Summary of survey findings – Quality of life, Minnesota general public attitudes, and views on health care

Background

For almost twenty years, the Minnesota Governor's Council on Developmental Disabilities (GCDD) has collected data on Minnesotans' views on a variety of topics surrounding developmental disabilities, including quality of life, health care, and education. The GCDD has commissioned over 25 studies, including interviews, focus groups, and online surveys of people with developmental disabilities, the general public, providers, educators, and businesses (refer to Table 1: Overview of surveys conducted during the period 1962-2018 on page 3 for an overview). This document summarizes findings from surveys on the topics of: (1) quality of life among people with a developmental disability, (2) Minnesota general public attitudes, and (3) health care opinions.

Summary of key findings

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 inclusion, productivity, self-determination, integration, and inclusion (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.

Key findings from the Minnesota general public attitudes surveys

- Minnesotans seem equally familiar with developmental disabilities and people with such disabilities in 1962 and four decades later.
- Minnesotans generally hold positive attitudes regarding all aspects of independence, productivity, self-determination, integration, and inclusion for people with developmental disabilities.
- Minnesotans' views on where people with developmental disabilities should live and be cared for have shifted dramatically between 1962 and 2007. Minnesotans are now much more likely to say that people with developmental disabilities should live with their families and not be placed in institutions.

- Minnesotans are near unanimous in having respect for companies that employ people with developmental disabilities, believing that they should be included in public places and social events, and that most of them can be very productive workers.
- Compared to 1962, Minnesotans are more likely to say people with disabilities should be allowed to vote or drink alcohol, but a sizable number of respondents disagree or are ambivalent.
- In 2017, over three-quarters of Minnesotans deemed it important for government to use taxpayer money on health care services, education services, protection services, and employment services for people with developmental disabilities.

Key findings from the health care surveys

- Both the 2004 and 2018 surveys found that over nine out of 10 Minnesotans have some form of health insurance.
- The number of respondents indicating they have Medical Assistance (MA)/Medicaid more than doubled between 2004 and 2018. This is at least partly a result of the expansion of Medicaid eligibility under the 2010 Affordable Care Act (ACA).
- Medicare recipients are generally more satisfied than respondents with private health insurance on all aspects of their health care experiences.
- Regardless of differences between respondents, most agree that:
    - Health care should be available to all citizens regardless of their income or employment status.
    - People should not be turned away from necessary medical treatment, even if they are uninsured and cannot afford the treatment.
    - Everyone should pay something for their health care, with people paying varying amounts depending on what they can afford.
    - People who need more services than others, such as the elderly and people with disabilities, should get them without paying more.
- Households with a person with a developmental disability are more likely to have a pessimistic near-future outlook regarding health care quality and affordability, especially federal cuts to MA/Medicaid and health care access in general.

Table 1: Overview of surveys conducted during the period 1962-2018

Year	Type	Name of survey
1962	General public	MN Survey of Attitudes Regarding Developmental Disabilities
2001	People with developmental disabilities	Quality of Life Survey
2002	Program participants	Consumer Directed Community Supports Survey
2003	People with developmental disabilities	Electronic Government Services Survey
2004	General public	Minnesota Health Care Opinion Poll Study
2005	Employers	Employer Focus Research
2006	Providers	GCDD 5-year plan research report service provider survey
2006	People with developmental disabilities and providers	GCDD 5-year plan research report individual survey
2006	People with developmental disabilities	GCDD 5-year plan research report - qualitative statements
2007	General public	MN Survey of Attitudes Regarding Developmental Disabilities
2008	Youth with and without disabilities	Information Technology Insights Focus Groups
2009	Employers	Innovative Employers in Minnesota Presentation
2009	People with and without disabilities	Information Technology Customer Research Study
2010	Minnesota businesses	Awareness, Attitudes and Impact of the ADA Among MN Businesses
2010	People with developmental disabilities	GCDD 5-year plan research report individual survey
2010	Providers	GCDD 5-year plan research report service provider survey
2012	Education (mostly parents)	K-12 Education Study for Students with Developmental Disabilities (qualitative study)
2012	General public	1962/2012 MN Survey of Attitudes Regarding Developmental Disabilities
2012	People with developmental disabilities	Quantitative survey of people with developmental disabilities
2012	Providers	Pilot interviews with service providers
2014	Education (students, parents, teachers, case managers, administrators)	The Minnesota Special Education Experience Study (quantitative study)
2015	People with developmental disabilities	GCDD 5-year plan research report individual survey
2015	Providers	GCDD 5-year plan research report service provider survey
2017	General public	2017 Minnesota General Population Survey of Attitudes Towards People with Developmental Disabilities
2017	General public by race and ethnicity	2017 Minnesota Racial and Ethnic Survey of Attitudes Towards People with Developmental Disabilities
2018	General public	2018 Minnesota General Population Survey of Attitudes and Outlook Regarding Healthcare Services and Costs

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

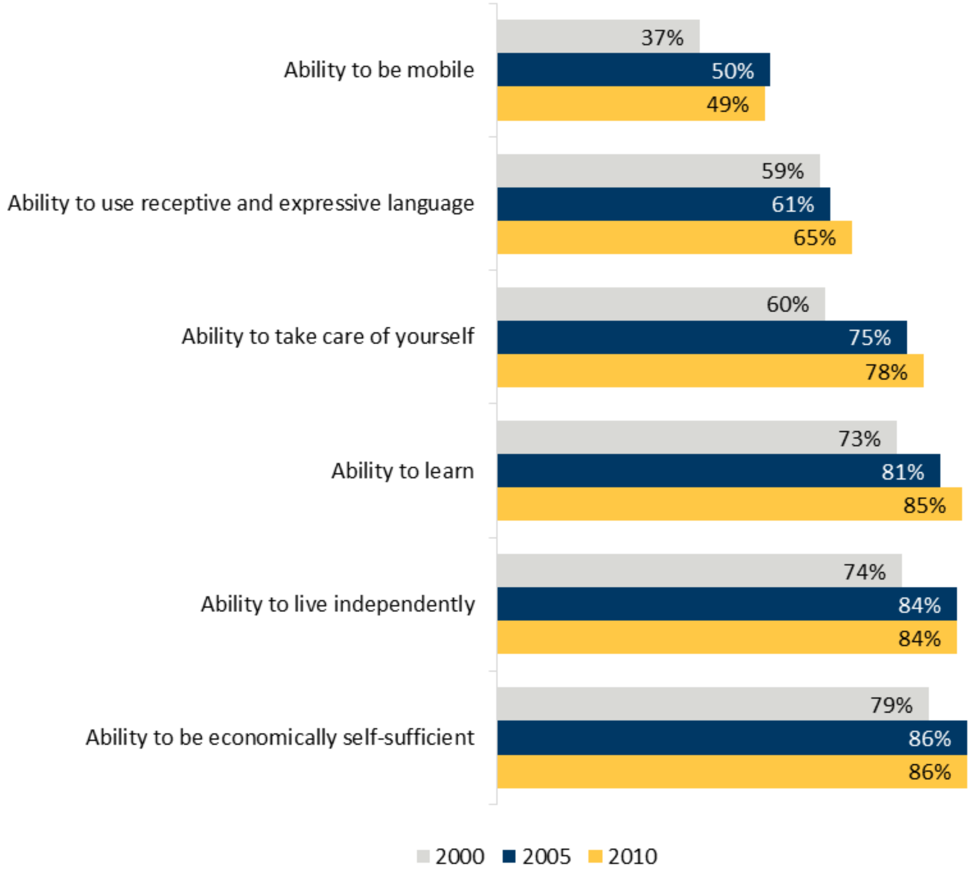
- The impact of a developmental disability is most pronounced for respondents' abilities to learn, to live independently, and to be economically self-sufficient.
- Overall, quality of life responses to IPSII questions have remained fairly steady from 2000 to 2015; levels of satisfaction with inclusion 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

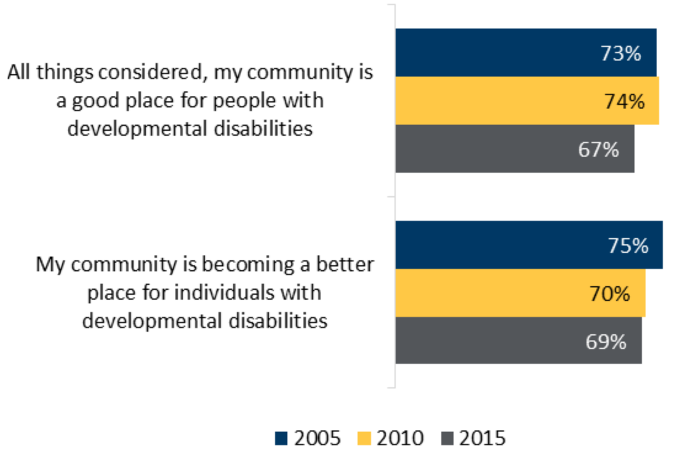
The 2000, 2005, and 2010 surveys asked respondents about the impact of their developmental disability on a number of abilities. In each survey, the abilities rated as most impacted by a respondent's disability included the abilities to learn, live independently, and be economically self-sufficient (Figure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



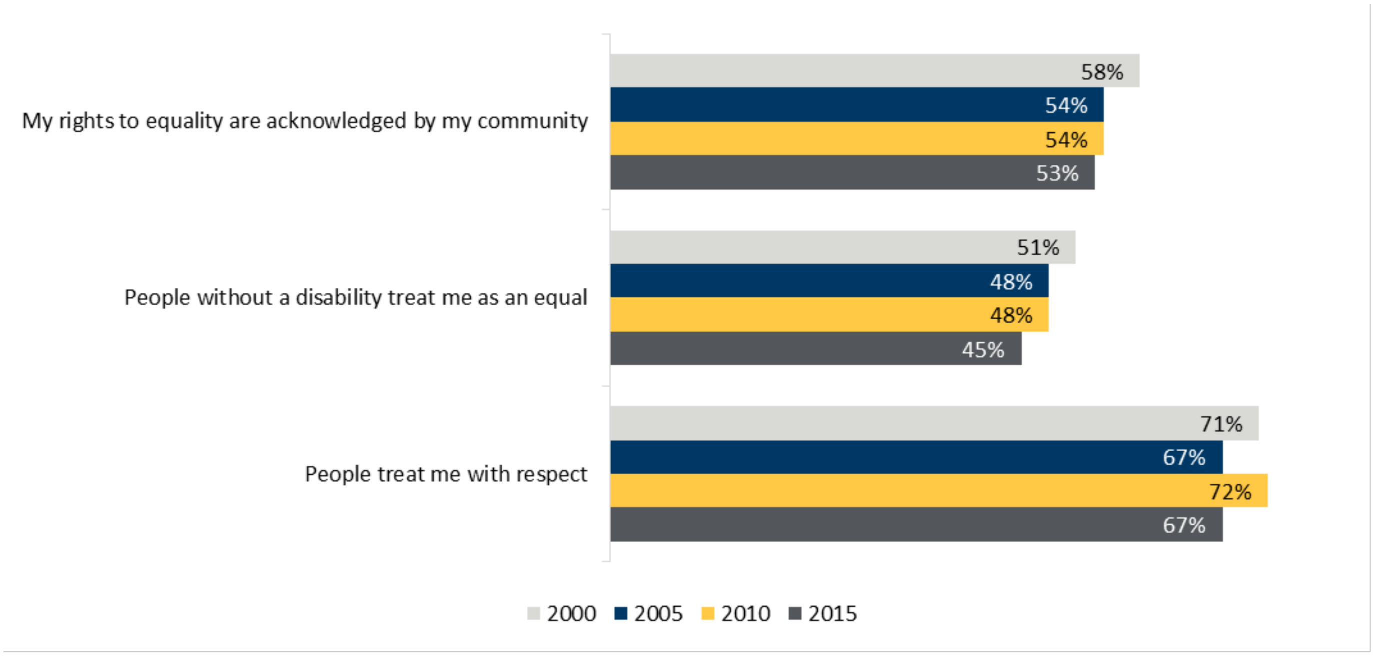
The 2005, 2010, and 2015 surveys also asked respondents to rate their communities. Respondents are overall fairly positive about their communities. Over two-thirds of respondents indicate their community is a good place for people with developmental disabilities and believe it is becoming better (Figure 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



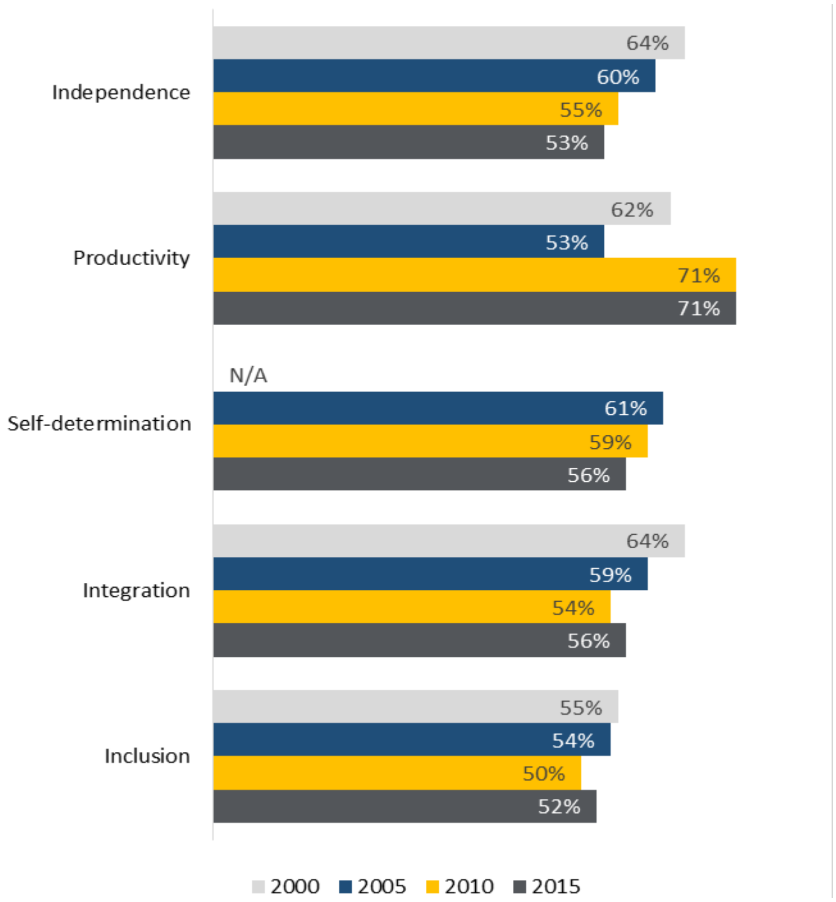
Satisfaction with independence, productivity, self-determination, integration, and inclusion (IPSII)

"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).

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[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."

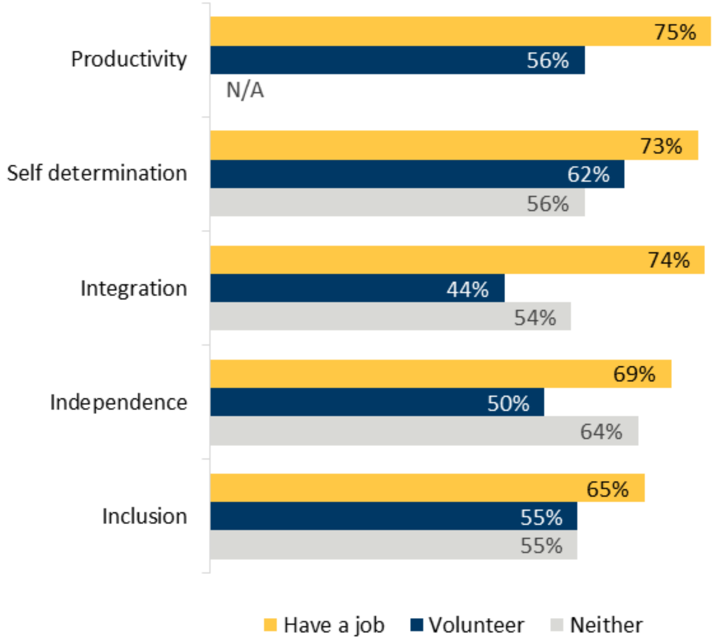
"In the fifth grade she started going to vo-tech to learn basic living skills. She now knows how to cook her own meals and take care of herself. She also knows when she should call for help."

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



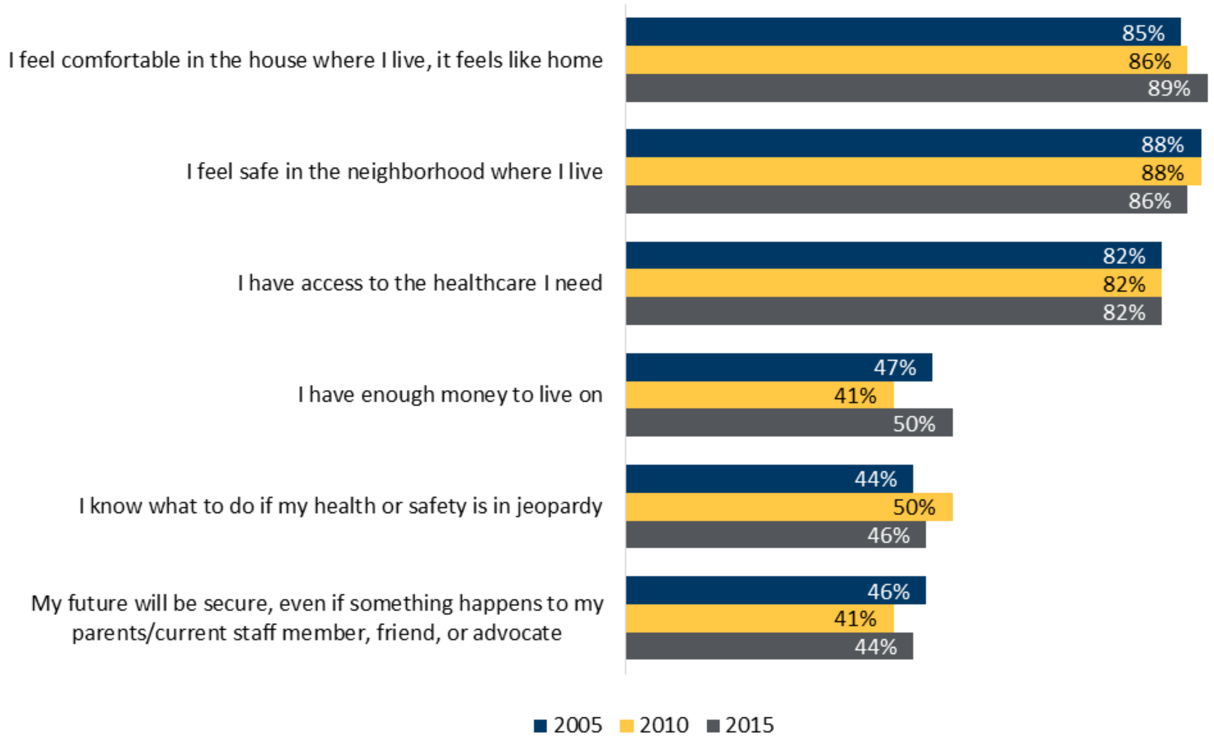
"Individuals are getting out. It is a social setting in the very least. For some [individuals with developmental disabilities] with high skill levels, it is a means of self determination, using talents and getting some reimbursement."

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

Year	Sample size
2000	300
2005	552
2010	222
2015	531

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[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.

Minnesota general public attitudes

Minnesotans' attitudes toward people with developmental disabilities were first surveyed in 1962. Forty-five years later in 2007, the survey was repeated for the first time and then again in 2012, fifty years after the original benchmark study. Some of the original questions were retained in each survey; new questions were added to the 2017 study to reflect modern issues and concerns. All surveys included questions designed to capture the Minnesota general public's perspectives regarding equality, equity, diversity, and inclusion of people with developmental disabilities.

Key findings from the Minnesota general public attitudes surveys

- Minnesotans seem equally familiar with developmental disabilities and people with such disabilities in 1962 and four decades later.
- Minnesotans generally hold positive attitudes regarding all aspects of independence, productivity, self-determination, integration, and inclusion for people with developmental disabilities.
- Minnesotans' views on where people with developmental disabilities should live and be cared for have shifted dramatically between 1962 and 2007. Minnesotans are now much more likely to say that people with developmental disabilities should live with their families and not be placed in institutions.
- Minnesotans are near unanimous in having respect for companies that employ people with developmental disabilities, believing that they should be included in public places and social events, and that most of them can be very productive workers.
- Compared to 1962, Minnesotans are more likely to say people with disabilities should be allowed to vote or drink alcohol, but a sizable number of respondents disagree or are ambivalent.
- In 2017, over three-quarters of Minnesotans deemed it important for government to use taxpayer money on health care services, education services, protection services, and employment services for people with developmental disabilities.

Detailed findings

Familiarity with developmental disabilities has remained stable

In 1962, 2007, and 2012, about four out of five Minnesotans indicate they have known of a person who was thought to have a developmental disability (Figure 7). This number drops to about three out of four in 2017, although this might have been a result of question wording and question placement in the survey.[3]

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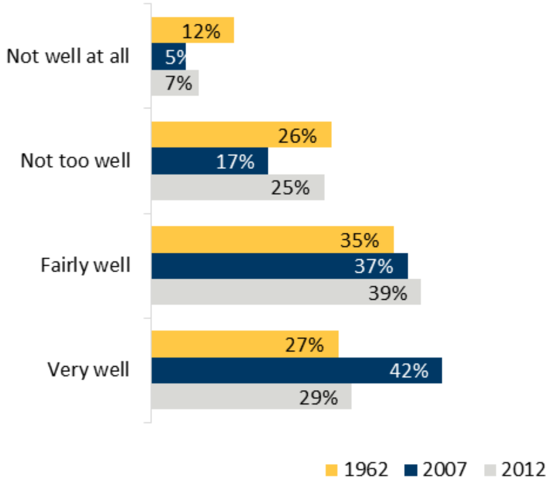
[3] Most notably, developmental disabilities were described differently in the 2017 survey than in the previous surveys. In 2017, no specific examples of developmental disabilities were provided, whereas in the previous surveys, respondents were provided examples such as cerebral palsy, autism, and epilepsy.

Figure 7: Percentage of respondents indicating they have known of a person who was thought to have a developmental disability

When asked how well respondents know the person, 62 to 79 percent indicate they know him or her fairly well or very well (Figure 8).

Figure 8: Familiarity with person with developmental disabilities ("How well would you say you know him/her?")



Attitudes on where people with developmental disabilities should live and be cared for have changed dramatically

In comparison to Minnesotans' attitudes in 1962, Minnesotans are now much more likely to say that people with developmental disabilities should be cared for by their immediate family as much as possible, and should not be kept in an institution (Figure 9 and Figure 10). This coincides with a change in Minnesota state policy in the 1990s to move people with disabilities out of state hospitals and into supported living homes and community-based services.

Figure 9: Percentage of respondent who agree or disagree that people with developmental disabilities should be cared for "at home" (1962) or "by the immediate family, as much as possible" (2007 and 2012)

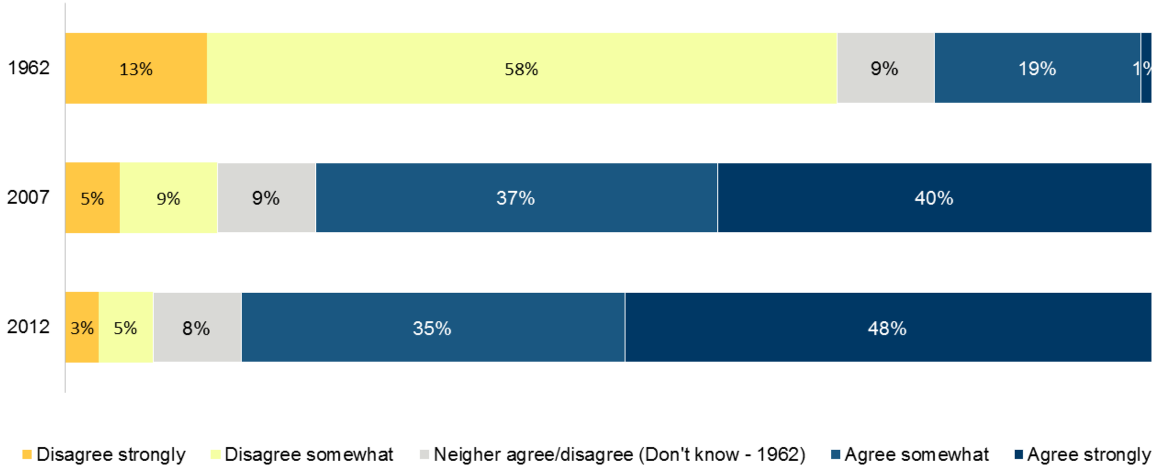
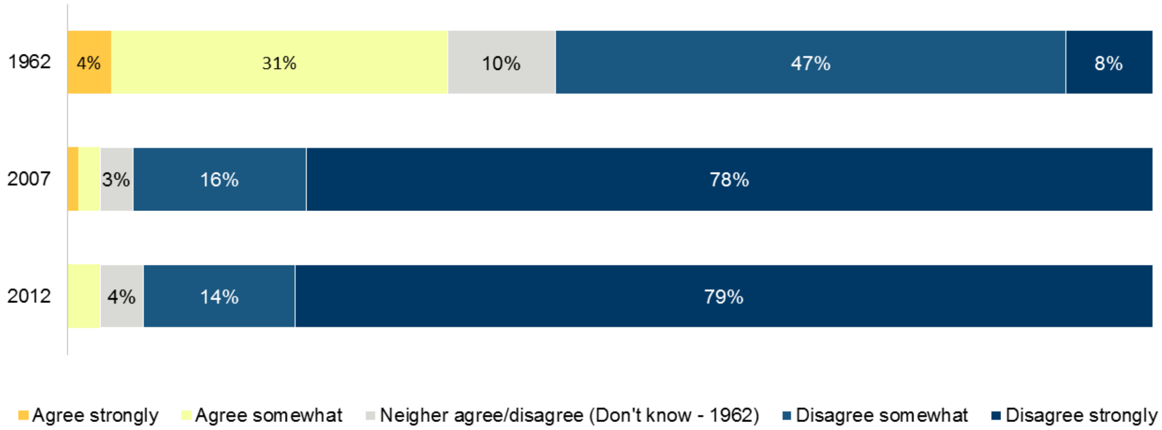


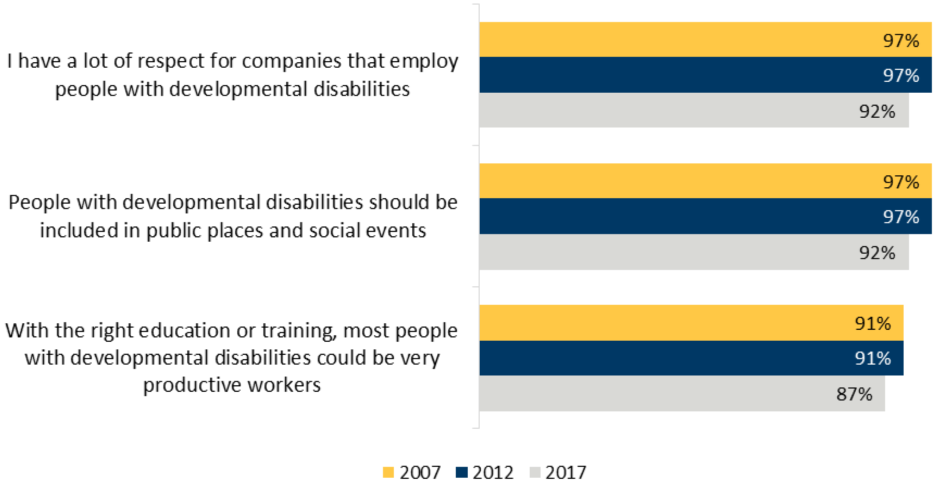
Figure 10: Percentage of respondents who agree or disagree that people with developmental disabilities should be kept in an institution



Attitudes towards people with developmental disabilities

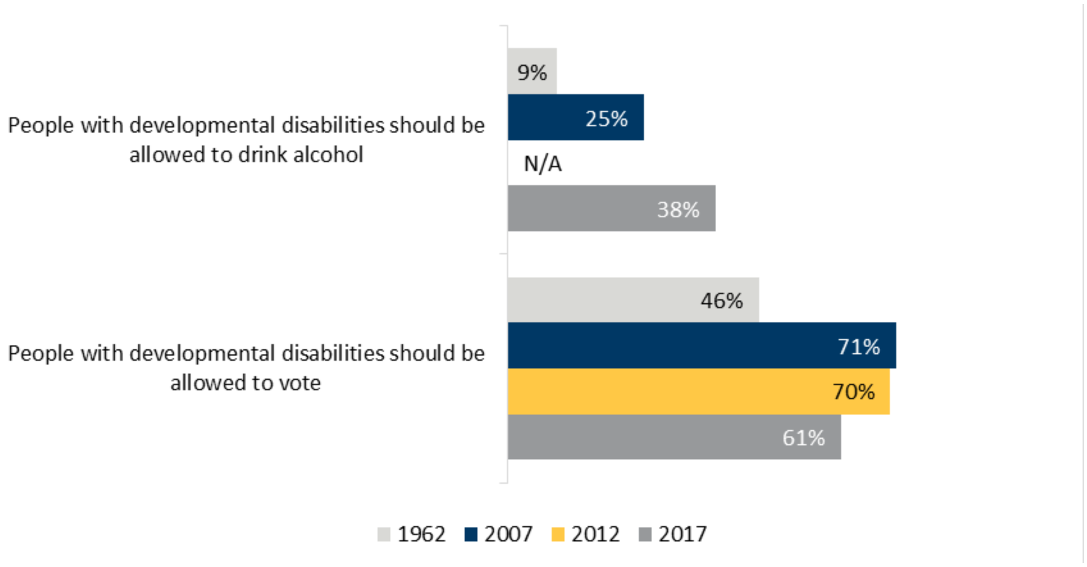
In general, respondents have very positive attitudes toward the role people with development disabilities can play in society. Most Minnesotans have a lot respect for companies that employ people with developmental disabilities, believe that they should be included in public places and social events, and agree that most of them can be very productive workers (Figure 11).

Figure 11: Percentage of respondents who agree somewhat or agree strongly with statements on the role of people with developmental disabilities in society



The survey results show less agreement on whether people with developmental disabilities should be allowed to vote or drink alcohol (Figure 12). Compared to 1962, the number of respondents who believe they should has grown dramatically, but on both issues, a sizable number of respondents still disagree or are ambivalent.

Figure 12: Percentage of respondents who agree somewhat or strongly that people with developmental disabilities should be allowed to drink alcohol or vote



Government services and taxpayer money

In 2007, 2012, and 2017, respondents were also asked about the importance of spending taxpayers' money on government services for people with developmental disabilities related to the areas of housing, education, employment, and other services, such as health care. Each year, only about one out of 10 respondents agree that too much taxpayer money is spent on people with developmental disabilities. Overall, a majority of respondents believe it is more than somewhat important for government to use taxpayers' money to provide such government services. The top five services which over 75 percent of respondents deemed important in 2017 were:

1. Access to quality, coordinated **health care services.**
2. **Early childhood special education services** (pre-kindergarten, birth to age 5) to help children with developmental disabilities prepare for school.
3. **Special education services** for students with developmental disabilities.
4. **Protection services** to prevent abuse of people with developmental disabilities.
5. **Employment services** so that people with developmental disabilities can learn job skills.

The more familiar respondents are with developmental disabilities, the more likely they are to say that it is important for the government to use taxpayers' money to provide various services to people with developmental disabilities.

About the respondents

Each survey included a random sample of Minnesotans with the sample profile closely matching the general population of Minnesota.[4] Additionally, the 2017 survey was administered among larger sample sizes of racial and ethnic communities in Minnesota. Detailed findings from this oversampling strategy can be found here.

Table 3: Sample sizes of the 1962, 2007, 2012, and 2017 general public attitudes surveys

Year	Sample size
1962	900
2007	806
2012	285
2017	1,001

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[4] For more detail on the methodologies of each survey, refer to the complete survey reports for 1962, 2007, 2012, and 2017 as posted on the Council's website.

Public views on health care

The Minnesota Governor's Council on Developmental Disabilities (GCDD), together with the Minnesota Citizens Forum and the Minnesota Board on Aging, conducted the first survey of Minnesotans' views on health care services and costs in 2004. Fourteen years later, in 2018, the GCDD replicated the survey with an updated questionnaire that also included questions on the Affordable Care Act. Topics in both surveys included:

1. **Satisfaction with health care quality and costs**, in general for the U.S. and specifically for Minnesotans based on respondents' personal experiences.
2. **Level and types of health care insurance coverage**, and related attitudes and satisfaction levels.
3. **Perceptions regarding changes** in health care costs and payment responsibilities.
4. **Attitudes and values** regarding a range of health care coverage, costs, and social responsibility issues.
5. **Preferences for universal health care versus private health care insurance**, and related tradeoffs and opinions.

Key findings from the health care surveys

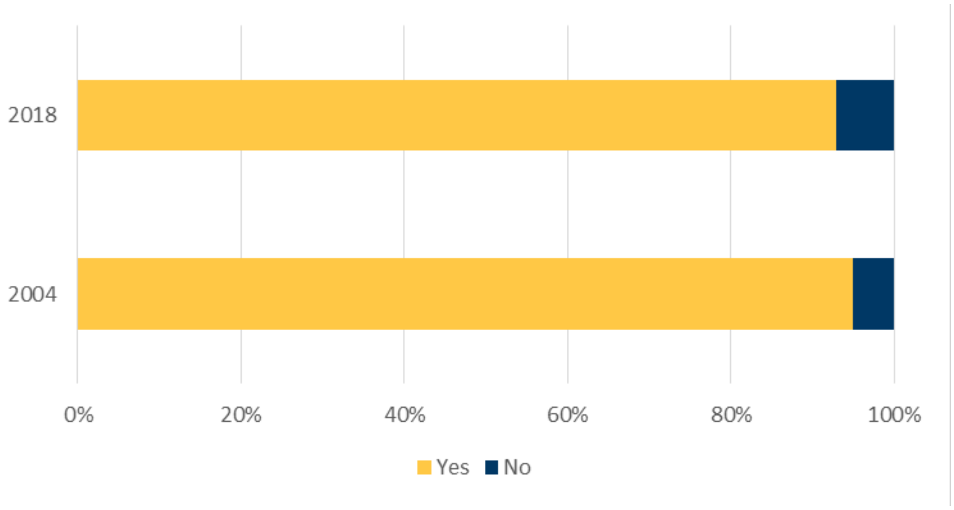
- Both the 2004 and 2018 surveys found that over nine out of 10 Minnesotans have some form of health insurance.
- The number of respondents indicating they have Medical Assistance (MA)/Medicaid more than doubled between 2004 and 2018. This is at least partly a result of the expansion of Medicaid eligibility under the 2010 Affordable Care Act (ACA).
- Medicare recipients are generally more satisfied than respondents with private health insurance on all aspects of their health care experiences.
- Regardless of differences between respondents, most agree that:
    - Health care should be available to all citizens regardless of their income or employment status.
    - People should not be turned away from necessary medical treatment, even if they are uninsured and cannot afford the treatment.
    - Everyone should pay something for their health care, with people paying varying amounts depending on what they can afford.
    - People who need more services than others, such as the elderly and people with disabilities, should get them without paying more.
- Households with a person with a developmental disability are more likely to have a pessimistic near-future outlook regarding health care quality and affordability, especially federal cuts to MA/Medicaid and health care access in general.

Detailed findings

Health care coverage

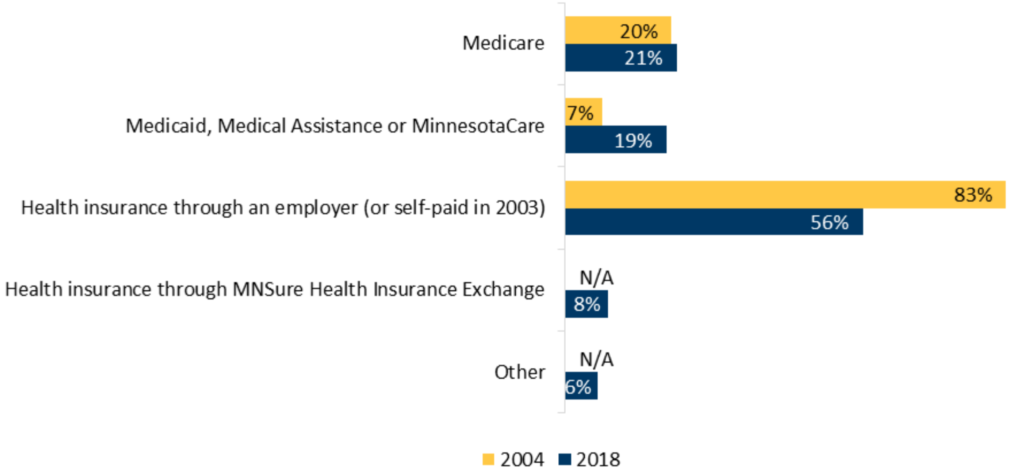
In 2004, 95 percent of respondents indicated they had some form of health insurance or health coverage. In 2018, this percentage was 92 percent (Figure 13).

Figure 13: Percentage of respondents indicating they have health coverage



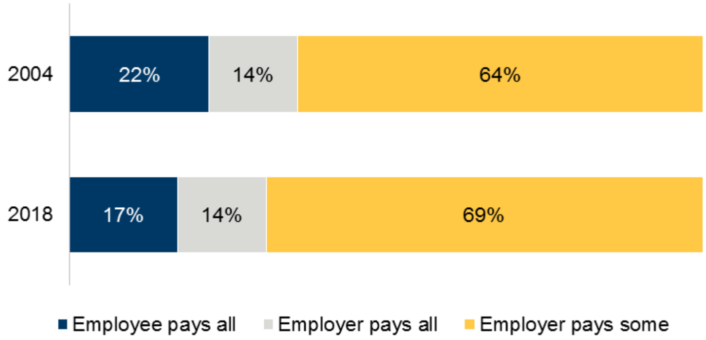
Between 2004 and 2018, the number of respondents with Medical Assistance/Medicaid grew from seven percent to 19 percent (Figure 14). This is at least partly a result of the expansion of Medicaid eligibility under the Affordable Care Act (ACA), which was passed in 2010.

Figure 14: Percentage of respondents covered by type of insurance for 2004 and 2018



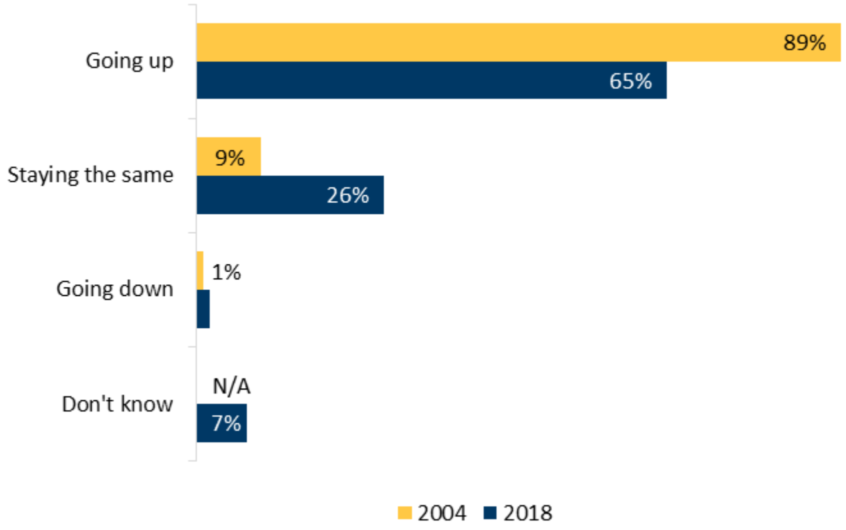
In 2004 and 2018, for about three-quarters of respondents with private insurance, their employer paid all or some of the health insurance premiums (Figure 15).

Figure 15: Percentage of respondents with private insurance whose employer pays none, some, or all of a respondent's health insurance premiums



Compared to 2004, fewer respondents in 2018 indicated they thought their health insurance premiums had gone up in the past few years (Figure 16).

Figure 16: Respondents' belief whether health insurance premiums have gone up in the past few years



Satisfaction with health coverage and care

In 2004, 27 percent of respondents rated their health insurance coverage excellent and another 46 percent rated it good; 28 percent rated it fair or poor. In 2018, 60 percent of respondents rated their health coverage and care as good to excellent. Older respondents and those with Medicare were typically more satisfied with their health insurance coverage and health care experiences.

"Over the last year I've developed significant health issues and have seen many doctors and specialists. I've never felt like it was a 'cattle drive,' I've been fortunate enough to have doctors who spend a lot of time listening and working together to come up with a diagnosis and treatment plans."

In both years, respondents were most satisfied with the health care provided, such as their ability to get a doctor's appointment when they want, their ability to see medical specialists when needed, and the amount of time they are able to spend with their doctor. Respondents were least satisfied with the total amount they pay for health insurance. In 2018, this last factor, in combination with the whole process of pricing, billing, and reimbursements for medical services, is also the most likely predictor of overall health care quality ratings.

"Medical bills are hard to understand. It's so easy for them to overcharge for things. Not everyone takes the time to review every line item. We have this certain trust that we won't be taken advantage of, and yet I think healthcare systems thrive on that."

Health care concerns

In 2018, one out of four respondents (27 percent) believed they will be worse off in three years regarding access to good quality, affordable health care. Respondents expressed most concern about the rising costs of health care premiums, deductibles, and co-pay fees, as well as drugs and other medical services. Households with a person with a developmental disability are more likely to have a pessimistic near-future outlook regarding health care quality and affordability, especially federal cuts to MA/Medicaid and health care access in general.

Views on the government's role in health care and the Affordable Care Act

The 2018 survey included a set of questions about the Affordable Care Act and the government's role in health coverage and care. A majority of respondents (58 percent) believe Congress should deal with health care reform on a gradual basis, as opposed to a comprehensive, repeal and replace approach to the Affordable Care Act.

"They should reform the healthcare system gradually so that they can experiment and see what will work and won't work in the future."

In 2018, 54 percent of respondents indicated that it is the responsibility of the federal government to ensure that all Americans have health care coverage, while 32 percent indicated this is not the government's responsibility.

"Healthcare companies, insurance companies and healthcare providers are not properly incentivized to provide care for everyone. It is expensive and logistically hard to provide healthcare to poor and disabled people. The government needs to make sure that everyone, regardless of whether they need high or low levels of care, have continued access at a price that is not going to make them lose their financial freedom."

"Healthcare you don't pay for is a handout. Social security payments to individuals who have never paid premiums is a handout. Welfare for individuals who are capable of working is a handout. Money for this does not grow on trees. It comes out of our taxes, insurance premiums, etc."

In both 2004 and 2018, respondents were fairly evenly split in terms of preference for a government-run health care system versus a system based mostly on private health insurance.

About the respondents

The 2004 survey was administered via telephone, while the 2018 survey was conducted online. The samples closely matched geographic dispersion and other demographics of the state's population (age, income, ethnicity, and race).[5]

Table 4: Sample sizes of the 2004 and 2018 health care surveys

Year	Sample size
2004	800
2018	1,009

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[5] For more detail on the sample and survey design, refer to the original reports for 2004 and 2018, as posted on the Council's website.