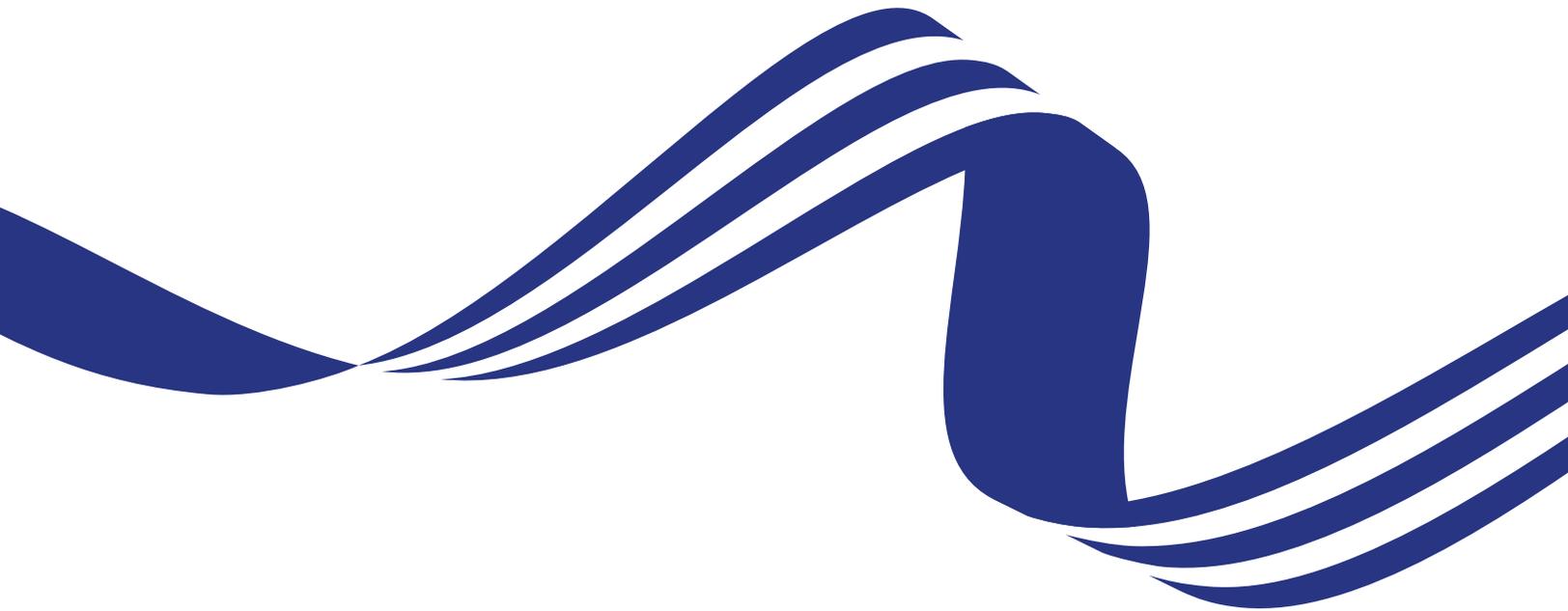




Community Partnerships

Improving Health Outcomes for People with Disabilities*

March 2023



Overview

As discussed in the issue brief [Improving Primary Care for People with Disabilities](#), co-authored by UnitedHealthcare Community & State's independent [Federally Qualified Health Center \(FQHC\) Advisory Board](#) and [National Advisory Board](#), many providers agree that individuals with disabilities are not receiving adequate primary care services or are facing barriers in accessing primary care. Challenges to delivering person-centered primary care for this population, as cited by health care professionals who responded to a survey conducted by the Boards, often pointed to a lack of patient resources and supports, limited provider training and education, and inaccessible facilities and equipment. Community-based organizations (CBOs) and Medicaid managed care organizations (MCOs) each offer specific expertise and services that can help inform and address these challenges, making them ideal partners. Together, primary care providers (especially FQHCs), CBOs, and MCOs can deliver comprehensive, holistic care and help individuals with disabilities meet their health goals. This brief outlines what can be done to bolster successful multi-sector efforts to support individuals in accessing needed primary and preventive care services.

Systems That Support People Living with Disabilities

The systems that support people living with disabilities today have been shaped by the great political and social strides that self-advocates and allies campaigned for in the 1960s and 1970s. A direct result of their efforts are the numerous laws, legislative amendments, and new Medicaid coverage authorities enacted to support people with disabilities retain access to their communities and independent living. A sample of these include¹:

- **The Rehabilitation Act.** The Rehabilitation Act of 1973 (Section 504) provided equal opportunity for employment within the federal government, in programs that receive federal funding, and the employment practices of federal contractors. The law prohibited discrimination based on disability for any of those programs.
- **The Developmental Disabilities Assistance and Bill of Rights Act (DD Act).** The DD Act is the fundamental law supporting and enhancing the lives of people with developmental disabilities and their families. The goal of the Act is to “assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life. The DD Act authorizes three programs that operate in each state and territory - University Centers for Excellence on Developmental Disabilities (UCEDD), State Councils on Developmental Disabilities (DD Councils), and PADD - known as the DD Network².
- **The Americans with Disabilities Act (ADA).** The ADA was a landmark civil rights law that clarified and affirmed that the “Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals.”³ The law prohibited discrimination by local and state governments and the workplace, established accessibility standards for public and private facilities, and protected individuals with disabilities rights to equal access to healthcare, social services, transportation, and telecommunications.
- **The Social Security Act.** The Act was amended in 1981 to provide authority for the Secretary to waive certain provisions of the Medicaid statute to allow states to provide home- and community-based services (HCBS) to eligible individuals who would otherwise require institutional services. In July 2022, CMS released a report exploring long-term services and supports (LTSS) use across different HCBS authorities and found that 7.4 million people (84.3%) received HCBS out of the 8.8 million Medicaid beneficiaries who received LTSS. This highlights the preference of individuals to receive care in their home or communities and the importance of creating community partnerships to support those preferences.⁴
- **Tax Equity and Fiscal Responsibility Act (TEFRA) Waiver:** Created by the Reagan Administration and expanded by Congress in 1982, a Katie Beckett or “TEFRA” waiver is a Medicaid waiver that allows Medicaid to cover institutional level care for children with disabilities or complex health care needs in the home, regardless of household income, when care in the home costs less than or the same as treatment in a nursing home or hospital. The waiver is named after Katie Beckett, whose family was prevented from caring for Katie at home because Medicaid eligibility accounted for the family's income and assets for HCBS but not when care was provided in an institution.⁵
- **Olmstead v. L.C.** The Olmstead Decision was a 1999 Supreme Court decision that ruled that the ADA prohibits unjustified segregation of individuals with disabilities in institutions or congregate settings, and public entities are required to provide community-based services to persons with disabilities when the community is an individual's setting of choice and community-based services meet their level of need.

Community-Based Organizations

CBOs are critical to helping individuals with disabilities access the necessary services and supports to become fully integrated within their communities and live healthy, independent lives. The following are examples of local, state, and national organizations that make up the disability networks:

- **Area Agencies on Aging (AAAs):** AAAs are a state designated public or private non-profit agency responsible for addressing the needs and concerns of all older adults and individuals with disabilities at the regional and local levels. AAAs are usually responsible for a geographic area, also known as a planning and service area (PSA), that is either a city, a single county, or a multi-county district. AAAs coordinate and offer services that help older adults and individuals with disabilities remain in their homes, aided by services such as home-delivered meals, homemaker assistance, and other services that assist with making independent living a viable option.
- **Aging and Disability Resource Centers (ADRCs):** ADRCs help older adults, people with disabilities, and family members become aware of the full range of available options for LTSS by providing objective information, advice, counseling, and assistance. ADRCs empower people to make informed decisions about their LTSS and help people access other public and private programs. ADRCs are often operated by local AAAs and are an important part of the No Wrong Door (NWD) system model.
- **Centers for Independent Living (CILs):** CILs are designed and operated by individuals with disabilities and provide independent living services for people with disabilities. Independent living is about individuals with disabilities being empowered to make their own decisions and being fully integrated into the mainstream of American society⁶. CILs provide tools, resources, and supports for integrating people with disabilities fully into their communities. This [graphic](#) from ACL illustrates how CILs make community living possible.
- **University Centers for Excellence on Developmental Disabilities (UCEDD):** UCEDDs are Administration on Disabilities grantees that are affiliated with universities and serve as liaisons between academia and the community. UCEDDs are a nationwide network of centers that serve as national resources for addressing issues, finding solutions, and advancing research related to the needs of individuals with developmental disabilities and their families.
- **State Councils on Developmental Disabilities (DD Councils):** DD Councils are federally funded, self-governing organizations committed to advancing public policy and systems change that help individuals with developmental disabilities gain more control over their lives. State DD Council members are appointed by a state's governor. By law, more than 60% of the members of each DD Council must be people with intellectual or developmental disabilities or close family members. Councils are founded on the principle that those with lived experience should always be included in conversations to find and foster solutions. The 56 councils across the United States and its territories work to address identified needs through advocacy and capacity building efforts to promote self-determination, integration, and inclusion. Every Council designs a five-year state plan to address new ways of improving service delivery.
- **Protection and Advocacy Systems (P&As):** There are 57 P&As in the U.S. and its territories. Each P&A works to protect individuals with disabilities by empowering them, advocating on their behalf, and providing legal support. For more information on P&As, see the [Protecting Rights and Preventing Abuse of People with Disabilities](#) webpage.
- **Parent Training and Information Centers (PTI):** The Individuals with Disabilities Education Act (IDEA) provides funding for each state to have at least one PTI. PTIs help families of kids from birth to age 26 who have a disability by disseminating free information on specific disabilities and issues; parental and child rights under the IDEA and ADA; support groups; and other local, state, and national resources.
- **Family to Family Health Information Centers (F2Fs):** F2Fs are family-lead centers funded by the Health Resources and Services Administration (HRSA). The staff of F2Fs are comprised of family members with first-hand experience in caring for and navigating the healthcare system for children and youth with special health care needs. The staff provides support to identify and access community support programs, become an effective member of their child's medical team, and more.



The No Wrong Door (NWD) System

The NWD initiative is a collaboration between the Administration for Community Living (ACL), the Centers for Medicare & Medicaid Services, and the Veterans Health Administration. The initiative acknowledges that the current LTSS system is complex, fragmented, and often confusing for individuals and their families. The initiative seeks to simplify access to LTSS by creating a “no wrong door” to services. This means that if an individual contacts one organization within a state’s network of LTSS providers they will be connected to needed information, referrals, and supports from the other NWD system partners.

Medicaid Managed Care Organizations

Medicaid is the primary insurer for individuals with disabilities^{7,8}. State Medicaid managed care programs have steadily increased to serve upwards of 70% of all Medicaid beneficiaries and most beneficiaries with disabilities are served in managed care programs⁹. MCOs have a deep understanding of serving complex populations and providing person-centered, holistic care across the service spectrum. Key elements of their work in serving people living with disabilities include:

- Care management teams with experience developing processes and interventions to effectively address members' health care needs and improve access to care.
- Infrastructure to allow members and caregivers to inform health plan services, benefits, and operations to best meet the needs of members, including Member Advisory Committees and engagement with frontline staff (e.g., case managers, community health workers).
- Data and robust analytics that can identify trends and gaps in care, which can inform interventions and enable outcomes research.
- A culture of innovation that fosters the bridging of social service gaps and delivers effective health services to members.
- Community investments and partnerships that are driven by the needs of members and the communities served by Medicaid.

State Medicaid managed care programs serve over

70% of all Medicaid beneficiaries.

Given this role and the fact that they often have strong relationships with CBOs and primary care providers serving people with disabilities, MCOs are well positioned to facilitate strong connections across the different systems.

Federally Qualified Health Centers

FQHCs are community-based health care providers that deliver comprehensive primary and preventive care across the life span of an individual. Health centers play a particularly critical role in Medicaid, serving 1 in 5 beneficiaries, and are especially vital sources of care for Black, Indigenous, People of Color (BIPOC), non-English speakers, and individuals in rural communities¹⁰. These providers also have a deep understanding of their community and often serve patients with complex health and social needs, including individuals with disabilities.

The health center mission and model has led to an emphasis on community-driven, integrated interventions. This is reflected in their:

- **Delivery model:** Focused on comprehensive, culturally competent care that includes such services as medical, behavioral health, dental, pharmacy, vision, social supports, and laboratory services on site.
- **Community engagement infrastructure:** Designed to be responsive to community needs with a patient-majority governing Board and a federal requirement to conduct regular community needs-assessments.
- **Social care services and connections:** Experienced in working to understand and address social risk factors that impact the health and wellbeing of the communities they serve, including the development of innovative partnerships, care models and [PRAPARE \(Protocol for Responding to and Assessing Patient Assets, Risks and Experiences\)](#), which is the leading screening tool for social risk factors.

Opportunities to Support Partnerships to Improve Health Outcomes

CBOs, MCOs, and FQHCs have many opportunities to build bridges and improve outcomes for individuals with disabilities. States and their MCO partners can also take actions to create an environment that enables partners to work together more effectively by initiating policies and practices that:

- Provide integrated information systems and data sharing capabilities to enhance screening, referrals, and resources related to social service needs.
- Support statewide data and analytic infrastructure to help partners support data integration and data sharing to identify social needs and link them to appropriate social support services while meeting HIPAA and cybersecurity guidelines.

- Make it easier for MCOs to cover nontraditional “in-lieu-of” services to enable innovative solutions with FQHCs and community organizations that address members’ social risk factors and improve health outcomes.
- Build system capacity and resiliency by implementing a community reinvestment requirement for MCOs that:
 - Establishes clear funding priorities that reinforce member access, system capacity to serve members more equitably, and pathways for adding social determinants of health.
 - Recognizes the opportunities for diverse funding models (pay for success, low-interest loans, grants) as well as non-monetary resources (technical assistance, data, tools) which contribute to community impact.
 - Layers program design elements, including reinvestment, population health goals, and provider partnership opportunities to amplify the positive impact of programmatic provisions.
 - Funds distribution mechanisms which reinforce health plan engagement and/or community planning districts.
- Support alternative payment models that offer FQHCs and other providers additional flexibility to best meet the care needs of individuals with disabilities.
- Increase communication between members, providers, and MCOs to ensure issues impacting members’ lives are raised and addressed.
- Encourage MCOs to develop methods for engagement with and meaningful interactions between providers and CBOs who are hearing about member care needs and access challenges.
- Identify supports CBOs require in order to have the strongest impact in a community. For example, a strong partnership can raise the profile of the CBO and FQHC which makes both a relied upon resource in the community. People seek assistance from those reliable resources instead of continuing with unmet needs.

Five Steps to Create Community Partnerships

At the heart of creating community partnerships is understanding the highest priority community health need through detailed community health data analysis paired with community listening to ensure the community's voice pulls through to guide what the most important needs are to be addressed.

1

Convene Partners and Listen

Local organizations, government, and employers should be truly unified in their approach and be working together to solve the most important problems facing the community. The first step in doing this is implementing a two-pronged approach of listening and utilizing data-informed community identification to focus on communities with the highest needs and ensure that nothing is done without the impacted community adhering to the philosophy of "Nothing about us, without us." Once communities are identified, it is imperative to listen to both individuals as well as collective voices to garner a holistic understanding of needs. These needs could be measurable or subjective “felt needs”, which are equally important.

2

Review Data and Identify Needs

The second step in creating partnerships is to begin to identify needs. This identification must begin with an analysis of community-level data that is specific to population health, encompasses clinical and social areas, and is the most descriptive and complete as possible. At the heart of every partnership must be qualitative and quantitative population health data for members and non-members along with thorough analysis.

3

Assess and Confirm Need

Community organizations, government agencies, health clinics, and private companies in states and cities across the country connect our collective assets and understanding. Sharing the data and analysis as well as what is heard from listening to partners and individuals with disabilities allows partners to focus efforts in the most effective way. Ongoing data collection allows outcomes to be tracked and shapes the direction and investment of future efforts.

4

Collaborate and Act

Too often different community partners each try to approach a solution alone, when the quickest path to success is working together and leveraging assets of the convened community partners in the solution design. The action plan is intentional and tangible with clear roles, responsibilities, and measurable outcomes for success for all partners.

5

Measure and Refine

Measure outcomes, refine approach, and ensure sustainability of investment. Efforts must be explicitly designed to be sustainable so that the population health intervention becomes woven into the fabric of the community, and echos with the voices of its members.

Conclusion

CBOs, MCOs, and FQHCs are strategically positioned to work together to improve the health outcomes of individuals with disabilities and facilitate the integration and inclusion of individuals with disabilities within their communities. There is tremendous opportunity for all stakeholders to support the creation and sustainability of community-based partnerships in efforts to improve access to care and address health disparities among people with disabilities. This alignment allows for improved health of populations and thus also that of communities.

Sources

- ¹ [Rebalancing Toolkit \(medicaid.gov\)](#)
- ² [AUCD - Developmental Disabilities Act](#)
- ³ [Rebalancing Toolkit \(medicaid.gov\)](#)
- ⁴ [Medicaid Beneficiaries Who Use Long-Term Services and Supports: 2019](#)
- ⁵ <https://www.macpac.gov/wp-content/uploads/2014/06/June-2014-Report-to-Congress-on-Medicaid-and-CHIP.pdf>
- ⁶ [Independent Living Services \(ILS\) Program | ACL Administration for Community Living](#)
- ⁷ [Medicaid and CHIP Payment and Access Commission](#)
- ⁸ [Frontiers in public health](#)
- ⁹ [Medicaid and CHIP Payment and Access Commission: 2021 MACStats, Exhibit 30. Percentage of Medicaid Enrollees in Managed Care by State and Eligibility Group.](#)
- ¹⁰ <https://www.nachc.org/research-and-data/research-fact-sheets-and-infographics/2021-community-health-center-chartbook/>