### marketresponseinternational



project :: 1713 january 2006

# GCDD 5-Year Plan Research Report Individual Survey

prepared for:

Minnesota Governor's Council on Developmental Disabilities

prepared by:

marketresponseinternational



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1:: project overview



#### **Background**

Under the Developmental Disabilities Assistance and Bill of Rights Act, each state was granted the authority to create a Council on Developmental Disabilities. For the past thirty-five years, the Minnesota Governor's Council on Developmental Disabilities (GCDD) has served as an advocate for people with developmental disabilities - people with the most severe disabilities who may require long term service and support (about 1.8% of the state population). With support from the GCDD this segment of the population strives to be "treated as people first".

The social model has redefined "disability" and has put responsibility on society to change its attitudes and practices to include persons with developmental disabilities, rather than changing this population to fit society. The GCDD's charter is to assure that individuals with developmental disabilities receive the necessary support to achieve increased independence, productivity, self determination, integration and inclusion (IPSII) in the community.

As part of this charter, the GCDD is required to develop a 5-year plan. The GCDD decided they wanted to repeat the Quality of Life Assessment Survey (QOLAS), which was initially conducted in fall 2000, and use the new findings for input for their next 5-year plan.

#### **Research Objective**

Our objective was to conduct a customer-focused study among people with developmental disabilities in Minnesota to measure the degree to which they believe they are independent, productive, self determined, integrated and included in the community. This research was conducted via online and mail surveys.



#### Methodology

#### previous studies

:: In fall of 2005, GCDD commissioned MarketResponse to conduct a study using the 2000 survey as a benchmark. The 2000 survey was adapted based on information learned over the past five years, but the majority of the questions remained the same for comparison's sake.

#### contacting respondents

- :: Historically, it has been difficult to survey the population of people with developmental disabilities because GCDD does not have a list of these individuals nor is a list available to be purchased from a list provider. Therefore, each time we survey this population, we use creative means of reaching the individuals.
- :: Providers of services to individuals with developmental disabilities including all organizations that receive GCDD funding -- identified through lists obtained from the GCDD, were asked to recruit their constituents to participate in this study. We asked the provider to send an e-mail invitation to everyone who would be interested in participating in the survey.
- :: The GCDD staff personally contacted 45 local self-advocacy groups and over 100 organizations, universities, schools, and listservs to notify people about the surveys. Several state agencies, including the Department of Human Services and the Ombudsman Office for Mental Health and Developmental Disabilities, placed a link to the surveys on their web sites.

#### survey format

- :: This survey was administered primarily via Internet.
- :: Paper copies were available upon request by calling a toll-free number. Some people called because they did not have access to the Internet but the majority of the hard copies were sent to providers who had direct contact with individuals (i.e. clinics, resource centers etc.) rather than an e-mail list of their constituents.
- :: 435 respondents completed the survey on the Internet, which is 79% of the total respondents. 117 respondents completed the survey by mail which is 21% of the total respondents.



#### accommodations

- :: A call-in center was set up to handle questions and distribute paper copies.
- :: To accommodate Spanish speaking respondents, the survey was translated into Spanish and distributed by mail only. We had 13 respondents return the survey in Spanish, which is 11% of the mail respondents.
- :: In some cases, both a person with a developmental disability and someone close to them (such as a parent or caregiver) completed the questionnaire together. When the person with the developmental disability was unable to participate in the questionnaire, the parent or care giver responded on this person's behalf.

#### future research

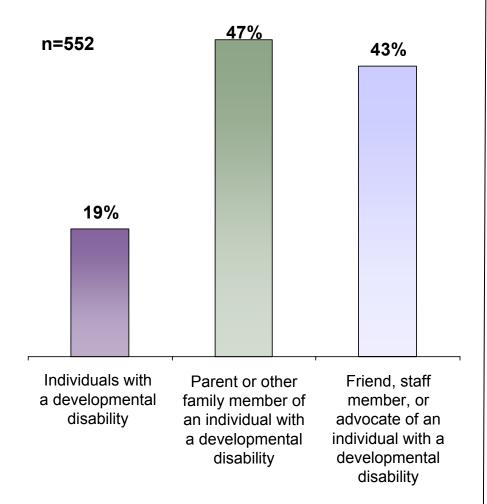
:: One enhancement of the study conducted in 2005, was asking for the respondents to give us their e-mail address to participate in future GCDD research. Fifty-one (51%) of the online respondents shared their e-mail addresses. This list will be shared with GovDelivery who will manage the e-mail addresses and notify respondents of upcoming surveys and GCDD website changes.

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2:: sample profile

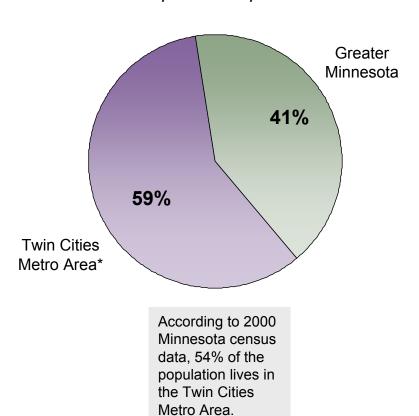


#### Which of the following statements best describes you?



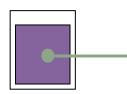
Note: Multiple responses allowed.

#### Respondent Zip Codes



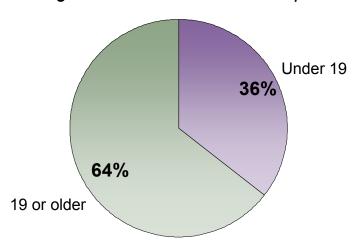
Respondents were limited to individuals with Minnesota zip codes. There was strong representation from both the Twin Cities Metro Area and the rest of the state.

\*The Twin Cities Metro Area is defined as the following seven counties: Anoka, Carver, Dakota, Hennepin, Ramsey, Scott and Washington.



### sample profile

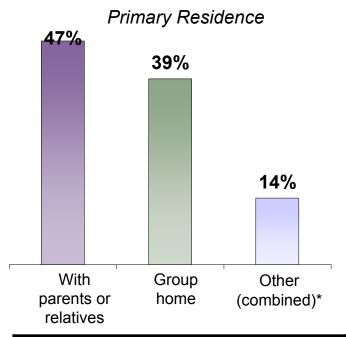
#### Age of individual with a developmental disability:



Under 10	15%
10-14	12%
15-18	9%
19-24	15%
25-34	16%
35-44	14%
45+	19%

#### I have lived in Minnesota for:

5 years or less	9%
6-10 years	13%
11-15 years	13%
16-20 years	13%
21-30 years	18%
31-40 years	13%
41-50 years	10%
Over 50 years	11%

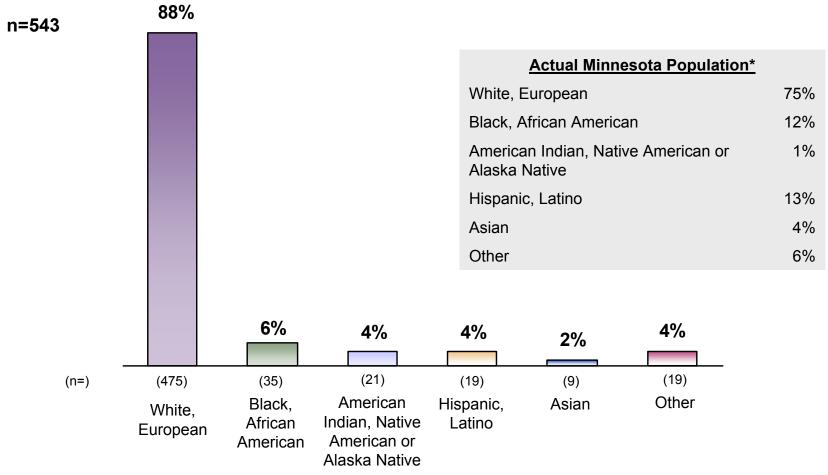


With parents or relatives	47%
Group home	39%
Own apartment or house, less than 24 hour supervision	9%
Own apartment or house, with 24 hour supervision	3%
Adult foster home/foster parents	2%

<sup>\*</sup>Other (combined) includes: Own apartment or house, less than 24 hour supervision; Own apartment or house, with 24 hour supervision; Adult foster home/foster parents; et al..



#### Ethnicity of individual with a developmental disability

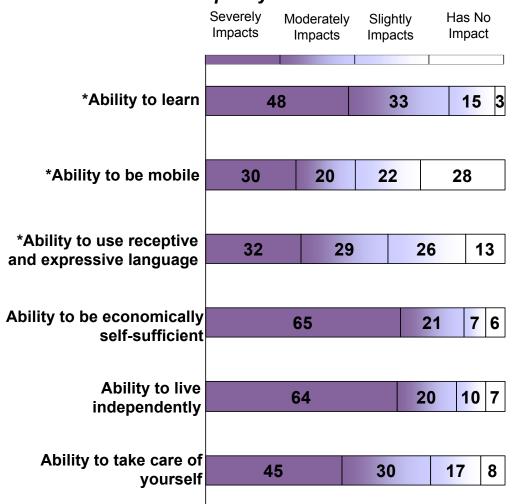


Note: Multiple responses allowed.

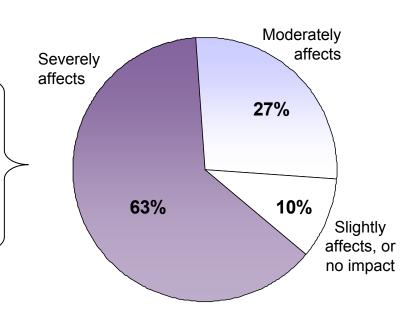
<sup>\*</sup>According to 2000 Minnesota Census data.



# At what level does your developmental disability impact your...



#### Degree disability affects individual



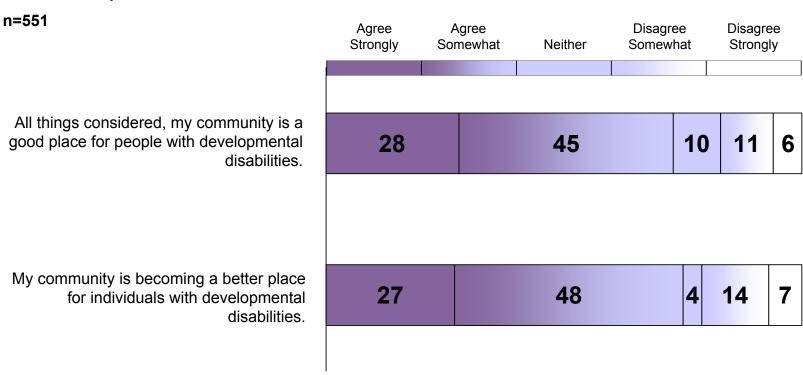
\*Respondents that checked "severely impacts" for any or all of ability to learn, ability to be mobile, and ability to use receptive and expressive language were classified as "severely affects." Those with a highest rating of "moderately impacts" for any or all were classified as "moderately affects." Respondents that did not check "severely impacts" or "moderately impacts" for these three statements were classified as "slightly affects, or no impact."

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3:: IPSII & basic needs detail



#### Percent of respondents who...



:: The majority of respondents agreed somewhat or strongly that their community is a good place for people with developmental disabilities and that it is getting better.



What is IPSII? -- Independence, Productivity, Self Determination, Integration and Inclusion

As we stated in the background section of this report:

The GCDD's charter is to assure that individuals with developmental disabilities receive the necessary support to achieve increased independence, productivity, self determination, integration and inclusion (IPSII) in the community.

In 2000, this list consisted of only Independence, Productivity, Integration and Inclusion (IPII), i.e. Self Determination was not included in the GCDD charter until later that same year. Since the GCDD was responsible for achieving these goals, the best way to determine its success was to measure these concepts. Federal law defines these terms; however, they were complex and did not represent the voice of the customer.

Therefore, our first step in 2000, was to interview individuals with developmental disabilities and their families to get an understanding of their situation and what these broader terms, IPII, might mean to them in everyday life. Through these interviews we developed a list of statements to help describe the larger concepts of IPII using the voice of the customer. These statements were then verified in the 2000 study, and reduced to a smaller set of drivers using statistical regression analysis. The smaller set of statements is what was used for this study.

Self Determination was added after the 2000 study and we did not have the opportunity to obtain the voice of the customer on this concept. The idea of Self Determination was somewhat overlapping with the original IPII terms. However, we saw it as partly a subset and partly an expansion of the concept of Independence.

We also added a list of "basic needs" statements to the survey. These statements covered aspects of an individual's situation that we felt were not covered by the IPII concepts-such as having enough money to live on.



#### What is IPSII? -- Independence, Productivity, Self Determination, Integration and Inclusion

Below is a description of how we defined IPSII for this study:

#### Independence:

#### Major aspects

- :: mobility
- :: privacy
- :: information access
- :: housing options (suitable, near family, etc.)
- :: choice of staff / provider

#### **Productivity:**

#### Major aspects

- :: productivity at home v. job /
- volunteering :: responsibility
- :: improvement
- :: recognition

#### **Self Determination:**

#### Major aspects

- :: self expression
- :: control of daily schedule
- :: goal setting / problem solving / decision making
- :: spending money (own, public funding, etc.)
- :: control over who I live with

#### **Integration:**

#### Major aspects

- :: resources
- :: support
- :: social opportunities
- :: rights to equality
- :: acceptance

#### **Inclusion:**

#### Major aspects

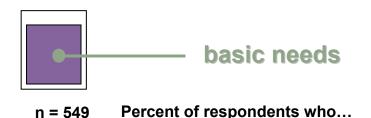
- :: treated with respect / as an equal
- :: develop meaningful relationships

#### Independence v. Self Determination

These concepts are somewhat overlapping; however, we define Independence as more related to access, privacy and having options; while we see Self Determination as the ability to make one's own decisions when given that access and those options.

#### Integration v. Inclusion

These concepts are somewhat overlapping; however, we define Integration as having the appropriate rights and resources within a community – meaning that the community is structured to support the individual; while we see Inclusion as more of a feeling of how one is treated.



I feel comfortable in the building or house where I live, it feels like home.

I have enough money to live on.

I know what to do if my health or safety is in jeopardy.

I have access to the healthcare I need.

I feel safe in the neighborhood where I live.

My future will be secure, even if something

happens to my parents / current staff

member, friend or advocate.

Agree Strongly	Agree Somewhat	Neither	Neither Disagree Somewhat	
	62		23	8 5 3
19	28	17	18	18
16	28	11	22	23
	47		35	4 10 4
	57		31	6 42
19	27	10	21	23

- :: Some individual basic needs require real improvement -- with less than half the respondents agreeing that they have enough money to live on, that they know what to do if their health or safety is in jeopardy or that their future will be secure. These and other similar basic needs should be addressed together before people can substantially improve their independence, productivity, self determination, integration or inclusion.
- :: Individuals who participated in the surveys were more likely to agree that their basic needs are being met than parents, friends and others who assisted individuals in completing the survey.
- :: Older respondents, respondents with less severe disabilities, individuals who work or volunteer, individuals who do not live at their parents' home, and people of European descent (white) also tended to rate their basic needs higher than others.



### basic needs by segment

Top 2 Box Agreement	Respondent		Ag	Age		Degree of Disability			Location	
	Ind w/ dd	Other	<19	19+	Severe	Mod	Other	Metro	Greater MN	
	(107)	(462)	(196)	(354)	(347)	(150)	(55)	(298)	(228)	
I feel comfortable in the building or house where I live, it feels like home.	81	85	79 ↓	88 <b>†</b>	85	84	80	85	84	
I have enough money to live on.	71 ↑	42↓	33↓	55∱	43 ↓	52	62	49	43	
I know what to do if my health or safety is in jeopardy.	70 <b>↑</b>	39↓	29 ↓	52∱	33 ↓	57	81	44	43	
I have access to the healthcare I need.	87	81	73↓	87 <b>↑</b>	79 ↓	85	91 <del></del>	79 ↓	86 🕈	
I feel safe in the neighborhood where I live.	85	89	84 ↓	91 <b>↑</b>	88	88	89	86	91	
My future will be secure, even if something happens to my parents / current staff member, friend or advocate.	70	42	28 ↓	57∱	40 ↓	53	73	43	47	

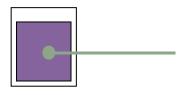
 $\uparrow$  Indicates statistically significant difference from other values in row at the 95% confidence level



### basic needs by segment

Top 2 Box Agreement	Job / Volunteer			W	/here Live	Ethnicity		
	Job	Vol	Neither	Parents home	Group home	Other	White	Of color
	(189)	(64)	(182)	(252)	(210)	(86)	(453)	(90)
I feel comfortable in the building or house where I live, it feels like home.	88	92	80↓	82↓	88 🕈	85 <b>↑</b>	87	72↓
I have enough money to live on.	62 <b>†</b>	52	38↓	38	59	48	48	41
I know what to do if my health or safety is in jeopardy.	52 ↑	53∱	32↓	33↓	47	71∱	44	41
I have access to the healthcare I need.	88 🕈	89 🕈	73↓	77↓	87 <b>↑</b>	84	83	75
I feel safe in the neighborhood where I live.	93 🕈	91	82↓	86↓	94 🕈	84 ↓	91	76↓
My future will be secure, even if something happens to my parents / current staff member, friend or advocate.	62 🕈	60 🕇	34↓	29↓	69 <b>†</b>	44	48	39

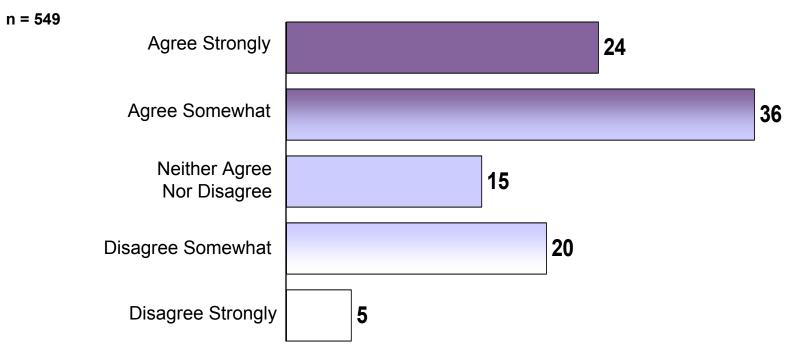
<sup>↑</sup> Indicates statistically significant difference from other values in row at the 95% confidence level



### satisfaction with independence

I am satisfied with my current level of Independence:

#### Percent of respondents who...



- :: 60% of respondents agreed with the statement that they are satisfied with their current level of independence.
- :: Responses varied by respondent segment in a very similar manner to the basic needs questions.



n = 549 Percer	nt of respondents who	Strongly	Agree Somewhat	Neit	ther	Disagree Somewha		Disag Stron	
I can (even i	if someone helps me) get to where I want to go.	4	40		39		7	9	5
I can meet peo	ople in private, when I want.	3	5	3	1	1	8	10	7
I can be alon	ne and have privacy, when I feel I need it.	44 34				10	9	4	
	who are allowed to know my formation have access to it.		45		33	3	10	)   1	0 2
Findin	ng a suitable housing option for me is possible.	26	2	25	2	25	1:	5	9
I can live near the	ne people who are important to me.	4	40		31		14	10	5
I choose	the staff who work with me.	15	24	2	3	18		20	)
I choose th	ne provider who assists me.	18	29		24		15	1	5
I am as indepe	endent as I can be given my developmental disability.	28		4	4		11	13	4

<sup>::</sup> Information access, privacy issues and mobility were rated relatively highly as aspects of independence that are being met; while housing options and being able to choose one's provider and staff received lower ratings.



### attributes of independence by segment

Top 2 Box Agreement	Respo	ondent	Αg	Age		Degree of Disability			Location	
	Ind w/ dd	Other	<19	19+	Severe	Mod	Other	Metro	Greater MN	
	(107)	(462)	(196)	(354)	(347)	(150)	(55)	(298)	(228)	
I can (even if someone helps me) get to where I want to go.	90	76	66	86	76	83	86	78	79	
I can meet people in private, when I want.	87	62	40 ↓	81 <b>↑</b>	58↓	76	93	64	66	
I can be alone and have privacy, when I feel I need it.	91 🕇	75↓	61	87	73	84	92	74	81	
Only the people who are allowed to know my personal information have access to it.	86	77	63↓	87 <b>↑</b>	76	81	85	76	80	
Finding a suitable housing option for me is possible.	76 <b>↑</b>	46↓	22↓	67 <b>↑</b>	45↓	55	77 ♠	49	52	
I can live near the people who are important to me.	77	70	61	77	69	71	89	68	75	
I choose the staff who work with me.	58 <b>↑</b>	35↓	33	42	35	47	43	42	34	
I choose the provider who assists me.	64 🕈	43↓	31↓	55	40↓	59 <b>↑</b>	60↑	46	47	
I am as independent as can be given my developmental disability.	82	70	57↓	80 <b>†</b>	70	75	74	70	72	

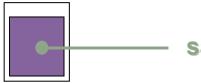
<sup>↑</sup> Indicates statistically significant difference from other values in row at the 95% confidence level



### attributes of independence by segment

Top 2 Box Agreement	Jo	b / Volunt	eer	V	Vhere Live	9	Ethnicity		
	Job	Vol	Neither	Parents home	Group home	Other	White	Of color	
	(189)	(64)	(182)	(252)	(210)	(86)	(453)	(90)	
I can (even if someone helps me) get to where I need to go.	87	86	69	70	88	84	79	78	
I can meet people in private, when I want.	81 <b>↑</b>	77∱	49↓	48↓	80 🕈	85 <b>↑</b>	68	55	
I can be alone and have privacy, when I feel I need it.	88	89	66	68	85	90	79	71	
Only the people who are allowed to know my personal information have access to it.	88	79	71	68↓	91 <b>↑</b>	81 <b>†</b>	78	81	
Finding a suitable housing option for me is possible.	70 <b>↑</b>	67 <b>†</b>	34↓	26↓	73 ↑	69 <b>↑</b>	52	44	
I can live near the people who are important to me.	73	73	67	68	77	69	73	64	
I choose the staff who work with me.	41	41	34	40	32	52	40	35	
I choose the provider who assists me.	54	58	39	42	49	58	48	39	
I am as independent as can be given my developmental disability.	79	86	63	60↓	80 🕇	86 🕇	74 🕇	59↓	

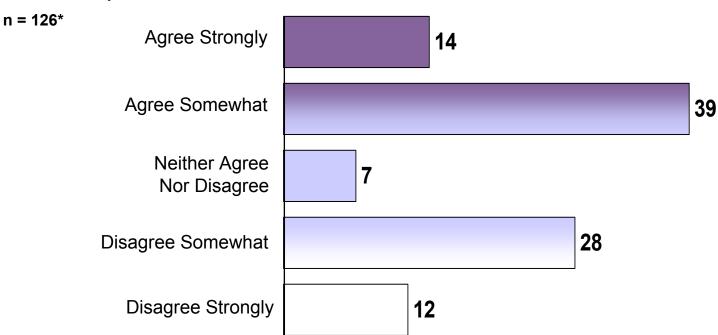
<sup>↑</sup> Indicates statistically significant difference from other values in row at the 95% confidence level



### satisfaction with productivity

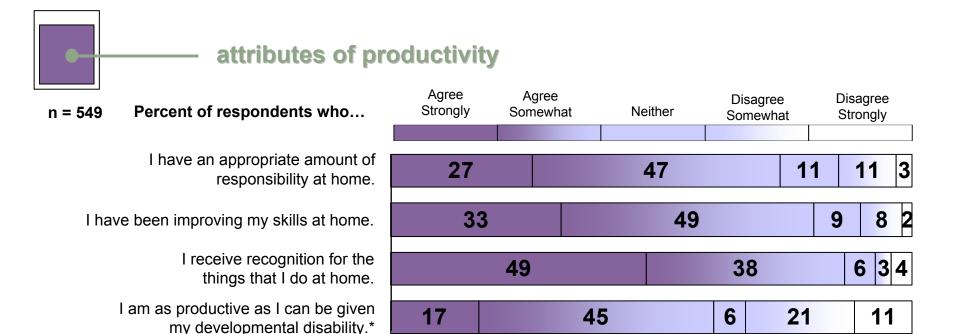
I am satisfied with my current level of Productivity:

#### Percent of respondents who...



- :: 53% of respondents agreed with the statement that they are satisfied with their current level of productivity.
- :: Respondents were more likely to 'disagree somewhat' with this statement than that of self determination, integration, and inclusion.

<sup>\*</sup>smaller sample of respondents weighted to represent total survey sample



- :: Individuals' feelings of productivity in the home environment were largely being met; however respondents were much more likely to disagree that they are as productive as they can be.
- :: Individuals with developmental disabilities who filled the survey out for themselves were significantly more likely to state that they had an appropriate amount of responsibility at home than the parents, friends and others who filled the survey out with/for them.
- :: Respondents who do not work or volunteer, who are under 19 and/or of color, were much less likely to agree that they are as productive as they can be.

<sup>\*</sup>smaller sample of respondents weighted to represent total survey sample



### attributes of productivity by segment

Top 2 Box Agreement	Respondent		Age		Degree of Disability			Location	
	Ind w/ dd	Other	<19	19+	Severe	Mod	Other	Metro	Greater MN
	(107)	(462)	(196)	(354)	(347)	(150)	(55)	(298)	(228)
I have an appropriate amount of responsibility at home.	84 🕇	73↓	63↓	81 <b>†</b>	70 ↓	79 <b>†</b>	87 <b>↑</b>	74	75
I have been improving my skills at home.	91 🕈	80↓	81	82	79 ↓	85	91	82	82
I receive recognition for the things I do at home.	85	88	88	87	86	89	89	87	88
I am as productive as I can be given my developmental disability.*	93 🕈	60↓	48↓	69 <b>†</b>	57	71	72	60	63

<sup>↑</sup> Indicates statistically significant difference from other values in row at the 95% confidence level

<sup>\*</sup>smaller sample of respondents weighted to represent total survey sample

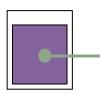


### attributes of productivity by segment

Top 2 Box Agreement	Job / Volunteer			W	/here Live	Ethnicity		
	Job	Vol	Neither	Parents home	Group home	Other	White	Of color
	(189)	(64)	(182)	(252)	(210)	(86)	(453)	(90)
I have an appropriate amount of responsibility at home.	86	81 <b>†</b>	61↓	67↓	79	85	76	68
I have been improving my skills at home.	89 <b>↑</b>	84↓	70 ↓	84	81	81	82	83
I receive recognition for the things I do at home.	90 🕈	94∱	82↓	90	87	79	89 🕇	77↓
I am as productive as I can be given my developmental disability.*	61 🕈	68 <b>†</b>	49↓	44↓	75 🕈	80 🕈	65 🕈	38▼

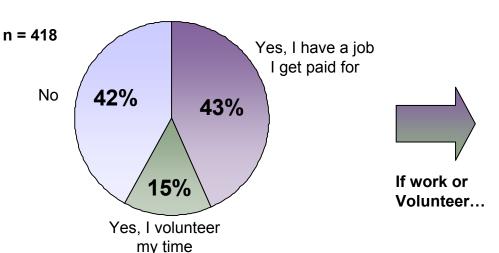
<sup>↑</sup> Indicates statistically significant difference from other values in row at the 95% confidence level

<sup>\*</sup>smaller sample of respondents weighted to represent total survey sample



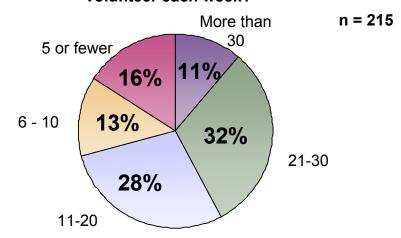
### attributes of productivity

# For respondents over 15 years of age, do you work or volunteer outside your home?

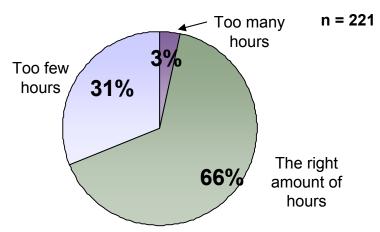


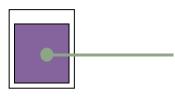
- :: 58% of respondents either work or volunteer outside their home
- :: The majority of individuals worked less than 20 hours per week
- :: Approximately 2/3rds of respondents thought they worked the appropriate number of hours; however 31% would like to work more hours than they do.

## On average, how many hours do you work or volunteer each week?



#### I work / volunteer...





### attributes of productivity

#### For respondents over 15 years of age, who work or volunteer

n = 223	Percent o	f respondents who	Agree Strongly	Agree Somewhat	Neither	Disagree Somewhat		Disagre Strongl		
		I am appropriately challenged by my	31		48		3	14	4	
Where I work or volunteer		responsibilities. I am rewarded for the things I do.	39		48			4 7 2		
		I have been improving my skills.	4	0		46		4 9	2	

- :: Individuals who work or volunteer gave relatively high ratings to these productivity aspects in their work environment. However, some feel that they could be more appropriately challenged by their responsibilities at work.
- :: There was less variance across the respondent segments on these statements. The exceptions were that Twin Cities Metro Area residents were more likely to agree than their counterparts in greater Minnesota, and individuals with disabilities completing the survey were more likely to agree than parents, friends and others who completed the survey with / for them.



### attributes of productivity by segment

Top 2 Box Agreement	Respo	ondent	Age		Degree of Disability			Location		
	Ind w/ dd	Other	<19	19+	Severe	Mod	Other	Metro	Greater MN	
Where I work or volunteer	(67)	(164)	(11)	(213)	(121)	(75)	(28)	(100)	(105)	
I am appropriately challenged by my responsibilities.	92 🕈	75 ↓	73	80	78	80	89	85 <b>↑</b>	73↓	
I am rewarded for the things I do.	92	86	82	88	85	91	89	94∱	82↓	
I have been improving my skills.	99 🕈	81 ↓	82	85	83↓	85	96	91	78↓	

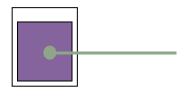
<sup>↑</sup> Indicates statistically significant difference from other values in row at the 95% confidence level



### attributes of productivity by segment

Top 2 Box Agreement	Job	Job / Volunteer			/here Live	Ethnicity		
	Job	Vol	Neither	Parents home	Group home	Other	White	Of color
Where I work or volunteer	(67)	(164)	(0)	(213)	(121)	(75)	(28)	(100)
I am appropriately challenged by my responsibilities.	81	84		71	82	81	80	79
I am rewarded for the things I do.	87	89		86	87	91	88	86
I have been improving my skills.	86	89		80	86	88	86	82

<sup>↑</sup> Indicates statistically significant difference from other values in row at the 95% confidence level

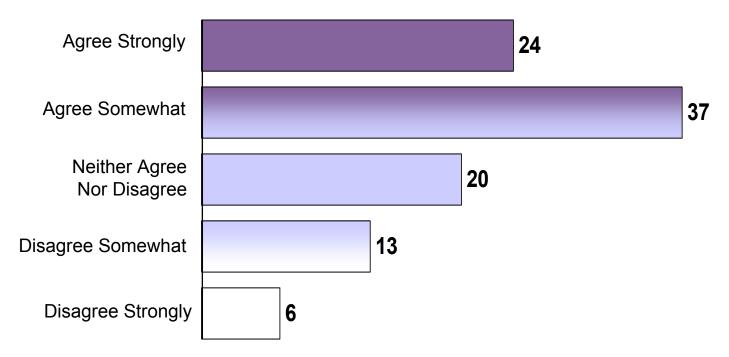


#### satisfaction with self determination

I am satisfied with my current level of Self Determination:

#### Percent of respondents who...

n = 549



- :: 61% of respondents agreed with the statement that they are satisfied with their current level of self determination
- :: The respondents' level of agreement with self determination aspects varied dramatically between the respondent segments. These variations were similar to those reported in the basic needs and independence statements.

attributes of se	If determ	ination				
Percent of respondents who	Agree Strongly	Agree Somewhat	Neither	Disagree Somewha		_
n = 549						
I can (even if someone helps me) decorate or arrange my living area how I like it.	3	8	33		17	8 4
I have control over how I present myself, what I choose to wear, my hairstyle, etc.	4	41		42	10	5 3
I have control over my daily schedule.	20	3	8	17	20	6
I can set outcomes (goals) for myself.	23		36	18	15	8
I can decide how I spend my money.	20	4	40	19	13	8
I can make decisions that will affect my future.	19	3	9	21	13	9
I solve my own problems (even if someone helps me).	20		42	12	19	6
I can decide how public funds are spent for my services and support.	10 15	5 2	<b>!9</b>	24	22	)
I have control over who I live with.	18	19	25	20	1	8
I have as much self determination as possible given my developmental disability.	27		38	15	14	6

<sup>::</sup> Self expression (decorating living space and personal presentation) received the highest ratings for self determination, while control over services spending and who they live with received the lowest ratings.



### attributes of self determination by segment

Top 2 Box Agreement	Respo	ondent	Age		Degree of Disability			Loca	Location	
	Ind w/ dd	Other	<19	19+	Severe	Mod	Other	Metro	Greater MN	
	(107)	(462)	(196)	(354)	(347)	(150)	(55)	(298)	(228)	
I can (even if someone helps me) decorate or arrange my living room how I like it.	81	69 ₩	51 ♥	82 <sup>†</sup>	66♥	77	89	69	72	
I have control over how I present myself, what I chose to wear, my hairstyle, etc.	90	81 ₩	68 ₹	91	80↓	87	93	84	81	
I have control over my daily schedule.	85	52 ▼	32▼	72	47▼	72	87	54	60	
I can set outcomes (goals) for myself.	88	53 ₹	35 ₹	72	50 ₩	71	83	57	59	
I can decide how I spend my money.	81	56 ▼	34 ▼	75	50 ₹	75	87	57	63	
I can make decisions that will affect my future.	82	53 ₹	31 ₩	72	50 ₩	68	83	54	60	
I solve my own problems (even if someone helps me).	82	59 ₩	47 ₩	71	55 ₹	71	90	58	66	
I can decide how public funds are spent for my services and support.	50	20 ↓	11 ₩	33	21 ♥	29 ₩	43	25	22	
I have control over who I live with.	54	33 ₩	18 ₹	46 <sup>†</sup>	31 ₩	41	55	36	33	
I have as much self determination as possible given my developmental disability.	79	61 ♥	48 ♥	<sub>73</sub> †	59 ₩	73	76 <sup>1</sup>	62	66	

<sup>↑</sup> Indicates statistically significant difference from other values in row at the 95% confidence level



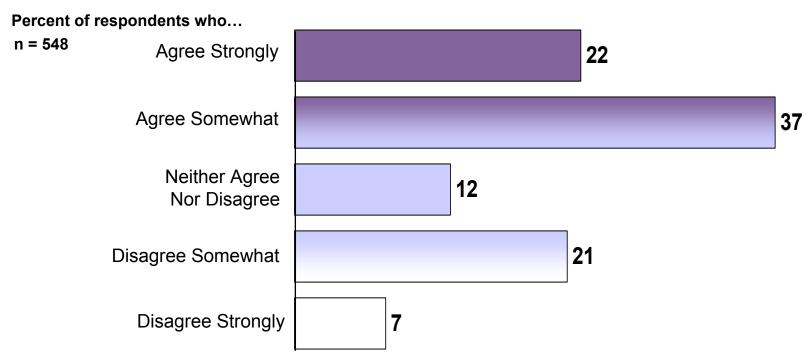
### attributes of self determination by segment

Top 2 Box Agreement	Jo	b / Volunte	eer	Where Live			Ethnicity		
	Job	Vol	Neither	Parents home	Group home	Other	White	Of color	
	(189)	(64)	(182)	(252)	(210)	(86)	(453)	(90)	
I can (even if someone helps me) decorate or arrange my living room how I like it.	82 🕈	81 🕈	58 ↓	59↓	80	90 🕇	74↑	58↓	
I have control over how I present myself, what I chose to wear, my hairstyle, etc.	93 🕇	89 🕈	69 ↓	74↓	90	93 🕈	84	81	
I have control over my daily schedule.	75 🕇	72 <b>↑</b>	41 ↓	40↓	68	80 <b>↑</b>	60∱	45 ↓	
I can set outcomes (goals) for myself.	76 ↑	78 <b>↑</b>	43 ↓	44 ↓	69	80 🕇	61	47↓	
I can decide how I spend my money.	79 🕇	78 <b>↑</b>	42 ↓	44 ↓	70	83 🕈	62	50 ↓	
I can make decisions that will affect my future.	75 🕈	77 🕈	41 ↓	41 ↓	69	81 🕈	60 🕈	48↓	
I solve my own problems (even if someone helps me).	76 🕇	81 🕈	47 ↓	52 ↓	70 <b>↑</b>	<b>75 ↑</b>	65 <b>†</b>	50↓	
I can decide how public funds are spent for my services and support.	32 🕈	33 ↑	14 ↓	17 ↓	27	45 <b>↑</b>	29	25	
I have control over who I live with.	39 ↑	38 ╋	24 ↓	30 ↓	29 ↓	72 🕇	35	39	
I have as much self determination as possible given my developmental disability.	77 🕈	75 🕈	51 ↓	55 ↓	72 <b>↑</b>	72 🕈	65	57	

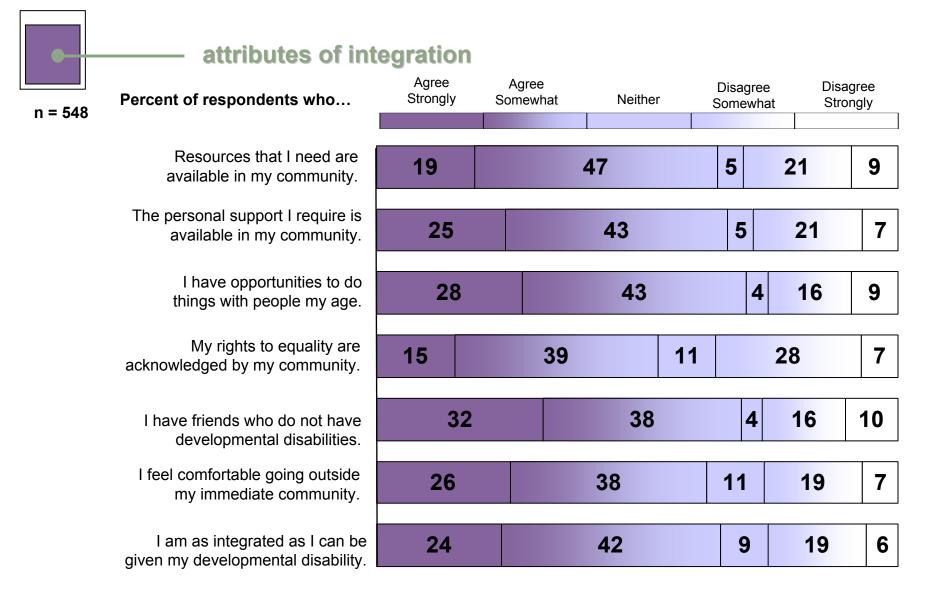
 $<sup>\</sup>uparrow$  Indicates statistically significant difference from other values in row at the 95% confidence level



I am satisfied with my current level of Integration:



- :: 59% of respondents agreed with the statement that they are satisfied with their current level of integration.
- :: Respondents were more likely to "disagree somewhat" with this statement than their satisfaction with independence or self determination.
- :: Responses varied by respondent segment in a manner similar to basic needs, independence and self determination.
- :: Parents, friends, or advocates of the individual with a developmental disability were more likely to disagree with this statement than the individuals themselves.



- :: Opportunities to make friends with people who do not have disabilities and to do things with people their own age received the highest levels of agreement for integration.
- :: Availability of resources and personal support in their community as well as an acknowledgement of rights to equality received the lowest levels of agreement.



# attributes of integration by segment

Top 2 Box Agreement	Respondent		Age		Degree of Disability			Location	
	Ind w/ dd	Other	<19	19+	Severe	Mod	Other	Metro	Greater MN
	(107)	(462)	(196)	(354)	(347)	(150)	(55)	(298)	(228)
Resources that I need are available in my community.	73	64	52↓	73 🕈	61 ↓	72	78∱	66	64
The personal support I require is available in my community.	73	66	53↓	75 <b>†</b>	64 ₩	73	77 🕈	64	72
I have opportunities to do things with people my age.	79 <b>↑</b>	69 ↓	64 ↓	75 <b>†</b>	67 ↓	77 🕈	79 🕈	72	70
My rights to equality are acknowledged by my community.	76 <b>↑</b>	50 ↓	40 ↓	62 🕈	48 ↓	60	77 🕈	52	54
I have friends who do not have developmental disabilities.	78 🕇	69 ↓	71	70	69 ↓	69↓	86 🕇	69	74
I feel comfortable going outside my immediate community.	87	59 ↓	45 ↓	74 🕈	58 ↓	71	89 🕈	62	65
I am as integrated as possible given my developmental disability.	77 🕈	64 ₩	56 ↓	72 🕈	62 ↓	73	79 <b>†</b>	64	68

 $<sup>\</sup>uparrow$  Indicates statistically significant difference from other values in row at the 95% confidence level



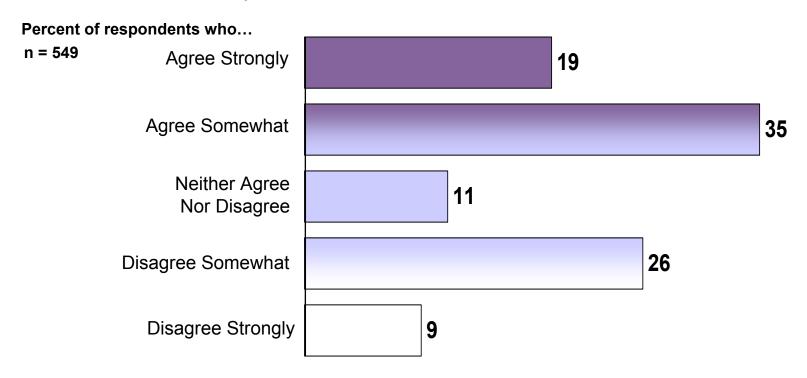
# attributes of integration segment

Top 2 Box Agreement	Jo	b / Volunt	eer	Where Live			Ethnicity	
	Job	Vol	Neither	Parents home	Group home	Other	White	Of color
	(189)	(64)	(182)	(252)	(210)	(86)	(453)	(90)
Resources that I need are available in my community.	75 🕈	73	56 ↓	55 ↓	77 🕈	69	70	57
The personal support I require is available in my community.	75	75	58 ↓	57 ↓	76 <b>†</b>	77 🕈	70 🕇	55 ↓
I have opportunities to do things with people my age.	76	77 🕈	66 ↓	63 ↓	77 🕈	78 <b>↑</b>	74 🕈	56↓
My rights to equality are acknowledged by my community.	62 🕇	60	43 ↓	43 ↓	65 🕇	59 <b>↑</b>	55	47
I have friends who do not have developmental disabilities.	71	78	70	73	66	75	71	66
I feel comfortable going outside my immediate community.	77 🕈	73	49 ↓	51 ↓	76 🕈	75 🕈	63	69
I am as integrated as possible given my developmental disability.	73	64	65	59 ↓	74 🕈	67 <b>†</b>	68	58

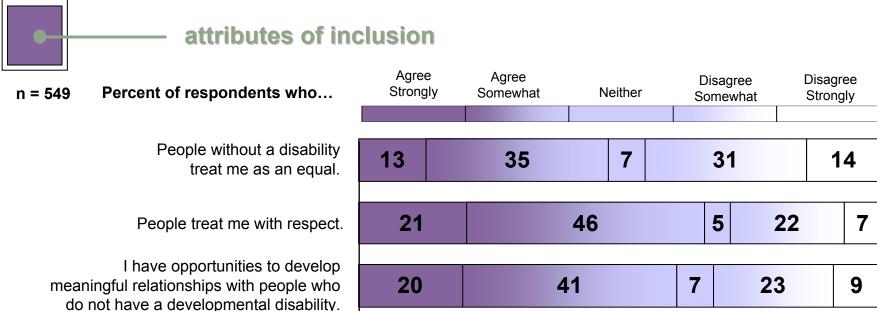
 $\uparrow$  Indicates statistically significant difference from other values in row at the 95% confidence level



I am satisfied with my current level of Inclusion:



- :: 54% of respondents agreed with the statement that they are satisfied with their current level of inclusion which is the lowest rating for IPSII.
- :: Respondents were more likely to "disagree somewhat" with this statement than their satisfaction with independence or self determination.
- :: Responses again varied by respondent segment in a manner similar to basic needs, independence and self determination.
- :: Respondents of color were more likely to disagree with this statement than those of white/European descent.



I have opportunities to develop meaningful relationships with people who have a developmental disability.

I am as included in society as I can be.

Agree Strongly	Aç y Som	gree ewhat	Neither		Disa Some	gree ewhat		isagree trongly	
13		35	7		3	1		14	
21		4	6		5		22		7
20		41		•	7	2	3	(	•
28	8		49				7	12	4
20		36		9		24		1	1

- :: Respondents agreed most that they have opportunities to develop friendships with other individuals who have developmental disabilities.
- :: Respondents were less likely to agree that they are treated as an equal, treated with respect and have opportunities to develop friendships with individuals who do not have a developmental disability.



# attributes of inclusion by segment

Top 2 Box Agreement	Respondent		Age		Degree of Disability			Location	
	Ind w/ dd	Other	<19	19+	Severe	Mod	Other	Metro	Greater MN
	(107)	(462)	(196)	(354)	(347)	(150)	(55)	(298)	(228)
People without a disability treat me as an equal.	71	44 ↓	34 ↓	56 ↑	40 ↓	59	70∱	50	43
People treat me with respect.	83 🕈	64 ↓	53 ↓	75 <b>↑</b>	63 ↓	71	84 🕈	67	66
I have opportunities to develop meaningful relationships with people who do <u>not</u> have a developmental disability.	69	60	62	60	58 ↓	63	77 🕇	60	63
I have opportunities to develop meaningful relationships with people who have a developmental disability.	76	78	67 ↓	83 🕈	76	78	81	75	79
I am as included in society as I can be.	75 🕈	52 ↓	43 ↓	63 🕇	50 ↓	63	77 🕈	54	57

 $<sup>\</sup>uparrow$  Indicates statistically significant difference from other values in row at the 95% confidence level



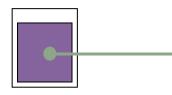
# attributes of inclusion by segment

Top 2 Box Agreement	Job / Volunteer			Where Live			Ethnicity	
	Job	Vol	Neither	Parents home	Group home	Other	White	Of color
	(189)	(64)	(182)	(252)	(210)	(86)	(453)	(90)
People without a disability treat me as an equal.	57 <b>†</b>	56	39 ↓	39 ↓	57 <b>↑</b>	53 <b>↑</b>	49	42
People treat me with respect.	76 <b>†</b>	78∱	56 ↓	58↓	75 🕈	75 <b>†</b>	69 🕇	55 ↓
I have opportunities to develop meaningful relationships with people who do not have a developmental disability.	61	65	59	61	60	66	64 🕇	49 ₩
I have opportunities to develop meaningful relationships with people who have a developmental disability.	84 🕈	82	68 ↓	68 ↓	88 🕈	79	79	70
I am as included in society as I can be.	64 🕇	59	48 ↓	46 ↓	65 <b>†</b>	66 <b>†</b>	59 🕇	40 ↓

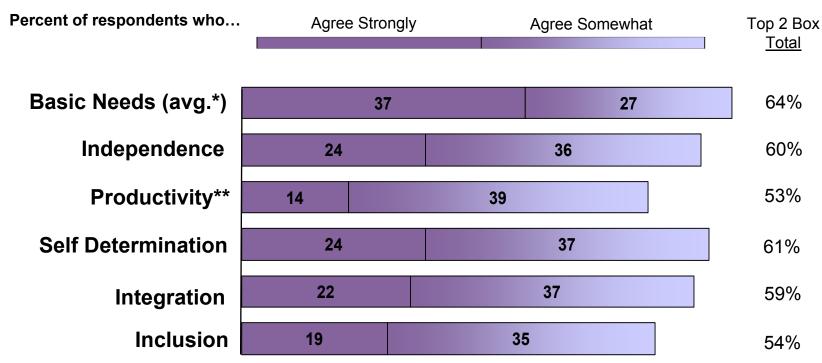
 $<sup>\</sup>uparrow$  Indicates statistically significant difference from other values in row at the 95% confidence level

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4::
IPSII & basic
needs
summary



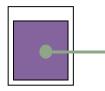
I am satisfied with my current level of...



<sup>\*</sup> Average of 6 basic needs statements

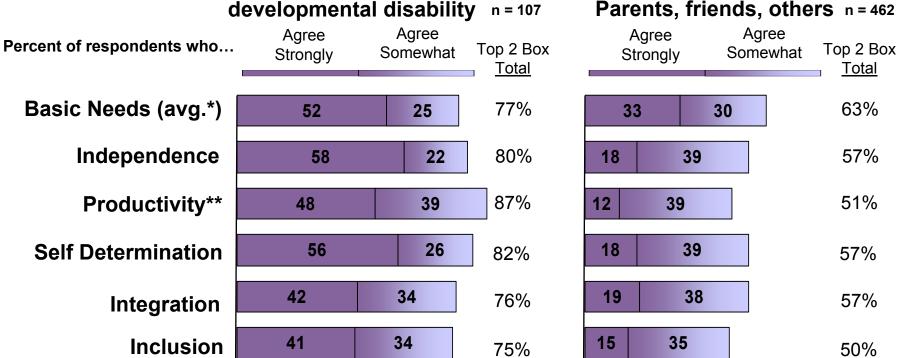
:: Of the ISPII statements, respondents were most satisfied with their current levels of Self Determination and Independence and least satisfied with their current levels of Productivity and Inclusion.

<sup>\*\*</sup>Smaller sample of respondents weighted to represent total survey sample



### Person Responding to Survey

### | Individual w/ |opmental disability | n = 107



<sup>\*</sup>Average of 6 basic needs statements

:: Individuals with a developmental disability who completed this survey were much more likely to be satisfied with their levels of IPSII than parents, friends, and others who completed the survey with/for them. This may be because the individuals completing the survey described themselves as having less severe disabilities; however since the impact of the disability is also self reported, this may be a reflection of optimism among this group relative to their parents, friends and others who are advocates fighting the battle for improvement.

<sup>\*\*</sup>Smaller sample of respondents weighted to represent total survey sample



### Age of the Individual with a Developmental Disability

	Under 19 Y	ears Old	n = 196	19	+ Years Old	n = 354
Percent of respondents who	Agree Strongly	Agree Somewhat	Top 2 Box <u>Total</u>	Agree Strongly	Agree Somewh	at Top 2 Box <u>Total</u>
Basic Needs (avg.*)	29 25		54%	41	31	72%
Independence	12 28		40%	31	40	71%
Productivity**	4 33		37%	20	42	62%
Self Determination	12 30		42%	31	40	71%
Integration	12 34		46%	27	39	66%
Inclusion	8 29		37%	24	39	63%

<sup>\*</sup>Average of 6 basic needs statements

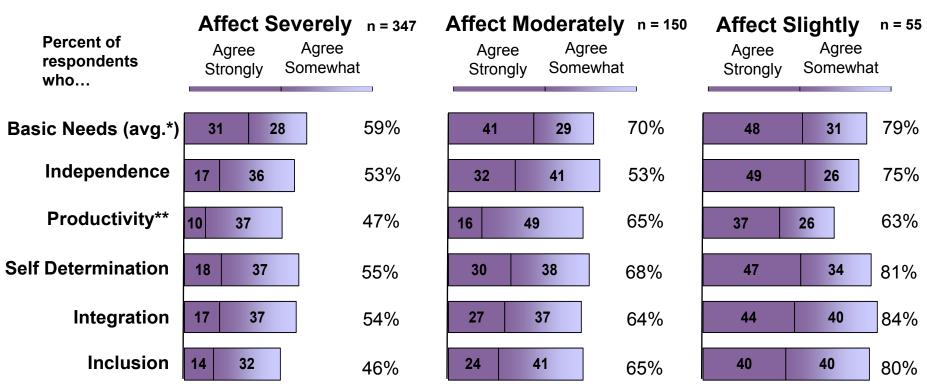
- :: Respondents over age 19 were much more positive about their situation than those under 19. In general, it's natural that adults would be more independent and productive than children. Other possible explanations for this can be seen when looking at the demographic make up of these groups. In the over 19 group, the respondents were much more likely to:
  - :: participate in the completion of the survey
  - :: describe themselves as having a less severe disability, and
  - :: be of white/European descent,

all of which were identified as leading to more positive responses. marketresponseinternational

<sup>\*\*</sup>Smaller sample of respondents weighted to represent total survey sample



# Self-reported Degree Disability Affects Individual's Learning, Mobility and Language



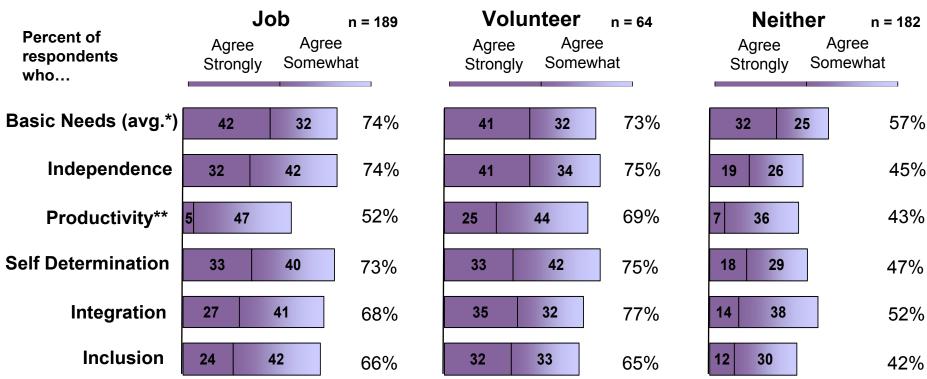
<sup>\*</sup>Average of 6 basic needs statements

:: Individuals who reported having disabilities that had less of an effect on their abilities to be mobile, use language, and learn were much more positive about their current situation.

<sup>\*\*</sup>Smaller sample of respondents weighted to represent total survey sample



### Individuals with a Developmental Disability who Work or Volunteer



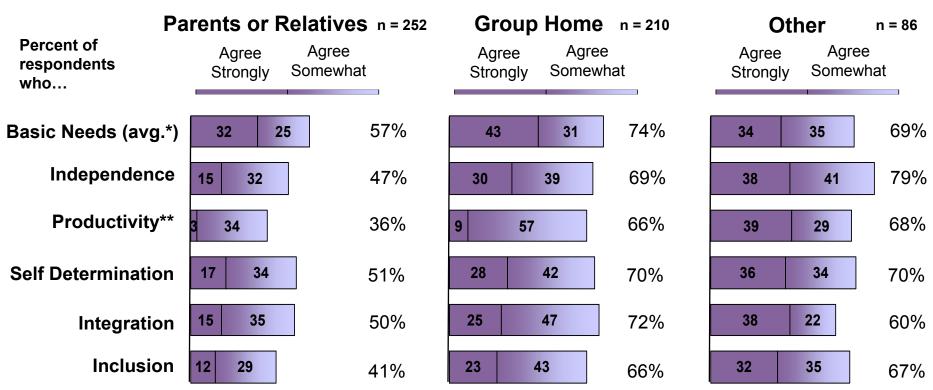
<sup>\*</sup>Average of 6 basic needs statements

- :: Individuals who currently work or volunteer were much more positive about their current situation. It is important to note as well that respondents who work or volunteer were more likely to:
  - :: be over 19 years of age
  - :: report having disabilities of less impact
  - :: live outside their parents' home, and
  - :: be of white/European descent,
    - all of which were identified as leading to more positive responses.

<sup>\*\*</sup>Smaller sample of respondents weighted to represent total survey sample



### Primary Residence of the Individual with a Developmental Disability



<sup>\*</sup>Average of 6 basic needs statements

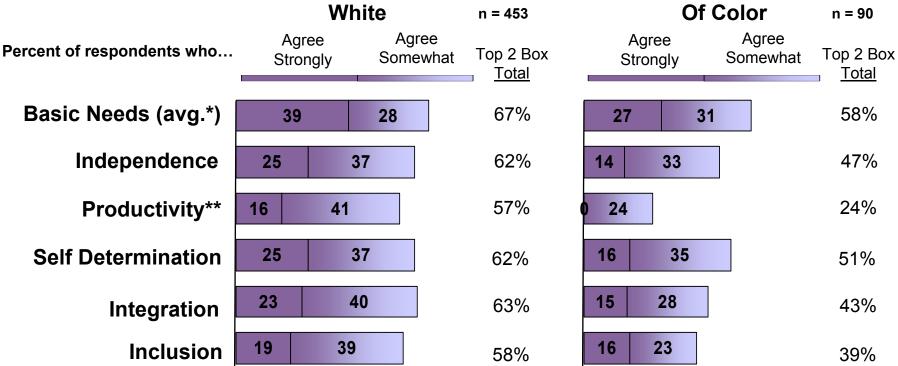
- :: Respondents who lived outside their parents' home were much more positive about their current situation. Factors which may be contributing to this are that people living outside their parents' home are much more likely to:
  - :: be over 19 years of age
  - :: have a job or volunteer, and
  - :: be of white/European descent,

all of which were identified as leading to more positive responses.

<sup>\*\*</sup>Smaller sample of respondents weighted to represent total survey sample



### **Ethnicity of the Individual with a Developmental Disability**



<sup>\*</sup>Average of 6 basic needs statements

- :: Respondents of white/European descent were much more positive about their current situation than respondents of other ethnic backgrounds. Factors which may be contributing to this are that respondents of white/European descent were also more likely to:
  - :: be over 19 years of age, and
  - :: live outside of parents' home,

both of which were identified as leading to more positive responses. It is also important to consider that households of white/European descent have a higher median and average income, according to 2000 census data--providing them with more means to satisfying their needs.

<sup>\*\*</sup>Smaller sample of respondents weighted to represent total survey sample

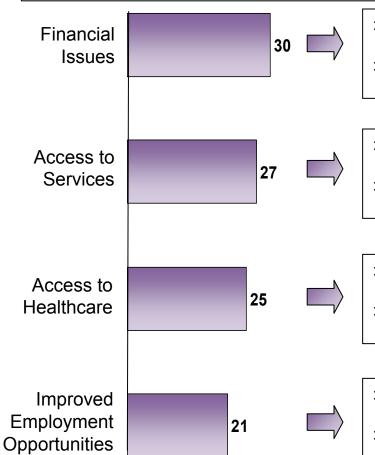
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5:: critical improvements

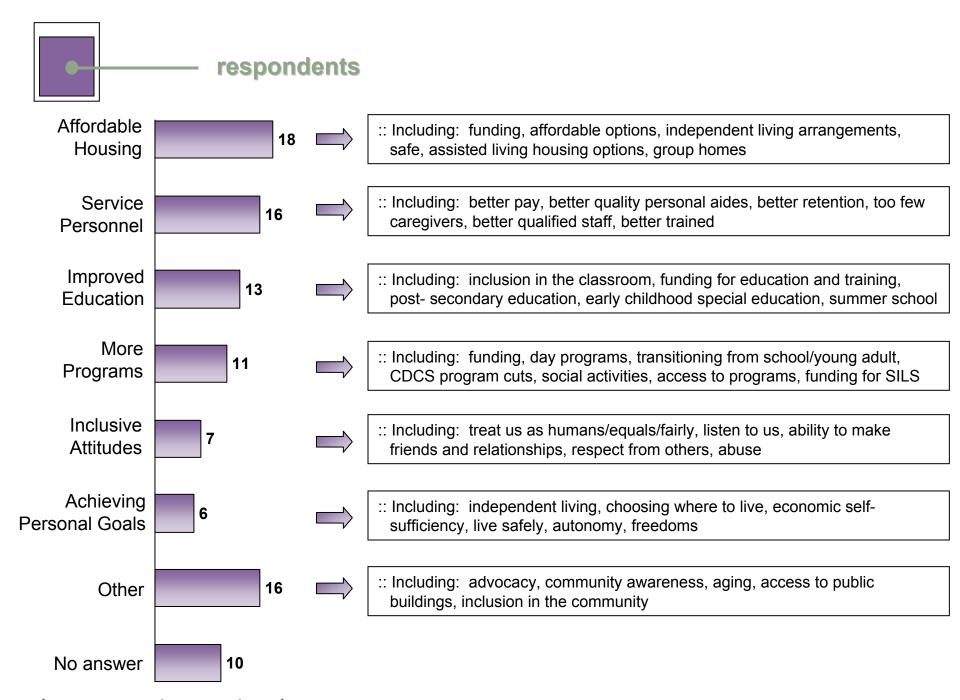


### most critical issues

Open-ended question where respondents were asked to identify the most critical issues that Minnesotans with developmental disabilities will face in the next years.



- :: Including: funding cuts, increased cost of healthcare, insurance, money issues.
- :: This was more important to family and friends, etc. (33%) than those with a disability (21%)
- :: Including: transportation, recreational opportunities, cuts in waiver services, access to waivers
- :: This was more important to individuals with severe disabilities (29%) than those with less severe disabilities.
- :: Including: access to quality/appropriate health care, affordable healthcare, medications, and therapies
- :: This was more important to people in greater Minnesota (31%) than in the Twin Cities Metro Area (21%).
- :: Including: better jobs, more places to work, equal opportunities, funding for job supports and training, fair pay and living wages
- :: This was more important to people who volunteer (30%) than those that neither work nor volunteer (14%).
- :: Many of the stated concerns related to funding cuts, accessibility to resources—both financial and human—and better opportunities for employment and interaction.



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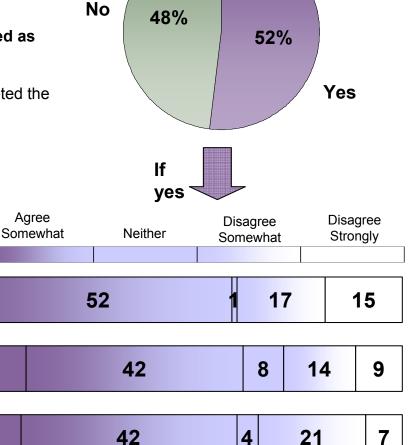
6:: family support



Are you currently receiving any family support services (defined as services that keep the family together)? n=206\*

\*Question only asked of parent or other family member who completed the survey on behalf of an individual with a developmental disability.

n = 108 (those families that receive family support services)



Percent of respondents who...

The types of services our family needs are available to us.

Services are provided by qualified and competent staff.

Our family receives enough support to keep the family together.

:: Less than half of respondents receive any family support services.

:: Of those receiving family support services, most agree that the types of services they need are provided by competent staff, and that they receive enough services to keep their families together.

Agree

Strongly

15

27

26

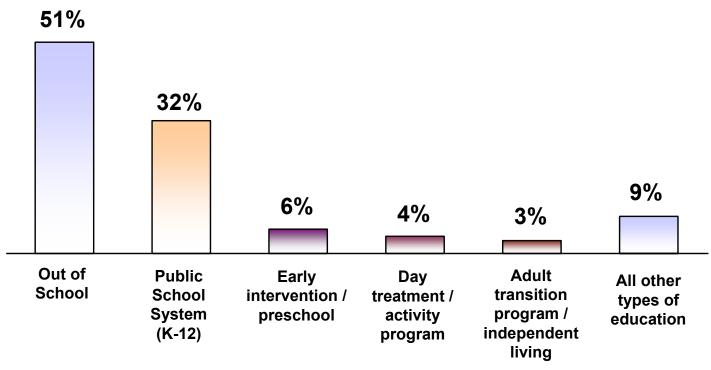
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7:: education



What type of education program are you currently enrolled in?

n = 541



Note: Multiple responses allowed.

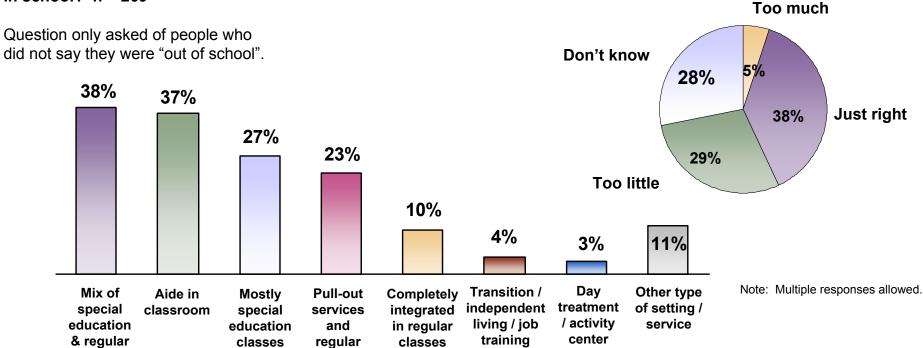
:: Over half of respondents reported being out of school.

:: Of those enrolled in school most reported attending public school.



What type of education setting or service(s) do you currently receive in school? n = 269

How do you feel about the amount of time you spend in regular classes? n = 261



:: Of those respondents currently in school, the most common education settings were a mix of special education and regular classes, having an aide in the classroom or mostly special education classes.

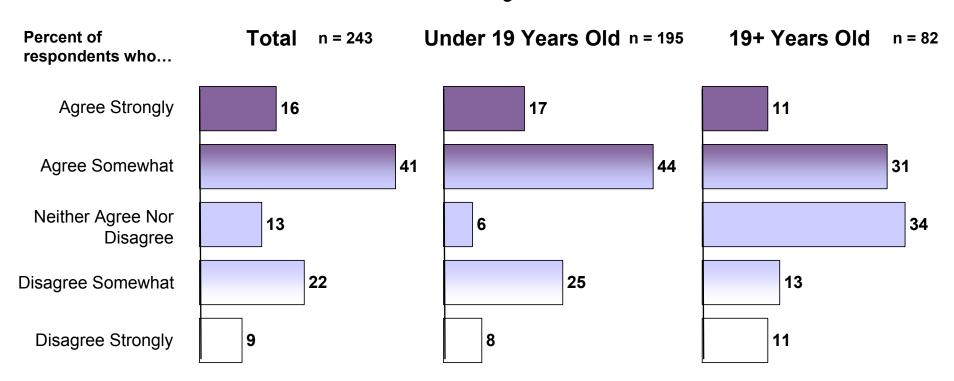
classes

:: Individuals reporting more severe disabilities were much more likely to be in mostly special education classes, and/or have pull-out services and regular classes. They were also more likely to say that they spend too little time in regular classes.

classes



I am satisfied with the education I am receiving:



- :: Respondents under 19 were more satisfied (agree strongly/somewhat) with their education (61%) than respondents 19 and older (42%).
- :: Individuals with less severe disabilities (56%) agreed strongly or somewhat with "I am satisfied with the education I am receiving" than those individuals with moderate or severe disabilities (53%).



## education by degree of disability

### School system:

% in public school system

### Classroom setting:

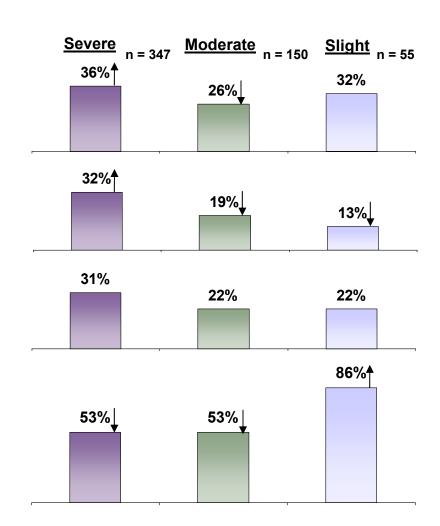
Mostly special education classes

#### Time:

I spend too little time in regular classes

#### Satisfaction:

I am satisfied with the education I am receiving (strongly/somewhat agree)

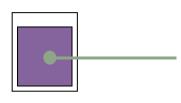


:: Individuals with more severe disabilities are more likely to attend public school, be in special education classes, and be less satisfied with the education they are receiving.

↑ Indicates statistically significant difference from other values in row at the 95% confidence level

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8:: comparison with 2000 study



### comparison with 2000 — methodology

The survey in 2000 was used as a benchmark for the 2005 study. However, in 2005 the recruiting and survey format were enhanced to increase the number of completes. The chart below describes the difference between the two studies:

Methodology	2005	2000
Recruiting	Through the service provider network (via phone) who then e-mailed the invitation to the Internet survey to individuals with developmental disabilities that they work with	Through the Partners in Policymaking graduates (via phone) who were then mailed multiple copies of surveys to distribute to individuals with developmental disabilities that they know
Survey format	E-mail invitation to Internet survey and mail option for those without Internet access	Mail
Survey language	English and Spanish (mail version only)	English
Total number of completes	n = 552	n = 300



### comparison with 2000 study – sample profile

Sample	Profile	2005	2000
Respondent Type*	Individual	19%	21%
	Other	84%	90%
Age	<19	36%	51%
	19+	64%	47%
Ethnicity*	White	88%	94%
	Black	6%	2%
	American Indian	4%	2%
	Hispanic	4%	***
	Asian	2%	1%
	Other	4%	3%
Employment	Job	45%**	42%
	Volunteer	36%	22%
	Neither	44%	46%

<sup>\*</sup>Multiple responses allowed.

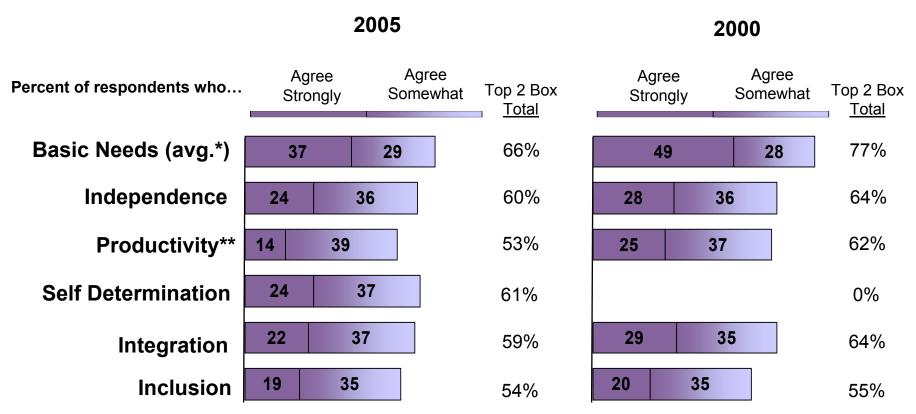
:: The 2005 study had more adults over age 19 participating in the study and higher ethnic minority representation.

<sup>\*\*</sup>Base includes respondents age 15 or older.

<sup>\*\*\*</sup>Not a specifically asked category in 2000.



### comparison with 2000 study - IPSII & basic needs satisfaction



<sup>\*\*</sup>Smaller sample of respondents weighted to represent total survey sample

:: Comparing the 2000 study to the 2005 study, it appears as though the ratings for the 2000 study were a bit higher. However, it is important to keep in mind the methodology and demographic differences between the two studies, which may be driving some of the differences.

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9:: summary



#### **IPSII** Evaluation

The most obvious result of this study is that there are huge differences in satisfaction with independence, productivity, self determination, integration, and inclusion (IPSII) within the total population of individuals with developmental disabilities in the State of Minnesota. If you are over 19 years of age, have a job or volunteer, have a less severe disability and are white, you are much more likely to be satisfied with your current IPSII.

These significant demographic differences suggest that the population of individuals with developmental disabilities should not be treated as a single entity. Big differences in satisfaction imply that policies and procedures designed to improve IPSII have had different effects on different segments of the population. Therefore, as an example, the State should consider different policies, procedures and possibly measurement criteria for individuals with developmental disabilities under age 19 when compared to adults.

Because we do not know what the true statistics of this population are, it is difficult to interpret the results at a total level; however it is clear that people are more satisfied with their current levels of Independence, Self Determination & Integration, than with their current levels of Productivity & Inclusion.

### **Productivity & Inclusion**

Whether an individual has a job or is volunteering appears to have a strong positive impact on his/her level of satisfaction with Productivity. There were significant differences in overall satisfaction with Productivity between the demographic sub groups; however when we only looked at individuals working or volunteering these differences diminished dramatically.

Inclusion received low overall satisfaction ratings driven by lower ratings on statements such as being treated as equals, being treated with respect, and having opportunities to develop friendships with individuals who do not have a developmental disability.



### Independence, Self Determination & Integration

Independence, Self Determination & Integration rated better than the other IPSII measures. Information access, privacy issues and mobility were rated relatively highly as aspects of Independence that are being met; while housing options and being able to choose one's provider and staff received lower ratings.

With regards to Self Determination aspects, self expression (decorating living space and personal presentation) received the highest ratings; while control over services spending and who individuals live with received the lowest ratings.

Opportunities to make friends with people who do not have disabilities and to do things with people their own age received the highest levels of agreement for Integration. Availability of resources and personal support in their community as well as an acknowledgement of rights to equality received the lowest levels of agreement.

### **Community and Basic Needs**

The majority of respondents agreed that their community is a good place for people with developmental disabilities to live and that it is getting better. That said, however, some individual basic needs require real improvement.

While most people agreed that they feel comfortable and safe where they live and that they have access to the healthcare that they need; the majority of people with developmental disabilities in Minnesota do not feel that they have enough money to live on, are unsure about their security in the future, and don't know what to do if their health or safety is in jeopardy. These and other similar basic needs should be addressed together before people can substantially improve their independence, productivity, self determination, integration, and inclusion (IPSII).



### **Family Support**

This survey included a couple of questions related to family support. We found that less than half of the parents or other family members that participated in this survey receive any family support services. Of those receiving family support services, most agree that the types of services they need are provided by competent staff, and that they receive enough services to keep their families together.

#### **Education**

Of individuals still in school, those individuals with less severe disabilities were more satisfied with the education they were receiving than those with more severe disabilities. Individuals reporting more severe disabilities went to public schools more often, were likely to be in mostly special education classes, and/or have pull-out services and regular classes, and were also more likely to say that they spend too little time in regular classes.

### **Critical Improvements**

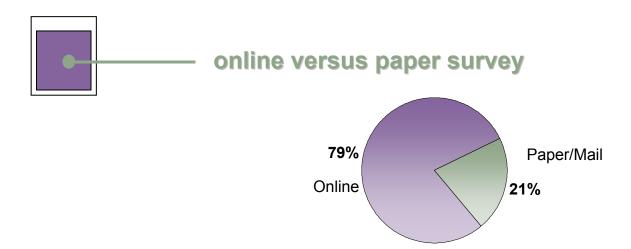
We asked respondents to identify the most critical issues that Minnesotans with developmental disabilities will face in the next five years. Many of the stated concerns related to funding cuts, accessibility to resources—both financial and human—and better opportunities for employment and interaction.

The top responses were related to:

- financial issues (i.e. funding cuts, increased costs of healthcare and insurance, and money issues),
- access to services (i.e. transportation, recreational opportunities, cuts in waiver services, access to waivers),
- access to healthcare (i.e. access to appropriate, affordable, quality healthcare, medications and therapies), and
- improved employment opportunities (i.e. better jobs, more places to work, more and equal opportunities, funding for job supports and training, fair pay and living wages).

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10:: appendix



Respondents were recruited via e-mail invitation from a service provider contacted by GCDD or MarketResponse. The majority of these respondents completed the survey online. A few individuals called the toll free number and requested a paper version. Some providers requested that we send multiple copies of the mail version, which they could distribute in person. Similarly, one provider in the Hispanic community requested the Spanish paper version. We did not receive any other calls for a Spanish version of the survey.

We looked at the differences between the online responses versus the paper responses. There were some significant differences, however since the demographics between the groups were very different, we cannot say whether the response differences were due to the technological capability/availability or other reasons.

Originally, we offered the paper version for people that do not have access to the Internet. In the end, the majority of the requests for the paper version came from providers who didn't have e-mail addresses for their clients – so we don't know whether the respondents had internet access or not. Also, nearly all the Hispanic respondents (68%) were by mail because we only offered the Spanish survey on paper. We do not know how many of those respondents might have completed a Spanish version online. Therefore, we do not recommend that specific conclusions be drawn based on the format of the survey.



### **Recommendations for future surveys**

Our recommendation for future surveys is to offer all quantitative studies on the Internet. It is a very efficient and effective way of collecting data. Respondents tend to be more responsive because it requires less effort than completing and returning a mail survey. Additionally, we have over 200 new e-mail addresses of people that have agreed to participate in future studies. With the help of GovDelivery, GCDD is building a sample list of e-mail addresses, which will be a useful base for future Internet research studies.

However, GCDD and MarketResponse are dedicated to ensuring that the survey is accessible to everyone possible. Therefore, a mail survey option is very important.

#### Other recommendations include:

- :: Consider offering the Spanish survey online or at least let people taking it online know that there is a Spanish paper version available
- :: Consider offering the survey in other languages to accommodate other communities such as Hmong or Somali
- :: Attempt to validate the e-mail addresses (i.e. ask respondents to enter their e-mail address twice)
- :: Offer mail respondents the opportunity to share their e-mail address for future research
- :: Attempt to obtain statistics that represent the true population of individuals with developmental disabilities within the state of Minnesota across important demographic subgroups (i.e. age, level of disability, and ethnicity) in order to weight the results to be projectable to the total sample.
- :: 'Family Supports' as defined did not appear to be understood by respondents and should be explained in more detail in future studies.