

## Speed bumps and Detours on the Road to Meaningful Inclusion: Are We Making Progress?

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In our work through the National Leadership Consortium on Developmental Disabilities we strive to develop leaders in the field of intellectual and developmental disabilities who will be influential in supporting their organizations to make the shift away from traditional, congregate services (group homes, center-based day programs and sheltered workshops). We provide the tools and encourage the values needed that help people who participate in our leadership development programs to support people with disabilities to figure out what their interests are, what they like to do, how they want to live, and then to achieve lives of their own design. Using flexible, individualized approaches to services not only recognizes people's right to self-determination but offers better lives and richer outcomes for people who have generally been in overly-structured, restrictive and expensive services.

People who graduate from our Leadership Institutes gain both leadership skills and confidence. Institute participants make significant, measurable progress. We track their success in implementing their learning by assessing the degree to which they are able to change services for people with disabilities for the better. Again and again we hear from people who have closed or are closing group homes and day programs and who are instead offering people diverse, rich lives that respond to the interests and needs of each person supported.

But ... not everything we hear from Leadership Institute participants sounds exactly like good news to us. While we often hear about great strides in important, positive directions, we sometimes hear things like the following; these are changes that, while described as achievements, we would not necessarily consider descriptions of success. Things like:

- “We moved five people into apartments”;
- “We downsized three group homes from eight to five beds”;
- “We are training people in this practice-setting to prepare them for community life”;
- “We’ve started a year-long classroom training program to teach people job skills”;
- “We have identified four people who we think could live in their own place”;
- “We’re having way more community outings now”
- “We moved nine people from six bed homes to four bed homes”;
- “We started three small businesses in our old day program space that employ ‘our folks’. We wish we could pay them minimum wage; that’s the goal”;
- “We moved him to his own apartment but it didn’t work out so unfortunately, we had to move him back to the group home”;
- “We’d love to see her move to her own place but her parents aren’t keen on the idea”.

I urge you to check yourself when you are thinking about changes like these as successes. Clearly we shouldn’t be “moving people” or picking people who we assess as being ‘ready’ for freedom and choice. We shouldn’t be focusing on filling beds, slots or openings. We shouldn’t be approximating real experiences in simulated settings or inching toward real work by practicing for jobs through low paid stints through ‘in-house businesses’. Surely we should be engaging, listening to and involving families, but our allegiance should be to the adults we serve. We shouldn’t be limiting people based on the wishes or comfort level of family members. The goal is for people’s lives to improve through our collective efforts. It is about supporting people to attain outcomes they choose and value.

It is hard to measure the degree to which old ways of thinking have a hold on us, even when we have good intentions and even when we understand the critical social justice issues inherent in our work. We want to believe that *our* day programs, group homes, etc. are different. These may be comforting beliefs, but by their nature, congregate settings limit, restrict and underestimate people’s potential. They also typically impose more staff oversight than the vast majority of people want or need and are therefore more expensive.

Change is hard and resistance is encountered at multiple levels. We therefore may be willing to accept incremental changes when we know that major, landscape-shifting changes are needed. We appease ourselves by asserting that the new setting in which we have ‘placed the person’ is better than where he/she was before and, besides, it’s only temporary until we can offer the kind of life we know would be responsive to the person’s wants and needs. We tell ourselves that the person can *practice* needed life skills in interim or simulated settings or learn to perform work skills in practice-work environments.

Explanations like these, while self-soothing, do little toward achieving the progress that is needed. Once someone moves from an institution to a group home, from a bigger group home to a smaller one, or into an enclave-type job, the likelihood of achieving a life of full participation is eroded.

Clearly this is tough work. Change doesn't happen easily and it doesn't happen as quickly as any of us would wish. After making an incremental change it is human nature to rest easy for a while. It is tempting to think that significant change would be more easily accomplished if we achieved a series of small changes toward a broader future goal. But sometimes these incremental steps give the comforting impression of progress while delaying or even undermining the changes that would be required for people to live full, engaged lives. When we make changes that represent small steps in the right direction we can be pretty sure the person will spend way too long in the still-not-right setting, wasting time that could be spent living a good life. It isn't right to impose climbing the ladder step-by-step when you could instead, support people to leap over rungs and land squarely and safely in the life they deserve and want.

People should move when and where they want. There isn't a set of skills that must be acquired for an individual to be able to lead a self-directed life. Everyone can. It is incumbent upon us to provide the support that each person needs and wants to achieve the life he/she envisions. Living a full and connected life of one's own design isn't an issue of readiness, it's an issue of rights.

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