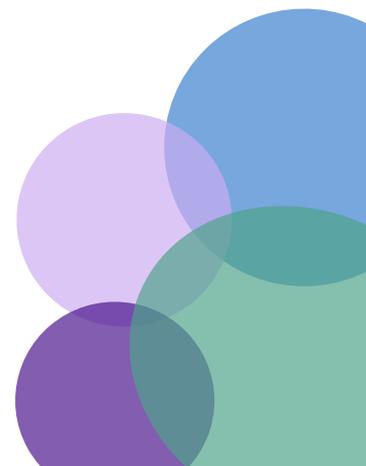




# Assessing and Improving Disability Services: Lessons from Lived Experience

University of Cincinnati Center for Excellence  
in Developmental Disabilities at Cincinnati  
Children's Hospital Medical Center

**C**hear  
December, 2021



# Contents

**03**

Introduction

**22**

Remove Roadblocks

**04**

Who We Engaged

**27**

Foster Connections

**05**

Recommendations

**31**

Pilot Interventions

**06**

Change Culture of Care

**32**

Conclusion

**15**

Ensure Access for All

# Introduction



A more inclusive and equitable future for people with disabilities is only possible when their voices are elevated by the leaders and institutions which provide disability services. This is crucial in light of the centuries of abuse and dehumanizing treatment people with disabilities have faced at the hands of the United States' systems. Though people with disabilities have made strides toward securing rights and shaping the services that impact their lives in recent decades, medical and disability services systems were still designed by the those without disabilities, and often lack decision-making input from those who live with disabilities every day--the everyday experts. Additionally, communities of color are still largely underrepresented in disability advocacy organizations and efforts.

The University of Cincinnati Center for Excellence in Developmental Disabilities at Cincinnati Children's Hospital Medical Center (UCCEDD) has recognized how crucial it is to change this culture moving forward. As a result, UCCEDD partnered with Cohear to proactively seek out feedback and ideas from people with disabilities, caregivers, and the

industry professionals who work with them, in order to shape their goals and priorities for the next five years.

This engagement took place in the form of four focus groups which included self-advocates, caregivers, and professionals from diverse backgrounds throughout Ohio.

These groups included residents of urban and rural locations, new Americans, African-Americans, and low-income individuals. The sessions revolved around participants' experiences within disability systems and society at large, their priorities for UCCEDD's research, training, and advocacy initiatives during the next five years, and their overall ideas for improving the lives of people with disabilities. This report represents the substance of what these participants shared.



# Who We Engaged:

**Four** focus groups with **43** total participants:

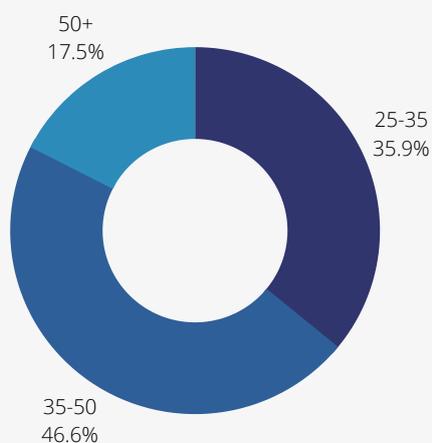
- 12 Self-Advocates
- 12 Professionals
- 19 Caregivers

**9** New Americans

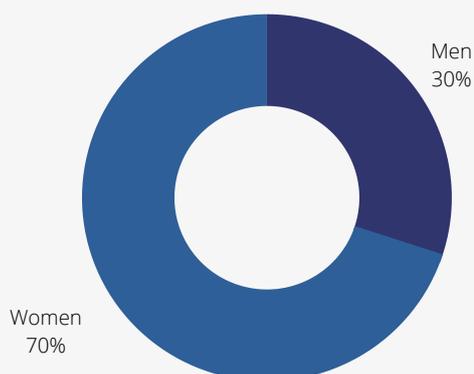
**Participants** from all over **Ohio**:

- Akron
- Hamilton
- Cincinnati
- Forest Park
- Lebanon
- Waynesville
- Columbus

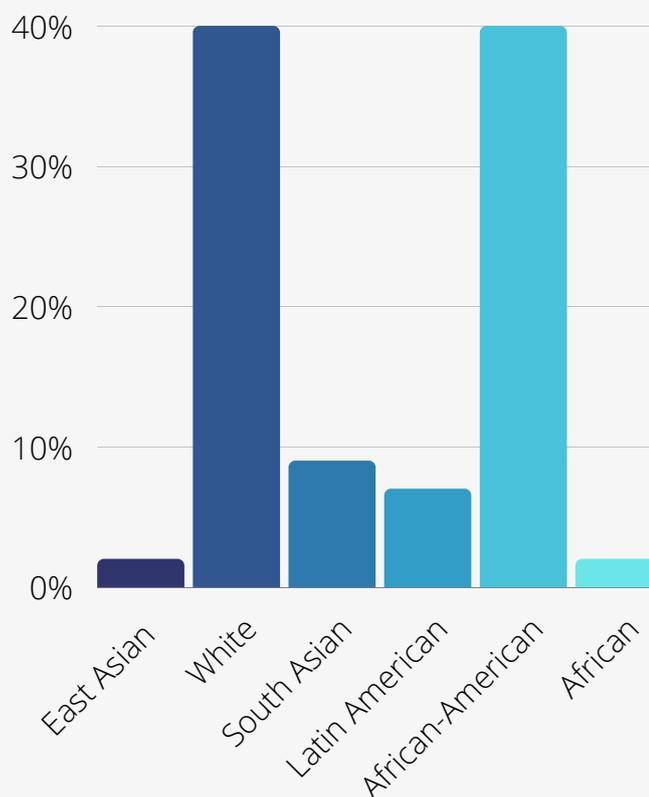
## Age



## Gender



## Race



# Key Recommendations

## 1: Change the Culture of Care:

Foster a better, more inclusive future for people with disabilities in Ohio



## 2. Ensure Access for All:

Connect people to the help they need, when they need it, for as long as they need it

## 3. Remove Roadblocks:

Advocate for full inclusion in work, recreation, and education



## 4. Foster Connection:

Create opportunities for socialization and support for people with disabilities and their caregivers

# 1. Change the Culture of Care: Foster a better, more inclusive future for people with disabilities in Ohio

## In Their Words:

### Examples of Current Challenges

Healthcare professionals tend to overlook people with disabilities when communicating about their medical care, turning instead to caregivers by default.

"[Medical professionals] tend not to be very skilled in the area of how to approach and how to have conversations with a person with a disability, [and they] instead move towards the parent or the caregiver, or family or friend, instead of just talking to [the person with the disability] directly... There may be instances of clarification needed [when talking to a medical professional], but [people with disabilities] are not stupid. We shouldn't be belittled by our caregivers or doctors." --R, Self-Advocate

Medical professionals do not always listen to the health expertise of caregivers and people with disabilities, who have relevant lived experience with their conditions.

"Every time I go to the doctor, it doesn't matter how many years I've lived with this, they always think that they know better than me and they never listen to what we, the patients, or even our family members, say." --M, Self-Advocate

New Americans face additional challenges within the medical system.

"I struggle because when I ask for an explanation, people treat me with indifference... [I think it's] because I'm Hispanic. ...It's very difficult to handle the balance of my three kids with one of the kids having this difficulty and not finding clear resources and information about the diagnosis." --N, New American Caregiver

"I have felt indifference from some people in the hospital. I just want to be treated equally." --C, New American Caregiver

Education and medical spaces are built to anticipate typical behavior, which creates pressure for people with disabilities and their families to conform.

"Whether it is school or the doctor's office, there's a lot of disconnect. They have these parameters that they've already set, and if your kid doesn't fit in that parameter, then there's something wrong with you. ...My child is an individual. What fits one does not fit all." --N, Caregiver



# Change the Culture of Care



## Next Steps

### **Educate healthcare professionals on best practices for caring for people with disabilities, including the use of preferred language.**

Some healthcare and school staff may be unfamiliar with terminology that is preferred in the disability community, or uneducated as to what it is like to live with a disability. Create training and education opportunities for these professionals in order to help them better communicate with, understand, and accept people with disabilities. Advocate for more programs like the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program, and the expansion of existing programs.

“When I was in school... there really wasn’t much discussion about developmental disabilities or even health counseling.... If I weren’t in the LEND program, I wouldn’t have had the opportunity to refine some of those skills. I would like to see that that’s incorporated into schooling.”  
--L, Professional

“I think a little bit of sensitivity to the fact that the term is neurodiverse for a reason [is important].” --E, Caregiver

“When [children with special needs] are in the hospital, they want to be treated equally.” --C, New American Caregiver

















## 2. Ensure Access for All: Connect people to the help they need, when they need it, for as long as they need it

### In Their Words:

#### Examples of Current Challenges

Significant staffing shortages among providers of home health care and direct support have left many participants anxious and uncertain about meeting their basic, daily needs.

“There’s been some challenges right now with [home health] provider agencies, with staffing shortages that I’ve noticed... all through the state of Ohio.” --A, Self-Advocate

“For most of my life I was fortunate enough that my parents were able to pay for my caregiving tasks because I have cerebral palsy... In April 2018 I actually moved into a long-term care facility... I thought I could get my needs met better here... But they too are dealing with the shortages... I am going to try to move out to my own accessible apartment for the first time in December but I am so worried about the shortage still impacting my life because if I don’t have the aides... I can’t do anything.” --S, Self-Advocate

Due to poor information distribution by the plethora of agencies engaged in providing disability services, many people with disabilities and their caregivers are in the dark about some of the forms of assistance for which they are eligible.

“I didn’t even know that I was eligible for 24-hour care out in the community... but through [UCCEDD] I found out about the DD waiver, which gives me a lot more coverage because I need it.” --S, Self-Advocate

“There is a lot of disconnect. There are things I did not know. ...[My friend] is the one who told me we could get PediaSure [through our insurance]. It wasn’t brought up to me at the doctor’s office.” --N, Caregiver

Securing resources and services too often involves complicated, redundant applications that take too long to process.

“One of the things that makes it difficult is how many hoops [OOD] make you jump through. I did a business plan through them to start my business, and they provided funding. But it was like 10 months of hurdle after hurdle after hurdle... There’s resources out there, but why does everything take so long? They need to expedite things, especially when they are necessary.” --A, Self-Advocate

“I think application processes to a lot of these agencies are long-winded and a little unnecessary for a lot of the things and information and documents that they ask you for... You can spend time, or three days, or a week getting all this paperwork done for your application to be sitting in a prior-authorization state, and that may take another three weeks, or 30-day turnaround time for a decision to be made.” --T, Caregiver



# Ensure Access for All



## Next Steps

**Create best practice recommendations for medical providers that will facilitate continuity of care, even when seeing the same healthcare professional consistently is not possible.**

It can be exhausting and counter-productive for people with disabilities and their caregivers to explain their circumstances and goals over and over. Improving information-sharing between medical professionals, building time into providers' schedules to review information, and ensuring patients see the same providers as much as possible would make a big difference.

"I think tying all the pieces [of care] together is important, because I think I've heard a lot of people say that they've been re-explaining their circumstances over and over again, and doctors not reading their charts before [seeing them]." --K, Caregiver

"[Therapy at Cincinnati Children's Hospital] was so limited by the system. We were limited to sixty minute sessions... We were really limited by the therapists that had availability, and some of them did not specialize in kids with cerebral palsy. ...Who had time open on their schedule is who we were able to see." --D, Caregiver











### 3. Remove Roadblocks: Advocate for full inclusion in work, recreation, and education

#### In Their Words: Examples of Current Challenges

Limited accessible housing options make it difficult for some people with disabilities to live independently.

"I've had some successes in housing at a unique housing complex... But what I found is once I came home, housing options are limited, especially if you don't have a developmental disability. Like if you get a spinal cord injury or any kind of injury after the age of 22, I think those people are really affected with housing options, because they don't get the assistance that people with developmental disabilities do to modify homes. I mean you can get a waiver, but other than that, that's it." --A, Self-Advocate

Securing employment for people with disabilities can be an uphill battle, particularly since the beginning of the COVID-19 pandemic.

"My son is 25, he lives at home. He had been working pre-pandemic at a movie theater. It was a job he got on his own and he had a job coach briefly until he was comfortable with it and then the pandemic hit... Now he is struggling to find a job. The effect that the pandemic has had on him emotionally, mentally, even intellectually --I've noticed he's really backslid quite a bit, just being isolated at home... it's really taken a toll." --L, Caregiver

"When it comes to employment... I had trouble... I did not have an intellectual disability but there's very little I can do physically... I found a job on my own that I love but then I was downsized and couldn't find another... they didn't want to have any sense of failure on their books. There is a lack of employment support for people with severe physical disabilities." --S, Self-Advocate

Educational difficulties for children with disability accommodations have worsened during the COVID-19 pandemic.

"As a provider, I have heard parents talk about how their kids are on an IEP or they have a behavior plan at school, and not being in-person last year, just being able to have those accommodations was a little more challenging." --L, Professional

"The IEP is a little hard to implement if you're not going into school. I know that [my daughter] was able to receive her services which was great, but this year we've had to implement a behavioral plan, and I'm not sure how they would've been able to implement any of that." --E, Caregiver

"Now what I'm seeing is a lot of children [who] have fallen so far behind. ...Just trying to get these kids back on track, especially the ones that have an IEP and have a disability, is a struggle." --K, Caregiver

# Remove Roadblocks



## Next Steps

**Partner to provide families with education advocates who can consistently support children with disabilities and their parents throughout their schooling and help mediate with teachers and administrators.**

Consistency is key when it comes to advocating for students with disabilities. Connect their families to someone who can be a resource for the duration of their schooling would be helpful. Where it is not possible for a single advocate to commit to a student for the duration of their education, encourage commitment for a specified number of years with the promise of a warm hand-off to a new advocate when that time draws to a close.

“Advocates are out there but they change frequently: high turnovers, and sometimes it depends on the agency. Once you age out of that agency, there’s not another advocate or you have to go somewhere else... It would be really great if, even in the school systems, there was just somebody that was going to stick with that family or that person who is living with disabilities and follow their journey or have that consistency.” --T, Caregiver

“I never know the things to ask for in an IEP... share where to get an IEP advocate, someone who can enforce my rights during an IEP meeting.” --M, Caregiver





## Remove Roadblocks | Next Steps >>>>>>>>>>

“At some point, honing in on children with special needs to see what their strengths and skills are, and start providing the life skills and support to be able to do any type of work. So if a child’s cognitive level isn’t high, but they are great at housekeeping or filing, that [Cincinnati Public Schools] would start to utilize those last two years to partner with a certain type of company, they can do a certain number of hours there, and after they graduate they’ve already formed that relationship where they are able to be productive citizens.” --T, Caregiver

### **Advocate for better transportation solutions for people with disabilities.**

Encouraging more organizations to provide free bus passes is an excellent first step to improving transportation, but for those living in rural and suburban areas, this may not be adequate. Advocate for better funding for those services currently providing transportation assistance to people with disabilities. Explore creative transportation solutions in partnership with medical providers and employers of people with disabilities.

“Transportation for people in our community is very [challenging]. The services are not the greatest, so that’s something we’re trying to address as well.” --M, Professional

“I personally drove to houses to drop off the [virtual learning] supplies [to families who didn’t have access] so they could at least participate in the sessions.” --J, Professional

“I would tackle accessibility issues when it comes to transportation and language barriers. For transportation, it could be easier and cheaper to provide bus passes for people so they don’t miss their appointments. A lot of people miss their appointments because they have transportation issues or because they have health insurance issues. These appointments are sometimes difficult to get and then they are missed because of these barriers.” --M, New American Caregiver

“Transportation assistance. If there is some working place where these sort of people can work all day, providing all transportation back home.” --T, New American Professional

“Double down on accessibility of transportation. Access to reliable transportation is hard.” --C, New American Caregiver





## 4. Foster Connection: Create opportunities for socialization and support for people with disabilities and their caregivers

### In Their Words:



#### Examples of Current Challenges

Caregivers require systems of support that are tailored to their specific needs.

"As a parent, I feel like I kind of need an advocate on an advocate... Trying to keep up with all these different doctors' appointments, different assessments that need to be done, and I'm only one person."  
--T, Caregiver

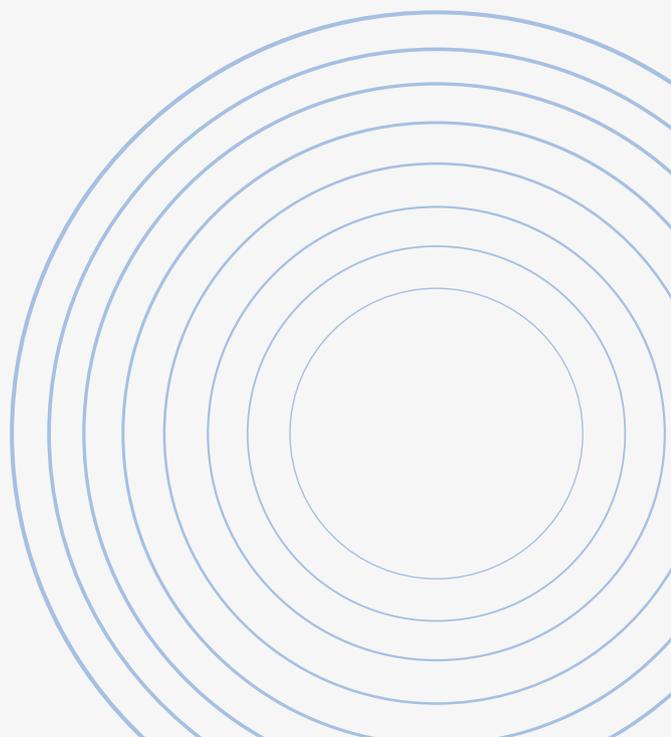
"...There should be something done with being able to identify [caregivers] and seeking them out and giving them support and accessible resources... and also advocacy. Because I often see those people in and out of my portal... and nothing's changed with regards to the support that they have. I worry about those that fall through the cracks, those are the ones that are really, really vulnerable, that need to be identified."  
--M, Caregiver

The pandemic has exacerbated many of the difficulties faced by people with disabilities, their caregivers, and those who work with and advocate for them.

"Some of [the people we service] struggle because of the pandemic with the isolation like other people have talked about... The things I miss [are] the personal and social interactions. Just being in a room with someone else and talking to them."  
--R, Self-Advocate and Professional

"On the other hand, [COVID-19 has led to] isolation and job loss and anxiety and trauma. A lot of [my clients'] disability symptoms have changed during the pandemic."  
--A, Professional

"Social-emotional challenges and mental health challenges are very prominent [among the people I serve], not just because of some of the social conditions that many families are facing, but also because of the impact that COVID has had on families as well."  
--M, Professional



# Foster Connection



## Next Steps

### **Work with caregivers to design a support network structure from the ground up.**

Collaborating with a group of caregivers to design and implement a resource network from scratch might help fill the gaps left by existing networks, and facilitate peer support in addition to information sharing.

“Some kind of parent support network that could be built [would be helpful]. I think it [could be] easier now since a lot of people are getting used to technology. ...Just trying to find a time and a space for parents who can connect with other people who might have similar kinds of challenges and lifestyle issues.” --M, Professional

“I know it’s my responsibility to go out and find that kind of support [for parents and caregivers] or those kind of groups to join, but it sounds so good in theory, and I just never seem to find the time to either find the group or then participate if I find one.” --R, Caregiver

“We as parents or grandparents need support, or to know where to get that support.” --K, Caregiver



## Foster Connection | Next Steps



### **Find safe ways to facilitate social groups for children with disabilities.**

Social isolation has been extremely challenging for many children with disabilities during COVID-19. Create more opportunities for these children to safely interact with others.

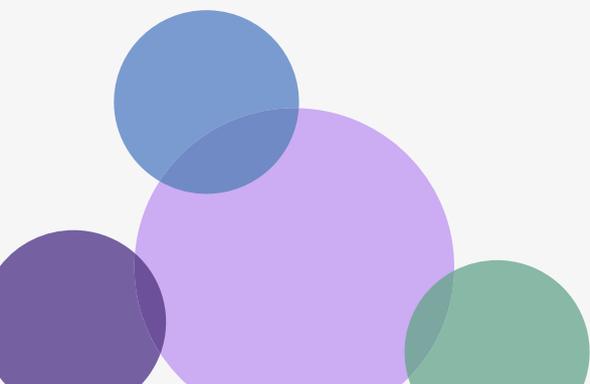
“If [my daughter] had the opportunity to go to a play group once a week with other kids, she could benefit hugely. ...That’s a gap that she’s missing [in part because of COVID].” --E, Caregiver

“[I would like to see UCCEDD] collaborating with schools. ...Maybe just rolling out trials with other schools to encourage socialization, or so that parents don’t have to try to do it all on their offtime.” --L, Professional

### **Create opportunities for children with special needs to connect with one another across the boundaries of schools, and even school districts.**

Especially for children who attend small schools with low numbers of students with disabilities, it can be isolating not to know anyone going through similar experiences. Creating social opportunities which allow for children and young people to meet others like themselves could be helpful.

“I went through the special education in Cincinnati public schools and I remember the days of being separated or segregated in [the] special needs classroom and I remember being very isolated in that process. It would have been nice to be around others who maybe looked like me, or who just simply had a hearing loss and have conversations and grow with each other... Even if it's not possible to do it with one school, with Cincinnati Public Schools for example, it’s a huge district. There has to be connection and community between all schools of this district.” --C, Self-Advocate



## Foster Connection | Next Steps



### **Facilitate the development of more recreational programs and activities that are equipped to include kids with disabilities.**

Both programs which are designed only for children with disabilities, and programs designed to accommodate both typical children and those with disabilities, are important social and developmental outlets. Ensuring adequate resources and disability awareness training among staff running these programs would allay some parents' concerns around their children's participation.

"I'm trying to figure out how to get our kids more involved in life experiences outside of school, outside of our house. ...I think I've stolen part of what my kids should have experienced [out of a desire to avoid disrupting other kids with my kids' atypical behavior]." --R, Caregiver

"...Information and support about extra curricular and life experiences in the pediatric setting [would be helpful]." --D, Caregiver

### **Provide social opportunities for adults with disabilities.**

Loneliness can be a challenge for adults with disabilities under normal circumstances, but has been particularly exacerbated by the COVID-19 pandemic. Establishing regular opportunities for adults with disabilities to connect with one another could make a substantial impact in these individual's lives.

"The things I miss [are] the personal and social interactions. Just being in a room with someone else and talking to them."  
--R, Self-Advocate



# Recommended Pilot Interventions

- **Recruit** a network of new American volunteers who can be available to attend doctors' appointments and navigate the healthcare system alongside other new Americans who have disabilities.
- **Advocate** for the state to increase Medicaid reimbursement rates for home health aide services to help the industry compete with rising wages in other fields and direct support.
- **Partner** with OhioMeansJobs and major Ohio school districts to recruit 3-5 employers willing to facilitate a work-based learning program for high school students with disabilities.
- **Create** a training program for people with disabilities who are interested in applying to serve on civic boards and commissions.
- **Collaborate** with community members of color and new Americans to develop a strategy for recruiting and retaining:
  - Diverse employees to work in disability services
  - Academics of color to lead disability research
  - People of color with disabilities to participate in research studies
- **Develop** a mediation program at each major Ohio hospital in which advocates work with health professionals, people with disabilities, and caregivers to facilitate better individualized care for patients with disabilities.
- **Design and launch** an inclusive disability support network through which members can create social connections, share information and advice, and get connected to needed resources.
- **Advocate** for the state to expand the Service and Support Administrator program to increase the number of SSAs available in each county, and expand SSA duties to include in-person advocacy between people with disabilities, schools, and medical providers.

# Conclusion



“In order to do any kind of community assessment... you need to assemble people and stakeholders who are actually interested in this issue. Second... putting words into action... We always speak about different types of issues, but we do not put our words into action.” --M, New American Professional

In order to facilitate true systems change, it is crucial for members of impacted communities to shape and guide that change. UCCEDD has taken this insight to heart by seeking out the feedback of the everyday experts in the disability community, across axes of diversity which have traditionally been left out of disability advocacy conversations. Focus group participants were grateful to have their voices heard, and are excited to hear the UCCEDD will be including their feedback in the five-year planning process.

They made it clear that continuing to involve members of the disability community moving forward should be a priority, and were eager to see how UCCEDD will translate their ideas into action. Ultimately, there is no one solution which will lead to an Ohio in which people with disabilities can thrive and participate fully in society. Every recommendation participants shared out of their lived experience, however, is an important step on the path to that future.

