

# Lessons Learned from Community Engagement

## ABOUT US:

The Arc of King County protects and promotes the rights of people with developmental disabilities (DD) and actively supports their full inclusion in community life. We serve people across the lifespan and offer a mix of direct support, information and referral, and civic engagement and leadership development for both individuals with DD and their family members.

Much of our work revolves around helping people navigate complex systems for education, employment, housing and health care.



## WHAT IS DEVELOPMENTAL DISABILITY?

Most people do not know, and the definition varies depending on the state (they define it for purposes of regulating who has access to Medicaid services) or federal agency. According to the federal Developmental Disabilities Act:

Developmental disabilities originate at birth or during childhood and are characterized by impairments in cognitive functioning (reasoning, learning, problem solving) and/or adaptive behavior (social and practical skills).

They are substantial and likely to continue indefinitely, and they result functional limitations in three or more of the following areas of major life activity:

- Self-care
- Receptive and expressive language
- Learning
- Mobility
- Self-direction
- Capacity for independent living, and
- Economic self-sufficiency

**Year to date** (11 months into fiscal year) ... **483,633** points of contact with social media ... **3,297** engaged in training ... **1,187** supported in public events ... **5,919** supported in civic engagement events.

The term includes intellectual disability, cerebral palsy, epilepsy, autism, and others.

## OUR PROJECT: DOOR TO INCLUSION

We are working to help people understand Medicaid and its community-based long-term care services. Our motivation is helping people understand the precarious nature of funding and limited access to habilitative care. People with DD rely on habilitative services to participate in the community, but most are only available through Medicaid’s waiver services and are not entitlements.



Phase I of our project is mostly complete: We held a series of workshops and listening sessions, sent out a survey, and increased our interaction with groups and individuals who interact with developmental disability but who do not necessarily know much about it, long-term care or habilitative services.

In Phase II, we will facilitate community deliberations where attendees propose and weigh in on policy suggestions to improve access to long-term services.

## THE QUESTIONS

### How have you engaged, convened, and maintained relationships with your community?

- Our outreach team designs programs to nurture relationships and help people connect with us and each other to develop natural supports. We pair families in mentoring programs and facilitate dozens of online support groups. We also offer a peer group for people with I/DD interested in advocacy.
- We provide information and education via workshop and individual consultation. We host monthly in-person meetings in three locations in King County.
- We connect people to decision makers and help people develop leadership and civic engagement tools.
- We have a robust social media presence, curating news about disabilities and communicating via blog, marketing email, Facebook and Twitter.
- We used all the above to some extent during Phase 1 of the Medicaid Door to Inclusion project, but mostly we relied on our social media channels and monthly meetings.



### How have you co-designed or co-created solutions with your community?

Our approach is not to create solutions for someone else, even someone in our community. On outreach activities, one major stream of money is strictly for information and family support. Another major stream of money is for civic engagement and leadership development. We are designed as an organization to empower the people we serve to identify and push for solutions.

That said, we routinely collect information about what people are experiencing and we share it. For example, our listening sessions for the Medicaid project flagged two trends: People were not aware of the variety of services available to them, and people were not able to use services because of lack of providers. Our related survey flagged unevenness in case management and communications from the Department of Social and Human Services. A listening session devoted to behavior supports flagged gaps where people with a dual DD and mental health diagnosis could not access public health services. Ongoing meetings with foster youth advocates and DSHS staff highlighted loss of access to habilitative services offered only through long-term care.

We interpret our contracts for providing information as a two-way process: Out to individuals and family members (what the systems need them to know), and back to policy makers and people who run day-to-day health and human service operations (what people are experiencing). We layer in skill building so people with DD and their family members can help policy makers resolve gaps and improve services.



We also partner with King County to host an annual legislative forum where community members testify to their experiences and a citizens' board presents priority recommendations. And during the state legislative session, we take advocates down to Olympia weekly to learn about proposed legislation and engage with legislators.

### How have you addressed systematic inequities that affect health (such as power differentials or racism) as part of your community engagement work?

People with developmental disabilities are among the most marginalized groups in society. When in school they often lack access to the general education curriculum and are not given the opportunity to learn alongside their typically developing peers. As adults, employment rates hover at 8 percent. People with DD are more likely to experience trauma and have high rates of dual diagnosis with mental health conditions. The list is long.

Much of our work is about ensuring people with DD have the right to self-determination and are included in the community. Our leadership and skill-building focuses on supporting people through the steps to inclusion – from being present, to participating, to engaging meaningfully, to self-actualization. We offer experiential learning – role play, etc. We advocate for and make people aware of habilitative services such as employment support, supported living and person-centered planning.

We also constantly work to make communities aware of the ways people with developmental disabilities are isolated and segregated. We testify; we join coalitions and speak up. We make sure our outreach team represents the DD community. (The advocacy team of five includes two self-advocates, a parent and a sibling with direct experience with DD.)

Our biggest challenge is working with groups already focused on equity. Many people do not consider disability when thinking of equity, and the experiences of people with disabilities are often left out of stories that other community advocates and policy makers promote. For instance, that people with disabilities are most disproportionately represented in homelessness counts. Or that young children with disabilities make up 75 percent of suspensions and expulsions in early learning – and that more children are suspended in preschool than in K-12. Or that people with DD experience one of the nation's highest rates of sexual



assault. Very few social activists consider the implications of intersectionality – for instance, being an African American male who also has autism and who also has a co-occurring mental health diagnosis. This contributes to social isolation.

For years we have advocated “nothing about us without us” and supported self-advocates with legislative advocacy. More recently, we have launched disability awareness training for organizations and businesses, and we are cultivating alliances with organizations who care about equity but aren’t necessarily familiar with developmental disabilities.

For these challenges we do our best to connect people who have a disability or their family members to leadership opportunities. We also curate news and publish analysis on our blog. We have moved away from newsletters and mailings and mostly distribute through social media where our network can share the information with their circles to amplify the voices and experiences of people with DD.

### What about your organization’s way of working has made you successful?

Our staff and board of trustees are deeply committed to inclusion and most have a direct tie to developmental disability – they have a diagnosis, are a parent or sibling of someone with DD, or have professional experience working with people with DD. We also strive for language and racial diversity.

On our outreach staff:

- 38 percent are people of color
- 23 percent speak Spanish as their first language
- 85 percent are either people with a developmental disability or family members of someone with a developmental disability
- The coordinators of our programs for self-advocates, Spanish-speaking families, and African American families all reflect the ability, race, culture, or first language of those they support

On our board of trustees:

- 25 percent are people of color
- 100 percent are either individuals with DD, family members, or professionals who work in the field of developmental disability

We are part of the DD community and are informed by the experiences of the community. We routinely host Let’s Talk events, workshops and listening sessions to pull out those experiences and solicit feedback. We plan social events. We devote significant resources to keeping the community informed about systems of care and policy issues. We also take the time to work one-on-one with community members.



## What have been your most significant challenges, obstacles, missteps?

- It is important to understand that caregivers may be processing trauma of their own.
- It can be difficult to connect with self-advocates if they do not use or have access to the internet and direct communications may always be limited.
- Usually you first need to earn the trust of guardians and family members.
- Professionals outside the DD world often need basic DD 101
- Transportation and access to child care and personal care are often barriers to participation.
- Most younger families prefer robust online communications (for many reasons they can't make in-person gatherings), but older caretakers rely more on direct communication (postcards, emails).
- Finding allies who view equity through disability lenses.

## What changes have you seen that give you hope about a future that is more equitable?

- More people sharing their story and the greater story of developmental disabilities
- More parents challenging low expectations
- Stable and growing integrated employment with competitive wages
- Popularity of events like Wings for Autism and the Special Olympics
- Commitment of leading businesses like Microsoft to employment of people with DD
- Advances in technology and more people embracing the principles of accessible design
- Coalitions that link healthcare to housing and education – more integration of causes
- A greater access to healthcare for people with disabilities and their family caretakers
- More workshop participants reporting increased confidence in speaking about services and engaging with policy makers
- More people seeing individuals with developmental disabilities as peers



Thank you  
for promoting  
equity!

