

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 could see our children happily established in their adulthoods? What if we could see what the world of services and supports for adults with disabilities would look like a dozen years from now?

One of the things I love about working in this field is that we can all be embarrassed by everything we did more than ten or fifteen years ago. It's good to be embarrassed? I think it can be; in this case it means that things are constantly changing for the better. 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 never did 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 care person in a group home for ten men with intellectual disabilities. Together, we had a great time – we cooked great meals, explored our town, went on trips to baseball games, county fairs, and just about every imaginable kind of adventure, and we all learned some important things in the process. The downside was that the power differences between “staff” and “clients” were well accepted. *We* were the teachers – *they* were the learners. Reflecting back now, I see how often those roles were reversed.

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 guys 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 in this country?” Chris took a moment. He carefully studied the bus. He turned it this way and that in his hands, 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 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.

So -- if few of us would brag about how much foresight we conveyed through our work in the disability field a decade and more ago, 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 our work 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 system of services that supports 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-selected goals.** We will have abandoned the hat-in-hand attitude and will understand that people with disabilities no more want or deserve lives that are tedious and lack meaning than would anyone else.
- ❖ **More resources will be available for people living with their families and in their own homes** – rather than requiring a Medicaid Waiver when people choose to live lives of their own design, a waiver will be required to use public funds for services in traditional settings that we have already proven to be less effective and less life-affirming.
- ❖ **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 to treat the people they support as valued, important participants who have impact, within organizations that offer staff so little of the same.
- ❖ **Society will be as unwilling to tolerate the abusive treatment of people with disabilities as they are the treatment of others.** If information became known about substandard treatment for people with disabilities, the public would rise up with the same energy and outrage as when abuses of prisoners at Guantanamo and Abu Ghraib became public.
- ❖ **We will offer an array of supports that are 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 and **not** a support system that exists because it fits with the way funding is provided. In architecture there is a saying, “Form Follows Function.” It means that structures are designed based on the way 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 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, in order to receive salaries that would appear to reflect more value on staff.
- ❖ **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 “unreal” settings. We will similarly abandon the readiness model – we denigrate people when we demand that they demonstrate readiness before we will “allow” them to move on.

- ❖ **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 responding with efforts to impose greater and greater amounts of power over them.**
- ❖ **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 other¹.
- ❖ **We will train and develop professionals to become leaders who understand how to use their talents and gifts to help people with intellectual and developmental disabilities achieve their dreams, not the dreams and ideas of other ...** and this will be more rewarding to professionals than telling people what is wrong with them and prescribing a program to "fix" them.
- ❖ **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 the ability to fold laundry, balance a checkbook or set a proper table.** We will acknowledge that the promotion of choice and control needs to 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 helping people assume their rightful place at the hub of their own universes and supporting the discovery of their own power that awaits them there.

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