

The Women and Girls Foundation launched the Training Regional Advocates to Influence Leadership (TRAIL) program in 2020, in collaboration with Dr. Josie Badger. The goal of the program is to develop a statewide legislative advocacy training program for people with disabilities. TRAIL supports advocates with disabilities in learning strategies to make systemic change.

Recommendations represent the ideas of TRAIL members and do not represent those of the Women and Girls Foundation or any partners. For additional information please contact Dr Josie Badger at Josie @JBadgerConsultingInc.org

Written by:

Monica Albert Still, RN, BSN has been a TRAIL member since 2020. She has advocated for disability justice at both the Commonwealth and Federal levels. She serves on the Board of Disability Rights PA and on the Adult Advisory Council of the Spina Bifida Association.

Healthcare for Pennsylvanians with Disabilities

Article 25 of the UN Convention on the Rights of Persons with Disabilities (CRPD) reinforces the right of persons with disability to attain the highest standard of health, without <u>discrimination</u>. However, healthcare has gone from being a mechanism to sustain a better life to a questionable expense for many Americans.



Images' Source: CDC

Financial Barriers

- According to the <u>National Disability Institute</u> a household with an adult with a disability requires, on average, 28% more money to obtain the same standard of living as a similar household without a member with a disability.
- Nationwide, medical expenses are the number one reason that families file for bankruptcy. Many people with disabilities report being unable to afford the costs associated with medical care, including the costs of medications or transportation, which are not always covered by government benefits.

Inaccessibility

- In spite, of the Americans with Disabilities Act, healthcare services and offices are often located in inaccessible locations and are physically inaccessible due to stairs; inaccessible exam rooms and tables; and lack of accessible restrooms. In a survey of US physicians 36% reported knowing little or nothing about their legal responsibilities under the ADA.
- Health information may be presented in inaccessible ways including: use of jargon, lack of written instructions, or unavailability of Braille or large print.
- People with disabilities commonly do not see all of the necessary care providers, particularly primary health care. Women with disabilities face particular barriers to sexual and reproductive health services and information.

Lack of Integrated Care

- Health care practices often do not have the capacity to work with providers from other specialties to coordinate care. Even in comprehensive health clinics, it can be difficult to get teams to collaborate due to: high patient loads, limited reimbursable time, and ill-established lines of communication.
- A lack of collaborations forces patients or families to keep their own records and communicate between providers.

Attitudinal barriers

- People with disabilities commonly report experiences of prejudice, stigma and discrimination by health service providers and other staff at health facilities.
- Many service providers have limited understanding of the rights of people with disabilities and have inadequate training and professional development about disability.

Healthcare for Pennsylvanians with Disabilities Policy Recommendations

Standardize coverage of medical supplies and medications across all MCO's

- Coverage for medical supplies or medications can vary greatly from one company to another.
 Further, certain medical supplies that are necessary to maintain the health and wellness of an individual are often not covered by insurance (such as incontinence supplies, needles for insulin...).
- MCO's need to reevaluate and standardize supplies and medications that are covered throughout the state, ensuring that all necessary medications or supplies are covered.

Improve disability awareness for medical professionals and staff

- Even though many disabilities can be directly related to medical conditions, professionals often lack a full understanding of the disability experience and sensitivity.
- Continuing education credits and mandated college classes should be developed by people with disabilities on disability awareness and sensitivity for all medical professionals.

Healthcare providers and facilities receiving state funding MUST be in compliance with the Americans with Disabilities Act

- In spite of state and federal laws on accessibility, a large percentage of medical, psychiatric, and addiction providers work in an inaccessible or barely accessible facility.
- Establish an oversight commission consisting of at least 51% people with disabilities to work with DHS and accrediting bodies to audit providers and facilities for access.

Focus on preventative care

- People with disabilities often do not visit all of the recommended medical professionals that the general population sees and are less likely to be involved in activities that promote healthy lifestyle.
- Patients should be incentivized to participate in ongoing health and wellness activities.
- Health and medical professionals should be encouraged to accept Medicare or Medicaid.
- Incentivize purchasing accessible gym equipment and accommodations

Supporting Medical Homes

- Medical Homes are popular in pediatric complex care practices. They provide comprehensive services that limit the number of appointments, coordinate care, and provide holistic services.
- Medical Homes need to be expanded for adult patients, particularly in underserved communities

Paid Family and Medical Leave

- Improves health outcomes and decrease hospitalization rates for all people.
- Allows people with disabilities to plan for surgeries and treatments without fearing the need to leave their jobs to go back on benefits to survive during their time off.