



Disabilities

Health disparities related to disabilities include physical, mental, and emotional conditions that substantially limit life activities, which can lead to lower health outcomes due to lower quality of care. Understanding the barriers to medication use and health outcomes due to disabilities can help managed care identify the gaps in care and develop interventions to address these health inequities due to disabilities for their health plan members.



CALL TO ACTION

- Educate health care professionals on collecting and updating information annually about members and patients with disabilities.
- Foster member trust with plans by providing a rationale as to why disabilities data are collected, who has access to the data, and how the data about disabilities will be used.
- Understand the challenges those with disabilities in diverse racial and ethnic groups face in participating health promotion and disease prevention programs or activities.
- Develop and implement strategies that are inclusive, diverse, and address the specific needs of those with disabilities.⁴

WHY THIS MATTERS

An estimated **1.3 billion people** experience significant disability, representing 16% of the world's population, or **1 in 6 in the United States**.⁶



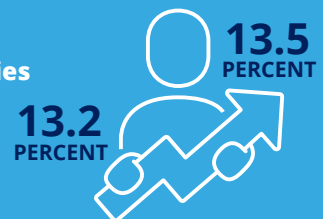
Persons with disabilities have **twice the risk of developing conditions** such as depression, asthma, diabetes, stroke, obesity, and poor oral health.⁶



Some persons with disabilities die up to **20 years earlier** than those without disabilities and face many health inequities.⁶



The percentage of civilians with disabilities increased from 2019 to 2021.⁶



WHY THIS MATTERS *cont'd*

- Expanding and improving disability data collection and assessment can help plans understand their members' unique needs. Customizing the services provided to members with special needs can lead to more vital member trust, leading to more substantial health outcomes.
- People with disabilities have high rates of chronic health conditions and often require complex medication regimens to manage their health. Approximately 20–50% of people with disabilities fail to take medications as prescribed which can lead to negative outcomes that can be fatal.
- Patients with disabilities face higher level of difficulties taking medications as prescribed. Medication adherence rates are estimated at 49.5% for those with intellectual disabilities, 65.6% for those with stroke history, and 60–80% of those with multiple sclerosis (MS), and 60–80% for those with arthritis.¹²

Existing Standards

- There are limited standards for the collection of disability data. The US Department of Health and Human Services provides minimum standards for collecting disability data.⁴ However, disability data is collected in other areas, including the American Community Survey (ACS), the Survey of Income and Program Participation (SIPP), the Current Population Survey (CPS), the Bureau of Labor Statistics, the Behavioral Risk Factor Surveillance System (BRFSS), National Health Interview Survey, and Social Security Administration DI and SSI Statistics.⁵
- Some states and organizations have published recommendations and developed models, standards, and resources for disability data collection beyond health care standards, including the World Health Organization, Oregon Health Authority, Disability: National Organization on Disability, and National Council on Disability.^{6,7,8,9,10}

Example of Disabilities Questions: Oregon Health Plan

Your answers will help us find health and service differences among people with and without functional difficulties. Your answers are confidential. (*Please write in "don't know" if you don't know when you acquired this condition, or "don't want to answer" if you don't want to answer the question.)	Yes	*If yes, at what age did this condition begin?	No	Don't know	Don't want to answer	Don't know what this question is asking
7. Are you deaf or do you have serious difficulty hearing?						
8. Are you blind or do you have serious difficulty seeing, even when wearing glasses?						
Please stop now if you/the person is under age 5						
9. Do you have serious difficulty walking or climbing stairs?						
10. Because of a physical, mental or emotional condition, do you have serious difficulty concentrating, remembering or making decisions?						
11. Do you have difficulty dressing or bathing?						
12. Do you have serious difficulty learning how to do things most people your age can learn?						
13. Using your usual (customary) language, do you have serious difficulty communicating (for example understanding or being understood by others)?						
Please stop now if you/the person is under age 15						
14. 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. Do you have serious difficulty with the following: mood, intense feelings, controlling your behavior, or experiencing delusions or hallucinations?						

Disability Data Sources Used by Health Plans

Disabilities data can also be collected in case management programs, through diagnosis codes in medical claims data, electronic medical records, or from transferred clinical data. Much of the disability data collected is related to medical disabilities like multiple sclerosis or diabetes, but does not include other types of disabilities data like mobility related disabilities.

Disability data can be augmented with data from CMS which increases the amount of data by generating new data points from existing data. This provides the opportunity for diverse disability data collection.

Challenges and Opportunities Related to Disabilities Data



CHALLENGE

Health care professionals are unaware of how collecting disability data can improve health care outcomes.¹¹



OPPORTUNITIES

- Incorporate education and training on why, when, and how to ask disability questions into health care professionals (e.g., pharmacists, nurses, and physicians) curriculum and post-graduate training.
- Work with patient organizations to identify appropriate communication methods for information delivery.



CHALLENGE

Plan members are hesitant to provide disability information due to fear of stigma and discrimination. There is a lack of trust in how the data will be used to impact care.^{6, 11}



OPPORTUNITIES

- Include standard language regarding ethical disability data collection and use. Information should be publicly available in multiple languages.
- Certify appropriate data security standards for secure data transfer and ensure information is used ethically (e.g., non-discriminatory, and non-biases practices).



CHALLENGE

Multiple definitions of disability are used across health care.¹¹



OPPORTUNITIES

- Utilize HHS standards to collect disability data, at minimum.
- Partner with other organizations to develop an inclusive definition for disabilities, including physical, mental, or emotional conditions.



CHALLENGE

There is a lack of standardization in the collection, format, and reporting of disability data.^{5, 11}



OPPORTUNITIES

- Use and expand existing resources and standards when developing disability standards.
- Partner with care coordinators, community health workers, providers, pharmacists, and other health care workers to collect and report plan member disability data.

What Managed Care Pharmacy is Doing



Alliance Health¹

Alliance Health is a Tailored Plan approved by North Carolina. The Tailored Plan is a managed care health plan that provides Medicaid members with integrated physical health, pharmacy, behavioral health, intellectual/developmental disability (I/DD), and traumatic brain injury (TBI) services to meet their health care needs. In this handbook, “behavioral health” means mental health and substance use disorders.

For People with Hearing Loss

If you are deaf, hard of hearing, or deaf-blind, or you feel that you have difficulty hearing and need help communicating, there are resources to help.

These include but are not limited to:

- Qualified American Sign Language interpreters
- Certified deaf interpreters
- Communication Access Realtime Translation (CART) captioning
- Personal amplification listening devices (ALDs) for your use
- Information in large print
- Staff trained to appropriately handle your relay service calls (videophone, captioned phone, and TTY)

For People with Vision Loss

If you have vision loss, resources available to help you include, but are not limited to:

- Written materials in accessible formats (large print, Braille, audio, accessible electronic format)

For People with Speech Disabilities

If you have a speech disability, some services may include but are not limited to:

- Speech-to-Speech Relay (STS)

For People with Multiple Disabilities Access

Needs for people with disabilities vary. Special aids and services are provided free of charge.

Other Special Aids and Services for People with Disabilities

- Help in making or getting to appointments
- Care managers who can help you get the care you need
- Names and addresses of providers who specialize in your condition
- If you use a wheelchair, we can tell you if a doctor’s office is wheelchair accessible and can help you in making or getting to appointments
- Easy access to and from services (like ADA-accessible ramps, handrails, and other services)

These changes are expected to take effect on October 1, 2023.

What Managed Care Pharmacy is Doing *(continued)*



Vaya Health²

Vaya Health has two tailored plans that serve Medicaid members and State-funded Services.

For Medicaid beneficiaries with serious mental illness, serious emotional disturbance, severe substance abuse disorder, intellectual/developmental disabilities, or traumatic injury.

For qualifying North Carolina residents with no insurance or not enough insurance. Services include mental health, substance use recovery, intellectual/developmental disability, and traumatic brain injury services.

State-Funded Services are not an entitlement, and funding is limited. This means that even if someone is eligible to receive services, they may not be able to get services if there are not enough funds. If this happens, the person may be put on a waiting list by Vaya until additional funds are available.

Services include:

- All-Disability
 - Diagnostic assessment
 - Facility-based crisis for adults
 - Inpatient behavioral health services
 - Mobile crisis management
 - Outpatient services
- Adult Mental Health
 - Assertive community treatment
 - Assertive engagement
 - Case management
 - Community support team
 - Peer support services
 - Psychosocial rehabilitation
 - Mental health recovery residential services
 - Individual placement and support-supported employment (IPS-SE)
 - Transition management service
 - Critical Time Intervention
 - Behavioral health comprehensive case management
- Intellectual/developmental disabilities and traumatic brain injury
 - Residential supports
 - Day supports
 - Community living and support
 - Supported living periodic
 - Adult developmental vocational program
 - Supported employment
 - Respite

These changes are expected to take effect on October 15, 2023.

What Managed Care Pharmacy is Doing *(continued)*



Blue Shield of California: the80 Mapping Tool³

How It Works

- As part of the Health Reimagined initiative, the80 transforms how Community Health Advocates (CHAs) use data to create opportunities for action in their work with patients, providers, and community-based organizations.
- Make the connection between community-centered data and chronic illness in seconds by applying mySidewalk's automation infrastructure; CHAs simply enter their patient's ZIP Code into the platform to generate a report specific to that community.
- Each report also includes local data on the prevalence of chronic illnesses, including cardiovascular disease, asthma, diabetes, cancer, and mental and behavioral health. A brief review of academic research accompanies regular illness data to provide a comprehensive report that links social determinants to health outcomes.
- Translate data to action with clinical providers and community-based organizations. After selecting a ZIP Code, CHAs select the social determinant of health most relevant to their patient's needs.
 - Housing
 - Food Access & Insecurity
 - Transportation
 - Community and Context
 - Education
 - CHAs can customize the report further for their target audience: clinical providers or community-based organizations. Content in each report is adapted to equip CHAs with best practices for communicating about and framing social determinant information for each audience.
 - These reports are web-based, interactive, shareable, ADA-accessible, and mobile optimized.

References

- ¹ Alliance Health. Behavioral Health and Intellectual/Developmental Disabilities Tailored Plan. March 15, 2023. <https://www.alliancehealthplan.org/document-library/72702>
- ² Vaya Health. Embracing whole-person care. There's a New Way to Receive Medicaid Health Care in North Carolina. <https://www.vayahealth.com/medicaid-transformation/>
- ³ Blue Shield of California. How the80 Works. 2023. <https://www.bcbs.com/the-health-of-america/healthequity/this-mapping-tool-gives-community-health-advocates-data-to-understand-local-health-inequities>
- ⁴ HHS Standards. HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status. October 30, 2011. <https://aspe.hhs.gov/reports/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-disability-0>
- ⁵ United States Census Bureau. How Disability Data is Collected from The American Community Survey. November 21, 2021. <https://www.census.gov/topics/health/disability/guidance/data-collection-acs.html>
- ⁶ World Health Organization (WHO). Disability. March 7, 2023. <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>
- ⁷ Oregon Health Authority. Equity and Inclusion Division. December 2021. <https://www.oregon.gov/oha/EI/Pages/REALD-Providers.aspx>
- ⁸ DisabilityIN. Disability Equality Index. 2023. <https://disabilityin.org/what-we-do/disability-equality-index/>
- ⁹ National Organization on Disability. NOD Employment Tracker. 2023. <https://www.nod.org/tracker>
- ¹⁰ National Council on Disability. Civil Rights. 2023. Search | NCD.gov
- ¹¹ Academy of Managed Care Pharmacy Health Disparities Advisory Group discussions from May to September 2022.
- ¹² Schwartz JK, Unni E. Inclusion of People with Disabilities in Research to Improve Medication Adherence: A Systematic Review. Patient Prefer Adherence. July 26, 2021;15:1671-1677. doi: 10.2147/PPA.S314135. PMID: 34345167; PMCID: PMC8324980.

ACKNOWLEDGEMENTS

Developed in partnership with the AMCP Health Disparities Advisory Group, Atlas Clarity, and AMCP staff.

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* We thank and acknowledge the individuals listed above who participated in the AMCP Advisory Group. The content of the brief does not represent the views of any particular member and the Advisory Group did not have editorial control of the content. Engagement in this Advisory Group should not imply endorsement by the participant's respective organization.