



Community Living and Participation for People with Intellectual and Developmental Disabilities:

What the Research Tells Us

To: Interested Parties

From: The Association of University Centers on Disabilities (AUCD) and the American Association on Intellectual and Developmental Disabilities (AAIDD)

Re: Community Living and Participation for People with Intellectual and Developmental Disabilities

Date: July 24, 2015

Monday, July 26th is the 25th Anniversary of the signing of the Americans with Disabilities Act (ADA). As he signed the law on the south lawn of the White House, President George H. W. Bush, surrounded by people with disabilities and members of Congress, closed his remarks by stating, “Let the shameful wall of exclusion come tumbling down.” Despite great advances in physical access and technology that have made schools, workplaces, and neighborhoods more accessible, there continue to be barriers to equal opportunity, full participation, independent living, and economic self-sufficiency for all people with disabilities.

AUCD supports and promotes a national network of university-based interdisciplinary programs to advance policies and practices that improve the health, education, social, and economic well-being of all people with developmental and other disabilities, their families, and their communities.

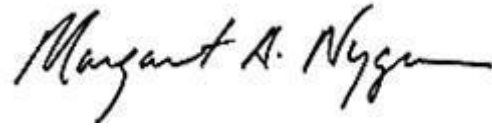
AAIDD is a national organization that promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities. Established in 1876, AAIDD is the oldest and largest professional society in the US concerned with intellectual and developmental disabilities.

On this 25th anniversary, we are releasing the attached paper, based on over 50 years of research, to describe how AUCD and AAIDD think the next 25 years of the ADA should translate into access, opportunity, and support for people with disabilities. This work has been shaped by two primary sources: the voices of people with disabilities themselves and the research evidence on achieving the best possible outcomes for people with disabilities. These sources, of course, have also been shaped by our national laws and policies, the most significant being the ADA.

On this 25th anniversary of the signing of the ADA, we hope this paper will provide direction for the road ahead, a road leading to greater access, better economic opportunities, and true equality throughout our country.



Andrew J. Imparato
Executive Director, AUCD



Margaret A. Nygren, EdD
Executive Director & CEO, AAIDD

Community Living and Participation for People with Intellectual and Developmental Disabilities

Since the passage of the Americans with Disabilities Act (ADA) in 1990 and particularly since the Supreme Court *Olmstead v. L.C.* decision in 1999, the question of where people with intellectual and developmental disabilities live has been a major part of disability policy.

Recent authors (Lutz, 2015; Montross, 2015) have called for the increased availability of segregated residences, citing such concerns as long waiting lists for services, significant stress on family caregivers, high rates of staff turnover in community settings, and the lack of specialized caregiver training that results in supports and services that are unstable and sometimes unreliable. The calls have been to create larger, more segregated facilities that can provide more targeted support.

These concerns are both real and significant. However, the solution is not to return to the building of large, segregated, isolated institutions and to call them farmsteads, campuses or some other label. Solutions should come from the experience of people with intellectual and developmental disabilities (IDD) and from five decades of research, practices and policies. These evidence-based sources will inform us what policies should be implemented to efficiently and effectively use our limited resources to address these challenges and ensure the best possible quality of life for all.

The Voice of People with Disabilities

Self-advocacy groups representing people with disabilities have clear positions on residential services and supports. They demand smaller, community, person-centered residential services that promote community living and participation.

Self-Advocates Becoming Empowered (SABE) and the Autistic Self-Advocacy Network (ASAN) are national organizations representing people with autism, intellectual, and other developmental disabilities. These organizations have taken strong, clear positions on what their members want and need regarding residential services and long-term services and supports.

"Self-advocacy groups...have clear positions on residential services...smaller, community, person-centered...settings that promote community living and participation."

SABE, in their 1995 statement about institutions, said "We believe that all institutions, both private and public should be closed. All people regardless of the severity of their disabilities should live in the community with the support they need" (SABE, 1995). SABE has restated this position for two decades.

ASAN, likewise, has issued clear statements about community living. The organization has called for supports and services so that autistics* can live in the most integrated settings. They have also called for increased funding for long-term services and supports so that autistics have opportunities for community living and for increased and mandatory training for professionals who provide services to autistics in order to promote independent living and full participation (ASAN, 2015).

This year the National Council on Disability (NCD, 2015), a council composed of a majority of people with disabilities and charged with making recommendations to the President and Congress, released a report titled, *Home and Community-Based Services: Creating Systems for Success at Home, at Work and in the Community* calling for more small-scale, community residential supports for people with disabilities. The report concludes that individuals receiving home and community-based services and supports in smaller, more dispersed and individualized community settings demonstrated signs of greater community integration and positive life outcomes. The majority of studies conducted in the U.S. found that outcomes such as greater individual choice, satisfaction, housing stability, higher levels of adaptive behavior, and community participation are positively related to smaller and more integrated residential settings (NCD, 2015).

Five Decades of Research

Over the past half-century we have learned that large institutions do not promote positive outcomes for people with IDD and limit community interaction and involvement for some of our most vulnerable citizens. These settings have negative outcomes for their health, well-being, quality of life, independence, and overall happiness. As a society we have moved from providing residential supports for people with intellectual and other developmental disabilities in the large, segregated, isolated institutions of the first half of the 20th century – such as Willowbrook in New York state and the Polk center in Pennsylvania – to smaller group homes, shared apartments, and individually-owned or rented houses or apartments.

With this shift from large-scale institutions to smaller, more community-based settings, the primary residential setting for most adults with IDD is now their family home. In the United

"Large institutions do not promote positive outcomes...and limit community interaction and involvement for some of our most vulnerable citizens."

States, family members are the primary providers of long-term services and supports to people with IDD. More than three of every four people with IDD of all ages live in the home of a family member (Braddock et al., 2015; Larson et al., 2015). In 2013, of the 383,556 individuals with IDD in the United States who did not live with a family member, most shared a home with five or fewer people with disabilities. The number of

people with disabilities living in institutional settings has declined dramatically over the last five decades. For those with IDD living in state facilities with 16 or more residents, the number has declined from 194,650 in 1967 to 23,802 in 2013. Taking into account state-operated facilities and nursing homes, the number of people with IDD living in institutions has decreased from approximately 275,000 in the 1960s to fewer than 50,000 (Larson et al., in press).

Recent arguments have been made that many people with IDD may be better served on large campuses or farmsteads instead of in small group homes. This conclusion runs counter to almost all of the research of the past 30 years examining residential services for people with IDD. Three decades of deinstitutionalization studies have found that people who move from institutions to smaller community settings are happier, healthier, have more control over their lives, and are better able to function independently after they move (Larson, Lakin & Hill, 2013).

Another substantial source of evidence, the National Core Indicators (NCI) project, provides insight into the quality of services available to people with disabilities and the outcomes of those services. Findings from the NCI indicate that overall rates of choice and decision-making related to where people live, work, and what they do during the day differ greatly by type of residence. Those who live in their own homes report the greatest amount of choice compared to those living in an institution, community residence, family home, or foster care (Bradley et al., 2015).

An overview of Projects of National Significance (PNS) studies published between 2008 and 2012 examined different types of residential settings in which people with IDD lived, and their health, obesity, loneliness, well-being and satisfaction, as well as financial expenditures related to their residential settings. The study authors found that, overall, the best outcomes occurred among individuals with IDD living in their own homes (owned or rented). Those living in their own homes, with appropriate supports, were less lonely, healthier, financially better off, and more satisfied with their lives. Those living with their own family or a host family had more opportunities to make their own choices related to their daily living and were more satisfied with their lives than those living in agency-operated settings (Tichá, Hewitt, Nord, & Larson, 2013).

In a recent policy research brief, Nord et al. (2014) reviewed NCI studies published over the last decade, examining numerous outcomes for people with IDD living in different residential settings. The review found that across all outcome areas, smaller settings, on average, produce better quality of life outcomes for people with IDD. People living in their own homes, family homes, host family homes, or in small agency residences (six or fewer residents) ranked consistently better in achieving positive outcomes than moderate size (7-15 residents) and large agency residences and institutions (more than 15 residents). Also, people living in their own homes, small agency residences, and host family homes reported more independence and more satisfaction with their lives.

It is clear from decades of studies that people with IDD have happier, healthier, and more independent lives when they live in smaller community-based residences than in larger institutional settings.

"It is clear from decades of studies that people with IDD have happier, healthier, and more independent lives when they live in smaller community-based residences..."

Federal and State Policy

Research findings and the experiences of people with disabilities should be the prime drivers of residential services policy. In addition, federal and state policies, statutes, regulations, and litigation also shape residential services and supports policies for people with IDD. Both the ADA and the 1999 Supreme Court decision, *Olmstead v. L.C.*, direct the federal government and states to ensure services for people with disabilities are available in inclusive, community settings.

The recent rule published by the Centers for Medicare and Medicaid Services (CMS) on home and community-based settings reinforces this established public policy that residential settings should be smaller, within inclusive communities, and support control and decision-making by the people who live in those settings. The policy makes clear that any residential settings supported with CMS funds must be inclusive and assure that those being supported have control and decision-making authority about such aspects of daily life as having guests and when to eat.

Characteristics of High-Quality Community Living

The research of the past 50 years related to high quality community living for those with IDD has resulted in a set of key components. These components include:

- 1) where and with whom a person lives;
- 2) where a person works and how he or she earns money;
- 3) what a person does during the day;
- 4) the quality of relationships developed with others during daily activities;
- 5) what and with whom a person does activities of personal interest;
- 6) an individual's health, both physical and emotional;
- 7) if, where, and with whom they worship;
- 8) their interest and opportunities to engage in learning and personal growth; and
- 9) their ability to make informed decisions about their lives (Hewitt, 2014).

People who live in inclusive community settings have more opportunities to control these aspects of their lives than those who live in segregated community living in institutional settings.

As we have seen above, the benefits of living in smaller, community settings include increased choice and self-determination, larger social networks and more friends, increased access to mainstream community facilities, greater participation in community life, more chances to

"...the benefits of living in inclusive community settings include increased choice and self-determination...and...a better standard of living."

develop and maintain skills that foster independence, a better material standard of living, increased acceptance from other members of the community, and greater overall satisfaction with their lives as expressed by people with IDD themselves and their families (Kozma, et al., 2009; Larson, Lakin & Hill, 2013).

Next Steps

While much progress has been made regarding the opportunity for people with autism, intellectual, and other developmental disabilities to live in their communities, many people with the need for significant supports have limited choices, unstable supports, and limited access to services designed to meet their residential needs.

Individuals with IDD who have higher support needs often require support in areas related to health and safety, and those necessary to support growth, development, and participation in community life. Typical services and supports include healthcare, employment, transportation, recreation, education, and residential services. In addition, their families struggle to meet these needs, and often need relief themselves. As a result of their unmet support needs, family caregivers can have difficulty in keeping jobs, experience social isolation due to limited opportunities to spend time with friends and family, and may be sleep-deprived due to 24-hour caregiving demands. Many of these families are struggling to make it from one day to another; and even in these crisis situations, families wait for services. Far too often in many states, access to a residential setting is the result of its mere availability when an individual or family is in crisis, rather than as the result of a well-designed person-centered process to optimally meet the needs of the person.

While such challenges exist, the solution is not to revert to building large congregate settings that segregate people with IDD from their communities. Fifty years of studies and research, and the voices of people with disabilities themselves, make the solutions clear.

As a nation, the use of our scarce resources and the policies that determine how we use those resources should:

- Ensure that children, youth, and adults with IDD have equal access to long-term services and supports in their homes and communities;

- Ensure that children, youth, and adults with IDD, and their families, have the support they need to be independent, earn a living, and interact with others with and without disabilities;
- Provide access to specialized services that support individuals with IDD with an emphasis on communication, social interaction, and positive behavioral supports;
- Ensure the availability of trained, committed, and caring professionals who have the knowledge, skills, and ability to deliver needed supports and services to people with IDD;
- Implement evidenced-based interventions designed to promote a stable and competent direct support workforce; and
- Ensure access to effective residential services for people with IDD who need them.

As we expand existing and develop new effective residential services and supports, the following characteristics should be embedded in those services and supports:

- **Person-centered and based on the specific needs of the individual with IDD.** An effective residential support team works together with the individual, to determine what is best for the individual using person-centered planning. Services should be individually tailored and might include therapeutic clinical interventions, and services to increase independence and personal skills. Funding should allow for individualized services that can be customized to the needs of the person. Most critically, the person with a disability and their family should be at the center of the planning process and have control over that process.
- **Family-focused.** Effective residential service providers encourage family involvement when the person with a disability desires that involvement. Families are expected to be an active participant of the individual's support team. Services are individualized to the needs of the individual and reflect the choices, desires, and culture of the person with a disability and the person's family.
- **Safe and purposefully-designed environments.** Effective residential settings are small and in neighborhoods that are centrally located in a community chosen by the individual and his or her family. Residences are universally-designed for optimal access and home-like, comfortable and predictable; and have areas that encourage socialization, modifications that reflect the needs of residents regarding sensory issues and safety; private rooms under the control of their residents; and use technology to enhance safety and independence.
- **Staffed by highly trained individuals who specialize in IDD.** Effective residential settings use a workforce that are multidisciplinary and have extensive preparation and ongoing professional development in supporting people IDD.
- **Informed by data.** Effective residential service providers conduct frequent, ongoing assessment of the needs of the people they are supporting and their progress toward

goals, and routinely report and respond to the service delivery team and the individuals' families.

- **Culturally-responsive and inclusive.** Effective residential service providers support the culture and beliefs of the person with a disability, such as attending or not attending religious services, observing specific food preferences or dietary restrictions related to culture or ethnicity, and celebration of holidays and special events.
- **Flexible and Nimble.** Effective residential services systems can move quickly to address emerging needs of an individual with IDD and their family.

As a nation we need to ensure that residential services for people with IDD are comprised of the components described above with the accompanying characteristics. These components and characteristics are what people with disabilities and research tell us about how residential services should be provided. Reverting to failed, antiquated ideas that involve large congregate settings with little choice and independence will not address the needs of people with disabilities, their family members, and the communities in which they wish to live and to which they want to belong.

The solutions to the very real challenges faced by individuals with complex needs and their families are in innovation, effective training and credentialing programs for staff, increased funding, and development of a shared vision to reach the goals articulated in the ADA 25 years ago: equality of opportunity, full participation, independent living, and economic self-sufficiency. These are the goals we must work toward as we move into the next quarter century of the ADA.

"the solution [to real challenges] is not to revert to building large congregate settings that segregate people with IDD from their communities."

* The term "autistic" is being used here because this is the term preferred and used by the Autistic Self-Advocacy Network (ASAN)

Thank you to the staff of the Research and Training Center on Community Living at the Institute on Community Integration at the University of Minnesota for their assistance drafting this document.

References

Bradley, V., Fay, M.L., Giordano, S., Melda, K., Smith, D., Ficker-Terrill, C., & Tichá, R. (2015). 25 years after ADA: what story does the data tell? *Impact: Feature Issue on the ADA and People with Intellectual and Developmental Disabilities*. Minneapolis MN: Institute on Community Integration.

Hewitt, A.S., Stancliffe, R.J., Johnson Sirek, A., Hall-Lande, J., Taub, S., Engler, J., Bershadsky, J., Fortune, J., & Moseley, C.R. (2012). Characteristics of adults with autism spectrum disorder who use adult developmental disability services: Results from 25 US states. *Research in Autism Spectrum Disorders*, 6, 741–751.

Hewitt, A. (2014). *Embracing Complexity: Community Inclusion, Participation and Citizenship*. Presidential Address: American Association on Intellectual and Developmental Disabilities 138th Annual Meeting, Orlando, Florida.

HSRI (2011). What does NCI tell us about people who self-direct? *NCI Data Brief, 1*. Retrieved from <http://www.hsri.org/publication/nci-data-brief-what-does-nci-tell-us-about-people-who-self-direct>

Kozma, A., Mansell, J., & Beadle-Brown, J. (2009). Outcomes in different residential settings for people with intellectual disability: A systemic review. *American Journal on Intellectual and Developmental Disabilities*, 114(3), 193-222.

Lakin, K.C., Gardner, J., Larson, S.A., & Wheeler, B.Y. (2005). Access to support for community lives, homes and social roles. In K.C. Lakin & A.P. Turnbull (Eds.). *National goals and research for persons with intellectual and developmental disabilities* (pp. 179-215). Washington, DC: American Association on Mental Retardation.

Larson, S.A., Lakin, K.C., & Hill, S.L. (2013). Behavioral outcomes of moving from institutional to community living for people with intellectual and developmental disabilities: U.S. studies from 1977 to 2010. *Research and practice for persons with severe disabilities*, 37(4), 1-12.

Lutz, A. S.F. (2015, May 26). Who Decides Where Autistic Adults Live? *The Atlantic*. Retrieved from <http://www.theatlantic.com/health/archive/2015/05/who-decides-where-autistic-adults-live/393455/>

Montross, C. (2015, February 18). The Modern Asylum [Editorial]. *New York Times*. Retrieved from http://www.nytimes.com/2015/02/18/opinion/the-modern-asylum.html?_r=0

National Council on Disability (NCD) (2015). *Home and Community-Based Services: Creating Systems for Success at Home, at Work and in the Community*. Retrieved from <http://www.ncd.gov/publications/2015/02242015>

Nord, D., Kang, Y., Tichá, R., Hamre, K., Fay, M., & Mosley, C. (2014). Residential size and individual outcomes: An assessment of existing National Core Indicators research. *Policy Research Brief, 24*(3). Minneapolis, MN: Research and Training Center on Community Living, University of Minnesota.

Rizzolo, M.K., Larson, S.A., & Hewitt, A. (in press). Long-term supports and services for people with IDD: Research, Practice and Policy Implications. In *Research, Practice and Policy in Intellectual and Developmental Disabilities: National Goals 2015*.

Tichá, R., Hewitt, A., Nord, D., & Larson, S. (2013). System and individual outcomes in services and support for people with IDD and their predictors. *Intellectual and Developmental Disabilities, 51*(5), 298-315.