Health Resources and Services Administration
Office of Rural Health Policy

National Advisory Committee on Rural Health and Human Services

Fall Meeting
Colorado Springs, Colorado
September 6-8

Meeting Summary

The 93rd meeting of the National Advisory Committee on Rural Health and Human Services (NACRHHS) was held September 6-8 in Colorado Springs, Colorado. The meeting topic was Disability and Independence in Rural Communities.

The committee members in attendance: Jeff Colyer, Committee Chair; April Anzaldua; Isabel Garcia-Vargas; Craig Glover, MBA, MA, FACHE; Clifford Hunter; George Mark Holmes, PhD; Cara V. James, PhD; Michelle A. Mills; Brian Myers; Mathew Probst, PA-C; Patricia Schou.

Present from the Department of Health and Human Services: Tom Morris, Executive Secretary; Office of Rural Health Policy (ORHP); Sahira Rafiullah, Senior Advisor, ORHP; Sarah Heppner, Associate Director, ORHP; Meredith Anderson, Public Health Analyst, ORHP; Lee Steuer, Public Affairs Leader, ORHP; Jocelyn Richgels, Director National Policy Programs, Rural Policy Research Institute (RUPRI).

Additional attendees: Jennifer Johnson, Administration on Disabilities (AoD)/Administration for Community Living (ACL); Ben Smith, Indian Health Services (IHS); Darcy Graves, Special Projects Office of Minority Health (OMH); Lisa Zingman, Administration for Children and Families (ACF); Kellie Kubena, United States Department of Agriculture (USDA); Scott Miller, Centers for Disease Control (CDC), Percy DeVine, Administration for Community Living (ACL); Humberto Carvalho, Substance Abuse and Mental Health Services (SAMHSA).

Wednesday September 6, 2023

Governor Jeff Colyer, Chair of the Committee, convened the meeting.

WELCOME AND INTRODUCTIONS

Jeff Colyer, MD
Committee Chair

Jeff Colyer welcomed the committee and stated that the topic of the meeting is Disability and Independence in Rural Communities. He stated that the topic is near and dear to his heart and is an important topic for the committee to examine.

WELCOME TO COLORADO

Michelle Mills
CEO, Colorado Rural Health Center

Michelle Mills welcomed the committee to Colorado. She shared that she is the CEO of the Colorado Rural Health Center which is also the State Office of Rural Health and the Rural Health Association. Colorado Rural Health Center is a nonprofit organization, so it is not funded by the state. There are sixty-four counties in Colorado with forty-seven being rural or frontier areas. She shared that the subcommittee members would visit Hugo in Lincoln County which is a frontier and Canon City in Freemont County which is rural. Twelve percent of the population in Colorado is rural living within 77% of the land mass in the state. There are several counties with no hospitals and two counties with no hospitals or clinics. The distance to a hospital or clinic from those counties is about 5 hours. The incomes are lower in rural areas, so it is difficult to recruit and retain providers. For example, in Hugo, a nurse left the hospital to become a traveling nurse during the COVID-19 pandemic because she would make a significantly larger salary. She planned to come back to Hugo because it is her hometown and where she wants to live.

Last year, some hospitals and clinics gave bonuses to employees so they would not relocate to urban areas, but it is not sustainable to continue giving bonuses. In rural Colorado, there are thirty-two critical access hospitals (CAHs), eleven rural hospitals, fifty-six rural health clinics (RHCs), and fifty rural clinics that are not designated as federally certified rural health clinics. Sixteen of the rural hospitals are operating at a loss.

The western slope of Colorado is the mountainous region and eastern slope is the plains. The western slope has tourism and is the wealthier region, so the cost of housing is higher. In the eastern slope, Bent and Crowley Counties have the highest percentages of people facing food insecurity, with the state rate of food insecurity at 10%. Within the rural regions, Costilla County has the highest Medicaid and Medicare caseload of 94% and Eagle County has the lowest rate at 27%. The leading causes of death in Colorado include cancer, heart disease, accidents, and chronic lower respiratory disease. There is a shortage of dental providers, psychologists, and social workers in rural Colorado. Twenty-four rural counties do not have an addiction counselor.

The six counties with the lowest rate of broadband coverage are in rural or frontier regions with less than a 55% cover rate in Ouray, Lincoln, Washington, Park, Jackson, and Kiowa. The six counties with broadband coverage that is greater than 94% are Adams, Douglas, Jefferson, Arapahoe, Denver, and Bloomfield. The county with the lowest broadband coverage is Ouray at 38.3% and the highest broadband coverage is 98.5% in Broomfield County.

Colorado became a state in 1876. John Fremont was the first person to explore and map the Rocky Mountains and was the first nominee for the Republican Party. Scenic areas in the state include Royal Gorge, Garden of the Gods, Cave of the Winds, Castlewood Canyon State Park, Sand Dunes National Park and Reserve, and Mesa Verde National Park. Interesting facts about Colorado are that the US Olympic Training Center is in Colorado Springs and the Nuclear Command Center in Cheyenne Mountain. There are two federally recognized tribes in Colorado which are the Southern UTE Tribe and the UTE Mountain Tribe.

NATIONAL DISABILITY LANDSCAPE

Meg Ann Traci
Research Associate Professor, Research and Training Center on Disability in Rural Communities

Meg Ann Traci shared that nationally 17% of individuals with disabilities live in rural communities representing 7.4 million Americans. In rural areas, 23% of individuals with disabilities are living in poverty, compared to 14.5% of individuals without disabilities. Half a million individuals with disabilities in rural communities do not have insurance.

The majority of American Indians and Alaskan Natives (AI/Ans) with disabilities reside in urban areas. The remaining rural population represents around one million people with 17% with disabilities. American Indians and Alaskan Natives experience higher rates of disabilities than causations.

Many individuals with disabilities are institutionalized and/or living in congregate care settings and are disproportionately represented in congregate care settings compared to non-disabled people. It is important to remember the impact of infectious disease within congregate care settings on those who are the most vulnerable.

It is necessary to view disability within a social framework instead of a medical model framework and this expands the number of interventions for those with disabilities. Disability is not about a health condition or physical differences, rather it is about how a person interacts with their environment. The United Nations Convention on the Rights of Persons with Disabilities International Agreement states that persons with disabilities have equal human and civil rights and share important aspects of identity, culture, and pride and have aspirational goals for themselves and their communities. Healthy People 2030, the nation's 10-year plan for addressing the most critical health priorities, states that public health priorities for individuals with disabilities include deinstitutionalization, preventing secondary health conditions, increasing access to health care and social determinants of health.

Individuals with disabilities can thrive in rural communities even though these areas are underserved and under resourced. Though there are less resources, people in rural communities find creative ways to fill the needs of their residents but there are many challenges. Factors like race, education and class can intensify disparities for individuals with disabilities who live in rural communities. The counties that are the most rural have greater disparities for people with disabilities. Community norms and values shape perceived need for preventative and needed health care.

The ways to support rural community living for individuals with disabilities include the availability, affordability and appropriateness of home and community-based services (HCBS), housing, healthcare, and transportation. To have success in rural communities, there needs to be disability leadership, person-centered service delivery, knowledgeable providers, and data-driven continuous improvement efforts. There is limited data and varied definitions across data sets for both rural and for disability variables. Rural data collection is difficult because of the smaller population and the need to preserve anonymity but also collect useful data. If the data includes a statement about a 12-year-old boy with spina bifida, there is the likelihood that people in that community will know his identity. Stories and personal testimony are essential to complement quantitative data services.

Meg Ann Traci thanked the committee for focusing the meeting on disability. It is vital to put accessibility and inclusion of individuals with disabilities at the forefront to advance health equity.

Amged Soliman
Senior Attorney Advisor, National Council on Disability

Amged Soliman stated that he was pleased to have the opportunity to speak to the committee. The National Council on Disability (NCD) has been working on the Framework to End Health Disparities for People with Disabilities. He stated that he would specifically discuss the considerations for rural communities. Other topics discussed included HCBS and emergency preparedness. The NCD's framework addresses decades-long health disparities, addresses ableism, physical, and other barriers.

NCD's five core components are:

- Special Medically Underserved Population (SMUP) Designation
- Health Disparities Population Designation
- Comprehensive Disability Clinic-Care Curricula
- Accessible Medical Diagnostic Equipment
- Improving Data Collection

Core Component No. 1 – Special Medically Underserved Population (MUP) Designation will entail congress to direct the Health Resources and Services Administration (HRSA) to designate all individuals with disabilities as a Medically Underserved Population under the Public Health Service Act. Typically, MUP designations require population groupings based on geography, however this is not applicable to individuals with disabilities. Congress must revise the Public Health Service Act to designate individuals with disabilities as a special medically underserved population. Some benefits of the designation are federal funding for federally qualified health centers (FQHCs) and other health centers, loan repayment for medical professionals who care for individuals with disabilities, higher Medicaid reimbursement rates, and federal research preference and funding.

Core Component No. 2 – Health Disparities Population (HDP) Designation under Minority Health and Health Disparities Research and Education Act of 2000 can be done administratively. HDP exists if there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival rates in the population compared to the health status of the general population.

Core Component No. 3 – Comprehensive Disability Clinical Care Curricula refers to medical professionals being trained to treat individuals with disabilities. Sec. 5307 of the Patient Protection and Affordable Care Act is applicable to the US Undergraduate medical, nursing, healthcare professional, and allied health programs, graduate residency, and fellowship programs, and international medical schools. Grants can be offered to encourage entities that train medical providers to treat individuals with disabilities. There are medical schools that have a curriculum to teach their students to treat individuals with disabilities but there is not a national standard.

Core Component No. 4 – Accessible Medical Diagnostic Equipment (AMDE) refers to the adoption of US Access Board's 2017 Voluntary Standards to be considered in the regulation of the Department of Justice Americans with Disabilities Act and HHS Office of Civil Rights Section 504 of the Rehabilitation Act of 1973.

Core Component No. 5 – Improved Data Collection through access to data through the public health surveillance systems and electronic health records (EHR), and a recommendation that the National Academy of Sciences Comprehensive Study of HHS' Data Collection Systems and Practices be pursued.

Two congressional bills being considered are the Healthcare Extension and Accessibility for Developmentally Disabled and Underserved Population Act ("HEADS UP Act") and the Health Equity for People with Disabilities Act.

Oral health professionals were not typically trained to treat individuals with disabilities, so NCD made a recommendation to the American Dental Association (ADA) that they change the professional code to add that a dentist could not turn away a patient based on their disability and if a dentist does not have the training to serve the patient, they make a referral to a provider that is qualified. The ADA changed the professional code, and several states adopted the code as a professional responsibility. The Commission on Dental Accreditation (CODA) sets standards for dental schools, and they require students to be trained to treat individuals with disabilities.

Q&A

Mark Holmes asked if there is information about what is causing higher rates of disability in rural people. He questioned if it could be occupational, environmental, or health care access, or what other factors.

Meg Ann Traci responded that the high percent of older populations in rural America is one cause of a higher rate of disabilities. There needs to be consideration of how to support older adults so that they can age in place. Other issues in rural America include health problems related to extraction industries such as in Colstrip, Montana. People in rural areas also have hard labor jobs which can contribute to disabilities.

Pat Schou asked about the use of telemedicine in rural areas to assist individuals with disabilities who have issues with transportation.

Meg Ann Traci responded that there are bandwidth issues in rural areas that interfere with the ability to use telemedicine, and services such as video for ASL interpreters. Individuals with disabilities need ongoing support sometimes to manage secondary conditions and could benefit from telemedicine for continuum of care but they also require direct care and observation for some conditions.

Matthew Probst said remote technology cannot take the place of in-person care but can supplement patient care.

In New Mexico, the Aging and Long-Term Service Division aims to keep the ancestral roots and care for elderly and disabled people at home. Las Vegas, New Mexico has the state psychiatric hospital where people who are discharged are staying in the community and live in boarding homes so there is a high population of individuals with disabilities. There is no training for physicians and specialists, or other health care professionals to care for individuals with disabilities. He asked if the academic standard for credentialing is for nurse practitioner programs or nursing programs.

Amged Soliman responded that the recommendations are for all allied health care programs. When CODA required training for dentists it included all levels of oral health care training. The recommendation is that this should be the same for all allied health medical professionals.

FEDERAL EFFORTS IN RURAL DISABILITY

Jennifer Johnson
Deputy Commissioner, Administration on Disabilities, Administration for Community Living

Jennifer Johnson thanked the committee for inviting her to the meeting and focusing on disabilities and shared that she was going to do an overview of disability in the U.S. and discuss programs within the Administration for Community Living. ACL was created with the idea that older adults and individuals with disabilities should be able to live where they choose, with the people they choose, and with the ability to participate fully in their communities. There is a nationwide aging and disability network of programs across the United States that are funded by ACL. The ACL's mission is to maximize the independence well-being and health of older adults, people with disabilities, and their families and caregivers.

The leadership role of ACL is to serve as an advisor to the HHS Secretary, other HHS divisions and agencies on aging and disability. Twenty seven percent of adults in the United States have some type of disability. In the past, individuals with disabilities did not have opportunities, particularly people with intellectual and developmental disabilities. They lived in harsh conditions where they experienced abuse and neglect and were institutionalized with very few opportunities. Now, most individuals with disabilities are living full lives in the community.

In 1963, President Kennedy called for and signed a law that provided for the creation of a community services infrastructure, including what later became the University Centers for Excellence in Developmental Disabilities. In the 1990s, the Americans with Disabilities Act

(ADA) was enacted which protects the rights of individuals with disabilities. Children with disabilities are now attending community schools and many grow up to have a career and work in the community. There are still barriers that people face including ableism, when low expectations are placed on them, and they are viewed as having less value and are not capable of doing things. The stigma that society places on them is the barrier. Race and ethnicity can impact people being over identified as having a disability because of the intersection between ableism and discrimination.

Individuals with disabilities often have complex underlying health conditions and disadvantages related to social determinants of health. Inadequate training of health care professionals and ableism in the medical community hinders adequate health care for individuals with disabilities. There is a lack of medical diagnostic equipment, including weight scales and exam tables. Health research is minimal and often medicine is not evidence-based. Individuals with disabilities are excluded from randomized clinical trials conducted to test treatment effectiveness and generate scientific evidence. Health surveillance data is minimal concerning individuals with disabilities. Compared with adults with disabilities living in urban areas, those in rural areas may face additional barriers including lower socioeconomic position, transportation problems, access to education and vocational rehabilitation services, access to health care and opportunities to maintain and improve their health, quality of life, and community participation.

Individuals with disabilities report more transportation barriers than nondisabled people. Many individuals with disabilities live in poverty, making transportation costs a barrier. Transportation barriers can cause individuals with disabilities to forego preventive care and use the emergency department more frequently, resulting in both lack of medical care continuity and poorer health. The Administration on Disabilities state programs include fifty-six state Councils on Developmental Disabilities (DDCs), 56 State Independent Living Councils (SILCs), and twenty-nine traumatic Brain Injury State Partnerships (TBISPG). AoD program strategic activities include transforming fragmented approaches into coordinated and effective systems that support individuals with disabilities leading independent, productive, and integrated lives in the community.

The AoD coordinates disability programs authorized under:

- Developmental Disabilities Assistance and Bill of Rights Act (DD Act)
- Title VII of Rehabilitation Act, as amended by the Workforce Innovation and Opportunity Act (Rehab Act)
- Help America Vote Act (HAVA) Disability Provisions
- Assistive Technology Act (AT Act)
- Traumatic Brain Injury Act (TBI Act)
- Public Health Service Act (PHSA)

AoD supports the President’s Committee for People with Intellectual Disabilities (PCPID)

The Native American Disability Law Center (NADLC) is a successful program that is:

- Protecting the rights of children with disabilities who are in the foster care system and advocating for increased accessibility of tribal services, programs & buildings.
- Monitoring of group homes & other congregate care locations for adults.

- Conducting outreach and workshops to expand awareness of transition services and other services that support employment.
- Advocating for more accessible, community-based housing by tribal housing authorities.
- Advocating for comprehensive policies & procedures to ensure that Navajo Division of Social Services fully investigates allegations of abuse & neglect.
- Assisting students with disabilities in obtaining appropriate special education services and addressing inappropriate exclusionary discipline.

Centers for Independent Living (CILS) facilitate independent living by aiding people who are moving from institutions to the community, support to avoid entering institutional settings, help for young people transitioning to community living as an adult, information and referrals to services, training on independent living skills, peer counseling, and systems advocacy.

Karyl Rattay
Director, Division of Human Development and Disability, National Center on Birth Defects and Developmental Disabilities, CDC

Karyl Rattay thanked the committee for the opportunity to speak. The National Center on Birth Defects and Developmental Disabilities (NCBDD) was established by the Children's Health Act of 2000. NCBDD's mission is to promote the health of babies, children, and adults to enhance the potential for full, productive living. Within NCBDD there are three divisions with focuses on birth defects, blood disorders, and children and adults with disabilities. Ms. Rattay stated that she is the Director of The Division of Human Development and Disability which focuses on children and adults with disabilities.

The Division of Human Development and Disabilities (DHDD) vision is better health and brighter futures for children and adults with and at risk for disabilities. The DHDD Life Span Approach identifies and supports early childhood and school-aged children with disabilities, supports young adults with successful transitions after high school, and supports optimal health care for adults with disabilities. The Disability and Health Promotion Branch supports surveillance, research, and health promotion data related to autism spectrum disorder (ASD), Cerebral Palsy, ADHD, Tourette Syndrome, and Fragile X Syndrome.

Individuals with disabilities are a diverse population. There are many types of disabilities, such as those that affect a person's: vision, movement, thinking, learning, communicating, hearing, mental health, and social relationships. A person with a disability should not have poorer health outcomes, but they often do. There are some health conditions that do lead to disabilities.

The Disability and Health Data System (DHDS) is an interactive tool on the CDC website with access data on disabilities that can be used to help shape more targeted, effective public health prevention and treatment programs for the Person with Disabilities (PWD) Programs. Through the DHDS, states can easily identify disability status by approximately thirty measures of health that include smoking, physical activity, obesity, hypertension, heart disease, and diabetes, and use this information to inform policies and practices that address health disparities and support individuals with disabilities. This work will have a sustainable impact on national, state, and local response capacity to detect and monitor the health and well-being of individuals with disabilities during current and future public health emergencies.

The COVID-19 Pandemic emphasized inequities facing individuals with disabilities. Social inequities and other characteristics increase the risk of COVID-19 and severe outcomes for individuals with disabilities. The causes for higher risk of disease for individuals with disabilities are chronic health conditions, living in congregate settings, increased barriers to health care, limited mobility, the requirement for direct support, difficulty practicing preventative measures, and challenges communicating symptoms of illness.

Over three million individuals with disabilities live in mostly rural counties where disability prevalence is highest. One in four people with disabilities living in rural areas experience poverty compared to one in five in the most urban places. In rural communities, individuals with disabilities report lower rates of private insurance and higher rates of public insurance or no insurance coverage. Prevalence of any disability, functional disability type, and multiple disabilities were highest in rural counties. Adults living in rural counties were 9% more likely to report having a disability, 24% more likely to report having three or more disabilities and more likely to report specific disability types than the adults living in large metropolitan centers.

The CDC will take steps to determine how to better support individuals with disabilities in rural areas. These steps are to address gaps in disability and rural health data, address access issues, examine the role of telehealth, and identify promising policy, systems, and environmental interventions to improve disability inequities in rural areas.

Darci Graves
Technical Advisor, Special Projects, Office of Minority Health, Centers for Medicare and Medicaid Services

Darci Graves shared that she would contextualize some of the work being done within the framework of health equity. Ms. Graves said she leads rural efforts in the Office of Minority Health and co-chairs the CMS Rural Health Council, which is an internal body that brings together individuals across the agency to improve communication, coordination, and collaboration within CMS and across CMS programs, policies, and operations, to improve healthcare in rural and frontier communities as well as tribal nations, island communities and United States territories.

The first pillar of the CMS Strategic Plan is to advance health equity by addressing the health disparities that underlie the health system. CMS is working to identify and remedy systemic barriers to equity so everyone served can attain their optimal health, regardless of race, ethnicity, disability, sexual orientation, gender identity, and socioeconomic status.

In collaboration and consultation with the tribal, national, state, and local partners, CMS is developing and implementing innovative payment and policy solutions designed to meet the needs of rural, tribal, and geographically isolated communities. CMS is also trying to lead the way to help transform and improve health care systems in these communities. Integrating health equity principles, including those inclusive and intersectional lenses into all agency centers programs, policies, and activities. In November of 2022, CMS published the CMS framework for

advancing health care in rural, tribal, and geographically isolated communities. The framework was updated to reflect changes in the health care landscape since the release of the original CMS Rural Health Strategy in 2018. The framework supports CMS's overall efforts to advance health equity, expand access to quality, affordable health coverage, and improve health outcomes.
It is important to think about all aspects of disability and how they interact or do not interact within the healthcare system. The accessibility of equipment is necessary, for example, whether there is equipment available for a woman in a wheelchair to get a mammogram or the availability of sufficient broadband for video, and remote interpreters to ensure that a deaf patient can understand their diagnosis.

John Hannigan
Regional Administrator – Denver (Region 8), Centers for Medicare and Medicaid Services

John Hannigan stated that CMS touches about 170 million people with a 60-billion-dollar program that is mostly funding health care. The Medicare program interfaces with disability eligibility at the age of sixty-five, but if a person has been receiving social security disability benefits for 24 months, then they also get the Medicare benefit. About 14% of Medicare enrollees are under the age of sixty-five. Building a better and more robust healthcare system requires having medical professionals in the area and there is a shortage in rural areas. The services that disabled individuals receive in their community depends on how strong the health care system is in their geographical area. Medicare advantage plans offer the standard benefits as well as nonmedical covered safety devices.

There are regions with only one insurance carrier, and they are not servicing the rural areas as well as other areas. The CMS Framework for Advancing Health Care in Rural, Tribal, and Geographically Isolated Communities addresses this issue. The advancement of telehealth expands the methodology and places where services can be provided.

The Medicaid program funding is federal funding matched with state funding. States have individual programs and can add benefits depending on the state plan and waivers. This allows more flexibility and additional options to meet medical needs in homes. There are Medicaid benefits for services such as physical and occupational therapy that target specific populations, such as rural communities. There is the Section 1915 Waiver for self-directed personal assistance services (PAS) and home and community-based services (HCBS).
Eighteen percent of overall beneficiaries are dual eligible for Medicare and Medicaid. Dual Eligible Special Needs Plans (D-SNPs) enroll individuals who are entitled to both Medicare and medical assistance from a state plan under Medicaid. There are also Institutional Special Needs Plans (I-SNPs) and Chronic Care Special Needs Plans (C-SNPs). In rural areas, there are not contractors who are opening these programs, so they are not available.

There are Center for Medicare and Medicaid Innovation (CMMI) Models that can support individuals with disabilities. The Guiding and Improved Dementia Experience (GUIDE) Model provides payment and incentivization for Part B providers to care for a special population. There is a move for valued-based care and other innovation-based models to create a team concept or medical home concept to integrate behavioral health services with primary care.

STATE PROGRAMS AND POLICIES ON DISABILITY IN RURAL

Bonnie Silva
Director, Office of Community Living, Colorado Department of Health Care Policy and Financing

Bonnie Silva thanked the committee for the opportunity to speak and shared that Colorado is considered a national leader with the work they are doing with Medicaid. The Colorado Department of Healthcare Policy and Financing (HCPF) mission is to improve health care equity, access and outcomes for the people served while saving Coloradans money on health care and driving value for Colorado.

As of July 2023, HCPF serves 1.7 million people equaling one in four Coloradans with a budget of 15.5 billion dollars. Out of the 1.7 million people, 4% of members receive long-term services and supports (LTSS). If a person develops a disability and requires long-term services, the services will be available. Forty percent of Colorado's children and 40% of births receive services. Long-term services and supports include Home and Community-Based Care Services (HCBS), Program of All-Inclusive Care for the Elderly (PACE), and institutional settings including nursing homes, intermediate care facilities, or the Hospital Back-Up (HBU) programs. There are also options for people to receive long-term home health services. Eighty-two thousand Coloradans are served through these service delivery options.

Medicaid is the primary payer for all LTSS, and each state operates its own Medicaid program. Medicare only covers short-term LTSS needs so states are required to cover state plan services, such as nursing facility care and home health, for all that are eligible. States have flexibility to target populations or change eligibility requirements through Home and Community-Based Services (HCBS) waivers. Coloradans have options of where they receive care and 96% of people choose to receive their care in community-based settings. HCBS are offered across the state with 73% of Colorado's sixty-four counties being rural and 77% of Colorado's land mass is rural.

Current Challenges in Rural Colorado Include:

- Lack of providers, including workforce to meet member needs.
    - Lack of infrastructure and access more broadly (housing, transportation) directly impacts the provider network.
    - Low population density limits provider growth and ability to find efficiencies; thus, more costly.
- Unique Challenges of members related to social determinants of health that make meeting their needs more complex.
- Limited flexibility around licensure, service structure, to accommodate rural and frontier needs.

Recommendations Include:

- Maximize opportunities to leverage technology and increase people's access to providers and services that are not available in their community.
- Allow for flexibility in service design and provision, reimbursement, and licensure to accommodate the needs of rural and frontier providers.
- Continue opportunities such as ARPA and HCBS to innovate and create systemic change, particularly by investing in the workforce and new models of care.

Jayla Warren Sanchez
Director, Area Agency on Aging, Denver Regional Council of Governments

Jayla Warren Sanchez thanked the committee for inviting her to speak and stated that the Denver region has the largest rural population in the state, and rural counties are challenging to serve. Area Agencies on Aging (AAA) assist older adults and people with disabilities to live as independently as possible with dignity by providing services, funding services, planning for current and future needs, and advocating for older adults and their caregivers. AAAs get authority and funding from the Administration on Aging through the Older Americans Act, State Unit on Aging through the Older Coloradoans Act, and State Funds for Senior Services.

Colorado has 16 Agencies on Aging. There are 516,000 older adults in the state and about half live in the DRCOG region. AAA prioritizes services for individuals who are ages seventy-five and older, have lower incomes, are more socially isolated, and are part of the low-income minority population. AAA's advocate for adults who often have disabilities, mental health issues, behavioral issues, and live in poverty.

AAA are part of a national network of service providers and were vital during the COVID-19 pandemic because they have partnerships with community service providers. Some of the partnerships are with churches and other programs, but there are also nonconventional partnerships to meet people's needs that include veterinarians and pest control. During the COVID-19 pandemic, the AAA was delivering food to people, taking people to cancer treatments, dialysis treatments, and working to meet as many needs as possible for older adults and individuals with disabilities.

AAA provides and contracts for essential services that include:

- Transportation – medical, nutrition, personal
- Nutrition – home delivered meals, congregate meals, monthly food boxes, medical meals, blizzard boxes, restaurant vouchers, education, counseling.
- In-home services – dressing, bathing, shopping, meal preparation
- Chore – Cleaning, laundry, yard work, snow shoveling, hoarding service.
- Caregiver Support – education, training, counseling, support, respite, and grandparents
- Material Aid – hearing aids, eyeglasses, home modification, ramps, grab bars, widen hallways.
- Legal assistance – benefits, general, housing, consumer
- Health promotion – HIV/Aids, fall prevention, heart health, diabetes management.
- Visually impaired – Education, training, special equipment

Challenges for AAAs are due to the growth in population, demographic shift in the state, lack of resources, and lack of services and support. Older adults and individuals with disabilities have difficulties with access to services, access to health care, food and nutrition, transportation, broadband connectivity, affordable housing, and increased cost of services. The drive for dialysis treatments from some rural areas is ninety miles and people have difficulty with transportation. There are people who do not have electricity or plumbing. There are families who turn their lights out in the evening to conserve energy because they cannot afford to pay their electricity bill. There are numerous challenges for AAA's that include lack of contracted service providers, distance to travel for service, lack of workforce, the need for additional funding, and difficulties serving the homeless.

For the last 30 years there has been huge growth in the older population. In the next thirty years, there will only be a 17% growth rate in the 18–64-year-old workforce population. The social service industry will experience a huge shortage of people caring for older adults and those with disabilities.

STATE PROGRAMS AND POLICIES ON DISABILITY ON RURAL

Peter Pike
Project Manager, Offices of Independent Living Services

Peter Pike thanked the committee for the invitation to speak and welcomed them to Colorado. He shared that he oversees contracts with Centers for Independent Living (CIL). The centers are non-profit agencies that provide services to individuals with disabilities with a focus on supporting people living in communities independently in rural and frontier communities. They provide services to people transitioning out of nursing homes and institutions. Mr. Pike also works with the Governor Appointed Council and Statewide Independent Living Councils to develop and monitor the State Plan for Independent Living. Many of the representatives on the council are individuals with disabilities from different geographies including rural and frontier communities. The Atlantis Community Center for Independent Living demonstration, known as the American Disabled for Accessible Public Transit (ADAPT), resulted in many cities restructuring their public transit system with full accessibility. The demonstration also assisted in the passing of the Americans with Disabilities Act in 1990.

About five years ago, there was a federal budget proposal that would decrease the amount of funds going to the Administration for Community Living. There was also consideration to consolidate the advisory councils which were governor appointed councils that were required by law. The chair of the Statewide Independent Living Council decided that the agencies should have a unified response and created the Colorado Administration for Community Living Partnership Group.

The budget was not passed, and the councils were not consolidated, so the federal funding remained. Colorado's Administration for Community Living Partnership Group was a positive way to enhance the ability to better meet the needs of individuals with disabilities. The Colorado ACL Partners include The Statewide Independent Living Council (SILC), Centers for Independent Living, The State Unit on Aging, MINDSOURCE Brain Injury Network, Developmental Disabilities Council, Assistive Technology Partner, Projects of National Significance, Disability Law Colorado, (advocacy and protection agency), JFK Partners, University Center of Excellence, NIDILRR research project, and Office of Independent Living Services. Federal ACL Partners also joined Colorado's ACL Partnership Group including Percy DeVine III with ACL Region 8, Ed Ahern with the Office of Independent Living Programs, and Charlie Smith with the Substance Abuse and Mental Health Services Administration. Colorado's ACL Partnership Group meets every other month for an hour and the meeting begins with partners sharing their purpose and mission to enhance partnering opportunities. The group shared knowledge about federally approved plans which created opportunities for uniting around needs for individuals with disabilities. Other opportunities that arose from bringing together stakeholders was the collaborative approach on grant applications, a network to obtain input from individuals with disabilities, and consolidating and creating data that illustrated federally approved state plans and priorities.

Ginger Stringer
Community Outreach Specialists, Resource Exchange

Ginger Stringer shared that she grew up in Anchorage, Alaska. She met her husband in college, and they moved to San Diego after graduation. They decided to move to Colorado to be near family and shortly after she had a baby girl named Cassie, and then had a son named Ryan. He started getting ear infections when he was five months. He would wake up every night screaming. The first year of his life he went to the doctor's office twenty-three times and to the emergency room four times. She asked the pediatrician why he was getting so sick, and he said it was because he was in daycare. Ryan kept having chronic ear infections and after he turned one, he vomited and had diarrhea daily. He was at the daycare providers until he was five years old. The doctor still said it was viruses that he was getting from daycare. Ryan had delayed speech and the doctor said it was because Ms. Stringer was not encouraging him to talk. The daycare provider had concerns because Ryan was not connecting on a level as the other children, so Ms. Stringer made an appointment with a pediatric neurologist. The pediatrician was given the results and said that Ryan had Fragile X Syndrome.

Ms. Stringer started studying special education and Fragile X Syndrome. She went to a Fragile X Syndrome conference and Ryan and another child were laying on the floor near the band banging their heads on the floor. Ms. Stringer was talking to a young man at the event who was Ryan's age. When talking to his mother, she found out that he also had Fragile X Syndrome but there were no indications. His mother said that he had received early intervention because she found out when she was pregnant with her son that he had Fragile X Syndrome. He received early intervention from the age of three months old to three years old that included speech, occupation therapy, and physical therapy. Ryan's pediatrician ignored the signs that Ryan could have a developmental disability (IDD) so he was not able to receive the early interventions that could have made a significant difference in his development.

Later, Ryan went to college and decided to move to an apartment. Ms. Stringer said she was concerned but let him move in anyway. Ms. Stringer had home maker services and personal care services through the supportive services waiver. Ryan only stayed for two days and was ready to come home so she told him that he had to at least stay at the apartment for a couple of days a week. He did well and started working at an arts center and volunteering at a hospital. During COVID-19, he started doing online courses and it was difficult for him. Ryan graduated from college in 2022 and told his mother that he wanted to work at the Broadmoor Hotel in the banquet room. Ms. Stringer and Ryan were hired together so she could collaborate with him as a banquet server.

Ms. Stringer learned that the Resource Exchange did the early intervention for children with Fragile X Syndrome. She began working for the Resource Exchange in 2009 to talk to doctors about doing developmental screening for early intervention. When she started at the Resource Exchange, fourteen children a year were referred by doctors and now there are over nine hundred referrals a year. The Resource Exchange is a Community Center Board and a single-entry point that was established in 1964 and serves Park, Teller, and El Paso County. The Community Center Boards do early intervention, enrollment into Community Based Service Waivers, and case management.

Eighty percent of a child's brain is developed by three years of age and by five years of age it is 90%. If intervention is instituted before kindergarten age, then trouble can be prevented. The federal and state government invests in early intervention programs so children with intellectual disabilities will develop skills before they turn three years old. If children receive intervention at an early age this helps them to live independently.

The Individuals with Disability Education Act (IDEA) requires each state to implement early identification polices so there are early interventions and special education opportunities for children and young adults with disabilities.

Part B – "Childfind" requires that students with disabilities from the ages three to twenty-one receive a Free and Appropriate Public Education (FAPE).

Part C – "Early Intervention" is a federal grant program that assists states in operating a comprehensive statewide program of early intervention services for infants and toddlers with disabilities, age birth through two years and their families.

Home and community-based service waivers (HCBS) allow individuals to remain in their home and community and provide long-term care and support. Supported Living Services Waivers fund day habilitation services, personal care services, homemaker services, dental services, life skills training, supported employment, assistive technology, behavioral services, prevocational services, buy-n for working adults with disability, and vision services.

Q&A

Craig Glover asked Bonnie Silva to elaborate on her comment about the need to change licensure requirements so that providers can do more than one role.

Bonnie Silva responded that she was talking about rural communities specifically. There should be flexibility in mixed licensure options for the rural long-term care providers. They know their communities well so it would be productive to have one licensure to be a home health provider, day program provider, and home health provider. There are not enough providers or population density to have individual providers serve in those capacities and it is the same skillset across the continuum.

Clifford Hunter asked Jayla Warren Sanchez if there is research about how to address the aging workforce dilemma.

Jayla Warren Sanchez responded that there are a lot of states that are facing the dilemma of an aging workforce. There must be creative solutions that can include affordable housing, higher salaries, and other ways to retain workers, so they do not move out of the state. Maybe retired social workers and mothers who are considering part-time work would want to supplement their income.

Cara James asked what recommendations there are to assist those with disabilities whose caregivers are aging.

Jayla Warren Sanchez said that when she started in the field, one of her jobs was to help place people with IDD whose parents had passed. Several of them have lived over 30 years in a nursing home. In rural communities, there are not many options, and it requires dependable service providers and case managers to assist people when a caregiver passes away or can no longer care for them.

PUBLIC COMMENT
There was no public comment.

Thursday, September 7th, 2023

Thursday morning the subcommittees departed for site visits as follows:

SITE VISIT
Lincoln County Human Services
Hugo, Colorado
Tour of Lincoln County Community Hospital

Carrie Owens
Chief Operations Officer, Lincoln Health Community Hospital

Rachel Smith
Director, Lincoln Health Nursing Acute Care Services

John Hewing
Vice President, Government Affairs, Colorado Hospital Association

Subcommittee Members: Clifford Hunter (Chair), Isabel Garcia-Vargas, April Anzaldua, Matthew Probst

Ex Officio Members: Lisa Zingman, Ben Smith, Kellie Kubena

Federal Office of Rural Health Policy: Tom Morris, Sarah Heppner, Lee Steuer

Local Representatives: Meggan Grant-Nierman, Kevin Stansbury, Andrew Lorenson, Kelly Meier, Candace Myers, Dami Brandy

The subcommittee returned to the Hilton Garden Inn, in Colorado Springs, Colorado.

SITE VISIT
Starpoint – Canon City
Fremont County, Colorado

Subcommittee Members: Brian Myers (Chair) Michelle Mills, Patricia Schou, Brian Myers, Craig Glover, Cara James

Ex Officio Members: Darci Graves, Percy DeVine, Humberto Carvalho, Scott Miller

Federal Office of Rural Health Policy: Sahira Rafiullah, Meredith Anderson, Jocelyn Richgels

Local Representatives: Michelle Mills, Bryanna Marisicano

The subcommittee returned to the Hilton Garden Inn, in Colorado Springs, Colorado.

Friday, September 8, 2023

OUTLINE THEMES FOR POLICY RECOMMENDATIONS

Jeff Colyer, MD
Committee Chair

Jeff Colyer welcomed the committee members to the final day of the meeting. The committee will make recommendations to advise the Secretary of Health and Human Services. He stated that the support of individuals with disabilities is especially important to him. There is a need to create metrics for funding so that individuals with disabilities can have independence, quality of life, and longevity.

Disability and Independence in Rural Communities

Lincoln County Human Services Site Visit Key Points:

- A need for additional transportation for disabled patients.
- Specialized services are not available in the area, so people do not have to travel long distances for specialty care.
- Adults with disabilities need additional services and supports in the community and their homes.
- The medical and social service providers are taking on numerous responsibilities because of a lack of workforce.
- The hospital has plans in place to build a new facility and make it more ADA compliant but needs additional funding.
- Services are provided that are not able to be reimbursed.
- The hospital is not reimbursed for durable medical equipment for patients who are returning home.
- The primary physician in the area is going to retire and there is difficulty recruiting workforce.
- There is a limitation in federal funding and reimbursement and the procedures to receive funding, there is a lack of data, and it is difficult for a limited number of staff.
- Lack of home visitation services for parenting support, mental health services, cognitive training, family skills and safety
- Specialized mental health services are needed.
- There is not a fulltime OB/GYN physician who can perform procedures in the area.

Starpoint Site Visit Key Points:

- Lack of sidewalks and accessibility for people with physical disabilities
- Lack of affordable housing
- Recruiting and retaining workforce in the area

- Community colleges can provide training opportunities but there is not an infrastructure for people to stay after graduation.
- There is only one pharmacy for three counties.
- Difficulties with administrative grants and the amount of documentation for individuals with disabilities to retain funding.
- Funding needs to be channeled to local organizations.
- Local hospitals are uncomfortable administering anesthesia for individuals with disabilities.
- There are broadband issues in the area.
- There is a need for navigators to reach those in the community who do not know how to access services.
- Transportation is an issue in rural communities.

RECOGNITION OF GOVERNOR COLYER – CHAIR OF THE COMMITTEE

Governor Colyer, Chair of the Committee, completed his term. The committee thanked Governor Colyer for serving as Chair of the National Advisory Committee on Rural Health and Human Services.

Tom Morris thanked Governor Colyer for his service and shared that Governor Colyer did not let the COVID-19 pandemic hinder the progress of the committee, in fact there were many policy briefs completed during that year. Governor Colyer created a vision statement and a set of principles for the committee. Governor Colyer brings a perspective as a clinician, state legislator, lieutenant governor, and governor that proves invaluable to the committee’s efforts.

Governor Colyer stated that he talks to the ORHP staff every other week and sometimes every week and that Tom Morris and Sahi Rafiullah are two of the finest public servants that he has known. He also shared that during the COVID-19 pandemic, the Office of Rural Health Policy was incredibly engaged and did fantastic work.

FINALIZE TOPIC IDEAS FOR SEPTEMBER MEETING IN COLORADO

The topic of Technology and Innovation in Rural Health and Human Services is the topic being considered for the fall meeting. Committee members will continue the discussion and make a final decision.

PUBLIC COMMENT

There was no public comment.