

For Arcadia Institute Blog

What We Learned

Connie Lyle O'Brien and I had the privilege of learning from people involved in the Community Participation Initiative on our visit last week. We are grateful to George Martin and Allison Hammond for the invitation and their hospitality and to those who made time to tell us about the work of three community partners in the Initiative, Jenny at the Kalamazoo Nature Center, Chris and Rebecca at the YMCA, and Jill at the Boys and Girls Club.

The most important thing we learned is that investing in the work of organizing and supporting a network of partnerships with and among community associations generates rich opportunities for participation by a growing number of children, young people, and adults with developmental disabilities (more than 200 to date). As the Initiative's partners have become intentional about inclusion, growing numbers of people with developmental disabilities have joined them in an increasing variety of ways. Sustained investment by Kalamazoo Community Mental Health and Substance Abuse Services allows the flexible support to people, families and partners that's necessary to open new opportunities.

We have the chance to see what's happening in many communities. In too many other places, families face many barriers to their children's involvement in the same activities and organizations that benefit their brothers and sisters and withdraw. The Community Participation Initiative smooths the road that families travel. In too many places, developmental disabilities service staff struggle to find community opportunities. The Community Participation Initiative offers staff the chance to join with the people they support in personally meaningful engagement in community life.

One of the most important things that community partners report learning is that including people with developmental disabilities is a straightforward process of getting to know a person, figuring out the individual accommodation a person may require, and finding the most natural possible way to offer what the person needs to participate. This takes willingness to listen, observe, try things, and problem solve

(often with some help from a person with developmental disability expertise), but it mostly involves applying the same skills and resources that make their organizations successful for anyone.

These are the initial lessons on how to substantially increase opportunities for inclusion that we take away from our time in Kalamazoo to share with people in other communities.

- Build on strength by allying with organizations that positively represent the community's history of civic action and create a cross organizational network of leaders committed to including people with developmental disabilities.
- Support the network with people who combine commitment to inclusion with relevant expertise in devising practical supports to participation for people with developmental disabilities. A good network support person has a deep belief in the capacities of people with developmental disabilities and community organizations to figure out how a person can successfully participate and positive expectations that people will be welcoming and accommodating to one another. Good network supporters are confident enough in their own abilities capacities to allow themselves to "not know" the answer to every problem that might arise and deeply respect the expertise of those who lead partner programs. When situations are difficult, they encourage those directly involved to step back and take another look, offer alternative ways to understand the situation, and join in generating new options.
- Invest in bringing organizational leaders together to assist and support each other and the Initiative as a whole.
- Effective leaders within organizations...
 - ...think through the ways that including people with developmental disabilities support their organization's mission and identity. Leadership involves thoughtfully sorting what is essential to the organization's identity and must be conserved from practices that are "just the way we have done things around here". Inclusion may challenge some familiar practices and the challenge may strengthen the organization's capacity to deliver on its mission. The "all" in a mission statement truly includes people with an interest in the organization's activities whose

participation may require some extra effort because of developmental disability. This understanding is the foundation of leading for inclusion.

...suspend the assumptions that come up around particular disability labels or predictions based on a person's responses to other settings. They work from a stance that combines "not knowing exactly what it will take for this person to participate successfully" with responsibility for trying and revising strategies in order to find out what works best for each person.

...expect positive responses from other program participants and staff and deal openly with exceptions as they arise

...take responsibility for real limits to participation in their settings and activities (for example, inaccessible parts of buildings or rules that reflect the core of a program's identity) without falling into defensiveness or blaming.

...ask for help from other members of the network or people with relevant expertise without expecting magic answers or a rescue from whatever real problems may have come up.

...act as a strong voice for inclusion within their organization.

- Cultivate a desire for continual development. We heard active interest in...

...increasing the depth and extent of participation by figuring out how even more people with developmental disabilities can move from engagement in activities to making an even stronger contribution to the organization

...strengthening the network by increasing the number of committed partner organizations

...developing a parallel initiative to strengthen the contribution that service staff make to community participation

...taking network action on issues that will further increase opportunities for inclusion. Some of the issues we heard about: creating a peer review process for network members; allying with concerned others to offer better options for transportation; assuring that the number of involved people who need high levels of assistance grows; examining rules, policies and practices that limit access to opportunities for inclusion).