



University Center for Excellence in Developmental Disabilities

## National Core Indicators: Four Topical Analyses

Health Indicators

County Developmental Disability Programs (CDDP) and Brokerage Services

Loneliness

Housing Satisfaction

PREPARED FOR: Oregon Office of Developmental Disability Services

PREPARED BY: OHSU University Center for Excellence in Developmental Disabilities

AUTHORS: Willi Horner-Johnson, Ph. D., Amy Jeon, M.S., Rhonda Eppelsheimer, M.S.W.

June 2021

## Contents

Health Indicators .....	3
County Developmental Disability Programs (CDDP) and Brokerage Services.....	19
Loneliness .....	23
Housing Satisfaction .....	27
References.....	32

## Health Indicators

The information in this report came from Oregon participants in the 2016-2019 National Core Indicators (NCI) surveys. We combined three years of data to increase the sample sizes available for analysis. The report describes health and wellness, healthcare receipt, and barriers to healthcare among NCI respondents. We provide information for the overall NCI sample, followed by comparisons between subgroups of NCI respondents. For the subgroup comparisons, only those that were statistically significant or approaching statistical significance are shown in charts. Statistical significance refers to the probability that an event or difference occurred by chance alone. For this report, we considered differences to be statistically significant if there was less than a 5% probability ( $p < .05$ ) that the observed difference happened by chance. We considered differences to be approaching statistical significant if the probability that they happened by chance was greater than 5% but less than 10%. In the text, differences approaching statistical significance are described using the word “trend” (e.g. “there was a trend toward women engaging in moderate physical activity less frequently than men”).

Where possible, we also compare findings from the NCI to 2018 Oregon data from the Behavioral Risk Factor Surveillance System (BRFSS). The BRFSS is a telephone survey that asks about health, behaviors that affect health, and access to healthcare. It is conducted every year by each state and U.S. territory health department. The survey is random, meaning that any resident might be called. However, some groups of people are not included. Children under age 18 and people who are in an institution, such as a jail or nursing home, are not included in the survey. People who have no telephone are not included. Those who do not speak English or Spanish are not included. Some people who have a disability may not be included because they do not understand the questions, cannot get to the phone in time, or use a special telephone that sounds to the caller like a fax machine. In the BRFSS survey, people are considered to have a disability if they answer “Yes” to one or more of the following questions:

1. Are you deaf or do you have serious difficulty hearing?
2. Are you blind or do you have serious difficulty seeing, even when wearing glasses?
3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?
4. Do you have serious difficulty walking or climbing stairs?
5. Do you have difficulty dressing or bathing?
6. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor’s office or shopping?

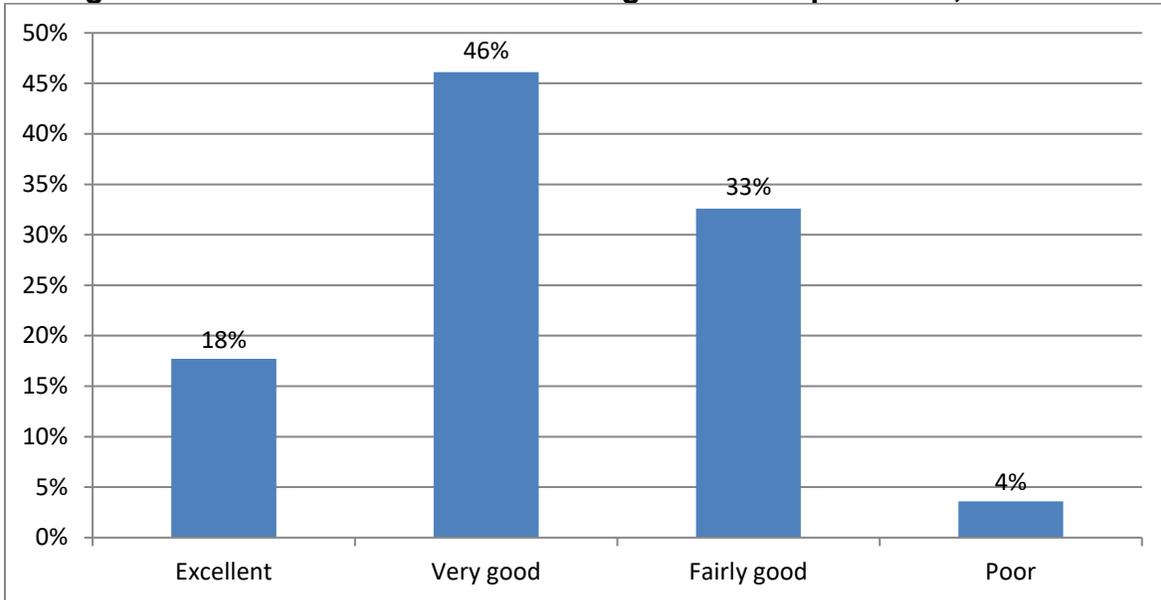
When similar health questions were used on both the BRFSS and the NCI survey, we report data for NCI participants, BRFSS respondents with disabilities, and BRFSS respondents without disabilities. We were not able to conduct statistical tests comparing NCI and BRFSS respondents, but the BRFSS data provide some context for understanding the health of NCI participants relative to the general adult population of Oregon.

## Health and Wellness

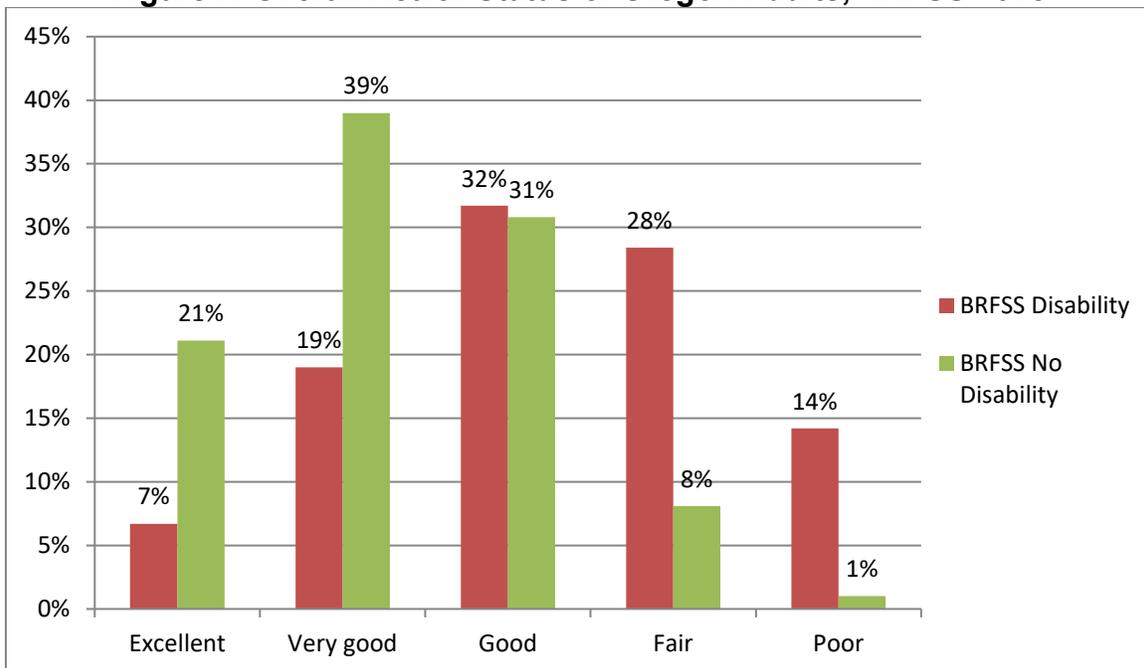
### Health Status

Among Oregon NCI participants, 18% had excellent overall health, 46% had very good health, 33% had fairly good health, and 4% had poor health (Figure 1). While these categories are not directly comparable to the categories used in the BRFSS, the data suggest that the perceived health of people with I/DD is more similar to the Oregon adult population without disabilities than to other adults with disabilities in Oregon (see Figure 2).

**Figure 1. Overall Health Status of Oregon NCI Respondents, 2016-2019**



**Figure 2. Overall Health Status of Oregon Adults, BRFSS 2018**



In the NCI data, there were no statistically significant differences in health status of men and women with I/DD.

There was a trend toward white, non-Hispanic adults with I/DD being more likely than those in other racial and ethnic groups to describe their health as fairly good (39% vs. 32%) rather than as excellent or very good ( $p=0.086$ ).

Similarly, there was a trend ( $p=0.087$ ) toward lower percentages of adults in rural/small town/micropolitan areas (hereafter referred to as rural) describing their health as excellent (13% vs. 19%) and higher percentages describing their health as fairly good (39% vs. 32%) compared to respondents in metropolitan areas (hereafter referred to as urban).

There was also a trend ( $p=0.078$ ) toward differences in health status by level of ID (see Table 1).

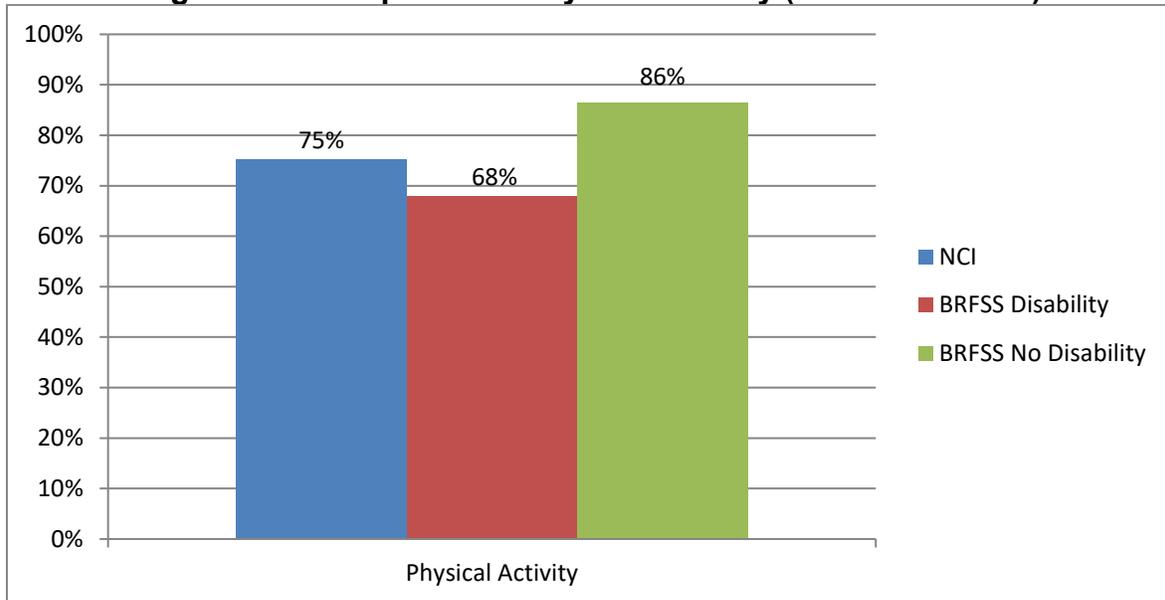
**Table 1. Overall Health of Oregon NCI Respondents, by Level of ID**

<b>Health Status</b>	<b>Mild ID</b>	<b>Moderate ID</b>	<b>Severe/Profound ID</b>
Excellent	16.7%	21.6%	12.6%
Very Good	44.5%	48.1%	52.0%
Fairly Good	35.2%	27.3%	12.9%
Poor	3.6%	3.0%	5.5%

**Physical Activity**

In the Oregon NCI sample, 75% of participants engaged in moderate physical activity at least once per week. This is higher than the percentage of BRFSS respondents with disabilities who reported exercising but lower than the percentage of BRFSS respondents without disability who exercised (Figure 3). However, the BRFSS asked about *any* exercise during the past month, rather than *weekly* exercise, so the percentages are not entirely comparable.

**Figure 3. Participation in Physical Activity (NCI and BRFSS)**



Among NCI respondents, there was a trend ( $p=0.096$ ) toward women engaging in moderate physical activity less frequently than men (Table 2). Women were also significantly less likely to do exercise that made their muscles work hard (25% vs. 34%,  $p=0.029$ ).

**Table 2. Moderate physical activity participation among male and female NCI participants**

# times exercised per week	Male	Female
None	24.0%	25.9%
1-2	27.8%	31.6%
3-4	19.4%	20.0%
5 or more	28.8%	22.5%

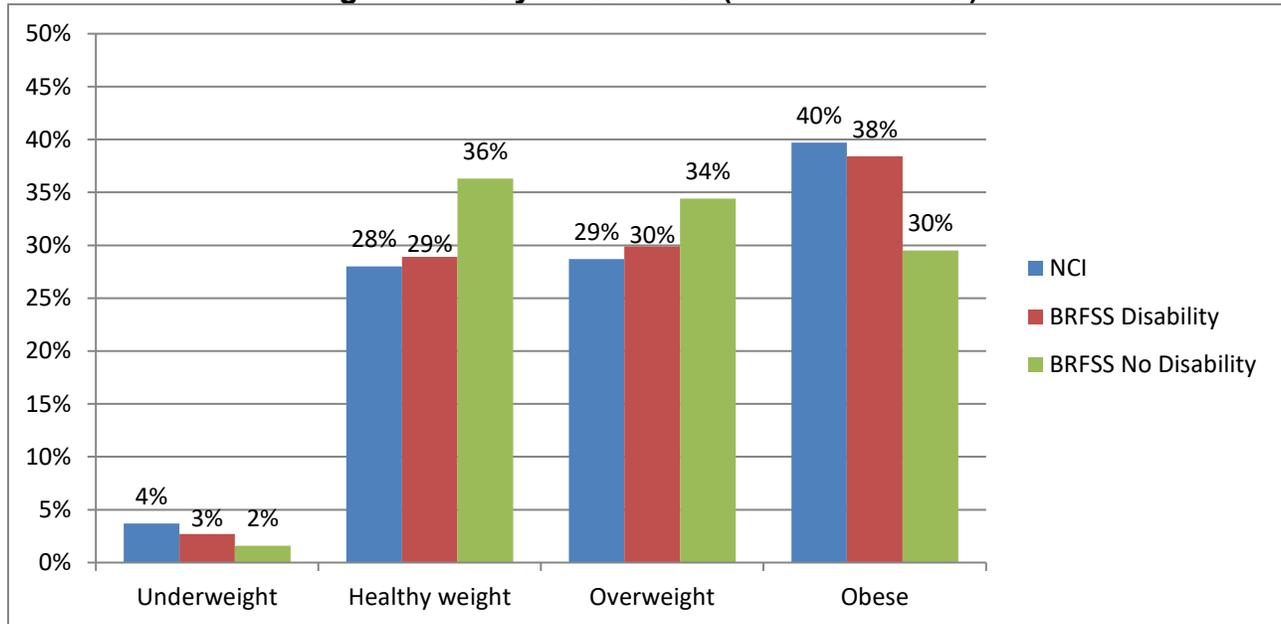
We found no race/ethnicity or urban/rural differences in moderate physical activity or in doing exercise that makes muscles work hard.

For level of ID, there were no statistically significant differences in participation in moderate physical activity. However, people with severe/profound ID were significantly less likely to participate in activity that made their muscles work hard (13% vs. 31-33% of people with mild or moderate ID,  $p=0.007$ ).

## **Body Mass Index**

Overweight and obesity are common; 29% of NCI participants were in the overweight range and 40% were obese. The proportion who were obese was slightly higher than among Oregon adults with disabilities in BRFSS data, and markedly higher than among adults without disabilities in Oregon (Figure 4).

**Figure 4. Body Mass Index (NCI and BRFSS)**



Among NCI participants, women were significantly more likely to be obese than men (47% vs. 34%,  $p < 0.001$ ).

We found no significant differences in body mass index by race/ethnicity or urban/rural location.

People with severe/profound ID were much less likely to be obese than people with mild or moderate ID ( $p < 0.001$ , Table 3.)

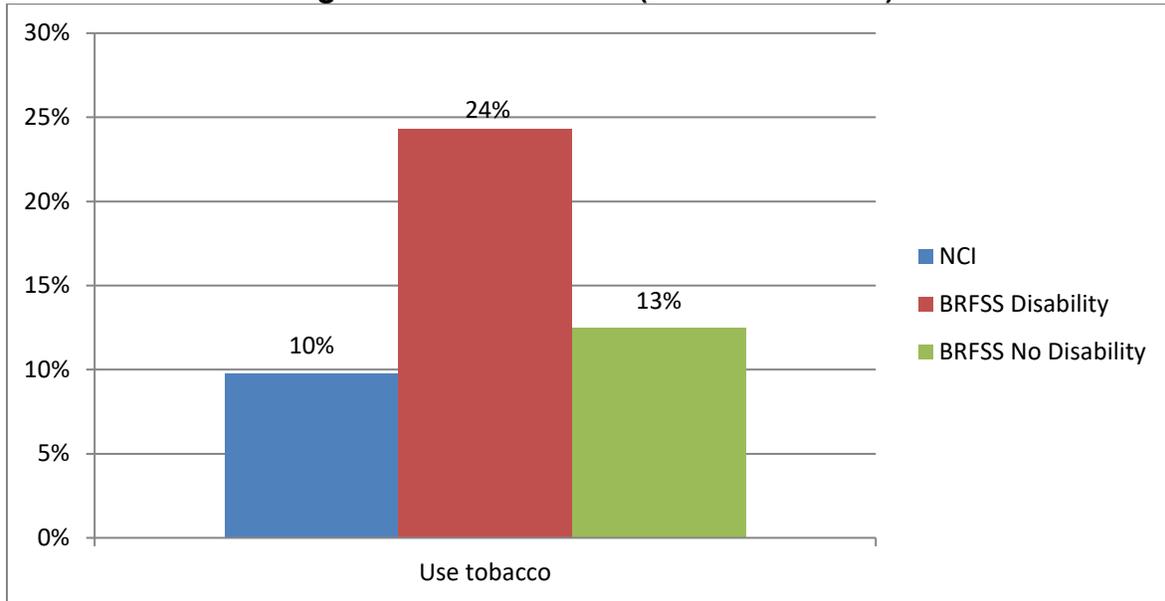
**Table 3. Body Mass Index by Level of ID**

	<b>Mild ID</b>	<b>Moderate ID</b>	<b>Severe/Profound ID</b>
<b>Healthy weight</b>	23.7%	28.5%	47.5%
<b>Overweight</b>	29.6%	26.0%	27.1%
<b>Obese</b>	43.8%	40.8%	17.8%
<b>Underweight</b>	2.9%	4.7%	7.6%

**Tobacco Use**

Among NCI participants, 10% smoked or chewed tobacco. This is slightly lower than the percentage of BRFSS respondents without disabilities who are current smokers and much lower than the proportion of BRFSS respondents with disabilities who are current smokers (Figure 5).

**Figure 5. Tobacco Use (NCI and BRFSS)**



In NCI data, there was a trend toward women being less likely to use tobacco products than men (7.5% vs. 11.4%, p=0.069).

There was also a trend toward differences by race/ethnicity (p=0.069). White, non-Hispanic respondents were more likely to have a response indicating no use of tobacco products, while the “don’t know” response option was more frequently selected (8.8% vs. 4.3%) for people in other racial/ethnic groups.

Differences in tobacco use by urban/rural location were not statistically significant. There were significant differences in use of tobacco products by level of ID (p<0.001). People with moderate ID were less likely to use tobacco products than those with mild ID; adults with severe/profound ID were the least likely to use tobacco products (Table 4).

**Table 4. Use of Tobacco Products by Level of ID**

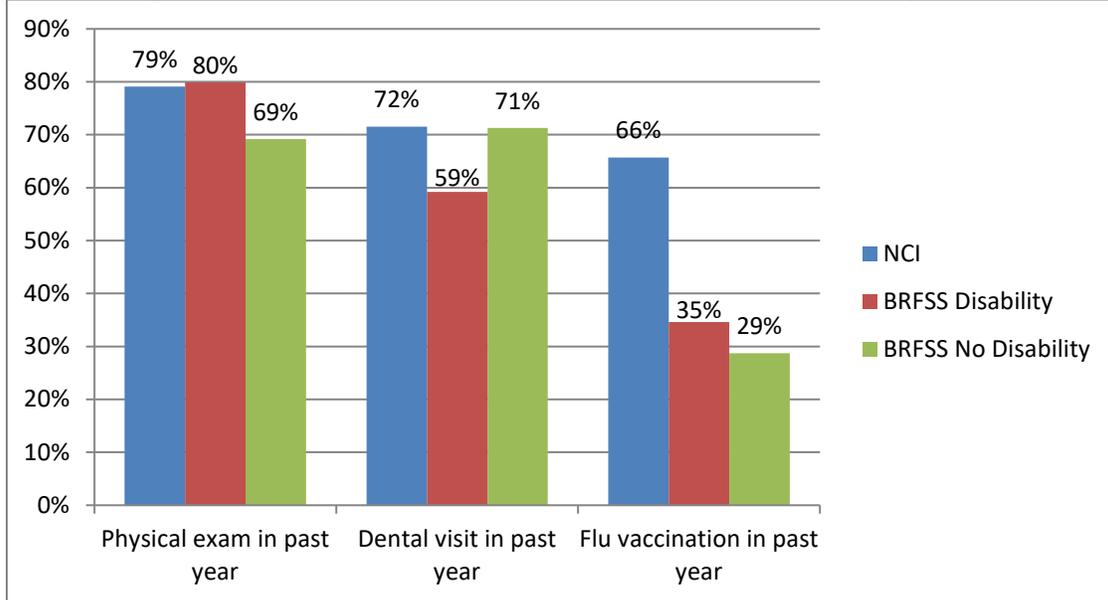
	<b>Mild ID</b>	<b>Moderate ID</b>	<b>Severe/Profound ID</b>
<b>No</b>	79.3%	91.2%	95.3%
<b>Yes</b>	15.1%	5.1%	0.8%
<b>Unknown</b>	5.6%	3.7%	3.9%

## Receipt of Healthcare

### Routine Physical Exams, Dental Visits, and Flu Vaccination

Most NCI participants had received a routine physical exam in the past year, visited a dentist in the past year, and received a flu vaccine in the past year. Flu vaccination, in particular, was much more common among NCI participants than it was among BRFSS respondents with or without disabilities (Figure 6).

**Figure 6. Physical Exams, Dental Visits, and Flu Vaccinations (NCI and BRFSS)**



In NCI data, there was a trend toward women being more likely than men to have had a dental visit in the past year (75% vs. 69%,  $p=0.056$ ). In addition, women were significantly more likely than men to have received flu vaccination in the past year (69% vs. 63%,  $p=0.033$ ).

There were no significant differences in receipt of routine exams, dental visits, or flu vaccines by race/ethnicity, urban/rural location, or level of ID.

### **Eye Exams and Hearing Tests**

The NCI asks about eye exams and hearing tests, while the BRFSS does not include data on these types of health checks.

Forty-two percent of NCI participants had received an eye exam within the past year. An additional 17% had received an eye exam between 1 and 2 years ago.

- Women were significantly more likely than men to have received an eye exam within the past year (47% vs. 38%,  $p=0.005$ ).
- People living in rural areas or small towns were more likely have had an eye exam in the past year than people living in metropolitan areas (49% vs. 39%,  $p=0.004$ ).
- People with severe/profound ID were significantly less likely to have had an eye exam in the last year compared to people with mild or moderate ID (23% vs. 46% and 47%, respectively;  $p<0.001$ ).
- Racial/ethnic differences in receipt of eye exams were not statistically significant.

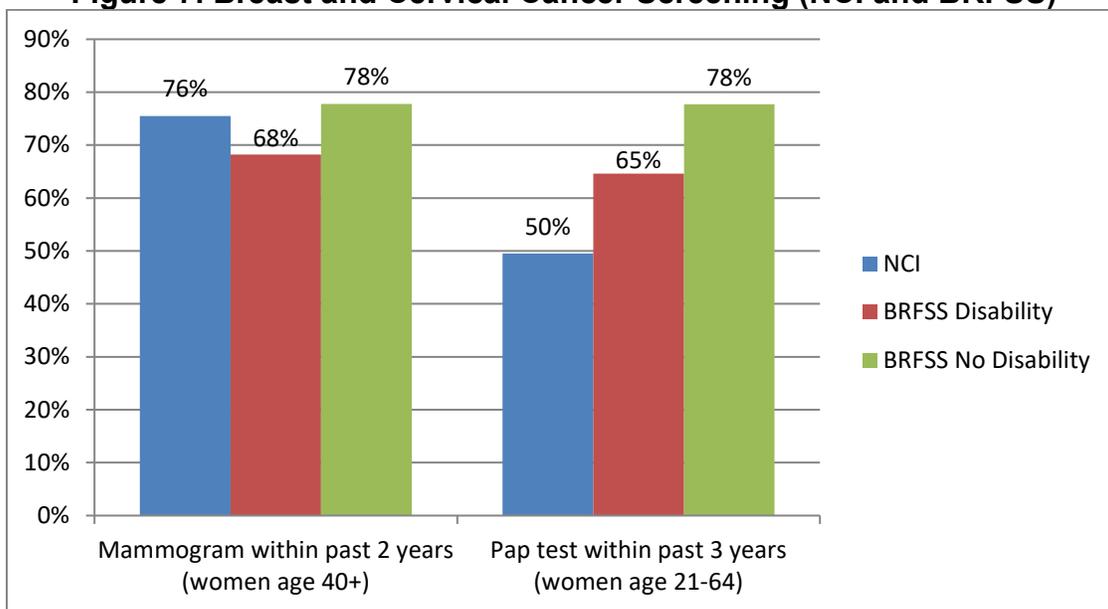
Only 25% of NCI participants were known to have received a hearing test within the past 5 years; however, for 32% of participants, the length of time since they'd had a hearing test was unknown.

- There were no statistically significant differences in receipt of hearing tests by gender or urban/rural residence.
- There was a trend toward non-Hispanic White participants being more likely to have received a hearing test within the past 5 years compared to people in other racial or ethnic groups (26% vs. 18%,  $p=0.094$ ).
- Participants with severe/profound ID were less than half as likely to have received a hearing test in the past 5 years as participants with mild or moderate ID (12% vs. 29% and 24%, respectively,  $p<0.001$ ).

**Breast and Cervical Cancer Screening**

The U.S. Preventive Services Task Force (USPSTF) recommends a screening mammogram every 2 years for women age 50-75 years. For women ages 40-49 and women over 75, the choice to screen is an individual one, based upon risk factors. The NCI survey asks about mammograms for women ages 40 and up. The USPSTF recommends that women ages 21-64 receive a Pap test every 3 years to screen for cervical cancer. For more than half of the NCI participants who were eligible for breast or cervical cancer screening, the response regarding how recently they had been screened was “don’t know” (56% for each type of screening). Of the remaining women (those whose screening interval was known), receipt of a mammogram within the past 2 years was comparable to percentages among BRFSS respondents with and without disabilities, but receipt of Pap testing within the past 3 years was markedly lower (Figure 7).

**Figure 7. Breast and Cervical Cancer Screening (NCI and BRFSS)**



Among NCI participants, we did not observe statistically significant differences in breast or cervical cancer screening by race/ethnicity or by urban/rural residence. However, there were significant differences by level of ID. For breast cancer screening, a “don’t know” response was most common for those with mild ID (60% vs. 49% for moderate ID and 47% for severe/profound ID,  $p=0.025$ ). Similarly, “don’t know” responses for cervical cancer screening were most common among those with mild ID (61% vs. 48% for moderate ID and 41% for severe/profound ID,  $p<0.001$ ). Among those for whom the date of last screening was known, there were significant differences by level of ID for both breast cancer screening ( $p=0.021$ ) and cervical cancer screening ( $p=0.002$ ) (Table 5).

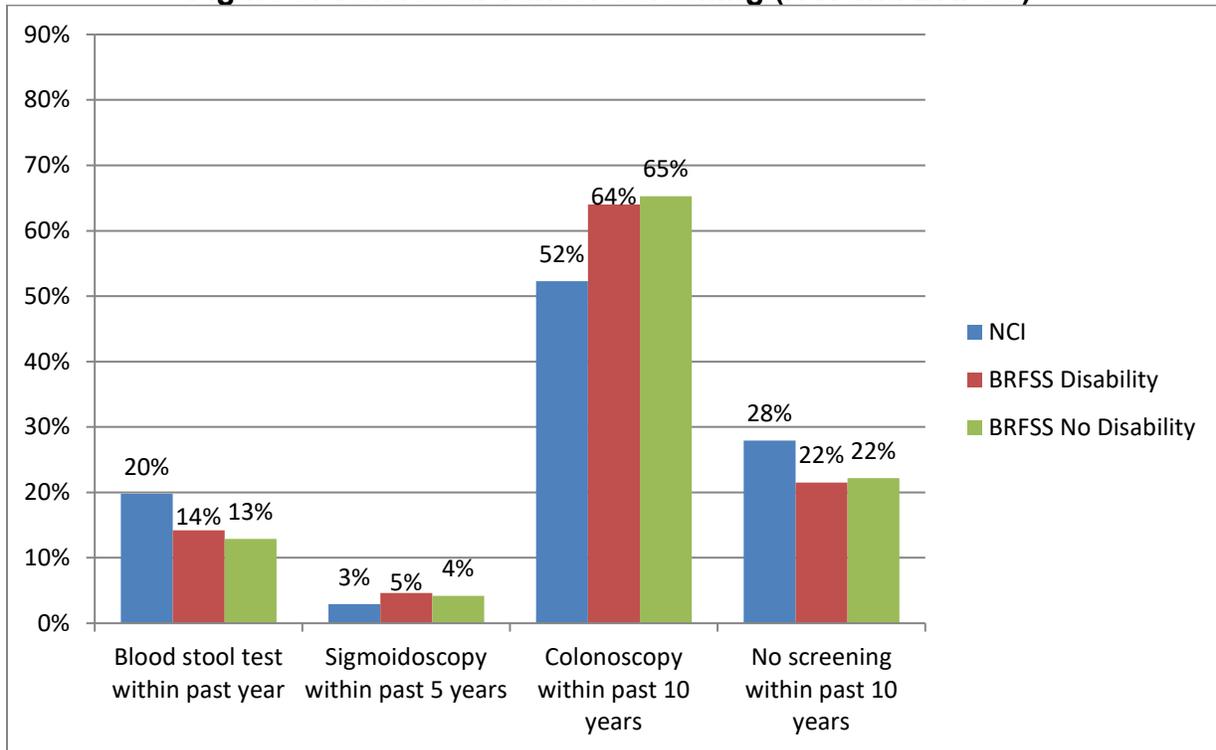
**Table 5. Breast and Cervical Cancer Screening by Level of ID**

	Mild ID	Moderate ID	Severe/Profound ID
<b>Mammogram in past 2 years</b>	84.2%	61.5%	56.3%
<b>Pap test in past 3 years</b>	58.3%	41.7%	18.2%

### **Colorectal Cancer Screening**

For adults ages 50-75 years, the U.S. Preventive Services Task Force recommends a blood stool test every year, sigmoidoscopy every 5 years, or colonoscopy every 10 years to screen for colorectal cancer. Colorectal cancer screening status was unknown for 54% of eligible Oregon NCI participants. Among those for whom screening status was known, the percentage who had received a blood stool test in the past year was somewhat higher than among BRFSS respondents, while the percentage who had received a colonoscopy in the past 10 years was lower and the percentage who had not received any screening within the past 10 years was somewhat higher (Figure 8).

**Figure 8. Colorectal Cancer Screening (NCI and BRFSS)\***



\*Percentages for each group can total more than 100% because some people may have had more than one type of test.

Among NCI participants ages 50-75, women were twice as likely as men to have received no form of colorectal cancer screening at all in the past 10 years (40% vs. 20%,  $p=0.009$ ). With regard to specific tests, there was a trend toward women being less likely to have received a colonoscopy than men (43% vs. 58%,  $p=0.60$ ). There were no statistically significant differences in screening by race/ethnicity, urban/rural residence, or level of ID.

## Health Care Coverage and Access

### Health Insurance

Virtually all NCI participants had some type of health insurance. The vast majority (91%) were covered by the Oregon Health Plan (Medicaid). Many were also covered by Medicare. Only 9% had private insurance (Table 5).

**Table 5. Health Insurance Coverage, NCI and BRFSS**

Insurance Type	NCI*	BRFSS Disability	BRFSS No Disability
None	0.2%	10.0%	9.9%
Via own or someone else's employer, or privately purchased	9.3%**	30.7%	60.2%
Medicaid/OHP	91.0%	18.9%	10.9%
Medicare	37.9%	29.1%	13.2%
Other***	2.9%	11.3%	5.7%

\*Percentages add up to more than 100% because NCI participants were asked to indicate all sources of coverage. (BRFSS respondents were only asked to indicate primary source of coverage.)

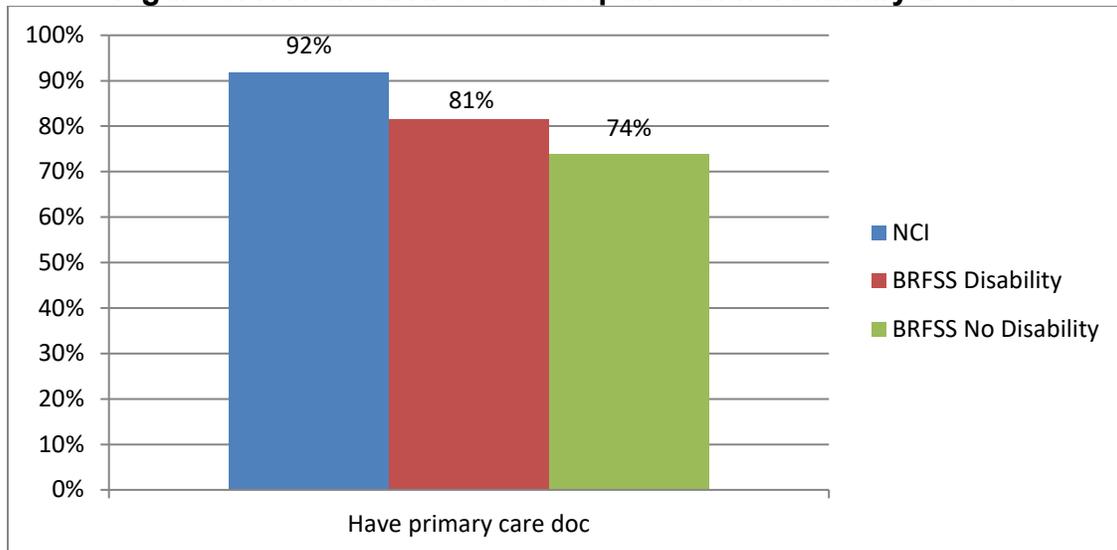
\*\*Includes individuals covered through their parents' insurance.

\*\*\*Includes military/VA, Indian Health Service, and unspecified other sources.

### Primary Care Doctor

Most (92%) of Oregon NCI participants had a primary care doctor. In contrast, 81% of Oregon BRFSS respondents with disabilities and 74% of BRFSS respondents without disabilities said they had at least one person they thought of as their personal doctor (Figure 9).

**Figure 9. NCI and BRFSS Participants with a Primary Doctor**



There were no significant gender, race/ethnicity, urban/rural, or level of ID differences in whether or not NCI participants had a primary care doctor.

### **Delays in Getting Medical Care in Past 12 Months**

Most NCI participants were able to get the medical care they needed when they needed it. Among those who indicated delays in getting medical care, the most common reason specified was that they could not get an appointment soon enough (Table 6). There were no statistically significant gender, race/ethnicity, urban/rural, or level of ID differences in experiencing delayed medical care.

**Table 6. Reasons for Delays in Getting Medical Care (NCI and BRFSS)\***

	<b>NCI</b>	<b>BRFSS Disability</b>	<b>BRFSS No Disability</b>
No delay or no care needed	83.1%	67.6%	84.6%
Couldn't get through on telephone	1.1%	1.7%	1.0%
Couldn't get appointment soon enough	4.0%	9.9%	6.8%
Once there, wait to see doctor was too long	0.5%	3.2%	1.7%
Didn't have transportation	1.6%	9.9%	1.9%
Clinic building/office was not physically accessible	0.1%	N/A	N/A
Couldn't find doctor who understood my health needs	2.0%	N/A	N/A
Couldn't find doctor who would accept my insurance	2.1%	N/A	N/A
Could not see doctor because of cost	2.6%**	18.1%	9.9%
Other	6.7%	7.6%	4.0%

\*Percentages in each column can add up to more than 100% because some people experienced more than one reason for delayed medical care.

\*\*Cost was more frequently indicated as a barrier in 2016-2017 when there was a separate question about cost, as opposed to cost being just one item in a list of possible barriers.

N/A = Not asked in BRFSS

**Challenges with Taking Medications in Past 12 Months**

Most NCI participants were able to take medications when needed. Among those who could not, the most common reason specified was cost (Table 7). Men were twice as likely as women to indicate some type of difficulty with taking medications if needed (14% vs. 7%, p<0.001). There were no statistically significant differences for race/ethnicity, urban/rural residence, or level of ID.

**Table 7. Reasons for Not Taking Medications (NCI and BRFSS)**

	<b>NCI*</b>	<b>BRFSS Disability</b>	<b>BRFSS No Disability</b>
No medications or no problems** taking them	82.4%	86.2%	95.6%
Couldn't get prescriptions filled in time	3.1%	N/A	N/A
The medicine is hard to swallow/tastes bad	1.1%	N/A	N/A
Don't like the way it makes me feel	1.2%	N/A	N/A
No one was available to help when it was time to take meds	0.2%	N/A	N/A
No transportation to pick up medication(s)	0.1%	N/A	N/A
Could not take my medication because of cost	4.1%	13.8%	4.4%
Other	10.0%	N/A	N/A

\*Percentages add up to more than 100% because some people experienced more than one reason for not taking medications.

\*\*For BRFSS data, this only means that cost was not a problem (no other problems were addressed)

N/A = Not asked in BRFSS

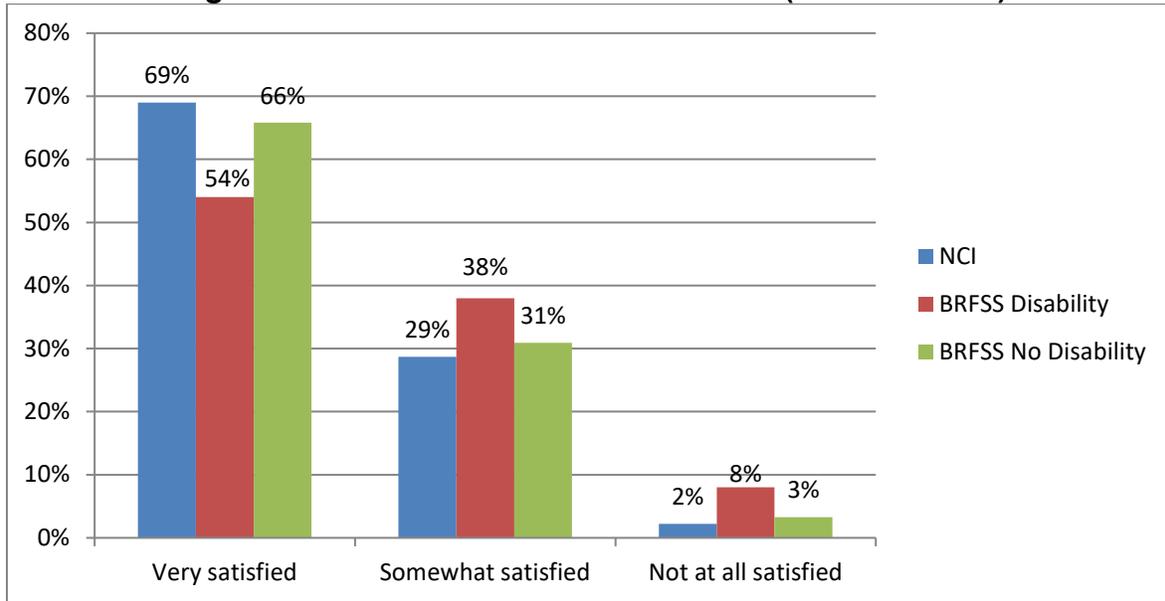
**Access to Mental Health Services**

In the 2018-2019 survey year, Oregon NCI participants were asked about difficulty with accessing mental health services. Thirty-one percent of participants had not needed any mental health services or had not tried to access mental health services during the past year. Among those who did try to access mental health services, 23% said they experienced barriers or challenges with receiving the mental health services the needed. With the limited sample size available in just one year of data, we did not find statistically significant gender, race/ethnicity, urban/rural, or level of ID differences in barriers to mental health services.

### **Satisfaction with Health Care**

More than two-thirds of NCI participants were very satisfied with their health care, and only 2% were not at all satisfied. Satisfaction levels among NCI participants were similar to those among BRFSS respondents without disabilities. BRFSS respondents with disabilities were notably less satisfied with their care (Figure 10).

**Figure 10. Satisfaction with Health Care (NCI & BRFSS)**



Among NCI participants, there were no significant gender, race/ethnicity, urban/rural, or level of ID differences in satisfaction with health care.

---

## Recommendations

These initial analyses suggest some areas for possible action to improve the health of adults receiving developmental disabilities services in Oregon.

Physical activity. Among Oregon NCI participants, women exercised less frequently than men and were less likely to engage in exercise that made their muscles work hard. Women may need more opportunities for physical activity as well as additional support and encouragement to be physically active.

Obesity. While obesity is common among Oregon adults in general, it is especially common among adults with I/DD, with 40% of NCI participants meeting the definition of obesity. Adults with I/DD need information, resources, and support to help them develop and maintain healthy eating habits. Physical activity is also helpful in maintaining a healthy body weight, but changes in diet are most important for losing weight and keeping it off.

Tobacco use. Overall, relatively few NCI participants used tobacco. However, 15% of those with mild ID used tobacco, which is slightly higher than the percent of adults without disabilities in Oregon that smoke. Moreover, in listening sessions about tobacco use, the OHSU UCEDD and the Oregon Office on Disability and Health have learned that adults with I/DD who currently smoke or are former smokers often started smoking very early in life – as young as 12 years old. Thus, efforts are needed to educate children and youth with I/DD about the dangers of smoking and provide skills to help them resist starting tobacco use. We also learned that people with I/DD are heavily influenced by their caregivers' tobacco use, even if their caregivers do not smoke in front of them. Helping caregivers quit smoking would therefore have significant health impacts, both for them and for the individuals with I/DD they support.

Eye exams. Only 59% of NCI participants had received an eye exam within past 2 years. Further, people with severe/profound ID were about half as likely to have received a recent eye exam, compare to people with mild or moderate ID. Regular eye exams are important because people with I/DD are at greater risk for vision problems than the general population.<sup>1</sup> Failure to identify and treat eye problems may result in reduced functioning and quality of life.

Hearing checks. Only 25% of NCI participants were known to have received a hearing test within the past five years. Data from Special Olympics health screenings indicate that the prevalence of hearing loss is 1.4 times greater than in the general population.<sup>2</sup> Undetected hearing loss may contribute to social isolation and poor quality of life. Routine hearing checks are important for detecting hearing loss and providing appropriate treatment or assistive technology.

Cervical cancer screening. Among those whose screening status was known, only half of female NCI participants in the eligible age range had been screened for cervical cancer within the past three years. Prevalence of screening declined as level of ID increased. Health care providers and others may assume that women with I/DD are not sexually active and therefore not at risk of cervical cancer. However, people with I/DD may be

sexually active even if their caregivers are not aware of it. Further, people with I/DD are at very high risk of sexual abuse.<sup>3</sup> Thus, cervical cancer screening may be relevant for more women than are currently receiving screening.

Access to mental health services. More than two thirds (69%) of Oregon NCI participants used or needed mental health services. Of those, almost one quarter (23%) said they experienced barriers or challenges to accessing needed services. Substantial efforts are needed to: a) train mental health care providers in providing care to adults with I/DD; b) increase the number of providers willing to accept patients with I/DD; and c) connect adults with I/DD to accessible and appropriate services.<sup>4</sup>

We also suggest some possible changes to NCI data collection in Oregon to improve the level of detail available for future analyses:

Increase sample diversity. Sample sizes were very small for people in racial or ethnic groups other than non-Hispanic White. In future years, Oregon should consider stratifying the eligible NCI sample by race and ethnicity and oversampling from smaller racial and ethnic groups. This would provide larger sample sizes for examining possible racial/ethnic differences in health and access to health care.

Increase detail on barriers to mental health services. Oregon may wish to consider a state-added NCI question asking about specific types of barriers to mental health services to provide more detail about the challenges with accessing these services in Oregon.

Reduce missing data. Oregon has large amounts of missing data on diagnoses, etc. in the background section. Oregon also has high proportions of “don’t know” responses on receipt of cancer screening (>50%) and hearing testing (32%).

## County Developmental Disability Programs (CDDP) and Brokerage Services

The purpose of these exploratory analyses is to identify subgroup differences in who receives services through CDDPs versus Brokerages, and examine possible differences in satisfaction with services. For these analyses, we combined 2 years of Oregon NCI data (2017-2018 and 2018-2019). We considered differences to be statistically significant if there was less than a 5% probability ( $p < .05$ ) that the observed difference happened by chance. We considered differences to be approaching statistical significance if the probability that they happened by chance was greater than 5% but less than 10%. In the text, differences approaching statistical significance are described using the phrase “there was a trend toward...”.

Overall, nearly two-thirds (65%) of adult NCI participants in Oregon received services through a CDDP, while the remaining 35% received services through a Brokerage.

### Group differences in who is more likely to receive CDDP or Brokerage services

- Level of ID – Significant ( $X^2=24.57$ ,  $p < 0.001$ ). People with mild ID were the most likely to receive services through Brokerages (39%), followed by people with moderate ID (29%). People with severe/profound ID were the least likely to receive Brokerage services (13%).
- Age – Significant ( $X^2=65.05$ ,  $p < 0.001$ ). High proportions of clients under age 25 or over age 55 receive services through CDDPs (83-87% in these age groups). Among those in the 25-54 age range, 53%-59% receive services through CDDPs.
- Gender – Men were significantly more likely to receive services through CDDPs than women (68% vs. 61%;  $X^2=4.53$ ,  $p=0.033$ ).
- Race/ethnicity – not significant
- Rurality – not significant

### Service satisfaction differences

- We did not find statistically significant differences between people receiving services through CDDPs and people receiving services through Brokerages on any of the following questions:
  - Have you met your case manager/service coordinator?
  - Does your case manager/service coordinator ask what you want?
  - At your service planning meeting, did you talk about learning new things?
  - Do you have a service plan?
  - Does your service plan include things that are important to you?
  - Do staff come and leave when they are supposed to?
  - Do you have a way to get places you need to go?
  - Are you able to get places when you want to do something outside your home?

- Are services and supports helping you live a good life?
  - Do support staff have right training for person's needs?
  - Does person hire and manage own staff?
  - Can person make changes to budget/services if needed?
  - Do you have enough help deciding how to use budget/services?
  - Does person get enough info about how much money is left in services budget?
  - How often does person get information about how much money is left in budget/services?
- There was a significant difference in being able to contact case manager/service coordinator when individual wants to ( $X^2=9.85$ ,  $p=0.007$ ). Those receiving services through a CDDP were more likely to say no (11% vs. 4%).
  - There was a significant difference in whether or not respondents took part in the last service planning meeting ( $X^2=7.17$ ,  $p=0.027$ ). People receiving services through a CDDP were less likely to have done so (96% vs. 99%).
  - There was a significant difference in whether or not respondents said they understood what was being talked about at the service plan meeting ( $X^2=10.99$ ,  $p=0.004$ ). Three fourths (75%) of people receiving services through a CDDP said they understood, compared with 87% of people receiving services through a Brokerage.
  - There was a significant difference in whether or not the service planning meeting included the people the respondent wanted to be there ( $X^2=7.19$ ,  $p=0.027$ ). People receiving services through a CDDP were less likely to say yes (92% vs. 97%).
  - There was a significant difference in whether or not respondents said they remembered what was in their service plan ( $X^2=7.79$ ,  $p=0.020$ ). More than half (59%) of people receiving services through a CDDP said no, compared to 43% of people receiving services through a Brokerage.
  - There was a significant difference in whether or not respondents were able to choose what services they got as part of their service plan ( $X^2=8.29$ ,  $p=0.016$ ). Less than three fourths (74%) of people receiving services through a CDDP said yes, compared with 83% of people receiving services through a Brokerage.
  - There was a significant difference in whether or not respondents knew whom to ask if they want to change something about their services ( $X^2=13.32$ ,  $p=0.001$ ). About three fourths (76%) of people receiving services through a CDDP said yes, compared with 92% of those receiving services through a Brokerage.
  - There was a significant difference in whether or not respondents had staff to help them ( $X^2=18.36$ ,  $p<0.001$ ). A higher proportion of those receiving services through a CDDP said yes (94% vs. 83% of people receiving services through a Brokerage).

- There was a significant difference in whether or not respondents could change their case manager/service coordinator ( $X^2=12.96$ ,  $p=0.002$ ). People receiving services through a Brokerage were more likely to say yes (93% vs. 86% of people receiving services through a CDDP).
- There was a significant difference in who makes decisions about how the person's budget for services is used ( $X^2=11.45$ ,  $p=0.010$ ). People receiving services through a Brokerage were more likely to make their own decisions, with or without help. People receiving services through a CDDP were more likely to have decisions made by someone else (see Table 1).

**Table 1. Differences in who makes budgeting decisions**

<b>Who Makes Decisions</b>	<b>CDDP Clients</b>	<b>Brokerage Clients</b>
Individual mostly controls	6.45%	15.69%
Individual has input; others help	19.35%	34.31%
Family or friends make decisions	48.39%	32.35%
Case manager makes decisions	25.81%	17.65%
Total	100%	100%

- There was a significant difference in whether or not the respondent participated in decisions about how to use supports budget, hiring staff, or managing services ( $X^2=4.81$ ,  $p=0.028$ ). A higher proportion of people receiving services through a Brokerage said they participated in such decisions (79%), compared with 65% of people receiving services through a CDDP.
- There was no significant difference in whether or not respondents said they receive enough info about how much money is left in their services budget. However, there was a significant difference in whether or not respondents found the information they received easy to understand ( $X^2=9.84$ ,  $p=0.007$ ). Respondents receiving services through a Brokerage were more likely to say yes (86% vs. 76%) or maybe (13% vs. 6%), while respondents receiving services through a CDDP were more likely to say no (18% vs. 1%).
- There was a trend ( $X^2=4.68$ ,  $p=0.096$ ) toward people receiving services through Brokerages being more likely to say that staff are respectful (94% vs. 89% of people receiving services through CDDPs).
- There was a strongly significant difference in whether or not people chose their own staff ( $X^2=114.69$ ,  $p<0.001$ ). More than half (59%) of people receiving services through Brokerages chose their own staff, compared with 20% of people receiving services through CDDPs.

### Recommendations for future analysis

- 1) Thus far, we only have two years of data with information included about whether adults received services through a CDDP or a Brokerage. We recommend continuing to include this as a state-added question so that we can combine more years to yield larger sample sizes for future analyses.
- 2) Sample sizes were very small for people in racial or ethnic groups other than non-Hispanic White. In future years, we should consider stratifying the eligible sample by race and ethnicity and oversampling from smaller racial and ethnic groups. This would provide larger sample sizes for examining possible racial/ethnic differences in receipt of services through a CDDP versus a Brokerage, as well as possible differences in satisfaction with services.
- 3) It is possible that some of the differences we found in satisfaction with services may be explained by other things (e.g., level of ID) rather than differences between CDDPs and Brokerages. In future years, when we will have a larger cumulative sample size, we recommend follow-up analyses to see whether satisfaction differences are still present when we adjust for differences in the underlying characteristics of people who receive services through a CDDP versus a Brokerage.

## Loneliness

The proportion of adults with I/DD reporting loneliness is higher in Oregon than the national NCI average. The purpose of these analyses is to identify subgroup differences in loneliness, and explore associations between responses to other interview questions and reported loneliness. For these analyses, we combined 3 years of Oregon NCI data (2016-2017, 2017-2018, and 2018-2019). We considered differences to be statistically significant if there was less than a 5% probability ( $p < .05$ ) that the observed difference happened by chance. We considered differences to be approaching statistically significant if the probability that they happened by chance was between 5% and 10%. In the text, differences approaching statistical significance are described using the word “trend”.

### Group differences in who reported loneliness

We did not find statistically significant differences in loneliness for any of the following:

- Age
- Gender
- Race/ethnicity
- Rurality
- Type of home
- Length of time in that residence

### Factors associated with loneliness

- ***Relationships with friends and family***
  - The following items were not statistically associated with loneliness:
    - Has friends
    - Do you have other ways of communicating with your friends when you cannot see them?
    - Can see/communicate with family
    - Want to live closer to family and friends
  - BESTFRIEND16 – Trend ( $X^2=5.89$ ,  $p=.052$ ). Well over half of respondents indicated that they had a best friend. However, people who said they were often lonely were less likely to have a best friend (63% of them did) than people who were only sometimes lonely (74% had a best friend) or rarely lonely (68% had a best friend).
  - FRNDSHELP15 – People who were often lonely were significantly more likely to say they would like more help to make friends or keep in touch with friends: 68% of those who were often lonely indicated a desire for such help versus 49% of those who were sometimes lonely and 42% of those who were rarely lonely ( $X^2=29.77$ ,  $p < 0.001$ ).

- SEEFRNDS15 – Ability to get together with friends was significantly associated with loneliness ( $X^2=33.99$ ,  $p<0.001$ ). People who said they were rarely lonely were the mostly likely (83%) to indicate they could see their friends as often as they wanted, compared with 68% of people who were sometimes lonely and 61% of people who were often lonely. People who were often lonely were much more likely to say they were unable to see their friends (14%) than people who were sometimes (7%) or rarely lonely (4%). People who were often or sometimes lonely were more than twice as likely as people who were rarely lonely to say that they were sometimes unable to see their friends (25% vs. 12%).
- CANDATE15 – Trend ( $X^2=8.89$ ,  $p=.064$ ). Higher proportions of people who were often or sometimes lonely indicated restrictions on dating (13% and 10% respectively vs. 7% of those who were rarely lonely).
- **Access to communication tools**
  - We did not find statistically significant associations between any of the following variables and loneliness:
    - Able to use phone or internet whenever want to
    - Have a smart phone
    - Want a smart phone (if don't have one). Sample size for this item was very small. Although the difference was not significant (likely because of lack of statistical power due to small sample size), the difference in percentages appears meaningful. Among people who did not have a smart phone, higher proportions of those who were often or sometimes lonely indicated that they wanted a smart phone (58% in each group) compared with people who were rarely lonely (36%) ( $X^2=3.95$ ,  $p=0.139$ ).
- **Employment, volunteering, structured activities**
  - The following variables were not statistically significantly associated with loneliness:
    - Do you volunteer?
    - Do you go to a day program?
  - HAVEJOB15 – People who were often lonely were significantly less likely to have a job (24%) than people who were sometimes (38%) or rarely (36%) lonely ( $X^2=7.98$ ,  $p=0.019$ ).
  - LIKEAJOB15 – Among those who did not have a job, people who were often or sometimes lonely were significantly more likely to say they wanted a job (61% and 63% respectively), compared to people who were rarely lonely (47%) ( $X^2=18.92$ ,  $p<0.001$ ).

- LIKEJOB15 – Among those who did have a job, people who were often lonely were less likely to like their jobs (77%) than people who were sometimes or rarely lonely (94% and 91% respectively) ( $X^2=19.88$ ,  $p<0.001$ ).
- ***Community participation and leisure***
  - GOOUT15 – There was a significant association between loneliness and having opportunities to go out and do things one enjoys ( $X^2=21.27$ ,  $p<0.001$ ). People who were often or sometimes lonely were less likely to say they could go out and do the things they like to do (79% and 81% respectively), compared with people who were rarely lonely (89%).
  - GOOUTENOUGH15 – People who were often or sometimes lonely were significantly more likely to say they would like to go out and do more than they currently do (43% and 38% respectively), compared with people who were rarely lonely (27%) ( $X^2=14.28$ ,  $p<0.001$ ).
  - GETPLACES15 – There was a significant association between loneliness and being able to get places to do things outside the home ( $X^2=19.06$ ,  $p<0.001$ ). People who were often or sometimes lonely were less likely to say they could almost always get places (73% and 76% respectively), compared with people who were rarely lonely (87%).
  - COMMGROUP16 – People who were sometimes lonely were significantly more likely to participate in community groups (39%) than people who were often or rarely lonely (30% and 31% respectively) ( $X^2=6.53$ ,  $p=0.038$ ).
  - PCP\_COMM\_GROUP – People who were always or sometimes lonely were significantly more likely to say they wanted to be part of more community groups (51% and 70% respectively) than was the case for people who were rarely lonely (37%) ( $X^2=24.39$ ,  $p<0.001$ ). This question was only included in the most recent year of data, so numbers are small; this finding should be interpreted with caution.
  - ENTERTAIN15 – The association between how often people went out for entertainment in the past month and loneliness was not statistically significant.
  - PCP\_ENTERTAIN – Association with loneliness was not statistically significant, but there does appear to be a possible pattern. People who were often or sometimes lonely were more likely to say they wanted to go out for entertainment more (61% and 57% respectively), compared with people who were rarely lonely (44%) ( $X^2=6.53$ ,  $p=0.163$ ). This question was only included in the most recent year of data, resulting in small numbers and limited statistical power.

### Recommendations for future analysis

- 1) Sample sizes were quite small for some questions, especially those that were not included in all data years. Thus, these findings should be interpreted with caution. If those questions remain on the NCI survey for additional years, we could revisit these analyses later with a larger cumulative sample size.
- 2) Sample sizes were also very small for people in racial or ethnic groups other than non-Hispanic White. In future years, we should consider stratifying the eligible sample by race and ethnicity and oversampling from smaller racial and ethnic groups. This would provide larger sample sizes for examining possible racial/ethnic disparities in loneliness.
- 3) For the factors that were significantly associated with loneliness in Oregon, we could examine national data to see if Oregon responses are significantly different from national averages on those factors. This could help in understanding what specifically may be contributing to Oregon's high prevalence of loneliness and point toward possible strategies for action. For example, if Oregon NCI participants are substantially less likely to be able to get places to do things outside the home, Oregon could potentially work on providing additional support with transportation to activities. This, in turn, may help reduce loneliness.
- 4) Most Oregon NCI participants did not have jobs. However, the vast majority of those who had jobs liked their jobs. Moreover, those with jobs were less likely to be lonely. We could consider future analyses to examine the benefits of employment. In addition to less loneliness, employment may be associated with better health and other positive outcomes. However, we will need additional years of data to have large enough sample sizes for these analyses.

## Housing Satisfaction

The proportion of adults with I/DD reporting dissatisfaction with where they live is higher in Oregon than the national NCI average. The purpose of these analyses is to examine subgroup differences in housing dissatisfaction among NCI participants Oregon and explore factors that may be associated with participants not liking where they live and/or wanting to live elsewhere. For these analyses, we combined 3 years of Oregon NCI data (2016-2017, 2017-2018, and 2018-2019).

We considered differences to be statistically significant if there was less than a 5% probability ( $p < .05$ ) that the observed difference happened by chance. We considered differences to be approaching statistical significant if the probability that they happened by chance was greater than 5% but less than 10%. In the text, differences approaching statistical significance are described using the phrase “trend toward...”.

### Association between liking one's home and wanting to live elsewhere

There was a strong and statistically significant association between how much respondents liked where they currently live and their desire to live somewhere else ( $X^2=129.70$ ,  $p < 0.001$ )

- Overall, the majority of respondents (86%) said they like their home. The percentage of people saying they liked their home was highest (97%) among those who said they did not want to live any place else, and lower (70%) among respondents who said they would like to live somewhere else.
- Even among those who liked their home, some (28%) would prefer to live somewhere else. Of those who said they did not like their home, a much higher percentage (88%) said they would prefer to live somewhere else.

### Group differences in liking home

- Age – not statistically significant
- Gender – trend toward men being less likely to say no and more likely to say in between ( $X^2=4.66$ ,  $p=0.097$ )
- Race/ethnicity – not significant
- Rurality – not significant
- Type of home – Significant differences ( $X^2=25.54$ ,  $p=0.001$ ). Similar percentages of people living in foster care or group settings said they like their home (87% and 86% respectively). People living in their own home or apartment were less likely to say yes (78%) and more likely to say in between (15%). People living in a relative's home were most likely to say yes (93%).
- Length of time in that residence – possible trend ( $p=0.102$ ) toward people who have been in their residence less than 1 year or more than 5 years being most likely to like their home. People who have been there 1-5 years were a bit more likely to say no or in between when asked if they like their home.
- Living in a home controlled by a provider? – not significant

### Group differences in wanting to live somewhere else

- Age – Significant ( $p < 0.001$ ). In general, older people were less likely to want to live somewhere else. However, some of the age groups were quite small, so this finding should be interpreted with caution.
- Gender – There was a significant association between gender and wanting to live somewhere else ( $X^2 = 8.48$ ,  $p = 0.014$ ). Women were more likely to say no they did not want to live somewhere else (59% vs. 51%) and men were more likely to say in between (13% vs. 8%).
- Race/ethnicity – not significant
- Rurality – not significant
- Type of home – There was a significant association between type of home and wanting to live somewhere else ( $X^2 = 28.28$ ,  $p < 0.001$ ). Those living in their own home or apartment were the group most likely to say yes they wanted to live somewhere else (42%) while those living in foster care were the ones least likely to say yes (27%). Those who lived in a relative's home were the group mostly likely to say in between (17%).
- Length of time in that residence – Significant ( $X^2 = 15.58$ ,  $p = 0.049$ ). Compared to other groups, those with unknown duration in residence were notably more likely to say they want to live somewhere else (57% vs. 32-38%). However, this “unknown” group was small, so this finding should be interpreted with caution.
- Home controlled by provider – Significant ( $X^2 = 16.99$ ,  $p = 0.002$ ). People living in a home controlled by a provider were more likely to say no they did not want to live somewhere else (60.5%) than people living in homes not controlled by a provider (50% said no) or where provider control was unknown (52%).

### What people don't like about their homes

Among people who didn't like where they lived or felt in between about it, the reasons for not liking their home varied. The largest proportion of the reasons (48%) fell into the “other” category. The next most common reason was problems with roommates (24%), followed by wanting more independence (18%). Counts in other categories were too small to report.

### Other issues associated with not liking home

- The following items were not significantly associated with whether or not people liked where they lived:
  - Can't see friends when want to because of rules or restrictions
  - People read mail without asking
  - Can be alone with guests
  - Rules about visitors
  - Can use phone and internet when want to
  - Who chose home

- Who chose housemates
  - Who decides schedule
  - Who decides how free time is spent
  - Has key to home
  - Can stay home when others go out (numbers too small)
  - Can lock bedroom door
- Feel afraid at home – Significant ( $X^2=21.08$ ,  $p<0.001$ ). Few people felt afraid in their homes, but the proportion who did so was higher among those who did not like their home or felt in between about it (~12%) than among those who liked their home (<4%).
  - Have enough things to do at home – Significant ( $X^2=39.17$ ,  $p<0.001$ ). People who did not like where they live were the least likely to say they had enough to do at home (57%), followed by people who felt in between about their homes (64% had enough to do). Among people who liked their homes, 81% said they had enough to do.
  - Have enough choice about schedule – Trend ( $X^2=5.91$ ,  $p=0.052$ ) toward those who don't like their home were less likely to say they have enough choice about their schedule (85% vs. 97% of those who like their home). Numbers are small though because this question was only included in one year of data and should be interpreted with caution.
  - Have enough choice about free time – Significant ( $X^2=14.03$ ,  $p<0.001$ ). People who said they don't like where they live were less likely to say they had enough choice about how to spend their free time (79% vs. 97% among those who liked where they live). Again though, this item was only included in one year of data and numbers are quite small and should be interpreted with caution.

#### Issues associated with wanting to live somewhere else

- The following items were not significantly associated with whether or not people wanted to live somewhere else:
  - Can't see friends when want to because of rules or restrictions
  - Can be alone with guests
  - Who chose home
  - Who chose housemates
  - Have enough choice about schedule
  - Who decides how free time is spent
  - Have enough choice about free time
  - Has key to home
  - Can lock bedroom door – not sig

- Feel afraid at home – Trend ( $X^2=4.80$ ,  $p=0.091$ ) toward people who want to live somewhere else being more likely to say they feel afraid at home (7% vs. <4% of those who do not want to live somewhere else).
  - Have enough things to do at home – Significant ( $X^2=20.98$ ,  $p<0.001$ ). People who wanted to live somewhere else or who felt in between about it were less likely to say they had enough to do at home (71% and 72% respectively) than people who did not want to live somewhere else (84%).
  - People read mail without asking – Significant ( $X^2=11.53$ ,  $p<0.003$ ). People who wanted to live somewhere else were more likely to say someone opens their mail without asking (15%) than people who did not want to live somewhere else (8%) or felt in between about living somewhere else (4%).
  - Rules about visitors – Trend ( $X^2=5.90$ ,  $p=0.052$ ). People who did not want to live somewhere else were more likely to say there were rules about visitors where they lived (44% vs. 38% of those who did want to live somewhere else and 30% of those who felt in-between).
  - Can use phone and internet when want to – Trend ( $X^2=5.18$ ,  $p=0.075$ ). Higher percentage of people who wanted to live somewhere else said yes to this question, compared to people who did not want to live somewhere else (93% vs. 87%).
  - Who decides schedule – Trend ( $X^2=8.33$ ,  $p=0.080$ ). People who wanted to live somewhere else were somewhat more likely to decide their schedules on their own (72% vs. 67%) and a little less likely to have help in deciding (22% vs. 26%) than people who did not want to live somewhere else.
  - Can stay home when others go out – Significant ( $X^2=11.25$ ,  $p=0.024$ ). People who wanted to live somewhere else or felt in between about it were more likely to say they could stay home if they wanted to (65% and 63% respectively) than people who did not want to live somewhere else (43%).
-

### Recommendations for future analysis

- 1) Findings in the last four bullet points on the previous page seemed somewhat counterintuitive. For three of these, there was only a trend toward significance. With additional years of data (yielding a larger cumulative sample size), we could re-examine these items to see if the patterns above still hold. If so, we could consider listening sessions to gather more insights into people's opinions about where they live and what makes them want to live somewhere else.
- 2) Subgroup sizes were quite small for some of these analyses. Again, with more years of data, we could revisit these analyses to see whether the patterns we observed remain consistent.
- 3) In particular, sample sizes were very small for people in racial or ethnic groups other than non-Hispanic White. In future years, we should consider stratifying the eligible sample by race and ethnicity and oversampling from smaller racial and ethnic groups. This would provide larger sample sizes for examining possible racial/ethnic disparities in housing satisfaction.
- 4) For the factors associated with housing dissatisfaction that were statistically significant in Oregon, we could examine national data to see if Oregon responses are significantly different from national averages on those factors. This could help in understanding what specifically may be contributing to Oregon's differences in housing satisfaction and point toward possible strategies for action. For example, if Oregon NCI participants are substantially less likely to feel they have enough to do at home compared to respondents in other states, Oregon could potentially work on supporting additional activities. This, in turn, may improve satisfaction with housing.

## References

1. Waite, L. (2002). Sight problems and people with intellectual disabilities. *Intellectual Disability and Health* (website). University of Hertfordshire. <http://www.intellectualdisability.info/physical-health/articles/sight-problems-and-people-with-intellectual-disabilities>
2. Herer, G. R. (2012). Intellectual disabilities and hearing loss. *Communication Disorders Quarterly*, 33(4), 252-260. <https://doi.org/10.1177/1525740112448214>
3. Shapiro, J. (2018). *The sexual assault epidemic no one talks about*. NPR. <https://www.npr.org/2018/01/08/570224090/the-sexual-assault-epidemic-no-one-talks-about>
4. Whittle, E. L., Fisher, K. R., Reppermund, S., Lenroot, R., & Trollor, J. (2017). Barriers and enablers to accessing mental health services for people with intellectual disability: A scoping review. *Journal of Mental Health Research in Intellectual Disabilities*, 11(1), 69-102.