# 2025 Quality of Life Assessment Tracking Study for People with Developmental Disabilities

Research conducted by MarketResponse International



For the Minnesota Governor's Council on Developmental Disabilities (Project 2541; April 2025)



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# Project Overview



According to the Governor's Council on Developmental Disabilities (GCDD) current Five-Year Plan for FFYs 2022-2026, the following Goal Statement applies to Customer Research:

Conduct or commission research studies to measure and assess quality outcomes of the federal DD Act through annual qualitative and quantitative surveys on new topics and issues or further research on topics and issues previously studied.

As done every 5 years since the year 2000, in 2025 the State needed to conduct a Quality-of-Life Assessment Survey (QOLAS) to determine the degree to which people with developmental disabilities in Minnesota believe they are independent, productive, integrated and included in the community, and have self-determination (IPSII).



# Research Design

- 1. Meta Analysis Report Update. A Meta Analysis and summary report of prior IPSII studies completed in 2000, 2005, 2010, 2015 and 2020 was completed prior to conducting the 2025 study. The Meta study report served as a resource to identify gaps, refine focus areas, and lay the groundwork for the upcoming 2025 Five-Year Plan research.
- 2. Qualitative Research among advocates, self-advocates and other subject matter experts. In-depth interviews (IDIs) (total n=24): 60-minute interviews conducted among Council Members (n=9), plus leaders of various advocacy non-profit organizations and other subject matter experts. Additional focus groups and interviews with self-advocates were also conducted. This qualitative research uncovered relevant and timely insights to help inform the new Five-Year Plan. Throughout this report, *italicized* text represents direct quotations from these stake-holders and subject matter experts.
- **3.** A quantitative survey was administered online and in-person, sometimes with paper copies, to self-advocates and family member advocates of people with developmental disabilities. The survey instrument included comprehensive measures of independence, productivity, self-determination, integration and inclusion (IPSII), which have been asked in the same way since the year 2000. The 2025 wave of this longitudinal tracking study was conducted January-April, 2025.
- 4. Insights on Intersectionality: Questions were added to the survey, and outreach efforts were made, to gain insights into the impacts of the intersection of racial and ethnic communities, and developmental disabilities. (The series of Intersectionality Studies, initiated in 2022, were designed to gain insights into the life experiences and needs of people with developmental disabilities, who are identified as being members of other marginalized communities.)

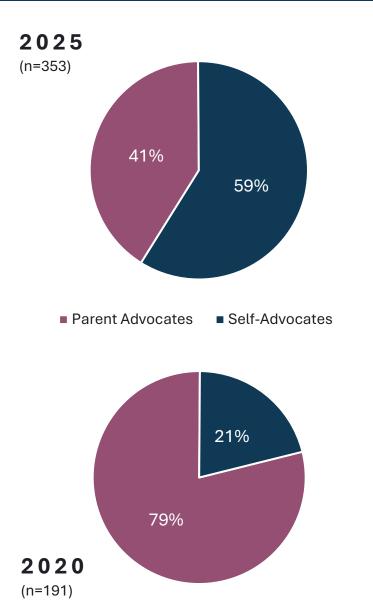
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Thank you to all the leaders of these businesses and advocacy organizations for participating in qualitative interviews, and helping to encourage participation in the study among advocates and self-advocates throughout their networks:

- Advocating Change Together (ACT)
- The Arc Minnesota
- Autism Society of Minnesota (AuSM)
- Autism Sibs Universe
- Cow Tipping Press
- Epilepsy Foundation of Minnesota (EFMN)
- Minnesota Diversified Industries (MDI)
- Minnesota State Academies for the Deaf and Blind
- MSS
- Newtrax
- Partners in Policymaking
- Somali Parents of Autism Network (SPAN)
- Self-Advocates Minnesota (SAM)



## Sample Profile – <u>Parent Advocates and Self-Advocates</u>



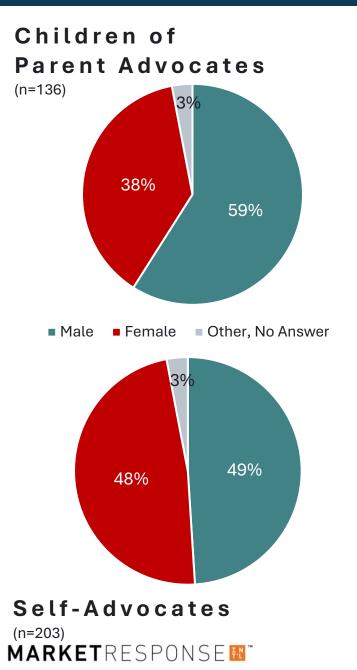
A total of 353 qualified respondents started the 2025 Quality-of-Life Assessment Survey (QOLAS), though not all answered every question. Approximately 315 respondents completed the entire survey.

Respondents to QOLAS studies have always included self-advocates, as well as parents and other family members of persons with developmental disabilities. The parent advocates were instructed to assist or answer the survey questions on behalf of their family members, as follows:

Answers to the questions throughout this survey should be provided by the person with a developmental disability to the extent they are able. Please assist as needed or complete this survey on their behalf.

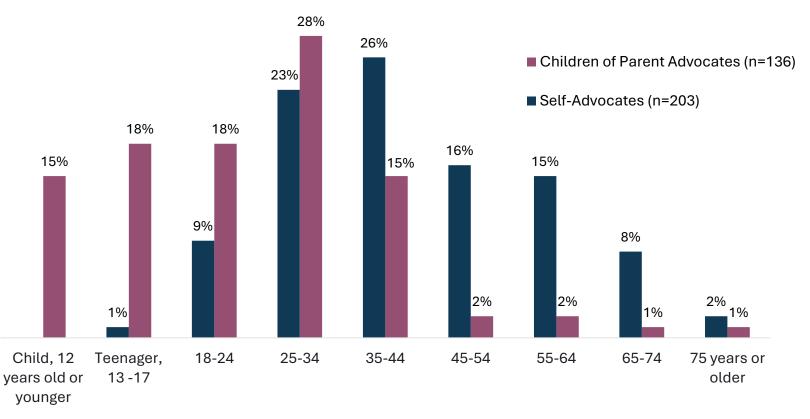
There was a much higher proportion of Self-Advocates in the 2025 sample, as compared to 2020 and previous years' QOLAS studies. The differences between these two respondent groups (as shown on the next two slides) should be kept in mind throughout the analysis of the survey results.

### Sample Profile – <u>Gender and Age</u>



There was a higher proportion of males among the children of parent advocates, as compared to the self-advocates sample of respondents. As expected, Self-Advocates are generally older than those who had a parent or other family member respond to the survey on their behalf.

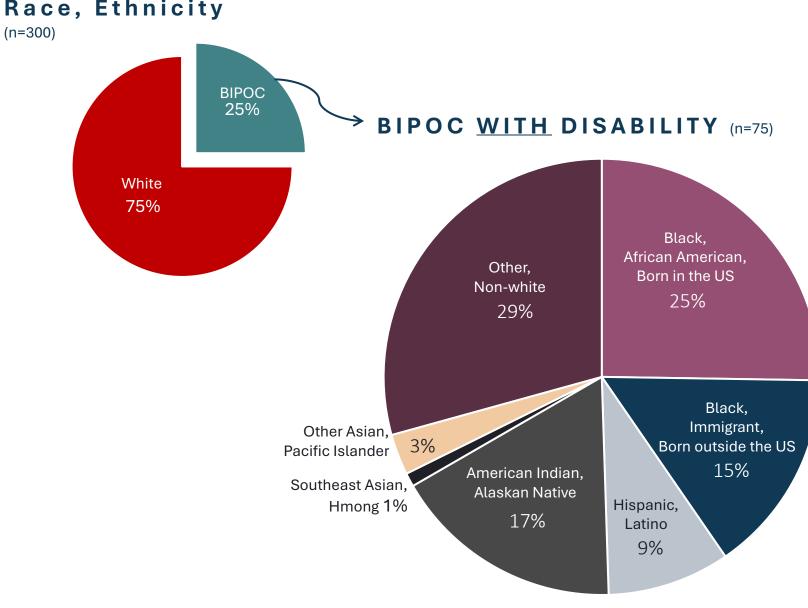
#### 2025 Survey: Age of Persons with Developmental Disabilities



## Sample Profile – <u>Race, Ethnicity</u>

Race, Ethnicity

MARKETRESPONSE **M**\*



Three-out-of-four respondents were White, Caucasian. The remaining 25% (n=75) make up the BIPOC total, which stands for Black, Indigenous, **People of Color.** 

The BIPOC grouping includes several racial and ethnic communities, though Black, African Americans have the most dominant share.

# Project Summary, Conclusions, and Recommendations

- Areas of Progress
- Persistent Challenges and Looming Headwinds
- Next 5 Years RECOMMENDATIONS

### **SUMMARY – Areas of Progress**

### There is tremendous power, momentum, and unity within the disability community right now.

Advocacy Non-Profit



- More communication between the people with disabilities themselves, learning from each other
- Chat rooms, sharing of experiences and ideas
- More awareness within the community about services, support, and resources available.
- Self-advocacy more empowered with technology

Efforts to enhance awareness and treatment of people with developmental disabilities appears to be paying off:



- Treat People Like People campaign
- Advocacy organizations educating the general public about developmental disabilities
- Disability Pride events attendance growing
- Statistically significant improvement in measures of Integration and Inclusion over previous studies

### MARKETRESPONSE 1

Legislative progress, including higher service provider pay, disability waiver rate increases, expanded employment supports, and waiver reforms, has improved life for people with developmental disabilities

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- Compensation (hourly rate) for PCA/CFSS staff has increased a lot of advocacy/legislative work went into this.
- DWRS (disability waiver rate system) has received rate increases.
- Employment support services have been added.

"

I am an optimist. I would say things have improved in multiple areas even though it may not always look that way.

(Self-Advocate, Non-Profit Community Leader)

### **SUMMARY – Persistent Challenges and Looming Headwinds**

In spite of progress in some areas, big challenges persist for people with developmental disabilities.



- Shortage of qualified staff affects the quality and availability of support services
- Lack of reliable and accessible transportation options limit access to employment, healthcare, and community engagement
- Securing gainful employment remains a significant challenge
- Accessible, affordable housing and healthcare is out of reach for many people with developmental disabilities

Federal policy changes and funding cuts could have devastating effects on people with disabilities



- Medicaid, Waivers, Social Security, school programs, housing, and more could be affected
- Lack of compassion at the federal level can encourage uncaring attitudes among the general population, and negative behaviors like bullying, discrimination, isolation, etc.

### MARKETRESPONSE **M**

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### Looking Ahead to the Next 5 Years – RECOMMENDATIONS

Continue grass-roots efforts to increase awareness and positive perceptions of people with developmental disabilities among the general population.



- Continue campaigns to enlighten the public regarding the lives of people with disabilities.
- Continue teaching people with developmental disabilities on how to tell their stories.
- Use the power and reach of local and social media to educate the community.
- Show that when marginalized groups are part of the community, the whole community is better off.

Call for systemic change in transportation, a linchpin issue for disability equity. Some ideas offered:



- Policy Advocacy: Protect/expand Medicaid transportation benefits and ADA enforcement.
- Innovation: Pilot ride-share programs that connect people with disabilities to transportation hubs.
- Awareness: Train transit staff (and general public) on disability inclusion in public transportation.
- Incentivize Accessibility: Tax credits for businesses improving transit access.
- **Community Partnerships**: Collaborate with nonprofits to fund local transport initiatives.

### Looking Ahead to the Next 5 Years – RECOMMENDATIONS

Share ideas with advocates, government and others on ways to improve the lives of people with developmental disabilities in Minnesota.



- Need for simplifying and improving bureaucratic processes for access to services and supports
- Look for innovative solutions to persistent problems related to healthcare, housing, accessible public spaces, transportation, employment, etc.
- Improve accessibility of public spaces and businesses to ensure people with developmental disabilities can fully participate in their communities.

# Current Quality of Life Status

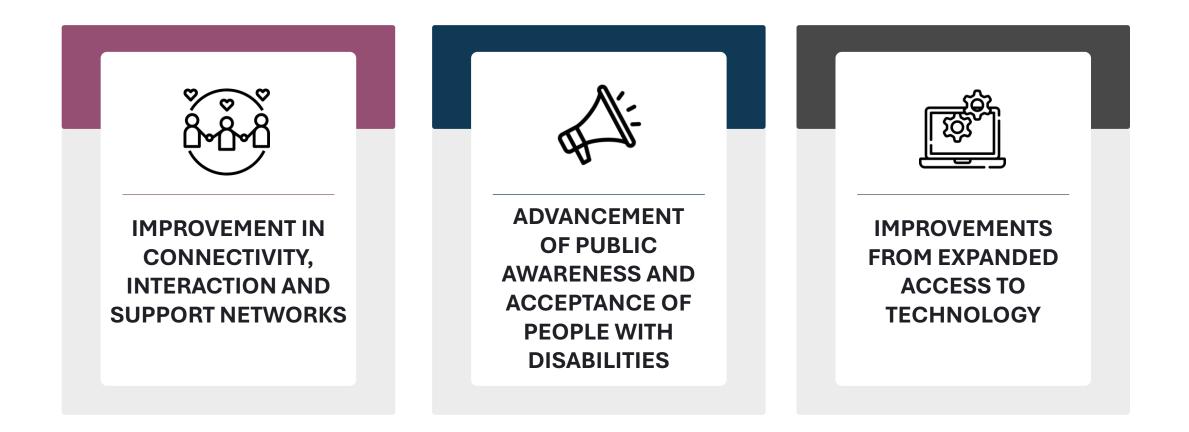
Minnesotans With Developmental Disabilities

#### Areas of Progress

- Disability Community Interaction
- Greater Public Awareness and Acceptance
- Improved Access to Technology
- Community and Basic Needs
- Satisfaction with IPSII
- Measures of Discrimination

### Areas of Progress Over Past 5 Years

Council members and other community leaders believe there have been significant improvements over the past 5 years related to social interaction, public awareness, and access to technology.





IMPROVEMENT IN CONNECTIVITY, INTERACTION AND SUPPORT NETWORKS

There is tremendous power, momentum, and unity within the disability community right now. Advocacy Non-Profit

Awareness of Services	Learning From Each Other	Progress In Education
I would say (people with developmental disabilities) are better off because there's more awareness due to what we and other organizations have done. There's more awareness about services, support, and resources available. BIPOC Community Advocacy Non-Profit	There is more communication between the people with disabilities themselves, they are learning from each other. Chat rooms and new technology have been improved, compared to the past. Disability Employer	I think educationally it is better than five years ago. I think there's been efforts to make parents and caregivers more aware of how IEPs work, and how education can be customized for their child. Council Member



## ADVANCEMENT OF PUBLIC AWARENESS AND ACCEPTANCE OF PEOPLE WITH DISABILITIES

There is a general sense that overall awareness and treatment of people with developmental disabilities have improved in recent years:

Recognition and Inc	lusion in Education	Disability Pride	Educating the Community
It's gotten better for sure. (In educational settings) they're less likely to be the kids down the hall that no one talks about. Now, "they're sitting right next to me in class." It's a whole different deal. Advocacy Consultant	There are a lot more colleges and universities that are recognizing the value of having a diverse population, including people with developmental disabilities, and creating opportunities for them to be as independent as possible through secondary or post- secondary education. Council Member	We hosted the 1st annual Disability Pride Festival in July of 2023, with about 150 folks. The second annual Pride Festival last year had around 650. Advocacy Non-Profit	We go to the houses of worship, community gatherings, and to the Somali media outlets to talk about autism itself and how it's affecting the community. We are educating the community because there is a lot of stigma. BIPOC Community Advocacy Non-Profit



### **IMPROVEMENT FROM EXPANDED ACCESS TO TECHNOLOGY**

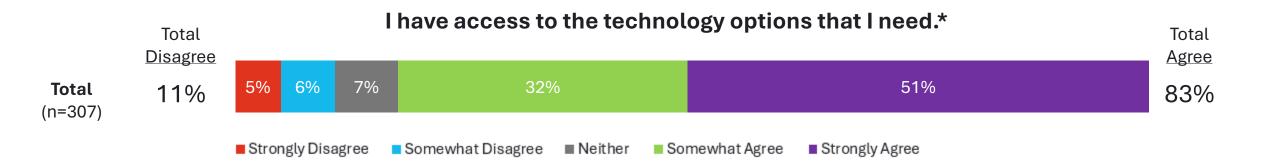
More widespread use of technology during the pandemic enabled new opportunities and access to education, employment, healthcare, and social interactions:

Greater Tech Access	Virtual Connections	Telehealth Outreach
(Most people with developmental disabilities) <i>now have cell phones or</i> <i>iPads, which would have been</i> <i>unheard of 10 years ago.</i> Advocacy Group Non-profit	Some of our programs and services have remained virtual because we've actually increased accessibility across the state. Anybody anywhere in the state now can jump on one of our social emotional support groups. Advocacy Group Non-profit	I think the whole move towards telehealth has made it more possible and easier for people to get some of their healthcare needs met. It has afforded opportunities for some services to be provided over tele- outreach services.
		Council Member



## **IMPROVEMENT FROM EXPANDED ACCESS TO TECHNOLOGY**

**Eight out of ten respondents agreed strongly or somewhat that they have access to the technology options they need.** (There were no differences between white and BIPOC respondents, or between those who live in the Twin Cities metro area and greater Minnesota residents.)



\* <u>Survey Question</u>: Think about all of the technology products and services that are currently available, including computers and mobile phones, internet access, and so on. To what extent do you agree or disagree with the statement?

## **Community and Basic Needs**



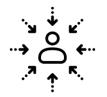
Perceptions of respondents' communities appear to have improved in 2025, compared to 2020 and 2015. (There were no differences between white and BIPOC respondents, or between those who

live in the Twin Cities metro area and greater Minnesota residents.)

Community Needs:	<b>2010</b> (n=221)	<b>2 0 1 5</b> (n=531)	<b>2020</b> (n=191)	<b>2025</b> (n=325)
All things considered; my community is a good place for people with developmental disabilities	74%	67%	70% 4	80% 1
My community is becoming a better place for individuals and developmental disabilities	70%	69%	62% 🗸	75% 🕇

Indicates a statistically significant difference at the 95% confidence level between measures from previous years.

## **Community and Basic Needs**



### Access to healthcare appears to have improved since 2015. (There

were no differences between white and BIPOC respondents, or between those who live in the Twin Cities metro area and greater Minnesota residents.)

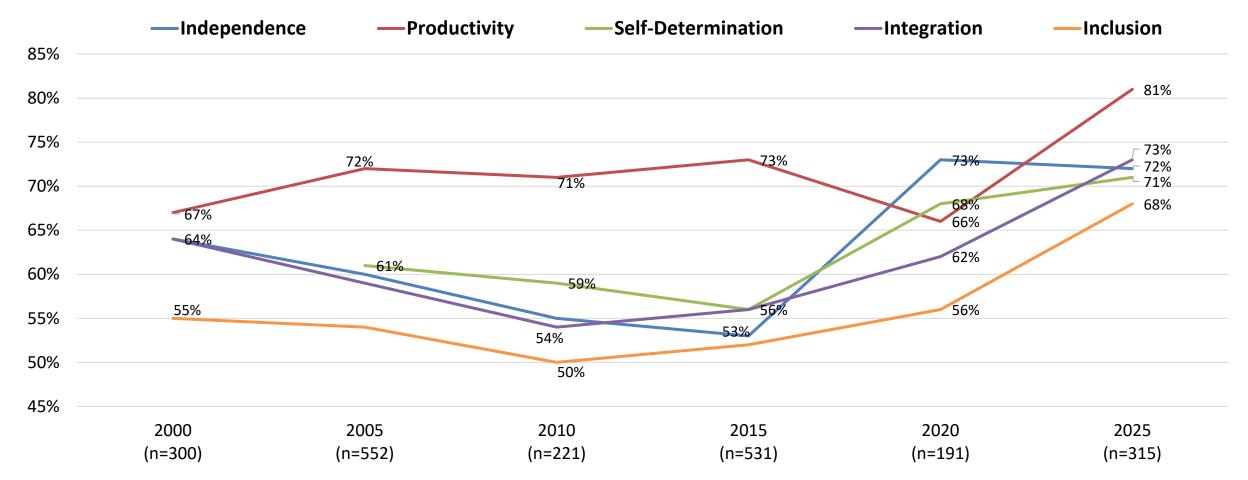
Basic Needs:	<b>2010</b> (n=221)	<b>2 0 1 5</b> (n=531)	<b>2020</b> (n=191)	<b>2025</b> (n=325)
I feel comfortable where I live, it feels like home	86% 🗸	89%	93% 🕇	91% 🕇
I feel safe in the neighborhood where I live	88% 🗸	86% 🖌	87%	93% †
I have access to the healthcare I need	82% 🗸	82%	88%	88% 🕇
I have enough money to live on	41% \downarrow	50%	60%	65% 🕇

1 Indicates a statistically significant difference at the 95% confidence level between measures from previous years.

## Satisfaction with IPSII

There is evidence of significant improvement in Integration, Inclusion, and Productivity in 2025, compared to past years.

Satisfaction with current levels of:



### MARKETRESPONSE **M**

There is evidence of significant improvement in Integration, Inclusion, and Productivity in 2025, compared to 2020.

l am satisfied with	2020			2025			
my current level of:	Agree Somewhat	Agree Strongly	<b>Total Agree</b> (n=191)	Agree Somewhat	Agree Strongly	<b>Total Agree</b> (n=319)	
INDEPENDENCE	39%	34%	73%	32%	40%	72%	
SELF-DETERMINATION	34%	34%	68%	31%	40%	71%	
INTEGRATION	33%	29%	62% 🗸	33%	40%	73% †	
INCLUSION	31%	25%	56% 🗸	32%	36%	68% †	
PRODUCTIVITY	28%	38%	(n=107) 66% ↓	29%	52%	(n=195) 81% ↑	

+ Indicates a statistically significant difference at the 95% confidence level, between 2020 and 2025 elements of IPSII.

### Satisfaction with IPSII – <u>Self-Advocacy Impact</u>

Self-Advocates were more likely to be satisfied with all aspects of IPSII, as compared to those whose responses were provided on their behalf by a parent or family member.

were provided on their benati by a parent of family member.					2025	
I am satisfied with my current level of:	<b>2010</b> (n=221)	<b>2 0 1 5</b> (n=531)	<b>2020</b> (n=191)	<b>Total</b> (n=318)	Self- Advocate (n=196)	Parent, Family Advocacy (n=122)
INDEPENDENCE	55%	53%	73%	72%	80% †	61%↓
SELF-DETERMINATION	59%	56%	68%	71%	79% 🕇	58%↓
INTEGRATION	54%	56%	62% 🖌	73% 🕇	81% 🕇	61%↓
INCLUSION	50%	52%	56% 🗸	68% †	78%	50%↓
PRODUCTIVITY	(n=97) 71%	(n=200) 73%	(n=107) 66% ↓	(n=195) 81% ↑	(n=155) 85%	(n=40) 65%

+ Indicates a statistically significant difference at the 95% confidence level, between 2020 and 2025 Totals; and between Self-Advocates vs. Parent, Family Advocacy in 2025.

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## Satisfaction with IPSII – Employment Impact

The importance of employment for people with developmental disabilities is clearly evident by its impact on satisfaction with all aspects of IPSII.

mpact on satisfaction with all aspects of IPSII.				2025			
am satisfied with ny current level of:	<b>2010</b> (n=221)	<b>2 0 1 5</b> (n=531)	<b>2020</b> (n=191)	<b>Total</b> (n=318)	Employed (n=199)	Not Employed (n=113)	
INDEPENDENCE	55%	53%	73%	72%	77% 1	66% ↓	
SELF-DETERMINATION	59%	56%	68%	71%	78%	61%	
INTEGRATION	54%	56%	62% 🗸	73% 1	77% 🕇	67% ↓	
INCLUSION	50%	52%	56% 🗸	68% 🕇	76%	54%↓	
PRODUCTIVITY	(n=97) <b>71%</b>	(n=200) 73%	(n=107) 66% ↓	81% 🕇	(n=195) <b>81%</b>	NA	

+ Indicates a statistically significant difference at the 95% confidence level, between the 2020 and 2025 Totals, and Employed vs. Not Employed people in 2025.

MARKETRESPONSE **B** 

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## Satisfaction with IPSII – <u>Race, Ethnicity Impact</u>

White people with developmental disabilities are more likely to be satisfied with their level of Integration and (possibly) Inclusion, as compared to those from the BIPOC communities. 2025 I am satisfied with White 2010 2015 2020 Total **BIPOC** my current level of: (n=221) (n=531) (n=191) (n=318) (n=225) (n=75) INDEPENDENCE 55% 53% 72% 73% 76% 73% SELF-DETERMINATION 59% 56% 68% 71% 74% 72% INTEGRATION 54% 62% 73% 77% 65% 56% INCLUSION 50% 52% 56% 68% 1 72% 65% (n=107) (n=97) (n=200) (n=195) (n=149) (n=41) PRODUCTIVITY 81% 71% 73% 66% 82% 80%

Indicates a statistically significant difference at the 95% confidence level, between the 2020 and 2025 totals, and White vs. BIPOC totals.

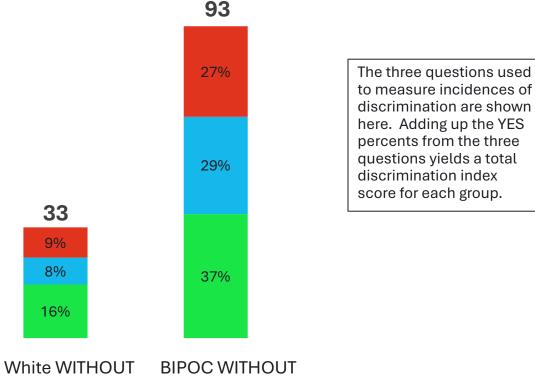
MARKETRESPONSE **M**<sup>\*\*</sup>

## Measures of Discrimination – <u>Benchmarks from 2023 Survey</u>

### 2023

These benchmark *Discrimination scores* were established from the Intersectionality II study completed in September 2023 (project #2508) The 2023 study showed that members of BIPOC communities who do not have any disabilities are almost 3 times more likely than white people without disabilities to experience unfair treatment, barriers from needed products or services, and restrictions from privileges that are available to others.

The Discrimination Score of 33 for White Without Disability represents a minimum level of discrimination that should be experienced by all groups within an inclusive society.



Disability (n=64) Disability (n=157)

#### Within the past 12 months, do you believe you.... (percent who responded YES)

- Were restricted from opportunities, privileges or activities
- Encountered barriers or obstacles to needed products or services
- Were unfairly treated, worse than others are treated

MARKET RESPONSE **M** 

### Discrimination Scores – Intersection of Disability with Race, Ethnicity

2025 2023 133 118 49% 93 27% 49% 49% 29% 33 9% 8% 37% 35% 32% 16% White WITHOUT **BIPOC WITHOUT** White WITH **BIPOC WITH** Disability (n=64) Disability (n=157) Disability (n=225) Disability (n=75)

MARKETRESPONSE

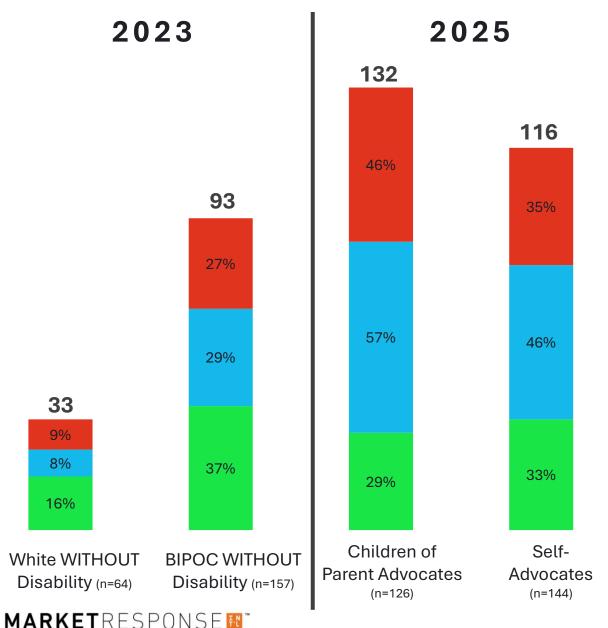
Having a developmental disability has more impact than race or ethnicity on discrimination experiences related to unfair treatment, barriers from needed products or services, and restrictions from privileges that are available to others.

However, those who live at the intersection between having a developmental disability and being part of the non-white BIPOC community appear to be more likely to experience restrictions from opportunities, privileges or activities that are available to others.

Within the past 12 months, do you believe you.... (percent who responded YES)

- Were restricted from opportunities, privileges or activities
- Encountered barriers or obstacles to needed products or services
- Were unfairly treated, worse than others are treated

### Discrimination Scores – <u>Children of Parent Advocates vs. Self-Advocates</u>



Parents or siblings who took the survey on behalf of a family member with developmental disabilities were more likely than self-advocates to indicate their child or sibling experienced barriers to needed products or services, or restrictions from opportunities, privileges or activities that are available to others. These differences may be due to differences in age, the nature of the disabilities\* between the two respondent groups, or both.

\*See Nature of Disabilities comparisons chart in the Appendix.

Within the past 12 months, do you believe you.... (percent who responded YES)

- Were restricted from opportunities, privileges or activities
- Encountered barriers or obstacles to needed products or services
- Were unfairly treated, worse than others are treated

# Looking Ahead

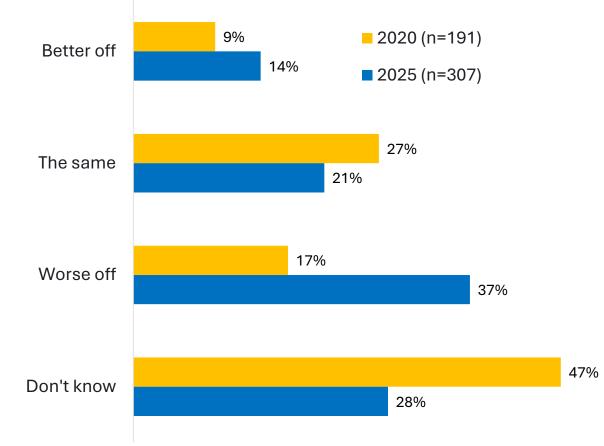


- Future Outlook
  - Special Education Services
  - Employment Services and Opportunities
  - Overall Financial Wellbeing
- Most Critical Issues

### Future Outlook- <u>Special Education Services</u>

Just over a third of the respondents (37%) believe special education services for students with developmental disabilities will be *worse off* in two years compared to today. This negative outlook is over twice as high as it was in 2020.

Looking ahead 2 years, do you believe we'll be better off, the same, or worse off, related to: SPECIAL EDUCATION SERVICES FOR STUDENTS WITH DEVELOPMENTAL DISABILITIES



#### Survey Responses to: Most critical issues

Special education funding (or possibly the Department of Education entirely) will be less, and there may not be programs and accommodations to make it so people with developmental disabilities can attend or be successful in schools. It is incredibly terrifying!

The Department of Education not holding districts accountable when they have done wrong. The Department of Education acts like a pal to the districts and does not support our children in their education.

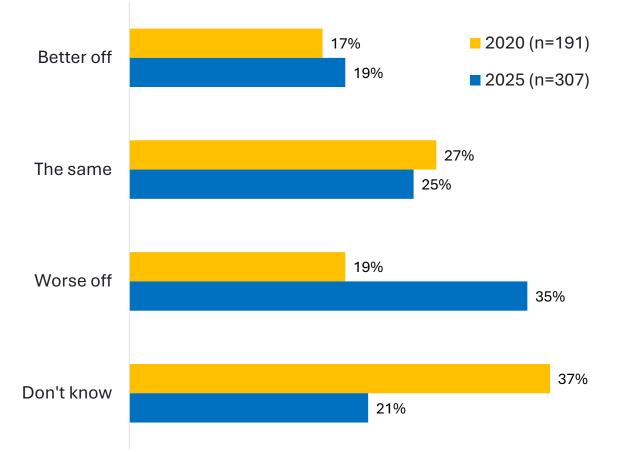
Worried school funds will be cut, knowing the special education funds are the first to be removed.

#### MARKET RESPONSE **B**

### Future Outlook- Employment Services and Opportunities

Just over a third of the respondents (35%) believe people with developmental disabilities will be *worse off* in two years related to employment services and opportunities. This negative outlook is significantly higher than it was in 2020 (19%).

#### Looking ahead 2 years, do you believe we'll be better off, the same, or worse off, related to: EMPLOYMENT SERVICES AND OPPORTUNITIES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES



#### Survey Responses to: Most critical issues

Being excluded from job opportunities because of disabilities, being robbed of what they need or want in order to get a job, being told they aren't going to get a job because of a disability.

Having adequate funding for programs we currently have. Having funding for the work program and staffing that help me have independence and good quality of life.

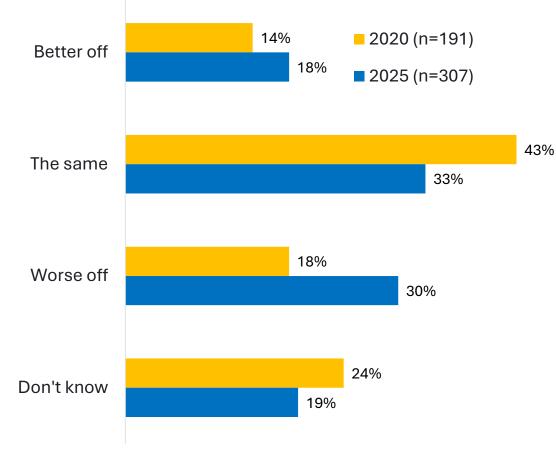
Competitive Integrated Employment for people with disabilities is also a big issue. People with disabilities need to have a job that pays a living wage and where the person can be fulfilled and feel accomplished, just like any other person.

### MARKETRESPONSE **M**<sup>\*\*</sup>

## Future Outlook – Overall Financial Wellbeing for Household and Family

In terms of overall financial wellbeing for household and family, 30% of respondents believe they will be *worse off* in two years compared to today. This negative outlook is significantly higher than it was in 2020 (18%).

#### Looking ahead 2 years, do you believe we'll be better off, the same, or worse off, related to: OVERALL FINANCIAL WELLBEING FOR HOUSEHOLD AND FAMILY



#### Survey Responses to: Most critical issues

Having Medicaid and waivers cut. These programs at their current funding aren't enough financial support for most individuals with disabilities. Then the burden falls on the families.

If you ask, individuals with disabilities just want to do what everyone else does. And financially it isn't always possible. So, any cuts in funding will be incredibly detrimental to the basic rights of individuals with disabilities.

Possible reduced funding from the State and Social Security. No places to live independently or not enough support workers, financial support to make it a viable option.

Funding being reduced, both at the state and local level. People will not be able to afford to live in their own homes with their families. We may not be able to hire people to take care of people with disabilities due to lack of funding.

MARKETRESPONSE

### Quotes from online focus group of self-advocates:

People with disabilities might get a raise, but it is nowhere near price increases. We really have to watch where our money goes. We have a certain amount for bills, medication and food. It's getting harder and harder. I have a full-time job, so I don't qualify for most services. I have to sit down and really look at my budget. I have to make hard decisions every week, every month, every year. I wish I could qualify for some services to help with my housing, groceries, and transportation.

The more you try to make, the more they take away. If I make over \$2,000, I lose services. We need these services! Don't knock us down when we're trying to build ourselves up.

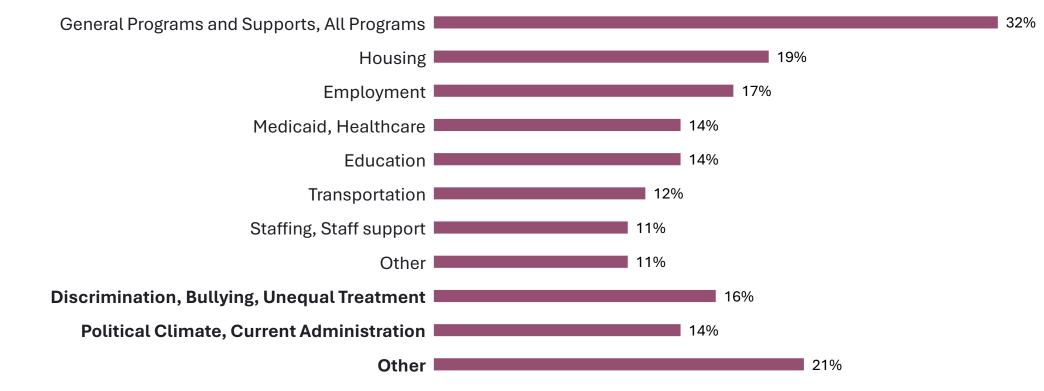
### MARKETRESPONSE

## Most Critical Issues – Loss of Supports, Discrimination, Political Climate

Thinking of the next five years, fear of funding cuts and the resulting lack of accessible and affordable services was of most concern to Minnesotans with developmental disabilities.

What are the most critical issues that Minnesotans with developmental disabilities will face over the next five years? (coded open-end responses, total sample n=307)

#### Fear of Defunding, Lack of Accessible and Affordable Services:



MARKETRESPONSE **m**"

# Most Critical Issues – Loss of Supports, Discrimination, Political Climate

## Fear of Defunding, Lack of Accessible and Affordable Services:

General Programs and Supports, All Programs Housing Employment Medicaid, Healthcare Education Transportation Staffing, Staff support Other

MARKETRESPONSE

Continued funding, especially for transportation, housing, employment, day treatment, and other such programs. I do not trust the federal government to be the party responsible for disability funding. I have much more faith in state and county funding.

# Most Critical Issues – Loss of Supports, Discrimination, Political Climate

## **Discrimination, Bullying, Unequal Treatment**

Defunding of Medicaid and closing the Department of Education and other current political agendas... These things also negatively affect the attitudes of the general population and encourage things like bullying, discrimination, isolation and uncaring attitudes that so many have worked to change over the years.

Current US administration and population seem to consider those with a disability as lesser or expendable people.

Being integrated into society and having the same opportunities without being made to feel "special."

Being teased by others and being called names. Not being understood by others.

Lack of compassion at the federal level could result in more discrimination against people with disabilities.

# Most Critical Issues – Loss of Supports, Discrimination, Political Climate

**Political Climate, Current Administration** 

There are current proposals to cut important programs that affect people with disabilities: Medicaid, Waivers, Social Security, School Programs, and Housing. Cuts to waiver programs that I access and rely on to remain at home and be a part of my community... So many programs we as disabled people rely on.

With the cuts to important programs, the next two years look extremely scary!

# **Qualitative Insights**

from Community Leaders, Advocates, and Self Advocates

From qualitative interviews among MN GCDD Council Members, developmental disabilities community leaders, advocates and self-advocates, 7 themes representing the most critical issues facing Minnesotans with developmental disabilities were revealed:



Transportation plays a critical role in the overall wellbeing of people with developmental disabilities. However, Minnesota's transportation system fails many people with developmental disabilities, with inconsistent service in rural and suburban areas, inadequate support for high-needs riders, and a shift toward metro-wide providers that deprioritize individualized care.



For our community, transportation is really tied
to independence and mental health. It's really
basic, people need to get to the doctor, to work,
to live their lives. But right now, the system isn't
working for them. (Advocacy Non-Profit)

# **Transportation Shortcomings - Inconsistent Infrastructure**



The lack of accessible and affordable transportation options in Minnesota – particularly in outer-ring suburbs, smaller cities, and rural areas – creates significant barriers for individuals with developmental disabilities. Limited public transit infrastructure, high costs for alternative services like taxis, and geographic disparities leave many without reliable mobility, exacerbating social and economic inequities. If you live in an outer-ring suburb or Greater Minnesota, your public **transportation options are very, very limited**. (Advocacy Non-Profit)

> Many people living with disabilities aren't able to drive, and so one of their biggest challenges has to do with transportation, because **we just don't really have a robust public transportation system in Minnesota**. (Advocacy Non-Profit)

I look at the transportation around here, up in the Duluth area. You think it wouldn't be that difficult, but **there's not much access for people with disabilities unless you want to take a cab and can pay for it. But who can?** I don't even want to pay for a cab. Council Member

#### MARKET RESPONSE **B**

# **Transportation Shortcomings - The Higher-Needs Transit Gap**



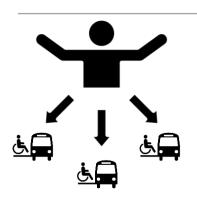
While Minnesota may have made progress in transportation accessibility for more independent individuals, significant gaps remain for high-needs riders, particularly those with complex medical or behavioral requirements.

I think for the most independent folks, transportation in Minnesota has taken some really, really positive steps forward. **My concern really lies in where we're at and where we're headed for transportation for people that have the highest needs**, both medical and behavioral. (Disability Transportation Consultant)



Tiered reimbursement rates to fairly compensate high-needs transportation are needed. Current reimbursement structures fail to incentivize adequate service for users with more intensive needs, as providers receive the same compensation regardless of passenger requirements.

If you're paid the same for an ambulatory ride as a wheelchair ride, **the motivation to not provide high-needs rides is huge**. (Disability Transportation Consultant)



The trend of shifting toward outsourcing to metro-wide providers (e.g. Metro Mobility) risks deprioritizing personalized care. Whereas community-based, non-profit services demonstrate stronger accountability and rider-centered service due to their direct relationships with clients.

The closer you are to the rider and service provider, the more motivated you are to **care about each individual rider**. (Disability Transportation Consultant)

#### MARKETRESPONSE B

# EMPLOYMENT GIVES VOICE TO PEOPLE WITH DEVELOPMENTAL DISABILITIES

Employment for people with developmental disabilities achieves two very important interconnected dimensions of wellbeing: societal inclusion and personal empowerment. Participation in the workforce is not just an economic necessity, but a vital pathway to dignity, participation, and visibility in society.

#### **Societal Inclusion**

There are transformative psychological and social benefits to work, such as confidence, belonging, and self-worth.



It is underestimated how people gain confidence when they are working. We see that difference after they have the opportunity to experience success. We see people come in that won't talk to hardly anybody, and a year later, six months later, they have friends. They're talking. They feel really good about what they're doing. And that's just immeasurable.

#### **Personal Empowerment**

Employment gives people with developmental disabilities a voice in society, preventing isolation and marginalization.



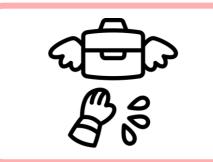
If you don't have people with disabilities being employed, you're pulling on society. And so, there's a gain as a taxpayer; and **if you're a taxpayer, you have a voice**, which says, 'These are my tax dollars, here's how they should be spent.' Keeping people with disabilities in the home isolates them, and then they just don't exist in society.

#### MARKETRESPONSE **M**<sup>\*\*</sup>

# **EMPLOYMENT Advances and Challenges**

Despite progress from several federal and state initiatives, employment opportunities for people with developmental disabilities face challenges, including employer reluctance, Medicaid cuts, and staffing shortages. While the decline of sheltered workshops marks positive change, the push to eliminate subminimum wages risks unintended job losses. Sustained progress requires addressing systemic barriers while promoting inclusive hiring.









Closure of sheltered workshops, moving towards paid integrated employment Ending subminimum wages may inadvertently reduce opportunities to attend day programs Not enough businesses actively hire people with developmental disabilities

Funding cuts and staff shortages threaten employment progress Sheltered Workshops

"I think there have been some real positive outcomes that COVID really shook. It catapulted organizations that were providing sheltered work, segregated piece work inside large day program centers. It catapulted them into changing the way they deliver services. They have closed some big, sheltered workshops, and are **moving toward meaningful day activities in the community and paid integrated employment.**" Council member

The COVID-19 pandemic acted as a catalyst for positive change in disability services, accelerating the shift away from segregated, sheltered workshops toward more inclusive community-based day activities and integrated paid employment.

Integrated Employment



While Minnesota took steps to eliminate subminimum wage\* with the aim to promote fairness, it may have unintentionally reduced work options for some people with developmental disabilities. Those with higher support needs risk losing structured employment opportunities which could result in:

- Lost income and purpose even small paychecks provide dignity and self-worth
- **Risk of increased isolation** if community-based work options are no longer available
- **Reduced employment opportunities** for individuals whose productivity may not meet minimum wage requirements

\*Section 14C of the Fair Labor Standards Act (FLSA) permits employers to pay certain workers with disabilities less than the federal minimum wage.

The majority of providers in the state of Minnesota have or are in the process of getting rid of their 14C certification... If it's eliminated, none of those organizations will be able to [pay subminimum wage], and so individuals won't be able to work. I just don't see them being able to get a job.

> If 14C goes away, many individuals won't find work. Employers can't subsidize the wage gap. (Employer of people with disabilities)

Somebody forgot that each person's an individual... [For some], that was their place. **That was where they worked. That was their job**. (Employment Specialist)

# **EMPLOYMENT Challenges: Funding Cuts & EMPLOYER RELUCTANCE**

Chronic underfunding of disability services has created a crisis of low wages, severe staff shortages, and reduced vocational services, leaving individuals without critical supports and worsening systemic barriers to employment.

Data shows unemployment rates for people with disabilities have dropped... but funding instability could reverse gains.





State-level budget shortfalls in vocational rehabilitation services have led to severe cuts, and without intervention, this trend threatens to further diminish critical supports for individuals with disabilities in the coming years.

There are issues at the state level that vocational rehabilitation services has overspent, and now they're cutting services way back. If the trajectory continues in this direction, definitely in five years, things could be worse.





Despite policy advancements, many employers have failed to follow through with meaningful workplace inclusion. Corporate disability initiatives often prioritize optics over structural change, leaving workers with developmental disabilities without real opportunities for advancement.

Most employers do not hire people with developmental disabilities; there has to be something in it; it has to be intentional. Employer of People With Disabilities

#### MARKETRESPONSE M

The pandemic worsened systemic inequities in special education, exposing gaps in accommodations, funding, and support, while weakened oversight and ongoing struggles for resources threaten long-term recovery for students with disabilities.



Rising issues of segregation, restriction, and restraint.

The shift to remote learning exacerbated existing inequities

## Uncertainty about the future of special education if states are given more control

Obtaining necessary school resources can be very difficult.



In the years following COVID, special education has faced growing challenges, including rising issues of segregation, restriction, and restraint. Special education has been challenged in the last five years in a way that has led to things like more segregation, more restriction in some cases, more restraint. We had done a lot of work to try to prevent those things from happening. Unfortunately, the education landscape has been so challenged that we can't really report a lot of progress in those areas in the last five years. (Community Leader, Advocate)

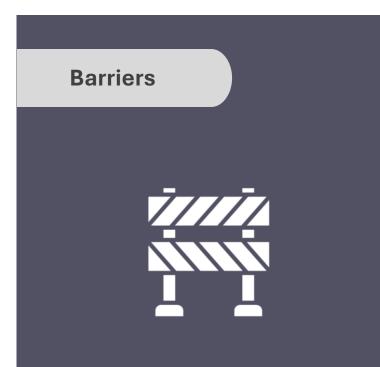




existing inequities, leaving many students without appropriate accommodations. The lack of recovery efforts for this group has had long-term consequences, with some still struggling to reintegrate into structured learning environments. Distance learning affected our entire cohort of students who basically just kind of got the shaft. There was no real compensatory action that was very adequate to support them. (Community Leader, Advocate)



There is uncertainty about the future of special education if states are given more control and less federal oversight, especially given that special education is seen as never having been fully funded nationally or in Minnesota. Most people would feel that we've never fully funded special education throughout our country and in Minnesota as well. So, if that comes back to the states it will allow a lot more flexibility for states, and they won't have to provide all the supports and services they are currently required to provide. (Community Leader, Advocate)



Obtaining necessary school resources, such as Individualized Education Programs (IEPs) can be very difficult. I think about young people with developmental disabilities and making sure that they're getting what they need in school. We hear from people who are having a really hard time getting IEPs because their child has developmental disabilities, and the school district decides whether or not they're going to recognize a student's educational needs. It's just amazing how challenging it can be for people to get the resources and the support that they need for their kids. (Community Leader, Advocate)

MARKETRESPONSE **m** 

# **DIFFICULTY ACCESSING SERVICES**

Accessing needed services and supports for people with developmental disabilities is significantly difficult, largely due to a complex and confusing system. This difficulty is a critical challenge impacting their lives and well-being.



## Complex to Navigate

Accessing needed services and supports for people with developmental disabilities is significantly difficult, largely due to a complex and confusing system. This difficulty is a critical challenge impacting their lives and well-being.

#### Cultural Barriers

For immigrant families, specific barriers include language barriers, cultural barriers, and a lack of system navigation skills. These barriers can set a child years behind. This leaves a large burden on those who need the services.

### Inconsistent Implementation

Although policies and laws are meant for these programs to be available, there are lots of inconsistencies across the state that shouldn't exist. This suggests that the system designed to be implemented equitably is, in practice, not.

## Healthcare Challenges

Access to the right level of healthcare can be difficult. Many clients often don't know there's a higher level of care available when needed. Getting diagnosed and finding the right treatments and therapies can be a huge challenge for families.

## Risk of Lost Services

The system penalizes progress, even small income gains or paperwork mistakes can cut off Medicaid and waiver programs. Reapplying is risky; simple errors can strip away vital support.

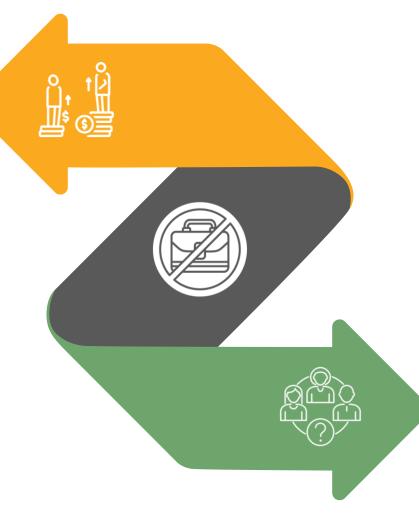


# **STAFFING SHORTAGES**

## **Wage Disparities**

Significant wage disparities between developmental disability service providers and other care sectors create recruitment and retention challenges, as workers are incentivized to pursue higher-paying roles elsewhere.

> If you look at other similar types of services, individuals don't get paid as much to provide those supports in the disability services as they do, for instance, in like nursing homes. So that, I think, is a big problem.



Severe staffing shortages in disability support services are exacerbating growing waiting lists and limiting job placement opportunities, leaving individuals unable to access the tailored support they need to succeed in suitable employment.

Providers can't find staff to support job placements. Waiting lists are growing. This is worse than five years ago.

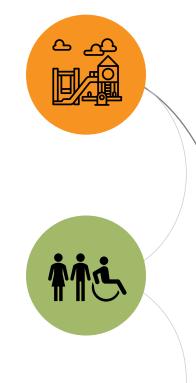
If there were enough support staff, then everyone could be supported in the job that best fits them. But without that support, some people aren't able to be successful.

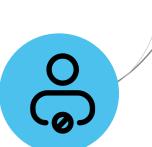
## **Missed Opportunities**

# Need for Sensory-Friendly and Secure Public Spaces

## **Universal Design Benefits Everyone**

## **Barriers to Inclusion and Accessibility**





There is strong support for universally designed spaces intentionally created to accommodate people with developmental disabilities, neurodivergence, and sensory sensitivities. Spaces planned in this way not only meet the needs of individuals with disabilities but also enhance usability and comfort for all members of society.

Designing spaces for people with developmental disabilities from the outset creates better environments for everyone. Accessibility is not a niche; it's a foundation for a more equitable and functional society.

## **Need for Sensory-Friendly and Secure Public Spaces**

The lack of sensory-friendly parks and gyms make it difficult for families of children with autism. Risks of overstimulation in public spaces force families to isolate rather than integrate.

We need public parks that are designed for kids with autism. Families don't know where to take their children. Integration is very challenging and limited for these parents.

(BIPOC Community Leader, Advocate)



## **Universal Design Benefits Everyone**

Designing spaces to include people who are neurodivergent inherently benefits neurotypical people. But the reverse is not true.

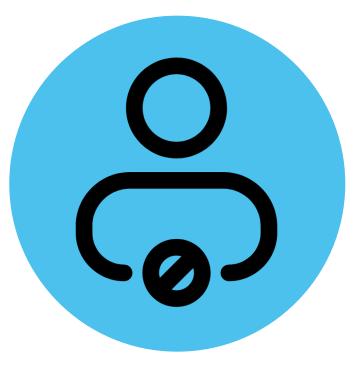
These ideas can work to even calm and de-stress people without disabilities, increasing their productivity and quality of life. For example, sensory-friendly lighting and acoustics help those with autism, but also reduce stress for the public. And visual calming techniques aid neurodivergent individuals while also improving focus and relaxation for others. (Self Advocate)



## **Barriers to Inclusion and Accessibility**

Despite progress, many places still fail ADA compliance, excluding individuals with disabilities from full community participation.

*If I can't get into a space, I'm not part of the community.* (Community Leader, Parent Advocate)

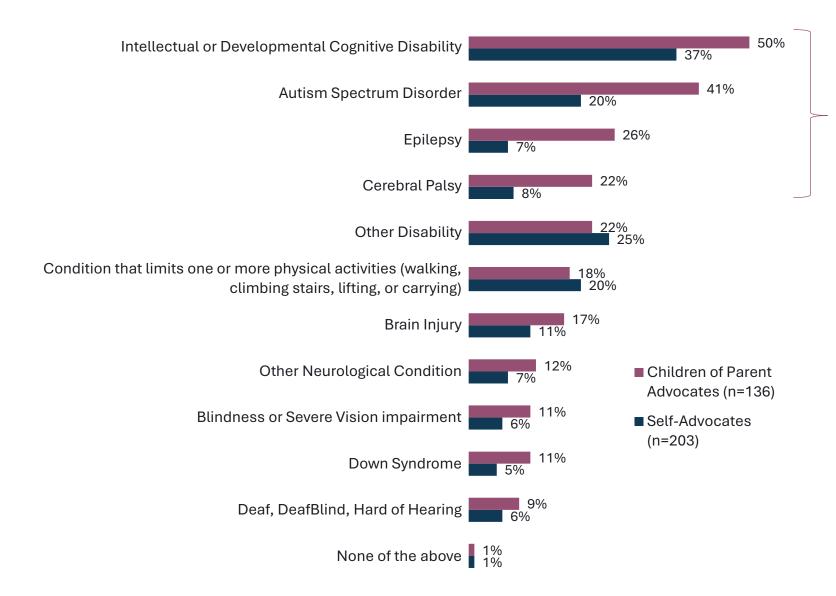




# Appendix

- Nature of the Disabilities
- Community and Basic Needs
- Attitudes Regarding IPSII
  - Independence
  - Self-Determination
  - Integration
  - Inclusion
  - Productivity
- Employment Status

# Nature of the Disabilities



There are some clear differences in the nature of the disabilities between selfadvocates and those whose survey was completed by (or with the help of) a parent advocate.



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# **Community and Basic Needs – <u>Detailed Findings</u>**

Although *total agreement* is relatively high on all statements, *strong agreement* is relatively low for the two community statements, and for the statement: *I have enough money to live on*. This suggests there is room for improvement, especially in these three areas.



	<b>2025</b> Total Sample: n=325					
Aspects of COMMUNITY	Strongly Disagree	Somewhat Disagree	Neither	Somewhat Agree	Strongly Agree	TOTAL AGREE
My community is a good place for people with developmental disabilities	3%	6%	11%	38%	42%	80%
My community is becoming a better place for individuals with developmental disabilities	4%	7%	14%	42%	32%	74%

# Aspects of BASIC NEEDS

I feel comfortable where I live, it feels like home	3%	2%	4%	26%	65%	91%
I have enough money to live on	8%	14%	14%	33%	32%	65%
I have access to the healthcare I need	2%	4%	5%	34%	54%	88%
I feel safe in the neighborhood where I live	2%	2%	3%	29%	64%	93%

#### MARKET RESPONSE **M**

# **ATTITUDES REGARDING IPSII – Independence**

Having more choice of support staff, and being able to find suitable housing, are two areas of independence in most need of improvement.



Aspects of INDEPENDENCE						
	Strongly Disagree	Somewhat Disagree	Neither	Somewhat Agree	Strongly Agree	TOTAL AGREE
I can be alone and have privacy, when I feel I need it	4%	5%	8%	27%	55%	82%
I can find housing that suits my needs	11%	11%	17%	21%	40%	61%
I choose the staff who works with me	11%	9%	32%	19%	28%	48%
I am satisfied with my current level of independence	5%	11%	12%	32%	40%	72%

# **ATTITUDES REGARDING IPSII – <u>Self-Determination</u>**

Though there is room for improvement on all areas of self-determination, ability to decide how public funds are spent for services and support appears to be an area of improvement that is most needed.



Aspects of SELF-DETERMINATION	Strongly Disagree	Somewhat Disagree	Neither	Somewhat Agree	Strongly Agree	TOTAL AGREE
I have control over how I present myself and my living space	3%	8%	10%	30%	49%	79%
I have control over my daily schedule	5%	9%	10%	34%	42%	76%
I can decide how I spend my personal money	3%	7%	12%	26%	51%	77%
I can make decisions that will affect my future	3%	7%	15%	29%	45%	74%
I can decide how public funds are spent for my services and support	13%	15%	29%	22%	21%	43%
I am satisfied with my current level of self determination	4%	9%	15%	31%	40%	71%

# **ATTITUDES REGARDING IPSII – Integration**

Although integration has improved over previous years, given that half –or less– of the survey respondents *agree strongly* with each statement, suggests there is much room for overall improvement in integration of people with developmental disabilities.



Aspects of INTEGRATION						
	Strongly Disagree	Somewhat Disagree	Neither	Somewhat Agree	Strongly Agree	TOTAL AGREE
The personal supports I require are available to me	4%	12%	10%	35%	39%	74%
I have opportunities to do things with people my age	7%	13%	8%	30%	42%	72%
I have access to adequate transportation when I need it	5%	10%	7%	27%	51%	78%
Restaurants, stores, parks are accessible to me	3%	8%	5%	32%	52%	84%
I am satisfied with my current level of integration	6%	11%	10%	33%	40%	73%

# ATTITUDES REGARDING IPSII – Inclusion

Compared to all aspects of IPSII, overall satisfaction is lowest for inclusion. Being treated with respect and as an equal by people without disabilities would go a long way in improving societal inclusion of people with developmental disabilities.



# **ATTITUDES REGARDING IPSII – <u>Productivity</u>**

Being challenged by work responsibilities, and rewarded fairly, appear to be areas most in need of improvement related to feelings of productivity.



Aspects of PRODUCTIVITY						
	Strongly Disagree	Somewhat Disagree	Neither	Somewhat Agree	Strongly Agree	TOTAL AGREE
I am challenged by my responsibilities	4%	10%	12%	40%	33%	74%
I am rewarded fairly for the things I do	7%	7%	10%	34%	43%	77%
I have been improving my skills	3%	4%	8%	30%	56%	86%
I am as productive as I can be given my developmental disability	5%	6%	11%	26%	53%	76%
I am satisfied with my current level of productivity	6%	7%	7%	29%	52%	81%

The proportion of survey respondents who work or volunteer has remained consistent going back to the survey in 2010.



<b>Do you work or volunteer</b> <b>outside your home?</b> (Adults 18+)	<b>2010</b> (n=127)	<b>2015</b> (n=257)	<b>2020</b> (n=107)	<b>2025</b> (n=313)
Yes, I have a job I get paid for	54%	56%	57%	50%
Yes, I volunteer my time	22%	13%	11%	14%
No	24%	31%	37%	36%

1 Indicates a statistically significant difference at the 95% confidence level between measures from previous years.

There appears to be gradual improvement since 2010 in perceptions of having *the right number of hours* of work.



<b>Do you feel your work or</b> <b>volunteer is</b> (those who work or volunteer)	<b>2010</b> (n=92)	<b>2015</b> (n=174)	<b>2020</b> (n=107)	<b>2025</b> (n=196)
Too many hours	4%	5%	3%	6%
The right amount of hours	61%	70%	72%	77% †
Too few hours	35%	25%	25%	17%

Indicates a statistically significant difference at the 95% confidence level between measures from previous years.





from your MarketResponse team

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