DISABILITY AND INDEPENDENCE IN RURAL AMERICA

WHITE PAPER

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NACRHHS

National Advisory Committee on Rural Health and Human Services

EDITORIAL NOTE

In September 2023, The National Advisory Committee on Rural Health and Human Services (hereinafter referred to as "the Committee") convened for its 93rd meeting in Colorado Springs, Colorado to discuss access to and delivery of health care and human services support to rural Americans living with a disability.

Throughout the meeting, the Committee engaged with subject matter experts and local community stakeholders regarding access to disability services. As part of the meeting, Committee members participated in site visits to Lincoln Health Community Hospital in Hugo, Colorado and Starpoint Community Center Board in Canon City, Colorado.

Given the limited data on disability in rural America and the variability of needs and experiences of people with disabilities, the paper does not issue policy recommendations. Instead, it gives a brief overview of disability and independence in rural America, and outlines key issues identified by the Committee during its discussion. The Committee may choose to further explore issues impacting rural Americans with disabilities, including those discussed in this paper, in future meetings.

EXECUTIVE SUMMARY

Rural residents of all ages who live with disabilities often face structural challenges when attempting to access health and human services in their communities. The presentations and discussions during the September 2023 meeting of the National Advisory Committee on Rural Health and Human Services (NACRHHS or the Committee) highlighted the barriers to expanding access to disability services in rural America and identified opportunities for growth. Site visits to Starpoint and Lincoln Community Hospital further illustrated the resourcefulness and flexibility of rural America to the Committee. Both facilities showcased how rural areas are maximizing resources, creating innovative approaches to service delivery, and leveraging social capital in their communities to meet the needs of individuals and families affected by disability. In its discussions, the Committee approached this topic from the viewpoint that rural disability programs and policies should acknowledge the whole person, rather than focus on their disability. The emphasis should be on maximizing an individual's independence and recognizing that Americans with disabilities are often family members, neighbors, community leaders, and children, all of whom are valuable members of our communities. Resources should be available to give rural Americans with disabilities the opportunities they need to live their lives to their fullest potential and ability. These programs and policies should also emphasize care coordination to enhance connection across myriad federal programs.

INTRODUCTION

Defining Disability

There is no single, standard definition of "disability" that is consistently used across the federal government. Many federal agencies rely on legislation to define disability for their programs' eligibility standards. States can also define disability criteria for their state level programs. Still, some similarities exist across definitions used to determine eligibility for receiving disability benefits and assistance. These definitions are generally inclusive of any physical, mental and/or intellectual impairment that negatively affects one's health and well-being and that limits or hinders the ability to do certain activities. This white paper uses this broad definition, unless noted otherwise.

Disability Prevalence and Rural Vulnerability

According to the Centers for Disease Control and Prevention (CDC), roughly 27% of adults in the United States have some type of disability.[1] This means that about 1 in 4 Americans over the age of 18 have a disability.[2]

Although disability rates are high nationally, they are even higher within rural, aging, and Medicare beneficiary populations. Data from the 2021 American Community Survey (ACS) (conducted by the U.S. Census Bureau) showed that while 12.6 percent of urban Americans experience a disability, the rate of disability increases to 14.7 percent in rural areas.[3] An analysis of ACS 5-year data from 2014-2019 by the University of Montana's Rural Institute for Inclusive Communities also found that disability rates are higher in rural areas across all disability types (as defined by ACS, which includes disabilities that affect a person's hearing, vision, cognition, mobility, and ability for self-care or independent living), as well as across all ages, races, and ethnicities.[4]

Older age seems to deepen rural-urban disability disparities. The University of Montana's analysis found that the highest rates of disability are in populations that are 65 years old or older.[5] Because rural areas have a higher percentage of residents who are 65 and older than urban areas (19.9 percent compared to 16.0 percent),[6] rural areas are more likely to house older disabled populations. Middle-to-older aged rural residents are also more likely to report living with a disability than urban populations of the same age.[7]

Relatedly, rural, Medicare-eligible populations appear to make up a large proportion of those living with disabilities.[i] One in three rural adults (about 19.8 million people) is enrolled in Medicare – equal to about 29.6 percent of the total Medicare population.[8, 9, 10] Of this Medicare population, 7.6 million Medicare enrollees in calendar year 2023 were disabled (about 11 percent of Medicare's total enrollment) according to the 2024 Medicare Board of Trustees Report.[11]

Although older populations face the greatest rural-urban disability disparities, younger rural residents are also disproportionately impacted. For populations between ages 18 and 64, the disability rate is 9.7 percent in metropolitan areas, compared to 13.7 percent in micropolitan (i.e., more populated rural areas) and 15.3 percent in noncore areas (less populated rural areas).[12] In addition, a 2020 CDC National Health Statistics report found that children living in rural areas are more likely to have a developmental disability.[13] Between 2015 and 2018, the report found the prevalence of children aged 3-17 ever diagnosed with a developmental disability[ii] was 19.8 percent among children living in rural areas, compared to 17.4 percent among their urban counterparts and 17.8 percent among all children.

[i] Although Medicare beneficiaries may develop disabilities as they age, the Committee's discussions focused largely on disabilities not caused by aging, even when discussing populations ages 65 and older. Increasing rates of disability can be expected with older age; focusing on non-age-related disabilities allowed the Committee to highlight shared experiences across age groups with disabilities in rural America.

[ii] The authors of the CDC report defined developmental disability as "a group of conditions, typically lifelong, resulting from impairments in physical, learning, language, or behavioral areas."

Department of Health and Human Services Programs for People with Disabilities

The U.S. Department of Health and Human Services (HHS) has oversight over disability policy in the following contexts through the Office of Civil Rights (OCR). [14] According to the OCR, the office enforces:

- Section 504 of the Rehabilitation Act of 1973, including programs and activities that are conducted by HHS or receiving Federal financial assistance from HHS.
- Section 508 of the Rehabilitation Act of 1973, covering access to electronic and information technology provided by HHS.
- Title II of the Americans with Disabilities Act (ADA) of 1990, covering all health care and social services programs and activities of public entities.
- Section 1557 of the Patient Protection and Affordable Care Act (ACA), ensuring that an individual is not excluded from participating in, denied benefits because of, or subjected to discrimination as prohibited under Section 504 of the Rehabilitation Act of 1973 (disability), under any health program or activity, any part of which is receiving federal financial assistance, or under any program or activity that is administered by an Executive Agency or any entity established under Title I of the Affordable Care Act or its amendments.

Table 1 lists a selection of programs in HHS and other federal departments that the Committee members believe represent important opportunities to provide needed services to support persons with disability living in rural America, in addition to the work already done by the OCR.

Table 1: HHS Federal Disability Resources

Program Type	Federal Agency
Direct State Entities	
State Disability Councils	ACL
State Independent Living Councils	ACL
State Medicaid Programs	CMS
State Health Insurance Programs	CMS
Title VI Block (New-Born Screening, Medical Home, Family to Family Resource Centers)	HRSA
Indirect State Entities	
State Offices of Rural Health	HRSA
State Rural Health Associations	HRSA
State Primary Care Associations	HRSA
State Disability Research Centers	ACL
State TBI Programs	ACL
Regional and/or TA Resources	
ACL Self Advocacy Resource and TA Center	ACL
Area Agencies on Aging	ACL
Community Services Block Grant	ACF
Social Services Block Grant	ACF
Runaway and Homeless Youth Programs	ACF
Adolescent Pregnancy Prevention Programs	ACF
Child Care and Development Fund Lead Agencies	ACF
Head Start Collaboration Office	ACF
Aging and Disability Resource Centers	ACL
Assistive Technology Program	ACL
Veteran Directed Care Program	ACL
Surveillance; Health Promotion, Research and Analysis	CDC Programs
Other Federal Players	
Disabled Veterans	VHA
Housing and Technology	USDA
Housing	HUD
Transportation	Dept. of Transportation
Broadband	Dept. of Commerce; FCC; USDA

KEY CONSIDERATIONS FOR DISABILITY SERVICES IN RURAL AREAS

Rural areas require considerations for providing disability services that may not be issues in urban areas. Access, insurance coverage, workforce, and telehealth and technology may each pose unique challenges for rural areas working to provide disability services. These considerations provided the foundation for the Committee's discussions of disability in rural America.

Rural Access Issues

Long-Term Services and Supports

Since the 1970s, care for older adults and people with disabilities in the U.S. has shifted from a focus on institutional-based care to independent living via long-term services and supports (LTSS),[iii] particularly home and community-based services (HCBS).[15] However, rural communities have inadequate access to HCBS.[iv] A 2016 study by the Maine Rural Health Research Center found that fewer rural Medicaid LTSS users received at least one HCBS than urban LTSS users (75 percent vs. 81 percent) and more rural LTSS users received nursing facility services than in urban areas (48 percent vs. 38 percent).[16]

Transportation

Inadequate transportation is another barrier to independent living and community participation for people with disabilities.[17] Rural residents travel nearly double the distance to medical or dental care than urban residents (8.10 vs. 17.8 miles).[18] Based on a 2020 analysis of the National Household Travel Survey data conducted by the University of Montana, rural residents also report a slightly higher rate of travel-related disability (a condition or handicap that makes it difficult to travel outside of the home) than urban residents (7.3 percent vs. 6.6 percent).[19] With little to no public transportation services, individuals with disabilities often have to rely on friends or family to take them to their appointments, often causing loss of pay for those providing this assistance.

[iii] Long-term services and supports (LTSS) cover a wide range of health and social services that assist individuals with functional limitations due to aging, chronic conditions, and disabilities. LTSS assists with activities of daily living (including eating, bathing, and dressing) and instrumental activities of daily living (including medication management, housekeeping, and money management). They are delivered in institutional and home and community-based settings. Examples of LTSS include nursing facility care, caregiver support, adult daycare programs, home health aide services, and transportation.

[iv] The Committee assessed the disjointed nature of LTSS and HCBS delivery and financing as it relates to aging in rural America in the 2019 policy brief, "Supportive Services and Caregiving for Older Rural Adults" and the 2023 policy brief, "Programs of All-Inclusive Care for the Elderly".

Housing

Access to quality and affordable housing is another critical element of health, wellbeing, and independent living. For people with a disability, the cost of functional housing can be prohibitive. A 2023 policy brief by the University of Minnesota's Rural Health Research Center (RHRC) assessed the housing cost burden among people with disabilities. The authors report that "nearly 30 [percent] of rural adults with disabilities are housing-cost burdened (spending 30 [percent] or more of their income on housing)."[20] Another 2023 policy brief by the University of Minnesota's RHRC reports that adults with disabilities living in rural areas have the highest proportion of incomplete plumbing out of all the groups they examined. [21] Moreover, findings from the 2019 American Housing Survey show that 20 percent of households include a person with accessibility needs, and 40 percent of those households report that that their homes currently do not have accessibility features (such as entry-level bedrooms or full bathrooms). This survey also finds that households in micropolitan or nonmetropolitan areas (22 percent) are more likely to include persons with accessibility needs compared with those in large metropolitan areas (16 percent) and those in moderate-sized metropolitan areas (19 percent).[22]

Medicaid and Medicare Coverage

Medicaid and Medicare are vital components of the U.S. healthcare system and are relied on heavily by both people with disabilities and rural residents. Although data on Medicaid, the Children's Health Insurance Program (CHIP) and Medicare coverage for people with disabilities living in rural communities is not readily available, there are data on people with disabilities. Medicaid covers 43 percent of nonelderly, noninstitutionalized adults (ages 19-64) with disabilities, who are defined as having one or more difficulties related to hearing, vision, cognition, ambulation, self-care, or independent living.[23] Additionally, a recent study from Georgetown University noted that Medicaid/CHIP cover 47 percent of children and 18 percent of adults in small towns and rural areas, compared to 40 percent of children and 15 percent of adults in urban counties.[24]

State Medicaid programs provide the majority of HCBS through waivers[v], which allow states to offer targeted services to specific populations (older adults and/or people with disabilities).[25] A 2023 U.S. Government Accountability Office (GAO) report estimated Medicaid spending on LTSS resources for people with intellectual and developmental disabilities (including HCBS) at $23 billion in 2018. [26] The GAO report also found that people with intellectual or developmental disabilities comprised the majority of individuals on waiting lists for HCBS programs as of 2021, with wait times averaging over 5 years.

Georgetown University's Center for Children and Families reports that 44 percent of children and youth with special health care needs (CYSHCN) have Medicaid/CHIP coverage. Some 36 percent of CYSHCN rely on Medicaid/CHIP as their only source of coverage, while another 8 percent have Medicaid/CHIP in combination with private insurance. Nineteen states cover more than half of the CYSHCN in their state through Medicaid/CHIP.[27]

[v] The HCBS waivers include Section 1915 (c), Section 115, and Section 195 (i).

Workforce

Workforce shortages in rural areas are a notable problem for people with disabilities. The literature indicates that people with disabilities face health disparities, including higher rates of heart disease, lower respiratory disease, and diabetes, and lower utilization of preventive services.,[28, 29, 30] National trends show that the demand for rural doctors will continue outpacing projected supply, with a predicted shortage of nearly 24,000 primary care physicians by 2025.[31] The per capita rate of physicians per 10,000 people in rural areas is 12.7 compared to 33.6 in urban areas. Likewise, there are 63.9 registered nurses per 10,000 people in rural areas, markedly fewer than the number of registered nurses in urban areas (93.6 per 10,000 people).[32]

The services and supports provided by the direct care workforce (including personal care aides or PCAs, job coaches, home health aides, and residential workers) are essential in ensuring that people with disabilities can live independently in their homes and communities.[33] Research conducted by the University of California San Francisco and the University of Montana found that the most rural areas in the country have the lowest ratio of PCAs per 1,000 people with self-care disability needs (142 PCA per 1,000 vs. 206 per 1,000). [34] The research also found that PCAs in rural areas are more likely to be living in poverty than those in urban areas (20.9 percent vs. 18.4 percent).

People living with disabilities are also likely to need more specialized human services, including counseling, personal assistance, case management, and other resources. Finding those services can be more challenging in rural areas. The RUPRI Rural Human Services Panel reports that, "at times, even the most basic essential services may not be accessible or may not even exist. Beyond that, those in need often cannot access human service providers with sufficiently specialized knowledge […]. " [35]

Telehealth and Technology in Rural

While there is a dearth of data and literature on the use of telehealth among people with disabilities living in rural areas, the available information still suggests that access is a challenge. According to a 2021 survey conducted by the Pew Research Center, 72 percent of rural Americans say they have a broadband internet connection at home, compared to 77 percent and 79 percent for urban Americans and suburban Americans, respectively.[36] A separate 2021 Pew Research Center survey did not find a statistically significant difference in broadband access between people with disabilities and those without; however, a lower percentage of adults with a disability own a desktop or laptop computer (62 percent vs. 81 percent of those without a disability), or a smartphone (72 percent vs. 88 percent of those without a disability). [37] Even when access to suitable devices and bandwidth are available to people with disabilities, there can be gaps in knowledge of how to use technology platforms and devices (digital literacy).[38] Additionally, people with intellectual and developmental disabilities (I/DD), those who are cognitively impaired, and older adults may need additional assistance navigating the use of virtual technologies.[39]

DISCUSSION

Over the course of the meeting, the Committee came to understand that the circumstances that limit an individual's ability to live independently may vary widely. Some disabilities are congenital, while others

result from accident or illness or other events. Many disabilities are dynamic and may improve or worsen over time. A one-size-fits-all approach in disability policy will not provide the needed flexibility to meet the spectrum of needs of an individual with a disability or their families may have.

During site visits, guest speakers and presentations, the Committee heard four consistent themes that may be target areas for disability and independence policy improvement. These were:

1. Access to transportation and supportive housing
2. Assistance with resource navigation
3. Family education and support
4. Flexibility on how providers use federal and state funding

The Committee heard from caregivers for individuals with a disability, whose lived experience highlighted the need for navigation tools to identify resources and caregiver supports. Of particular concern was the need for ongoing support and assistance by children as they move into adulthood. The Committee heard from other family caregivers, who relayed that one of their biggest concerns is the continuum of care available to their children, especially after they are no longer able or available to provide support. Practical consideration of the transition from family caregiving to community support as caregivers age or pass away is paramount. The Committee also engaged with family caregivers about the burden of completing paperwork from multiple agencies. This paperwork is often duplicative. The Committee understands this frustration and believes this is an opportunity for the federal government to explore registration systems that enable more coordination between different programs.

Other key takeaways from the September meeting are summarized below.

Availability of Rural Disability Data

The Committee members heard from presenters about the need for better rural disability data, distinct from national statistics that factor in urban populations. The Committee considers the following data-related issues worthy of further attention and discussion:

- There is inadequate data on disability in rural areas. Expanded data collection and reporting on rates of disability, types of disability, and impact of living with a disability is an important concern.
- Improved data on the impact of disability on cost of living, access to services, and other measures of well-being are needed.

In this context, the National Institute on Minority Health and Health Disparities has formally designated people with disabilities as a National Institutes of Health research population experiencing health disparities since September 2023.[40] Academy Health noted the designation as an opportunity for health services researchers to prioritize work exploring the intersection of disability and rurality.[41] The needs of individuals living with a disability in rural areas are distinct. The Committee believes these differences are significant enough that individuals with disabilities and their families, rural health care providers,

rural researchers, and policymakers would be well served if rural disability research were an independent HHS focus area.

Navigating and Expanding Resources

A consistent theme during the meeting was the difficulty of navigating existing disability programs and resources. The Committee considers the following issues worthy of further attention and discussion:

- People with disabilities have multiple needs, but resources are often siloed through various federal, state, and local agencies and not easily known or navigated at the local level.
- People with disabilities and their caregivers face significant challenges with understanding eligibility requirements that are different from program to program and constantly evolving.
- The administrative burden of paperwork and eligibility determination processes discourages some individuals and families from engaging with available programs.
- Access to developmental screening for early intervention is important, and families and caregivers must be made aware of early intervention resources.
- Caregivers confront problems with their own health and well-being. The physical and mental toll of continuous caregiving with little ability for respite and worry about the future is noticeable.

Table 1 (pg. 6) offered a general overview of how federal dollars are administered through the states and indicated where there are resources available for disability services. However, there are also many different programs that administer these services, which can be confusing to navigate.

The Committee heard from family caregivers who had navigated siloes of uncoordinated care, which they noted as a factor in delayed evaluation of their child for disability resources. Additionally, the significant paperwork and administrative burden of applying for programs, sometimes annually, accessing resources, and receiving a disability determination were particularly taxing for the family caregivers.

Family caregivers also spoke to the Committee about the challenges they face when accessing support services for their family member and themselves. According to a report by AARP and the National Alliance for Caregiving, one in five Americans (21.3 percent) acted as a caregiver to an adult or child with special needs in 2020. [42] The same report states that rural caregivers report greater difficulty finding affordable services, like meal delivery, transportation, or in-home health services in their recipient's local area (32 percent vs. 25 percent of those caring for someone who lives in a suburban or urban area).

Respite support is needed for family caregivers. Transitioning away from family caregiving, as older parent caregivers experience disabilities themselves or pass away, is a policy concern noted by the Committee. When someone with a disability who cannot live independently no longer has a family caregiver, they may face increased isolation, and potentially, institutionalization.

Access to Support Services: Home and Community-based Services (HCBS), Transportation, and Housing

Difficulties with accessing the social supports and services needed for daily living in rural communities was noted during the meeting. The Committee considers the following issues worthy of further attention and discussion:

- There is inadequate access to home and community-based services (HCBS) in rural areas due to workforce and infrastructure challenges. HCBS are key in providing specialized services for individuals living with disabilities and as a source of respite support for caregivers.
- Medicaid is a significant source of funding for HCBS in nearly all states through the use of waivers.[43] Due to variability across states regarding who is eligible and which services are covered, relying on Medicaid for HCBS is not sufficient to provide necessary stability in the HCBS infrastructure.
- The use of Medicaid waivers to fund HCBS creates a level of uncertainty in the ability to provide consistent access to services. Once approved, waivers become a stable source of support, but they must be renewed every five years.[44]
- The inflexibility of payment policies makes it difficult to address the variability of individual service needs. State Medicaid programs that provide payment for transportation services and housing are one example of needed flexibility.
- Access to transportation is a barrier to independence and access to care.
- Inadequate affordable and adaptive housing in rural areas in a concern for individuals with disabilities, their families and/or caregivers, and providers.

Several speakers discussed the long waitlists for HCBS and variability of LTSS by state. The Kaiser Family Foundation reports that in 2021, there were 656,000 people on waitlists that waited an average of 45 months to receive HCBS waiver services.[45] People with intellectual and developmental disabilities (I/DD) made up 73 percent of the total waiver waiting list population, while seniors and adults with physical disabilities made up 24 percent. The remaining people on HCBS waitlists include medically fragile or technology dependent children, people with traumatic or spinal cord injury, and people with mental illness. [46]

Workforce Challenges

Both workforce challenges and lack of education and training for health care providers treating people with disabilities were noted by the Committee. The Committee considers the following workforce issues worthy of further attention and discussion:

- Shortages of available workers to adequately care for people with disabilities exist, and these shortages are worsening over time.
- Clinicians and other medical providers may not have the type of specific training needed to effectively care for their disabled patients.

A family caregiver who presented to the Committee noted that the US medical system is not well set up to treat people with I/DD. The ideal system for such individuals provides for a care coordinator who takes a "whole person approach" to service delivery, which includes access to resources in the health care, human services, and education system, among others. Additionally, there is an increasing demand for direct care workforce home health and personal care attendants. The services and supports provided by the direct care workforce (PCAs, job coaches, home health aides, and residential workers) are essential in ensuring that people with disabilities can live independently in their homes and communities.[47] The Committee noted that anticipated demographic changes will result in fewer workers in this labor sector in the decades ahead.

CLOSING THOUGHTS

Despite facing various challenges, rural communities are strong, resourceful, innovative, and work to provide their residents with disabilities with the safety and services they deserve to live full lives as independently as possible. In addition, rural providers have strong connections and leverage social capital to meet the needs of their patients and community members. For these providers, leveraging informal communication and handoff systems are integral to effectively managing care.

The delivery of health and human services for people with disabilities in rural areas is complex and entails blending federal, state, local, and private sources of funding. Additionally, the needs and experiences of people with disabilities vary. A "whole person approach" that emphasizes independence and provides resources that allow people with disabilities the opportunity to lead full lives should be a priority for the federal government and service delivery providers.

The September 2023 NACRHHS meeting marked the first time the Committee focused on disability and independence in rural committees and served to introduce its members into the issues surrounding rural disability. By laying out the landscape that people with disabilities and their caretakers must traverse to access services and care, this white paper points out some of the most difficult hurdles rural Americans may encounter. This paper also outlines the concerns that families and providers have related caring for disabled individuals. Instead of issuing recommendations from the Committee, this paper will serve as a starting point for the members to use in identifying potential focus areas for future meetings.

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APPENDICIES

APPENDIX A: Site Visit Summaries

Lincoln Health Community Hospital

The first NACRHHS subcommittee members visited Hugo, Colorado in Colorado's eastern plains to tour Lincoln Memorial Hospital, a Critical Access Hospital (CAH). meeting with staff involved in care coordination for residents in the greater area, including people living with disabilities. Rachel Smith, Chief Nursing Officer, and Carrie Owens, Chief Operations Officer, both with Lincoln Health, led the tour and shared their experiences. Josh Ewing of the Colorado Hospital Association was also onsite to provide policy background and context.

The full Committee staff also met with Andrew Lorensen, the Lincoln County Human Services Director and the county coroner, as well as other county staff members to hear their experiences serving people living with disabilities. NACRHHS members learned that in Lincoln County, human services staff wear many hats and work closely together behind the scenes to coordinate care for residents. County staff gave the example that when there is a loss of power in the community, the local fire department goes door to door to make sure elderly residents and people with disabilities are safe. Likewise, the hospital pays for in-home oxygen when insurance will not cover it.

County staff noted that community-based mental health centers struggle due to inadequate staffing and occasionally must bring in providers from Denver who are often not Medicaid providers. A Lincoln County staff member noted that telehealth has not been a helpful solution in serving individuals with disabilities in their community, given the technology is either difficult to navigate or does not hold the attention of the person in need of services. Access to transportation was also noted as a concern for individuals with certain types of disabilities.

The Committee noted the presence of home-grown health and human services providers who left Hugo for education programs and returned to provide care to the community. The staff demonstrated strong working relationships and connection to the community, resulting in ongoing collaboration and resourcefulness in providing care coordination.

Key takeaways from the Lincoln County Site Visit included:

- Local providers hope for more flexibility in leveraging federal dollars to serve their community.
- Care coordination and home-and community-based community services for adults and children living with disabilities are important lifelines.
- There is a need for improved access to transportation services.
- Educating and supporting parents/families of children diagnosed with a developmental disability remains important.

Starpoint

The second NACRHHS subcommittee visited Starpoint, a local nonprofit Community Center Board providing disabilities services in Fremont County. Members also visited a local supportive housing home owned by Starpoint. Starpoint was founded in 1977 and provides essential services to vulnerable populations, including children, adults and their families with physical and intellectual disabilities. The Committee met with Starpoint staff, including CEO Bryana Marsicano, as well individuals and their family members who utilize Starpoint services. Staff from other local health and services organizations that partner with Starpoint also joined the meeting. These staff members included Melissa Gossett (Child Welfare Supervisor at Lincoln County Human Services) and Kelly Meier **(**Public Health Director, Lincoln County Public Health).

When asked about their biggest obstacles to adequately serving people with disabilities, Starpoint staff and community partners identified the following barriers:

- Inadequate affordable and accessible housing
- Workforce shortages
- Not enough reliable and available childcare
- No public transportation

Starpoint staff and community partners stressed that there is an administrative burden associated with funding. They explained that the administrative complexity that comes with funding from sources including block grants is a serious challenge for understaffed health and human services organizations. The group stressed the need for sustained funding with a lower administrative burden.

Family members also described administrative burdens. The paperwork required to prove that a patient require services is time consuming and restrictive, and access to information is difficult. Families must retell their disability story time and time again to obtain services because there is not a shared database across health and human service providers.

The Subcommittee then visited one of Starpoint's residential homes. Several individuals live in the home as roommates. The focus is on independence. The residents have their own bank accounts, cook and clean, maintain the home, and have jobs whenever possible. Starpoint staff are available 24/7 to provide support.

The residents stressed that Colorado is one of the best states when it comes to supporting people with disabilities. Several family members said they were fortunate to live in Colorado because of the high availability of services. A few family members shared that it is easier to find supportive services in a rural community. They experience less bureaucracy than urban areas, and information about services is easier to share via word of mouth. They also explained that the tight-knit nature of a rural community means their disabled family member is known and seen, which provides them with a higher level of safety than in urban areas.

APPENDIX B: FEDERAL SUPPORT FOR INDIVIDUALS WITH DISABILITIES

This Appendix is provided to offer a bit more information on some of the federal programs that focus on offering care and services to individuals with disabilities, their families, and caregivers. It is a snapshot of a moment in time and readers who are interested should look to the websites of each agency for additional information.

The Administration for Community Living (ACL)

The Administration for Community Living (ACL) funds aging and disability organizations in every community. It is the main HHS operating division responsible for supporting programs for aging people and those with disabilities. [48] ACL advises the HHS Secretary, HHS divisions and offices, and other relevant agencies on aging and disability, establishing national policies and priorities, providing program leadership, technical assistance, and disseminating and influencing aging and disability management best practices. The mission of ACL is to "Maximize the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers". [49]

Within ACL, the Administration on Disabilities (AoD) collaborates with states, communities, and partners in the disability network to equip individuals with disabilities of with opportunities, tools, and supports to lead lives of their choice in their community.

ACL Initiatives

ACL has state and national disability initiatives, which include:

State Level Initiatives:

- 56 State Councils on Developmental Disabilities (DDCs)
- 56 State Independent Living Councils (SILCs)
- 29 Traumatic Brain Injury State Partnerships (TBISPG)
- 68 University Centers for Excellence in Developmental Disabilities (UCEDDs)

Strategic Activities:

- Transforming fragmented approaches into coordinated and effective systems that support individuals with disabilities leading independent, productive, and integrated lives in the community.

National ACL priorities to support people with disabilities:

- Building the direct care workforce
- Strengthening and supporting caregiver infrastructure
- Coordinating access to affordable

Regional and Technical Assistance Resources:

- Self-Advocacy Resource and Technical Assistance Center
- Area Agencies on Aging
- Aging and Disability Resource Centers

- Assistive Technology Program
- Veteran Directed Care Program

Aging and Disability Networks

ACL's aging and disability networks are made up of local, state, and national organizations and committed advocates working to support older adults and people with disabilities. Some organizations focus on a particular type of disability, age group, or type of service, whereas others have a more comprehensive mission. [50] The networks include the following:

- Aging and Disability Resource Centers: Provide information and counseling to help individuals make informed decisions about long-term services and supports and help accessing programs.
- Americans with Disabilities Act National Network: Funds 10 regional centers for providing information, training, and technical assistance to individuals, businesses, and agencies with rights and responsibilities under the Americans with Disabilities Act.
- Area Agencies on Aging (AAAs): AAAs address the needs of older adults at the regional and local level through services and supports (like home-delivered meals and homemaker assistance) to support independent living.
- Assistive Technology: Support making assistive technology devices and services more available and accessible to individuals with disabilities and their families.
- Centers for Independent Living: Provide tools, resources, and supports for integrating people with disabilities fully into their communities to promote equal opportunities, self-determination, and respect.
- Protection and Advocacy Systems: State systems that work to protect individuals with disabilities by empowering them and advocating on their behalf to defend their personal and civil rights.
- Senior Centers and Supportive Services for Older Adults: Provide grants to states and territories that fund multi-purpose senior centers that coordinate services for older adults, such as congregate meals, community education, health screening, exercise and health promotion programs, and transportation.
- State Councils on Developmental Disabilities: Self-governing organizations that identify and address the most pressing needs of people with developmental disabilities in their state or territory through conducting advocacy, facilitating systems change, and capacity building efforts to promote self-determination, integration, and inclusion.
- State Units on Aging - State-level agencies that develop and administer plans to provide assistance to older adults and families. In many states, adults with physical disabilities also qualify for assistance from state units on aging.
- University Centers for Excellence in Developmental Disabilities: Grants affiliated with universities allow these institutions to serve as liaisons between academia and the community for advancing research, information sharing, and community services.

Family Caregiver Support

ACL's National Strategy to Support Family Caregivers includes nearly 500 actions that can be adopted at every level of government and across the public and private sectors to ensure that family caregivers have the resources they need to maintain their own health, well-being, and financial security while providing crucial support for others.[51]

The Rehabilitation Research and Training Center (RRTC) on Disability in Rural Communities

The Rehabilitation Research and Training Center (RRTC) on Disability in Rural Communities generates new research-based knowledge that can be used to improve outcomes for people with disabilities living in rural communities. The RRTC works to improve community living and participation, employment, and health and function.[52]

No Wrong Door (NWD) Systems

A collaboration between ACL, Centers for Medicare & Medicaid Services (CMS), and the Veterans Health Administration, the NWD initiative supports states working to streamline access to LTSS for older adults, people with disabilities, and their families. The NWD System builds upon the Aging and Disability Resource Center (ADRC) program and CMS's Balancing Incentive Program to create NWD requirements that support state efforts to streamline access to LTSS.[53]

ACL Collaborative Research Arm

The Interagency Committee on Disability Research (ICDR)'s mission is to promote coordination and cooperation among federal departments and agencies conducting disability, independent living, and rehabilitation research programs—including those that relate to assistive technology research, and research that incorporates the principles of universal design.[54]

Centers for Medicare & Medicaid Services (CMS)

The CMS Office of Minority Health's Framework for Health Equity aims to address health disparities as a foundational element across all its work.[55] Within the CMS OMH Framework for Advancing Health Care in Rural, Tribal, and Geographically Isolated Communities. [56] Priority #5 of the Framework is "Increase All Forms of Accessibility to Health Care Services and Coverage," which identifies CMS' responsibility to ensure people with disabilities can access all CMS benefits, services, supports, and coverage.

Centers for Disease Control and Prevention (CDC)

The CDC's Disability and Health Promotion Branch currently funds 10 State Disability and Health Programs under the cooperative agreement CDC-RFA-DD21-2103 ("Improving the Health of People with Mobility Limitations and Intellectual/Developmental Disabilities through State-based Public Health Programs").[57] Several state programs support activities in rural areas, including:

- The Georgia Disability and Health Program, which created responsive practice provider trainings that have reached providers in 9 rural counties.

- The New York Disability and Health Program, which currently implementing *Living Well in the Community*, an evidence-based program for people with disabilities in three rural counties in upstate New York.
- The Oregon Disability and Health Project, which addresses access gaps in rural Oregon by focusing on rural program implementation across programs. Provider training outreach, the ORDH Linkage project, the community directory, and the ORDH Policy, Systems, and Environmental approaches are key parts of the project.

National Disability Council (NDC)

The National Council on Disability (NCD) is an independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, and procedures that affect people with disabilities.[58] The NDC has Five Core Components:

1. Special Medically Underserved Population (SMUP) Designation
2. Health Disparities Population Designation
3. Comprehensive Disability Clinical-Care Curricula
4. Accessible Medical Diagnostic Equipment
5. Improved Data Capturing

Indian Health Service (IHS)

According to 2021 ACS data, American Indians and Alaska Natives (AI/AN) have higher rates of disability compared to the general population (18 percent vs. 13 percent).[59] Approximately 36.5 percent of AI/AN people live in rural areas.[60] The combination of highly remote tribal communities, long distances to travel for care, persistent health disparities, lower incomes, and chronic underfunding of the Indian Health Service (IHS) results in a high need for LTSS among AI/AN people with disabilities.[61, 62] IHS supports AI/AN people with disabilities in the form of primary care and health disparity reduction programs, including the Improving Patient Care program,[63] and targeted condition resource and information provision, including the IHS Division of Diabetes Treatment and Prevention.[64] The IHS also has an Elder Care Initiative, which focuses on increasing access to LTSS for AI/AN elders through partnerships with Tribes and Urban Indian Organizations and collaborating across HHS with CDC, CMS, ACL, and the Veterans Administration (VA).[65]

Health Resources & Services Administration (HRSA): Maternal and Child Health Bureau (MCHB)

The Maternal and Child Health Bureau (MCHB) within HRSA supports Children and Youth with Special Health Care Needs (CYSHCN). HRSA MCHB defines CYSHCN as children "who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."[66] HRSA MCHB conducts the National Survey of Children's Health (NSCH) to provide critical data on CYSHCN.

The CYSHCN population is also supported through a wide variety of investments to improve systems of services, genetic newborn screening services, support for specific conditions including Autism Spectrum Disorder (ASD) and related Developmental Disabilities (DD), and technical assistance to help administer services.[67]

In 2022, HRSA MCHB and the American Academy of Pediatrics launched the Blueprint for Change, which is a national framework to advance a system of services for CYSHCN. [68] The Blueprint is described in a series of articles that comprise a supplement in *Pediatrics*.[69] Together, the Blueprint articles describe how sizable and diverse the CYSHCN population is, the role of public health in building a well-functioning system of services, and the critical areas of equity, quality of life, access to services, and financing of CYSHCN services. The Blueprint also offers a rationale, guiding assumptions, principles, and strategies to achieve their vision for a more supportive CYSHCN system.

Federal Agencies Outside of HHS Impacting Disability Services

Department of Housing and Urban Development (HUD)

Through the Section 811 Supportive Housing for Persons with Disabilities program,[70] HUD provides funding to develop and subsidize rental housing with supportive services for very low- and extremely low-income adults with disabilities.

Department of Veterans Affairs (VA)

The Department of Veterans Affairs (VA) provides medical care and compensation to veterans in recognition of the effects of disabilities, diseases, or injuries incurred or aggravated during active military service.[71] The VA also works with HUD on supportive housing for eligible veterans.

Department of Transportation (DOT)

The US Department of Transportation (DOT)'s Coordinating Council on Access and Mobility is a federal interagency council that works to coordinate funding and provide expertise on human services transportation for three targeted populations: people with disabilities, older adults, and individuals of low income. The section code of the grant program from federal transit law (49 U.S. Code, Chapter 53) guides the Council's work, including:

- Section 5307: Urbanized Area Formula Grants - 5307 | FTA (dot.gov)
- Section 5310: Enhanced Mobility of Seniors & Individuals with Disabilities - Section 5310 | FTA (dot.gov)
- Section 5311: Formula Grants for Rural Areas - 5311 | FTA (dot.gov)
- "Other" is a placeholder for all other FTA programs (e.g., TTP: Tribal Transit Competitive Program - 5311 (c)(1)(A) | FTA (dot.gov); ICAM: Innovative Coordinated Access and Mobility Grants | FTA (dot.gov), etc.)

United States Department of Agriculture (USDA)

The U.S. Department of Agriculture's (USDA's) Rural Development mission area offers more than 70 programs and initiatives that support rural families and farmers impacted by domestic and global economic issues.[72] USDA also works to expand broadband service in rural America, which has implications for telehealth access for people with disabilities.

APPENDIX C: SELECTED FEDERAL ACTION & DISABILITY LEGISLATION

National Academy for State Health Policy: States Will Continue to Focus on Older Adults and People with Disabilities in 2024 (from January 12, 2024)

Throughout 2024, states will continue to address disability challenges with a special emphasis on older adults and people with disability. To do so, the National Academy for State Health Policy recommends strengthening policies in four key areas:

- Supporting the workforce of professional and family caregivers: Many states are planning to sustain payment increases to direct care workers (e.g., personal care and home care aids, certified nursing assistants) that went into effect during the pandemic. In addition, states are working to develop career pathways, and additional training opportunities for direct care workers.
- Health Disparities: States are integrating the principles of equity and inclusivity into their aging initiatives in response to CMS's "Framework for Health Equity."
- Home and Community-Based Services: In 2024, people with Medicare and Medicaid coverage will continue to enroll in integrated managed care special needs plans or dual eligible special needs plans (D-SNPs). Many dual eligibles are low-income older adults or people with disabilities.
- Nursing Home Quality and Accountability: States are making an effort to improve on a variety of quality challenges, including transparency, interagency collaboration on long-term integrity and oversight, minimum staffing requirements, and web-based complaint platforms.

Census Bureau plan would change data on people with disabilities: NPR (from December 18, 2023)

- Changes to the Census Bureau's procedures for representing people with disabilities in the U.S. is receiving push back, as many believe that these changes will shrink the estimated share of the U.S. population with any disability by about 40%.
- The Agency has shifted from "yes-or-no" questions to asking a person to rate their level of difficulty doing certain functional activities (i.e., walking, concentrating, seeing, etc.,).
- New estimates for people living with disabilities will only be based on survey participants who report "A lot of difficulty" or "Cannot do it all." Anyone reporting "Some difficulty" would be left out of calculations.
- Supporters of the change argue that shifting away from "yes-or-no" questions will limit the how nuanced data can be and will not allow for the examination of outcomes for people experiencing different levels of functioning.
- Advocates also worry that these changes may make it harder to ensure that disabled people have access to housing and health care, enforce legal protection against discrimination, and prepare communities for disasters and emergencies.

Updated Resource to Support the Inclusion of Children with Disabilities in Early Childhood Programs | U.S. Department of Education (from November 28, 2023)

- The Department of Health and Human Services, in conjunction with the Department of Education, released a joint policy statement in November 2023 reaffirming their commitment to the inclusion of children with disabilities in early childhood programs.
- The updated policy statement for states, local educational agencies (LEAs), schools, early intervention providers, and early childhood programs advance the department's positions by:
    - Continuing to increase public awareness and understanding of recent science advancements that support the inclusion of children with disabilities in early childhood programs.
    - Reinforcing foundational legal statutes that support inclusion in early childhood programs.
    - Reiterating and updating recommendations to state and local agencies that implement Individuals with Disabilities Education Act (IDEA) programs into Head Start, childcare, home visiting, preschools, and public schools. Updates will be aimed at increasing inclusive early learning opportunities for all children.

HHS Invests $8 Million to Improve Health Care Access by Training New Physicians to Care for Individuals with Disabilities and Individuals with Limited English Proficiency | HHS.gov (September 15, 2023)

- In September 2023, the Department of Health and Human Services invested $8 million to train primary care medical students, physician assistant students, and medical residents in providing culturally and linguistically appropriate care for individuals with limited English proficiency and individuals with physical or intellectual and developmental disabilities.
- A 2022 Survey showed that out of more than 700 physicians, only 41 percent of respondents were "very confident" about their ability to provide the same quality of care to people with disabilities as those without.
- Through clinical and classroom training and rotation, this investment will allow for building a culturally competent workforce to better address community needs.

HHS Issues New Proposed Rule to Strengthen Prohibitions Against Discrimination on the Basis of a Disability in Health Care and Human Services Programs (September 7, 2023)

- The Nondiscrimination on the Basis of Disability Program or Activities Receiving Federal Financial Assistance rule, originally proposed in September 2023, revises provisions created by Section 504 of the Rehabilitation Act of 1973.
- Due to the inaccessibility of healthcare for persons with disability, this rule will help ensure that these individuals are not subjected to discrimination in any program or activity receiving funding from HHS on the sole basis of their disability.

- The rule aims to clarify obligations in several crucial areas not explicitly addressed in current regulations, including ensuring that medical decisions are not based on biases or stereotypes, establishing enforceable standards for accessible medical equipment, and providing services in the most integrated setting appropriate for the needs of individuals with disabilities.

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