Chris the keychain of the double-decker bus that I had brought for him and, wanting to capitalize on every teaching moment, I said, “So, Chris – what's *different* about this bus than the kind of buses we have here?” Chris took a moment. He carefully studied the keychain. He turned the little bus this way and that, glancing up at me to see if I might be trying to trick him. Finally he said, in a voice that conveyed wonder at why I would even be asking something so obvious .... “It's smaller.” It was among my first lessons toward understanding that teaching and learning go both ways. While the supports we offered the men who lived in that group home came from the heart, I now look back, embarrassed by the degree to which we as staff held ourselves out as being more important and more powerful than the people we supported. And today, I cannot imagine thinking that ten people who didn't know or choose each other would be able to live the lives they wanted in a big house, all together.

What will services and supports for people with intellectual and developmental disabilities look like ten years from *now*? What changes will cause us to wince in looking back from that vantage point? Acknowledging that things are changing more, not less rapidly, we can assume we will look back and wonder what we were thinking when we recall the supports we are certain are so forward-thinking today.

How do we articulate a vision for the lives of people with disabilities if we don't know where trends will take us? Unfortunately, we don't have a crystal ball – but if we did, what would a gaze into those murky depths tell us about the lives of people with disabilities and the services that support them a dozen years from now?

Here are my guesses – or more accurately, my hopes – for a better future for people with disabilities and the supports we provide:

- ❖ **People and their families will be less willing to accept standard packages of mediocre services and will demand quality supports that help them achieve self-directed lives and self-selected goals.** We will understand that people with disabilities no more want or deserve (or will accept) lives that are tedious and lack meaning than would anyone else. People will be fully included in their communities and have full and meaningful lives pursuing interests and work that challenge and engage them.
- ❖ **More resources will be available for people living with their families and in their own homes –** It has always been the case that the vast majority of people with disabilities (both children and adults) live at home with their families. We need to better support people who live at home and their family members so that both have good lives with each other and apart from one another as they choose.
- ❖ **We will do for people what they want and ask for, rather than what licensing or other standards say are needed. We will document the information that will be useful for that person rather than doing for people what needs to be documented.** We will keep in mind that Martin Luther King, Jr. said, “I have a dream.” He did not say, “I have an annual plan, a bunch of uninspired quarterly goals, and a three-pound pile of paper that keeps track of it all.”
- ❖ **We will realize that you can't give what you don't get –** we will stop expecting staff of agencies that support people with disabilities to treat the people they support as valued, respected people, who have every right to have impact on their worlds while working within organizations that offer *them* so little of the same. Both parties need to be treated with respect and offered lives of impact and meaning.
- ❖ **Society will be just as unwilling to tolerate the abusive treatment of people with disabilities as they are the mistreatment of others.** I hope for a day when, if information became known about substandard treatment for people with disabilities, the public would rise up with the same energy and outrage as when the abuses of prisoners at Guantanamo and Abu Ghraib became public. Our tolerance of a different standard betrays the degree to which people with disabilities are still inherently devalued.
- ❖ **We will offer an array of supports that is responsive to what people want ...** not a support system that still contains relics of old models just because it is hard to find the momentum to rid ourselves of inherently controlling and coercive approaches. Our support system will not be built around the ways funding is provided. In architecture there is a saying, “Form Follows Function.” It means that structures are designed in response to the ways they will be used. In our field the influencing principle has been “Form Follows Funding.” Do we think opening another group home is a good idea? No, but we'll do it anyway if funds are available. We will rid ourselves of the ball-and-chain of traditional funding streams and celebrate when the ‘form’ of supports is directly responsive to the needs and desires of the person requesting those supports.
- ❖ **We will offer supports in ways that acknowledge that people have needs and interests that are interconnected.** “Day providers”, “residential providers” and “employment providers” will be terms from a day gone by. We will realize that even the term, “Provider” conveys a power differential – we provide; you accept, and gratefully. We will instead become “Offerers” of supports that are responsive to the needs and dreams of the people who choose to accept support from us. People need

a place to live; meaningful and enjoyable things to do during the day; opportunities for accomplishment, mastery, and fun; and especially, a range of relationships because relationships form the lynchpin of a good life. People and families may choose to manage supports on their own, may choose one organization to help in all of these areas or opt to engage several different organizations as they see fit.

- ❖ **We will pay people who work in this field salaries that reflect the value that we place on this kind of work.** People will not need to work in settings that place less value on the people receiving support (such as institutions or nursing homes) in order to receive salaries that appropriately reflect the complexity and importance of this work. Direct support staff would not need to work two or three jobs in order to earn a decent wage.
- ❖ **It will be recognized that institutions and other highly controlled congregate settings are not good for people and they will become a thing of the past.** We will once-and-for-all give up on the alluring concept of preparing people to live and work in the real world by providing training in “practice” settings. We will abandon the readiness model and remember Lou Brown’s admonition that “pre” means never. We denigrate people when we demand that they demonstrate readiness before we will “allow” them to move on. People will not be rewarded for their accomplishments by forcing them to move out of their homes in a process we euphemistically term, “graduation.” People will have the right to live their lives in homes that are truly theirs, while the supports to which they have access are adjusted regularly to give them their best shot at a quality life in whatever way they define such a life.
- ❖ **We will finally figure out that it is not only unethical but downright illogical to respond to people’s desperate attempts to assert a degree of control over their lives by imposing greater and greater amounts of power over them.** Positive behavioral approaches are only those which enhance a person’s life and are characterized by collaboration versus control. The focus of behavioral change will be much more on *illumination* (or understanding the meanings and purposes of behaviors from the individual’s point of view) than on *elimination*, or simply extinguishing a behavior we find problematic.
- ❖ **We will recognize that loneliness may be the most debilitating disability of all and we’ll figure out ways to support our communities to embrace all of their members.** As Norm Kunc reminds us, no one should have to earn the right to belong. We will recognize that people shouldn’t have to be *like* each other to be *with* each other<sup>1</sup>.
- ❖ **We’ll have a new generation of leaders** who recognize that the goal isn’t to figure out what is wrong with people and fix them, but to create and sustain organizations in which people share a vision of a better future and are empowered to continuously achieve positive change. Leaders will understand how to use their gifts to help people with intellectual and developmental disabilities achieve their dreams, not to keep them safe and busy or to reinvent them in our own images.
- ❖ **We will recognize that quality of life has a whole lot more to do with personal relationships and a sense of community than it does with the ability to fold laundry, balance a checkbook, or set a proper table.** We will have figured out that the promotion of choice and control over one’s own life must supersede all else.

**We will take a page from Copernicus’s book.** Copernicus asserted, contrary to what the world knew to be true, that it was the sun, not the earth that is at the center of the universe. The heart of our work will be in relinquishing our roles of centrality, helping the individuals we support assume their rightful places at the hub of their own universes, and supporting the discovery of the power that awaits them there.

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<sup>1</sup> Kunc, N. , in Villa, R., Thousand, J., Stainback, W. & Stainback, S . *Restructuring for Caring & Effective Education*. Baltimore: Paul Brookes, 1992.

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