Housing

People with intellectual and/or developmental disabilities (IDD), like all Americans, have a right to live in their own homes, in the community. Children and youth belong with families. Adults should control where and with whom they live, including having opportunities to rent or buy their own homes, and must have the freedom to choose their daily routines and activities.

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.

Historically, families with a child with a disability had to either place their child in an institution, or manage without any supports or services at home. Institutions create an isolated, unnatural way of life that is inappropriate and unnecessary, while consuming a disproportionate share of limited public resources. As people with IDD have left institutions or their family homes, they frequently have been placed in group homes, often larger than family-sized, typically owned or leased by provider agencies. People in those settings may have little control over where and with whom they live, the services they receive, or the routines of daily life.

The recognition that people with IDD belong in the community has led to a growing demand for community-based housing. This demand is fueled by persons choosing to leave institutional settings, by young adults educated in inclusive schools, and by adults with IDD who live with elderly parents.

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.

1 Intellectual Disability (ID) is a lifelong condition where significant limitations in both intellectual functioning and adaptive behavior emerge during the developmental period (before adulthood).

Developmental Disabilities (DD), first defined in 1975 federal legislation now known as “The DD Act”, are a group of lifelong conditions that emerge during the developmental period and result in some level of functional limitation in learning, language, communication, cognition, behavior, socialization, or mobility. The most common DD conditions are intellectual disability, Down syndrome, autism, cerebral palsy, spina bifida, fetal alcohol syndrome, and fragile X syndrome.

The acronym “IDD” is used to describe a group that includes either people with both ID and another DD or a group that includes people with ID or another DD. The supports that people with IDD need to meet their goals vary in intensity from intermittent to pervasive.
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.

**POSITION**

People with IDD have the right to live in safe, accessible, affordable housing in the community.

- People must have freedom, authority, and support to exercise control over their housing, including choice of where and with whom they live, privacy within their homes, access to flexible supports and services when and where they choose, choice in their daily routines and activities, freedom to come and go as they please, and housing that reflects their personal preferences and styles. Providers should honor individual choices and preferences.

- 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.

- Public policy should promote small, typical living situations for people with IDD. Information about innovative housing models that promote independence should be widely disseminated.

- 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. Affordable housing programs must be expanded and funded to eliminate long waiting lists. Public policies must ensure that people with IDD receive their fair share of all local, state, and national housing resources.

• Universal design and visitability\(^2\) 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.

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Joint statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

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\(^2\) **Universal design** means buildings, products and environments that are inherently accessible to both people with and without disabilities. **Visitability** is a set of construction standards through which housing offers a few specific accessibility features making it possible for people with disabilities to visit friends, family and neighbors.