

Quality of life surveys

The Minnesota Governor’s Council on Developmental Disabilities (GCDD) commissioned quality of life surveys in 2000, 2005, 2010, and 2015. Quality of life surveys ask people with development disabilities and their families or caregivers to assess their living conditions, including the quality of services they receive and obstacles they face in their daily lives. The GCDD has used data from these surveys to inform and develop its five-year state plans.

The surveys aim to answer the following questions:

1. How are Minnesotans who have developmental disabilities being treated in their day-to-day life?
2. How satisfied are the people who have developmental disabilities with the products and services being provided by government agencies and their suppliers?
3. Are there distinct segments (subgroups) of this population, who have developmental disabilities, with unique needs and circumstances, which may require different approaches or services from the Council and other service provider agencies?

The first quality of life survey included questions about inclusion, productivity, integration, and inclusion (IPII) in the community of people with developmental disabilities—core goals of the federal Developmental Disabilities Act (DDA). In 2005, self-determination was added as a fifth goal under the DDA and IPII became IPSII.

Accordingly, questions on self-determination were added to the quality of life surveys, as well as a list of “basic needs” statements. Another set of questions focuses on respondents’ views on the role of education and government.

Key findings from the quality of life surveys

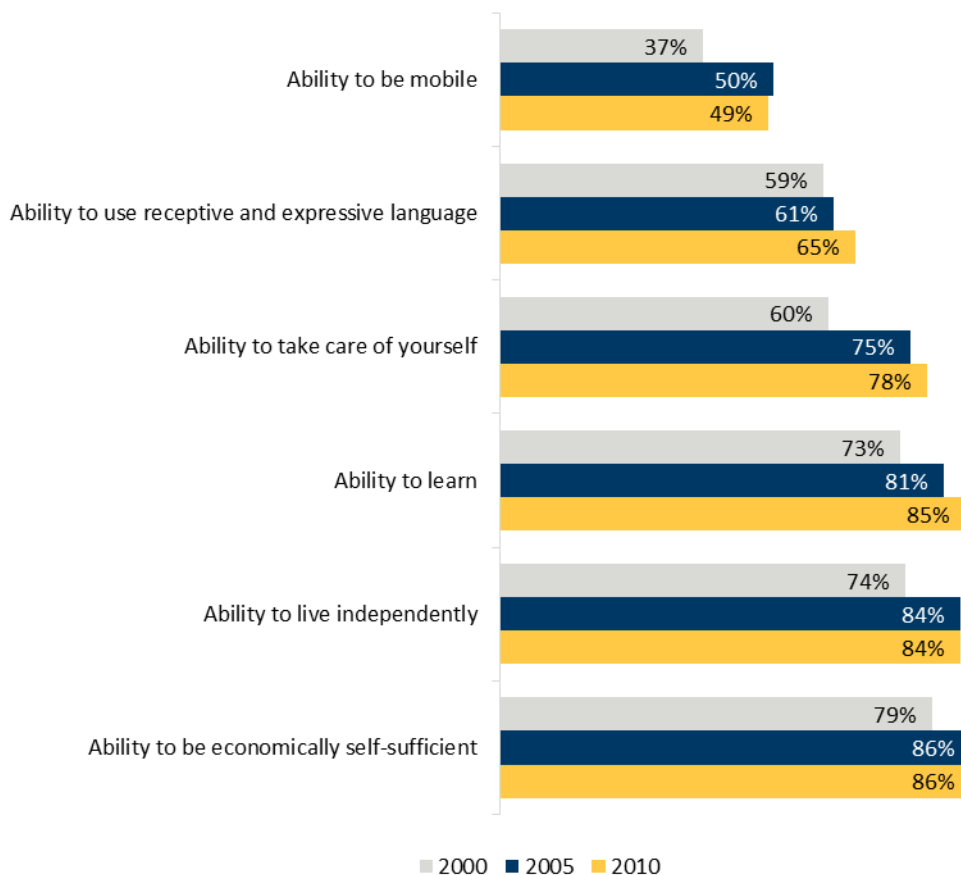
- The impact of a developmental disability is most pronounced for respondents’ abilities to learn, to live independently, and to be economically self-sufficient.
- Overall, quality of life responses to IPSII questions have remained fairly steady from 2000 to 2015; levels of satisfaction with inclusion are generally the lowest, while the level of satisfaction with independence has seen the largest decline among survey respondents.
- Having a job is associated with higher levels of satisfaction with one’s quality of life, especially feeling productive and integrated into the community.
- Respondents with developmental disabilities between the ages of 19-34 have the highest unemployment rate, with about half of respondents without a paying job (based on 2015 data).
- Age matters, with respondents under the age of 18 feeling less satisfied with their quality of life, in particular in terms of inclusion and integration.
- In the most recent survey (2015), respondents identified economic security, access to services, and affordable housing as critical issues for improvement. For younger respondents, access to and inclusion in public education were most important.

Detailed findings

Impact of developmental disability

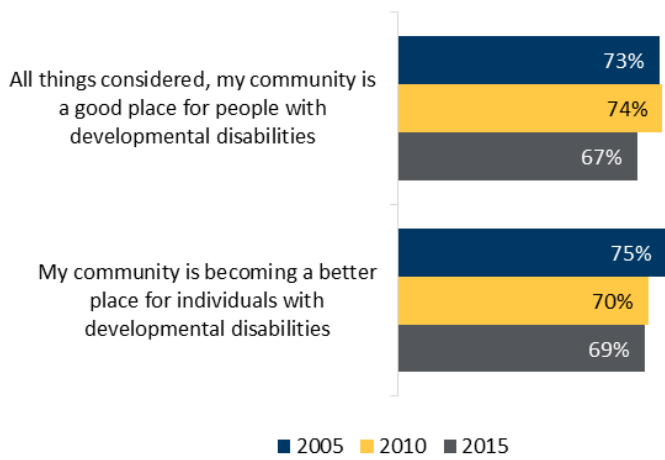
The 2000, 2005, and 2010 surveys asked respondents about the impact of their developmental disability on a number of abilities. In each survey, the abilities rated as most impacted by a respondent's disability included the abilities to learn, live independently, and be economically self-sufficient (Figure 1). The ability to be mobile is least impacted, according to respondents.

Figure 1: Percentage of respondents who indicate their disability moderately or severely impacts their ability to do a number of activities



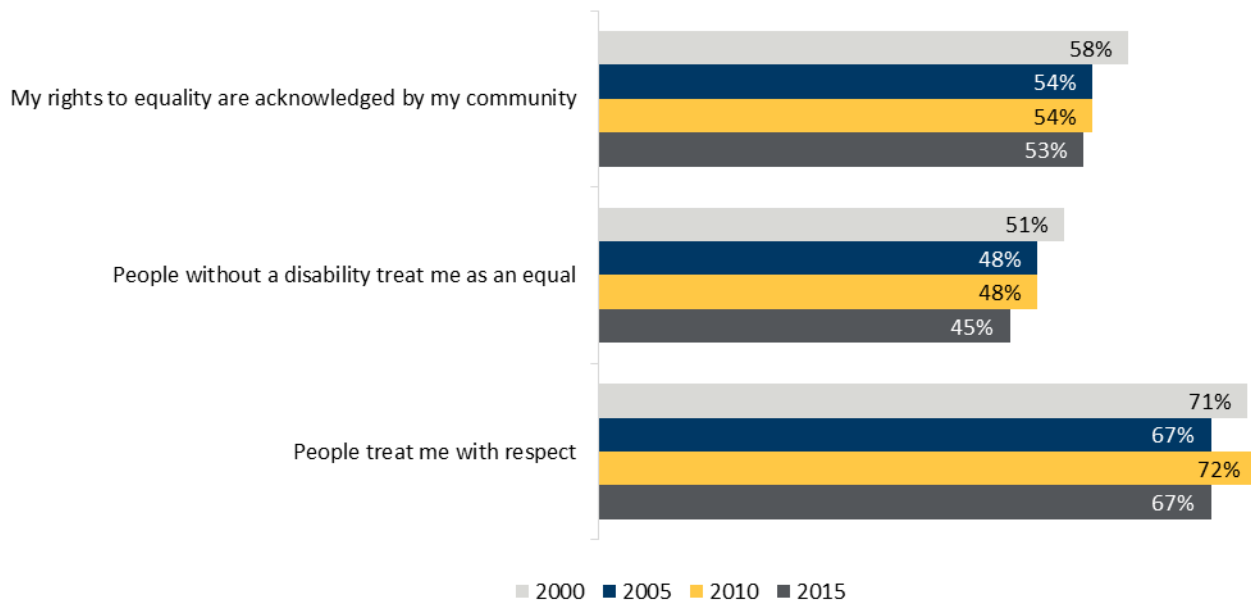
The 2005, 2010, and 2015 surveys also asked respondents to rate their communities. Respondents are overall fairly positive about their communities. Over two-thirds of respondents indicate their community is a good place for people with developmental disabilities and believe it is becoming better (Figure 2). Yet, another third of respondents disagree or neither agree nor disagree with these statements.

Figure 2: Percentage of respondents who agree that their communities are good places and are becoming better for people with developmental disabilities



All four surveys also asked respondents whether they agree their rights are acknowledged and whether people treat them as equals and with respect. Respondents are most positive about the way people treated them with respect (Figure 3).

Figure 3: Percentage of respondents who somewhat or strongly agree with statements on equal treatment and respect



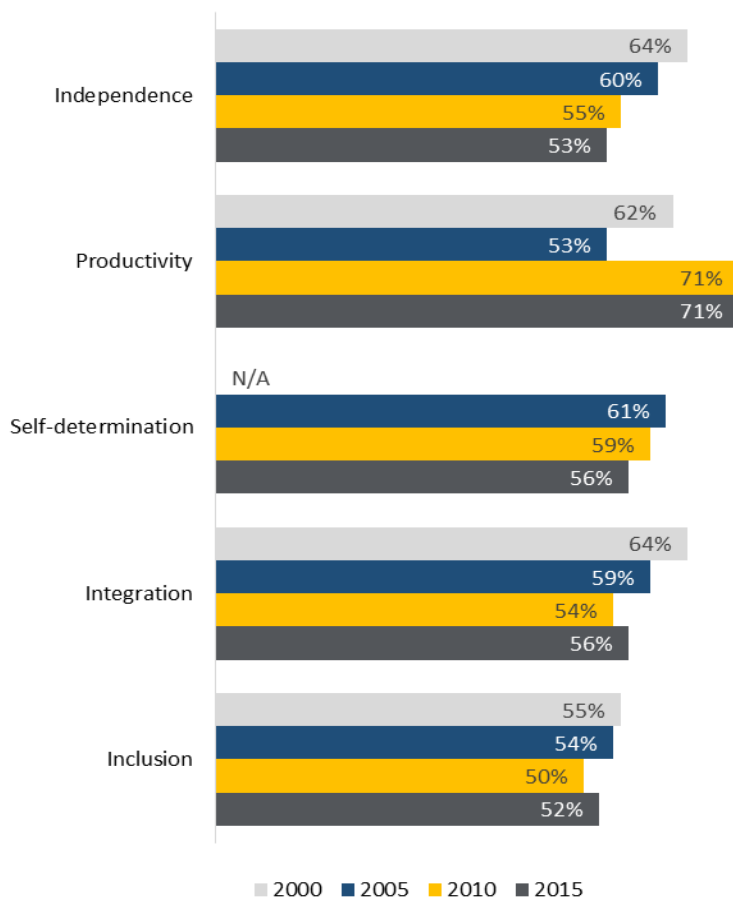
Satisfaction with independence, productivity, self-determination, integration, and inclusion (IPSII)

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

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

All four quality of life surveys asked respondents to rate their levels of satisfaction with the following quality of life indicators: independence, productivity, self-determination, integration, and inclusion (IPSII).¹ From 2000 to 2015, levels of satisfaction with all quality of life indicators have remained fairly stable. Respondents are generally least satisfied with their levels of inclusion. Satisfaction with the level of independence has seen the largest decline among survey respondents (Figure 4).

Figure 4: Percentage of respondents who somewhat or strongly agree that they are satisfied with their levels of independence, productivity, self-determination, integration, and inclusion



Note on Figure 4: In 2010 and 2015, satisfaction with productivity was only asked of a subset of respondents who were over 19 years old (2010) and who worked or volunteered outside their home (2015).

¹ In 2005, the U.S. Congress changed federal law and added self-determination as a fifth goal under the Developmental Disabilities Act (DDA); data on this indicator is not available for 2000.

Age matters for levels of satisfaction with IPSII

The survey data reveal that age has an impact on levels of satisfaction, with respondents under the age of 19 feeling less satisfied overall, but especially with their levels of inclusion and integration. For instance, the 2015 survey shows that only 37 percent of respondents under the age of 14 agree somewhat or strongly that they are satisfied with their level of inclusion. By comparison, this is true for about 60 percent of respondents over the age of 18.

“There is no way she is independent. She is 18 years old, but she doesn’t have a job and she can’t drive.”

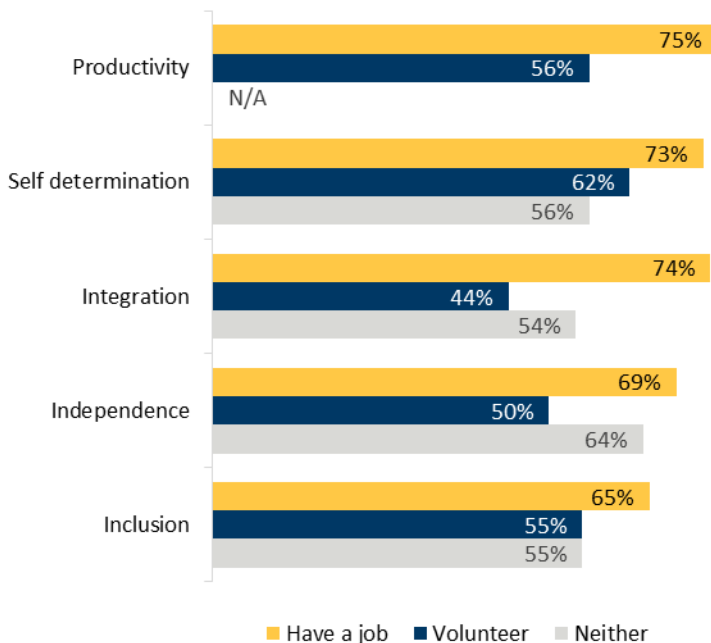
“In the fifth grade she started going to vo-tech to learn basic living skills. She now knows how to cook her own meals and take care of herself. She also knows when she should call for help.”

Employment matters for levels of satisfaction with IPSII

The 2015 survey results suggest that having a job outside the home is highly correlated with satisfaction with all elements of IPSII. In fact, having a job, rather than just volunteering, makes someone much more likely to be satisfied with levels of productivity and integration (Figure 5).

“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.”

Figure 5: Percentage of respondents in 2015 who somewhat or strongly agree that they are satisfied with their levels of independence, productivity, self-determination, integration, and inclusion, by employment status



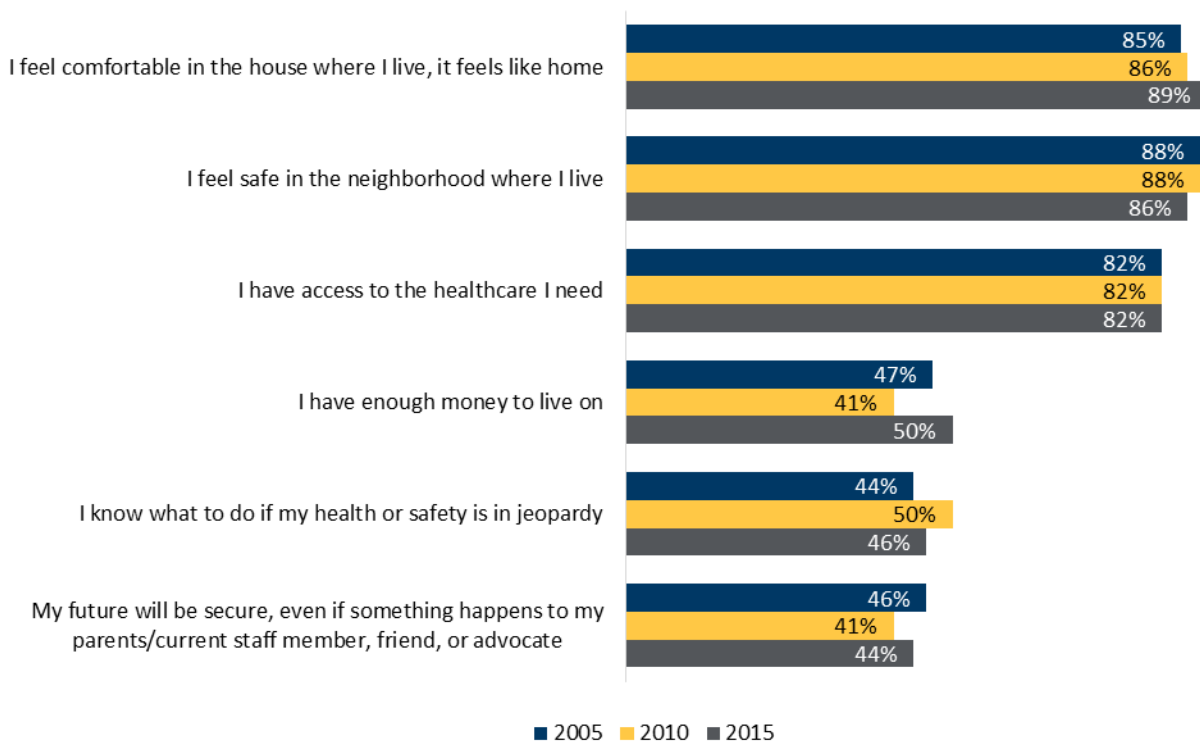
“Individuals are getting out. It is a social setting in the very least. For some [individuals with developmental disabilities] with high skill levels, it is a means of self determination, using talents and getting some reimbursement.”

In 2015, the youngest adult age group (ages 19-34) had the highest unemployment rate, with 51 percent without a paying job, versus 37 percent and 43 percent for the two older age groups, ages 35-54 and 55 and up, respectively.

Basic needs

The 2005, 2010, and 2015 surveys also explored to what extent respondents’ basic needs are met. While a large majority of respondents indicate they feel comfortable and safe in their homes and neighborhoods and have access to health care, fewer than half of respondents indicate they have enough money to live on, know what to do in emergency situations, or feel their future is secure (Figure 6).

Figure 6: Percentage of respondents who somewhat or strongly agree that a set of basic needs are met



Critical issues

In 2015, respondents identified what they believed to be the four most critical issues Minnesotans with developmental disabilities will face in the next five years. These are:

1. **Services**, including access to services and shortage of staff.
2. **Funding**, including funding for daily living and funding for services and programs.
3. **Housing**, including affordability, availability of housing, and appropriate living arrangements.
4. **Employment**, including suitable and meaningful jobs and wages.

These issues align with the views of service providers, who were surveyed about these issues at the same time. They rated the quality of housing and employment among the lowest and identified employment and housing among the top priorities of improvement.

About the respondents

Respondents in each survey sample included people with developmental disabilities and their parents, family members, or other caregivers. Because the exact population of people with developmental disabilities in Minnesota is unknown, the sampling method employed was to contact organizations and individuals who work with, or are in contact with, people with developmental disabilities or their families and caregivers. As a result, the samples are not random samples.²

The nature of respondents' developmental disabilities varied: most common were autism, cerebral palsy, epilepsy, and brain injury. In each sample, about one-third to half of the respondents were younger than 18.

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 caregiver responded on this person's behalf.

Table 1: Sample sizes of the 2000, 2005, 2010, and 2015 quality of life surveys

Year	Sample size
2000	300
2005	552
2010	222
2015	531

² For more detail on the methodologies of each survey, refer to the complete survey reports for [2000](#), [2005](#), [2010](#), and [2015](#) as posted on the Council's website.