

Quality of Life Assessment Survey

Prepared for:

Minnesota Governor's Council on
Developmental Disability

Conducted by:

MarketResponse **International**

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I. MANAGEMENT SUMMARY

I. MANAGEMENT SUMMARY

Overall IPII Satisfaction

- Three of five respondents agree to being satisfied with their levels of IPII.
- People are least likely to be satisfied with their level of Inclusion.
- Graduates of the Partners in Policymaking™ program are overall less satisfied with their IPII, than non graduates.

Independence

- Independence is more tangible for people than the other IPII dimensions. Many of the aspects that drive feelings about Independence, such as **Mobility** and **Information Access**, could be objectively measured.
- People with mild developmental disabilities felt they had more **Control of their Destiny** than those with moderate or severe disabilities. Consequently, this group had a more positive rating on Independence.

Productivity

- Adults had higher ratings on productivity than minors. As people develop **Skills** and are given **Responsibility** both at home and where they work or volunteer, their ratings on Productivity improve.
- When people feel they are being **Recognized** for their achievements, especially in school and at home, their ratings on Productivity improve.
- There appears to be opportunities for enhancing the productivity of the population with developmental disabilities: some who currently work would prefer to work more hours; and some who are currently unemployed would like to have a job.

I. MANAGEMENT SUMMARY

Integration

- Integration within a community sometimes involves breaking down barriers. When people with disabilities have the **Resources** they need, their ratings on Integration improve.
- When people with developmental disabilities are **Treated as an Equal**, their rating on Integration improve.

Inclusion

- Satisfaction with Inclusion was rated the lowest, and appears to have potential for the most improvement.
- Inclusion is the most subjective area for people. It is a measure of their feelings about **Relationships, Equality** and **Respect**. As people feel better about these aspects their ratings on inclusion become higher.

Education

- Almost all respondents currently in school attend public schools.
- One of four parents/advocates feel their child spends too little time in regular classes.
- Almost one-third of parents/advocates feel their concerns are neither addressed promptly nor professionally by their school.

Government

- All levels of Government - County, State and Federal - received low ratings on their performance as it relates to people with developmental disabilities.
- Many people find the process of learning the government system - in order to get assistance - confusing and time consuming.
- Graduates of the Partners in Policymaking™ program were less satisfied with government than non-graduates.



II. PROJECT OVERVIEW

II. PROJECT OVERVIEW

- Background, Objectives and Methodology -

Background

By order of the Developmental Disabilities Assistance and Bill of Rights Act, each state was granted the authority to create a Developmental Disabilities Council. For the past thirty years, the Minnesota Council 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 Council this segment of the population strives to be “treated as people first”.

The Self-Advocacy Movement (1980-present) has redefined the “disability problem” 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 Minnesota Council’s charter is to assure that individuals with developmental disabilities receive the necessary support to achieve increased independence, productivity, integration and inclusion (IPII) in the community.

Objectives

The Minnesota Council conducted a quality assessment in 2000, to determine how people with developmental disabilities evaluate the quality of services they receive from the array of service providers, and what obstacles they may face in their day to day living. Additionally, the Council intends to conduct reevaluation research on a regular basis to measure if conditions are improving statewide for people with developmental disabilities. In order to successfully implement the research, three areas of questioning needed to be fully addressed:

1. How are Minnesotans, who have developmental disabilities, being treated in their day to day life? Are they being “treated as people first”? Do they perceive there are adequate opportunities for increased independence, productivity, integration and inclusion?

II. PROJECT OVERVIEW

- Background, Objectives and Methodology -

2. How satisfied are the people, who have developmental disabilities, with the products and services being provided by government agencies and their suppliers? What does government need to do in order to improve its service and support for the this population?
3. Are there distinct segments (subgroups) of this population, who have developmental disabilities, with unique needs and circumstances, which may require different approaches and/or “service packages” from the Council and other service provider agencies?

Methodology

The following research design was used in order to define a benchmark that will be used by the Minnesota Council to gauge how people with developmental disabilities statewide perceive the level of services being provided by government agencies and their suppliers. Our three phase process is summarized below.

Phase 1: Designing a comprehensive measurement instrument

- First we conducted background research using past studies, telephone logs and insight that the Council members had, to design a draft of a comprehensive measurement instrument.
- Next we pilot tested the questionnaire during eighteen (18) one-on-one interviews among people with developmental disabilities and family/care givers, either at their residence or a convenient location. Interviews lasted up to 2 hours. These interviews ensured that the questionnaire addressed all of the relevant issues for measuring IPH of this population. Respondents represented a broad spectrum of people with developmental disabilities in Minnesota.
- We interviewed: 13 Partners in Policymaking™ Graduates and 5 non-graduates; 8 people living in the Twin Cities metro area and 10 living outside the area; 6 people who have a developmental disability actively participated in the interviews.

II. PROJECT OVERVIEW

- Background, Objectives and Methodology -

Phase 2: Survey Administration - 2000

- Due to privacy issues we used a list of Partners in Policymaking™ graduates to aid in survey distribution. Almost 320 graduates statewide were contacted and of those 148 were available and willing to distribute approximately 1,200 survey packets to qualified respondents in their communities. Due to the holidays and other circumstances an estimated 950 surveys were actually distributed and received from mid-November until mid-December.
- 300 completed surveys were returned, which represents a 32% response rate.
- *In some cases, both a person with a developmental disability and someone close to them (such as a parent or care giver) 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.*

II. PROJECT OVERVIEW




- Respondent Profile -

The respondent profile clearly demonstrates the broad spectrum of people with developmental disabilities in Minnesota represented in this study.



Age of Person with Developmental Disability

| | Overall | Minor Less than 19 years | Adult 19 years or older | |
|---|----------------|-------------------------------------|------------------------------------|--|
| <i>Who is responding to this survey?</i> _____% | % | % | % | |
| Parent or family member | 76 | 94 | 57 | Nine out of ten surveys were completed by parents, family members or other care givers either on behalf of the person with the developmental disability or together with them. |
| Other primary care giver | 14 | 7 | 21 | |
| Person with developmental disability | 22 | 10 | 35 | |

What is the nature of your developmental disability? _____

| | | | |
|--------------------|----|---|--|
| _____ Autism | 14 | 20  | 7 |
| Cerebral Palsy | 27 | 28 | 26 |
| Epilepsy | 16 | 16 | 16 |
| Mental Retardation | 60 | 52 | 68  |
| Other | 41 | 47  | 35 |

The number of youth with autism was higher (20%) as compared to the adults (7%) represented in this research. Mental retardation was the most often mentioned disability among all survey respondents.

Note: Arrows ( ) indicate significant differences between means or percentages, at the 95% confidence level or more.

II. PROJECT OVERVIEW

- Respondent Profile -

Age of Person With Developmental Disability

| <i>What is the severity of your developmental disability?</i> | <u>Overall</u> % | <u>Age of Person With Developmental Disability</u> | | |
|---|---------------------|--|--|--|
| | | Minor Less than 19 years % | Adult 19 years or older % | |
| Net Mild | 17 | 14 | 20 | Eight of ten respondents were either moderately or severely developmentally disabled. |
| Net Moderate | 42 | 43 | 42 | |
| Net Severe | 41 | 43 | 38 | |
| <i>Where do you primarily live? _____</i> | | | | |
| With parents or family | 64 | 93 | 33 | Only one-third of adults with a developmental disability were living with parents or family. |
| Group home | 17 | 5 | 28 | |
| Own apartment or house, less than 24 hour supervision | 7 | 0 | 15 | |
| Own apartment or house, 24 hour supervision | 4 | 1 | 7 | |
| Other | 8 | 1 | 17 | |

Household Income

| | <u><\$35K</u> | <u>\$36 - 50K</u> | <u>>\$51K</u> |
|---------|------------------|-------------------|------------------|
| Overall | 51 | 18 | 31 |
| Minor | 24 | 27 | 49 |
| Adult | 79 | 9 | 12 |

For minors, the household income reported is for their family or legal guardian plus any government funding; whereas, the income for adults is likely to be their own income only. Eight out of ten adults reported an income less than \$35,000.

II. PROJECT OVERVIEW

- Respondent Profile -

AGE

- Fifty-four percent of respondents were **diagnosed at birth**, one-fourth were diagnosed before the age of two and the remainder were diagnosed thereafter.
- The **average age** of the person with the developmental disability was **twenty-two years old**.
- Only 17% were under ten years old, 35% were between 10 and 18 years old and almost half of those with a developmental disability were **over nineteen years old**.

WHERE THEY LIVE

- Respondents have lived in Minnesota for an average of 22 years.
- One third of our respondents **reside in the metro area** and the other two-thirds live outside of the Twin Cities metro area.
- Respondents from **fifty counties** are represented in this report.

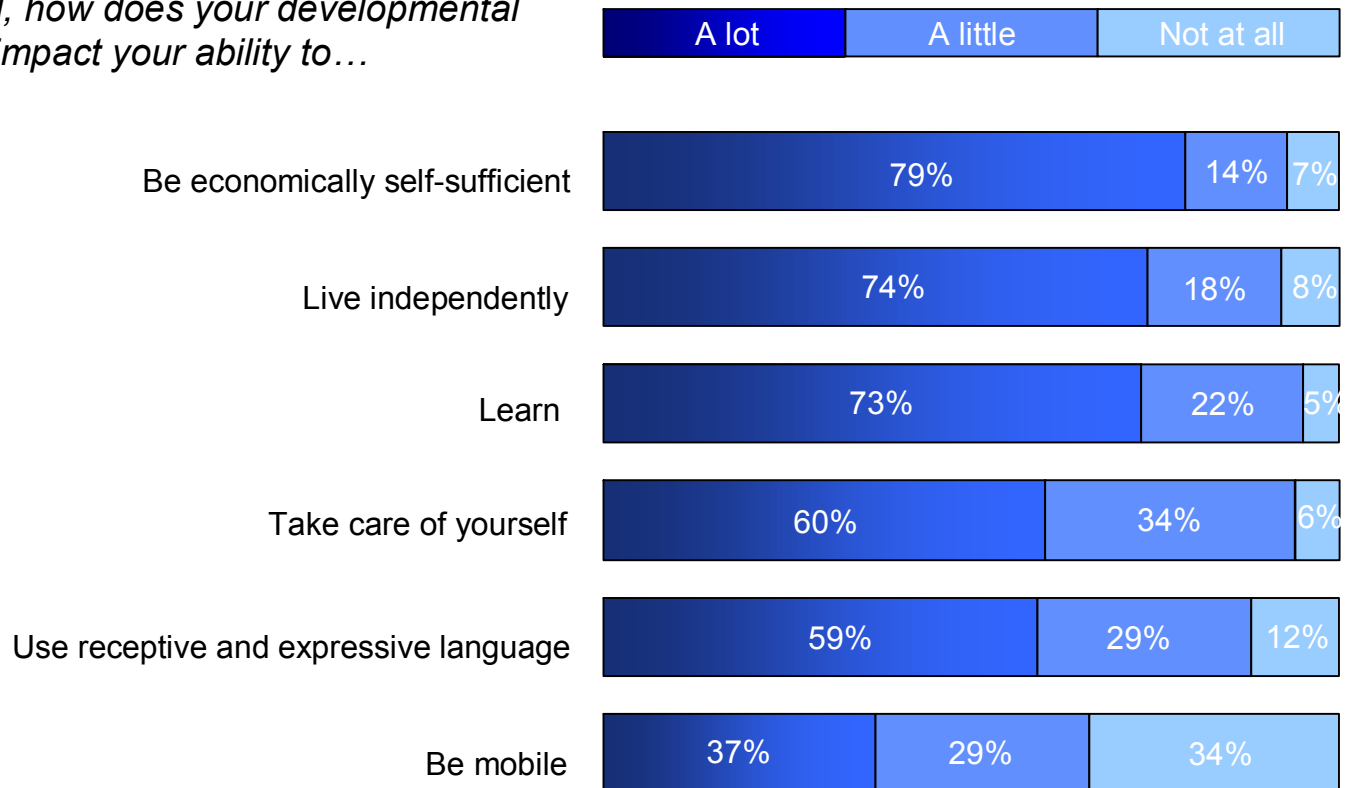
INCOME & RACE

- The household income of half of the respondents was under \$35,000. Eighteen percent (18%) have a household income between \$36,000 - \$50, 000 and 31% have a household income over \$51,000.
- Ninety-four percent (94%) of people with developmental disabilities participating in our study were white.

II. PROJECT OVERVIEW

- Respondent Profile -

In general, how does your developmental disability impact your ability to...



Being economically self-sufficient, living independently and learning are the most significant challenges for people with developmental disabilities. Of all the challenges listed above, mobility appears to be an area where (perhaps) most progress has been made to meet their needs.

III. DETAILED FINDINGS

A. IPII

B. Ratings of Education System

C. Ratings of Government

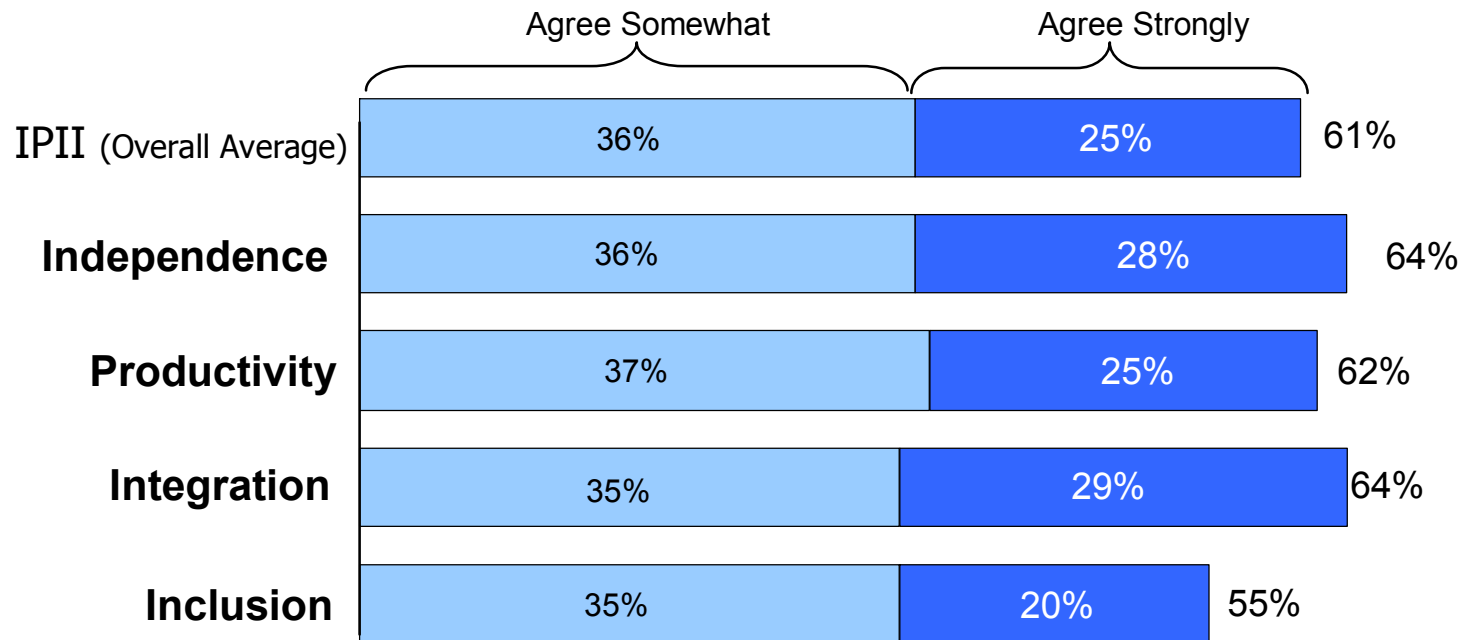
III. Detailed Findings

A. **IPII**

- Overall IPII Satisfaction
- Independence
- Productivity
- Integration
- Inclusion

Overall IPII Satisfaction

I am satisfied with my current level of...



People with a developmental disability were significantly more satisfied with their current level of *Independence* than their level of *Inclusion*. There are nearly as many people dissatisfied with their current level of *Inclusion* as satisfied.

Overall IPII Satisfaction

The values in the table are the percent of people who agree they are satisfied with their current level of IPII.

| | Partners in Policymaking™ | | Age | | Household Income | | |
|---------------------|---------------------------|---------------|--------|--------|------------------|----------|--------|
| | Graduates | Non-Graduates | Minors | Adults | <\$35K | \$36-50K | >\$51K |
| Independence | 57 ↓ | 69 | 55 | 74 ↑ | 74 ↑ | 56 | 53 |
| Productivity | 56 | 65 | 57 | 66 | 61 | 63 | 61 |
| Integration | 50 ↓ | 70 | 59 | 67 | 63 | 65 | 61 |
| Inclusion | 47 ↓ | 60 | 47 | 63 ↑ | 61 | 51 | 46 |

People with a developmental disability who are Graduates of the Partners in Policymaking™ program were significantly less satisfied with their current level of *Independence*, *Integration* and *Inclusion* than Non-Graduates of the program. At least half of the graduates were dissatisfied with their level of *Integration* and *Inclusion*.

The lowest income category, <\$35K, is highly skewed towards adults (80%). Thus, that group's IPII satisfaction ratings are almost identical to the 'Adults' category.

Note: Arrows (↑ ↓) indicate significant differences between means or percentages, at the 95% confidence level or more.

III. Detailed Findings

A. **IPII**

- Overall IPII Satisfaction
- **Independence**
- Productivity
- Integration
- Inclusion

In the fifth grade she started going to vo-tech to learn basic living skills. She now knows how to cook her own meals and take care of herself. She also knows when she should call for help.

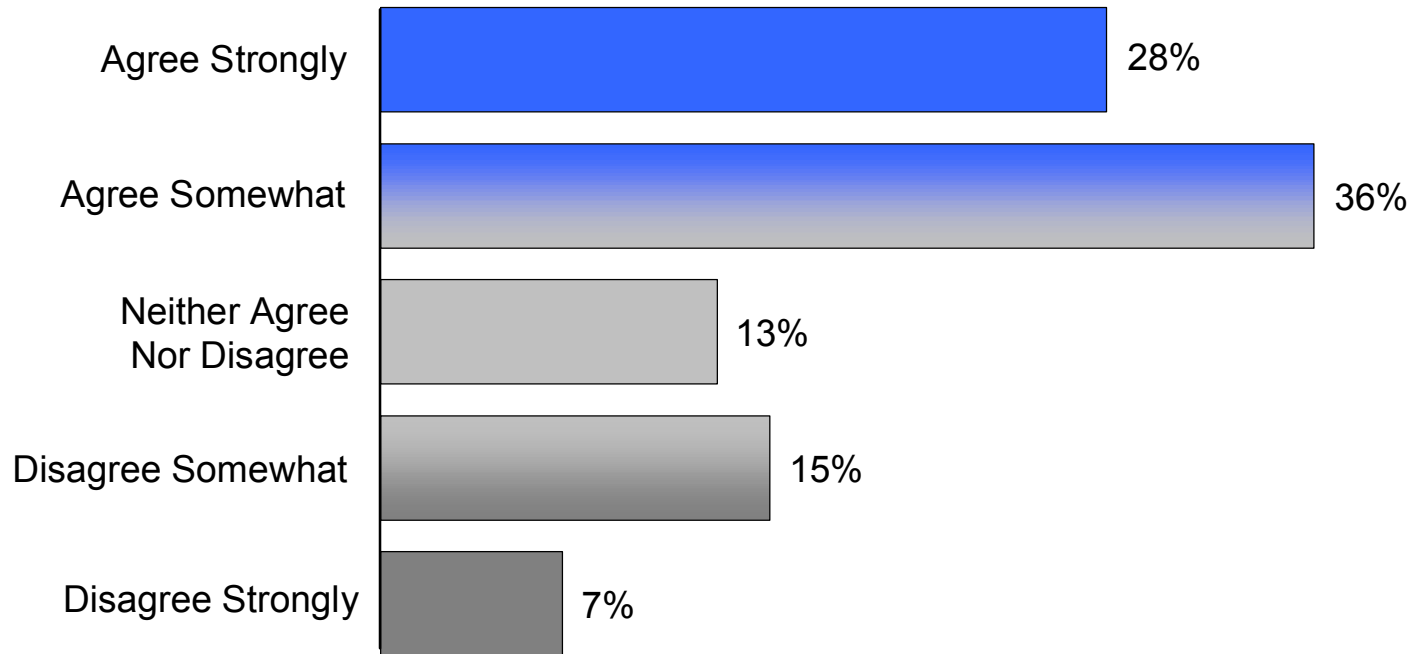
There is no way she is Independent. She is 18 years old, but she doesn't have a job and she can't drive.

I am my own guardian. This is very important to me.

Note: Quote(s) were obtained from parents and self-advocates during the qualitative interviews.

Satisfaction With Independence

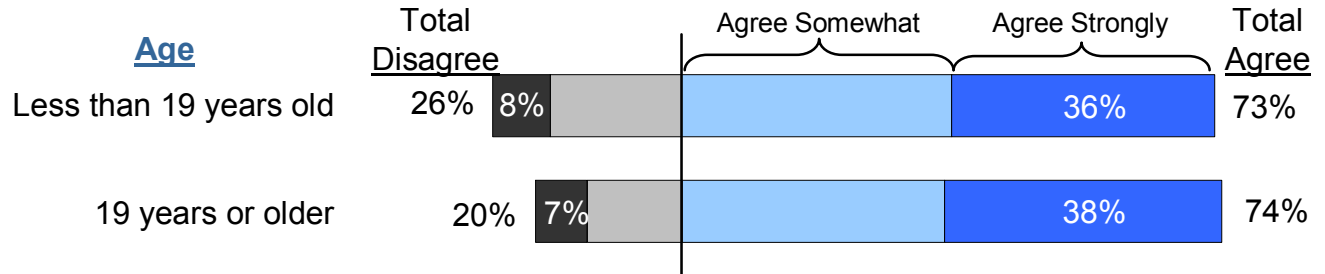
I am satisfied with my current level of Independence:



The survey indicates that 22% of the population of Minnesota, who have developmental disabilities, are clearly not satisfied with their current level of independence.

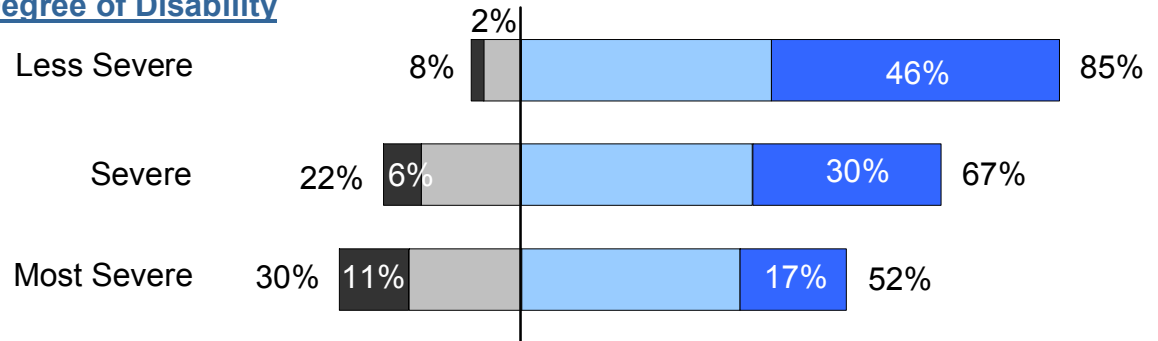
Satisfaction With Independence

I am satisfied with my current level of Independence.



Younger people with disabilities are more likely to say they are not satisfied with their current level of independence. This feeling may be in part a function of age. Among the adults with developmental disabilities, one in five are not satisfied with their level of independence.

Degree of Disability



Satisfaction with independence is related to degree of disability. Those with a more severe disability are over 3 times as likely as those with a less severe disability to say they are not satisfied with their level of independence.

Key Aspects of Independence

When comparing the level of overall satisfaction with detail questions on the survey, the key aspects in determining people's independence were as follows:

Mobility *I can (even if someone helps me because of my disability) go where I want to go.*

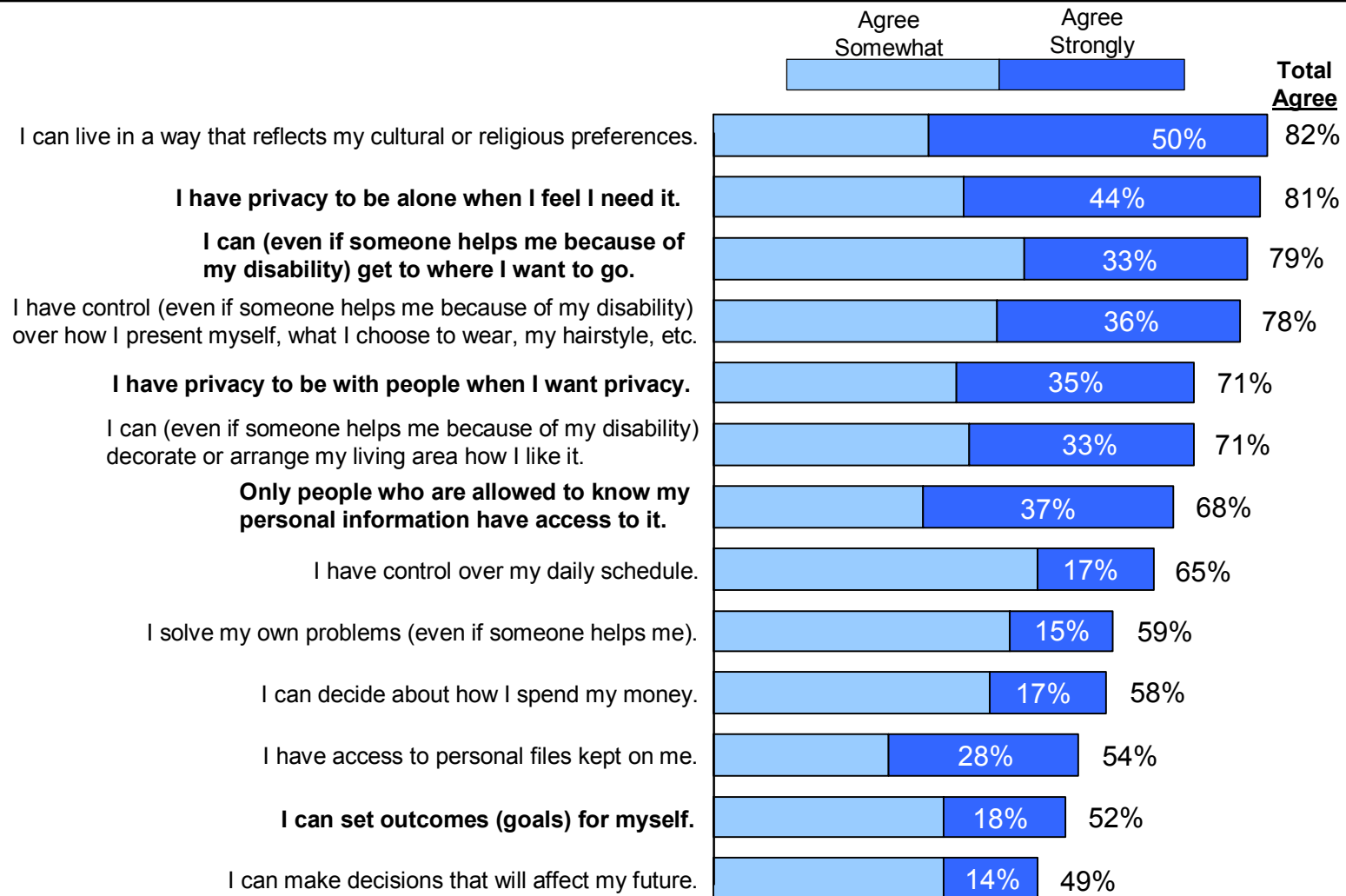
Privacy *I have privacy when I feel I need it.
I have privacy to be with people when I want privacy.*

Information Access *Only people who are allowed to know my personal information have access to it.*

Destiny - Control of the future *I can set outcomes (goals) for myself.*

The level of agreement respondents had with the statements above is closely related to how satisfied they are overall with their independence. People who strongly agreed with these statements are more likely to be very satisfied with their level of independence.

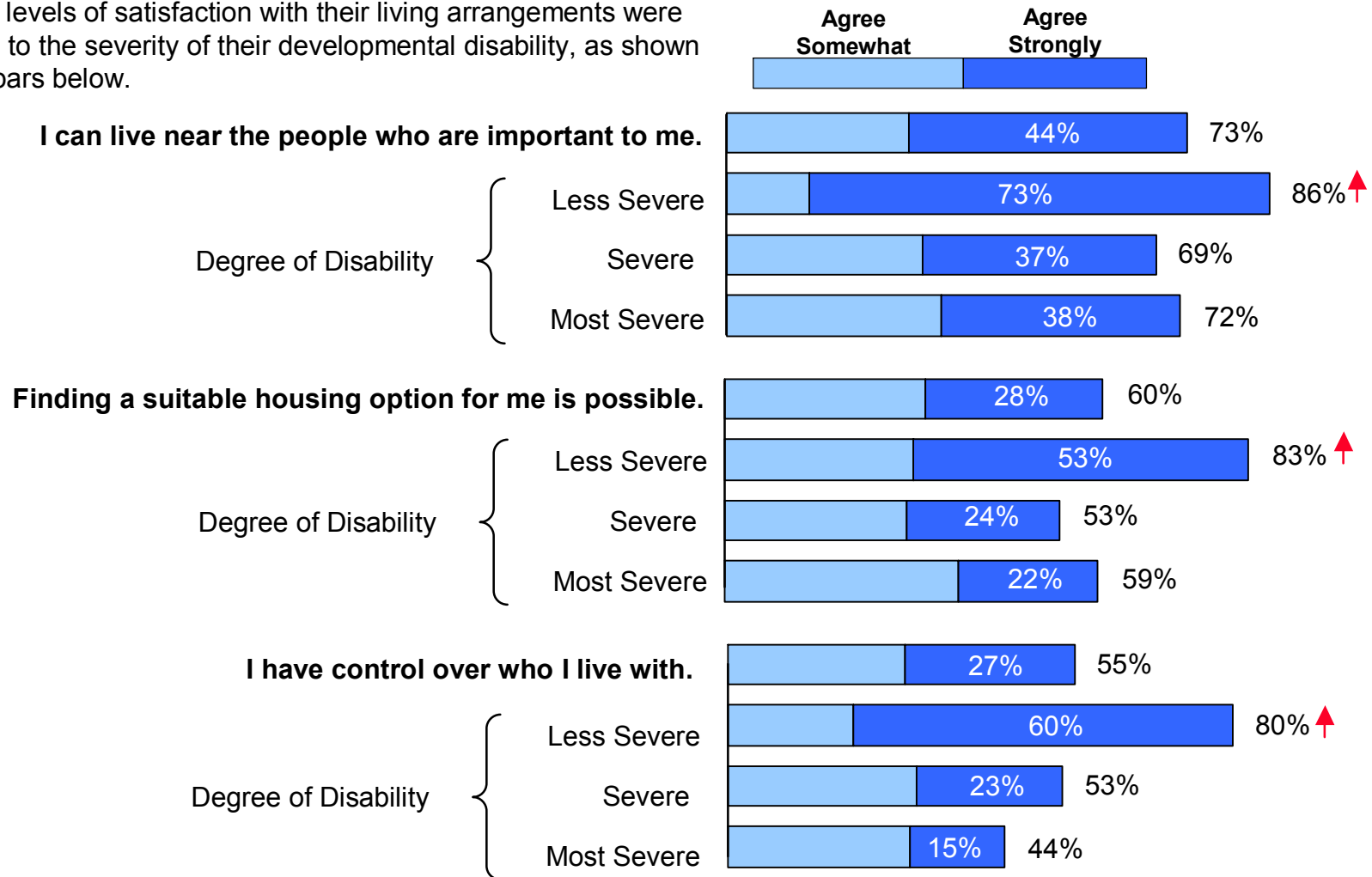
Attributes of Independence



There is room for improvement on these attributes of independence, especially on those lower on this list. The items in bold are key aspects of independence. Thus, helping people feel more *able to set outcomes (goals) for themselves*, represents a potentially more effective opportunity for improving overall satisfaction with their independence.

Attributes of Independence Specific to Adults

Adults' levels of satisfaction with their living arrangements were related to the severity of their developmental disability, as shown in the bars below.



Adults who assessed the level of their developmental disability as mild, were significantly more satisfied with their ability to find suitable housing and choose who they live near and with, as opposed to those with more severe developmental disabilities.

Note: Arrows (↑↓) indicate significant differences between means or percentages, at the 95% confidence level or more.

III. Detailed Findings

A. **IPII**

- Overall IPII Satisfaction
- Independence
- **Productivity**
- Integration
- Inclusion

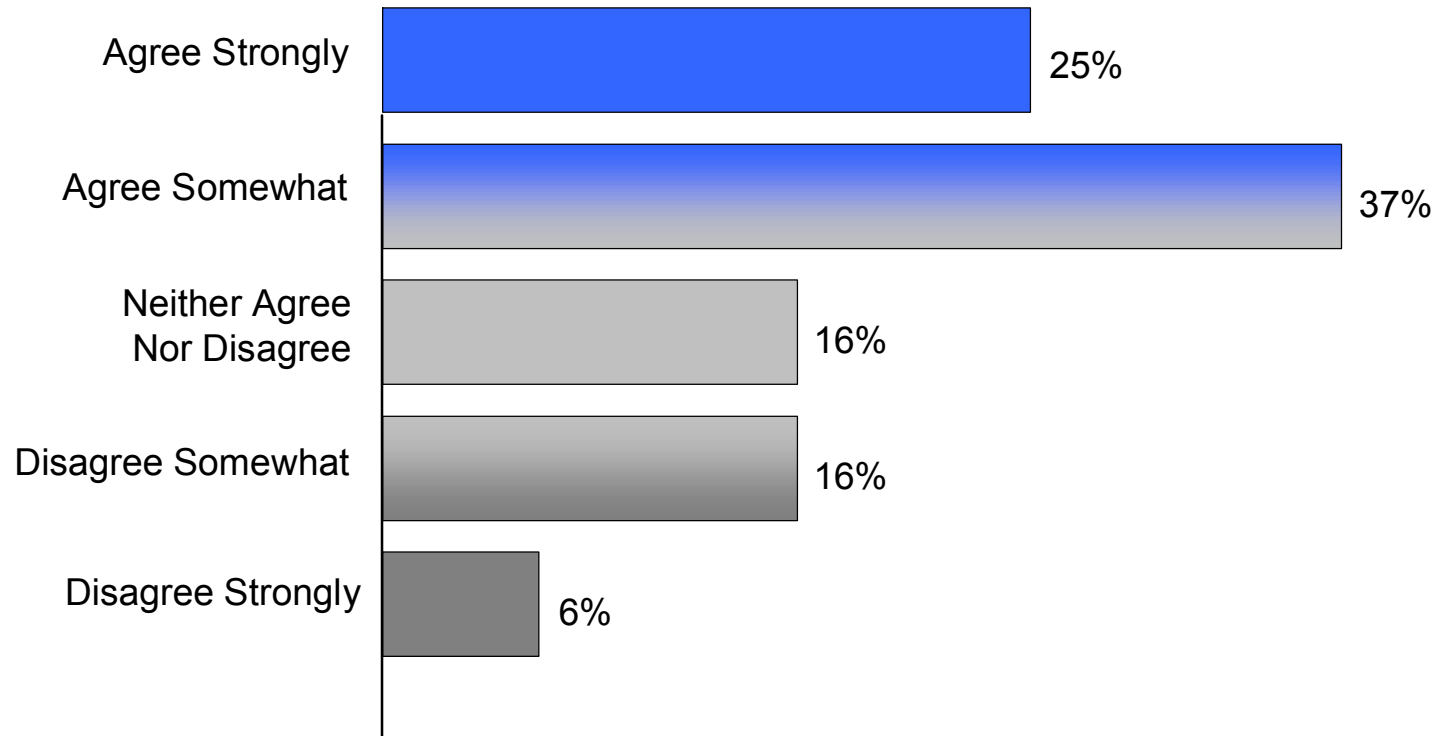
Everyone said you can't expect him to work because he is disabled. He didn't want to work at first, but now he is proud to bring home a paycheck.

My daughter does not like to do chores and unfortunately the staff at her group home often does everything for her. When she comes to my home she helps with the things I ask.

Note: Quote(s) were obtained from parents and self-advocates during the qualitative interviews.

Satisfaction With Productivity

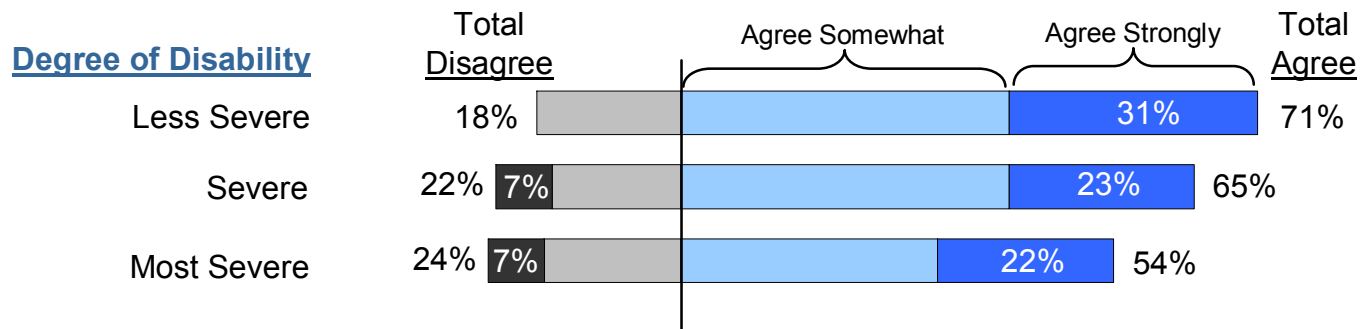
I am satisfied with my current level of Productivity:



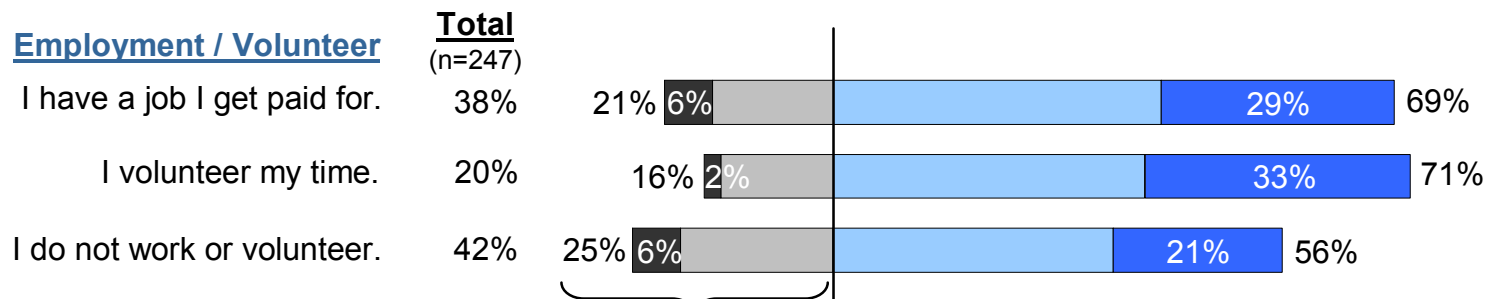
The survey indicates that 22% of Minnesotans with developmental disabilities are clearly not satisfied with their current level of Productivity. Some feel their potential to be productive is untapped.

Satisfaction With Productivity

I am satisfied with my current level of Productivity.



Satisfaction with productivity is related to degree of disability. Those with a severe disability are more likely than those with a less severe disability to say they are not satisfied with their level of productivity. These levels of dissatisfaction represent an opportunity for increasing productivity among the people who have developmental disabilities.



Opportunity!

Right now I work part-time at a toy store. I hope to work at a day care one day because I really love children.

Those working are very proud to be bringing home a paycheck even though some may not understand the concept of money. Many think the work that they do is important and they enjoy making friends in their community.

Key Aspects of Productivity

When comparing the level of overall satisfaction with detail questions on the survey, the key aspects in determining people's Productivity were as follows:

Overall

Skills *I have been improving my skills at home.*

Responsibility *I have an appropriate amount of responsibility at home.*

Recognition *I receive recognition for the things that I do.*

If working....

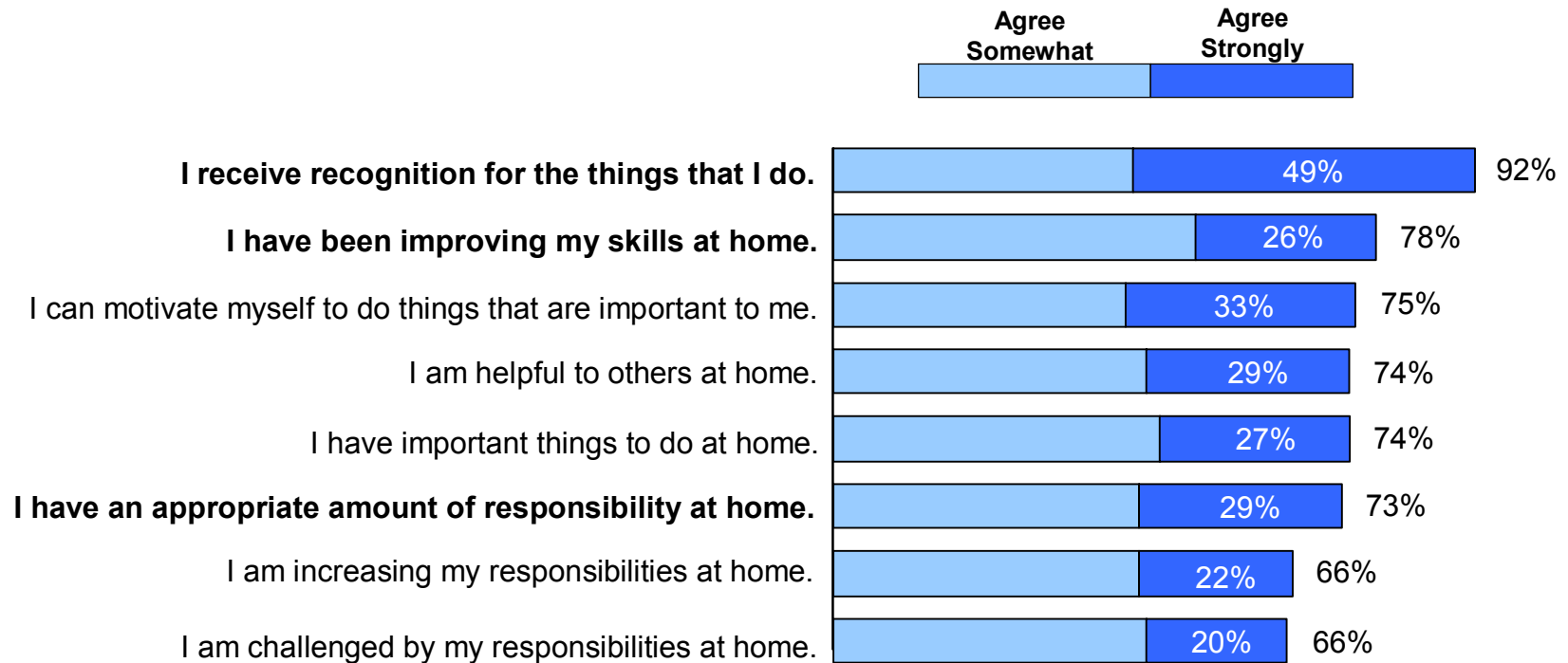
Reward *I am rewarded for the things I do.*

Challenged *I am appropriately challenged by my responsibilities.*

Skills *I have been improving my skills.*

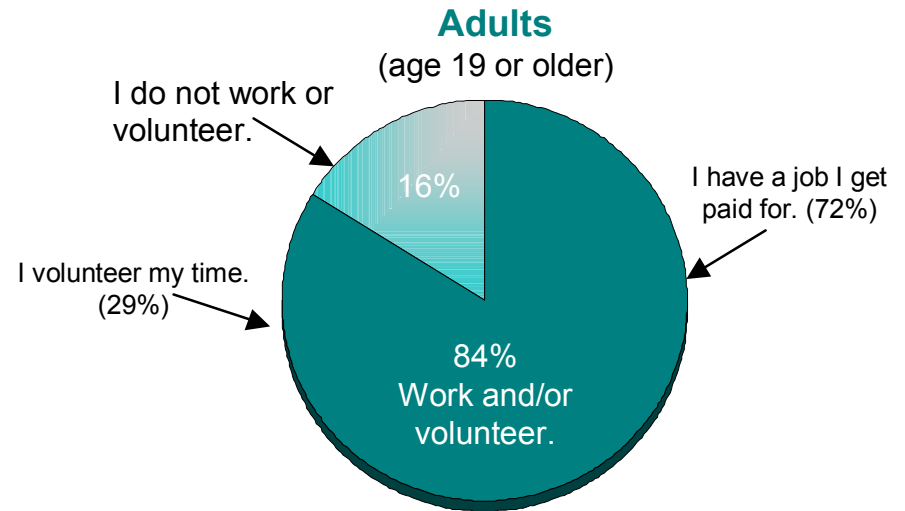
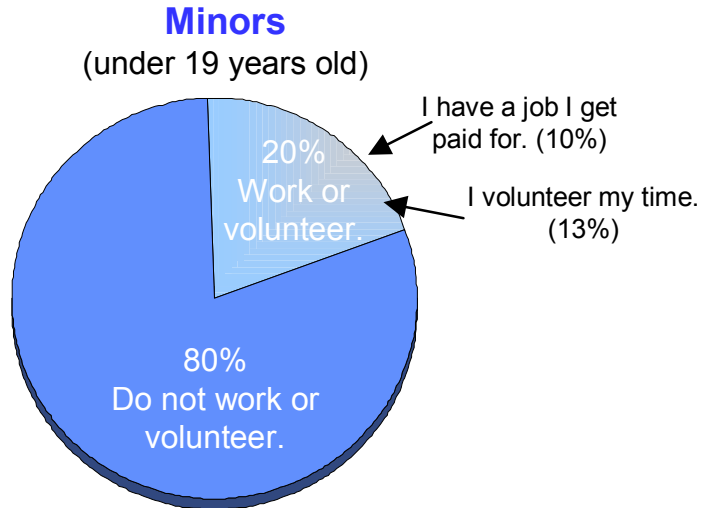
Among those who are working, either for a paycheck or volunteer hours, their satisfaction with productivity is driven by feelings of being rewarded, challenged and improving their skills. When looking at all of the respondents, including those who do not work, being responsible for things at home, getting recognition for helping out, and improving skills are the aspects most closely tied to overall productivity satisfaction.

Attributes of Productivity: At Home



Parents/guardians, of the people who have developmental disabilities, have some opportunity to improve feelings of productivity, without looking beyond their own doorstep. Productivity satisfaction can be enhanced by giving people with developmental disabilities an appropriate amount of challenging responsibilities around the home.

Productivity: People who Work or Volunteer



How many hours do you work/volunteer each week?

| | 5 hours or less | 6 - 10 hours | 11 - 20 hours | 21 - 30 hours | 31+ hours |
|---------------------------|-----------------|--------------|---------------|---------------|-----------|
| Overall (n=113) | 27% | 21% | 18% | 26% | 9% |
| Adults (n=93) | 21% | 20% | 21% | 30% | 11% |
| Minors (n=18) | 58% | | 37% | | 5% |

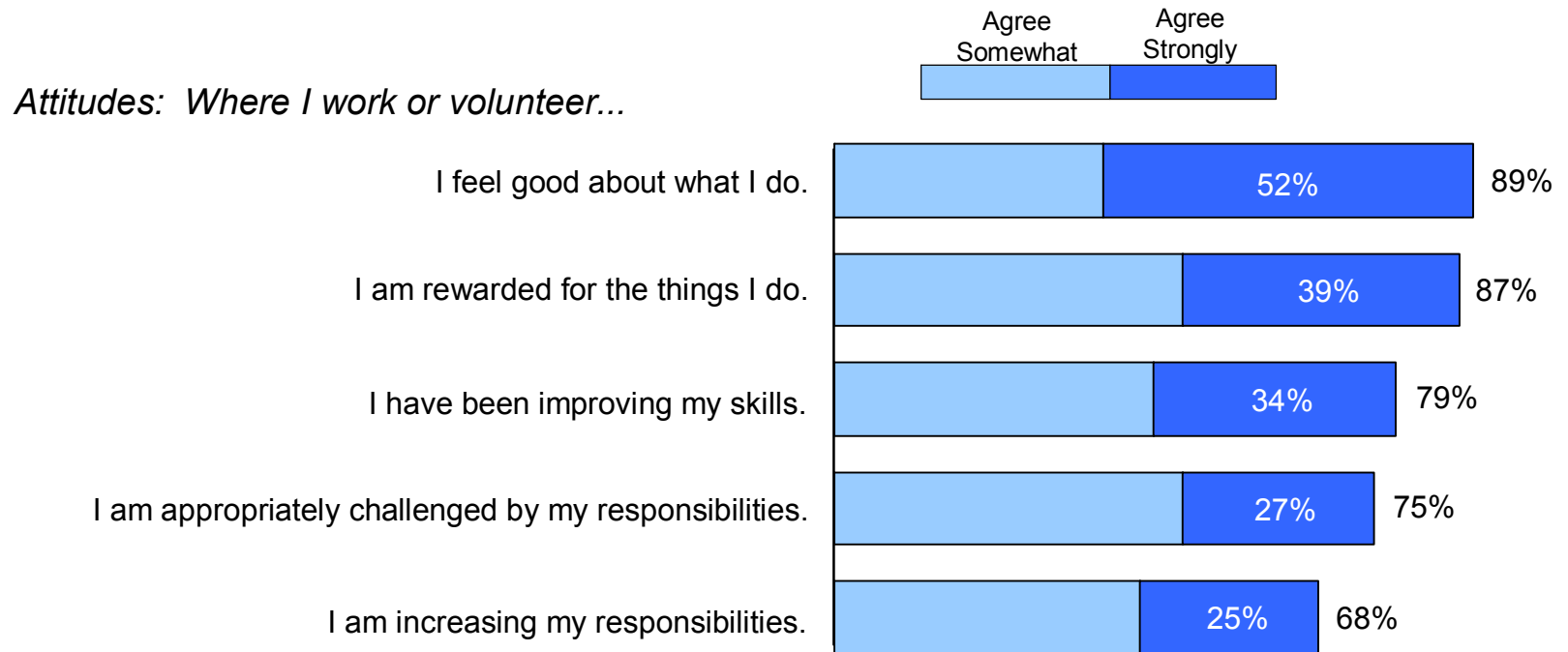
I work/volunteer:

| Weekly Mean Hours | Too Many Hours | Just Right # of Hours | Not Enough Hours |
|-------------------|----------------|-----------------------|------------------|
| 16 | 4% | 79% | 18% |
| 18 | 3% | 80% | 17% |
| 6 | -- | 78% | 22% |

Most adults have a job they get paid for and/or volunteer their time (84%). On average, they work/volunteer 18 hours a week, and 8 out of 10 say they work just the right number of hours. There may be an opportunity for greater productivity, as 17% of these adults would prefer to work/volunteer more hours than they do now.

Attitudes of Productivity: At Work or Volunteering

Attitudes of the people with developmental disabilities who work or volunteer. (n=130)



People with developmental disabilities who work or volunteer tend to feel good about what they do, and most believe they are adequately rewarded. There appears to be some more opportunity for improving skills, and increasing responsibilities and challenge.

III. Detailed Findings

A. **IPII**

- Overall IPII Satisfaction
- Independence
- Productivity
- **Integration**
- Inclusion

Integration

As a parent I wish my son had friends who don't have developmental disabilities, but I don't blame society when I realized that I (a person without disabilities) don't have any friends who have disabilities either.

Our daughter lives in a group home in a nice residential neighborhood, but she is still separated instead of integrated.

The more severely disabled you are, the less opportunity you have to be integrated.

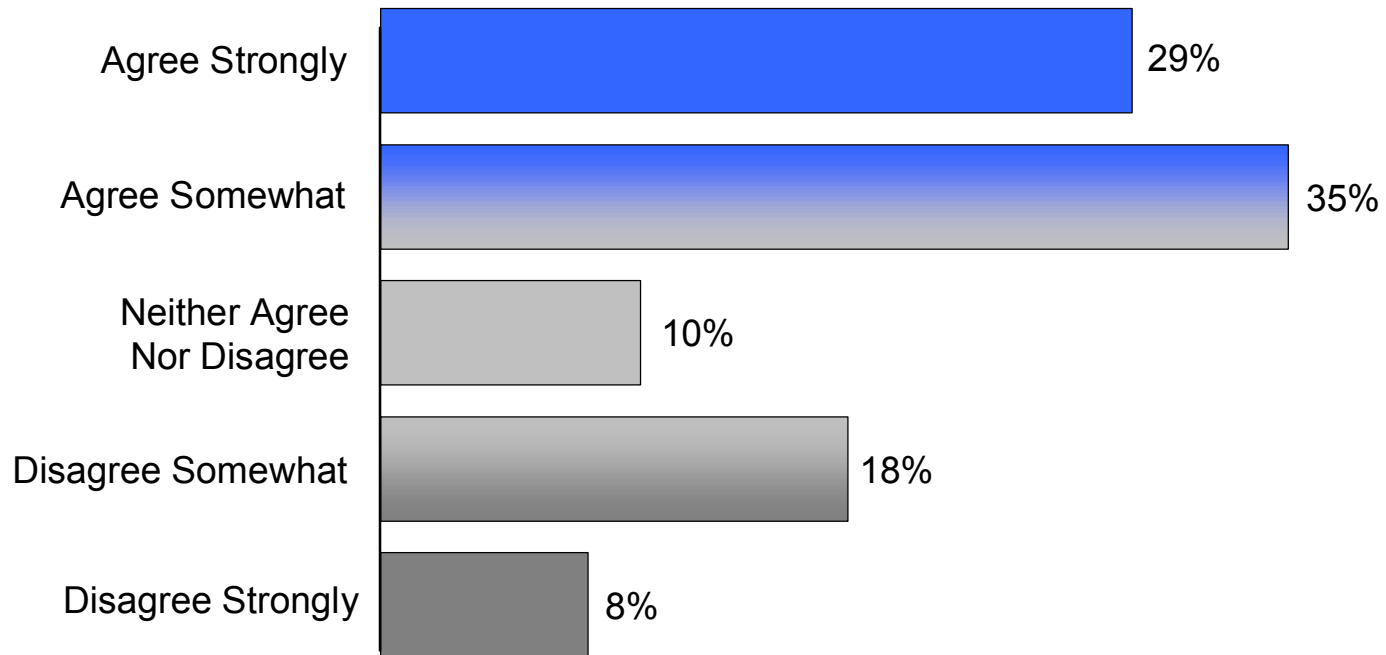
Even among the population of people with developmental disabilities there is segregation. People labeled as severely disabled, like my son, are segregated, but I know my son prefers to be around non-disabled people.

The people I work with at McDonald's are nice but they aren't my friends. My best friend is also developmentally disabled.

Note: Quote(s) were obtained from parents and self-advocates during the qualitative interviews.

Satisfaction With Integration

I am satisfied with my current level of Integration:



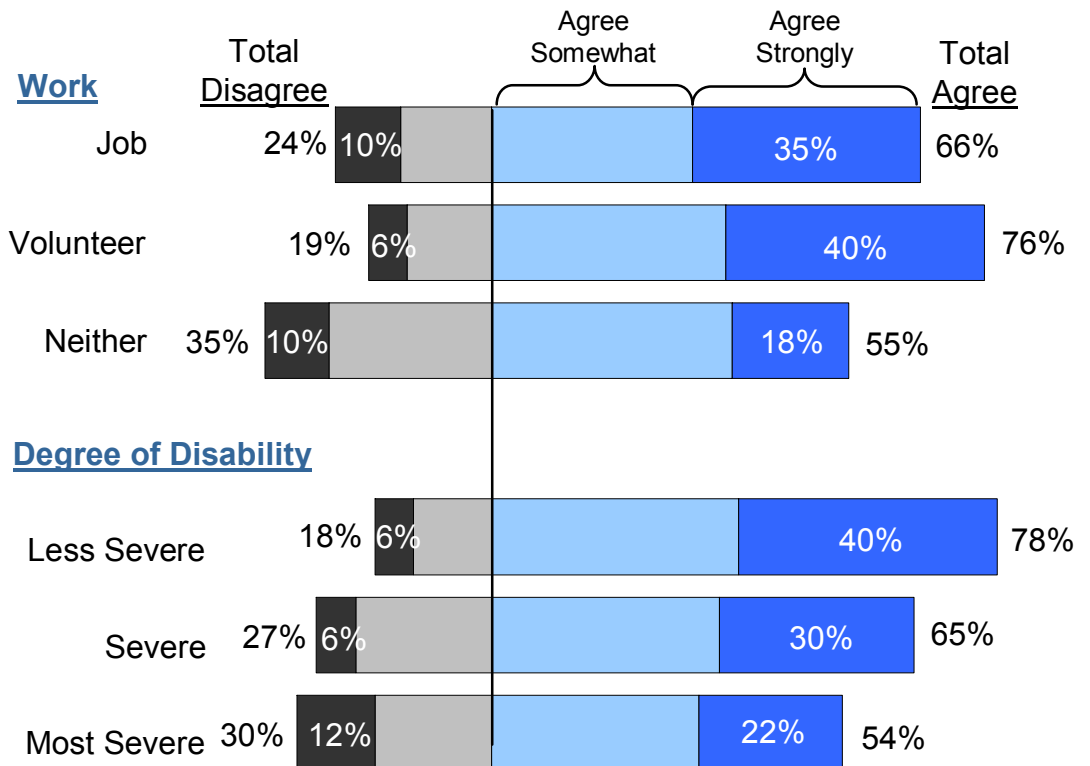
About one-fourth of respondents are not satisfied with their current level of integration. Integration is the first step for many people toward inclusion. As they participate in programs and activities - Integration - they are able to develop relationships and a sense of belonging - Inclusion.

Satisfaction With Integration

People who work or volunteer will sometimes have positions that allow them to interact with the general public; for example, working/volunteering in a restaurant, department store or daycare facility. These experiences add to their feeling of integration.

A person's level of integration is closely tied to the severity of their disability. People who assessed their disabilities as severe are sometimes separated from people without disabilities as well as those with less severe disabilities.

I am satisfied with my current level of Integration.



Key Aspects of Integration

When comparing the level of overall satisfaction with detail questions on the survey, the key aspects in determining a person's feeling of Integration were as follows:

Equality *My rights to equality are acknowledged by my community.*

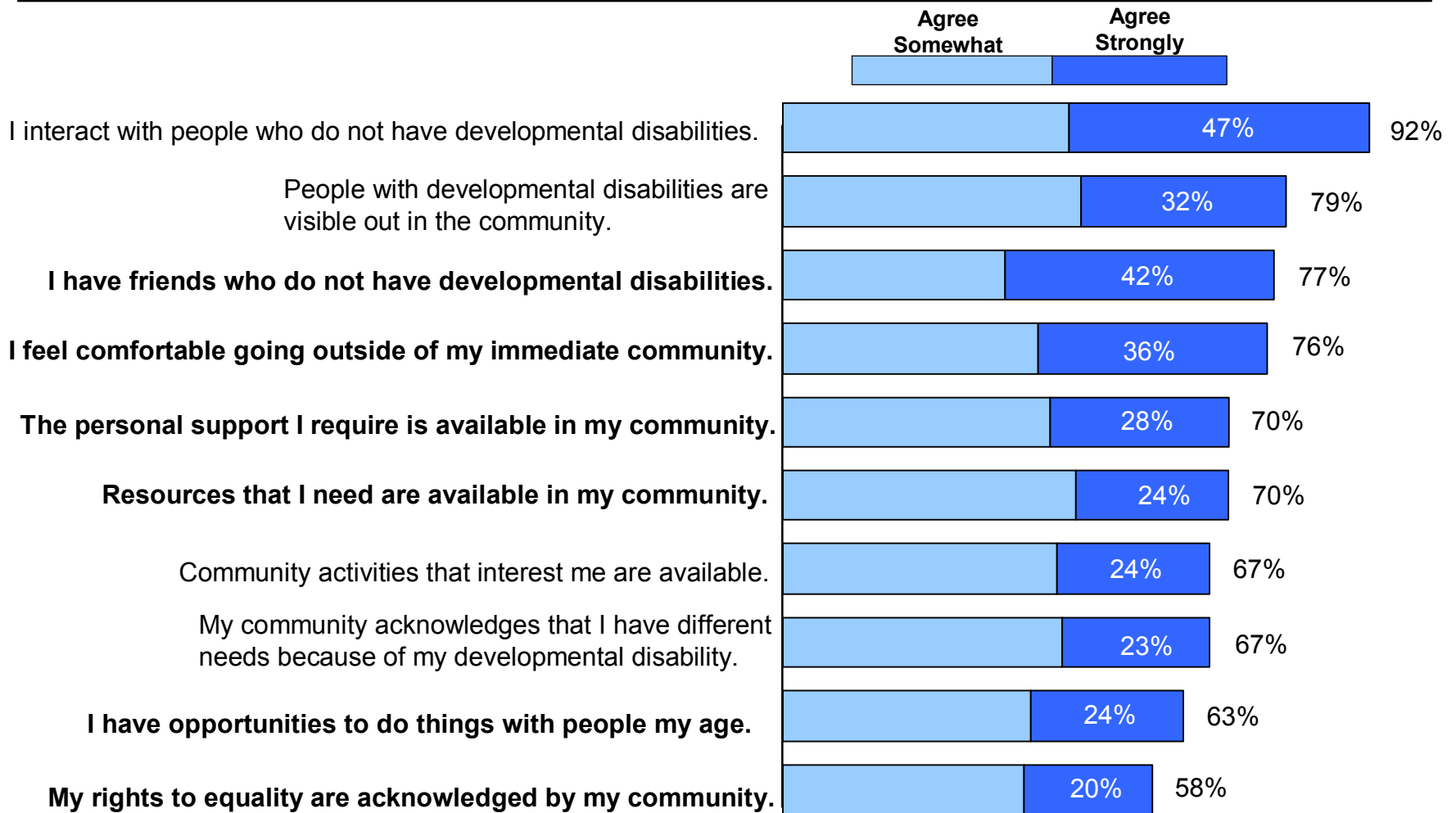
Resources *Resources that I need are available in my community.*

Friends *I have opportunities to do things with people my age.
I have friends who do not have developmental disabilities.*

Confidence & Support *I feel comfortable outside of my immediate community.
The personal support I require is available in my community.*

Being treated as an equal (a person without a developmental disability) and having the resources and support available to create and nurture relationships drive overall satisfaction with integration.

Attributes of Integration



People with developmental disabilities interact with people who do not have developmental disabilities, 92%. However, nearly 40% felt their rights to equality were not acknowledged by their community, an important aspect that drives overall satisfaction with Integration.

Attributes of Integration - Level of Agreement

The numbers below reflect the percent of respondents who either somewhat or strongly agree with the key aspects of Integration.

| | Job or Volunteer | | | Degree of Disability | | | Age | |
|---|------------------|-----------|---------|----------------------|--------|-------------|-------|-------|
| | Job | Volunteer | Neither | Less Severe | Severe | Most Severe | Minor | Adult |
| <u>Equality</u> My rights to equality are acknowledged by my community. | 67 | 64 | 48 ↓ | 74 ↑ | 57 | 50 | 50 ↓ | 64 |
| <u>Resources</u> Resources that I need are available in my community. | 78 | 82 | 60 ↓ | 78 | 72 | 65 | 61 ↓ | 79 |
| <u>Friends</u> I have opportunities to do things with people my age. | 71 | 74 | 50 ↓ | 86 ↑ | 64 | 51 | 56 ↓ | 69 |
| I have friends who do not have developmental disabilities. | 74 | 84 | 75 | 88 ↑ | 76 | 71 | 74 | 79 |
| <u>Confidence & Support</u> I feel comfortable going outside of my immediate community. | 82 | 86 | 68 ↓ | 88 ↑ | 77 | 70 | 71 ↓ | 81 |
| The personal support I require is available in my community. | 81 | 75 | 59 ↓ | 82 | 74 | 61 ↓ | 61 | 78 |

People who are working or volunteering feel more integrated with their community than those who are not, especially those with a less severe developmental disability. An equal number of people who assessed their disabilities as mild or moderate are working or volunteering. As people get older, they appear to feel more integrated.

Note: Arrows (↑ ↓) indicate significant differences between means or percentages, at the 95% confidence level or more.

A. IPII

- Overall IPII Satisfaction
- Independence
- Productivity
- Integration
- Inclusion

Our family stopped going to church as a family because people looked at us thinking we didn't know how to discipline our daughter. They didn't understand she has autism and we couldn't "control" her.

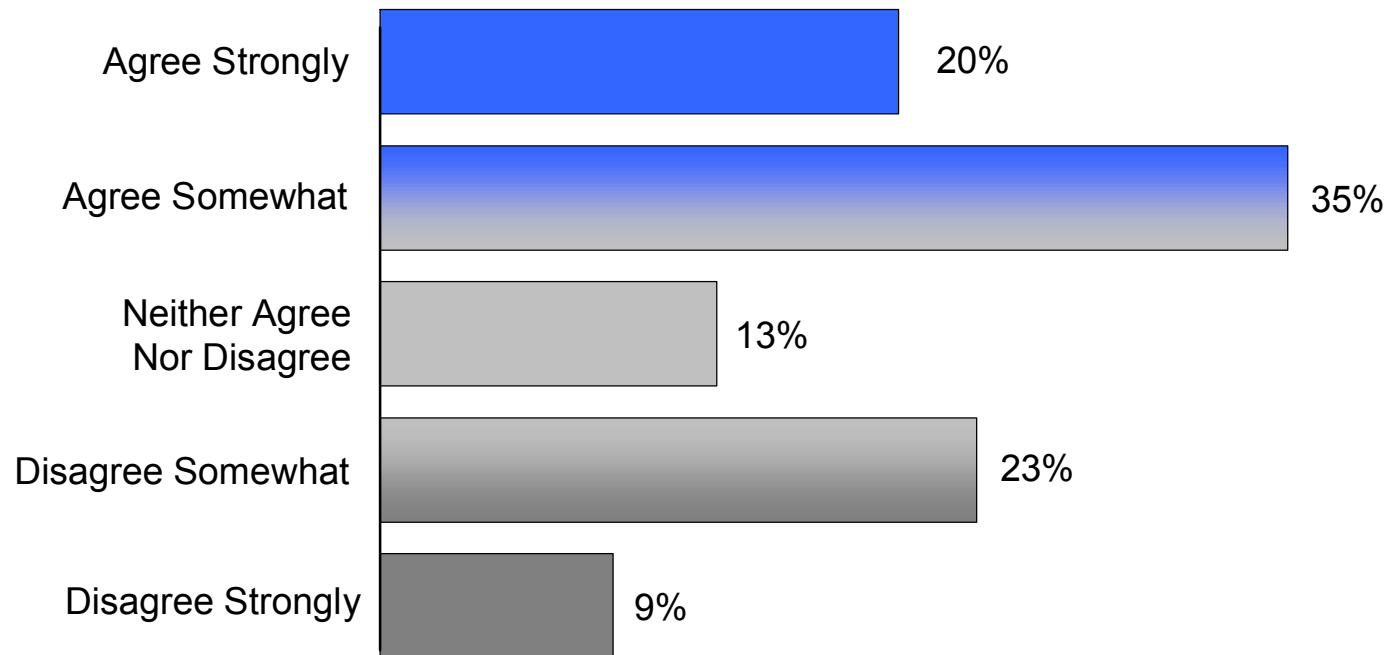
No one is shouting the word "retard" anymore.

It's his world too, but sometimes in public, people look at my son in such a way that I don't think they realize this. My son doesn't know people are looking down on him, but I do.

Note: Quote(s) were obtained from parents and self-advocates during the qualitative interviews.

Satisfaction With Inclusion

I am satisfied with my current level of Inclusion:



Inclusion was rated the lowest of all four IPII dimensions with one-third of all respondents being dissatisfied.

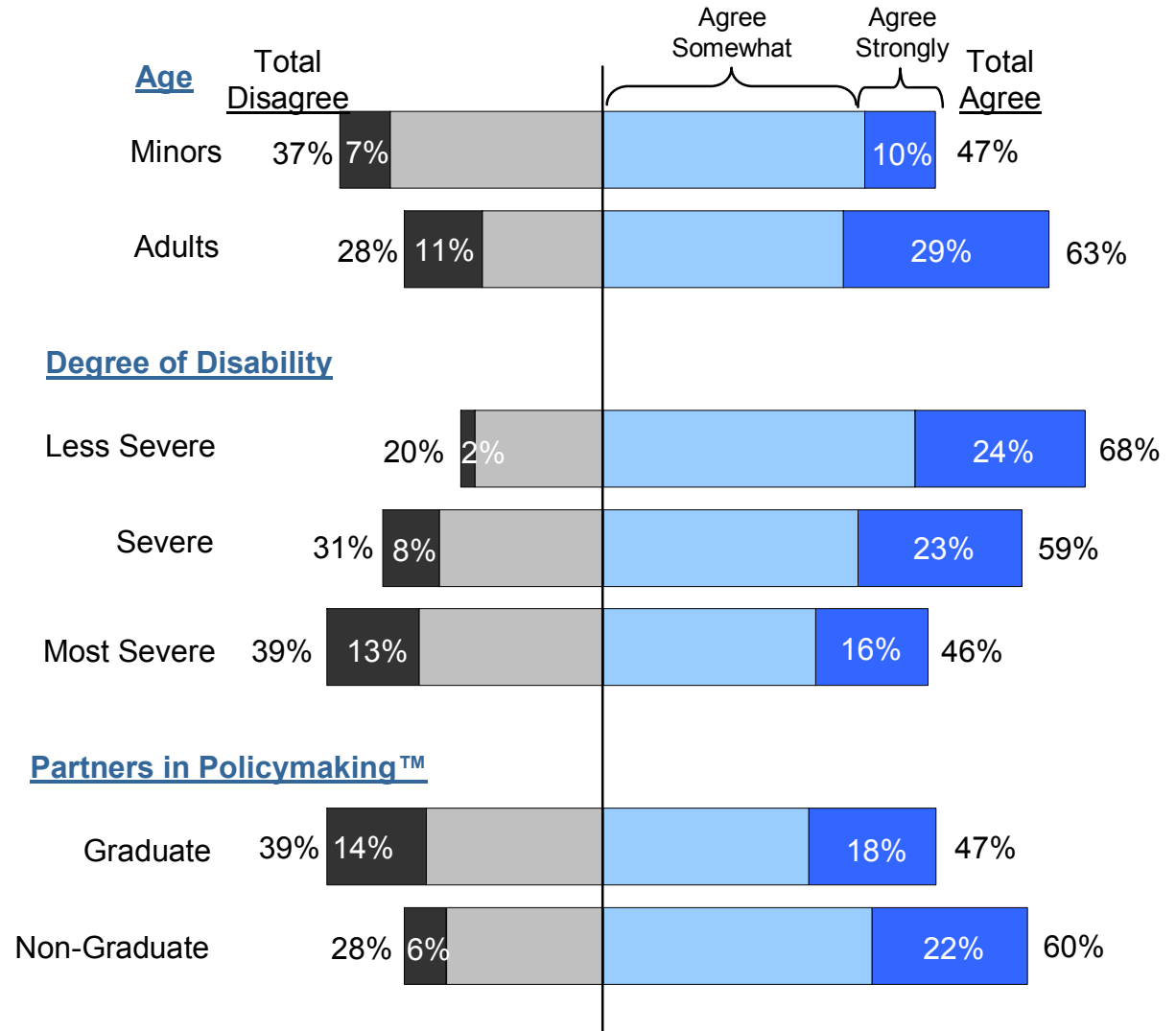
Satisfaction With Inclusion

I am satisfied with my current level of Inclusion.

Youth in school are often limited in their opportunities to interact with other children, which makes them feel less included.

People are sometimes intimidated by his wheelchair or just stare at him since he looks different.

Graduates may be more likely to see areas that can be improved related to inclusion than non-graduates



Key Aspects of Inclusion

When comparing the level of overall satisfaction with detail questions on the survey, the key aspects in determining a person's feeling of inclusion were as follows:

Relationships

I have opportunities to develop meaningful relationships with people who do not have developmental disabilities.

Equal

People without a disability treat me as an equal.

Respect

People treat me with respect.

Developing meaningful relationships and being treated as an equal and with respect are areas that drive a person's sense of belonging or inclusion.

When I wanted to sign my son up for an after school program they said they didn't know if they could handle him. They were intimidated. I trained them on what they needed to know and they were willing to try. This isn't always the case.

Attributes of Inclusion - Level of Agreement

The numbers below reflect the percent of respondents who either somewhat or strongly agree with the key aspects of Inclusion.

Respect

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

Equality

People without a disability treat me as an equal.

Relationships

People treat me with respect.

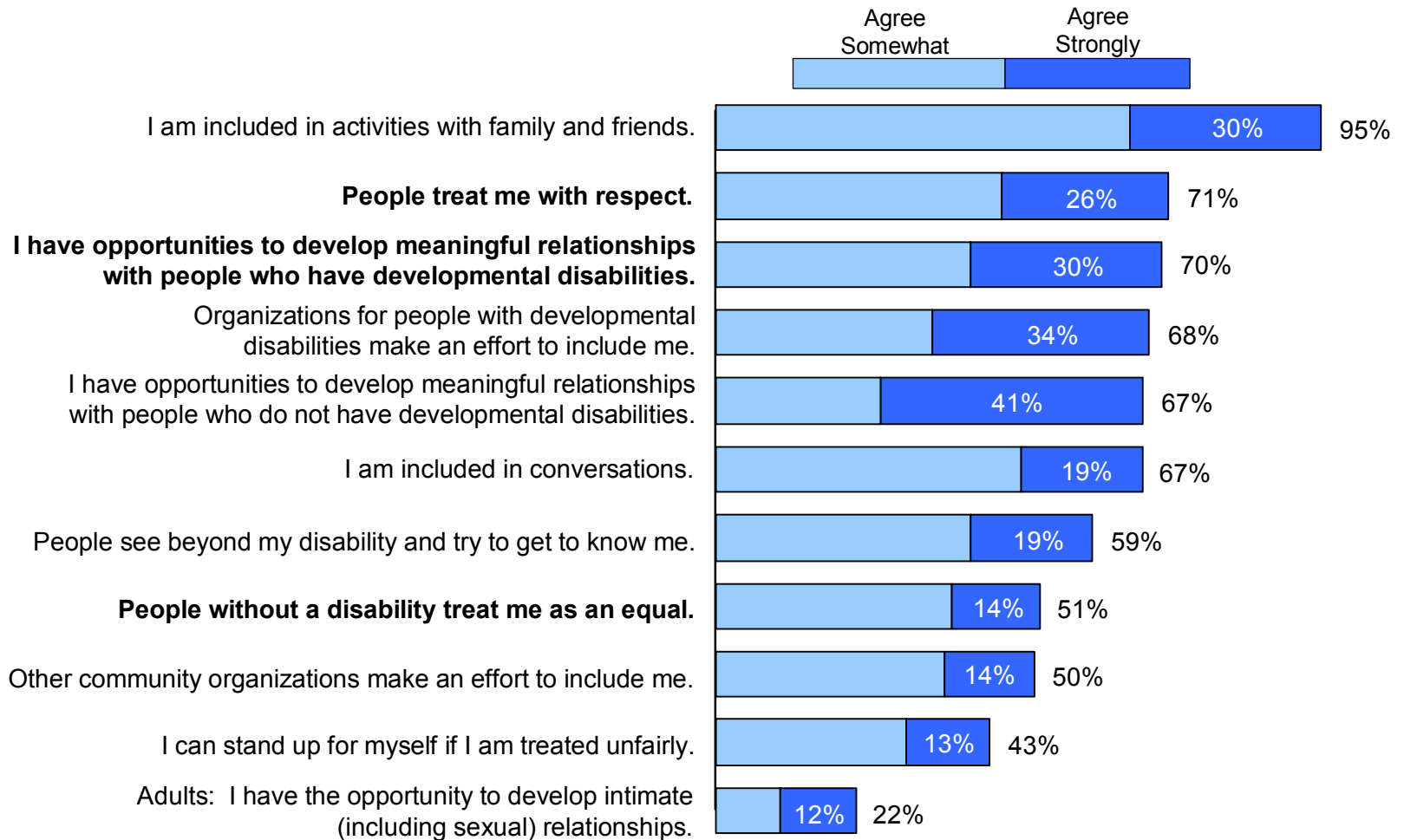
| | Age | | Degree of Disability | | | Partners in Policymaking™ | |
|---------------|-------|-------|----------------------|--------|-------------|---------------------------|---------------|
| | Minor | Adult | Less Severe | Severe | Most Severe | Graduates | Non-Graduates |
| Respect | 61 ↓ | 74 | 84 ↑ | 65 | 62 | 59 ↓ | 72 |
| Equality | 47 | 53 | 72 | 51 | 40 | 41 ↓ | 56 |
| Relationships | 67 | 75 | 76 | 78 | 63 | 66 | 74 |

Those who rated the level of their disability as mild are significantly more likely to feel they can develop meaningful relationships than those who are more severely disabled. This may be an area that could improve with assistive technology:

My son can't talk and we haven't been able to program his Dynamite box, which he could potentially use to communicate with me and his peers.

Note: Arrows (↑ ↓) indicate significant differences between means or percentages, at the 95% confidence level or more.

Attributes of Inclusion



People feel *included in activities with family and friends* (95%) but not within society as a whole in terms of being *treated as an equal* (51% agreement). Some parents felt their children with developmental disabilities are more vulnerable than other children their age and for this reason they are sometimes more protective:

I worry about my daughter's safety when I'm not with her. I think she is too trusting.



III. DETAILED FINDINGS

A. I P I I

B. Ratings of Education System

C. Ratings of Government

Education

There are times when my daughter has worked on a school project as hard as she could, probably ten times harder than every other student, but receives no recognition. Teachers mark her down for not being neat, but she is doing her best.

The school doesn't treat me like an important customer. There are no consequences for their negative actions. I feel like I need to continuously police their performance. It is hard to get straight information on what my son is doing in school, what he is learning.

Our son can't do math. He does not physically have the part of the brain that controls this ability. His teacher accused him of not trying over and over. I told her to go out to the parking lot and pick up my car. I asked her how she would feel if I told her to do this every day, and when she failed, I told her she wasn't trying.

Schools don't want to find these kids because they cost money. It is not in their best financial interest to raise a concern to the school or the parents even if it is in the best interest of the child.

It is important that teachers come up with creative ways to motivate all children, even those with disabilities.

It is important that our daughter's IEP is challenging her. We meet yearly to make a plan with her teachers for the year and our daughter participates in this process.

If I filed a complaint with the school every time it was warranted, I'd be filing all the time. However, I gain nothing by filing a complaint.

Note: Quote(s) were obtained from parents and self-advocates during the qualitative interviews.

Education Ratings

What type of education program is the person with the developmental disability currently enrolled?

| | | |
|--------------------------------|-----|--|
| Public School | 59% | } Approximately 200 respondents were asked to evaluate the education that the person with developmental disabilities is receiving or has received. Those answers are shown next. |
| Private School | 1% | |
| Vocational School | 1% | |
| Out of school within 5 years | 9% | |
| Out of school for over 5 years | 23% | |
| Other answer | 7% | |

Our daughter who has a developmental disability goes to a public school because they have special programs for her. Our other two daughters go to a private school.

Education Ratings

What type of education setting or services were received during school?

Mostly special education classes. 42%

A mix of special education and regular classes. 40%

Pull-out services and regular classes. 14%

An aide in the classroom. 34%

How do you feel about the amount of time the person with developmental disabilities spends in regular classes?

Too much 3%

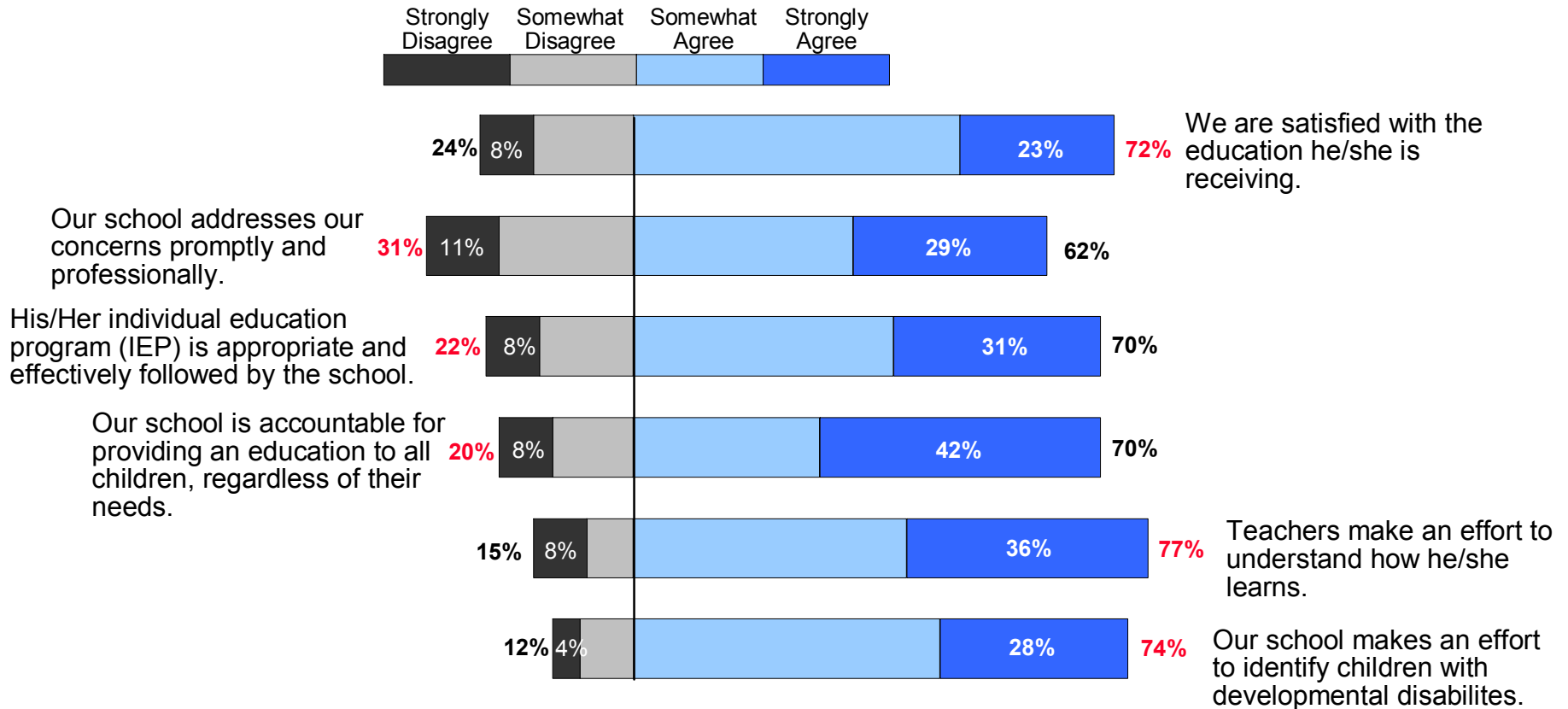
Just right 62%

Too little 28%

Just over one of four parents/advocates, of people who have developmental disabilities, believe more time should be spent in regular classes.

When they tried full inclusion in Chicago classrooms, grades went up.

Education Ratings



Approximately one-fourth of the parents/advocates are not satisfied with the education provided to people who have developmental disabilities. It appears the most room for improvement is in the way in which schools address the concerns of these people.



III. DETAILED FINDINGS

A. I P I I

B. Ratings of Education System

C. Ratings of Government

Government

The government is like a dysfunctional family. They don't communicate, they don't know what the others are doing. It's like government itself is developmentally disabled. The federal government is like a wealthy father who's never around. He could help a lot more, but he's just not there.

When the federal government is looking to cut costs at their level, my son is an easy target; he is expensive.

By the time any money gets to my son, there isn't much since it has gone through many layers of government.

People with developmental disabilities haven't had any power in government. It is hard to have any impact unless you unite, but families with children with developmental disabilities get bogged down with just surviving.

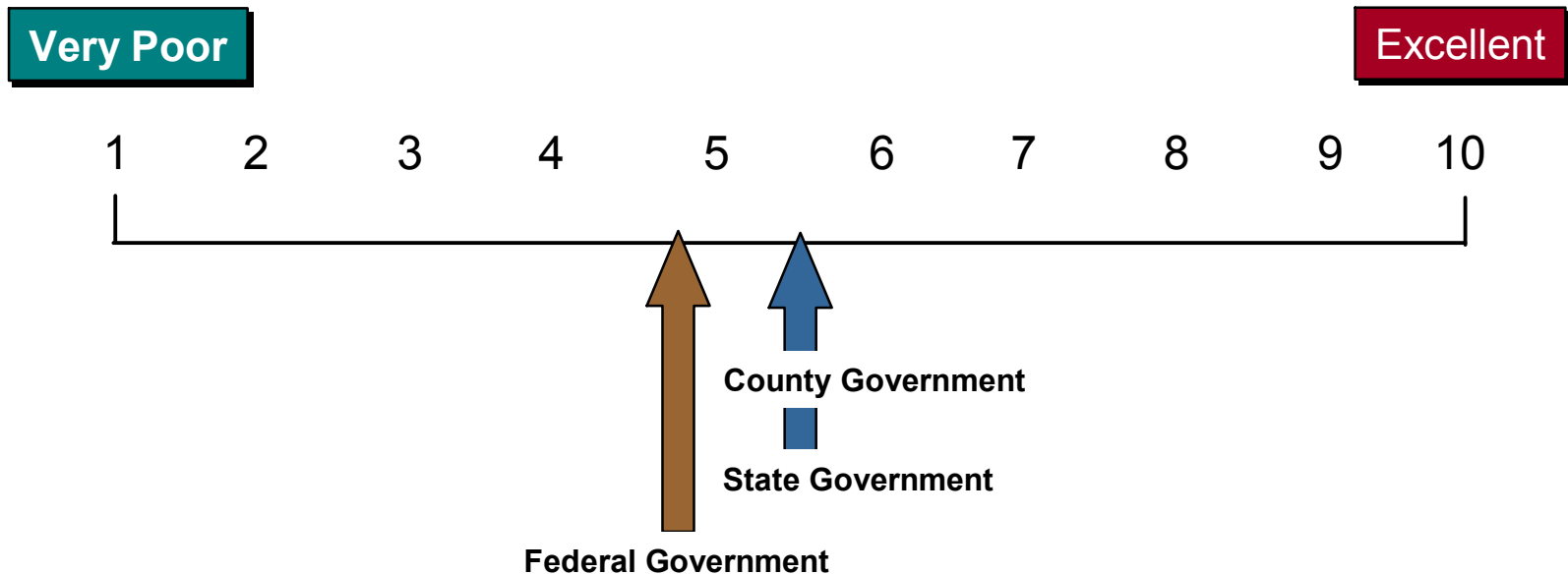
Her future is so dependent on me and my abilities. I've spent so much time learning about the system and ways to advocate for her. A lot of kids don't have an advocate like my daughter does.

We are not receiving enough financial support, as we are operating at a loss and have depleted most of our savings.

Note: Quote(s) were obtained from parents and self-advocates during the qualitative interviews.

Overall Ratings of Government

Government is charged with insuring that people with developmental disabilities receive the necessary services and support to achieve increased independence, productivity, integration and inclusion in society. Please rate how government is doing in fulfilling this objective.



All levels of government received low ratings on delivering the necessary services for increased IPII. Federal government was rated lowest overall (4.9 mean rating).

Government Ratings

Feelings about government's performance are related to a person's age and developmental disability.

Mean Ratings:

| | Age of People with Disabilities | | Degree of Disability | | | Living Arrangement | | |
|--------------------|---------------------------------|-------|----------------------|--------|-------------|---------------------|------------|-------|
| | <19 | 19+ | Less Severe | Severe | Most Severe | w/Parents Relatives | Group Home | Other |
| | County Government | 5.3 ↓ | 5.7 | 6.0 ↑ | 5.4 | 5.3 | 5.2 ↓ | 6.2 |
| State Government | 5.3 | 5.7 | 5.9 ↑ | 5.5 | 5.3 | 5.2 ↓ | 6.1 | 6.1 |
| Federal Government | 4.6 ↓ | 5.2 | 5.7 ↑ | 4.8 | 4.7 | 4.5 ↓ | 5.7 | 5.8 |

Government receives lowest ratings from households with young people with more severe disabilities living at home. This finding is not surprising, as we observed in the qualitative interviews the desperation of some parents, as they struggle to obtain the government services they need for their children with developmental disabilities grow older.

Note: Arrows (↑↓) indicate significant differences between means or percentages, at the 95% confidence level or more.

Government Ratings

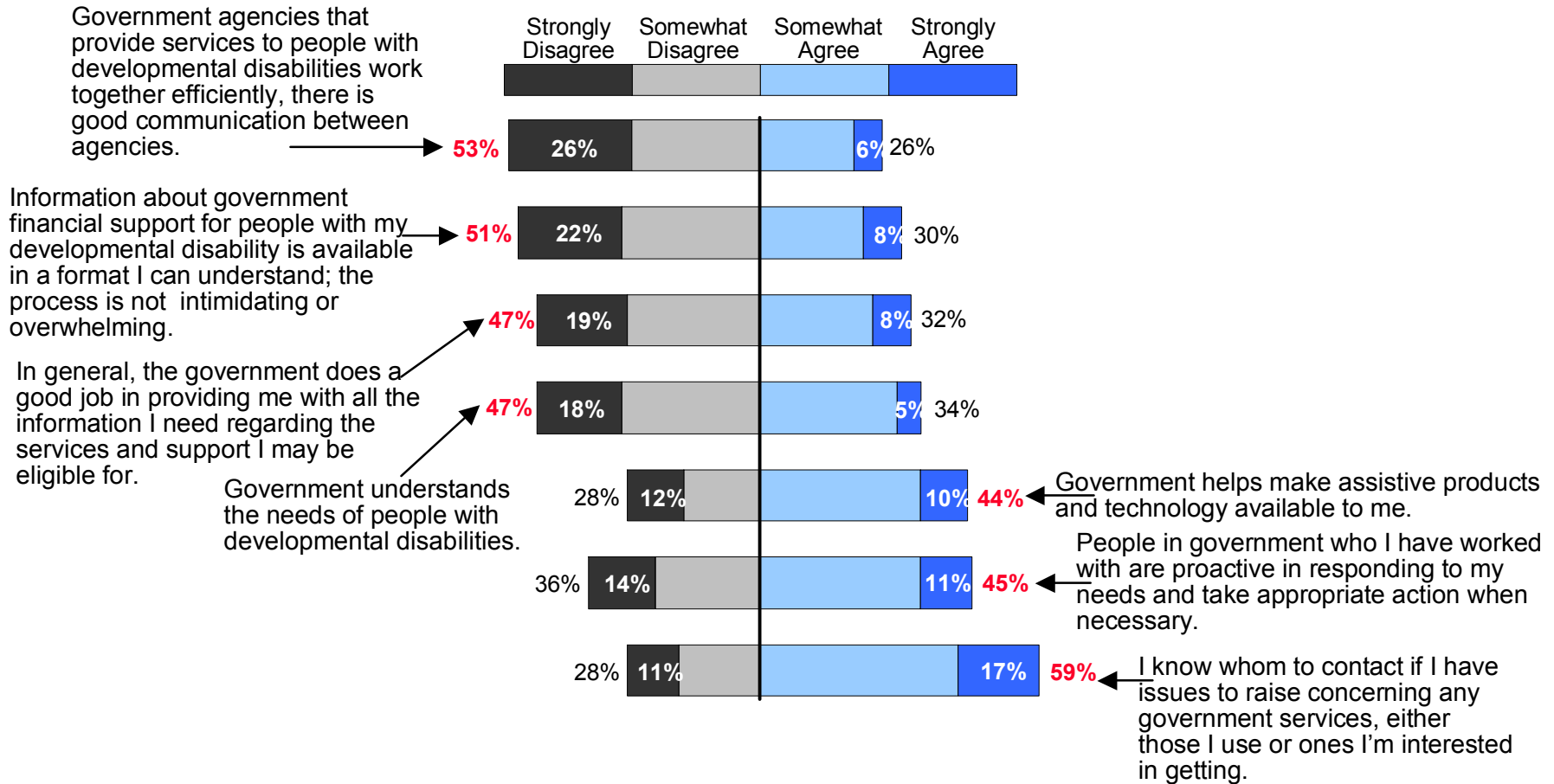
Partners In Policymaking™ Graduates rate County and Federal Government substantially lower than Non-Graduates.

| | Partners In Policymaking™ | |
|--------------------|---------------------------|----------------------|
| | <u>Graduates</u> | <u>Non-Graduates</u> |
| County Government | 4.9 ↓ | 5.9 |
| State Government | 5.4 | 5.5 |
| Federal Government | 4.7 | 5.1 |

The correlation with low county and federal government ratings may be a function of the Partners In Policymaking™ Graduates' higher expectations, based on what they learn about the roles of county and federal government in providing services to people with developmental disabilities.

Note: Arrows (↑ ↓) indicate significant differences between means or percentages, at the 95% confidence level or more.

Government Ratings



The questions related to government asked in this research were high level. Given the low ratings, it appears that many areas would warrant further research. People become confused and frustrated trying to figure out how to best utilize government services and resources. Some have found success by forming support groups and sharing information with each other in regards to how the system works.



IV. APPENDIX