



October 11, 2022

Special Rapporteur

UN Convention on the Rights of Persons with Disabilities

Re: Re-Imagining Services in the 21st Century to give effect to the right to live independently and be included in the community for persons with disabilities.

About The Arc:

The Arc is the largest national community-based organization advocating for and with people with intellectual and developmental disabilities (IDD) and serving them and their families. We work tirelessly to uphold our vision that every individual and family living with IDD in the United States has access to the information, advocacy, and skills they need to support their full inclusion and participation in the community throughout their lifetimes. [More information about The Arc can be found here.](#)

Policy Goals and Principles:

[Medicaid Home and community-based services \(HCBS\)](#) provide opportunities for people with disabilities and older adults to receive services in their own home or community rather than in large institutions. The primary principle of HCBS is to ensure that people with disabilities have access to the benefits of community living and can receive services in the most integrated settings. In 2014, the Centers of Medicare and Medicaid Services (CMS) [issued the HCBS Settings Rule](#) which put forth requirements to ensure that HCBS meet minimum standards for integration, access to community life, choices, autonomy, and other protections. [A summary of the HCBS settings rule can be found here.](#) While these rules were not modified to take explicit account of Article 19 of the CRPD, they share many of the same purposes and goals. These goals are ultimately linked directly to broader policy imperatives to ensure people with disabilities can receive meaningful services in their community. [More information about HCBS for people with IDD can be found here.](#)

Service Delivery

Home and Community Based Services (HCBS) are funded through [Medicaid](#). Medicaid is a federal system of health insurance that is administered by states, according to federal requirements. The program is funded jointly by state and federal government dollars. [HCBS are often funded by state waivers, which are part of the state's Medicaid program.](#) Waivers provide a special group of services to certain populations—such as individuals with IDD. These waivers usually require medical and/or financial eligibility, but these waiver eligibility requirements differ from state to state and can even differ from the state's Medicaid eligibility requirements.

HCBS are delivered through a mix of public and private providers—including religious organizations, state agencies, non-profit organizations, for-profit providers, and others. Service providers contract with a lead agency in a specific area that they provide services to. That lead agency



acts as the primary care coordinator for its region. Providers are reimbursed under a federal statutory structure. New proposals have suggested payments through general grants or per capita spending—both proposals that The Arc of the United States opposes. [An overview of HCBS can be found here](#). The goals of the HCBS system are communicated through federal regulations, mainly through the [HCBS Settings Rule](#). As previously mentioned, these federal guidelines serve as requirements that every HCBS provider must abide by. There are also funding incentives to states to encourage them to invest in HCBS. This incentive is known as Federal Medical Assistance Percentage (FMAP). The Center for Medicaid Services (CMS) reimburses each state for a percentage of its total Medicaid expenditures. This percentage varies by state but encourages states to invest in Medicaid services such as HCBS. [An overview of FMAP for Medicaid can be found here](#).

In many states, family members can be paid as caregivers. This practice increased during the COVID-19 pandemic as many regulations were relaxed to allow greater flexibility. This allows financial compensation for family caregiving responsibilities that often go unpaid. This also allows greater choice for individuals who sometimes would prefer a family member to provide HCBS. The use of technology has also increased during the COVID-19 pandemic. This includes the increased use of remote monitoring, and telehealth. The hope is that these flexibilities and technologies will be continuously improved and not withdrawn after the pandemic is over.

The main goal of HCBS is to provide personalized, tailored services to individual needs in a community-based setting rather than a large institution. Some states have self-directed HCBS in place. Self-directed services allow for individuals to determine what mix of services and supports works best for them within the parameters of their person-centered service plan. There are two forms of self-direction. The first is employer authority which means that individuals have control over hiring and supervising their personal care attendants and direct care workers. The second form is budget authority which means individuals have control over an individualized budget and they decide what services and supports are purchased. [The latest inventory of self-direct programs identified 265 programs nationally, with over 1.2 million participants enrolled](#). In both forms, individuals have the power to hire and fire workers, choose schedules, and designate responsibilities and services that individuals or agencies provide. However, many states and providers do not allow for self-directed HCBS and instead provide state-directed HCBS which do not allow people with disabilities as much control over the services they receive.

Many people who receive HCBS still have financial insecurity. HCBS provides services but not financial supports. [Supplemental Security Income](#) is a federal income supplement program that provides limited financial supports to many people with intellectual and developmental disabilities. However, these programs have strict rules that make it harder for people to save money, work, or even marry. [The Arc has long advocated for changes to the SSI program](#). There are other programs that serve as “wealth accumulation strategy” such as Special Needs Trusts and ABLE accounts. However, ABLE accounts are currently only available to individuals who acquired their disability prior the age of 26. There is current legislation, the [ABLE Age Adjustment Act](#), which would raise this age to 46, enabling over



6.1 million additional people with disabilities to be eligible for an ABLA account. The Arc is supportive of this legislation.

Monitoring and Oversight

There is limited data regarding HCBS. States are required to report data to the federal government on their HCBS programs, but this data is often out of date, insufficient, or calculated in different ways which can make it unreliable. [General data on HCBS can be found here](#). Medicaid technically does have enforcement provisions, but these are often ineffective. Enforcement of providers is a complicated issue because if a provider is removed from the Medicaid HCBS program, that further limits available providers and services in an already under-resourced system. However, providers could be disqualified from competing for future state or federal support if they do not comply with enforcement provisions.

Re-Shaping the Market/Challenges and Opportunities

There are major barriers to Medicaid HCBS because of lack of funding and variability in state programs. Because HCBS are state administered, much of the program's success is due to the local economy, state legislatures, state administrators and other factors that impact the quality of HCBS. Furthermore, because of lack of funding across the country, there are workforce shortages, inadequate wages, lack of resources, and constant turnover in all HCBS programs. This was a crisis prior to the COVID-10 pandemic but the pandemic has certainly exacerbated the problem.

Process of Reform

To build support for HCBS, The Arc and other advocacy organizations have partnered with disability, aging, and labor organizations to advocate for an investment in HCBS that would benefit all three groups. This partnership has proven to be impactful in raising awareness and support of HCBS. We have also worked to educate the public and lawmakers about the care infrastructure which has shifted the way we look at and talk about care and HCBS. [The Arc has a National Council of Self Advocates that informs the work we do](#). This disability-lead advisory council identifies important issues to people with disabilities, advises on advocacy, programs, services, and how The Arc can better support people with disabilities. Additionally, self-advocates hold positions on our Board of Directors and various national committees. People with disabilities are fundamental to our entire structure. For decades, The Arc has advocated to enhance the quantity, availability, and effectiveness of home and community-based services for people with disabilities. [Our position statement on Long Term Supports and Services outlines these goals and can be found here](#).

Please contact Michael Atkins (atkins@thearc.org) for further information.

Sincerely,

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The Arc of the United States