

Attitudes Regarding Quality of Life for People with Developmental Disabilities in Minnesota

Prepared for The Minnesota Governor’s Council on Developmental Disabilities

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Background and Objectives

According to the GCDD’s current Five-Year Plan for FFYs 2017-2021, 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.

During January to March 2020, three surveys were conducted to fulfill the requirements of the Five- Year State Plan for FFYs 2022-2026. The field work for this study ended in mid-March. Please note that all attitudes and opinions from these studies were taken prior to the effects of the COVID-19 pandemic.

These three reports provide the foundation for the next Five-Year State Plan. This report is entitled: **Attitudes Regarding Quality of Life for People with Developmental Disabilities Among Advocates and Self-Advocates**

Two other studies conducted concurrently were:

- Impact of Federal Disabilities Laws – Among General Population of Minnesotans
- The Voice of Service Providers for People with Developmental Disabilities in Minnesota

Research Design

A quantitative survey was administered online and with paper copies to people with developmental disabilities and or their advocates or guardians. The survey instrument included comprehensive measures regarding independence, productivity, self-determination, integration and inclusion, which have been asked in the same way in a longitudinal tracking study that has been conducted every five years since the year 2000. The 2020 survey included additional topics and took approximately 25 minutes to complete.

Sample Sources Used

Using Partners in Policymaking® Graduate database:

- 515 email addresses were sent invitations and online survey link were sent, each address was sent 1 initial invitation and two follow reminder emails
- 60 phone calls were made to those who did not have an email address (the list of numbers seemed to be dated; many of the phone numbers were out of service, no longer lived there, were fax machines)
- The Arc Minnesota has posted the survey link on their Facebook page
- Autism Society of Minnesota has put the survey link on their website
- Service providers who completed the *Voice of Service Providers for People with Developmental Disabilities* survey were sent an email asking them to distribute the IPSII *Quality of Life* survey link to their clients
- Personal friends and acquaintances who work for organizations that provide services for people with developmental disabilities provided the link to the online survey to their associates and clients
- The Down Syndrome Association of Minnesota published the survey link in their February newsletter on Monday the 17th
- We also reached out to these other organizations:
 - Epilepsy Foundation of Minnesota
 - Minnesota Brain Injury Alliance
 - PACER

Survey Respondents' Affiliations	Total sample: (n=191)
Graduate of the Partners in Policymaking® program	27%
Member of The Arc Minnesota	21%
Member of the Autism Society of Minnesota	11%
Member of the Down Syndrome Association of Minnesota	10%
Member of the Epilepsy Foundation of Minnesota	4%
Member of Self Advocates Minnesota	3%
Member of Brain Injury Alliance	1%
None of these	48%

Respondent Profiles

In 2020, about one fifth (21%) of the respondents were people with a developmental disability.

Are you the person with this developmental disability or is it someone else in your household or family?	(A) 2005	(B) 2015	(C) 2020
	n=552	n=531	n=191
I am the person with the developmental disability	19%	14%	21% _B
Someone else in my household or family has the developmental disability	47%	69%	79%

A total of 47% of the respondents in 2020 were between the ages of 18 and 34, a higher proportion representing that age group compared to samples in previous tracking waves.

Age of the person with developmental disability	(A) 2005	(B) 2015	(C) 2020
	n=552	n=531	n=191
Under 14 years	36%	41%	22% _{AB}
14-17			
18-24 years	31%	29%	47% _{AB}
25-34 years			
35-44 years	14%	15%	18%
45+	19%	15%	14%
55-64 years			
65-74 years			
75 years and over years			

ABC Indicates statistically significant differences between survey results, at the 95% confidence level.

When did this disability occur?	Total sample: (n=191)
At birth	73%
Between birth and age 22	27%

Identification	Total sample: (n=191)
Male	58%
Female	40%
Other	1%
Prefer not to say	1%

Executive Summary

There is evidence of improvement in Independence, Self-Determination and (possibly) Integration in 2020, compared to past years

- Incremental improvements are shown in several aspects of independence, especially related to privacy and access to personal information.
- Improvements in control over personal finances and public funds for services, could be driving improvement in overall satisfaction with Self Determination
 - However, there appears to be room for improvement regarding ability to solve one’s own problems, along with control over how public funds are spent, and choice of roommates
- One aspect of integration showing the most improvement over past years is the perception of being treated with respect by people without disabilities.

<i>I am satisfied with my current level of...</i>	Percent who Agree Somewhat or Strongly				
	(A) 2000 n=300	(B) 2005 n=552	(C) 2010 n=221	(D) 2015 n=531	(E) 2020 n=191
Independence	64%	60%	55%	53%	73%A-D
Self Determination	NA**	61%	59%	56%	68%B-D
Integration	64%	59%	54%	56%	62%C
Inclusion	55%	54%	50%	52%	56%
Productivity (Based to those who work or volunteer)	(n=159) 67%	(n=223) 72%	(n=97) 71%	(n=200) 73%	(n=107) 66%

ABC Indicates statistically significant differences between survey results, at the 95% confidence level.

**Self Determination was included as a specific measure with the adoption of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) later in 2000, after the Study was conducted.

Evidence of improvement in some basic needs were also found, specifically:

- Feeling more comfortable where they live
- Having access to needed healthcare
- Having enough money to live on
- Feeling secure about their future

No evidence of improvements in Inclusion and Productivity

- The most significant impediments to inclusion appear to be feelings of not being treated as an equal, and lack of opportunities to develop meaningful relationships with people without a disability.
- Feelings of being productive at home remain relatively steady, and positive, over the years.
- However, there was no change in employment levels in 2020, compared to previous years

The top 3 most used services and supports were in-home personal care, transportation services, and vocational or employment services

- While 72% are at least *somewhat satisfied* with the services and support they receive, one-in-five (21%) are *dissatisfied*
- The top 3 reasons for dissatisfaction with services and or support were: inadequate availability of services and or supports, staffing issues, and shortage of job opportunities

The most used transportation method by people with developmental disabilities is a personal vehicle driven by someone else. Other most used transportation methods are day program services and Metro Mobility.

- These three transportation options are used far more often than public transportation and other options.
- Approximately half of all respondents feel their inclusion in their community is limited by the transportation options that are currently available to them.
- There simply needs to be more transportation options available and accessible to people with developmental disabilities in order to enhance their inclusion in their communities.

Two-thirds of the survey respondents have applied for a Medicaid waiver.

- Approved levels of support were perceived to be at least somewhat less than needed by almost 1 out of 4 respondents (24%).
- Almost one-third (31%) of people with developmental disabilities who had applied for a Medicaid waiver are dissatisfied with the assessment and application process.
- Only 9% expect the waiver application process will be better in 2 years than it is today.

Among the population of people with developmental disabilities, almost half (46%) are concerned about the possibility of abuse toward someone in their family

- This overall level of concern is slightly higher than the level of concern of the general population of Minnesotans (40% concerned).
- People with developmental disabilities and their advocates are most concerned about abuse in the form of physical restraint and seclusion, and financial exploitation.
- All forms of abuse are more concerning to people with developmental disabilities, as compared to the general population of Minnesotans.

Present and future outlook regarding education, employment and financial well-being, Compared to the general population: Minnesotans with developmental disabilities . . .

- Are less likely to believe that education services have improved over the past 2 years, or will improve over the next 2 years
- Are less likely to believe that employment services have improved over the past 2 years, and more likely to believe they will be worse in 2 years than they are today
- Are less likely to believe their overall financial well-being has improved over the past 2 years, and more likely to believe they will be worse off in 2 years than they are today

Most Critical Issues

Gains in meaningful employment tops the list of most critical issues that people with developmental disabilities believe they will face over the next 5 years.

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=191
Meaningful employment	28%
Funding and oversight for services and training	25%
Housing	25%
Quality staffing	24%
Healthcare	13%
Inclusion and Socialization	8%
Education	7%
Abuse and Safety issue	5%
Aging Parents	3%

Community and Basic Needs

There is evidence of improvements in 2020 measures regarding basic needs, compared to previous years' measures. Between 2010 and 2015 (five year time period) there were few changes or improvements, actually declines in both basic needs and community needs. Between 2010 and 2020, changes or improvements in basic needs were marked although declines continued regarding community needs.

ABC Indicates statistically significant differences between survey results, at the 95% confidence level.

Community Needs	Total Sample: n=191					Percent of those who agree		
	Strongly Disagree		Neither		Strongly Agree	(A) 2010 n=221	(B) 2015 n=531	(C) 2020 n=191
All things considered, my community is a good place for people with developmental disabilities	8%	14%	9%	47%	23%	74%	67% ^A	70%
My community is becoming a better place for individuals and developmental disabilities	6%	13%	19%	42%	20%	70%	69% ^A	62% ^{AB}
Basic Needs								
I feel comfortable in the house where I live, it feels like home	2%	4%	2%	29%	64%	86%	89%	93% ^A
I feel safe in the neighborhood where I live	3%	4%	7%	29%	58%	88%	86%	87%
I have access to the healthcare I need	1%	7%	4%	35%	53%	82%	82%	88% ^{AB}
I have enough money to live on	15%	10%	14%	32%	28%	41%	50%	60% ^{AB}
I know what to do if my health or safety is in jeopardy	22%	14%	12%	29%	24%	50%	46%	53% ^B
My future will be secure, even if something happens to my parents and or current staff member, friend, or advocate	20%	19%	9%	34%	19%	41%	44%	53% ^{AB}

Attitudes Regarding Independence, Productivity, Self-Determination, Integration and Inclusion (IPSII)

Perceptions of INDEPENDENCE

Lack of choices regarding service providers and staff, and availability of suitable housing options, appear to be issues that are most limiting to achieving higher satisfaction levels regarding independence among people with developmental disabilities.

Aspects of INDEPENDENCE	Total Sample: n=191				
	Strongly Disagree	Somewhat Disagree	Neither	Somewhat Agree	Strongly Agree
I can (even if someone helps me) get to where I want to go	5%	12%	9%	40%	34%
I can meet with people in private when I want	8%	7%	23%	32%	30%
I can be alone and have privacy when I feel I need it	4%	6%	13%	31%	46%
Only people who are allowed to know my personal information have access to it	1%	5%	10%	36%	48%
Finding a suitable housing option for me is possible	16%	13%	16%	27%	28%
I can live near the people who are important to me	6%	10%	17%	26%	41%
I choose the staff who works with me	19%	15%	28%	23%	15%
I choose the provider who provides services to me	10%	16%	24%	25%	25%
I am as independent as I can be given my disability	8%	8%	9%	41%	34%
All things considered, I am satisfied with my current level of independence	4%	12%	12%	39%	34%

Independence – Comparisons to Past Years

Incremental improvements in several aspects of independence, especially related to privacy and access to personal information, may have led to gains to overall satisfaction with feelings of independence among people with developmental disabilities.

Perceptions of INDEPENDENCE: Past Comparisons	Percent Who Agree		
	(A) 2010 n=221	(B) 2015 n=531	(C) 2020 n=191
I can (even if someone helps me) get to where I want to go	82% ^C	76%	74%
I can meet with people in private when I want	56%	56%	62%
I can be alone and have privacy when I feel I need it	71%	71%	77%
Only people who are allowed to know my personal information have access to it	75%	78%	84%^{AB}
Finding a suitable housing option for me is possible	51%	45%	55%^B
I can live near the people who are important to me	67%	64%	67%
I choose the staff who works with me	37%	38%	38%
I choose the provider who provides services to me	43%	44%	50%
I am as independent as I can be given my disability	71%	64%	75%^B
I am satisfied with my current level of independence	55%	53%	73%^{AB}

ABC Indicates statistically significant differences between survey results, at the 95% confidence level.

Perceptions of Self-Determination

There appears to be room for improvement regarding ability to solve one's own problems, along with control over how public funds are spent, and choice of roommates.

Aspects of SELF DETERMINATION	2020 Total Sample: n=191				
	Strongly Disagree	Somewhat Disagree	Neither	Somewhat Agree	Strongly Agree
I can decorate or arrange my living area how I like it	2%	12%	19%	29%	38%
I have control over how I present myself, what I choose to wear, my hairstyle, etc.	3%	11%	15%	36%	36%
I have control over my daily schedule	5%	19%	18%	39%	19%
I can set outcomes (goals) for myself	10%	12%	26%	28%	25%
I can decide how I spend my personal money	6%	13%	18%	38%	25%
I can make decisions that will affect my future	9%	12%	28%	31%	20%
I solve my own problems	16%	23%	24%	28%	10%
I can decide how public funds are spent for my services and support	17%	20%	28%	20%	15%
I choose who I live with (if I have roommates)	12%	19%	37%	14%	18%
I have as much self-determination as possible given my developmental disability	5%	13%	13%	30%	39%
I am satisfied with my current level of self-determination	5%	12%	16%	34%	34%

Self Determination – Comparisons to Past Years

Improvements in control over personal finances and public funds for services, could be the driving improvement in overall satisfaction with Self Determination among people with developmental disabilities.

SELF DETERMINATION: Past Comparisons	Percent Who Agree		
	(A) 2010 n=221	(B) 2015 n=531	(C) 2020 n=191
I can decorate or arrange my living area how I like it	70%	69%	67%
I have control over how I present myself, what I choose to wear, my hairstyle, etc.	80%	76%	72%
I have control over my daily schedule	59%	48%	58%B
I can set outcomes (goals) for myself	59%	50%	53%
I can decide how I spend my personal money	56%	50%	63%B
I can make decisions that will affect my future	52%	47%	51%
I solve my own problems	56%	54% ^C	38%
I can decide how public funds are spent for my services and support	26%	23%	35%B
I choose who I live with (if I have roommates)	39%	35%	32%
I have as much self-determination as possible given my developmental disability	66%	61%	69%B
I am satisfied with my current level of self determination	59%	56%	68%AB

ABC Indicates statistically significant differences between survey results, at the 95% confidence level.

Perceptions of Integration

Lack of needed resources and required personal support, and lack of socialization opportunities (friends) appear to be aspects of integration in most need of attention and improvement.

Aspects of INTEGRATION	Total Sample: n=191				
	Strongly Disagree	Somewhat Disagree	Neither	Somewhat Agree	Strongly Agree
Resources that I need are available in my community	14%	15%	12%	42%	17%
The personal support I require is available in my community	10%	21%	13%	39%	17%
I have opportunities to do things with people my age	10%	13%	10%	40%	28%
I am treated with respect by people without disabilities in my community	3%	9%	13%	45%	31%
I have friends who do not have developmental disabilities	13%	14%	15%	31%	26%
I feel comfortable going outside my immediate community	6%	13%	18%	42%	21%
I am as integrated as I can be given my developmental disability	9%	15%	14%	34%	27%
I am satisfied with my current level of integration	9%	13%	16%	33%	29%

Integration – Comparisons to Past Years

One aspect of integration showing signs of improvement over past years is the perception of being treated with respect by people without disabilities.

INTEGRATION: Past Comparisons	Percent Who Agree		
	(A) 2010 n=221	(B) 2015 n=531	(C) 2020 n=191
Resources that I need are available in my community	63%	57%	59%
The personal support I require is available in my community	66%	60%	56%
I have opportunities to do things with people my age	61%	63%	68%
I am treated with respect by people without disabilities in my community	54%	60%	76%AB
I have friends who do not have developmental disabilities	63%	61%	57%
I feel comfortable going outside my immediate community	65%	60%	63%
I am as integrated as I can be given my developmental disability	61%	59%	61%
I am satisfied with my current level of integration	54%	56%	62%A

ABC Indicates statistically significant differences between survey results, at the 95% confidence level.

Perceptions of Inclusion

The most significant impediments to inclusion appear to be feelings of not being treated as an equal, and lack of opportunities to develop meaningful relationships with people without a disability.

Aspects of INCLUSION	Total Sample: n=191				
	Strongly Disagree	Somewhat Disagree	Neither	Somewhat Agree	Strongly Agree
People without a disability treat me as an equal	13%	27%	17%	30%	13%
People treat me with respect	2%	14%	16%	46%	22%
I have opportunities to develop meaningful relationships with people who do not have a disability	11%	18%	15%	34%	23%
I have opportunities to develop meaningful relationships with people who have a disability	5%	8%	12%	42%	33%
I am as included in society as I can be	10%	24%	14%	28%	24%
I am satisfied with my level of inclusion in society	10%	18%	16%	31%	25%

Inclusion – Comparisons to Past Years

There is no evidence that any progress in inclusion has been made over the years.

Aspects of INCLUSION: Past Comparisons	Percent Who Agree		
	(A) 2010 n=221	(B) 2015 n=531	(C) 2020 n=191
People without a disability treat me as an equal	48%	46%	43%
People treat me with respect	72%	67%	68%
I have opportunities to develop meaningful relationships with people who do not have a disability	55%	61%	57%
I have opportunities to develop meaningful relationships with people who have a disability	73%	75%	75%
I am as included in society as I can be	50%	56%	52%
I am satisfied with my level of inclusion in society	50%	52%	56%

ABC Indicates statistically significant differences between survey results, at the 95% confidence level.

Perceptions of Productivity

Feelings of being productive at home remain relatively steady, and positive, over the years.

Perceptions of PRODUCTIVITY at Home	Total Sample: n=191				
	Strongly Disagree	Somewhat Disagree	Neither	Somewhat Agree	Strongly Agree
I have an appropriate amount of responsibility at home	3%	9%	14%	46%	29%
I have been improving my skills at home	3%	7%	15%	46%	29%
I receive recognition for the things that I do at home	3%	5%	8%	41%	43%

Productivity at Home – Comparisons to Past Years

PRODUCTIVITY at Home: Past Comparisons	Percent who Agree		
	(A) 2010 n=220	(B) 2015 n=442	(C) 2020 n=191
I have an appropriate amount of responsibility at home	71%	65%	75%B
I have been improving my skills at home	81%	76%	75%
I receive recognition for the things that I do at home	86%	82%	84%

ABC Indicates statistically significant differences between survey results, at the 95% confidence level.

Work or Volunteer: Past Comparisons

There was no change in employment levels in 2020, compared to previous years. Just over half (57%) of adults with developmental disabilities report having a job they get paid for and 11% volunteer their time, with a quarter of them concerned about too few hours of work and volunteer time.

Do you work or volunteer outside your home?	Adults Ages 18+		
	(A) 2010 n=127	(B) 2015 n=257	(C) 2020 n=107
Yes, I have a job I get paid for	54%	56%	57%
Yes, I volunteer my time	22%	13%	11%
No	24%	31%	37%

Do you feel your work or volunteer time is	Those Who Work or Volunteer		
	(A) 2010 n=92	(B) 2015 n=174	(C) 2020 n=107
Too many hours	4%	5%	3%
The right amount of hours	61%	70%	72%
Too few hours	35%	25%	25%

ABC Indicates statistically significant differences between survey results, at the 95% confidence level.

Do you work or volunteer outside your home by age group	Adults Ages 18 and Over – 2020			
	Total (n=150)	18-34 (n=89)	35-54 (n=51)	55 and over (n=10)
Yes, I have a job I get paid for	57%	58%	57%	50%
Yes, I volunteer my time	11%	15%	6%	10%
No	37%	27%	37%	40%

Amount of work or volunteer hours

On average, how many hours do you work or volunteer each week?	Those Who Work or Volunteer – 2020		
	Total (n=107)	Work (n=87)	Volunteer (n=20)
5 or fewer	25%	17%	60%
6 to 10	8%	8%	10%
11 to 15	17%	18%	10%
16 to 20	20%	23%	5%
21 to 30	17%	20%	5%
Over 30	10%	11%	5%

Work or Volunteer Experience

Perceptions of work or volunteer experience	Those Who Work or Volunteer: n=107				
	Strongly Disagree	Somewhat Disagree	Neither	Somewhat Agree	Strongly Agree
I am challenged by my responsibilities	4%	12%	7%	44%	34%
I am rewarded for the things I do	3%	7%	10%	35%	46%
I have been improving my skills	1%	6%	7%	37%	50%
I am as productive as I can be given my developmental disability	8%	16%	4%	34%	38%
I am satisfied with my current level of productivity	8%	16%	9%	28%	38%

Work/Volunteer Experiences – Past Comparisons

There was virtually no change in perceptions of work or volunteer experiences over the years.

Perceptions of work or volunteer experience – Past Comparisons	Percent Who Agree (Among Adults Who Work or Volunteer)		
	(A) 2010 n=97	(B) 2015 n=200	(C) 2020 n=107
I am challenged by my responsibilities	79%	76%	78%
I am rewarded for the things I do	85%	84%	81%
I have been improving my skills	91%	87%	87%
I am as productive as I can be given my developmental disability	76%	77%	72%
I am satisfied with my current level of productivity	71%	73%	66%

ABC Indicates statistically significant differences between survey results, at the 95% confidence level.

Services and Supports

The top 3 most used services and supports were in-home personal care, transportation services, and vocational and or employment services.

Which of the following services or supports are you currently using?	Total Sample: n=191
In-home personal care, personal assistance, home healthcare	49%
Transportation services- paratransit, dial-a-ride, mainline	41%
Vocational and or employment services (skill development, job coaching and or training and on-site support, etc.)	38%
Home modifications, medical or adaptive equipment or assistance technology	26%
Education related professions (early childhood, pre-school, K-12, transition, post-secondary, adult education, etc.)	23%
Physical Therapy or Occupational Therapy	16%
In- and out-of-home respite	15%
Speech or language therapy	14%
Cognitive behavioral therapy	10%
Employment preparation program or pre-employment services	10%
Other	14%
None, I do not use any services or supports for people with developmental disabilities	8%

Satisfaction of Quality of Services and Support

While 72% are at least *somewhat satisfied* with the services and support they receive, one-in-five (21%) are *dissatisfied*.

All things considered, how satisfied are you with the quality of the services and or supports you are currently receiving?	Total Sample: n=191
Very Satisfied	29%
Somewhat Satisfied	43%
Neither Satisfied or Dissatisfied	8%
Somewhat Dissatisfied	15%
Very Dissatisfied	6%

Reasons for Dissatisfaction with Services and Supports

The top 3 reasons for dissatisfaction with services or support were: inadequate availability of services and supports, staffing issues, and shortage of job opportunities.

Reasons for a less than VERY Satisfied Response	Total Sample: n=125
Inadequate, not enough services options and choices, long wait lists	29%
Staff is negative, not well trained, inadequate, high turnover	27%
Employment is hard to find and there are not enough jobs	14%
Funding is inadequate, wages are low, there is not enough money	11%
Transportation	3%
Other reasons	11%
No response, do not know, or unclear answer	22%

Transportation

The most used transportation method by people with developmental disabilities, for both work and or volunteer and personal activities is a personal vehicle driven by someone else. Other most used transportation methods are day program shuttle services and Metro Mobility. These three transportation options are used far more often than public transportation and other options.

Which transportation options do you use...	For work, volunteer, or day program	For activities, errands, friends, personal leisure
Personal vehicle driven by someone else (i.e., parent, guardian, other relative or caregiver, etc.)	45%	70%
Shuttle service owned and operated by the Day Program I attend	25%	6%
Metro Mobility	17%	8%
City bus	8%	7%
Transit Link	7%	1%
Personal vehicle that I drive	5%	6%
Light rail	4%	2%
Uber	2%	1%
Lyft	2%	1%
Taxi	1%	1%
Bicycle that I own	3%	5%
Shared public bicycles (such as those provided by NiceRide Minnesota)	1%	0%
Electric scooter that I own	0%	0%
Shared public electric scooters (such as those provided by JUMP, Lyft, Spin, Lime, etc.)	0%	1%
Other	8%	6%
None, I do not use any transportation services for this purpose	14%	14%

How well do current transportation options enable you to be included in your community

Approximately half of all respondents feel their inclusion in their community is limited by the transportation options that are currently available to them.

Which statement best describes how well current transportation options enable you to be included in your community?	Who in the household has the developmental disability		Do you work or volunteer outside your home	
	I am the person with the developmental disability	Someone else in my home has the developmental disability	I have a job I get paid for	I volunteer my time
Transportation options that are currently available enable me to be included in the community as much as I want	55%	48%	45%	54%
Current transportation options <u>somewhat limit</u> my ability to be included in the community	35%	32%	15%	27%
Current transportation options <u>greatly limit</u> my ability to be included in the community	10%	20%	40%	19%

There simply needs to be more transportation options available and accessible to people with developmental disabilities in order to enhance their inclusion in their communities.

How would transportation services need to be improved to help you be more included in your community?	Total Sample: n=96
More availability of transportation services, expanded hours, need more options	40%
Alleviate safety concerns	11%
Need specialized staffing	9%
Need more affordable options	9%
Need to improve accessibility for people with developmental disabilities, and for people who use wheelchairs	7%
Other	20%

Medicaid Waiver Application Process

Two-thirds (67%) of the survey respondents have applied for a Medicaid waiver.

Have you ever applied for a Medicaid waiver to receive supports and services for the person with developmental disabilities?	Total Sample: n=191
Yes	67%
No	14%
Don't know	19%

Approved levels of support were perceived to be at least somewhat less than needed by almost 1 out of 4 respondents (24%).

Results of most recent application for Medicare waiver	Total Sample: n=128
A waiver was approved for the level of services and supports needed	75%
A waiver was approved for a level of support that was <u>somewhat less than needed</u> to meet my services and supports	15%
A waiver was approved for a level of support that was <u>a lot less than needed</u> to meet my services and supports	7%
My application for a waiver was denied	2%
My waiver application is still be processed	1%

Almost one-third (31%) of people with developmental disabilities who had applied for a Medicaid waiver are dissatisfied with the assessment and application process.

All things considered, how satisfied are you with the Medicaid waiver assessment and application process?	Total Sample: n=128
Very Satisfied	29%
Somewhat Satisfied	29%
Neither Satisfied or Dissatisfied	11%
Somewhat Dissatisfied	16%
Very Dissatisfied	15%

Future Outlook: Medicaid waiver assessment and application process

Only 9% expect the waiver application process will be better in 2 years than it is today.

Looking ahead 2 years, do you think the overall quality of the waiver assessment and application process for people with developmental disabilities will be better, about the same or worse?	Total Sample n=128
Better in two years than it is today	9%
About the same in 2 years as it is today	30%
Worse in 2 years than it is today	23%
Don't know	38%

Quotes expressing dissatisfaction with the Waiver Assessment Application Process

<i>Intake assessors, case managers, and county social workers appear to be ignorant of Olmstead Decision and other key policies, as well as the history of the person with the disability.</i>
<i>Annually the waiver renewal process is a large pain and is always delayed due to shortage or change in staffing. The amount approved changes, although the disability never changes.</i>
<i>We have a new social worker and from this point he seems good, but he doesn't have the knowledge of what our other social workers had. Turnover has been high.</i>
<i>My County kept the whole waiver opportunity a secret from me. It wasn't until I was in Partners in Policymaking that I found out about it. Had to request a new case manager from the County because she always held back information and never could answer my questions in any way.</i>
<i>It's hit or miss if the social worker knows/understands what is available and how to get it, so the guardian has to do most of the work to get/maintain the DD Waiver and services needed. If it was up to the social worker/case manager, at least 75% of the time the waiver would have not been renewed and/or additional funding would not have been received.</i>
<i>He qualifies but we can't actually find services to use the funding on.</i>
<i>It is a hard process taking a lot of time to get approval. It is complex and lengthy.</i>

Concerns Regarding Abuse

Among the population of people with developmental disabilities, almost half (46%) are concerned about the possibility of abuse toward someone in their family; this overall level of concern is slightly higher than the level of concern of the general population of Minnesotans (40% concerned).

Concerns about abuse towards any member of your household or immediate family:	Q1 2020 Surveys	
	(A) People with developmental disabilities (n=191)	(B) General Population (n=920)
Very concerned about the possibility of abuse toward someone in my family	21%	17%
Somewhat concerned about the possibility of abuse toward someone in my family	25%	23%
Not at all concerned about the possibility of abuse toward anyone in my family	47%	51%
Don't know	7%	9%

ABC Indicates statistically significant differences between survey results, at the 95% confidence level.

People with developmental disabilities and their advocates are most concerned about abuse in the form of physical restraint and seclusion, and financial exploitation.

Please indicate your level of concern towards each of the following forms of abuse.	Total sample: (n=191)		
	Not at all concerned	Somewhat concerned	Very concerned
Verbal abuse, emotional abuse, teasing, bullying, etc.	36%	40%	24%
Physical abuse such as shoving, hitting, etc.	50%	29%	20%
Neglect, such as lack of food and clothing	65%	21%	14%
Physical restraint and seclusion	62%	24%	14%
Financial exploitation	46%	37%	18%
Inappropriate touch or other forms of sexual abuse	44%	33%	23%

All forms of abuse are more concerning to people with developmental disabilities, as compared to the general population of Minnesotans.

Percent who are very or somewhat concerned	Q1 2020 Surveys	
	(A) People with developmental disabilities (n=191)	(B) General Population of Minnesotans (n=920)
Verbal abuse, emotional abuse, teasing, bullying, etc.	64%B	38%
Physical abuse such as shoving, hitting, etc.	49%B	31%
Neglect, such as lack of food and clothing	35%B	28%
Physical restraint and seclusion	61% B	28%
Financial exploitation	70% B	31%
Inappropriate touch or other forms of sexual abuse	56% B	32%

ABC Indicates statistically significant differences between survey results, at the 95% confidence level.

Past, Present and Future Outlook

Education and Special Education

Compared to the general population, Minnesotans with developmental disabilities are less likely to believe that education services have improved over the past 2 years, or will improve over the next 2 years.

	2020 Surveys	
	(A) People with developmental disabilities (n=191)	(B) General Population (n=920)
Perceptions of the overall quality of education and special education services today compare to two years ago:		
Better today than it was two years ago	11%	24%A
About the same today as it was two years ago	31%	41%
Not as good today as it was two years ago	11%	12%
Don't know	47%	23%

	(A) People with developmental disabilities (n=191)	(B) General Population (n=920)
Future expectations regarding overall quality of education and special education services:		
Better in two years than it is today	9%	33%A
About the same in two years as it is today	27%	35%
Worse in two years than it is today	17%	13%
Don't know	47%	19%

ABC Indicates statistically significant differences between survey results, at the 95% confidence level.

Employment Services

Compared to the general population, Minnesotans with developmental disabilities are less likely to believe that employment services have improved over the past 2 years, and more likely to believe they will be worse in 2 years than they are today.

Perceptions of employment services and opportunities, today compared to two years ago:	(A) People with developmental disabilities (n=191)	(B) General Population (n=920)
Better today than it was two years ago	19%	33%A
About the same today as it was two years ago	31%	40%A
Not as good today as it was two years ago	18%B	7%
Don't know	32%B	21%

Future expectations for employment related services and opportunities:	(A) People with developmental disabilities (n=191)	(B) General Population (n=920)
Better in two years than it is today	17%	38%A
About the same in two years as it is today	27%	36%A
Worse in two years than it is today	19%B	6%
Don't know	37%B	21%

ABC Indicates statistically significant differences between survey results, at the 95% confidence level.

Overall Financial Wellbeing

Compared to the general population, Minnesotans with developmental disabilities are less likely to believe their overall financial well-being has improved over the past 2 years, and more likely to believe they will be worse off in 2 years than they are today.

	(A) People with developmental disabilities (n=191)	(B) General Population (n=920)
Would you say your household and immediate family are better off today than two years ago?		
Better today than it was two years ago	23%	36%A
About the same today as it was two years ago	45%	39%
Not as good today as it was two years ago	18%	18%
Don't know	15%B	7%

	(A) People with developmental disabilities (n=191)	(B) General Population (n=920)
Two years from now, do you think the overall financial wellbeing of your household and immediate family will be better, or about the same or worse?		
Better in two years than it is today	14%	43%A
About the same in two years as it is today	43%B	36%
Worse in two years than it is today	18%B	10%
Don't know	24%B	10%

ABC Indicates statistically significant differences between survey results, at the 95% confidence level.