



Colorado Developmental Disabilities Council

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General Comments

Community Listening Session 03/05:

- A trend I see between them all is the complexity of the systems and the potential interconnectivity of them. For example, if someone works or has an increase in their work income - then it could impact their housing or healthcare (if they are using any public benefits in those areas). So having solid understanding of the potential impacts and advocacy for when the system does something unexpected or if there are negative outcomes in those areas. This will be particularly relevant as there are shifts in policy and budget impacts on the state and federal level.
- More sensory accessibility in general, there are a lot of sources of stress that don't have to be there. It's just that things are designed for people who aren't as bothered by ambient noises and fluorescent lighting and there's a lot of structural stuff that makes places potentially not very accessible for people with sensory sensitivities, so that's something I would definitely like to see improve.
- 5 years from now, maybe just more community living spaces for families and those with similar lived experiences, to be something you see throughout the United States in different states. I think just more inclusive thoughtfulness when it comes to project developments, healthcare laws. Maybe more inclusive

understanding and policies within the workforce for families who do have children with disabilities. It's just really all around the board, just being thought of as policies and housing in these laws that are being developed. When we are creating laws and policies and regulations, I feel like it almost should be a checkbox: Is this accessible? Is this inclusive? When changes are happening, who is it impacting? If that could be a standard across all things, when things are being voted on and things are being passed, that it's a checkbox. Have we thought about this? Does this contradict federal laws?

Online Survey Responses:

- Inclusive to all
- I personally am not I/DD but I am disabled, I don't see why we should discriminate against disability.
- Transportation that is accessible and affordable and promotes independence in where one lives and works.
- To have a holistic solution that allows maximum independence which can only be achieved through reliable and affordable transportation.
- Expand voucher availability and access.
- The DD Council should be directly supporting statewide self-advocacy through a coordinator position.
- Try to identify and facilitate public private partnerships.

Comments by Priority Area

This section looks at the comments from the perspective of the priority areas selected by the Council for inclusion in the next five-year plan.

1. Health Care
2. Housing
3. Employment

HealthCare

Community Listening Session 02/09:

- Promote exercise and nutrition.

Community Listening Session 03/05:

- I liked the idea raised earlier about creating/offering training for medical professionals to help build awareness and empathy.

- If health professionals were trained in knowing some sensitivity and some training about people with IDD and neurodivergent people. If there was some consistency there across the board. For example, something you tell your doctor that's going on with you physically several times over several different visits, and they're not responding at all. If there could be some system in place where they have to document, like, by the second time, this person says something about this physical thing, you know, we need to take action. I can't tell you how many times everything ends with, do you have a psychiatrist? And it's just very hard to counteract that, live with a healthcare person or anybody who is kind of in charge of what your freedoms are, or your autonomy.
- This goes bigger than Colorado. All of our medical schools should have a program and incorporate into it, interacting with individuals with IDD or disabilities, so that they learn that in medical school. And it should be in the nursing schools as well. That would be a huge benefit. That's a big, big mountain to climb, but it definitely should be part of our medical system and medical training.

Online Survey Responses:

- Spreading action guidelines for advocating to protect Medicaid.
- Teaching about Medicaid Buy In.
- Providers need to be better prepared to serve patients with IDD in their practices. Affordable housing (always an issue) and lack of housing options in people's own communities (most host homes, for example, are in Aurora, but someone may have been living and working in Lakewood). Employment is a concern, but the quality of supported employment services needs to be improved to create a better experience for employers.
- Could the DD Council work with hospital systems in the state to create/provide physician and staff education?
- Examples of Projects/Activities:
 - Disability Competent Healthcare Training Initiative.
 - Develop statewide training for healthcare providers on serving individuals with I/DD.
 - Focus on communication access, complex medical needs, and patient-centered care. Healthcare Transition Systems Change.
 - Support statewide models that improve transition from pediatric to adult healthcare systems for youth with I/DD.
 - Integrated Care Coordination Models.

- Identify and scale best practices that integrate healthcare, behavioral health, and long-term services and supports.
- Self-Advocate Leadership in Healthcare Policy.
- Invest in leadership development for individuals with I/DD to participate in healthcare system design and advisory roles.

Housing

Community Listening Session 02/09:

- Promote different types of housing in the desired community.
- Offer housing near transit/alternative forms of transportation.
- Partnerships with other organizations and state agencies.
- Agency to participate safely and as desired in their community.
- Increase opportunities for community connection.
- Significant increase in affordable and accessible options.
- Safe outdoor space near all housing.

Community Listening Session 03/05:

- We need a user-friendly matrix that allows the developers, property managers and leasing agents to understand the limitations and advantages of each waiver. The morass of federal and state regulations is difficult to understand and follow.
- I am on the Western slope. I know there was a community living area on the front range. I would like to see more conversations for rural areas. Like a place to regulate throughout the day. Actual guidelines how to prove retaliation because when we do advocate it's very hard to show when we are penalized or ignored. Like a federal criteria that is obtainable to prove.
- There were some exploratory research focus groups and stuff last year about potential intentional communities for neurodivergent people and their families. I know there's a neuro inclusive housing project to try to have more apartments. They brought us all in and got all of our suggestions for what we would like to see in the community, and a lot of us wanted safe outdoor walking paths and safe outdoor spaces and communal inside spaces. We got to give so much input. There's so many great opportunities that are happening on the front range areas, but not necessarily outside of that. I would love to know if there's a voice for more rural areas.

Online Survey Responses:

- Creation of more accessible housing and accessible laws that require accessible modifications when needed.
- Lack of inclusive affordable housing for children. On Western slope apartment units are consuming new development with no access to a yard or a play area when parks are too high risk for elopement and sensory challenges. Credit score barriers for parents to access housing.
- Housing developers should be required to order a certain square footage of outdoor fenced in spaces. No credit score required. Enforce landlords to report on time payments.
- People need to pay attention to caregivers whose children have IDD. I feel we are all overlooked when it comes to these topics. Especially with housing needs. What is affordable is not a safe environment.
- Community living for caregivers whose children have IDD. Where there would be a direct peer to support us who walk an isolating journey. A community housing development with safe outdoor and indoor play areas that are safe for children who elope or need a sensory break.
- Housing developments should have to require a certain amount of outdoor space to offer a safe play environment for children with disabilities. Or be required to include an outdoor space area with recreational options for children. When children have small spaces they are forced to seek sensory input outside the home and have to drive to parks that are not sensory friendly or elopement friendly.
- More statewide remote jobs that caregivers can contribute to our economy but flexible as I'm home needs are unexpected.
- Credit score was not required when applying for housing because many families struggle with credit because they choose to pay their need to live bills rather than focus on building credit recovery or paying towards debt. Many families are living in hotels because even though they have an income credit score prevents them from living in a safe area.
- Examples of Projects/Activities:
 - Innovative Housing Model Demonstrations.
 - Support research and policy development around models such as cooperative housing, shared living, and community-based housing networks.

- Housing Policy and Systems Alignment.
- Work with housing authorities, disability agencies, and policymakers to remove barriers that limit access to housing for people with I/DD.
- Housing Navigation and Planning Tools.
- Develop statewide tools and resources that help families plan earlier for housing options and understand pathways to independent living.
- Cross-Sector Collaboration.
- Build partnerships between housing developers, disability organizations, and state agencies to increase accessible housing stock.

Employment

Community Listening Session 03/05:

- From an employment perspective, I would hope that everyone with IDD is empowered to work, if they wish to. As others have articulated, there are a lot of barriers within the support networks that send the message that people are not capable, and that is not true! If we can shift the thinking that anyone can work (and there is support for them if they need it), I think it would make a big difference.
- Not necessarily day-to-day job coaching in the sense of how do I do this? Sometimes they know what to do, they're less focused that day, so they need somebody there to help them be focused. They are working full-time or almost full-time, and they get tired in the last few hours of their shift, and so they need somebody there just to help them. We've created a lot of natural support, but they just still need that person to help focus just for these certain hours. There's going to be a need for job coaching and for maintenance that may not match. It's going to be a better match, but it matches the needs of the individual.

Online Survey Responses:

- Expand incentives and support for employers to hire those with IDD into typical jobs, as opposed to directing those with IDD to pre-selected jobs and employers.
- Employers not allowing virtual options for positions that can be done at home effectively. Spouses having to use vacation days to care for disabled children when the primary caregiver mother also has mental health issues.
- Work to support employment service providers to better understand the impact that their work has, and how important it is to employers. Successful hires are not an accident.
- Examples of Projects/Activities:

- Employer Engagement and Workforce Education.
- Develop initiatives that help employers understand the value of hiring individuals with I/DD and how to create inclusive workplaces.
- Transition to Employment Systems Improvement.
- Strengthen collaboration between schools, vocational rehabilitation, and community partners to ensure youth with I/DD transition to employment, not unemployment.
- Career Pathway Development.
- Promote models that connect individuals with I/DD to career pathways, internships, and apprenticeships.
- Self-Advocate Leadership in Employment Policy.
- Invest in leadership training so individuals with I/DD help shape workforce and employment policy discussions.

Cross-Cutting Themes

This section looks at the comments from the perspective of cross-cutting themes that are important to consider in the next five-year plan.

1. Incorporate **self-advocates** into all decision-making and programming.
 - View disability as a strength that makes communities stronger.
2. Address **barriers and systemic challenges**.
 - Tension between formal systems and natural supports.
 - Deep concerns about system fragility, funding, and sustainability.
3. Center belonging, purpose and individual paths to a **meaningful life**.
4. Support families across the **lifespan**, including major times of **transition**.

Self-Advocates:

- More people with disabilities who are in policymaking roles or leadership roles such that there are more people inside of organizations and governing bodies who are familiar with disabled experiences and coming from that place of knowledge rather than all kinds of decisions about us being made by others. I think I would try to keep the conversation open with balances between. The technology that can help in some areas. In conversations with the people that I provide for there's still that desire and necessity for human contact. So as much as technology can help, not just relying on that, is the only solution or only way to grow.

- More people with disabilities inside of each of those governing areas, more people with disabilities in healthcare and in healthcare policy, in housing, affordable housing, the housing authorities, and also employment, everything to do with employment, more disabled people working and able to be allowed to do their job.

Online Survey Response:

- Expand stakeholder input from advocacy communities representing IDD, not the same groups who have always been at the table, but groups that have recently become more vocal due to lack of adequate representation.
- The disability community is not united. The old-school orgs that have the power are failing to represent the IDD community. Factions are forming and in-fighting is happening. We have to find a way to come together.

Barriers and Systemic Challenges:

- A trend I see between them all is the complexity of the systems and the potential interconnectivity of them. For example, if someone works or has an increase in their work income - then it could impact their housing or healthcare (if they are using any public benefits in those areas). So having solid understanding of the potential impacts and advocacy for when the system does something unexpected or if there are negative outcomes in those areas. This will be particularly relevant as there are shifts in policy and budget impacts on the state and federal level.
- In terms of education, that's another area where there's a lack of accessibility, there's a lack of understanding and a lot of bias from Policymakers and Professionals who are in charge of individual schools or classes and a lot of discrimination. Schools in general are really not accessible on a sensory level. They're set up with the kind of standardization that's sort of harmful because it positions a lot of people as if the problem is them, when really it's just that the school is designed for one specific type of learner, and doesn't accommodate others. A lot of people learn lessons in school about how seriously others are going to take them, and a lot of people end up getting the message that they don't count. It can make a lot of difference in the rest of people's lives.
- I think there needs to be (in all three areas) some consistency with reasonable accommodations, and some way to enforce them in those areas without getting unreasonable reactions and responses from the people who are in charge of those accommodations at those places.

- I was thinking about it more in relation to healthcare and employment, but I can see how it could also apply to housing. My understanding and experience is that a lot of professionals, including people in the medical field, but also hiring managers and bosses really just have a lot of misconceptions, and an ableist stigma. A lot of people who end up working with people with IDD, or in a position of power over people with IDD are really sort of scared of us, or put off by us. I'm thinking of, for example, a real barrier to employment for a lot of people is being judged as non-normative, I'm autistic, for instance. A lot of hiring managers might dismiss people who they think are weird, or they're looking for eye contact during interviews, or strong handshakes, or whatever, and those are not things that are actually correlated with your ability to do the job? There's a lot of bias that prevents people from being employed. Similarly with healthcare, I think there's a lot of bias that doctors sort of jump to a conclusion of, "you have some kind of disability that means you don't understand me". People don't get good healthcare from practitioners who sort of feel like "this is someone unreasonable, this is someone I can't talk to normally". There needs to be better awareness about and acceptance of people with IDD, rather than professionals just seeing us making a judgment about us not being normal and presuming that we're not competent.

Online Survey Response:

- Across Colorado, families and individuals with intellectual and developmental disabilities face persistent barriers in access, coordination, and long-term planning across these three systems.
 - Healthcare: Lack of providers trained in serving individuals with I/DD, particularly adults. Fragmented systems between healthcare, behavioral health, and disability services. Limited care coordination for individuals with complex needs, including those with sensory disabilities or medical complexity. Insufficient support for families navigating transitions from pediatric to adult healthcare systems.
 - Housing: Severe shortage of affordable, accessible, and supportive housing options. Long waitlists and limited pathways to independent or supported living. Lack of innovative housing models that allow people with I/DD to live in their communities with appropriate support.
 - Employment: Low expectations and limited opportunities for competitive, integrated employment. Insufficient employer engagement and workforce education. Limited access to transition planning and career exploration beginning in school.

Belonging, Purpose, Inclusion, Meaningful Life:

- For healthcare, try to create some lists of people like doctors that take long-term care. If people have had a positive experience or if they're looking for a doctor in a certain area there's some sort of list they can go to to see that person seems to have experience. Maybe creating some sort of list where we know people have had a positive experience in healthcare and with which providers those are. Like a directory of recommendations of neuro affirming providers.
- When it comes to parents, I feel like there's not a lot of emphasis on inclusion in those types of things for the children. There's so many projects, developments with all these apartments and all these things, and there's no actual space for kids to play. And, with housing being so expensive, I feel like the perfect world is that developers would be required to have a certain amount of square footage for outdoor space, especially if we're being confined into a smaller place because of affordability. But I think that it's something that people don't realize when you have two neurodivergent children: the sensory input needed, the elopement risk, just to go to a park that's obviously not fenced in is very scary, so we just don't do it. And so, I think that I would like to see more opportunities for families with children that are neurodivergent. That could be more inclusive, and I also think about these developments. If we are not having some sort of outdoor space, we should be doing more of a community space within these apartments and townhouses that they're building, because we just don't have those options. And so, it's something I would like to see. I saw an article on LinkedIn that there was actually a community living facility that they created. And I've heard this from a lot of parents, that we would love to see the same thing for families with children, because it would be a direct impact or direct access to other lived experience and other just peer support with other parents, and we would all have a safe space and understanding. That we could have a shared space.

Online Survey Responses:

- Five years from now, I would hope to see Colorado move toward a system where people with I/DD are fully included in community life and have meaningful choices.
 - Healthcare: More providers trained in disability-competent care. Better coordination between healthcare, Medicaid systems, and disability services. Accessible communication and care practices for individuals with diverse needs.
 - Housing: Expanded affordable and accessible housing options across the state. Innovative housing models that allow people with disabilities to live independently while remaining connected to community support.

Cross-system collaboration between housing authorities, disability systems, and community organizations.

- Employment: Significantly increased rates of competitive integrated employment. Employers actively recruit individuals with disabilities as part of workforce strategies. Transition systems that prepare youth with I/DD for careers, not just services. Ultimately, success would mean people with I/DD living self-directed lives with real choices about where they live, how they receive healthcare, and how they participate in the workforce.

Support Families Across Lifespan:

- For example, in housing, there's often a lot of affordable housing. A lot of units are set aside for people with disabilities, but my experience is that they don't fix the things in those apartments, and don't uphold the accommodations. The same thing happened to me at work and with my doctors. An example would be where I live. I mean, well, this wouldn't be a reasonable accommodation, but just getting discrimination. To the point of being told “just don't flush toilet paper down the toilet”, you know, because your toilet keeps flooding. And they're not going to give you a new toilet. There's a lot of things that people think they can just do, but there's not an easy recourse. When you advocate for yourself in these situations, it seems to cause strife with the other parties, but that seems to be part of what they're expecting, and then that seems to help them talk about you with their cohorts like the other people in the office at the apartment complex or at work, or the other doctors in such a way.
- I would just like to share something in regards to healthcare. I think it would be important to have a uniform system across all providers. It would be so nice to not have to tell your story over and over again, or explain everything, so that people understand, what your needs are, how you learn information, what's the best way to meet your needs, but to have all of that in one place where a provider could look at it and not have to get to know someone over and over again would be so, so helpful across the board. I know a lot of places are going to Epic, which then those systems can talk to each other, and that solves a lot of the problems, but not all places have that. Just advocacy for a uniform system that would support each individual.

Online Survey Responses:

- As both a professional working in disability systems and a parent of a young adult with intellectual and developmental disabilities, I have experienced firsthand how complex and fragmented these systems can be. Families often spend years navigating systems that were not designed with them in mind.

- True systems change happens when we center the voices of individuals with disabilities and their families, build strong cross-sector partnerships, and focus on long-term solutions rather than short-term fixes.
- Colorado has an opportunity to lead by investing in strategies that elevate lived experience, strengthen collaboration across systems, and create pathways for individuals with I/DD to live meaningful, self-directed lives in their communities.