



Statewide Advocates Influencing Leadership (SAIL) is a community-driven coalition and training project focused on fostering leadership and advocacy among people with disabilities across Pennsylvania. Our group is designed by and for individuals with disabilities, ensuring that the support we provide is both relevant and impactful.

Created in partnership with PA REV UP



Healthcare Barriers 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 discrimination. However, healthcare has gone from being a mechanism to sustain a better life to a questionable expense for many Americans.

Inaccessibility

- In spite of the Americans with Disabilities Act, healthcare services and offices are often 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.

Lack of Awareness and Acceptance

- 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.

Lack of Comprehensive, Integrated, and Preventative Care

- Health care practices often refuse to or cannot 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.
- People with disabilities are less likely to be involved in activities that promote healthy lifestyles.
- People with disabilities commonly do not see all of the necessary care providers, particularly primary health care. Women with disabilities face barriers to sexual and reproductive health services and information.
- A lack of collaborations forces patients or families to keep their own records and communicate between providers.

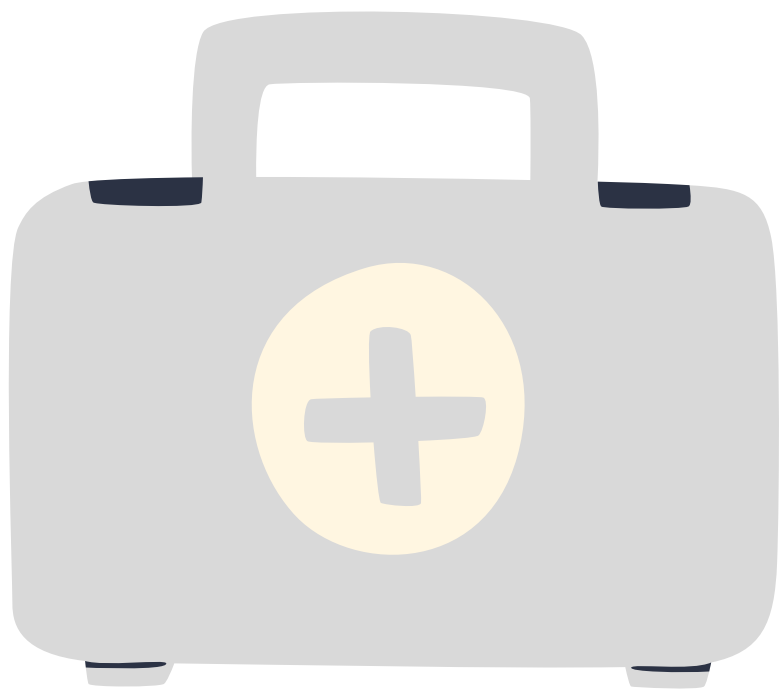
Financial Barriers

- According to the National Disability Institute, 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.



Healthcare for Pennsylvanians with Disabilities Recommendations

Residential and institutional care is often the default care option for individuals who need support. However, with adequate support, most individuals would prefer living in their home. Studies have shown that in-home care is cheaper with better care provision. Unfortunately, unless a social worker is involved (usually as a result of a hospitalization) evaluating alternative options and applying for supports is rarely completed before an individual is placed in a residential facility.



Accessibility

- Healthcare providers and facilities receiving state funding MUST be in compliance with the Americans with Disabilities Act and new Rehabilitation Act access requirements.
- 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.

Awareness and Acceptance

- Continuing education credits and mandated college classes should be developed by people with disabilities on disability awareness and sensitivity for all medical professionals.

Comprehensive, Integrated, and Preventative Care

- 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.
- Patients should be incentivized to participate in ongoing health and wellness activities.
- Health and medical professionals should be incentivized to accept Medicare or Medicaid.
- Develop grants for purchasing accessible gym equipment and accommodations

Addressing Financial Barriers

- MCOs need to reevaluate and standardize supplies and medications that are covered throughout the state, ensuring that all necessary medications or supplies are covered.

Statewide Advocates Influencing Leadership (SAIL) is a community-driven coalition and training project focused on fostering leadership and advocacy among people with disabilities across Pennsylvania. Our group is designed by and for individuals with disabilities, ensuring that the support we provide is both relevant and impactful.