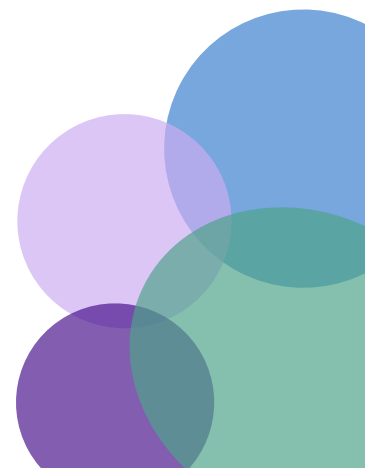




# Assessing and Improving Disability Services: Lessons from Lived Experience

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:

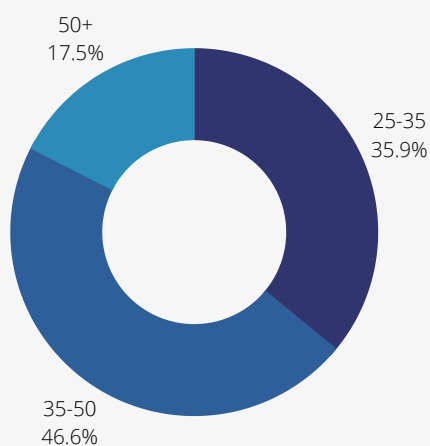
- 12 Self-Advocates
- 12 Professionals
- 19 Caregivers

**9** New Americans

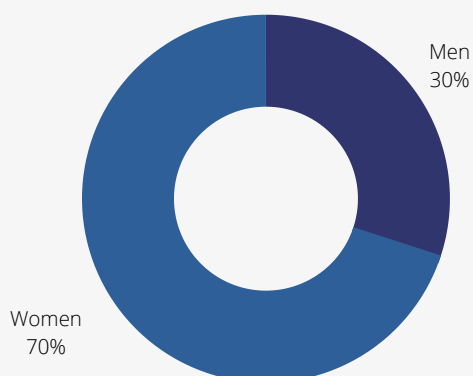
**Participants** from all over **Ohio**:

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

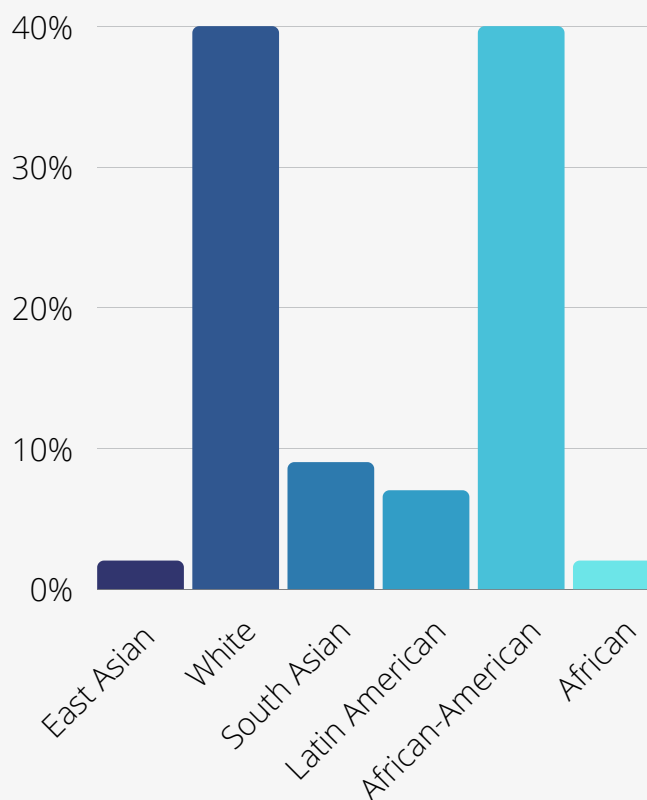
## Age



## 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



## Change the Culture of Care | Next Steps >>>>>>>>>>

### **Train doctors and other medical professionals to listen to people with disabilities and take their perspectives seriously, and create opportunities for patients to hold them accountable.**

People with disabilities are the true experts on their bodies and their care, but often feel dismissed or ignored by their doctors. Active listening techniques and comprehensive disability education for medical professionals might begin to help unravel this systemic issue.

"I'm going to be 40 years old next year and I would like for people to finally start listening to me and valuing me... When you've lived with [a disability], that gives you an experience beyond what any doctor can have, because you're hands-on with it every day whether you want to be or not." --M, Self-Advocate

"I think it's important for [medical staff] to listen to [me and my daughter with a disability] and take what we say for more value, even though they went to school for this and they have their degrees, [because] they're not living through it every single day." --M, Caregiver

### **Advocate for systems change within medicine from the prioritization of efficiency and profit to the prioritization of high-quality, individualized care.**

Many systems which affect people with disabilities, and the medical system in particular, are not designed to generate the best outcome for every individual--they are designed to make money. This influences negative doctor-patient dynamics, the inadequate time devoted to each appointment, and one-size-fits-all care approaches. Though changes in medical education can make a difference, advocating for funding structures to evolve could be even more impactful.

"A more systemic issue that we're probably not going to solve on this call [is the framework in which] doctors are constrained. It makes for a horrible patient experience, it makes for a horrible patient outcome." --M, Self-Advocate

"I used to trust that, if you're my doctor, you're going to tell me the correct thing. ...A lot of the way they do medical treatment is like a herd kind of practice. One for all, all for one. That's not what we should be doing." --M, Caregiver



## Change the Culture of Care | Next Steps >>>>>>>>>>>>>

### Encourage policymakers to increase funding for public disability services.

Publicly funded disability assistance programs are a key means of support for many people with disabilities and their families, but these systems require extensive paperwork which seems designed to “weed out” some applicants. Limited resources also mean that those who still need help are cut off before the time is right. Advocating for increased funding could help limit the strain on these systems, thus providing better services to those who need them.

“I guarantee that there are forms and processes out there that are meant to be so complex that you give up... Just say, ‘we don’t have enough resources for everyone.’ But instead, they make you jump and jump and jump and keep denying you. And I don’t think a lot of folks acknowledge the emotional toll that it takes on someone to go through all of these processes and then be denied. It makes me want to give up.” --B, Self-Advocate

“A few years back, we were told that we didn’t need [a Service and Support Administrator] anymore and we were told that we should relinquish our relationship so that people who needed one could have one. ...It was presented to us in a way that made us feel like we were stealing resources from someone else that needed them more than we did.” --R, Caregiver

### Establish structures to comprehensively educate new American caregivers, people with disabilities, and their support teams at every step of their journey.

Navigating the world of disability care and its accompanying paperwork is extremely complex, particularly for new Americans. Equipping families and their medical interpreters with some baseline information regarding disability care before they or a dependent are even evaluated for a disability, and continuing to provide support throughout their care, could make a difference.

“It [would] be really great for all the populations where you can have a workshop and have someone educate about children’s disabilities and all the paperwork. When the therapist is trying to evaluate the disability, sometimes there is a barrier between parents and doctors. Before the evaluation process, educate the parents and children and interpreters.” --M, New American Professional

## Change the Culture of Care | Next Steps >>>>>>>>>>

"With the language barrier, the doctor cannot explain what is going on... the parent might not understand all the things going on with their child. Maybe educating interpreters, training them more about mental health disabilities as well as other disabilities... I think that will make more progress with immigrants." --M, New American Professional

"For me, it would be very important to do information workshops for people or to make an application where there is someone who can clarify all the doubts and questions that someone has... Seek to help families with children with special needs so that they can lead a better life [and] live in a safe place. Teach parents how to help their children." --M, New American Caregiver

### **Encourage medical providers to provide detailed information to newly diagnosed individuals and their families, taking steps to ensure that new Americans are treated equally and the language barrier is not preventing understanding.**

Healthcare institutions need to be sure that when an individual is diagnosed with a disability, they and their families receive adequate information regarding both the disability more generally, how it manifests in the person in question, and what the next steps should be. This may be challenging when there is a language barrier present, but medical professionals should ensure, through interpreters when necessary, that families and individuals have all the information they need.

"I would ask to not treat us differently because we are immigrants or we are Hispanics. We want to be treated the same way fairly. Give people enough clarity and details about the diagnosis so they know how to act. The services are good, but it could be improved by providing better information to parents so they know how to treat [their children] well." --N, New American Caregiver



## Change the Culture of Care | Next Steps >>>>>>>>>>>>>>>>>>>>

### **Create cultural competency guidelines and encourage new and existing disability services providers to implement them.**

Cultural competency best practices, including the intentional hiring of staff from diverse communities, interpreter access, and respect for faith practices are essential for ensuring new Americans receive quality care which takes their unique backgrounds into account

"I would focus on organization policy and educating the staff and hiring intentionally from the community. I would review organization policy, see if it is indeed taking account of the needs of the community. I would provide a way to hire more representatives from the main communities. I would interpret a lot of stuff in different communities' languages and provide the organization website. I would require cultural competency training for all staff." --M, New American Professional

### **Host workshops to empower minority disability communities to advocate for themselves, both on the individual and organizational level.**

Black and new American communities are not proportionally represented within the disability advocacy movement, largely due to systemic barriers which make participation more challenging. Facilitating costless training and workshops for these individuals, their community leaders, and the organizations which are prominent in their communities, could help enable them to bring their voice to the table in the future.

"[The disability space is very white], so my ask is to do more workshops, trainings for people of color." --C, Self-Advocate

"I think we should let the community help themselves. Empowering local small organizations from these communities. Using them as a conduit will increase trust with these communities. Following through, not just coming to them to collect the data, but including the communities in the decision-making and treating them equal and learning from them because we all have enough to contribute." --M, New American Professional



## Change the Culture of Care | Next Steps >>>>>>>>>>>>>>>>>>>>>>

“Include all the diverse populations, such as people from different cultural backgrounds, different ages, socioeconomic status. ...if you can include more diverse populations for your program, that will be really good so that we can actually help people from different organizations.” --M, New American Professional

### **Find ways to connect people to disability advocates who can mediate between people with disabilities, caregivers, and professionals in medical, educational, and other settings.**

Disability advocates could be a helpful bridge between medical professionals, teachers, disability service providers, and the populations they serve. These advocates could lend authoritative weight to the concerns and desires of people with disabilities and their caregivers, assist them with paperwork, and connect them to helpful programs.

“My daughter could have died in 2017 because they weren’t listening to us. She said she had pressure in her head, and the ER insisted it was pain... So we went on this tangent for a whole week, going to the ER, before they finally admitted her and gave her the [shunt revision] surgery, and her surgeon said, ‘when we replaced her shunt, the [cerebrospinal] fluid shot out of her head like a geyser’... So she could have went to sleep and not woke up... but if I had an advocate, to say from me to them, ‘hey, this is what’s going on, we really need to sit down and figure this out’, maybe this could have been solved sooner.” --M, Caregiver

“I ended up having to make a friend who happened to be a doctor, and... the way she knew how to talk to another doctor to get me a service that I needed... it was something I wasn’t able to for myself. I’ll always be super grateful to her for that. But I wish everyone had that sort of advocacy... A lot of that information is inside information that you don’t necessarily have.” --B, Self-Advocate

“I think that if we had more patient advocates in patient care to begin with--even just checking in on people... to see how they’re doing--maybe they can tease out potential issues or missed issues in care at the forefront.” --M, Self-Advocate

## Change the Culture of Care | Next Steps >>>>>>>>>>>>>

### **Advocate for the inclusion of people with disabilities on civic boards and advisory groups for private organizations.**

Changing negative perceptions of disabilities, reforming systems which do not work in favor of people with disabilities, and creating lasting change all require that the everyday experts themselves--people with disabilities--are at the table. Encourage civic boards and commissions, as well as private companies' advisory groups, to incorporate people with disabilities.

"[Another opportunity for representation] is the County boards... There has to be opportunities where they just have a coffee chat, for example, and just have conversations among people with disabilities, not people on the behalf of disabilities. And I'm understanding that a lot of people cannot advocate or speak for themselves, but there's other ways of communication." --C, Self-Advocate

"I do wish there were more opportunities to network with one another. I wish organizations had an advisory council that was made up of people who are actually going through the issue... Inclusion requires intention." --B, Self-Advocate

### **Prioritize racial and ethnic representation in disability services and research.**

Bring on diverse professionals in order to improve cultural competency and better serve minority populations. Additionally, studies related to disability tend to focus on white subjects and their experiences, which may lead to gaps in care recommendations for other populations; so it is also important for Black and other minority voices to be represented within disability research as both researchers and subjects.

"We need... all the institutions to do better in hiring people that look like their clients. If you wanna help people, they have to be better at intentionally recruiting people that better represent their clients... I think the communities are talked out... [rather than just asking for advice] organizations really need to hire intentionally, recruit from these communities." --M, New American Professional



## 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





## Ensure Access For All | Next Steps >>>>>>>>>>

### **Partner with new American community leaders, such as faith leaders, to facilitate better care for new American people with disabilities and help them feel more comfortable in potentially stressful medical settings.**

When barriers of language and culture present themselves, having connections to trusted members of new Americans' communities is essential. Consider creating a network of these community leaders who could opt in to assist people with disabilities when needed.

"Include faith leaders and people that [new American] communities believe in and include them in these discussions. If someone is refusing to have a surgery... bring the priest or bring the imam or someone they trust." --M, New American Professional

### **Advocate for higher pay, better benefits, and more respect for home health and direct support professionals.**

Aides are essential for many people with disabilities to get by on a daily basis, yet home health and direct care professionals tend to be undercompensated and overworked. Advocate with home health services, direct support services, policymakers, and other relevant decision makers to raise the standards of home health and direct support work in terms of pay, benefits, and overall respectability.

"I think one thing that they need to do is raise the rates. Home health care agencies--it's only \$10 an hour--and anybody taking care of a living person should not make 10 bucks an hour. And you know, an independent provider makes 18, but I think they need to make an enforcement on agencies to, you know, charge a little more." --A, Self-Advocate

"I would like to see being a service provider become a respected profession that people actually want to go into instead of a fallback position because I can't say how important those people, and the work they do--without them, I don't have a life because I can't get out of bed or do anything." --S, Self-Advocate

"I used to serve individuals who couldn't get good staff, reliable staff... And in [the staff's] defense, they complained about benefits, and not getting paid enough, and my heart went out to them as well because I can understand... you got to take care of your family, yourself, and take care of someone else, and you're probably struggling to pay bills. So, it's a challenge for everyone who is involved." --C, Self-Advocate

## Ensure Access For All | Next Steps >>>>>>>>>>

### **Create a centralized space where caregivers and people with disabilities can connect to up-to-date resources.**

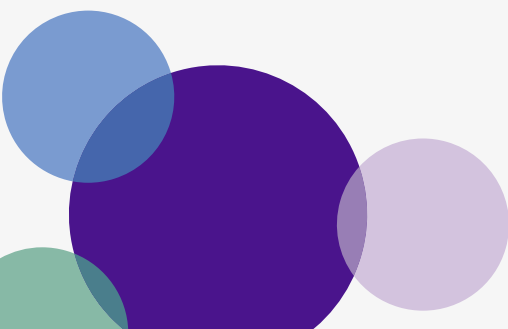
Resources tend to be scattered, making it difficult for people with disabilities and their caregivers to get the help they need, particularly when they also belong to marginalized communities. Creating a centralized, regularly updated resource navigator that is designed to cater to the unique needs of people with disabilities, their caregivers, and the professionals who serve them could help. Consider offering this resource in a print form upon request.

“As someone who has a lot of experience in different populations... I think what I hear most and what I see as some of the big issues are accessibility--having access to resources and also knowing who and where to go to, and the education piece. And specifically, in the Black community.” --M, Caregiver

“Centralizing services would be helpful, because as a provider, it’s hard to keep up with [different agencies] in addition to other responsibilities. And I would say the same for parents as well.” --L, Professional

“When I lived in Wisconsin, there was [a resource] for people that were caregivers and parents, and how to go through what you need to know about wills and trusts. And it was literally just a bound book. I want that, I don’t want to go through electronic resources every time necessarily.” --M, Caregiver

“Those resources [for kids with disabilities] half the time are not even updated, things are not in business [when you call], and a centralized location of resources and advocates, with staffing issues, is just very hard for us [to find] right now after COVID. So, it’s really scrambling to make sure those needs are met for tiny humans.” --T, Caregiver



## Ensure Access For All | Next Steps >>>>>>>>>>>>

**Partner with disability services providers to create roadmaps for care, so that people with disabilities and their caregivers are not overwhelmed by resources they may not need until a later time.**

The volume of resources available to people with disabilities can be daunting. Creating a step-by-step roadmap could help prevent information overload.

“Children’s had a roadmap... that is ‘this is where you are now, so we’re going to let you know about these services. Five years down the road when you’re looking at this stage of life, when your kid’s this age, then we’re going to tell you about these services.’ They kind of earmarked [it for] us, to mention certain things, at certain times... and not just throwing everything [at us] at once.” --A, Caregiver

**Establish mechanisms for interagency collaboration to help streamline transitions from one agency’s services to another, simplify application processes, and lessen the pressure on people with disabilities and caregivers.**

Because disability services come from so many different public and private institutions, people with disabilities and their caregivers often have to provide the same information over and over. Better interagency communication and partnerships could reduce that burden through centralized application processes, information transfer requests, and transition collaboration between organizations.

“As a parent I would love to see [collaboration between partner agencies] on a larger scale... that would make those transitions and handoffs easier. You would have the same contact team and resources where I wouldn’t feel overwhelmed... because I have a hub and a team that supplies all of these [resources]. I love that idea.” --T, Caregiver

“A lot of the times in the application process you have to send over documentation of the diagnosis, which I think should be on the agency to get that transfer from the primary care physician. A lot of the things, we shouldn’t have to provide... Especially if internet access or printing is an issue or is not as equitable for certain people... I think the organization should be able to pull the resources from other organizations or providers should be able to get that application completed.” --T, Caregiver

## Ensure Access For All | Next Steps >>>>>>>>>>>>

### **Advocate for the expanded accessibility of adult day services.**

It remains challenging for caregivers of adults with disabilities to work, in part because adult day services are not plentiful enough, are too expensive, or are not available in an individual's first language.

"[We need to] have daycare [for adults with disabilities]... Daycare and some work in the daycare itself. Teaching sign language to the immigrant population. They come to the US from abroad and their sign language is different... [provide] some sort of entertainment. Engage them in some kind of games and sports." --T, New American Professional

### **Connect caregivers and people with disabilities to assistance enrolling in Medicaid and finding healthcare providers who will accept it.**

Medicaid is a key resource for people with disabilities, but it can be daunting to apply for. Hosting workshops on the Medicaid application process with troubleshooting follow-up, and creating a system for identifying providers who accept Medicaid, would alleviate some of this stress.

"One of the main issues that I've been having is with my Medicaid application... it has happened several times that after a few days, it doesn't work anymore. I don't drive, so I have to take transport. When I coordinate transport to take the kids to the hospital, the transportation tells us that it is not active because the Medicaid card is not active." --C, New American Caregiver

"I just want help applying for [Medicaid]. I get different answers depending on which of the therapists or doctors I talk to. I think there needs to be more and easier information about financial assistance. Grants as well as Medicaid." --B, Caregiver

"[I need help] finding a psychologist or a therapist who will take [my daughter's Medicaid] insurance, and who will give her the services she needs." --A, 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 >>>>>>>>>>

### **Train employers on best practices for recruiting and retaining employees with disabilities.**

Employers may not understand what resources or supports employees with disabilities need in order to be successful, or how they might need to clarify expectations with someone who communicates differently. Offer training to these employers regarding how best to recruit, train, and retain employees with disabilities.

“I have a buddy who’s had 26 jobs he’s gone through because he has severe anxiety. ...There’s plenty of people out there that need a little more support, and need other options rather than the cookie cutter settings we have right now.” --M, Professional

### **Partner with workforce development agencies to improve employee training programs and provide specific guidance on training soft skills among people with disabilities.**

For people with disabilities and without, interpersonal and soft skills are a key element of success in the workforce. Creating programming which is accessible for people with disabilities to help improve soft skills could be helpful.

“Ninety percent of what makes a person employable and retainable is interpersonally related. ...Yes, obviously [people] need to learn job skills, but coming with those ‘soft skills’... I don’t think people realize what a huge variable that is when it comes to a 25 year old individual.” --A, Caregiver

### **Provide pathways for people with disabilities to secure employment through career training in schools and partnerships with local employers.**

People with disabilities have plenty of skills that are extremely valuable to the workforce, but may struggle to identify or develop them. Create dedicated structures, through schools, employers, and workforce development agencies, for the building of those skill sets with the promise of employment on the other side.

“We have a lot of big corporations here in Columbus... I find it hard to believe that they can’t provide some support for folks with disabilities who there is a niche for them in doing particular tasks... There are various skills that everyone has and I think there has to be a way to tap into some of these companies that need help and folks with disabilities can fill those gaps.” --L, 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



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

### **Partner with public policymakers, architecture schools, and property developers to encourage the building of more universally designed housing.**

Finding accessible, affordable housing can be extremely challenging. Push for public policy change to ensure a percentage of all new housing in Ohio meets universal design criteria. Bring architecture schools and property developers up to speed on the benefits of universal design.

“I’m on the board of the Housing Quality Panel. One of the things we’re pushing for is 30% of housing to be universally designed, and that’s housing built from the ground up, like sloped entries, no steps, roll in showers, wider doorways. What people don’t realize, this doesn’t just benefit the disabled population. It benefits aging populations, this benefits veterans, this benefits so many different people. And it doesn’t cost any more money than regular construction.” --A, Self-Advocate

“I think it would be great to collaborate with some of these college students... to think about how they view equity and what that looks like to them and how important that is when you are building housing and affordable housing at that. I think it would be great to start bridging those gaps and having those conversations.” --M, Caregiver

### **Prioritize creating culturally competent resources and services for new Americans with disabilities that they can access in their own language.**

Language and cultural differences create additional layers of complexity for new Americans with disabilities. Encourage providers to offer services in a wide range of languages, and to ensure they are respectful of different cultures and faiths. Encourage partnerships between these agencies and local faith communities, new American advocacy organizations, and community leaders in order to begin this process.

“A lot of our work goes into raising a child with a disability. Mental health is even more complicated because mental health services are not readily available, so for those who have language issues and different cultures, it is really challenging to get access to mental health services, but also it is even harder to maintain and take advantage of these services. I have had to refer people to mental health services and when they go in there, maybe they don’t like the food, they can’t practice their faith, and they cannot stay there anymore.” --M, New American Professional

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

"[One of my clients] does not have an interpreter... he uses sign language. American sign language is totally different. He doesn't understand American sign language. There is no question of a language barrier. What happens when his mom isn't there? His mom is elderly. What happens after? ...How can he go to the hospital? ...somebody has to go with him... it is difficult to find volunteers that can give their time and help these families." --T, New American Professional

### **Create training materials for childcare providers to educate them regarding disabilities and how best to serve children who exhibit unusual behaviors.**

The care and comfort of people with disabilities often rests in the hands of those who are not involved in the disability community, and do not know how to react to unusual behaviors or unique needs. Disability awareness training for daycare providers could go a long way toward helping families find competent care more readily. Advocate for disability awareness training to be a prerequisite of Step Up to Quality certifications in order to ensure widespread participation.

"We just found out our son is on the autism spectrum a year and a half ago... the hardest part for me is just finding support in my local community. He was just asked to leave his school's daycare because they couldn't handle his elopement and running away. Now I'm at a loss for who can take care of him while I try to work." --B, Caregiver

"I really think that there needs to be more awareness. For example, at [my son's] previous daycare, the staff didn't understand his stimming, his flapping arms, the weird little things that he does. The staff told me he needs to stop doing that. Okay, he's autistic." --B, Caregiver

"Daycares don't have enough education and proper training to know how to deal with kids with autism. How can the carers be better informed on how to treat children with the same respect they do for other ones. If they understand what the spectrum is, they will know enough not to discriminate against kids who have actions that are sometimes involuntary." --M, 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

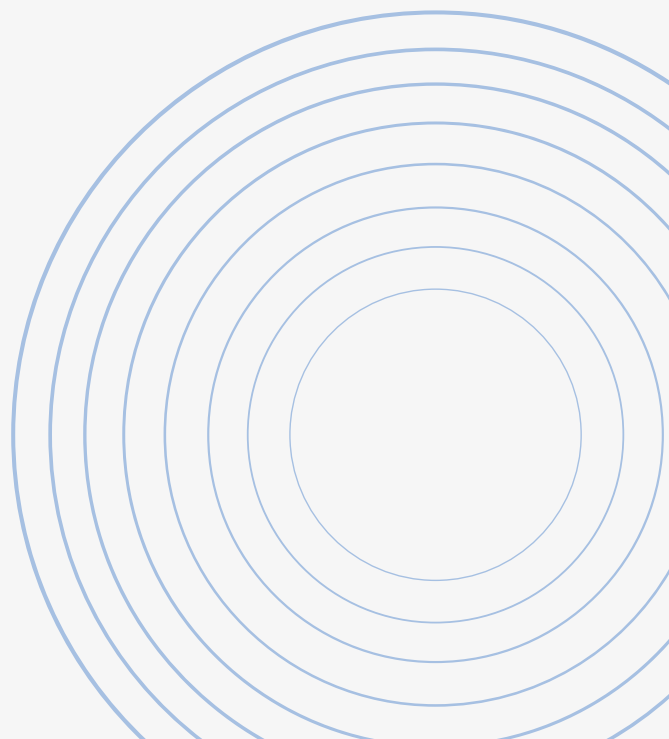
"...There should be something done with being able to identify [caregivers] and seeking them out and giving them support and accessible resources... and also advocacy. Because I often see those people in and out of my portal... and nothing's changed with regards to the support that they have. I worry 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.

