



Department of Health & Human Services, Centers for Medicare & Medicaid Services

LTSS Research: **Improving Care for Adults with Disabilities in** **Indian Country**

Highlights from the Literature

December 15, 2018





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This publication was supported by GS-00F-0012S/HHSM-500-2016-00065G awarded by the Centers of Medicare & Medicaid Services. The opinions, findings, conclusions, and recommendations expressed in this publication are those of the authors and do not necessarily represent the official position or policies of the Department of Health and Human Services or the Centers for Medicare & Medicaid Services.



Background and summary of the findings

While research indicates high levels of disability among American Indian and Alaska Natives (AI/ANs) (see Table 1), little is known about the current needs and challenges faced by AI/AN adults who have developmental and/or acquired disabilities. High disability rates, combined with a widespread exposure to traumatic events and preference for in-home care, suggest a significant need for long-term services and supports (LTSS) among this population.

LTSS

A broad set of health care, personal care, and social services that make it possible for many adults with developmental disabilities and adults with acquired disabilities to live at home or in the community¹

Table 1. Rate of disability among the AI/AN population compared to the general U.S. population²

Population	Rate of Disability
AI/AN population	23%
General U.S. population	18%

Developmental disabilities

Appearing before the age of 22 years, developmental disabilities are severe, life-long disabilities that impact intellectual and/or physical functioning (National Institutes of Health, 2018). Examples of developmental disabilities include:

- Down syndrome, fetal alcohol syndrome, and blindness from birth.

Acquired disabilities

The term acquired disabilities encompasses a variety of disabilities that occur after birth due to an accident, incident, or illness (Bogart, 2014), such as:

- brain injuries caused by accidents that affect mobility as a person ages and

¹ CMS. (2016). LTSS Overview. Retrieved from <https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/ltss-overview.html>

² U.S. Census. (2012). Selected population profile in the United States: American Indian and Alaska Native alone or in combination with one or more other races. Retrieved from http://factfinder2.census.gov/bkmk/table/1.0/en/ACS/12_1YR/S0201//popgroup~009



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- challenges resulting from chronic illness that limit a person’s ability to perform activities of daily living without assistance.

Themes from the literature

Much of the literature on the topic of AI/AN adults with disabilities is dated (Ma, Wares, Coyle, & Cornell, 1999; Marshall & Largo, 1999; National Council on Disability, 2003a; National Council on Disability, 2003b; Pichette, Berven, Menz, & LaFramboise, 1997). More recent literature on the overall adult population with disabilities reveals a range of themes. However, much of that research focuses on developmental disabilities, as opposed to acquired disabilities. Given these gaps in the literature, this report highlights key themes from research on the overall adult population with disabilities as a framework for future studies on the topic of AI/AN adults who have developmental and/or acquired disabilities.

Themes from the literature include:

- prioritizing home- and -community-based services (HCBS), which may offer culturally appropriate care options for AI/AN adults with disabilities;
- hearing the voices of LTSS recipients with developmental and acquired disabilities;
- realizing the benefits of trauma-informed care, especially for AI/AN adults; and
- considering the needs of family caregivers who provide a majority of LTSS in Indian Country.

Highlights from the literature

This section of the report reviews key themes from the literature on LTSS among adults with disabilities as they relate to the needs of AI/AN adults who have developmental and/or acquired disabilities.

Prioritizing home- and community-based services

As life expectancies increase in the United States, cost-effective HCBS are essential. They allow adults with disabilities to age in their communities, including those without family caregivers. HCBS provide care for adults with long-term physical, cognitive, and/or behavioral health needs while promoting their independence and wellbeing (National Quality Forum, 2015).



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Examples of HCBS

Assisted living facilities, home health care, caregiver training, home-delivered meals, and home repairs and modifications ³

Challenges of institutional care

The literature suggests that many AI/AN adults do not find institutional nursing facility care appealing due to a cultural preference for in-home care and a dearth of facilities that provide culturally appropriate care (Goins, Tincher, & Spencer, 2003; Aldrich, 2009). Additionally, in institutional care settings, adults with developmental disabilities often find it difficult to form meaningful relationships and participate in recreational activities that are typically designed to meet the needs of elderly patients (Bigby, Webber, Bowers, & McKenzie-Green, 2008). For adults with disabilities, other possible complications to fitting into institutional care communities include (Bigby et al., 2008; Chan, Sigafos, Watego, & Potter, 2001):

- challenging behaviors, such as aggression or self-injury;
- a lack of communication skills;
- a need for more individualized attention;
- social isolation;
- other residents' negative attitudes toward them;
- a lack of appropriate staff training on how to provide their care; and
- a shortage of resources that can adapt to meet their particular needs.

Benefits of HCBS

As more AI/AN adults move away from reservations to pursue opportunities in urban areas, access to family caregivers decreases (Aldrich, 2009). An absence of family caregivers increases the importance of HCBS for AI/AN adults with disabilities. HCBS can help ensure the continuity of social relationships, which are often disrupted when adults transfer to institutional care. This advantage is particularly relevant to adults with developmental disabilities.

Hearing the voices of LTSS recipients

The current approach to planning services for adults with disabilities in the U.S. is more person-centered and focused on quality of life than it was 40 years ago (Keesler, 2014). In keeping with the principles of person-centered care, the current system acknowledges that adults with disabilities can actively

³ CMS. (2014). *Supporting American Indian and Alaska Native People in the Community: Opportunities for Home- and Community-Based Services in Indian Country*. Retrieved from https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-Technical-Assistance-Center/Documents/CMS_HCBS_Lit-Rev_1-16-14_508.pdf



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participate in decisions about their care, and they need sufficient opportunities to express their opinions about the LTSS they receive.

Care challenges for adults with disabilities

People with developmental disabilities face many challenges that may improve with person-centered care. These challenges include assumed limitations about their ability to make choices, cognitive and communications barriers, pressure to please people they perceive as authority figures, and limited ability to visualize improvements.

- **Assumed decision-making limitations** – Care providers may erroneously assume that people whose “compromised levels of functioning” stem from developmental disabilities are unable to make choices regarding their care (Keesler, 2014, p. 38).
- **Cognitive and communications challenges** – Adults with developmental disabilities often face cognitive and communications challenges that make it difficult for them to comprehend or answer questions regarding the quality of their care during an interview or in a survey (Copeland, Luckasson, & Shauger, 2014).
- **Pressure to please perceived authority figures** – During an interview or in a survey, adults with disabilities who depend on others to meet their day-to-day needs may feel pressured to answer questions in a way that pleases their care provider if they see them as being in control or in authority. This challenge is especially true if the caregiver is present during the interview or survey (Copeland et al., 2014).
- **Limited ability to visualize improvements**– Furthermore, adults with developmental disabilities who have experienced a narrow range of living, working, or social situations may struggle to visualize how their current life circumstances could be improved (Copeland et al., 2014). That struggle may affect their responses during an interview or survey when asked to rate their satisfaction with LTSS.

Person-centered care for adults with disabilities

Whenever possible, LTSS program planning, implementation, and evaluation should consider input from the people receiving these services. Strategies to better assess life satisfaction levels among adults with developmental disabilities include (Copeland et al., 2014):

- simplifying interview question wording;
- reducing the number of answer choices;
- using visuals, such as photos, symbols, or other graphics, to improve question comprehension;
- interviewing people more than once; and
- including people with disabilities when field testing interview questions and during the interview process.



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Future assessment and research considerations

Future satisfaction assessment studies should include more people with significant intellectual disabilities and/or language impairment (Copeland et al., 2014). Additionally, more research is needed on the cultural appropriateness of LTSS regarding ethnicity, cultural diversity, and primary language (Copeland et al., 2014), specifically among AI/AN adults with developmental and acquired disabilities.

Realizing the benefits of trauma-informed care

In recent years, there has been increased awareness of how trauma affects adults with developmental disabilities. A paper by Keesler (2014) suggests that trauma-informed care may increase satisfaction among adults with developmental disabilities and the people who care for them. Keesler (2014) defines trauma-informed care as “a systems-focused framework for service delivery that ... acknowledges the pervasiveness of trauma in the lives of all persons.”

The five principles of trauma-informed care Safety, trustworthiness, choice, collaboration, and empowerment ⁴

Trauma-informed care, person-centered care, and LTSS

Trauma-informed care complements person-centered service delivery. It also helps LTSS providers become more aware of how their behavior and communication affect their clients’ wellbeing (Keesler, 2014). Additionally, integrating trauma-informed care into LTSS can enhance service providers’ wellbeing who may otherwise feel disempowered by traditional service delivery (Keesler, 2015).

Future assessment considerations

There is a body of research on the exposure to and impact of trauma among AI/ANs overall (Koss, et al., 2003; Ehlers, Gizer, Gilder, and Yehuda, 2013). Given the likely exposure to trauma among AI/ANs, there has been heightened interest in trauma-informed care and the Indian Health Service (IHS) is working to incorporate trauma-informed care into behavioral health care (IHS, 2017). Including AI/AN adults with developmental and acquired disabilities in studies on LTSS and trauma may be a particularly relevant area of focus for researchers.

Considering the needs of family caregivers

Due to cultural factors, including an emphasis on respect for elders and an assumed obligation to provide care, family members provide the majority of LTSS in Indian Country (Hennessy & John, 1996; National Indian Council on Aging, 2013). While the literature does not address the needs of caregivers for adults with disabilities in tribal communities, the findings likely apply to AI/AN caregivers.

⁴ Keesler, 2014; Keesler, 2015



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Family long-term caregivers

Family members provide 90% of long-term care in Indian Country—10% more than the general U.S. population ⁵

Challenges for caregivers

Family caregivers are an especially critical source of support for adults with disabilities. However, these caregivers typically have multiple, often conflicting roles and responsibilities. For example, they may provide their household's primary source of income and assist a spouse, parent, or sibling who has chronic medical conditions. Family caregivers may also shoulder the responsibility of being proactive in advocating for their family member's wellbeing (Williamson, et al., 2016).

Considerations for caregivers

Williamson and colleagues (2016) interviewed 16 family caregivers of people with intellectual and developmental disabilities to learn more about their experiences with LTSS. Based on this study, the authors concluded that the effective design, implementation, and evaluation of LTSS for adults with intellectual and developmental disabilities requires family caregiver engagement. When asked about access to services and care coordination, the interviewees emphasized the need for a person-centered approach to LTSS that allows for flexibility and individualization. Based on the prevalence and preference for family caregiving in Indian Country, caregiver engagement and a person-centered approach may be particularly effective for AI/AN adults with disabilities.

Next steps

Published literature on the topic of AI/AN adults with disabilities dates back to the late 1990s and early 2000s. Based on more recent literature on the overall adult population with disabilities, and in consideration of the needs of AI/AN adults with developmental and/or acquired disabilities, future studies on the design, implementation, and evaluation of LTSS should:

- prioritize HCBS;
- obtain input from AI/AN adults with disabilities who receive LTSS;
- address the cultural appropriateness of LTSS;
- consider the benefits of trauma-informed care for AI/AN adults; and
- consider the needs of family caregivers.

⁵ Institute of Medicine. (2008). *Retooling for an Aging America: Building the Health Care Workforce*. Retrieved from <http://www.nap.edu/catalog/12089/retooling-for-an-aging-america-building-the-health-care-workforce>



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