

# Community Conversation: Governor’s Council on Developmental Disabilities

## Background

### Governor’s Council on Developmental Disabilities

The mission of the Minnesota Governor’s Council on Developmental Disabilities is to provide information, education, and training to build knowledge, develop skills, and change attitudes that will lead to increased independence, productivity, self-determination, integration and inclusion for people with developmental disabilities and their families.

## Conversation

The conversation was held on Aug. 7, 2024 at The Masonic Institute for the Developing Brain in Minneapolis. Eighteen participants attended. The Olmstead Implementation Office (OIO) facilitated the conversation.

The participants responded to the following questions:

- What does integration mean to you?
- Tell us a story about a time you felt included or excluded. What helped you feel included? If you felt excluded, what would have made the situation better?
- What would you like to be different five years from now in the areas of choice and integration in Minnesota? What would need to change to get us there?

This report summarizes themes from participants’ responses to all three questions.

## Participant demographics

### Participant roles

Role	Count	Percentage
Parent	11	61%
Friend or ally	10	55.6%
Family member	9	50%
Caregiver	7	44.4%
Person with a disability	6	38.9%

Legal guardian of someone under 18	4	33.3%
Legal guardian of someone over 18	3	22.2%
Service provider	2	16.7%
State employee	2	11.1%

### Participant race/ethnicity

Race/ethnicity	Count	Percentage
Asian	1	5.6%
Black or African American	2	16.7%
White	14	77.8%
Self-describe	1	5.6%

### Participant age

Age range	Count	Percentage
25-34	2	11.1%
35-44	4	22.2%
45-54	5	27.8%
55-64	2	11.1%
65+	2	11.1%
No response	3	16.7%

### Participant gender

Gender	Count	Percentage
Man	5	27.8%
Woman	11	61.1%
No response	2	11.1%

## Participant county of residence

Location	Count	Percentage
Seven-county metro area	9	50%
Greater Minnesota	5	27.8%
No response	4	33.3%

## Conversation themes and representative quotes

### General themes

During the conversation, several participants shared broad comments around transportation and employment, stating that they want Minnesota to have more and better options in those areas for people with disabilities.

### **Theme: The systems to apply for and receive benefits and services are too complicated.**

Many participants described frustrations with the processes to apply for and receive benefits and services for themselves and for loved ones.

A parent of children with autism said the benefits and services systems are confusing and hard to navigate. “That in and of itself becomes a barrier for integration, because then you don’t understand how to access something, or the rules don’t make sense, and now you have to do 40 extra things that somebody else didn’t have to do to prove A, B, C or D. You make one mistake, you miss one thing, and you have to start over.”

“The system can choke people. If you call on the right day the right time, they’ll say, ‘Yes there’s a slot open, yes you can get in.’ But if people really understood how many people are not receiving services that should be – it’s horrifying. We have a long way to go. You always hate to criticize the system, but the system should be more responsive to the individuals.” – Advocate for people with disabilities and who has worked in the disability field for decades

“When I think about integration, I think about the right to access services, the right to choice and that a person can change their mind whether they access those services. I also think about all the barriers to getting those services. County websites are not easy to navigate. They’re not in languages other than English. It’s just not accessible. Sometimes there’s paper applications with the county, sometimes there’s electronic applications, different counties want different things. How do you figure out what they want if you can’t even figure out who to talk to?” – Participant who did not share their relationship to disability

“One of the goals should be that everyone who is eligible for services has access to them. I was just making a list of the things that I manage on behalf of my children: We have Medical Assistance eligibility, the waiver funding process and the annual funding for that, Supplemental Security Income eligibility, Supplemental Security Income

annual reports, employment services, (two inaudible eligibility assessments) ... Why do we have to do this every year? My kids aren't going to wake up one morning and not have [intellectual and developmental disabilities] ... If those could go two- or three-year cycles or something, the administrative burden that it would take off of caregivers, parents, everybody would be astronomical." – Parent of children with disabilities

### **Theme: People with disabilities don't feel they have choices in many areas of life.**

Several participants said they don't feel people with disabilities have real options in housing, services, and other areas, in part because of the shortage of direct support professionals and access to other resources.

"I have a client who lives in adult foster care, and she feels like she has no options to get out of the place she's in, even though she's extremely unhappy. She doesn't have the ability to get into the community, and the home she's living in doesn't help her find the options that she needs. I even asked her, 'Do you feel like you're institutionalized and a prisoner?' She said yes. She's afraid of the repercussions if she says that she wants to move. It's very disheartening to hear that she feels she doesn't have options." – Participant who works as a mental health therapist

"There aren't choices for a lot of things. I think in advocacy and state government, we speak good words about person-centered planning. The operationalization of person-centered planning doesn't exist because there aren't enough services and supports to provide choice. So stop with just the big ideas and really go to the implementation side and see what's not working." – Participant who did not disclose their relationship to disability

We need to be "making sure that we are providing legitimate choices in providers, homes, and not have one particular option be clearly what the powers that be want people to take. And that means investing in a workforce to promote independence for people, investment in non-group housing options, more and better paid PCAs to support people. While we don't have huge institutions for people with developmental disabilities anymore, we do still tend to rely on group homes as the default, and that's an option that some people choose, but our cases show that while group homes do work for some, they shouldn't be the default option, that people should have the ability to work and live in the community in different settings." – Participant who works in the disability field

### **Theme: Children with disabilities experience segregation, as well as lack of inclusion and choice, from a young age including in educational settings.**

Multiple participants said their children have been segregated and excluded at school. Parents described institutional segregation, where their children learned in different classrooms than non-disabled students, and social exclusion through bullying.

"I have [a middle schooler] who has always been on IEPs, and we've always had great relationships with the school ... He's always been on the short busses, and this year, he said, 'I want to ride the big bus this year. Why can't I? Why haven't I?' And that really threw me because I don't even really remember, in all those years of IEPs, anyone saying that's a choice. He just was put on the short bus – the very segregated short bus – when for him, there was no reason for that. I'm upset about it because I just went along with it and ... assumed that was the best thing to do. But he was the one who knew that wasn't what he wanted or needed. He felt separate and

different. It is a big deal in our household. We went through all the processes – once I figured out what they were – and now he’s all set to ride the big bus in a couple weeks. He’s really excited.” – Parent of a child with disabilities

A parent said her son experiences bullying at school, including being called the r-slur. “If he has to go to the resource room, students make fun of him. It’s looked down on rather than being looked at as a help that he needs with tasks. For him, it’s so embarrassing because all his peers are calling it ‘the SPED room’ and saying, ‘Look at you, you’re SPED.’ The language – I don’t see it changing with the culture and attitude of his peers. He’s going into high school, and I’m praying it was a middle school thing. I’m hoping.”

A parent said her preteen son has been homeschooled since early childhood because his school district wasn’t willing to let him learn in a less-segregated setting. “Our school district is unwilling to even try a least restrictive environment for him. They immediately go to a Level 4 setting, which is the kids with severe behavioral issues (and where students spend more than half the day in a different building.) My son is nonverbal and uses a wheelchair and he would not be safe in that environment – he couldn’t tell anyone if something was happening. We have homeschooled him to keep him safe because there is not integration like there should be.”

Several parents shared stories about their children with disabilities being excluded from school field trips. Parents also said that teachers told them their student could only go on field trips if the parent came along to support them. One parent said she chaperoned a field trip to the circus with her son, who uses a wheelchair, and they had to find an accessible elevator by themselves while the rest of the class ran up the stairs to their seating area. “Once we got upstairs, I couldn’t find his class, his teacher, or any of the other chaperones, so we sat by ourselves. I was so excited for him to experience this field trip with his classmates, but he had to sit with his mom. As a second or third grader, you don’t want to do that, you want to be with the other kids.”

One parent shared that she chaperoned a field trip to a historical site and learned after arriving to the site that snowshoeing was part of the field trip. “My daughter has cerebral palsy, and she can’t snowshoe – it’s not possible. It was a frustrating experience. I can’t imagine how she felt while her classmates were way ahead of her, and me and her grandma were trying to help her. I kept thinking about how that could’ve been planned so much better. The teacher could have offered alternatives. We could’ve brought a sled and pulled her. It could have been prevented.”

### **Theme: Physical inaccessibility is a barrier to integration, choice and inclusion.**

Some participants said that inaccessible buildings and other public spaces create obstacles to independence and integration.

One participant shared that he often encountered physical spaces that were not accessible to him as a wheelchair user on his college campus. “It was very difficult to keep advocating for better accessibility because it wasn’t there in the first place, even though that wasn’t my job at the time – I was supposed to be a student. That made me feel like I wasn’t having the same experiences as my peers ... If there are physical architectural barriers, then someone can’t freely go around like everyone else, and that’s completely against what integration means.” This participant also said health care facilities are often inaccessible and don’t have equipment like Hoyer lifts, which affect the quality of care he receives.

A participant who works in the disability field shared a story about taking a tour of the State Capitol with a group of people with disabilities. The senator showing them around the Capitol wanted to show them the House or Senate floor and said they'd have to "break some rules" to get there because the floor is not accessible. The participant said, "He took us through the 'retiring room' – only legislators are allowed in that room, even staffers aren't allowed in there" because it was the only accessible route to the floor.

### **Theme: Integration, choice and inclusion are just as important in recreational activities.**

Several participants described the impact of integration and inclusion – or the lack thereof – in hobbies and entertainment. They shared that they want to enjoy leisure activities, like going out to eat and seeing movies, alongside people with and without disabilities.

"We've had a series of experiences in at least six different types of venues where we're allowed one person to sit with my son, who uses a wheelchair, in the accessible seating. It's been going on since my older daughters were very young and not of an age where they should be separated from a parent. But we've been forced to separate many times. The State Fair, Twins games, stadiums, theatres, SeaWorld ... It's just blatant exclusion. It's inequality. People that need to sit in that seating are not allowed to fully participate like other families. His sisters and the second parent are unable to experience what he's there to experience with him. My point is that exclusion trickles down in families, and it doesn't just affect the person with a disability. He would've loved to experience these things with his sisters and both parents there next to him, and he couldn't, and in the same way, his sisters couldn't experience those things with him." – Parent of a child with disabilities

"Inclusion is very important, even at movie theaters we have access issues. Everyone should be included in the community, whether it's going to see a movie or going to a self-advocacy group." – Self-advocate with disabilities

"I think it's important to be included and with people that have disabilities and without. Just included in general, for a sleepover or a baseball game." – Participant with a disability

One participant who uses a wheelchair told a story about going to an event at a restaurant when he was in college. "The restaurant thought it was a good idea to block the accessible entrance with a table, so people are eating at a table that's blocking the only accessible entrance. It was like the restaurant didn't think that disabled people would go out to eat or do the normal things that everyone does. Luckily the people were nice enough to move, but they were in the middle of eating, and I had to ask them to move. Accessibility and the lack of awareness about it affects multiple areas, not just the most important, like health care and education, but even just activities that people do for fun, that are normal aspects of life."

### **Theme: Integration and inclusion require active allyship from non-disabled people.**

Participants said that people with disabilities can't achieve full community integration and inclusion on their own. Others in the community, especially non-disabled people, must work toward integration and inclusion as well.

“I think learning to include others is important for children, too. Especially children that don’t understand that when you go into school, there’s going to be multiple people that have some kind of disability – then you (as someone with a disability) can be included that way, like you can have lunch with somebody that doesn’t have a disability. Individuals with disabilities are kind of shy sometimes, so it’s important to include them.” – Participant with a disability

“Integration takes active participation from the community, collaborations, groups coming together, intentional inclusion. And it takes advocacy both from the person with the disability and from community members, peers, family members.” – Participant who works in the disability field

“Integration is acceptance as the norm, as well as access being the default – not having to always ask for accommodations or take that effort on by yourself. Having that be the default setting is a big thing.” – Participant with disabilities who works in the disability field