Evaluating Health Disparities of Medicaid Members Diagnosed with Intellectual and Developmental Disabilities in Oregon

FINAL REPORT

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About us

The Center for Health Systems Effectiveness at Oregon Health & Science University is a research organization that uses economic approaches and big data to answer pressing questions about health care delivery. Our mission is to provide the analyses, evidence, and economic expertise to build a more sustainable health care system.

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Acronyms

- AAIDD American Association on Intellectual and Developmental Disabilities
- ACL Administration for Community Living
- ACS American Community Survey
- APAC All Payer All Claims
- APD Aging and People with Disabilities
- BRFSS Behavioral Risk Factor Surveillance System
- **CCO** Coordinated Care Organization
- **CDC** Centers for Disease Control and Prevention
- **CHSE** Center for Health Systems Effectiveness
- **CMS** Centers for Medicare and Medicaid Services
- **DD** Developmental Disability
- **ED** Emergency Department
- **HEDIS** Effectiveness Data and Information Set
- ICD International Classification of Diseases
- ICS Integrated Client Services
- **IDD** Intellectual and Developmental Disabilities
- IQ Intelligence Quotient

- LTSS Long Term Services and Supports
- NCI-AD National Core Indicators Aging and Disabilities
- NCI-IDD National Core Indicators Intellectual and Developmental Disabilities
- NCQA National Committee for Quality Assurance
- OAR Oregon Administrative Rules
- **OCDD** Oregon Council on Developmental Disabilities
- **ODDS** Office of Developmental Disabilities Services
- **ODHS** Oregon Department of Human Services
- **OHA** Oregon Health Authority
- OHSU Oregon Health & Science University
- **ORRAI** Office of Reporting, Research, Analytics and Implementation
- **REALD** Race, Ethnicity, Language, and Disability
- **RISP** Residential Information Systems Project
- **SOGI** Sexual Orientation & Gender Identity
- UCEDD University Center for Excellence in Developmental Disabilities

Executive Summary

Intellectual and developmental disabilities include health conditions such as autism spectrum disorder or cerebral palsy. People with IDD often have complex and multifaceted health care needs. Many people with IDD rely on Medicaid for their health care needs and further receive social services, such as support with everyday activities (e.g., making meals, managing finances). Despite this support network, people with IDD may face a multitude of barriers and social risk factors that contribute to disparities in accessing and utilizing health care. Inadequate data collection and inconsistent definitions of the IDD population have made it difficult to comprehensively assess health care utilization and identify disparities for this population.

The Center for Health Systems Effectiveness (CHSE) at Oregon Health & Science University (OHSU) was contracted by the OHSU University Center for Excellence in Developmental Disabilities (UCEDD) to produce this report. The OHSU UCEDD and the Oregon Council on Developmental Disabilities (OCDD) were awarded grants from the Administration for Community Living (ACL). OCDD provided the UCEDD a subaward to improve the availability of health care data and knowledge of health care disparities for people with IDD. The COVID-19 pandemic emphasized the challenges of health disparities impacting people with IDD and the lack of adequate data collection to track health outcomes for this population.

This report had three objectives:

- To assess disparities in health care use and health status among Medicaid members with IDD compared to Medicaid members without IDD who had similar demographic characteristics, using Oregon Medicaid enrollment and claims data from 2022
- 2. To provide research and policy recommendations based on data findings
- **3.** To provide a detailed overview of existing sources of administrative and survey data with the potential either on their own or in combination with other data sources to improve understanding of barriers to accessing health care (physical, mental, oral, vision, and others) for people with IDD

Key Findings

Using Medicaid data, we identified 2,066 Medicaid members with IDD. We examined disparities across 17 measures in the areas of mental health, substance use, hospital use, diabetes care, oral health, and cancer screening for Medicaid members with IDD compared to Medicaid members without IDD who had similar demographic characteristics. Our analysis suggests a complex and nuanced pattern of disparities across categories of care:

Mental health

We included six measures related to mental health in our analysis: Clinical Depression Screening, Antidepressant Medication Management (Acute Phase / Continuous Phase), Nonfatal Suicide Attempts and Self-Harm, Emergency Department (ED) Visits for Suicidal Ideation, and 30-day Plan All-Cause (for any reason) Readmissions After Hospitalization for Mental Illness. Medicaid members with IDD fared worse on one of these six measures: they had an elevated risk of non-fatal suicide attempts and self-harm, with 2.2% of them experiencing such events in 2022, compared to 0.5% among Medicaid members without IDD.

Substance use

Three measures were related to substance use: Screening for Alcohol or Other Substance Abuse Treatment (which applies to all Medicaid members, with and without substance use disorder), Initiation of Substance Use Disorder (SUD) Treatment, and Engagement of Substance Use Treatment. Differences were not statistically significant for these measures.

Hospital use

Two measures related to general hospital use were part of the analysis: ED Utilization and 30-day Plan All-Cause Readmissions. Medicaid members with IDD had a 2.5 times higher number of ED visits compared to Medicaid members without IDD. The number of 30-day plan all-cause readmissions was also much higher for Medicaid members with IDD (533.9 readmissions per 1,000 member-years) compared to Medicaid members without IDD. (200.0 readmissions per 1,000 member-years).

Diabetes care

We included one measure for diabetes management in our analysis: whether Medicaid members with diabetes received at least one HbA1c test in 2022. We did not observe differences in levels of diabetes care among Medicaid members with and without IDD who had a diagnosis of diabetes.

Oral health care

We examined two measures of oral health care: Preventive Dental Services and Access to Any Dental Care. A higher percentage of Medicaid members with IDD received preventative or any dental care compared to Medicaid members without IDD. Specifically, 59.2% of them received any dental care and 44.0% received preventive dental care in 2022, compared to only 32.4% and 20.4% among Medicaid members without IDD, respectively.

Cancer screening

Our analysis included three cancer screening measures: Breast Cancer Screening, Cervical Cancer Screening, and Avoidance of Non-Recommended Cervical Cancer Screenings in Adolescent Women. A lower percentage of Medicaid members with IDD received cervical cancer screening compared to Medicaid members without IDD (20.7% vs 25.9%).

Findings for Subgroups

We also assessed disparities among Medicaid members with and without IDD within 13 subpopulations based on age, sex, race and ethnicity, and rural or urban residency. Across all groups, Medicaid members with IDD had elevated ED visits but better oral care compared to Medicaid members without IDD. Other key findings included:

Age

Younger Medicaid members with IDD did worse on several outcomes compared to younger Medicaid members without IDD. Most notably, 2.6% of Medicaid members with IDD ages 18-29 experienced nonfatal suicide attempts or self-harm in 2022, compared to only 0.5% of Medicaid members without IDD in the same age group. Negative disparities were less prevalent among older age groups.

Sex

Female Medicaid members with IDD experienced disparities compared to female Medicaid members without IDD that mostly mirrored disparities among the full study population. Additionally, they had a higher number of ED visits for suicidal ideation but were also more likely to initiate SUD treatment compared to female Medicaid members without IDD. Male Medicaid members with IDD were less likely to engage in SUD treatment compared with male Medicaid members without IDD. Other disparities were less apparent for male Medicaid members with IDD.

Race and ethnicity

Disparities for white Medicaid members with IDD compared to white Medicaid members without IDD were similar to disparities in the full study population. Disparities for other racial and ethnic groups were less apparent, which may partly reflect small sample sizes. Of note, 3.6% of Black Medicaid members with IDD had nonfatal suicide attempts or self-harm, the highest prevalence of all IDD population groups studied in this report.

Rural or urban residency

Most findings were like the full study population, with two exceptions. Medicaid members with IDD residing in urban areas were more likely to receive clinical depression screening and antidepressant medication management than Medicaid members without IDD residing in urban areas.

Overview of Oregon Data Sets with Disability Data

From our survey of existing administrative and survey data sets relevant for Medicaid members with IDD, we include information on 10 data sources. Four were administrative data (e.g., Aging and People with Disabilities data) and five were survey data (e.g., American Community Survey). One data source, Oregon's Race, Ethnicity, Language, and Disability (REALD) & Sexual Orientation and Gender Identity (SOGI) repository, could be classified as hybrid data: it is used for administrative purposes but collects demographic information using survey methods. These 10 data sources varied in how they identified people with IDD and included a considerable range of information related to health and health care, social services, and social risk factors.

Implications for Research

The evaluation team offers the following recommendations to advance research on health disparities experienced by people with IDD within the Medicaid program.

Conduct follow-up research on access challenges for mental health treatment. For instance, qualitative interviews with Medicaid members with IDD who experienced non-fatal suicide attempts and self-harm and their caregivers could illuminate factors that contributed to these events, and whether there were gaps between services that were needed versus services that were available or could be accessed.

Similarly, interviews with Medicaid members with IDD and their caregivers could identify access challenges for preventative depression screening and other mental health support services. Future research could also examine whether Medicaid members with IDD receive the same standards of care related to mental health assessment, diagnosis, and treatment compared to those without IDD, and the extent to which living arrangements contribute to mental health needs. For this research, special attention should be devoted to Medicaid members with IDD who have particularly severe mental health challenges, most notably Black Medicaid members with IDD.

Understand low rates of SUD screening as well as initiation and engagement in SUD treatment. While we generally did not observe disparities for measures related to SUD screening and treatment, rates were low among Medicaid members with IDD. Moreover, male Medicaid members with IDD were less likely to engage in SUD treatment compared with male Medicaid members without IDD. Qualitative interviews could help identify gaps between SUD services needed and SUD services accessible or available for Medicaid members with IDD and factors that might contribute to such gaps.

Assess factors contributing to high rates of ED visits and readmissions. Additional research could include a document review of policies and care plan protocols in group homes that may stipulate ED visits for certain health conditions for Medicaid members with IDD. Future research could also examine quality of care processes (e.g., discharge planning) and accommodations for people with IDD that could be related to lower levels of readmissions. Medicaid claims records could further be used to analyze conditions related to ED visits and whether these are more prevalent among Medicaid members with IDD, whether Medicaid members with IDD use ED instead of primary care because of lack of access, and how ED expenditures compare to expenditures in primary care settings. Qualitative interviews of Medicaid members with IDD and their caregivers could also illuminate gaps in follow-up care after an ED visit.

Examine disparities in diabetes diagnosis. While we did not observe disparities in diabetes treatment, our analysis did not assess potential disparities in diabetes diagnosis. Future research could examine the distribution of stages of diabetes when first diagnosed to assess whether Medicaid members with IDD are less likely to receive a diabetes diagnosis at earlier stages of the condition compared to Medicaid members without IDD.

Conduct follow-up analysis of oral services. Medicaid members with IDD had higher levels of access to oral health care, but our analysis did not examine which type of services they received. Further research could illuminate whether disparities exist regarding the types of dental services, and whether Medicaid members with IDD face access challenges for specific types of dental services.

Improve identification of Medicaid members with IDD in Medicaid data. Analysis for this report used International Classification of Diseases (ICD) codes to identify Medicaid members with IDD (see Appendix A for details). Thus, we were not able to capture Medicaid members with IDD who did not have corresponding ICD codes in their Medicaid claims records, for instance because they did not access care, or because health care professionals did not include these codes in claims. Identification of Medicaid members with IDD based on self-reported information would greatly improve analyses of their health care use in Medicaid data. REALD data may be useful in identifying people with IDD, but it is not clear yet whether its disability questionnaires can be used to identify this population.

Include sexual orientation and gender identify in subgroup analyses. Information related to sexual orientation and gender identity from the REALD & SOGI Repository was not available for our analysis. Future research could include this information to generate evidence on disparities by these characteristics.

Examine the role of social determinants of health. These factors include employment and housing. Future research could incorporate this information to assess their role in health care delivery and disparities.

Implications for Policy

Increase support and training for providers of health care needs for Medicaid members with IDD.

Medicaid members with IDD may have specific health care needs and challenges. Training for providers on topics related to mental health and substance use for this population could be highly valuable. For direct support professionals (DSPs), who work closely with individuals with IDD to support self-care and assist with daily living tasks, training should be developed about early warning signs of mental health problems and resources related to mental health treatment. Conversely, mental health and substance use specialists could receive training on working with patients with IDD and their accommodation needs. At a system level, better communication between disability service organizations and the mental health system could improve coordination of care. OHA could organize workshops for these organizations to present evidence on mental health care needs of people with IDD and facilitate better communication between agencies.

Increase number of behavioral care providers. Low rates of depression and substance use screening as well as initiation of and engagement in SUD treatment were consistent with other evidence documenting deficiencies in Oregon's behavioral health system.²¹ Increasing the number of behavioral care providers available to Medicaid patients, for instance by increasing behavioral health related reimbursement rates, could also improve access to behavioral care services for Medicaid members with IDD.

Improve cervical cancer screening rates among female Medicaid members with IDD. Cervical cancer screening was less prevalent among women with IDD compared to those without IDD. This finding suggests policy failures at the system level. The Oregon Health Authority should work with Oregon's Coordinated Care Organizations (CCOs) to identify potential barriers that may lead to low screening rates among the IDD population, in particular, and solutions to reduce or remove these barriers. For instance, Medicaid members with IDD might benefit from an accessible cancer screening guide that describes procedures and supports available to them. OHA and CCOs could also reach out to cancer advocacy groups to dispel myths about cancer screenings through targeted educational campaigns.

Update coordinated care organization contracts to include a requirement for hospital discharge planning and coordination. To address high rates of 30-day all-cause readmission rates for Medicaid members with IDD, OHA could consider adding a contractual requirement for coordinated care organizations to report on discharge planning and care coordination for the IDD population.

Strengthen integration of data sources for people with IDD. Several data sets identified people with IDD and collected valuable information related to their health care, social services and social risks. However, these data sources vary in how they identify people with IDD and often exist in isolation. Integrating data related to people with IDD could help identify factors associated with disparities in health care utilization and may help improve services and health care for this population.

Continue reporting on health disparities affecting Medicaid members with IDD. This report identified multiple health disparities experienced by Oregon's IDD population. The state should continue monitoring these on a regular basis, either as part of ongoing Medicaid REALD reporting or through commissioned reports such as this one. Adding children's data and All Payer All Claims Data would give a more comprehensive view of the experience of people with IDD. These data should be used to drive policy, research, and service practices and should be shared publicly and include feedback in the recommendation development from stakeholders, including Oregonians with IDD.

Introduction

People with intellectual and developmental disabilities (IDD) are a population often with complex health care needs with disabilities usually present at birth.¹ The American Association on Intellectual and Developmental Disabilities (AAIDD) defines intellectual disability as a "condition characterized by significant limitations in both intellectual functioning and adaptive behavior that originates before the age of 22."²

Adaptive behaviors encompass conceptual, social, and practical skills. Common conditions inclwude autism spectrum disorder, cerebral palsy, and Down syndrome.¹ People with IDD have higher rates of comorbidities (i.e., more than one medical condition) and chronic conditions compared to people without IDD.3 They experience less access to preventative care and have higher rates of preventable mortality.3,4 Providers frequently miss the presence of comorbid neurodevelopmental and other mental health disorders in children with IDD, which range in prevalence from 30 to 70 percent.5 Furthermore, the COVID-19 pandemic revealed significant health care disparities for people with IDD, including higher mortality outcomes, insufficient data collection for this population, and inadequate access to services.⁶⁻⁸

Before the age of 65, Medicaid is the primary health care insurance program for people with IDD, providing critical access to care.⁹ Recent efforts have led to great progress in defining the IDD population in Medicaid claims data and examining health care utilization for this population.¹⁰ Medicaid studies identified health disparities in diabetes care, emergency department (ED) use and reproductive health.¹¹⁻¹³ Despite increased attention to the quality of and access to health care for people with IDD, a comprehensive assessment of the degree to which people with IDD use various types of health care, and how their health care utilization compares to people without IDD, is still lacking. Even less is known at the state level on disparities in health care access and quality for people with IDD receiving Medicaid.¹⁴

The problem of inadequate health care information about people with IDD persists in Oregon. In addition to a scarcity of knowledge about Medicaid utilization for this population, inconsistent definitions for IDD populations among various state data sources hinder our ability to accurately assess the number of people with IDD in Oregon.^{10,14}

Data sources include state program administrative sources and surveys, such as the Behavioral Risk Factor Surveillance System (BRFSS). Specifically, state programs in Oregon vary on how they identify people with IDD, which may be based on medical diagnoses, service eligibility, or self-reported functional disabilities, referred to as "demographic disability" data. For instance, eligibility qualifications for people with IDD differ between Medicaid medical care and long-term care, also called Medicaid long term services and supports (LTSS). The Oregon Department of Human Services administers Medicaid LTSS services for people with IDD but defines this population based on need for services (e.g., assistance for daily living), age of onset, and severe physical or mental impairment including intellectual function.¹⁵

Opportunities exist to better understand health care and related needs of people with IDD in Oregon by analyzing various types of data sources as individual or combined data sets. Uniquely, Oregon is one of two states in the U.S. which require collection of demographic disability data, along with race, ethnicity, and language (REALD), in Medicaid and other state programs.^{16,17} Demographic disability data is considered the most comprehensive approach for identifying people with all types of disabilities among disability advocates and experts, since individuals may self-report on their functional limitations and levels of severity.¹⁶ Although REALD demographic disability data may not have sufficiently specific information to meet medical diagnostic criteria for IDD, when combined with Medicaid or other data sets, it provides a more thorough understanding of health care and related needs from both provider and consumer perspectives.

About this Report

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This report had three objectives:

- To assess disparities in health care use and health status among Medicaid members with IDD compared to Medicaid members without IDD who had similar demographic characteristics, using Oregon Medicaid enrollment and claims data from 2022.
- 2. To offer research and policy recommendations based on data findings.
- **3.** To provide a detailed overview of existing administrative and survey data sources with potential either on their own or in combination with other data sources to improve understanding of barriers to accessing health care (physical, mental, dental, vision, etc.) for people with IDD.

This report uses a linked data set with data from Medicaid claims and REALD & Sexual Orientation & Gender Identity (SOGI) Repository (a database pooling demographic data from multiple state administrative data sources) to improve the accuracy and completeness of race and ethnicity data in the Medicaid analysis; however, SOGI data was not yet available for use.¹⁸ We did not analyze demographic disability data in the REALD data set because the analysis is limited to evaluating Medicaid health care outcomes.

Together, this analysis aims to improve understanding of health care disparities in the IDD population receiving Medicaid services in Oregon and to provide an in-depth assessment of data sources available in Oregon with information on IDD for future studies including linked data set studies.

Approach to the Analysis

Overview

In this chapter, we describe the study population, measures used to assess disparities, and statistical approach that we used for our analysis of Medicaid claims data. We also briefly discuss limitations to our approach.

Quantitative Data

We used Medicaid enrollment and claims data for our analysis. Enrollment information included the period of enrollment in the Medicaid program along with demographic information (e.g., age). Claims data included diagnosis codes and procedure codes that were used to identify the study population and create outcome measures (see below). We linked Medicaid enrollment files to a REALD & SOGI repository data set using an encrypted identifier. The repository pools race and ethnicity from multiple state administrative data sets, allowing for more accurate demographic information. We first prioritized using repository data to populate race and ethnicity fields, followed by Medicaid enrollment race and ethnicity data for any remaining missing fields.

Study Population

The study population consisted of individuals enrolled in Medicaid in 2022 ages 18 to 64 years with IDD and a matched comparison group. The study population includes Medicaid members living in institutional care. We identified Medicaid members with IDD using diagnosis codes on claims from 2021-2022. The diagnosis codes were previously developed to identify people with IDD in Medicaid records¹⁰ and included a variety of conditions such as autistic disorder, cerebral palsy, and trisomy 21 (see Appendix A for a complete list and description of diagnosis codes).

A comparison group of Medicaid members without IDD was created using 1:1 exact matching on age group, sex, combined race and ethnicity groupings, and geography (rural vs. urban residence). We excluded Medicaid members from the analysis who were not continuously enrolled for 12 months in 2022. We also excluded Medicaid members who were eligible for both Medicaid and Medicare enrollment because we did not have access to Medicare claims for this study.

Quality Measures

We used quality measures in the domains of mental health, substance use disorders (SUDs), hospital use, diabetes care, oral health care, and cancer screening using specifications from the Centers for Medicare and Medicaid Services (CMS), the National Committee for Quality Assurance (NCQA), and the Oregon Health Authority (OHA) (Table 2.1). Detailed measure definitions are provided in the Appendix.

Domain	Measure	Measure Origin
Mental health	Clinical Depression Screening	CMS
	Antidepressant Medication Management - Acute Phase Treatment	NCQA
	Antidepressant Medication Management - Continuous Phase Treatment	NCQA
	Nonfatal Suicide Attempts and Self Harm	CHSE
	ED Visits for Suicidal Ideation	NCQA
	30-Day All-Cause Readmissions After Hospitalization for Mental Illness	CHSE
Substance use	Screening for Alcohol or Other Substance Abuse Treatment	OHA 2014
	Initiation of Substance Use Disorder Treatment	NCQA
	Engagement of Substance Use Disorder Treatment	NCQA
Hospital use	ED Utilization	NCQA ¹
	30-Day All-Cause Readmissions	NCQA
Diabetes care	Diabetes Management (HbA1c)	NCQA
Oral health care	Access to Any Dental Care	CHSE
	Preventive Dental Services	CHSE
Cancer screening	Breast Cancer Screening	NCQA
	Cervical Cancer Screening (incidence)	CHSE
	Avoidance of Non-Recommended Cervical Cancer Screenings in Adolescent Females	NCQA

1. Measure was modified from steward's specifications

Statistical Analysis

We performed a cross-sectional analysis of Medicaid claims data for the year 2022. We calculated mean or percentage values of outcome measures for the IDD and non-IDD populations and tested for statistical significance of differences between the two groups using t-tests with a significance level of 5%. Results were suppressed if the denominator included fewer than ten Medicaid members. We calculated outcome measures for the full study population as well as stratified by the following subgroups: age group (18-29, 30-39, 40-49, 50-64), sex (female, male), race and ethnicity (non-Latino White, non-Latino Black, Latino, other/unknown), and geography (rural, urban), defined using Rural-Urban Commuting Area Codes.¹⁹ Analyses were performed using R, version 4.3.2.

Limitations

We note several limitations of our analysis:

Using claims data to identify Medicaid members with IDD may not capture those with IDD without health care visits during the period used to identify this population (2021-2022 for this study). Identification of Medicaid members with IDD was limited to providers accurately identifying and coding for Medicaid members with IDD. Furthermore, health care encounters may be unrelated to IDD and not include IDD codes, which may also lead to undercounting of IDD.

- Sex was recorded as a binary variable in Medicaid enrollment records. Future research may be able to use the SOGI repository to include self-reported information on sexual orientation and gender identity in analyses.
- Observed differences in outcomes between the IDD population and matched comparison population could be due to disability status or other, unobserved factors, and we cannot distinguish between these two possibilities.
- The cross-sectional study design did not allow assessment of trends in outcomes over time. Future work may expand on this study using a longitudinal study design.
- Claims-based outcome measures, while extensively used to assess performance of Medicaid programs and disparities among Medicaid populations, do not capture all aspects of health care delivery.
- Our analysis focused on individuals with IDD enrolled in Medicaid, and thus may not generalize to individuals with IDD enrolled in other insurance programs (e.g., Medicare).
 Finally, we were not able to assess intersectionality of disparities beyond IDD and each subpopulation, such as examining combinations of subgroups (e.g., black women) due to sample size restrictions.

Findings

Overview

In this chapter, we describe the results of our statistical analysis. We first present characteristics of the study population, and then describe prevalence of outcome measures and differences in these measures between Medicaid members with IDD and their comparison group. A comparison for the full study population is followed by an assessment of differences stratified by subpopulations.

Tables showing results of the comparison between Medicaid members with and without IDD are organized as follows:

- Measure definition
- Average or percentage value of each measure for the non-IDD population
- Average or percentage value of each measure for the IDD population
- Difference between the two groups. Differences that were statistically significant from zero at the 5% level were highlighted **blue** (if results were better for the IDD population compared to non-IDD population) or **orange** (if results were worse for the IDD population compared to non-IDD population)

Color	Value
	Significantly Worse
	No Significant Difference
	Significantly Better

Overview of Population

Table 3.1 displays characteristics of Medicaid members with IDD included in our study and a matched comparison group. There were 2,066 Medicaid members with IDD and 2,066 Medicaid members without IDD in the study sample. Distributions of characteristics were identical for the two groups due to successful matching. More than half of Medicaid members with IDD were younger than 40 years old. They were more likely to be male than female. Approximately three out of five Medicaid members with IDD were classified as white, and more than three out of four resided in an urban setting.

Category	Subcategory	non-IDD (n,%)	IDD (n,%)
Age	18-20	2066	2066
	30-39	1096 (53.0)	1096 (53.0)
	40-49	505 (24.4)	505 (24.4)
	50-64	234 (11.3)	234 (11.3)
Sex	Female	231 (11.2)	231 (11.2)
	Male	944 (45.7)	944 (45.7)
Race or Ethnicity	Black/African American	1122 (54.3)	1122 (54.3)
	Latino/a/x	112 (5.4)	112 (5.4)
	Other/Multiple Races	248 (12.0)	248 (12.0)
	Unknown/Missing/Decline	232 (11.2)	232 (11.2)
	White	276 (13.4)	276 (13.4)
Residency	Rural	1198 (58.0)	1198 (58.0)
	Urban	440 (21.3)	440 (21.3)
		1626 (78.7)	1626 (78.7)

Table 3.1. Characteristics of the study sample.

Overall Results

Table 3.2 provides results of the comparison of outcome measures for the sample of Medicaid members with IDD and the matched comparison group.

Mental health

In mental health care, 10.4% of Medicaid members with IDD received a clinical depression screening. Medicaid members in the comparison group had a lower screening rate (8.7%), but the difference was not statistically significant. Among Medicaid members with IDD who were diagnosed with major depression and prescribed antidepressant medication, 55.1% continued receiving antidepressant medication for at least 12 weeks and 33.9% remained on antidepressant medication for at least 6 months. Antidepressant medication treatment was lower among Medicaid members without IDD (41.3% remained on antidepressant medication for at least 12 weeks and 21.7% remained on antidepressant medication for at least 6 months); differences were not quite statistically significant at the 5 percent level.

Approximately 2.2% of Medicaid members with IDD had a record of a nonfatal suicide attempt and selfharm, compared to 0.5% in the comparison population. The difference was highly statistically significant (difference: 1.7%; p-value < 0.001). The number of ED visits for suicidal ideation was 12.6 per 1,000 member-years among Medicaid members with IDD and 0.5 per 1,000 member-years among Medicaid members in the comparison group, but the difference was not quite statistically significant at the 5% level. Finally, Medicaid members with IDD had 564 readmissions after hospitalization for mental illness per 1,000 member-years, compared to 294 per 1,000 member-years among Medicaid members without IDD, with the difference not being statistically significant.

Substance use

We examined three measures related to substance use. Among Medicaid members with IDD, 9.1% received screening for alcohol or other substance abuse treatment. A similar percentage of Medicaid members without IDD received such screening (8.3%). Among those with a diagnosed substance use disorder, treatment initiation was similar for Medicaid members with and without IDD (33.6% and 32.5%, respectively). Engagement in substance use disorder treatment was 15.3% among Medicaid members with IDD compared to 19.9% among Medicaid members without IDD, but the difference was not statistically significant.

Hospital use

Regarding measures related to hospital use, the number of ED visits was higher among Medicaid members with IDD compared to those without IDD (1,570 vs. 612 visits per 1,000 member-years), with the difference being highly statistically significant (difference: 958 visits per 1,000 member-years, p-value < 0.001). Medicaid members with IDD also had an elevated 30-day all-cause readmission rate of 556 compared to 200 per 1,000 member-years, p-value < 0.01).

Diabetes care

One measure concerned with diabetes care. Among those diagnosed with diabetes, 91.2% of Medicaid members with IDD and 84.9% of Medicaid members without IDD had at least one HbA1c test in 2022, with the difference not being statistically significant.

Oral health care

Two measures related to oral health care. Among all Medicaid members with IDD, 59.2% received any dental care in 2022, compared to 32.4% among Medicaid members without IDD (difference: 26.8%; p-value <0.001), while just 44.0% and 20.4% received specifically preventive dental care, respectively (difference: 23.6%; p-value <0.001).

Cancer screening

We also observed differences for measures related to cancer screening. Among women aged 50-64, 42.1% with IDD were up to date with breast cancer screening recommendations, and 36.2% without IDD were compliant with such recommendations. The difference was not statistically significant. However, Medicaid members with IDD had a significantly lower cervical cancer screening rate (20.7%) in 2022 compared to those without IDD (25.9%; difference: -5.2, p-value < 0.05). Non-recommended cervical cancer screening was absent among female Medicaid members aged 18-20 years with IDD and nearly absent among female Medicaid members ages 18-20 years without IDD, with the difference not being statistically significant.

Table 3.2. Outcome levels, differences for Medicaid members with IDDand comparison population

Metric	Non-IDD	IDD	Difference
Clinical Depression Screening	8.7%	10.4%	+1.7
Antidepressant Medication Management - Acute Phase Treatment	41.3%	55.1%	+13.8
Antidepressant Medication Management - Continuous Phase Treatment	21.7%	33.9%	+12.2
Nonfatal Suicide Attempts and Self-Harm	0.5%	2.2%	+1.7*
ED Visits for Suicidal Ideation (mean per 1,000 member years (sd))	0.5 (22.0)	12.6 (304.7)	+12.1
30-Day All-Cause Readmissions After Hospitalization for Mental Illness (mean per 1,000 member years (sd))	294.1 (587.9)	564.4 (1564.7)	+270.2
Screening for Alcohol or Other Substance Abuse Treatment	8.3%	9.1%	+0.8
Initiation of SUD Treatment	32.5%	33.6%	+1.1
Engagement of SUD Treatment	19.9%	15.3%	-4.6
ED Utilization (mean per 1,000 member years (sd))	612.3 (1606.0)	1570.0 (6358.4)	+957.7*
30-Day All-Cause Readmissions (mean per 1,000 member years (sd))	200.0 (727.9)	555.9 (1775.7)	+355.9*
Diabetes Management (HbA1c)	84.9%	91.2%	+6.3
Access to Any Dental Care	32.4%	59.2%	+26.8*
Preventive Dental Services	20.4%	44.0%	+23.6*
Breast Cancer Screening	36.2%	42.1%	+5.9
Cervical Cancer Screening	25.9%	20.7%	-5.2*
Avoidance of Non-Recommended Cervical Cancer Screenings	97.6%	100.0%	+2.4

Subpopulation Results

Stratified by age groups

Medicaid members with IDD ages 18-29 had a prevalence of nonfatal suicide attempts (2.6%) which was significantly higher than those without IDD, whose rate was 0.5% (difference: 2.1%, p-value < 0.001).

They also had higher number of all-cause ED visits (difference: 668.0 visits per 1,000 member-years, p-value < 0.001) and 30-day all-cause hospital readmissions (difference: +476.6 visits per 1,000 member-years, p-value < 0.05) than Medicaid members without IDD in the same age group. They were less likely to receive cervical cancer screening (difference: -7.8%, p < 0.05), but more likely to receive any dental care (difference: 25.4%, p-value < 0.001) and preventative dental care (difference: 25.5%, p-value < 0.001) compared to the non-IDD population. For outcomes which were suppressed due to the low number of Medicaid members in each group, we have replaced them with "N/A" in the tables.

Table 3.3. Outcome levels, differences for Medicaid members with IDD ages18-29 and comparison population

Metric	Non-IDD	IDD	Difference
Clinical Depression Screening	9.2%	9.9%	+0.7%
Antidepressant Medication Management - Acute Phase Treatment	41.7%	50.8%	+9.1%
Antidepressant Medication Management - Continuous Phase Treatment	18.8%	28.8%	+10.0%
Nonfatal Suicide Attempts and Self-Harm	0.5%	2.6%	+2.1%*
ED Visits for Suicidal Ideation (mean per 1,000 member years (sd))	0.90 (30.2)	3.60 (60.3)	+2.7
30-Day All-Cause Readmissions After Hospitalization for Mental Illness (mean per 1,000 member years (sd))	272.70 (467.1)	388.90 (1122.9)	+116.2
Screening for Alcohol or Other Substance Abuse Treatment	8.7%	9.4%	+0.7%
Initiation of SUD Treatment	34.2%	35.6%	+1.4%
Engagement of SUD Treatment	24.7%	10.2%	-14.5%
ED Utilization (mean per 1,000 member years (sd))	542.00 (1500.7)	1210.00 (3827.2)	+668.0*
30-Day All-Cause Readmissions (mean per 1,000 member years (sd))	100.00 (378.9)	576.60 (2028.2)	+476.6*
Diabetes Management (HbA1c)	91.7%	86.3%	-5.4%
Access to Any Dental Care	33.0%	58.4%	+25.4%*
Preventive Dental Services	20.9%	46.4%	+25.5%*
Breast Cancer Screening	N/A	N/A	N/A
Cervical Cancer Screening	28.7%	20.9%	-7.8%*
Avoidance of Non-Recommended Cervical Cancer Screenings	97.6%	100.0%	+2.4%

Members with IDD ages 30-39 had higher number of all-cause ED visits (difference: 1,385 visits per 1,000 member-years, p-value < 0.01) and all-cause hospital readmissions (difference: 534.6, p-value < 0.05) compared to Medicaid members without IDD in this age group. Cervical cancer screening rates were also significantly lower among those with IDD compared to those without IDD in this age group (difference: -9.8%, p-value < 0.05). Prevalence of any dental care (difference: 28.5%, p-value < 0.001) and preventative dental care (difference: 23.9, p-value < 0.001) was higher among those with IDD than those without IDD in this age group.

Table 3.4. Outcome levels, differences for Medicaid members with IDD ages30-39 and comparison population

Metric	Non-IDD	IDD	Difference
Clinical Depression Screening	9.9%	11.5%	+1.6%
Antidepressant Medication Management - Acute Phase Treatment	40.7%	60.0%	+19.3%
Antidepressant Medication Management - Continuous Phase Treatment	18.5%	33.3%	+14.8%
Nonfatal Suicide Attempts and Self-Harm	0.6%	1.4%	+0.8%
ED Visits for Suicidal Ideation (mean per 1,000 member years (sd))	0.00 (0.0)	29.70 (585.1)	+29.7
30-Day All-Cause Readmissions After Hospitalization for Mental Illness (mean per 1,000 member years (sd))	N/A	N/A	N/A
Screening for Alcohol or Other Substance Abuse Treatment	9.1%	9.9%	+0.8%
Initiation of SUD Treatment	30.8%	23.1%	-7.7%
Engagement of SUD Treatment	19.2%	12.8%	-6.4%
ED Utilization (mean per 1,000 member years (sd))	704.90 (1956.4)	2090.00 (10591.0)	+1385.0*
30-Day All-Cause Readmissions (mean per 1,000 member years (sd))	142.90 (524.5)	677.40 (1677.0)	+534.6*
Diabetes Management (HbA1c)	83.3%	92.9%	+9.6%
Access to Any Dental Care	33.5%	62.0%	+28.5%*
Preventive Dental Services	21.2%	45.1%	+23.9%*
Breast Cancer Screening	N/A	N/A	N/A
Cervical Cancer Screening	30.3%	20.5%	-9.8%*
Avoidance of Non-Recommended Cervical Cancer Screenings	N/A	N/A	N/A

Medicaid members with IDD ages 40-49 had a statistically significant higher number of ED visits compared to Medicaid members without IDD in the same age group (difference: 1,426.0 visits per 1,000 member-years, p-value < 0.01). They were more likely to receive any dental care (difference: 32.9%, p-value < 0.001) and preventative dental care (difference: 23.1%, p-value < 0.001).

Table 3.5. Outcome levels, differences for Medicaid members with IDD ages40-49 and comparison population

Metric	Non-IDD	IDD	Difference
Clinical Depression Screening	6.1%	11.5%	+5.4%
Antidepressant Medication Management - Acute Phase Treatment	N/A	N/A	N/A
Antidepressant Medication Management - Continuous Phase Treatment	N/A	N/A	N/A
Nonfatal Suicide Attempts and Self-Harm	0.4%	2.6%	+2.2%
ED Visits for Suicidal Ideation (mean per 1,000 member years (sd))	0.00 (0.0)	4.30 (65.4)	+4.3
30-Day All-Cause Readmissions After Hospitalization for Mental Illness (mean per 1,000 member years (sd))	N/A	N/A	N/A
Screening for Alcohol or Other Substance Abuse Treatment	5.5%	7.9%	+2.4%
Initiation of SUD Treatment	N/A	N/A	N/A
Engagement of SUD Treatment	N/A	N/A	N/A
ED Utilization (mean per 1,000 member years (sd))	594.00 (1374.9)	2020.00 (5729.2)	+1426.0*
30-Day All-Cause Readmissions (mean per 1,000 member years (sd))	636.40 (1433.4)	571.40 (1768.9)	-64.9
Diabetes Management (HbA1c)	85.7%	93.6%	+7.9%
Access to Any Dental Care	30.8%	63.7%	+32.9%*
Preventive Dental Services	19.2%	42.3%	+23.1%*
Breast Cancer Screening	N/A	N/A	N/A
Cervical Cancer Screening	14.6%	16.8%	+2.2%
Avoidance of Non-Recommended Cervical Cancer Screenings	N/A	N/A	N/A

Medicaid members with IDD ages 50-64 had a higher rate of ED visits compared to Medicaid members without IDD in the same age group (difference: 938.1 per 1,000 member-years, p-value < 0.001). However, they were more likely to receive any dental care (difference: 24.2%, p-value < 0.001) and preventative dental care (difference: 14.7%, p-value < 0.001). Other measures were not significantly different between the two groups.

Table 3.6. Outcome levels, differences for Medicaid members with IDD ages50-64 and comparison population

Metric	Non-IDD	IDD	Difference
Clinical Depression Screening	7.0%	8.7%	+1.7%
Antidepressant Medication Management - Acute Phase Treatment	N/A	N/A	N/A
Antidepressant Medication Management - Continuous Phase Treatment	N/A	N/A	N/A
Nonfatal Suicide Attempts and Self-Harm	0.0%	1.7%	+1.7%
ED Visits for Suicidal Ideation (mean per 1,000 member years (sd))	0.00 (0.0)	26.00 (245.3)	+26.0
30-Day All-Cause Readmissions After Hospitalization for Mental Illness (mean per 1,000 member years (sd))	N/A	N/A	N/A
Screening for Alcohol or Other Substance Abuse Treatment	7.5%	7.4%	-0.1%
Initiation of SUD Treatment	N/A	N/A	N/A
Engagement of SUD Treatment	N/A	N/A	N/A
ED Utilization (mean per 1,000 member years (sd))	761.90 (1438.5)	1700.00 (3572.1)	+938.1*
30-Day All-Cause Readmissions (mean per 1,000 member years (sd))	222.20 (831.9)	311.10 (900.1)	+88.9
Diabetes Management (HbA1c)	82.9%	92.3%	+9.4%
Access to Any Dental Care	28.6%	52.8%	+24.2%*
Preventive Dental Services	17.3%	32.0%	+14.7%*
Breast Cancer Screening	36.2%	42.1%	+5.9%
Cervical Cancer Screening	16.7%	24.1%	+7.4%
Avoidance of Non-Recommended Cervical Cancer Screenings	N/A	N/A	N/A

Stratified by Sex

Female Medicaid members with IDD had a higher prevalence of nonfatal suicide attempts compared to female Medicaid members without IDD (difference: 3.0%, p-value < 0.001). They also had a higher number of ED visits for suicidal ideation (difference: 13.8 visits per 1,000 member-years, p-value < 0.01) and all-cause ED visits (difference: 1,047.8 per 1,000 member-years, p-value < 0.001). Furthermore, they were less likely to receive cervical cancer screening (difference: -5.2%, p-value < 0.05). However, they were more likely to initiate SUD treatment (difference: 23.0%, p-value < 0.05), receive any dental care (difference: 19.9%, p-value < 0.001), and receive preventative dental care (difference: 19.9%, p-value < 0.001).

Table 3.7. Outcome levels, differences for women with IDD and comparisonpopulation

Metric	Non-IDD	IDD	Difference
Clinical Depression Screening	8.7%	11.1%	+2.4%
Antidepressant Medication Management - Acute Phase Treatment	33.3%	48.6%	+15.3%
Antidepressant Medication Management - Continuous Phase Treatment	17.6%	28.6%	+11.0%
Nonfatal Suicide Attempts and Self-Harm	0.5%	3.5%	+3.0%*
ED Visits for Suicidal Ideation (mean per 1,000 member years (sd))	0.00 (0.0)	13.80 (155.6)	+13.8*
30-Day All-Cause Readmissions After Hospitalization for Mental Illness (mean per 1,000 member years (sd))	166.70 (408.2)	690.90 (1824.5)	+524.2
Screening for Alcohol or Other Substance Abuse Treatment	8.3%	9.9%	+1.6%
Initiation of SUD Treatment	17.9%	40.9%	+23.0%*
Engagement of SUD Treatment	10.7%	22.7%	+12.0%
ED Utilization (mean per 1,000 member years (sd))	682.20 (1660.0)	1730.00 (5067.8)	+1047.8*
30-Day All-Cause Readmissions (mean per 1,000 member years (sd))	130.40 (653.5)	570.40 (2084.7)	+440.0*
Diabetes Management (HbA1c)	82.9%	88.6%	+5.7%
Access to Any Dental Care	38.9%	58.8%	+19.9%*
Preventive Dental Services	25.2%	45.1%	+19.9%*
Breast Cancer Screening	36.2%	42.1%	+5.9%
Cervical Cancer Screening	25.9%	20.7%	-5.2%*
Avoidance of Non-Recommended Cervical Cancer Screenings	97.6%	100.0%	+2.4%

Male Medicaid members with IDD had a higher rate of ED visits (difference: 886.5 per 1,000 memberyears, p-value < 0.001) and were less likely to engage in substance use disorder treatment than male Medicaid members without IDD (difference: 16.0%, p-value < 0.05). A higher percentage of them received any dental care (difference: 32.7%, p-value < 0.001) and preventative dental care (difference: 26.8%, p-value < 0.001). Other measures were not significantly different between male Medicaid members with and without IDD.

Table 3.8. Outcome levels, differences for men with IDD and comparisonpopulation

Metric	Non-IDD	IDD	Difference
Clinical Depression Screening	8.8%	9.8%	+1.0%
Antidepressant Medication Management - Acute Phase Treatment	51.2%	63.2%	+12.0%
Antidepressant Medication Management - Continuous Phase Treatment	26.8%	40.4%	+13.6%
Nonfatal Suicide Attempts and Self-Harm	0.4%	1.1%	+0.7%
ED Visits for Suicidal Ideation (mean per 1,000 member years (sd))	0.90 (29.9)	11.60 (388.1)	+10.7
30-Day All-Cause Readmissions After Hospitalization for Mental Illness (mean per 1,000 member years (sd))	363.60 (674.2)	413.00 (1184.6)	+49.4
Screening for Alcohol or Other Substance Abuse Treatment	8.2%	8.5%	+0.3%
Initiation of SUD Treatment	40.0%	26.8%	-13.2%
Engagement of SUD Treatment	24.5%	8.5%	-16.0%*
ED Utilization (mean per 1,000 member years (sd))	553.50 (1557.5)	1440.00 (7268.5)	+886.5*
30-Day All-Cause Readmissions (mean per 1,000 member years (sd))	246.40 (774.7)	541.70 (1413.6)	+295.3
Diabetes Management (HbA1c)	86.7%	94.0%	+7.3%
Access to Any Dental Care	26.9%	59.6%	+32.7%*
Preventive Dental Services	16.3%	43.1%	+26.8%*
Breast Cancer Screening	N/A	N/A	N/A
Cervical Cancer Screening	N/A	N/A	N/A
Avoidance of Non-Recommended Cervical Cancer Screenings	N/A	N/A	N/A

Stratified byRace and Ethnicity

Results for white Medicaid members with IDD were very similar to results for the full study population because they constituted, by far, the largest race-ethnic group in Oregon.

Specifically, a higher percentage of white Medicaid members with IDD compared to white Medicaid members without IDD experienced a nonfatal suicide attempt (difference: 2.0%, p-value < 0.001). They also had a higher number of all-cause ED visits (difference: 977.2 visits per 1,000 member-years, p-value < 0.001) and 30-day all-cause hospital readmission (difference: 337.0 visits per 1,000 member-years, p-value < 0.05), and were less likely to receive cervical cancer screening (difference: 6.4% p-value < 0.05).

White Medicaid members with IDD were more likely to receive any dental care (difference: 28.9%, p-value < 0.001) and preventative dental care (difference: 23.5% p-value < 0.001). One measure was statistically significant for this subpopulation and not for the full study sample: White Medicaid members with IDD had a higher number of ED visits for suicidal ideation (difference: 9.2 visits per 1,000 member-years, p-value < 0.05) compared to white Medicaid members without IDD.

Table 3.9. Outcome levels, differences for white Medicaid members with IDDand comparison population

Metric	Non-IDD	IDD	Difference
Clinical Depression Screening	9.1%	10.7%	+1.6%
Antidepressant Medication Management - Acute Phase Treatment	50.9%	57.9%	+7.0%
Antidepressant Medication Management - Continuous Phase Treatment	28.1%	39.5%	+11.4%
Nonfatal Suicide Attempts and Self-Harm	0.3%	2.3%	+2.0%*
ED Visits for Suicidal Ideation (mean per 1,000 member years (sd))	0.80 (28.9)	10.00 (135.2)	+9.2*
30-Day All-Cause Readmissions After Hospitalization for Mental Illness (mean per 1,000 member years (sd))	250.00 (462.9)	736.80 (1932.1)	+486.8
Screening for Alcohol or Other Substance Abuse Treatment	8.5%	9.1%	+0.6%
Initiation of SUD Treatment	32.4%	33.8%	+1.4%
Engagement of SUD Treatment	19.0%	11.2%	-7.8%
ED Utilization (mean per 1,000 member years (sd))	652.80 (1748.5)	1630.00 (7289.1)	+977.2*
30-Day All-Cause Readmissions (mean per 1,000 member years (sd))	205.90 (744.3)	542.90 (1653.0)	+337.0*
Diabetes Management (HbA1c)	78.3%	90.7%	+12.4%
Access to Any Dental Care	30.6%	59.5%	+28.9%*
Preventive Dental Services	19.2%	42.7%	+23.5%*
Breast Cancer Screening	41.8%	45.8%	+4.0%
Cervical Cancer Screening	26.6%	20.2%	-6.4%*
Avoidance of Non-Recommended Cervical Cancer Screenings	94.1%	100.0%	+5.9%

Black Medicaid members with IDD were more likely to receive any dental care (difference: 25.9%, p-value < 0.001) and preventative dental care (difference: 26.8%, p-value < 0.001) compared to Black Medicaid members without IDD. They also experienced a higher number of all-cause ED visits (difference: 932.5 visits per 1,000 member-years, p-value < 0.05). Other measures were not statistically significant, which may in some cases reflect a small sample size. Of note, Black Medicaid members with IDD had the highest prevalence of non-fatal suicide attempts and self-harm of all populations studied in this report (3.6%).

Table 3.10. Outcome levels, differences for Black Medicaid members with IDD and comparison population

Metric	Non-IDD	IDD	Difference
Clinical Depression Screening	6.7%	11.0%	+4.3%
Antidepressant Medication Management - Acute Phase Treatment	N/A	N/A	N/A
Antidepressant Medication Management - Continuous Phase Treatment	N/A	N/A	N/A
Nonfatal Suicide Attempts and Self-Harm	0.0%	3.6%	+3.6%
ED Visits for Suicidal Ideation (mean per 1,000 member years (sd))	0.00 (0.0)	8.90 (94.5)	+8.9
30-Day All-Cause Readmissions After Hospitalization for Mental Illness (mean per 1,000 member years (sd))	N/A	N/A	N/A
Screening for Alcohol or Other Substance Abuse Treatment	5.6%	9.2%	+3.6%
Initiation of SUD Treatment	N/A	N/A	N/A
Engagement of SUD Treatment	N/A	N/A	N/A
ED Utilization (mean per 1,000 member years (sd))	937.50 (1871.0)	1870.00 (3879.9)	+932.5*
30-Day All-Cause Readmissions (mean per 1,000 member years (sd))	N/A	N/A	N/A
Diabetes Management (HbA1c)	N/A	N/A	N/A
Access to Any Dental Care	39.3%	65.2%	+25.9%*
Preventive Dental Services	23.2%	50.0%	+26.8%*
Breast Cancer Screening	N/A	N/A	N/A
Cervical Cancer Screening	31.8%	30.0%	-1.8%
Avoidance of Non-Recommended Cervical Cancer Screenings	N/A	N/A	N/A

A higher percentage of Latino Medicaid members with IDD received any dental care (difference: 24.6%, p-value < 0.001) and preventative dental care (difference: 20.6% p-value < 0.001) compared to Latino Medicaid members with IDD also experienced a higher number of all-cause ED visits than Latino Medicaid members without IDD (difference: 1,018.7 visits per 1,000 member-years, p-value < 0.05). Other measures were not significant.

Table 3.11. Outcome levels, differences for Latino Medicaid members with IDD and comparison population

Metric	Non-IDD	IDD	Difference
Clinical Depression Screening	8.0%	10.3%	+2.3%
Antidepressant Medication Management - Acute Phase Treatment	N/A	N/A	N/A
Antidepressant Medication Management - Continuous Phase Treatment	N/A	N/A	N/A
Nonfatal Suicide Attempts and Self-Harm	1.2%	1.6%	+0.4%
ED Visits for Suicidal Ideation (mean per 1,000 member years (sd))	0.00 (0.0)	0.00 (0.0)	+0.0
30-Day All-Cause Readmissions After Hospitalization for Mental Illness (mean per 1,000 member years (sd))	N/A	N/A	N/A
Screening for Alcohol or Other Substance Abuse Treatment	8.0%	9.1%	+1.1%
Initiation of SUD Treatment	N/A	N/A	N/A
Engagement of SUD Treatment	N/A	N/A	N/A
ED Utilization (mean per 1,000 member years (sd))	411.30 (1148.9)	1430.00 (4842.8)	+1018.7*
30-Day All-Cause Readmissions (mean per 1,000 member years (sd))	N/A	N/A	N/A
Diabetes Management (HbA1c)	N/A	N/A	N/A
Access to Any Dental Care	35.1%	59.7%	+24.6%*
Preventive Dental Services	25.4%	46.0%	+20.6%*
Breast Cancer Screening	N/A	N/A	N/A
Cervical Cancer Screening	22.3%	17.3%	-5.0%
Avoidance of Non-Recommended Cervical Cancer Screenings	N/A	N/A	N/A

Medicaid members with IDD who were in the "Other/Multiple Races" category had a higher number of ED visits (difference: 1,069.6 visits per 1,000 member-years, p-value < 0.05) compared to members without IDD in this group. They were more likely to receive any dental care (difference: 17.2%, p-value < 0.001) and preventative dental care (difference: 17.6%, p-value < 0.001). Other measures were not statistically significant, which may in some cases reflect a small sample size.

Table 3.12. Outcome levels, differences for Medicaid members with IDD andcomparison population with other/multiple Races

Metric	Non-IDD	IDD	Difference
Clinical Depression Screening	7.4%	10.5%	+3.1%
Antidepressant Medication Management - Acute Phase Treatment	N/A	N/A	N/A
Antidepressant Medication Management - Continuous Phase Treatment	N/A	N/A	N/A
Nonfatal Suicide Attempts and Self-Harm	0.9%	3.0%	+2.1%
ED Visits for Suicidal Ideation (mean per 1,000 member years (sd))	0.00 (0.0)	0.00 (0.0)	+0.0
30-Day All-Cause Readmissions After Hospitalization for Mental Illness (mean per 1,000 member years (sd))	N/A	N/A	N/A
Screening for Alcohol or Other Substance Abuse Treatment	7.4%	10.0%	+2.6%
Initiation of SUD Treatment	N/A	N/A	N/A
Engagement of SUD Treatment	N/A	N/A	N/A
ED Utilization (mean per 1,000 member years (sd))	590.50 (1579.2)	1660.00 (5482.1)	+1069.5*
30-Day All-Cause Readmissions (mean per 1,000 member years (sd))	N/A	N/A	N/A
Diabetes Management (HbA1c)	N/A	N/A	N/A
Access to Any Dental Care	39.7%	56.9%	+17.2%*
Preventive Dental Services	24.6%	42.2%	+17.6%*
Breast Cancer Screening	N/A	N/A	N/A
Cervical Cancer Screening	25.2%	24.7%	-0.5%
Avoidance of Non-Recommended Cervical Cancer Screenings	N/A	N/A	N/A

Medicaid members with IDD with unknown or missing race and ethnicity information had a higher number of ED visits (difference: 746.4 visits per 1,000 member-years, p-value < 0.01) compared with their counterparts without IDD. Prevalence of any dental (difference: 28.2% p-value < 0.001) and preventative dental care (difference: 31.2%, p-value < 0.001) was higher among Medicaid members with unknown missing race and ethnicity information and IDD to those without IDD.

Table 3.13. Outcome levels, differences for Medicaid members with IDD and comparison population with unknown or missing race and ethnicity information

Metric	Non-IDD	IDD	Difference
Clinical Depression Screening	9.9%	8.6%	-1.3%
Antidepressant Medication Management - Acute Phase Treatment	N/A	N/A	N/A
Antidepressant Medication Management - Continuous Phase Treatment	N/A	N/A	N/A
Nonfatal Suicide Attempts and Self-Harm	0.7%	0.7%	+0.0%
ED Visits for Suicidal Ideation (mean per 1,000 member years (sd))	0.00 (0.0)	47.10 (782.5)	+47.1
30-Day All-Cause Readmissions After Hospitalization for Mental Illness (mean per 1,000 member years (sd))	N/A	N/A	N/A
Screening for Alcohol or Other Substance Abuse Treatment	9.4%	8.6%	-0.8%
Initiation of SUD Treatment	N/A	N/A	N/A
Engagement of SUD Treatment	N/A	N/A	N/A
ED Utilization (mean per 1,000 member years (sd))	503.60 (1126.5)	1250.00 (4445.3)	+746.4*
30-Day All-Cause Readmissions (mean per 1,000 member years (sd))	N/A	N/A	N/A
Diabetes Management (HbA1c)	N/A	N/A	N/A
Access to Any Dental Care	29.0%	57.2%	+28.2%*
Preventive Dental Services	16.3%	47.5%	+31.2%*
Breast Cancer Screening	N/A	N/A	N/A
Cervical Cancer Screening	24.8%	18.0%	-6.8%
Avoidance of Non-Recommended Cervical Cancer Screenings	N/A	N/A	N/A

Stratified by Residency

Medicaid members with IDD residing in rural areas had a higher rate of nonfatal suicide attempts and selfharm (difference: 2.3% p-value < 0.01) and a higher number of ED visits (difference: 553.6 visits per 1,000 member-years, p-value < 0.01), but they were more likely to receive any dental care (difference: 29.6%, p-value < 0.001) and preventative dental care (difference: 24.1%, p-value < 0.001). Other differences were not statistically significant.

Table 3.14. Outcome levels, differences for Medicaid members with IDD andcomparison population residing in rural areas

Metric	Non-IDD	IDD	Difference
Clinical Depression Screening	5.9%	4.4%	-1.5%
Antidepressant Medication Management - Acute Phase Treatment	N/A	N/A	N/A
Antidepressant Medication Management - Continuous Phase Treatment	N/A	N/A	N/A
Nonfatal Suicide Attempts and Self-Harm	0.2%	2.5%	+2.3%*
ED Visits for Suicidal Ideation (mean per 1,000 member years (sd))	0.00 (0.0)	11.40 (157.9)	+11.4
30-Day All-Cause Readmissions After Hospitalization for Mental Illness (mean per 1,000 member years (sd))	N/A	N/A	N/A
Screening for Alcohol or Other Substance Abuse Treatment	5.0%	3.7%	-1.3%
Initiation of SUD Treatment	22.6%	29.4%	+6.8%
Engagement of SUD Treatment	9.7%	17.6%	+7.9%
ED Utilization (mean per 1,000 member years (sd))	586.40 (1291.9)	1140.00 (3479.8)	+553.6*
30-Day All-Cause Readmissions (mean per 1,000 member years (sd))	190.50 (872.9)	250.00 (808.6)	+59.5
Diabetes Management (HbA1c)	80.0%	86.0%	+6.0%
Access to Any Dental Care	33.6%	63.2%	+29.6%*
Preventive Dental Services	19.8%	43.9%	+24.1%*
Breast Cancer Screening	N/A	N/A	N/A
Cervical Cancer Screening	23.4%	22.8%	-0.6%
Avoidance of Non-Recommended Cervical Cancer Screenings	N/A	N/A	N/A

Medicaid members with IDD residing in an urban area were more likely than Medicaid members residing in an urban area without IDD to undergo screening for clinical depression (difference: 2.5%, p-value < 0.05). Among those with a diagnosis of major depression, those with IDD were more likely to continue antidepressant medication for at least 12 weeks (acute phase treatment; difference: 19.5%, p-value < 0.05) and at least 6 months (continuous phase treatment; difference: 15.3%, p-value < 0.05) consecutively than their counterparts without IDD.

However, they were more likely to have a nonfatal suicide attempt or self-harm than their comparison group (difference: 1.5% p-value < 0.001). They also had a higher number of ED visits (difference: 1,070.7 visits per 1,000 member-years, p-value < 0.001) and all-cause hospital readmission (difference: 403.6 visits per 1,000 member-years, p-value < 0.01), and were less likely to receive cervical cancer screening (difference: 6.5%, p-value < 0.01). They were more likely to receive any dental care (difference: 26.2%, p-value < 0.001) or preventative dental care (difference: 23.6%, p-value < 0.001).

Table 3.15. Outcome levels, differences for Medicaid members with IDD andcomparison population residing in urban areas

Metric	Non-IDD	IDD	Difference
Clinical Depression Screening	9.5%	12.0%	+2.5%*
Antidepressant Medication Management - Acute Phase Treatment	40.3%	59.8%	+19.5%*
Antidepressant Medication Management - Continuous Phase Treatment	20.8%	36.1%	+15.3%*
Nonfatal Suicide Attempts and Self-Harm	0.6%	2.1%	+1.5%*
ED Visits for Suicidal Ideation (mean per 1,000 member years (sd))	0.60 (24.8)	12.90 (333.5)	+12.3
30-Day All-Cause Readmissions After Hospitalization for Mental Illness (mean per 1,000 member years (sd))	333.30 (617.2)	560.40 (1600.1)	+227.1
Screening for Alcohol or Other Substance Abuse Treatment	9.2%	10.6%	+1.4%
Initiation of SUD Treatment	34.8%	35.0%	+0.2%
Engagement of SUD Treatment	22.2%	14.6%	-7.6%
ED Utilization (mean per 1,000 member years (sd))	619.30 (1681.3)	1690.00 (6931.1)	+1070.7*
30-Day All-Cause Readmissions (mean per 1,000 member years (sd))	202.10 (696.8)	605.70 (1883.1)	+403.6*
Diabetes Management (HbA1c)	86.4%	92.6%	+6.2%
Access to Any Dental Care	32.0%	58.2%	+26.2%*
Preventive Dental Services	20.5%	44.1%	+23.6%*
Breast Cancer Screening	36.9%	36.2%	-0.7%
Cervical Cancer Screening	26.6%	20.1%	-6.5%*
Avoidance of Non-Recommended Cervical Cancer Screenings	97.1%	100.0%	+2.9%

Overview of Oregon data sets with disability data

Here we present an environmental scan of data sources that include data on people with disabilities, with a focus on data sources relevant for people residing in Oregon. We conducted a web search of data sources, contacted agency representatives, and reviewed relevant literature for the scan.14 The following 10 data sets were included in the environmental scan:

- 1. Oregon Medicaid enrollment and claims data: a program that provides health care coverage for people with low incomes.
- 2. Oregon All Payers All Claims (APAC) data: health care coverage programs for Oregon's insured populations.
- **3. Oregon Department of Human Services Developmental Disability (DD) data:** the program supports people with disabilities and their families by providing and promoting services.
- **4. Oregon Department of Human Services Aging and People with Disabilities (APD) data:** the program provides services for people living with disabilities and people who need support as they age.
- 5. National Core Indicators Intellectual and Developmental Disabilities (NCI-IDD): a survey to assess the quality and outcomes of Developmental Disability (DD) services provided to people with IDD and their families.
- 6. Residential Information Systems Project (RISP): survey gathers longitudinal data of Medicaid funded long-term services and supports (LTSS) for people with intellectual and developmental disabilities (IDD). They conduct an annual survey of public residential facilities (PRF) describing the status of the facilities and the people that live t here.
- 7. Oregon Health Authority Race, Ethnicity, Language, and Disability & Sexual Orientation and Gender Identity (REALD & SOGI) repository: a relational database containing demographic data from at least seven databases to help gather more complete information.
- National Core Indicators Aging and Disabilities (NCI-AD): a survey to assess the outcomes of services provided to aging people with disabilities and families.
- **9. U.S. Census Bureau American Community Survey (ACS:** the survey provides vital information on a yearly basis about the United States of America and people who live there.
- **10.** Centers for Disease Control and Prevention Behavioral Risk Factor Surveillance System (BRFSS): the survey enables the Center for Disease Control and Prevention (CDC), state health departments, and other health agencies to monitor modifiable risk factors for chronic diseases and other leading causes of death.

Five of these data sources are survey-based (ACS, BRFSS, NCI-AD, NCI-IDD, RISP) and four contain administrative data (DD, APD, Medicaid and APAC data). The REALD and SOGI Repository is a database compiling demographic data from at least seven other state databases for the purposes of reporting of demographic information; ninety percent of records come from the state's eligibility system for Medicaid and other public benefits.¹⁸

Information collected by these data sources varies widely. DD and APD data primarily include information on eligibility and services received for assistance with daily living needs to people with disabilities. Medicaid and APAC data include information on health insurance enrollment and claims, which can be used to construct measures of health care utilization, and, in some instances, health status. REALD data includes information on race, ethnicity, language and disability. The surveys collect a wide range of information in areas such as employment, education, housing, and decision-making. Details about each of these data sources are included in Appendix B.

Some state administrative data sets could be linked by a unique member ID by Oregon's Integrated Client Services, creating a larger, combined data set that would allow for a more comprehensive understanding of a defined population. 20 The environmental data scan lists state data sets with disability data, which ICS can link to each other. The scan does not include data sets without disability data (e.g. vital statistics), which could also be linked to datasets with disability information.

Conclusion

Key Findings

In this report, we used Medicaid enrollment and claims data from 2022 to assess health care utilization of Medicaid members with IDD. We used a matching approach to identify a comparison group of Medicaid members without IDD with similar demographic characteristics. Our analysis suggested disparities for Medicaid members with IDD compared to Medicaid members without IDD on a number of measures. Specifically, they had a higher prevalence of suicide attempts and self-harm, were less likely to receive cervical cancer screening, and had higher number of all-cause ED visits and 30-day plan all-cause readmissions after hospitalization compared to Medicaid members without IDD. However, Medicaid members with IDD received better oral health care than those without IDD.

Subgroups analyses revealed a higher number of ED visits but better oral health care among Medicaid members with IDD compared to Medicaid members without IDD for every subgroup. Moreover, stratification by age group suggested that disparities for Medicaid members with IDD were mostly prevalent among Medicaid members ages 18-29.

Stratification by sex showed that female Medicaid members with IDD had disparities compared to female Medicaid members without IDD that mostly mirrored disparities among the full study population; additionally, they had a higher number of ED visits for suicidal ideation but also a higher prevalence of initiation of SUD treatment than female Medicaid members without IDD. Disparities were less apparent for male Medicaid members with IDD. They were, however, less likely to engage in SUD treatment than male Medicaid members without IDD.

Disparities were mostly apparent among white Medicaid members with IDD compared to White Medicaid members without IDD, reflecting the high share of white Medicaid members in the study population. Of note, Black Medicaid members with IDD had the highest prevalence of suicide attempts and self-harm of all population groups studied. Medicaid members with IDD residing in urban areas were the only subpopulation that had better clinical depression screening and antidepressant medication management compared to their counterparts without IDD.

We also conducted an environmental scan of data sources for people with IDD. Of the 10 data sources included in the environmental scan, four were administrative data, five were survey data, and one data source was a hybrid between administrative and survey data. Data sources varied in how they identified people with IDD. They also included a considerable range of information related to health and health care, social services, and social risk factors. Among these data sources, six could be linked to Medicaid for further analyses comparing differences in identifying IDD populations among data sources and evaluating service utilization more comprehensively.

Implications for Research

Conduct follow-up research on access challenges to mental health treatment. For instance, qualitative interviews with Medicaid members with IDD who experienced non-fatal suicide attempts and self-harm and their caregivers could illuminate factors that contributed to these events. This information could help determine whether there were gaps between services that were needed versus services that were available or could be accessed. Similarly, interviews with Medicaid members with IDD and their caregivers could identify access challenges for preventative depression screening and other mental health support services and explore the role of members' living setting on mental health needs.

Future research could also examine whether Medicaid members with IDD receive the same standards of care related to mental health assessment, diagnosis, and treatment compared to those without IDD, and the extent to which living arrangements contribute to mental health needs. For this research, special attention should be devoted to Black Medicaid members with IDD, who experienced the most negative outcome of all populations studied in this report.

Understand low rates of substance use disorder (SUD) screening, as well as initiation and engagement in SUD treatment. While we generally did not observe disparities for measures related to SUD screening and treatment, rates were low among Medicaid members with IDD. Moreover, male Medicaid members with IDD were less likely to engage in SUD treatment compared with male Medicaid members without IDD. Qualitative interviews could help identify gaps between SUD services needed and SUD services accessible or available for Medicaid members with IDD, and factors that might contribute to such gaps.

Assess factors contributing to high rates of emergency department (ED) visits and readmissions.

Additional research could include a document review of policies and care plan protocols in group homes that may stipulate ED visits for certain health conditions for Medicaid members with IDD. Future research could also examine quality of care processes (e.g., discharge planning) and accommodations for people with IDD that could be related to lower levels of readmissions.

Medicaid claims records could further be used to analyze conditions related to ED visits and whether these are more prevalent among Medicaid members with IDD, whether Medicaid members with IDD use ED instead of primary care because of lack of access, and how ED expenditures compare to expenditures in primary care settings. Qualitative interviews of Medicaid members with IDD and their caregivers could also illuminate gaps in follow-up care after an ED visit.

Examine disparities in diabetes diagnosis. While we did not observe disparities in diabetes treatment, our analysis did not assess potential disparities in diabetes diagnosis. Future research could examine the distribution of stages of diabetes when first diagnosed to assess whether Medicaid members with IDD are less likely to receive a diabetes diagnosis at earlier stages of the condition compared to Medicaid members without IDD.

Conduct follow-up analysis of oral health care services. Medicaid members with IDD had higher levels of access to oral health care. Further research could illuminate the mechanisms that helped achieve this favorable outcome and whether similar tactics could be used to increase utilization of other services for Medicaid members with IDD. Additionally, our analysis did not examine which type of services they received. Further research could illuminate whether disparities exist regarding the types of dental services, and whether Medicaid members with IDD face access challenges for specific types of dental services.
Improve identification of Medicaid members with IDD in Medicaid data. Analysis for this report used International Classification of Diseases (ICD) codes to identify Medicaid members with IDD (see Appendix A for details). Thus, we were not able to capture Medicaid members with IDD who did not have corresponding ICD codes in their Medicaid claims records, for instance because they did not access care, or because health care professionals did not include these codes in claims. Identification of Medicaid members with IDD based on self-reported information would greatly improve analyses of their health care use in Medicaid data. REALD data may be useful in identifying people with IDD, but it is not clear yet whether its disability questionnaires can be used to identify this population.

Include sexual orientation and gender identity (SOGI) information. Information related to sexual orientation and gender identity from the REALD & SOGI Repository was not available for our analysis. Future research could include this information to generate evidence on disparities by these characteristics.

Examine the role of social determinants of health factors. These environmental factors include employment, housing, food security, access to transportation, and neighborhood and social resources. Future research could incorporate this information to assess their role for health care delivery and disparities.

Implications for Policy

Increase support and training for providers of health care needs for Medicaid members with IDD.

Medicaid members with IDD may have specific health care needs and challenges. Training for providers on topics related to mental health and substance use for this population could be highly valuable. For direct support professionals (DSPs), who work closely with individuals with IDD to support self-care and assist with daily living tasks, training should be developed about early warning signs of mental health problems and resources related to mental health treatment. Conversely, mental health and substance use specialists could receive training on working with patients with IDD and their accommodation needs. At a system level, better communication between disability service organizations and the mental health system could improve coordination of care. OHA could organize workshops for these organizations to present evidence on mental health care needs of people with IDD and facilitate better communication between agencies.

Increase number of behavioral care providers. Low rates of depression and substance use screening as well as initiation of and engagement in SUD treatment were consistent with other evidence documenting deficiencies in Oregon's behavioral health system.²¹ Increasing the number of behavioral care providers available to Medicaid patients, for instance by increasing behavioral health related reimbursement rates, could also improve access to behavioral care services for Medicaid members with IDD.

Improve cervical cancer screening rates among female Medicaid members with IDD. Cervical cancer screening was less prevalent among women with IDD compared to those without IDD. This finding suggests policy failures at the system level. The Oregon Health Authority should work with Oregon's Coordinated Care Organizations (CCOs) to identify potential barriers that may lead to low screening rates among the IDD population, in particular, and solutions to reduce or remove these barriers. For instance, Medicaid members with IDD might benefit from an accessible cancer screening guide that describes procedures and supports available to them. OHA and CCOs could also reach out to cancer advocacy groups to dispel myths about cancer screenings through targeted educational campaigns.

Update coordinated care organization contracts to include a requirement for hospital discharge

planning and coordination. To address high rates of 30-day all-cause readmission rates for Medicaid members with IDD, OHA could consider adding a contractual requirement for coordinated care organizations to report on discharge planning and care coordination for the IDD population.

Strengthen integration of data sources for people with IDD. Several data sets identified people with IDD and collected valuable information related to their health care, social services and social risks. However, these data sources vary in how they identify people with IDD and often exist in isolation. Integrating data related to people with IDD could help identify factors associated with disparities in health care utilization and may help improve services and health care for this population.

Continue reporting on health disparities affecting Medicaid members with IDD. This report

identified multiple health disparities experienced by Oregon's IDD population. The state should continue monitoring these on a regular basis, either as part of ongoing Medicaid REALD reporting or through commissioned reports such as this one. Adding children's data and All Payer All Claims Data would give a more comprehensive view of the experience of people with IDD. These data should be used to drive policy, research, and service practices and should be shared publicly and include feedback in the recommendation development from stakeholders, including Oregonians with IDD.

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Appendix A

Diagnosis

IDD Identification Criteria and Measure Definitions

Identification of Medicaid members with IDD

Description: Had continuous enrollment in Medicaid for the calendar year 2022 and at least one Medicaid claim with an IDD diagnosis during calendar years 2021-2022.

(ICD) codes identifying IDD	Description of code
E7152	Childhood cerebral X-linked adrenoleukodystrophy
E7152	Adolescent X-linked adrenoleukodystrophy
E7152	Adrenomyeloneuropathy
E7152	Other X-linked adrenoleukodystrophy
E7152	X-linked adrenoleukodystrophy, unspecified type
E7521	Fabry (-Anderson) disease
E7522	Gaucher disease
E7523	Krabbe disease
E7524	Niemann-Pick disease type A
E7524	Niemann-Pick disease type B
E7524	Niemann-Pick disease type C
E7524	Niemann-Pick disease type D
E7524	Other Niemann-Pick disease
E7524	Niemann-Pick disease, unspecified
E7525	Metachromatic leukodystrophy
E754	Neuronal ceroid lipofuscinosis
E7871	Barth syndrome
E7872	Smith-Lemli-Opitz syndrome
E791	Lesch-Nyhan syndrome
F70	Mild intellectual disabilities

F71	Moderate intellectual disabilities
F72	Severe intellectual disabilities
F73	Profound intellectual disabilities
F78	Other intellectual disabilities
F79	Unspecified intellectual disabilities
F840	Autistic disorder
F843	Other childhood disintegrative disorder
F845	Asperger's syndrome
F848	Other pervasive developmental disorders
F849	Pervasive developmental disorder, unspecified
G3181	Alpers disease
G800	Spastic quadriplegic cerebral palsy
G801	Spastic diplegic cerebral palsy
G802	Spastic hemiplegic cerebral palsy
G803	Athetoid cerebral palsy
G804	Ataxic cerebral palsy
G808	Other cerebral palsy
G809	Cerebral palsy, unspecified
P043	Newborn affected by maternal use of alcohol
Q851	Tuberous sclerosis
Q860	Fetal alcohol syndrome (dysmorphic)
Q871	Congenital malformation syndromes predominantly associated with short stature
Q872	Congenital malformation syndromes predominantly involving limbs
Q873	Congenital malformation syndromes involving early overgrowth
Q875	Other congenital malformation syndromes with other skeletal changes
Q8781	Alport syndrome
Q8789	Other specified congenital malformation syndromes, not elsewhere classified
Q897	Multiple congenital malformations, not elsewhere classified
Q898	Other specified congenital malformations
Q900	Trisomy 21, nonmosaicism (meiotic nondisjunction)
Q901	Trisomy 21, mosaicism (mitotic nondisjunction)
Q902	Trisomy 21, translocation

Q909	Down syndrome, unspecified
Q910	Trisomy 18, nonmosaicism (meiotic nondisjunction)
Q911	Trisomy 18, mosaicism (mitotic nondisjunction)
Q912	Trisomy 18, translocation
Q913	Trisomy 18, unspecified
Q914	Trisomy 13, nonmosaicism (meiotic nondisjunction)
Q915	Trisomy 13, mosaicism (mitotic nondisjunction)
Q916	Trisomy 13, translocation
Q917	Trisomy 13, unspecified
Q920	Whole chromosome trisomy, nonmosaicism (meiotic nondisjunction)
Q921	Whole chromosome trisomy, mosaicism (mitotic nondisjunction)
Q922	Partial trisomy
Q925	Duplications with other complex rearrangements
Q9262	Marker chromosomes in abnormal individual
Q927	Triploidy and polyploidy
Q928	Other specified trisomies and partial trisomies of autosomes
Q929	Trisomy and partial trisomy of autosomes, unspecified
Q930	Whole chromosome monosomy, nonmosaicism (meiotic nondisjunction)
Q931	Whole chromosome monosomy, mosaicism (mitotic nondisjunction)
Q932	Chromosome replaced with ring, dicentric or isochromosome
Q933	Deletion of short arm of chromosome 4
Q934	Deletion of short arm of chromosome 5
Q935	Other deletions of part of a chromosome
Q937	Deletions with other complex rearrangements
Q9381	Velo-cardio-facial syndrome
Q9388	Other microdeletions
Q9389	Other deletions from the autosomes
Q939	Deletion from autosomes, unspecified
Q952	Balanced autosomal rearrangement in abnormal individual
Q953	Balanced sex/autosomal rearrangement in abnormal individual
Q992	Fragile X chromosome
2772	Other disorders of purine and pyrimidine metabolism

29900	Autistic disorder, current or active state
29901	Autistic disorder, residual state
29910	Childhood disintegrative disorder, current or active state
29911	Childhood disintegrative disorder, residual state
29980	Other specified pervasive developmental disorders, current or active state
29981	Other specified pervasive developmental disorders, residual state
29990	Unspecified pervasive developmental disorder, current or active state
29991	Unspecified pervasive developmental disorder, residual state
317	Mild intellectual disabilities
3180	Moderate intellectual disabilities
3181	Severe intellectual disabilities
3182	Profound intellectual disabilities
319	Unspecified intellectual disabilities
3300	Leukodystrophy
3301	Cerebral lipidoses
3302	Cerebral degeneration in generalized lipidoses
3303	Cerebral degeneration of childhood in other diseases classified elsewhere
3308	Other specified cerebral degenerations in childhood
3309	Unspecified cerebral degeneration in childhood
33371	Athetoid cerebral palsy
3430	Congenital diplegia
3431	Congenital hemiplegia
3432	Congenital quadriplegia
3433	Congenital monoplegia
3434	Infantile hemiplegia
3438	Other specified infantile cerebral palsy
3439	Infantile cerebral palsy, unspecified
7580	Down's syndrome
7581	Patau's syndrome
7582	Edwards' syndrome
75831	Cri-du-chat syndrome

75832	Velo-cardio-facial syndrome
75833	Other microdeletions
75839	Other autosomal deletions
7585	Other conditions due to autosomal anomalies
7595	Tuberous sclerosis
7597	Multiple congenital anomalies, so described
75981	Prader-Willi syndrome
75983	Fragile X syndrome
75989	Other specified congenital anomalies
76071	Alcohol affecting fetus or newborn via placenta or breast milk

Measure Definitions

Clinical Depression Screening

Description: Number of recipients who received a clinical depression screening among members with an outpatient visit during the measurement year.

Source: Medicaid claims Steward: CMS

Antidepressant Medication Management - Acute Phase Treatment

Description: Number of recipients who remained on an antidepressant medication for at least 12 weeks among members diagnosed with major depression and treated with antidepressant medication.

Source: Medicaid claims Steward: NCQA (HEDIS 2016)

Antidepressant Medication Management - Continuous Phase Treatment

Description: Number of recipients who remained on an antidepressant medication for at least 6 months among members diagnosed with major depression and treated with antidepressant medication.

Source: Medicaid claims Steward: NCQA (HEDIS 2016)

ED Utilization - All Cause

Description: Count of emergency department visits, reported per 1000 member years

Source: Medicaid claims Steward: NCQA (HEDIS 2016)

Nonfatal Suicide Attempts and Self-Harm

Description: Number of recipients diagnosed with 'acute nonfatal suicide attempt & self-harm'

Source: Medicaid claims Steward: CHSE

ED Visits for Suicidal Ideation

Description: Count of emergency department visits for suicidal ideation reported per 1000 member years

Source: Medicaid claims Steward: CHSE

30-day Plan All-Cause Readmissions

Description: Count of all-cause (for any reason) unplanned readmissions within 30 days of index hospital stay, reported per 1000 member years

Source: Medicaid claims Steward: NCQA (HEDIS 2016)

30-day Plan All-Cause Readmissions After Hospitalization for Mental Illness

Description: Count of all-cause (for any reason) unplanned readmissions within 30 days of index hospital stay due to mental illness, reported per 1000 member years

Source: Medicaid claims Steward: CHSE

Screening for Alcohol or Other Substance Abuse Treatment

Description: Number of recipients who received appropriate screening for alcohol or other substance use among members with an outpatient visit

Source: Medicaid claims Steward: OHA

Initiation of Substance Use Disorder Treatment

Description: Number of recipients who initiated treatment for alcohol or other drug dependence among members with a diagnosis of substance use disorder. Initiation is defined as an inpatient admission, outpatient visit, intensive outpatient encounter or partial hospitalization within 14 days of the diagnosis.

Source: Medicaid claims Steward: NCQA (HEDIS 2016)

Engagement of Substance Use Disorder Treatment

Description: Number of recipients who experienced alcohol or other drug dependence treatment engagement among members with a diagnosis of substance use disorder. Engagement is defined as having initiated treatment remain engage in ongoing treatment within 34 days of the initiation visit.

Source: Medicaid claims Steward: NCQA (HEDIS 2016)

Diabetes Management (HbA1)

Description: Number of recipients who received at least HbA1c test among members with a diagnosis of Type I or Type II diabetes.

Source: Medicaid claims Steward: NCQA (HEDIS 2016)

Access to Any Dental Care

Description: Number of recipients who received any dental care.

Source: Medicaid claims Steward: CHSE

Preventive Dental Services

Description: Number of recipients who received any specifically preventive dental care

Source: Medicaid claims Steward: CHSE

Breast Cancer Screening

Description: Number of recipients who received a mammogram in the last 27 months among women members.

Source: Medicaid claims Steward: NCQA (HEDIS 2016)

Cervical Cancer Screening (incidence)

Description: Number of recipients who received cervical cytology during the current measurement year among women members age 21-64

Source: Medicaid claims Steward: CHSE

Avoidance of Non-Recommended Cervical Cancer Screenings in Adolescent Females

Description: Number of recipients who did not receive unnecessary screening for cervical cancer among women members age 16-20 years.

Source: Medicaid claims Steward: NCQA (HEDIS 2016)

Appendix B

Oregon Data Sets with Disability Data

1. Medicaid Enrollment and Claims Data

Owner: Oregon Health Authority (OHA)

Description	This is member level administrative data that includes health insurance enrollment and payments to providers (claims). It contains administrative health care data on insurance coverage and health service cost and utilization for Oregon's population that is ensured by Medicaid, a joint federal and state program in the United States that helps with medical costs for some people with disabilities. Medicaid claims are one of the most powerful tools for identifying individuals of all ages with intellectual, development, and physical disabilities and determining how these individuals are accessing
	health care (physical, mental, dental etc.). Claims data can also be linked to many different sources of data which can provide additional information about member demographics, what additional services and supports they received, where individuals live and who their caregivers are, and the composition of their communities.
	In addition, because disability is defined through diagnosis codes in Medicaid claims data, linking this data to other sources could expand available definitions of disability. For example, joining claims with data from ODDS would also allow disability to be defined by eligibility for ODDS services.
Access and Rules or Restrictions on Use	Data available for request under a Data Use Agreement.
How Disability is Defined in the Data:	IDD and other disabilities can be identified at the individual level in Medicaid claims data using International Classification of Diseases (ICD) 10 diagnoses, as selected by the researcher
Can Individuals with IDD be Identified in the Data?	
yes no	

Medicaid Enrollment and Claims Data (continued)

Types of Variables	Patient Information: Demographics
the Data Captures	Beneficiary Age: all ages
	• Enrollment Information: enrollment details, length of coverage, and eligibility
	• Provider Information: What healthcare providers deliver the services?
	• Service Information: Specifics about the healthcare services, including types of services, dates of service, and locations
	• Diagnosis and Procedure Codes: ICD (International Classification of Diseases) codes for diagnoses and CPT (Current Procedural Terminology) or HCPCS (Healthcare Common Procedure Coding System) codes for procedures
	• Financial Information: Costs of services, amounts billed, amounts paid by Medicaid, and any patient cost-sharing
	• Medications: Details on prescribed medications, including drug names, dosages, and information on dispensing
	• Utilization Data: Patterns of service use, such as frequency and duration of hospital stays or outpatient visits
Years of Availability	2008-Present
Notable Limitations (e.g., known data quality issues)	 Undercounting if medical provider does not document IDD diagnosis in medical records. It does not describe the range, severity, and functional limitations of disability. Limited to members with Medicaid coverage only
Potential for Linkage to Other Data Sets (i.e., via individual identifiers that can be used by Integrated Client Services)	Yes. Integrated Client Services (ICS) would likely be needed to assist with linkage and deidentification.

Medicaid Enrollment and Claims Data (continued)

Other Information	OHA Medicaid Data
	https:/www.oregon.gov/oha/hpa/analytics/pages/medicaid.aspx
	OHA Integrated Client Services:
	https://www.oregon.gov/odhs/data/Pages/ics.aspx (Contact for linking and combining state datasets including Medicaid)
	Email: OHA.HealthAnalyticsRequest@state.or.us
	The Transformed Medicaid Statistical Information System (T-MSIS) collects Medicaid data from all U.S. states, territories, and the District of Columbia into a national resource of beneficiary information. This data is available to researchers as the T-MSIS Analytic Files (TAF). TAF data could allow for research to be conducted on the national-level or comparisons between Oregon and neighboring states. TAF data limitations, including cost and the large size of the data, make analyses using this data challenging.
	T-MSIS Website: https://www.medicaid.gov/medicaid/data- systems/macbis/transformed-medicaid-statistical-information- system-t-msis/index.html

2. All Payers All Claims Data (APAC)

Owner: Oregon Health Authority (OHA)

Description	This is member level administrative claims data. Oregon All Payer All Claims (APAC) is a database for statewide administrative health care data, such as health insurance enrollment and payments to providers (claims).
	APAC data can be used to assess the cost of health care, improve quality, reduce costs, and promote transparency for Oregon's insured populations of all ages. APAC claims are a powerful tool for identifying individuals with intellectual, developmental, and physical disabilities and determining how these individuals are accessing health care (physical, mental, dental etc.) as they combine claims from multiple different payers including Medicaid, Medicare, and private insurance.
	However, the ability to link these claims to other data sources is more limited than for Medicaid claims alone. APAC is not the correct source for those who need Medicaid data alone.
Access and Rules or Restrictions on Use	 Data are available for request under a Data Use Agreement. APAC collects a variety of data, but not all of it is available for request. A breakdown of current availability is below: Available Commercial claims Medicaid claims, if requested with at least one other payer type (commercial or Medicare Parts C or D) Limited Data not relevant to a contract or payment, such as race, ethnicity, language spoken, marital status, education, and others Denied and orphan claims are only available for limited data sets (APAC defines orphan claims as claims without eligibility data within the year of the claim service date. Orphan claims occur when eligibility data is missing, replaced, or removed and
	eligibility.)

All Payers All Claims Data (APAC) (continued)

Access and Rules or Restrictions on Use	 Internal state use only Medicare fee-for-service Parts A and B Payment arrangement files Claims related to substance use disorder treatment (Per 45 CFR part 2)
	Not collected
	 Test results, medical record, medical chart or electronic health record Electronic Health Record data are not collected by APAC
	APAC offers two data products, Public Use File and Limited Data Sets. Products vary in level of detail, requirements, cost and anticipated timeframe.
	Public use files:
	 Statewide, de-identified claims-level data Four annual premade files: Medical claims, pharmacy claims, medical member month and pharmacy member month. Denied and orphan claims are excluded Review Process: No review needed, as files already meet minimum necessary requirements Cost: \$500 per file Estimated Timeframe: 2-4 weeks
	Limited data sets:
	 -May contain personal health information, excluding direct identifiers (e.g., patient name or address). Package extracts are customized based on requested fields in Data Elements Workbook Review Process: Posting for public comment and review by the Data Review Committee Cost: Hourly rate of APAC staff + \$890 flat fee for vendor transfer Estimated timeframe: 3-6 months
	If requesters believe their project will identify concrete actions to eliminate health inequities stemming from historical and contemporary racial injustices and the inequitable distribution of resources and power, they can apply for an optional incentive.

All Payers All Claims Data (APAC) (continued)

How Disability is Defined in the Data: Can Individuals with IDD be Identified in the Data? yes no yes Lon	IDD and other disabilities can be identified at the individual level in APAC claims data using International Classification of Diseases (ICD) 10 diagnoses, as selected by the researcher
Types of Variables the Data Set Captures	 Patient Information: Demographics Beneficiary Age: all ages Enrollment Information: enrollment details, length of coverage, and eligibility Provider Information: What healthcare providers deliver the services? Service Information: Specifics about the healthcare services, including types of services, dates of service, and locations Diagnosis and Procedure Codes: ICD (International Classification of Diseases) codes for diagnoses and CPT (Current Procedural Terminology) or HCPCS (Healthcare Common Procedure Coding System) codes for procedures Financial Information: Costs of services, amounts billed, amounts paid by Medicaid, and any patient cost-sharing Medications: Details on prescribed medications, including drug names, dosages, and information on dispensing Utilization Data: Patterns of service use, such as frequency and duration of hospital stays or outpatient visits

All Payers All Claims Data (APAC) (continued)

Years of Availability	 APAC collects claims data on a rolling schedule to ensure that data are as complete and reliable as possible. It takes 15 months from the first submission deadline for a full calendar year of claims data to be complete and reliable. The earliest available year is 2011.
Notable Limitations (e.g., known data quality issues)	 Undercounting if medical provider does not document IDD diagnosis on medical bill. It does not describe the range, severity, and functional limitations of disability. Medicare fee-for-service data is shared with APAC through a Data Use Agreement between OHA and the Centers for Medicare and Medicaid Services (CMS). This agreement precludes OHA from releasing claims-level Medicare fee-forservice data from APAC unless the project is manage and funded by OHA. As such, Medicare fee-for-service data are available at the summary level through summarized data requests, but are not available through Public Use, Limited, or Custom data sets. Medicare Parts C and D data, on the other hand, are collected from Mandatory Reporters and are available for release as part of any of the APAC data sets described above. APAC is not the correct source for those who need Medicaid data alone.
Potential for Linkage to Other Data Sets (i.e., via individual identifiers that can be used by Integrated Client Services)	Linking external data is not allowed for public use files; but may be considered and explicitly approved by OHA for limited data sets.
Other Information	Website: https://www.oregon.gov/oha/HPA/ANALYTICS/Pages/ All-Payer-All-Claims.aspx Email: APAC.Admin@odhsoha.oregon.gov OHA Integrated Client Services: https://www.oregon.gov/odhs/ data/Pages/ics.aspx

3. Developmental Disabilities Data ("DD" Data)

Owner: Oregon Department of Human Services (ODHS)

Description	This is member level administrative data for the Oregon Department of Human Services (ODHS) Office of Developmental Disabilities (ODDS). ODDS supports members with disabilities, both children and adults, and their families by providing and promoting services including in-home supports and residential programs. ODHS maintains data on how individuals met the eligibility criteria for their programs (including a needs assessment for each individual), what services and supports they received, and who is
	providing those services and supports. This data could potentially be linked with Medicaid claims data, help to identify individuals with intellectual and developmental disabilities, and provide information about caregivers and location of residence.
Access and Rules or Restrictions on Use	 Data are available for request under a Data Use Agreement: ODDS could fulfill simple de-identified data requests. For more complex and/or linked data requests Integrated Client Services (ICS) or the ODHS Office of Reporting, Research, Analytics and Implementation (ORRAI) would be needed to assist with linkage and deidentification.
How Disability is Defined in the Data:	Disability is determined through a needs assessment conducted by a qualified professional based on an intelligence quotient (IQ), under a certain level OR a severe mental or physical impairment directly affecting the brain
Can Individuals with IDD be Identified in the Data? yes no	AND a lack of daily living skills AND disability started before 18 or 22 years of age. This needs assessment data could be used to identify individuals with IDD.

Developmental Disabilities Data ("DD" Data) (continued)

Types of Variables the Data Captures	 Functional criteria for meeting the program eligibility, information from the needs assessment, and approved services and hours Demographics: address, language, race, ethnicity Types, costs and settings of services received Number of caregivers and families supported Provider information: how many are credentialed, how many are providing services (including service workers) Member Age: children and adults
Years of Availability	At a minimum, the most recent five years of data are available
Notable Limitations (e.g., known data quality issues)	 Because the criteria is dependent on needs for daily living skills services and severe mental and physical impairment, data does not include people who do not require services, have less severe impairment, or are waiting to be approved. It only includes people who meet IDD and financial criteria for the program. The ability to pull some items from the needs assessment is limited at this time.
Potential for Linkage to Other Data Sets (i.e., via individual identifiers that can be used by Integrated Client Services)	Yes
Other Information	Website: https://www.oregon.gov/odhs/idd/Pages/default.aspx Data Website: https://www.oregon.gov/odhs/data/Pages/odds-data. aspx Program Contact: Christy Orcutt - DDBSU Analyst (ODDS Operations) Email: CHRISTY.L.ORCUTT@odhs.oregon.gov

4. Aging and People with Disabilities Data and related Programs ("APD" Data)

Owner: Oregon Department of Human Services (ODHS)

Description	This is member level administrative data for the Oregon Department of Human Services (ODHS) Aging and People with Disabilities (APD) program. The APD program provides services for people living with disabilities and people who need support as they age. Data from the APD program could be linked with Medicaid claims data and help identify individuals with intellectual, developmental, and physical disabilities and provide information about their location of residence and caregivers.
Access and Rules or Restrictions on Use	Data are available for request under a Data Use Agreement.

Aging and People with Disabilities Data and related Programs ("APD" Data) (continued)

How Disability is Defined in the Data:	Per Oregon Administrative Rules (OAR) 411-320-0010 (Aging and People with Disabilities and Developmental Disabilities Definitions and Acronyms):
Can Individuals with IDD	• "Developmental Disability" means a neurological condition that:
be Identified in the Data?	(a) Originates before an individual is 22 years of age;
yes no	(b) Originates in and directly affects the brain and has continued, or is expected to continue, indefinitely;
	(c) Constitutes significant impairment in adaptive behavior as diagnosed and measured by a qualified professional;
	(d) Is not primarily attributed to other conditions including, but not limited to, a mental or emotional disorder, sensory impairment, motor impairment, substance abuse, personality disorder, learning disability, or Attention Deficit Hyperactivity Disorder; and
	(e) Requires training and support similar to an individual with an intellectual disability
	• "Intellectual Disability (ID)" means significantly sub average general intellectual functioning defined as full scale intelligence quotients (FSIQs) 70 and under, as measured by a qualified professional, and existing concurrently with significant impairment in adaptive behavior directly related to an intellectual disability that manifested prior to an individual's 18th birthday. An individual with a diagnosis of intellectual disability that manifested prior to the individual's 18th birthday and who has a valid FSIQ of 71-75, may be considered to have an intellectual disability if the individual also has significant impairment in adaptive behavior directly related to the intellectual disability as diagnosed and measured by a licensed clinical or school psychologist.
Types of Variables the Data Captures	 Per Oregon Administrative Rules (OAR) 411-020-0000 (Aging and People with Disabilities and Developmental Disabilities Definitions and Acronyms): "Physical Disability" means any physical condition or cognitive condition such as brain injury or dementia that significantly interferes with a member's ability to protect themselves from abuse or self-neglect.

Aging and People with Disabilities Data and related Programs ("APD" Data) (continued)

How Disability is Defined in the Data (continued)	 The APD program reports on the Oregon LGBTQ+ Older Member Survey, as well as utilization of the following services: Member Protective Services Long Term Care, Home and Community Based Services Nursing Facilities, Member Foster Homes In-Home Services Residential Care Assisted Living Member Age: adults
Years of Availability	At a minimum, most recent five years of data available
Notable Limitations (e.g., known data quality issues)	 Because the criteria are dependent on needs for daily living skills services and severe mental and physical impairment, data does not include people who do not require services, have less severe impairment, or are waiting to be approved. It only includes people who meet disability and financial criteria for the program.
Potential for Linkage to Other Data Sets (i.e., via individual identifiers that can be used by Integrated Client Services)	Yes, Integrated Client Services (ICS) or the ODHS Office of Reporting, Research, Analytics and Implementation (ORRAI) would likely be needed to assist with linkage and deidentification.
Other Information	Website: https://www.oregon.gov/odhs/aging-disability-services/ Pages/default.aspx Website: https://www.oregon.gov/odhs/agency/Pages/apd.aspx Data Website: https://www.oregon.gov/odhs/data/Pages/apd-data.aspx OAR 411-020-000: https://secure.sos.state.or.us/oard/ displayDivisionRules.action?selectedDivision=1754 OAR 411-320-001: https://secure.sos.state.or.us/oard/ displayDivisionRules.action?selectedDivision=1804

5. National Core Indicators[®] – Intellectual and Developmental Disabilities (NCI-IDD)

Owner(s): Participating States; Oregon Department of Human Services (ODHS)

Description	This is national survey data that is available at both aggregate and respondent levels. The National Core Indicators – Intellectual and Developmental Disabilities (NCI-IDD) surveys are used across 48states and the District of Columbia to assess the quality and outcomes of Developmental Disability (DD) services provided to members with IDD and their families. NCI offers valid, reliable, person-centered measures that states use to demonstrate how publicly funded supports are impacting people's lives and to determine where they can improve the quality of those supports. NCI conducts an In-Person Survey, Family Surveys, and a State of the Workplace Survey. The NCI Member In-Person Survey can be used to collect information on outcomes experienced by members receiving publicly funded DD supports and the NCI Family Surveys can be used to understand how DD supports are impacting the lives of families. In addition, the NCI-IDD survey data could potentially be linked with Medicaid claims data, help to identify individuals with intellectual and developmental disabilities, and provide information about respondent's health, wellness, safety, employment, service coordination, caregivers and location of residence.
Access and Rules or Restrictions on Use	Per the NCI-IDD website: Research using NCI-IDD data and materials may be conducted by approved universities, governmental agencies and private organizations. Research activities must be consistent with the NCI-IDD mission, goals and guiding principles, model positive practice and steer decision-making toward areas of exploration that: (a) are relevant to the lives of people with intellectual and developmental disabilities, (b) demonstrate respect for the independence and individuality of people receiving support, (c) result in the development of practical information and instrumentation that can be used by member state agency officials to improve services and supports for all people with disabilities, and (d) contribute to the quality of the knowledgebase on community supports furnished to people with developmental disabilities. To request use of the NCI-IDD materials and/or data sets, researchers must review documented policies and procedures and complete a request and use agreement. Participating states own their data, and de-identified NCI data is available for secondary analysis for a small fee.

National Core Indicators® - Intellectual and Developmental Disabilities (NCI-IDD) (continued)

How Disability is Defined in the Data: Can Individuals with IDD be Identified in the Data? yes no yes Lon Lon Lon Lon Lon Lon Lon Lon Lon Lon	 The surveys are sent to members and their families who are receiving at least one paid service from the state, in addition to case management In Oregon, disability is defined by eligibility for services through The Office of Developmental Disabilities (ODDS) Eligibility for ODDS services is determined through a needs assessment conducted by a qualified professional and is based on an intelligence quotient (IQ), under a certain level OR a severe mental or physical impairment directly affecting the brain, AND a lack of daily living skills AND disability started before 18 or 22 years of age (see Developmental Disabilities Data (DD Data) for more information). Specific diagnosis information is limited. Some surveys, including the Child and Family survey, include self-reported health conditions. While this survey could be used to identify individuals with IDD and provide more information about them, the DD Data would likely be a better, more direct source for information on qualification for ODDS services.
Types of Variables the Data Captures	 The NCI-IDD surveys cover a variety of domains including: Self Determination Service Coordination & Access; Relationships & Community Inclusion Rights, Choices, & Decision-making Employment Status & Goals Health, Welfare, & Safety Age of Individual with IDD: In-Person Survey: 18 years of age or older Adult Family Survey: 18 years of age or older Family/Guardian Survey: 18 years of age or older Child Family Survey: Under age 18

Years of Availability	2014-Present
Notable Limitations (e.g., known data quality issues)	 Background information is provided by case management agencies. Background data is not available for all individuals and individuals are not asked to confirm or provide any additional information regarding their diagnosis for all surveys Health conditions are self-reported by caregivers for the Child and Family survey. Family surveys are either sent to all eligible families/guardians or a sample of families depending on total eligible families in the participating states and/or previous year response rates.
Potential for Linkage to Other Data Sets (i.e., via individual identifiers that can be used by Integrated Client Services)	Yes
Other information	 Website: https://idd.nationalcoreindicators.org/ State Website: https://www.oregon.gov/odhs/idd/Pages/default.aspx OHSU University Center for Excellence in Developmental Disabilities Website: https://www.ohsu.edu/university-center-excellence-development- disability/national-core-indicators Oregon State NCI-IDD Contact: Julie Hoyt - NCI Survey Coordinator Phone: (503)891-7405 Email: Julie.hoyt@odhs.oregon.gov

National Core Indicators® - Intellectual and Developmental Disabilities (NCI-IDD) (continued)

6. Residential Information Systems Project (RISP)

Owner: University of Minnesota/ Oregon Department of Human Services (ODHS)

Description	This is national survey data that is available at the aggregate level. The Residential Information Systems Project (RISP) gathers, maintains, and analyzes longitudinal data of Medicaid funded long-term services and supports (LTSS) for people of all ages with intellectual and developmental disabilities (IDD). They conduct an annual survey of public residential facilities describing the status of the facilities and the people that live there. Though this data is not available at the member level and cannot be linked to individuals, it could provide helpful information and context about the location of residence and supports that are available for people with IDD.
Access and Rules or Restrictions on Use	There are limited, publicly available aggregated data and reports available on the RISP website. The Oregon Office of Developmental Disabilities (ODDS) also compiles data and submits the reports annually to RISP. Specific data may be available through request by contacting ODDS. See Developmental Disabilities Data (DD Data) for more information on ODDS and contact information.
How Disability is Defined in the Data: Can Individuals with IDD be Identified in the Data? yes no yes Lon Lon	 Disability is defined by eligibility for services through The Office of Developmental Disabilities (ODDS) Eligibility for ODDS services is determined through a needs assessment conducted by a qualified professional and is based on an intelligence quotient (IQ), under a certain level OR a severe mental or physical impairment directly affecting the brain, AND a lack of daily living skills AND disability started before 18 or 22 years of age (see Developmental Disabilities Data (DD Data) for more information). While the focus population for the RISP is individuals with IDD, because the data is not readily available at the member level and cannot be linked to other data sources it could not be used to identify those with IDD. However. It could still provide valuable information and context about the IDD population.

Residential Information Systems Project (RISP) (continued)

Access and Rules or Restrictions on Use	 5 key questions: How many people have IDD? How many people with IDD get paid supports? Where do people who get paid supports live? How do the places people live differ by age and state? How have the places people with IDD live changed? Age of Individual with IDD: all ages
Years of Availability	1991 - Present
	 This is survey data that is not readily available at the member level and consequently cannot identify individuals with IDD Limited to those living in residential facilities Data that is available directly from University of Minnesota appears to be limited It does not include people not requiring services, having less severe impairment, or waiting to be approved. It only includes people with IDD who meet financial criteria for the program.

Potential for Linkage to Other Data Sets (i.e., via individual identifiers that can be used by Integrated Client Services)	No for data from University of Minnesota/RISP; Potentially yes for data from ODDS
Other Information	Website: https://risp.umn.edu/about/overview Oregon State Profile: https://publications.ici.umn.edu/risp/state-profiles/oregon Oregon ODDS Contact Information: Program Website: https://www.oregon.gov/odhs/idd/Pages/default.aspx Program Contact: Christy Orcutt - DDBSU Analyst (ODDS Operations) Email: CHRISTY.L.ORCUTT@odhs.oregon.gov

Residential Information Systems Project (RISP) (continued)

7. Race, Ethnicity, Language, and Disability (REALD) and Sexual Orientation and Gender Identity (SOGI) repository

Owner: Oregon Health Authority (OHA)

Description	This is member level administrative data for Oregon Health Authority (OHA) programs and services. REALD is a type of demographic information, like age, marital status, employment and more. Although all OHA and DHS programs are required to collect REALD and SOGI data, this repository dataset minimizes "missing" demographic data by combining this information from multiple datasets. Data are obtained from the REALD & SOGI Repository, which is a relational database that combines REALD demographic data from at least seven OHA databases (such as Medicaid, Vital statistics, and enrollment in benefits programs like SNAP).
	REALD & SOGI information helps us understand who is most impacted by health inequities and how we can best support these community members access the services and resources they need to be healthy and thrive. Unlike most other datasets, this dataset contains self-reported information.
	Though it does not contain questions specific to IDD, it contains general disability related questions, which can identify functional limitations from members' experiences. Extensive demographic information could be linked to other datasets (including Medicaid claims data) at the member level. This data could provide important context regarding the IDD population because REALD & SOGI categories serve as proxies of exposure to racism and other systems of oppression. As such, it would be particularly useful for intersectional analyses.

Race, Ethnicity, Language, and Disability (REALD) and Sexual Orientation and Gender Identity (SOGI) repository (continued)

Access and Rules or Restrictions on Use	Data are available for request under a Data Use Agreement. The REALD & SOGI Repository data is to be used for advancing health and service equity, per OHA and ODHS mission statements. The Repository Data Team will only provide the minimum necessary data required for a project.
	To access identifiable data, projects must qualify as one of the following under HIPAA restrictions:
	 Treatment activities, such as the provision, coordination, or management of health care by a health care provider organization;
	 Payment activities, including reimbursement for care, determination of eligibility or coverage, or billing;
	 Health care operations, such as quality assessment, improvement activities, provider or health plan performance, business planning and development including cost management
	 Public health activities, such as surveillance and interventions by a public health authority; and
	• Research that has received approval from an Institutional Review Board or patient consent.

Race, Ethnicity, Language, and Disability (REALD) and Sexual Orientation and Gender Identity (SOGI) repository (continued)

How Disability is Defined in the Data:

Can Individuals with IDD be Identified in the Data?



This dataset includes disability related questions; however, these are too broadly defined to identify people with IDD separately from other people with disabilities.22 While this dataset does not identify people with IDD, it can be linked to datasets which identify people with IDD.

REALD Disability Questions:

- Hearing: Are you deaf or have serious difficulty hearing?
- Vision: Are you blind or have serious difficulty seeing, even when wearing glasses?
- Memory or cognitive: Because of a physical, mental, or emotional problem, do you have serious difficulty remembering, concentrating, or making decisions? (age 5+)
- Physical/ mobility: Do you have serious difficulty walking or climbing stairs? (age 5+)
- Self-care: Do you have difficulty bathing or dressing (age 5+)
- Communication: Using your usual (customary) language, do you have serious difficulty communicating (for example understanding or being understood by others)? (age 5+)
- Learning: Do you have serious difficulty learning how to do things most people your age can learn?
- Mental Health: Do you have serious difficulty with the following: mood, intense feelings, controlling your behavior, or experiencing delusions or hallucinations? (age 15+)
- Independent living: Because of a physical, mental, or emotional problem, do you have difficulty doing errands alone such as visiting a doctor's office or shopping (age 15+)

Race, Ethnicity, Language, and Disability (REALD) and Sexual Orientation and Gender Identity (SOGI) repository (continued)

Types of Variables the Data Captures	 Detailed demographic information including: Race & Ethnicity: 43 Categories Language Sexual Orientation Gender Identity & Gender Modality Beneficiary Age: REALD data is available for individuals of all ages, though some questions may not be applicable to all age groups. For example, in the 'How Disability is Defined in the Data' section we see
	that some questions are restricted to those age 5+ and age 15+.
Years of Availability	2016-Present Note: data collected prior to 2017 used limited Oregon Medical Board standards and may be less reliable than later years of data.
Notable Limitations (e.g., known data quality issues)	The disability data is self-reported and does not indicate whether disability meets medical diagnosis criteria for IDD conditions.
Potential for Linkage to Other Data Sets (i.e., via individual identifiers that can be used by Integrated Client Services)	Yes
More Information	Website: https://www.oregon.gov/oha/El/Pages/REALD.aspx Email: ohareald.questions@odhsoha.oregon.gov Phone: (971)291-4342

8. National Core Indicators[®] – Aging and Disabilities (NCI-AD)

Owner: Participating States; Oregon Department of Human Services (ODHS)

Description	This is national survey data that is available at both aggregate and respondent levels. The National Core Indicators - Aging and Disabilities (NCI-AD) surveys are a voluntary effort by State Medicaid, aging, and disability agencies to measure and track their own performance. The core indicators are standard measures used across states to assess the outcomes of services provided to members and families. The surveys help address long-recognized gaps in assessing outcomes in long term services and supports (LTSS) service systems that go beyond measures of health and safety to address important social, community, and person-centered goals as well as quality of life. Data for the project are gathered through annual in-person surveys and a provider survey administered in each participating state. While the NCI-IDD surveys are more specifically focused on members with IDD, data from the NCI-AD could potentially be linked with Medicaid claims data and provide information about individuals with physical disabilities including details about their location of residence and caregivers.
Access and Rules or Restrictions on Use	Per the NCI-AD website: Research using NCI-AD data and materials may be conducted by approved universities, governmental agencies, and private organizations. Research activities must be consistent with the NCI mission, goals and guiding principles; must model positive practice; and must steer decision-making toward areas of exploration that: (a) are relevant to the lives of older members and people with physical disabilities, (b) demonstrate respect for the independence and individuality of people receiving support, (c) result in the development of practical information and instrumentation that can be used by member state agency officials to improve services and supports, and (d) contribute to the quality of the knowledgebase on community supports furnished to people receiving services. To request use of NCI-AD materials and/or data sets, researchers must review documented policies and procedures and complete a request and use agreement.

National Core Indicators® – Aging and Disabilities (NCI-AD) (continued)

How Disability is Defined in the Data: Can Individuals with IDD be Identified in the Data?	 Each participating state surveys a sample of at least 400 older members and members with physical disabilities who are receiving publicly funded services. Disability is defined by eligibility for services through the ODHS Aging and People with Disabilities (APD) program (see Aging and People with Disabilities Data (APD Data) for more information). This dataset does not identify people with IDD, but it can be linked to datasets which identify people with IDD.
Types of Variables the Data Captures	 Indicators address current areas of concern including: Service planning, Rights, Community inclusion, Choice, Health and care coordination, Safety Relationships Age of Individuals: adults age 18+
Years of Availability	2015-Present
Notable Limitations (e.g., known data quality issues)	 Every state does not participate in each survey every year Limited to members with a physical disability
Other Information	Website: https://nci-ad.org/ State Website: https://www.oregon.gov/odhs/providers-partners/ community-services-supports/Pages/default.aspx Oregon State NCI-AD Contact: Naomi Sacks – Policy Analyst Email: Naomi.E.Sacks@odhs.oregon.gov
9. American Community Survey Data ("ACS" Data)

Owner: U.S. Census Bureau

Description	This is national Census survey data that is primarily available in an aggregate form at the geographic level (i.e. county, state, etc.). The American Community Survey (ACS) is an ongoing survey that provides vital information on a yearly basis about the United States of America and those that live there. Though the ACS does not contain questions specific to IDD, it contains general disability related questions and extensive demographic, social, economic, and housing information that could be linked to other datasets at the geographic level, providing valuable information about the communities in which individuals with disabilities live and potential barriers and facilitators to service use. In addition, the data can be linked to Medicaid claims data.23
Access and Rules or Restrictions on Use	The American Community Survey (ACS) releases new data every year through a variety of data tables accessible with different data tools including: data.census.gov, QuickFacts, My Community Explorer, File Transfer Protocol, Application Programming Interface, and TIGER/Line Shapefiles with Selected Demographic and Economic Data For tables and estimates that are not available through ACS pre- tabulated data products, the Census Bureau's American Community Survey (ACS) Public Use Microdata Sample files enable data users to create custom estimates and tables. These files are free of charge. The ACS PUMS files are a set of records from individual people or housing units, with disclosure protection enabled so that members or housing units cannot be identified.

American Community Survey Data ("ACS" Data) (continued)

How Disability is Defined in the Data: Can Individuals with IDD	This dataset includes disability related questions; however, these are too broadly defined to identify people with IDD separately from other people with disabilities.22 While this dataset does not identify people with IDD, it can be linked at the geographic or member level to datasets which identify people with IDD.
be Identified in the Data?	ACS Disability Questions:
yes no	• Hearing: Are you deaf, or do you have serious difficulty hearing?
	• Vision: Are you blind, or do you have serious difficulty seeing, even when wearing glasses?
	• Memory or cognitive: Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older)
	• Physical/mobility: Do you have serious difficulty walking or climbing stairs? (5 years old or older)
	• Self-care: Do you have difficulty dressing or bathing? (5 years old or older)
	 Independent living: Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (15 years old or older)
Types of Variables the Data Captures	Extensive demographic information including: Ancestry
	US citizenship status
	Educational attainment
	• Income
	Language proficiency
	Migration
	Employment
	Housing characteristics
	• Age of Individuals: ACS data is available for individuals of all ages, though some questions may not be applicable to all age groups. For example, in the 'How Disability is Defined in the Data' section we see that some questions are restricted to those age 5+ and age 15+.

Years of Availability	2010 - 2022
Notable Limitations (e.g., known data quality issues)	Data are primarily available at the geographic level.There are no questions that are specific to IDD.
Potential for Linkage to Other Data Sets (i.e., via individual identifiers that can be used by Integrated Client Services)	Could be linked at the geographic level (county, state, etc.) and have been shown to be linkable to Medicaid claims and enrollment data.23
Other Information	Website: https://www.census.gov/programs-surveys/acs/ Website: https://data.census.gov/