

NJ Statewide Self-Advocacy Network Position Statements

The New Jersey Self-Advocacy Project (NJSAP) is a program of The Arc of New Jersey established in 1983 to challenge individuals with intellectual and developmental disabilities to become involved in events, legislative policies, and issues that affect their lives or lives of others with disabilities.

We work together with these individuals to form The New Jersey Statewide Self-Advocacy Network (NJSSAN), which is used as means of supporting positive change on both a personal and social level. The NJSSAN consists of five Councils based on geographic location within the state.

1. [Home & Community-Based Services \(HCBS\)](#)
2. [Housing for People with IDD](#)
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Self-advocates speak about...

Home & Community-Based Services (HCBS)

People with disabilities and their families want access to a life in the community, no matter the level of supports necessary to make that happen. But when they try to find what they need, too often the system fails them.

ISSUE

Everyone benefits when people with disabilities are a part of the fabric of our communities, not locked away in the archaic institutions that still exist in 36 states. Institutions are large, often crowded places that limit people and their choices and force them to live segregated lives away from their family and friends without access to the supports needed to live in their own homes and communities. Yet this country has treated access to the services that help people with disabilities gain independence as an option, not a right. This is even more urgent during the pandemic, as crowded institutions and nursing homes have put people at much greater risk of contracting COVID-19. The current Medicaid system is set up to always pay for nursing homes and institutions, but home and community-based services are “optional.” That is why people with disabilities are often stuck waiting for years to access the services they need.

A variety of barriers continue to exist for people with IDD who require Home and Community Based Services (HCBS) to live their fullest life in communities of their choice. These include:

- Insufficient Medicaid funding;
- Institutional bias in the Medicaid program;
- Continued and worsening crisis of unmet need; and
- Persistent and worsening workforce crisis.

HOME AND COMMUNITY-BASED SERVICES (HCBS)

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Position

A comprehensive system of Home and Community-Based Services (HCBC) services must include the following:

- An HCBC system that is sustainable and enables all eligible individuals to obtain HCBC whenever needed;
- Elimination of the need for individuals or their families to impoverish themselves to receive supports and services;
- Services which are portable and allow people who move from one state or political jurisdiction to another to receive uninterrupted, self-directed supports;
- Individuals who are eligible for and want HCBC should not have to wait to receive services;
- Public systems must actively reach out to individuals and to families with un- and undermet needs to make them aware of the process for obtaining Long Term Supports and Services (LTSS) and must maintain transparency until waiting is eliminated;
- People must receive crucial supports that assist them while they wait for comprehensive community supports and services; System funding must provide for living wages and benefits to DSPs;
- Wages, benefits, and professional development opportunities remain consistently insufficient and must improve to attract and retain the workforce needed to fully support people living in the community;
- Competency-based training must be available to Direct Support Professionals (DSPs) that covers the essential knowledge, ethical principles and practices, and skills necessary to provide direct support;
- State, and local private and public entities must engage in policy initiatives to recruit, train, and retain a high quality DSP workforce;
- State quality assurance programs must incentivize DSP retention and competence as part of licensure, in order to recognize positive performance and to direct assistance to those programs with unacceptable performance; and
- States must utilize a Nation-wide system for criminal and related background checks, including a system for tracking people for whom abuse, neglect, and exploitation charges have been substantiated, for all public and private DSPs working in the state.

Source: [The Arc US Position Statement on Long Term Supports and Services](#)

Self-advocates speak about...

Housing for People with IDD

Securing safe, affordable housing in areas with public transport and creating residential programs in walkable areas continues to be a priority for the Network. Privacy is highly valued and must be respected for people with IDD. Most of all, self-advocates support integrated, community-based housing.

ISSUE

People with IDD face a housing crisis with many contributing factors, such as a serious lack of safe, affordable, accessible and integrated housing, and significant housing-related discrimination. Outmoded public policy and programs which unnecessarily segregate people with IDD, as well as lack of coordination among funding systems, also pose major barriers.

However, people with IDD are among the nation's poorest citizens. For many, Social Security and Supplemental Security Income benefits, which are often far lower than typical rents, are their primary or sole source of income; beneficiaries are generally priced out of rental markets across the country.

Affordable housing programs are drastically underfunded, with long waiting lists. In addition, Medicaid, the principal source of funding for services and supports for people with IDD, typically does not allow funds to be used for rent or other community-based housing-related costs. These factors pose major barriers to community living, making it difficult for people to move from segregated facilities into the community, and putting many people with IDD at risk of unnecessary institutionalization or homelessness. Security Income benefits, which are often far lower than typical rents, are their primary or sole source of income; beneficiaries are generally priced out of rental markets across the country.

Position

People with IDD have the right to live in safe, accessible, affordable housing in the community as well as:

- People must have freedom, authority, and support to exercise control over their housing.
- Housing should afford people with IDD the opportunity to interact with people without disabilities to the fullest extent possible.
- The health and safety of people with IDD must be safeguarded wherever they live, but should always be balanced with the right to take risks and exercise choice and control.
- To ensure that people with IDD can make informed decisions about where and with whom they live, they and their families must be given understandable information about the benefits of living in the community, have the chance to visit or have other experiences in community settings, have opportunities to meet other people with disabilities who are living in the community, and have any questions or concerns addressed.
- All children and youth need a home with a family that provides an atmosphere of love, security, and safety.
- Adults with IDD should receive the supports they need to transition out of the family home when they wish to do so.
- Housing for people with IDD must be coordinated with home and community-based support systems, including transportation services, and should ensure access to other typical public resources.
- There must be adequate funding of services to support people to live in the community. Funding must be stable and not subject to arbitrary limits or cuts.
- People with IDD must not be subjected to unnecessary institutionalization or removal from their homes and communities due to state budget cuts.
- Housing for people with disabilities should be scattered within typical neighborhoods and communities, and should reflect the natural proportion of people with disabilities in the general population.
- Public funds must be shifted from restrictive institutional settings to community supports. Institutional settings and large congregate living arrangements are unnecessary and inappropriate for people with IDD, regardless of type or severity of disability.
- Affordable housing options must be available to people with IDD, including those with very low incomes.
- Universal design and visitability standards should be adopted for all new housing. New and significantly renovated multifamily housing should include fully accessible units in numbers that reflect the natural proportion of people with disabilities in the general population.
- People with IDD have the right to be free from housing discrimination, and there must be robust education, outreach, and enforcement of that right.
- People with IDD must have opportunities comparable to those of people without disabilities to rent or buy their own homes.

Source: [The Arc US Position Statement on Housing](#)

Self-advocates speak about...

Transportation

Having accessible and reliable public transportation is a critical part of achieving true community integration for people with IDD. Often, people with IDD rely on caregivers and family members for transportation which poses a unique set of challenges. We want to address this complex issue and support an investment in improving public transportation services statewide.

ISSUE

People with intellectual and/or developmental disabilities (IDD) must have access to both public and private transportation to lead full, self-directed lives. People with IDD lack sufficient access to reliable, accessible, and safe modes of public and private transportation. Every mode of transportation, including air, water, road, rail, and even pedestrian transportation, presents barriers for individuals with IDD. These barriers prevent people with IDD from meaningful participation in everyday activities that promote high quality community living experiences. In the U.S., millions of individuals with disabilities use public transit to maintain their autonomy and participate fully in society. For many, it is their only transit option. However, even where accessible public transportation exists, adults with IDD consider transportation options inadequate.

Federal and state legislation encourages economic self-sufficiency for people with all types of disabilities, which requires transportation. Inadequate transportation inhibits community involvement, including successful employment. Where there is available transportation, there is often little to no training available to support individuals with IDD to make full use of it. For those providing the transportation, there is insufficient training to understand and meet their customers' needs, including cultural competencies. Those living in rural areas often face the greatest challenge of all due to lack of public transportation, limited private transportation options, and long distances between destinations.

TRANSPORTATION

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Position

Transportation industries, agencies, service providers, and advocacy organizations must ensure that:

- Transportation at comparable cost and service models is available to individuals of all abilities.
- When making decisions, planning, and testing transportation options and payment methods, individuals with IDD are involved in the process.
- Improved coordination maximizes existing transportation services.
- Public transportation is adequately funded, fully financially and physically accessible, reliable, and equipped to suit the physical, sensory, and cognitive needs of all people.
- As technological innovations emerge (such as virtual wayfinding, autonomous vehicles, and digital ticketing), transportation modalities are designed to be accessible, usable, and reliable, including such things as language access, visual cues, safety considerations, and audio and hands-free options to meet individuals' needs and preferences.
- Technological platforms that relay information from users with IDD to transportation providers utilize inclusive research design to ensure accessibility and ease of use.
- Travel training is available for users covering all modes of travel, prioritizing peer-to-peer training where possible. The NJ Travel Independence Program (NJTIP) at Rutgers is one such resource available to riders with disabilities in New Jersey.
- Appropriate disability awareness training is available for service and transportation providers.
- The unique challenges and lack of options within suburban and rural areas are addressed.
- Technology and service providers protect a user's privacy by ensuring data such as contacts, camera, photos and files, health and disability status, and locations visited is not shared, or used for commercial or tracking purposes, without permission of the individual. For any information to be accessed or shared, customers must opt-in, versus opting-out, and have clear explanations of with whom and what will be shared. In light of data management, people with IDD must have the opportunity to receive training on self-directed data management and use.
- At the same time, transportation navigation software allows an individual to share appropriate information with a third party, to enhance efficiency and safety – for example, confirming arrival and indicating off-route warnings, as directed by users.
- Innovative vehicles and transportation options do not create additional barriers, based on where vehicles are parked, stored, and operated.
- People with IDD have the option of owning, modifying, and operating vehicles and other transportation options of their choice at affordable costs.
- All vehicles, public and privately owned, meet applicable federal, state, and local safety requirements.
- Autonomous Vehicles (AVs) are fully accessible and universally designed to take into account all individuals' abilities and disabilities to safely access and operate. Regulation of AVs must consider the needs of people with IDD, and avoid unnecessary licensing requirements that would restrict or eliminate access.

Source: [Joint statement produced by The Arc of the United States and the American Association on Intellectual and Developmental Disabilities \(AAIDD\)](#)

Self-advocates speak about...

Supported Decision Making and Alternatives to Guardianship

The personal autonomy, liberty, freedom, and dignity of each individual with IDD must be respected and supported. Legally, each individual adult or emancipated minor is presumed competent to make decisions for himself or herself, and each individual with IDD should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime.

ISSUE

Current trends presume the decision-making capacity of individuals with IDD and the preservation of legal capacity as a priority for all people needing assistance with decision making. Like their peers without disabilities, individuals with IDD must be presumed competent; they must also be assisted to develop as decision-makers through education, supports, and life experience. Communication challenges should not be misinterpreted as lack of competency to make decisions.

Individuals with IDD and their families should have access to supports and experiences to learn decision making skills from an early age and throughout their lifetimes. Less restrictive means of decision-making supports should be tried and found to be ineffective in ensuring the individual's decision-making capacity before use of guardianship as an option is considered.

Serving in the dual roles of guardian and paid service provider or paid advocate creates a conflict of interest or the appearance of a conflict of interest. Such conflicts must be mitigated or avoided. Some statutory privacy measures have made it more difficult for those assisting other individuals to have access to their records, make decisions, or both. Thus, to obtain or modify needed medical care, services, and supports, an individual with IDD may be adjudicated to be incompetent and subjected to guardianship. This result conflicts with the legal presumption of competence and with principles of autonomy, decision-making supports, presumption of competence, and the use of less restrictive alternatives.

Position

The primary goals in assisting individuals with IDD should be to assure and provide supports for their personal autonomy and ensure equality of opportunity, full participation, independent living, and economic self-sufficiency (Americans with Disabilities Act, 1990, section 12101 (a)(7); Individuals with Disabilities Education Act, 2004, section 1400 (c)(1)). Each individual adult and emancipated minor is legally presumed competent to make decisions for himself or herself and should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime. All people with IDD can participate in their own affairs with supports, assistance, and guidance from others, such as family and friends. People with IDD should be aware of and have access to decision-making supports for their preferred alternatives.

- If legal limitations on autonomy are necessary, then National Guardianship Association or equivalent standards that are consistent with the values expressed in this position statement should be followed. If any restrictions on autonomy are legally imposed, each individual has the right to the least restrictive alternative, due process protections, periodic review, ongoing training and supports to enhance autonomy and reduce reliance on approaches that restrict individual rights, and the right to ultimately seek to restore rights and terminate the restriction when possible.
- Information and training about less restrictive alternatives to guardianship should be available to people with IDD, their family members, attorneys, judges, and other professionals.
- If the use of a guardianship becomes necessary, it should be limited to the fewest restrictions necessary for the shortest amount of time and tailored to the individual's specific capacities and needs.
- Strict monitoring must be in place to promote and protect the autonomy, liberty, freedom, dignity, and preferences of each individual even when placed under guardianship.
- Regardless of their guardianship status, all individuals with IDD should be afforded opportunities to participate to the maximum extent possible in making and executing decisions about themselves. Guardians should engage individuals in the decision-making process, ensuring that their preferences and desires are known, considered, and achieved to the fullest extent possible.
- Regardless of their guardianship status, all individuals with IDD retain their fundamental civil and human rights (such as the right to vote and the right to make decisions related to sexual activity, marriage and divorce, birth control, and sterilization) unless the specific right is explicitly limited by court order.
- States should provide systematic access to decision-making supports for all individuals with IDD.
- Financial incentives that benefit professionals or guardianship corporations should never drive guardianship policy or result in expensive and unnecessary costs to individuals or their families.
- Individuals with IDD must have access to all the accommodations and supports, including communication supports, they need to demonstrate their competency at initial evaluations for guardianship and at all periodic reviews of any guardianship.

Source: [The Arc US Position Statement on Autonomy, Decision-Making Supports, and Guardianship](#)

Self-advocates speak about...

Raising Awareness of IDD Issues

The more people who speak out about issues the better chance we have to make changes. It is important to teach the world, the next generation and professionals what is important to people with IDD.

ISSUE

People in the public spotlight are still casually using terms that are offensive towards people with IDD. Professionals within social services and beyond need more training on topics relating to people with IDD. Law enforcement officers do not receive adequate training on how to properly interact with people with IDD, which can have distress effects. Even amongst guardians themselves and judges who make decisions about guardianship, there is a culture of misinformation or lack of knowledge on where self-advocates stand on these issues. Improving outreach and awareness about people with IDD, led by people with IDD, needs to be the first step in addressing all of the issues contained in this document.

Position

It is paramount that outreach and awareness trainings involve people with IDD in all aspects of planning from the start as well as contributing to the trainings themselves, preferably leading or co-leading the sessions, as well as the following.

- When creating a syllabus, people with IDD and issues of importance to community members should be part of the process and not an afterthought.
- When extending invitations to trainings, meetings or events, people with IDD should be given proper consideration for their availability, transportation, accessibility of the location and content of the training, and should be appropriately compensated for their contributions just the same as people without disabilities.
- Erasing the 'R word' and similar offensive terms, as it still persists in public and private speech.
- Increased training for Direct Support Professionals before and throughout the duration of their employment.
- Increased trainings for those in the teaching and medical profession while they are still students on language, etiquette, and best practices in working with people with IDD.
- More comprehensive training for law enforcement, including State Police cadets, on best practices in safely and respectfully interacting with people with IDD.
- Members of the judiciary, attorneys, and other professionals need training and education on alternatives to guardianship for individuals with IDD, and they must zealously advocate for preserving the substantive and procedural rights of all individuals with IDD.