Life Experiences of Young Minnesotans With Disabilities

Qualitative Research Report 22 August 2024

Research Conducted by, MarketResponse International Project #2526



For the Minnesota Governor's Council on Developmental Disabilities

Research Overview

Starting in 2022, MarketResponse International has conducted research studies focused on the intersection of developmental disabilities with race and ethnicity and other marginalized communities, which leads to social discrimination and disparities in areas such as:

- Health Care
- Employment
- Education
- Housing
- Social Services (home and community-based services)



This qualitative research report is part of the Phase III Intersectionality study, completed in July 2024, which is focused on young Minnesotans (ages 13-22), to better understand their life experiences and the extent to which those with marginalized identities feel included in the One Minnesota promise of diversity, equity and inclusion.

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Research Method

Qualitative Research Method

A qualitative online community discussion was conducted among a sampling of young Minnesotans with disabilities (and parents) who participated in a statewide online One Minnesota survey. A total of 7 respondents participated in the online dialog, which took place over a 2-week period.

Variety of Subject Areas Covered in this Qualitative Report:

- 1) Experiences in the Community
- 2) Positive Education Experiences
- 3) Negative Education Experiences
- 4) Frustration in Accessing Waivers and Receiving Support Services
- 5) Hopes, Desires, Dreams, Goals

SUMMARY:

- Benefits of knowing youth with disabilities
- Supporting young Minnesotans with disabilities

APPENDIX: Letters to the Governor

All respondents' quotes, from both parent advocates and self advocates, are shown in *italics*.



Qualitative Research Caution Advisory

Caution is advised in interpreting the findings from this research and making inferences to the larger populations of people with disabilities, as it is qualitative in nature and based on opinions of a small number of people with disabilities, including some family members who assisted in completing the survey.

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Detailed Findings



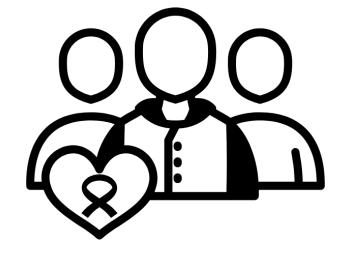
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Experiences in the Community

A Little Patience Can Go a Long Way in Creating Positive Experiences

For this youth with disabilities, by receiving a little bit of help, he is not only able to be included, but also able to volunteer in his community, which is a benefit to all.

In my community the experiences have been pleasant. In Gonvick, which is the town next to Clearbrook, I had always volunteered to help at the Gonvick Lions Club rodeo. Every year I had helped, the people in the Lions Club had helped me participate. For example, I had need to step away to cool off when I was getting overwhelmed while handling money or helping explain how to do something a couple times before I remembered it.



Experiences in the Community Negative Experience - Compassion Needed

For some young Minnesotans with disabilities, occasional meltdowns can happen. Those who can empathize with these moments are saddened when others aren't compassionate and understanding.



A meltdown is an involuntary reaction to nervous system overload. <u>Meltdowns & Calming Techniques in Autism - Autism</u> Research Institute I have seen people snicker or speak rudely to others like me that are in the middle of a meltdown or just not acting "normal" in public. This makes me sad and wonder why people can't just understand.

Experiences in the Community

Negative Experience - Mental Health in the Workplace

Misunderstanding mental health symptoms can lead to job insecurity. There is opportunity for workplace awareness and support to ensure fair treatment and proper accommodations for all employees.



I nearly lost the job I had for the last semester of school, **because when I was having a panic attack** they thought it was a seizure and didn't want me to come back. There were even supports in place to help, but they had my mom take me to the doctor so the doctor could write them a note saying that I've never even had a seizure. I was able to go back to work after that. And I'm grateful I don't have seizures because I don't even know what would've had to happen then. It's hard to not always have access to a quiet place, to process if something comes up, and (hard not having) people who could understand.

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Experiences in the Community Negative Experience - Summer Camp Disaster

A 14-year-old boy with autism had previous positive experiences at youth YMCA summer day camps. After moving to a new town, he was able to sign up to the local program through a grant. Despite extensive family preparation and the mother taking off work to assist, it was a disaster.

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- "They violated the Americans with Disabilities Act, as well as his human rights"
- When concerns were brought to the community the family was told to move away.
- Untrue statements were made about how the child's IEP needed to carry over to the summer camp.

It was a terrible time for our family, and we felt incredibly isolated. We contemplated moving, but ultimately stayed. We have never come across as much **ignorance and** pure hatred towards those who are different since moving here. We are doing what we can to try to make it a more *inclusive community.*

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Experiences in the Community

Negative Experiences - Not Enough Accessible Bathrooms

Access to accessible bathrooms can be a challenge in public buildings. "Is there a good (accessible) restroom?" is a big deciding factor (determining) where we go for events.

Accessibility bathroom issues	Quotes from a mother with a 14-year-old daughter who is nonverbal and uses a wheelchair		
Long wait times and not enough accessible stalls	We stand in line like everyone else. But when it is our turn, we also need to wait for the family camping out in the only (accessible) stall, while my daughter is uncomfortably sitting in her soiled garments.		
	The extended wait times to use the only stall designed for her wheelchair seems to always be in use.		
Can lead to not going out at all	Sometimes I wish we were back at home, so she is able to use the restroom in dignity in a timely manner. But that is not fair for her to not go to events with the family either.		
Places that accommodate are remembered	We also have favorite events we attend because they have "a good (accessible) stall", that can fit her wheelchair, a caregiver, and a sink with soap and paper towels.		

Positive Education Experiences

For Minnesota youth with disabilities, positive education experiences are underscored by the critical role of individualized supports in promoting inclusivity and enhancing the educational experiences of students with disabilities. These supports not only facilitate participation in key events, but also foster a sense of belonging and accomplishment, contributing to memorable and positive educational experiences.



Classroom Inclusion



Comprehensive Support at Events



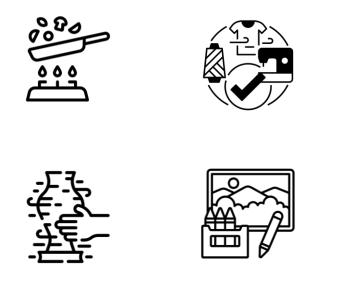
Extracurricular Activities



Graduations and Milestones

Positive Education Experiences Classroom Inclusion

The inclusion in various classes such as cooking, fashion and design, art, ceramics, and drawing facilitated not only learning but also creativity and peer interactions, contributing significantly to the students' overall positive educational experiences.



Each of the girls took classes with peers - cooking, fashion and design, art, ceramics, and drawing. The inclusion and being able to create and learn were awesome highlights which made for really good days.

Positive Education Experiences Comprehensive Support at Events

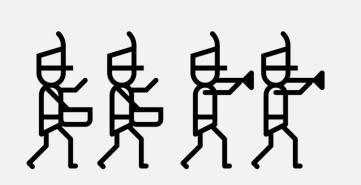
Events like school dances are made accessible and enjoyable through the provision of para support, which included help with ticketing, navigating the venue, ensuring dietary needs are met, and facilitating social interactions. These events can be considered highlights for students when inclusive practices are considered, even in traditional school activities.



For Prom, we had para support. They met us at the prom venue, helped us navigate through the ticketing process, and then also supported us during the dance to make sure we had breaks when needed. **The supports were extremely helpful in making sure we had a great time**. The school really did everything necessary to make for a wonderful event.

Positive Education Experiences Extracurricular Activities

In this example, participation in the extracurricular activity of the school band trip to Wisconsin Dells provided a sense of belonging and opportunities for social engagement outside the regular classroom setting.





I was able to go on the school band trip to Wisconsin Dells. It was a wonderful experience and **made me feel like I was part of the group**.

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Positive Education Experiences Graduation and Milestones

Full inclusion in the graduation ceremony, with appropriate supports, enabled students to participate fully and be recognized alongside their peers, marking significant milestones in their educational journey.

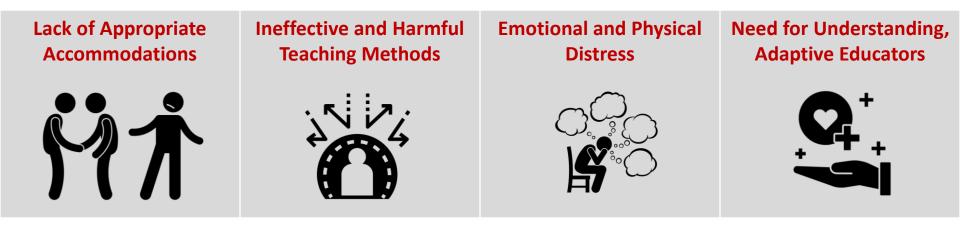
> My kids graduated last year. They were **fully included in the graduation ceremony** and activities. They had all the **appropriate supports to make them comfortable and successful**. It was a **huge honor** to see them walk across the stage and be recognized.



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Negative Education Experiences

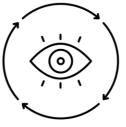
Young Minnesotans with disabilities encounter various challenges in educational settings. There are many instances where the needs of students were not adequately understood or met, leading to frustration, exclusion, and emotional distress for both the students and their families. The themes that emerged include:



Negative Education Experiences Lack of Appropriate Accommodations

Young Minnesotans with disabilities frequently encounter situations where educators fail to provide the necessary accommodations. This lack of tailored support often left students struggling with tasks that could have been made accessible with minimal adjustments. These unmet needs result in frustration, hindered learning, and feelings of exclusion for both the students and their families. The absence of visual aids, adaptive materials, and other essential supports make the educational experience unnecessarily challenging.

During our freshman and sophomore years, we had a lead **teacher who was not open to adapting** things to make them more understandable. We tried for an entire year to get this educator to understand that **some students need the visual cues** to help them navigate and understand, but **she never understood that inherent need**.



I know my **daughter felt excluded**, because something that should be simple, like identifying which classroom was hers by picture rather than by name, became much harder than it needed to be. It was very frustrating and also very eye-opening that **not everyone 'gets it.'**

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Negative Education Experiences Ineffective and Harmful Teaching Methods

Some young Minnesotans with disabilities encounter experiences where educators use teaching methods that are not only ineffective, but also harmful to the student's well-being. In these cases, educational approaches do not align with the student's abilities or needs, leading to distress and a sense of failure.

Repetitive and overly simplistic lessons can cause frustration and emotional outbursts in students who were capable of more advanced learning.

The teacher would hold up a letter in front of her and say 'A' and proceed to do this for some time before moving on to 'B'. My daughter would pound on the tray and scream at the top of her lungs. She was obviously upset with all of this. When were they going to teach something more? I felt like I was failing her, all I could do was leave and cry in the parking lot that day.



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Negative Education Experiences *Emotional and Physical Distress*

Emotional and physical distress for students with disabilities can occur when understanding and proper accommodations are not met, which may reveal a deep impact of feeling misunderstood, excluded, or even physical harm. Feeling of being different or "wrong" because of their disabilities is often compounded by the inappropriate actions of educators, leading to a deep sense of inadequacy and emotional pain.



Physical restraint, used as a method of control, leaves deep emotional scars.

I had a **teacher hold me down during a meltdown that left bruises**. It made me **feel like there was something wrong with me** or that I was a bad kid for not being able to control my emotions at that point in time.

Negative Education Experiences Need for Understanding, Adaptive Educators

There is a critical need for educators to be trained not only in academic aspects but also in understanding the diverse needs of students with disabilities

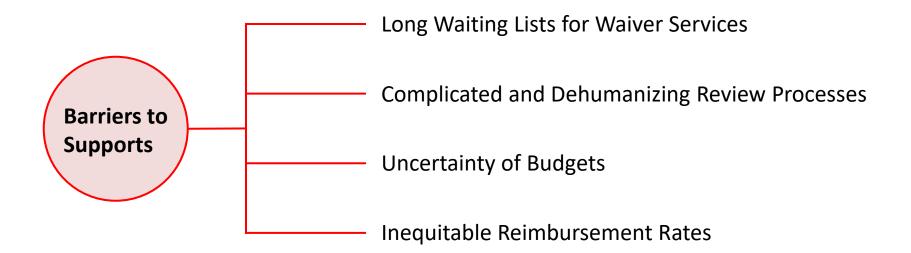
- While many educators are compassionate and professional, a lack of understanding in a few can have a disproportionately negative impact
- Essential qualities for educators working with students with disabilities include:
 - Adaptive teaching methods
 - Individualized support
 - Willingness to learn and adjust

We ran across **a few who 'didn't get it,'** and that was **frustrating and difficult to navigate**. The vast majority have been awesome, compassionate, understanding, and extremely professional.

Adapting work to students' abilities is crucial, yet it was often overlooked.

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There are significant barriers in the process of receiving support for people with disabilities. Access to waiver funds are a focus of frustration to some families. Solutions include requesting the same reviewer each year to avoid the learning curve, extending the SMRT review cycle, ensuring consistent budget support, and basing reimbursements on support needs rather than types of residential settings.





Frustration in Accessing Waivers and Receiving Support Services Long Waiting Lists for Waiver Services

The initial process of getting on a waiver is lengthy, with long waiting periods.

First, getting on a waiver takes time. There are waiting lists - there have been times when there were not long lists - but we've waited several years to get on a waiver.



However, once on a waiver, the services seem to be more consistent.

On the flip side of that, once you're on a waiver, it seems to 'stick.' At least that has been our experience.

Frustration in Accessing Waivers and Receiving Support Services Complicated and Dehumanizing Review Process

The annual SMRT review requires individuals to repeatedly prove their need for services, which is time-consuming and often feels degrading.

The process to receive supports - especially waiver funds - is difficult, time-consuming and at times dehumanizing.

Every year we have to redo our SMRT review. It feels like we have to prove that we are still disabled, and the services required are still needed.

Going through the same info, year after year, and sometimes it seems we have to convince someone who just met your child (or young adult) who you live with 365x24x7 that they need supports. It is a dehumanizing and degrading process.

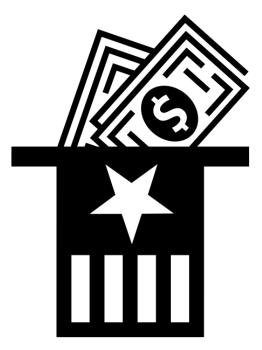
It was suggested that a streamlined process, such as extending the review cycle to every 2, 3, or 5 years, would make better sense, compared to current practices.

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Frustration in Accessing Waivers and Receiving Support Services Uncertainty of Budgets

There is a constant uncertainty regarding the budget allocations for basic services and supports, which causes stress and unpredictability for families.

> There is always uncertainty about budgets. What will the budget be? Will it cover the basic services and supports that are needed?





Frustration in Accessing Waivers and Receiving Support Services Inequitable Reimbursement Rates

The possibility of differential reimbursements based on living situations, is a frustration to some. It is believed that reimbursements should be based solely on the individual's needs rather than their living arrangements.



There shouldn't be different reimbursements for various living situations on the waiver. There are discussions going on now that seem to be moving in the direction of providing greater funding to a group home or residential setting than a person's own home (or with family). This is just wrong. **Reimbursements** should be based on what supports the person needs, independent of where they choose to live.

Hopes, Desires, Dreams, Goals Education Goals and Desires

Families of students with disabilities have a commitment to nurturing their student's unique abilities, preparing them for a fulfilling future, and ensuring they have opportunities for both personal and social growth. This is achieved through a deep educational foundation and consistent individualized support. Success is measured by:

Personalized Learning and Communication	 The importance of a tailored educational experience is evident in how families strive to create an educational environment that aligns with their students' needs and abilities. Communication is a significant milestone, with achievements centered around enhancing the ability to express oneself.
Preparation for Independent	 There is a strong emphasis on helping students transition into adulthood by acquiring practical skills and exploring various job opportunities. This preparation extends to those aiming for independence in work, relationships, and daily living.
Living and Career Goals	 Aspirations such as obtaining a driver's license, finding fulfilling employment, and pursuing relationships are central to their goals.
Creative and Social Expression	 Opportunities for artistic and social engagement, such as acting classes and art lessons, which provide avenues for self-expression and joy are valued.

Hopes, Desires, Dreams, Goals Education Goals and Desires

Fulfilling education goals and desires can mean pursuing academic interests and steps towards independence.

I am hoping to learn more about science and history. It will mean a lot to me when I achieve those goals.



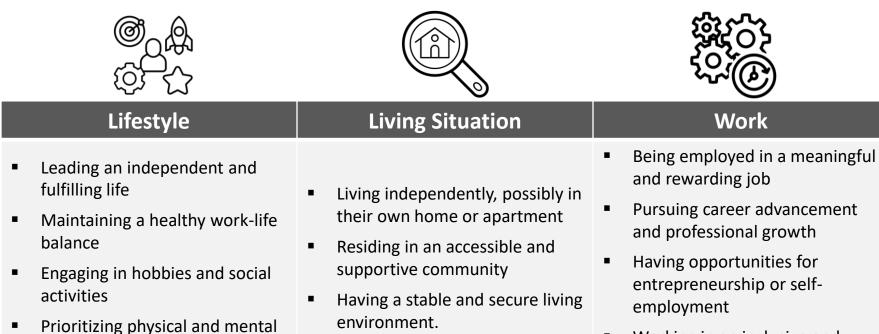


I want to get my driver's permit. I want to learn how to drive. My transition program has been helping me study and learn what it will take to get a driver's permit. I got a perfect score on the mock test.

Hopes, Desires, Dreams, Goals

Life Goals and Desires for Young Minnesotans with Disabilities

Goals and desires for young Minnesotans with disabilities have to do with *lifestyle*, their *living situation*, and *work*. The significance of reaching their goals means:



 Working in an inclusive and accommodating workplace

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well-being

Hopes, Desires, Dreams, Goals Achieving Goals for Young Minnesotans with Disabilities

For young Minnesotans with disabilities, reaching their goals signifies:

- Personal and financial independence
- A sense of accomplishment and improved quality of life
- The ability to contribute positively to society while being recognized for their abilities.



In five years, I want to be living on my own in an accessible apartment, working at a job that I love and that values my contributions. Achieving this will make me feel truly independent and fulfilled.

My goal is to have a balanced life where I can engage in hobbies, maintain my health, and work in a supportive environment. Reaching **this will** give me a sense of accomplishment and allow me to contribute positively to my community.

Hopes, Desires, Dreams, Goals Achieving Goals for Young Minnesotans with Disabilities

The aspirations of young Minnesotans with disabilities are to achieve independence and fulfillment through education, meaningful work, and personal milestones.

Supportive environments, whether through friends, family, or professionals are important to realize goals and feel valued in their communities. In five years from now I want to see myself in college and living with some friends. For work I want to continue working at my tech job. When I reach my goals, I will feel very good.

I want to continue to **live with my family**. I would like to **have a driver's license so I can help out more with my family**. I would like to have **a job where I feel valued and respected**. It was a dream come true to attend a NASCAR race. Meeting my goals would make me feel like I am worthy. It would be good to **have support from family and possibly a PCA to meet my daily needs**.

Hopes, Desires, Dreams, Goals Importance of Supports and Accommodations

Young Minnesotans with disabilities may have varying levels of need for accommodations and support. Some feel confident in their ability to access necessary help, while others recognize the need for specific support services, to achieve greater independence and meet their goals.



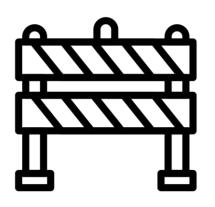
I don't really need any accommodations at the moment, but if I do need them, I know who to ask. Either my parents or staff at college. The process is simply just having a conversation with them about it.

I would benefit from an (individual learning) specialist and a PCA to help me achieve my goals. I want to be independent, but I just need a little help. I would be better supported to meet my goals if I had the help I needed.

Hopes, Desires, Dreams, Goals

Barriers to Achieving Goals for Young Minnesotans with Disabilities

Societal perceptions, can hinder young Minnesotans with disabilities the ability to fully participate and be accepted in the community. They emphasize the importance of being recognized for their unique abilities and valued for who they are, rather than being judged for their differences.



Some societal barriers that are holding me back is the fact that **I have** slower processing times than other people, and that hinders me from working with others.

The general public looks at us differently. We are different but that is not a bad thing. We are differently abled. WE have value to the general population. **Being accepted for who I am would be the ultimate goal**.

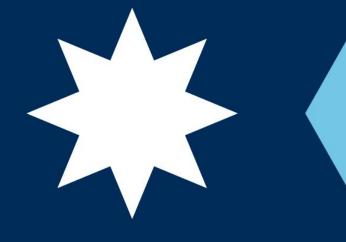
Hopes, Desires, Dreams, Goals

Barriers to Achieving Goals for Young Minnesotans with Disabilities

Discrimination and lack of understanding from others are significant barriers to achieving goals, and impact confidence and well-being. Patience, kindness, and education are essential to creating a more supportive and inclusive environment for young people with disabilities. A lot of barriers that people with disabilities are faced with when trying to achieve their goals are rude people and discrimination. This has had a toll on my confidence as I was treated very poorly in elementary school. I wish they would be more accepting of kids with disabilities, and to be more educated on how to help them.

I think **people just don't understand how I am able to function and that causes a barrier to accomplishing my goals**. If people would just be patient and kind and understanding that would help me.

Summary



- Benefits of knowing youth with disabilities
- Supporting young Minnesotans with disabilities

SUMMARY – Benefits of knowing youth with disabilities What the Minnesota Youth Want You to Know About Them

Young Minnesotans with disabilities were asked:

Thinking about other people in your community who may see you around from time to time, but don't know you personally,

- What would you want them to know about you?
- How would it benefit you if they knew you better?
- How would it benefit them if they knew you better?

Youth with disabilities often face significant challenges when stepping outside their comfort zones and participating in public life, frequently feeling judged by others. Recognizing their strengths and including them fully in the community can help break down barriers and foster a more supportive and understanding environment.

I am a caring, interesting, loving, awesome individual that just wants to be included. You might see a different side of the puzzle if you could just live a day in my shoes. They would see how hard it is for me to leave my home and be in the public. I go outside my comfort zone just to leave the house. It's just hard. My mom says I don't see the looks I get sometimes, and I really don't care and neither does she. But she notices all the same.

SUMMARY – Benefits of knowing youth with disabilities What the Minnesota Youth Want You to Know About Them

Young Minnesotans with disabilities desire to be understood beyond appearances, as pity and fear from others lead to avoidance rather than connection. They believe that recognizing shared similarities could foster meaningful relationships, which will create an environment where they feel truly included and valued in the community.

Sometimes there are "looks" of pity, sadness, nervousness, or fear that lead to avoidance. I want them to know that **they don't need to pity or be afraid of me**. It would help them be better able to make a connection and understand **we are more alike than different**, and **they could gain a friend or at least have a meaningful conversation** or a good laugh. That would help me to be more of an actual part of the community, more valued, more included; not just tolerated or accepted, but actually included, engaged, and appreciated.

SUMMARY – Benefits of knowing youth with disabilities What the Minnesota Youth Want You to Know About Them

When youth with disabilities are included, and the community knows more about them, everyone benefits.

What should the community know about me?		How I would benefit	How the community would benefit
Acceptance Without Pity	There is no need to pity or fear me.	I would feel more included and valued in the community.	They could make a connection, understand our similarities, gain a friend, or have meaningful conversations.
Communication Abilities	Despite expressive communication deficits, I can communicate using an augmentative and alternative communication device.	I would be treated with dignity and spoken to directly.	They would get the chance to know me.
Understanding Nonverbal Communication	My daughter, though nonverbal, understands everything and has feelings, wants, and interests.	My daughter would feel valued, accepted, and have dignity.	They would see her sense of humor and learn what a true friend is.
Uniqueness of Individuals	Each person is a unique individual with their own goals, dreams, fears, talents, and opinions.	Understanding and appreciation of our uniqueness and individuality.	They would be enriched by understanding perspectives they hadn't considered before.
Caring and Inclusion	I am a caring, interesting, loving individual who wants to be included.	More understanding of the challenges I face and better inclusion.	They would see different perspectives and understand the effort it takes for me to be in public.
Fun and caring personalities	I am a very fun person and very caring.	It would enable me to talk to more people.	They would have a caring person to talk to.

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SUMMARY - How Can We Support Young Minnesotans with Disabilities?

By focusing on improving these areas, Minnesota can be a place where young people with disabilities can work towards achieving their aspirations and leading fulfilling lives, rather than having to fight for their basic rights.

Accessibility	 Accessible housing and transportation Workplaces equipped with necessary accommodations Universal design in public spaces and services
Assistive Technologies	 Access to modern and effective assistive devices Regular updates and maintenance for assistive technologies Training and support in using these technologies
Education and Training	 Inclusive and supportive educational institutions Vocational training and skill development programs Continuous learning opportunities to stay updated in their field
Health and Wellness	 Comprehensive healthcare services, including mental health support Programs promoting physical fitness and well-being Assistance with managing chronic conditions and disabilities
Social Support	 Strong support networks, including family, friends, and community groups Peer support and mentorship programs Access to social services and advocacy organizations.
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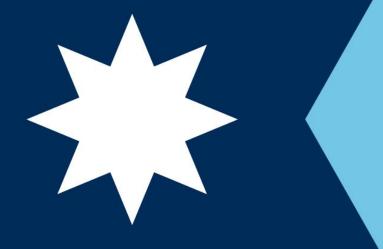
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SUMMARY – How do we support young Minnesotans with disabilities? Needed Supports and Accommodations - In Their Own Words

The single biggest help that the government/community can provide is **funding to support living with a disability**. This includes - **living support for daily tasks - (PCA or care assistance), transportation, job search assistance, housing assistance**. Each of these is a unique barrier if they are not available and accessible.

We also live in the metro - where there is access to many services and organizations. Not everyone in MN lives close enough to access these services, so being able to bring services statewide is a significant issue and needs to be addressed.

Appendix



• Letters to the Governor

Appendix Letters to the Governor

Respondents were asked to write Governor Tim Walz and Lieutenant Governor Peggy Flanagan, and other State leaders a letter regarding what life is like today, and how it can be enhanced, for a better future for young people with disabilities in Minnesota.

The letter below shows a positive perception for supports for people with disabilities in Minnesota, compared to other states.

We are grateful for the services that are available to us as Minnesotans. Traveling to other states and listening to other forums, it is apparent we are ahead of the country when it comes to supports for our people with disabilities in our communities.

We cannot go backwards, please do not limit/cut these programs that our youth need to move forward, live a full life and move towards living independently with these supports. Please help us keep PCAs, nursing and respite services, by reimbursing at a rate that retains these quality caregivers.

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Appendix Letters to the Governor

Continue to move forward, maintain an inclusive stance, and focus on what is possible. These are the main themes of this letter.

First, I would like to thank Governor Walz and Lt Governor Flanagan for their work and support of individuals with disabilities. The 2023 legislative session included a number of bills (passed) that were helpful to people living with a disability, such as increased wages for PCAs, allowing students to attend transition until their 22nd birthday and many others.

The challenge for all of us is to keep moving forward and not go backwards. Standing still is the same as moving backwards. We have to agree that disability rights are human rights - and the ability to make choices, live the type of life we choose and have the appropriate supports in place to allow us to do this is a basic human right.

Also, we need to maintain our inclusive stance - decisions need to be made with the community in mind. We work on person centered planning - the idea that the individual has the best information to make informed choices about health, money, living, education, transportation, work and community. Let's never forget that simple idea; never forget the humanity behind every decision and the people who are impacted and affected by the decisions we made.

Lastly - let's continue to make MN a place where all are warmly welcomed. We need to focus on what is possible - vs. what has been done before. One of the organizations that we work with has a statement in their mission which says, "Taking a position of possible". To those (and their families) - with a developmental disability - so much of our world has been centered and grounded by negative statements like, "they can't do that, or that might be too much." I love the concept of taking a position of possible. We all will be surprised at what can be achieved when we look at things through the lens of possibility!

Minnesota is a great state and a great place to live. We have natural beauty to enjoy, a rich history, people who care and a community that has been created to encourage and enrich. Let's continue to make sure it is accessible, available and all can enjoy.

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Thank you!

from your MarketResponse team

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