Housing and Independent Living for Individuals with Intellectual and Developmental Disabilities

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Abstract

This manuscript provides a review of housing and independent living options for individuals with intellectual and developmental disabilities (I/DD). While there has certainly been an increased emphasis on community integration and inclusion for people with I/DD, barriers to delivering housing supports and services in natural, integrated settings still exist. An overview of the various housing options that are currently available for individuals with I/DD is provided followed by a discussion of the main themes related to promoting full community integration and funding sources that are available to support these efforts. This essential information will help special education teachers involved in delivering transition services and supports better plan with students and families as they consider independent living options upon graduation from high school.

Housing and Independent Living for Individuals with Intellectual and Developmental Disabilities

Historically, housing for individuals with intellectual and developmental disabilities (I/DD) mainly consisted of forced institutionalization without consideration for the individual’s preferences, hopes, dreams, or quality of life (Prouty, Smith, & Lakin, 2006). Throughout the past several decades, national and international perspectives on housing for individuals with I/DD has continued to focus more and more on the use of person-centered planning approaches, the development of self-determination skills, quality of life considerations, and reducing inequalities (Bradley, Ashbaugh, & Blaney, 1994). However, there continue to be major barriers to providing safe, affordable, accessible, and integrated housing for individuals with I/DD. Public policy and programs often tend to promote more segregated living options due to funding issues and inflexibility with the use of Medicaid funds. This manuscript provides an overview of housing and independent living options for individuals with I/DD. This essential information will help special education teachers involved in delivering transition services and supports better plan with students and families as they consider independent living options upon graduation from high school.

AAIDD Position Statement

It is important to utilize the work of professional organizations that have a strong history of leadership and advocacy in the field of intellectual and developmental disabilities when developing plans and strategies to overcome housing barriers for individuals with I/DD. The American Association on Intellectual and Developmental Disabilities (AAIDD) is such a leading organization. In 2012, AAIDD adopted a position statement related to housing for individuals I/DD. Excerpts from this position statement are provided in Table 1. Go to http://aaidd.org/news-policy/policy/position-statements/housing#.UrIBQSivSJg to view the complete position statement. Unfortunately, there is much work to be done for AAIDD's position statement to become a reality in communities across the nation and throughout the world. However, it is essential that advocates do not lose sight of what individuals with I/DD should have access to when it comes to housing and community living regardless of the ongoing challenges of existing options.

Table 1

AAIIDD Position Statement

Excerpts from AAIDD Position Statement on Housing for Individuals with I/DD
People with I/DD 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. Housing should afford people with I/DD the opportunity to interact with people without disabilities to the fullest extent possible. The health and safety of people with I/DD 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 I/DD 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. Adults with I/DD should receive the supports they need to transition out of the family home when they wish to do so.

Housing for people with I/DD 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 I/DD 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 I/DD.

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, regardless of type or severity of disability.

Affordable housing options must be available to people with I/DD, including those with very low incomes.

Universal design should be adopted for all new housing..

People with I/DD have the right to be free from housing discrimination, and there must be robust education, outreach, and enforcement of that right.

Housing Options

In the literature on housing for individuals with I/DD (e.g., Kim, Larson, & Lakin, 2001; Kozma, Mansell, & Beadle-Brown, 2009) there are a variety of terms used to describe the options available such as family housing, out-of-family housing, clustered housing (i.e. village communities, intentional communities, residential campuses), dispersed housing, group homes, and supported living, In the sections that follow, each of these terms will be described followed by a review of recommended practices and research findings for each of the options discussed. The main focus will be on examining the quality of life of individuals with I/DD living in various housing arrangements. Quality of life considers a variety of factors including emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, independence, self-determination, social inclusion, occupation, and rights (Felce 1997; Schalock et al., 2002).

Family vs. Out-of-Family Housing

A large number of individuals with I/DD live in a family home supported by their parents or other relatives (Braddock, Emerson, Felce, & Stancliffe, 2001). This may be due to limited options for out-of-family housing, limited access to funding to support the needs of individuals with I/DD in out-of-family housing, and/or long waiting lists for options that are available for out-of-family housing. Most of the quality of life research for adults with I/DD has focused on those living in out-of-family supported accommodations (Seltzer & Krauss, 2001). There are mixed findings among the few studies focused on family vs. out-of family housing. A 2006 study (Stancliffe et al., 2006) analyzed self-reported satisfaction and well-being of individuals with I/DD living in six different states and reported higher ratings of well-being reported by those living with family members vs. those living outside of the family home. Specifically, adults with I/DD living in family homes were less likely to feel lonely, fearful, or sad and more likely to report liking where there were living than those who were not living with family members. Other studies (e.g., Krauss, Seltzer, & Goodman, 1992; Lunsky & Benson, 1999; McConkey, Naughton, & Nugent, 1983) comparing the quality of life of individuals with I/DD living in family homes vs. out-of-family homes indicate that those living in family homes often have limited contact with those living in their neighborhoods, and their leisure activities are often solitary in nature, passive, or are family dependent. A recent study in England (Felce, Perry, & Kerr, 2011) found that individuals with I/DD living independently had higher household participation than those living in family homes. Similarly, those living in staffed housing had higher household participation and did more community activities more frequently than those living in family homes.

Something that must be considered with family housing is that as older caregivers become unable to maintain their role in supporting the individual with I/DD, there is likely to be an increased demand for formal housing and support services for individuals with I/DD who are aging (Hogg, Lucchino, Wang, & Janicki, 2001). With the long waiting lists for such formal housing, this will not be a seamless transition. If individuals are supported in family housing vs. out-of-family housing, when it comes time that the family members are no longer able to provide the necessary care and support, the individual with I/DD must make a significant transition late in life as opposed to learning the skills required to live as independently as possible early on in supported living environments. A recent study (Shaw, Cartwright, & Craig, 2011) examined the housing and support needs of aging individuals with I/DD. Results indicated that many parents who provide family housing and support report that their adult child does not acquire the skills necessary for independent living when they can no longer support the individual in the family home.

Clustered Housing

Simply put, clustered housing means that individuals with I/DD are grouped together to live in close vicinity to one another forming a separate community from the surrounding population (Mansell & Beadle-Brown, 2009). There are three types of clustered housing: cluster housing, village communities, and residential campuses. Cluster housing entails a small number of houses on the same site within a wider community. For example, there may be three houses in which individuals with I/DD live that are very close to one another in a residential neighborhood. A village community is a self-contained community with services provided on site. Support workers (who may be paid or unpaid) and their families live in the village communities with the individuals with I/DD. Residential campuses are similar to village communities but usually include individuals with more severe disabilities, and paid staff members provide support to residents.

Proponents of clustered housing (e.g., Cox & Pearson, 1995; Segal, 1990) suggest the following three advantages of this option: 1) those living in clustered housing have a better social life, 2) clustered housing provides safety to residents, and 3) the cost associated with clustered housing is lower than dispersed housing. However, a 2009 study conducted by Mansell and Beadle-Brown found that dispersed housing results in better outcomes than clustered housing for individuals with I/DD when examining the following quality of life domains: social inclusion, material well-being, physical well-being, self-determination, personal development, and rights. The only exception was that village communities resulted in better physical well-being outcomes than dispersed housing due to increased hours of recreational activity, contact with medical professionals, contact with family and friends, visitors to the home, and satisfaction with relationships. The only difference in the safety of the individuals with I/DD was that those living in village communities were less likely to have been victims of crime or verbal abuse by the general public than those living in dispersed housing.

Dispersed Housing

The term "dispersed housing" refers to the model of providing housing and independent living supports to individuals with I/DD within the community. The apartments or houses in which the individuals live are scattered throughout residential neighborhoods (Mansell & Beadle-Brown, 2009). As far as cost is concerned, dispersed housing is likely to be just as expensive as clustered housing for individuals with high support needs. However, dispersed housing for individuals with low or moderate support needs is likely to be less expensive than clustered housing. Dispersed housing allows for a more individualized model of care in which residents only receive the supports they need rather than providing the same level of supports to all regardless of individual characteristics (Mansell & Beadle-Brown, 2009). This type of service delivery is referred to as targeted support and entails flexibility in staff allocation providing supports at the right level at the times when they are needed (Perry, Firth, Puppa, Wilson, & Felce, 2011). A study conducted in England (Emerson, 2004) compared cluster housing to dispersed housing and found that individuals with I/DD supported in cluster housing were more likely to be exposed to restrictive management practices such as seclusion, sedation, and physical restraint, and were also more likely to live sedentary lives with few leisure, social, and friendship activities than those living in dispersed housing. In general, the literature shows that dispersed housing offers a better quality of care and quality of life than clustered housing (Mansell, 2006).

Group homes. There are two main types of dispersed housing: group homes and supported living. Group homes are typically owned by a governmental or non-governmental organization. They house a small number of individuals with I/DD receiving support from full-time paid staff. With the de-institutionalization movement, more and more group homes have been established. Unfortunately, simply moving individuals out of large scale institutions into care facilities that are set up in single family homes, semi-attached homes, or apartment buildings doesn't guarantee that residents living in group homes will be treated the same as other neighbors in the community (Mansell & Beadle-Brown, 2009).

Neighborhood opposition to the establishment of group homes still exists and is usually based on two beliefs or fears: 1) the group home will bring down the property value of the homes in the neighborhood, and 2) the invalidated perception that individuals with I/DD are "deviant" and may be a threat to their neighbors (Cook, 1997). Of course these beliefs and fears should not deter the development of group homes simply because of the uninformed public. There will continue to be neighbors who have those invalidated concerns, but there will also be neighbors who are supportive. In a study examining the views of people with I/DD about their neighbors, a group home resident indicated that there was a petition to prevent the development of a group home when neighbors learned of the plans. However, that was also a petition started to encourage neighbors to welcome the new residents (van Alphen, Dijker, van den Borne, & Curfs, 2009). In this same study results indicated the following:

- Residents who traveled in a group mini-van to work or community places had fewer interactions with neighbors than those who traveled by bicycle or public transport.
- Several residents indicated that staff would invoke rules that would inhibit the development of relationships with neighbors such as not being able to talk to strangers and not being able to go for walks.
- Many residents indicated that although they would like to interact with their neighbors, they do not feel comfortable making those initiations. They worry that they would not be understood and that they will feel different.

A follow-up study (van Alphen, Dijker, van den Borne, & Curfs, 2010) examined the relationships between individuals with I/DD living in group homes and their neighbors, identifying the following themes:

- The presence of staff often inhibited relationships between residents and their neighbors. Staff members who do not live in the home typically do not display the expected behaviors of neighbors. Unfortunately, the staff members are often more visible to neighbors than the residents themselves, so this disconnect can negatively impact neighbor relationships.
- The organization that manages the group home often has paid workers engaging in gardening and home maintenance activities instead of residents. This takes away possible opportunities for residents to interact with neighbors during such natural activities that typically result in casual interactions between neighbors.
- The high turnover of residents may deter neighbors from establishing relationships with residents since they may not stay in the home for very long.
- The presence of staff members may deter the development of relationships between individuals with I/DD and their neighbors because neighbors are likely to interact directly with staff members instead of the residents.

These findings suggest that staff members supporting individuals with I/DD in group homes need to reconsider the manner in which they are delivering services and interacting with the residents and neighbors. Involving residents in the day-to-day home maintenance activities, teaching them ways to interact appropriately with their neighbors, and making themselves less visible to the neighbors whenever possible can help foster more meaningful relationships between residents with I/DD and their neighbors. Research shows that the more a group home resembles the neighbors' homes and the more functionally autonomous the residents, the greater the likelihood that there will be positive contact and recognition of similarities between individuals with I/DD and their neighbors (Makas, 1993).

Supported living. Supported living involves the individual with I/DD owning or renting his/her own home, sharing it with a roommate or roommates if desired, and receiving independent living supports from an agency if they choose to do so. Emerson and colleagues defined supported living as having no more than three people with I/DD living in the same residence (Emerson et al., 2001). The main difference between group homes and supported living is that with supported living, individuals with I/DD have the same housing rights as other citizens (Mansell & Beadle-Brown, 2009). Lakin and Stancliffe (2007) discuss several factors that define the differences between supported living and other housing options. These include:

- With supported living, the purpose is to shift the power to the individual with I/DD when it comes to making decisions about how they live, work, and participate in their communities.
- Living in one's own home changes how services are delivered because service delivery is not dependent on a relationship with a particular service provider. Instead the individual with I/DD controls who enters the home to provide support services.
- There is a focus on natural supports and efforts to limit formal support provided by paid staff. This shift to natural supports has led to some changes in funding provisions that allow payment to family members so that those that know the individual best are the ones providing supports to help the individual achieve their independent living goals.

Research shows that individuals with I/DD who live in smaller, individualized accommodations are more likely to engage in community activities and to have wider social networks than those living in congregated settings (Emerson et al. 2001; McConkey et al. 2007). Research also shows that supported living achieves better outcomes in some quality of life domains than group homes for individuals with low or moderate support needs (Stancliffe, 2004; Stancliffe & Keane, 2000). Individuals with I/DD who receive supported living supports in their own homes report a greater variety and frequency of community and social activities, more participation in preferred activities, better compatibility with living companions, and greater self-determination than those in more traditional group home settings (Howe, Horner, & Newton, 1998). However, social activities with typically developing peers or friends are not necessarily frequent simply because an individual with I/DD lives in the community (Cummins & Lau, 2003). Supports must be put in place to ensure the individual is not isolated. A great deal of collaboration and support among key stakeholders must be in place to achieve true integration within the community. A 2010 study (McConkey & Collins) indicated that paid staff hired to serve individuals in supported living arrangements place a greater emphasis on social inclusion than staff that work in group homes or in day programs. This study also found that part-time staff members are less likely to emphasize social inclusion than full-time staff members. Thus, training and support must be given to part-time staff members who provide supported living services to ensure they focus not only on care tasks but also on increasing the individuals' social integration in the community.

Moving to a Focus on Community and Public Services

Historically, and presently, housing solutions for individuals with I/DD focuses on government funding to social service agencies. The reality is, however, that government funding alone is significantly insufficient, and this results in agencies having to seek funds from donors. Even when agencies put forth efforts to acquire funds beyond government allocations, long waiting lists for housing supports remains to be a great problem across the nation. When individuals are taken off a waiting list to receive housing supports, there are often limited choices when it comes to location of housing, types of living arrangements, level of support and integration into the community, and roommate selection. Thus, the narrow focus on service agencies needs to move to a more broad focus on community participation and public services (Lemon & Lemon, 2003).

Microboards. A fairly new approach for providing housing supports to individuals with I/DD is what is called a microboard. A microboard consists of a small number of family members, friends, advocates, and professionals who understand the individual's unique strengths and needs working collaboratively to provide housing supports to the individual with I/DD (Lemon & Lemon, 2003). When a microboard is established, government funds can be accessed to provide housing supports to the individual without the necessity of going through an established agency. This allows for a greater deal of person-centered planning as opposed to forced choices or no choices at all.

Public services. One of the greatest contributors to whether or not an individual with I/DD is enabled to live independently and experience true community integration is the quality of public services available in the geographical location in which the individual lives. Cities and towns that provide the following services and legislation to ensure access to services for individuals with disabilities create universal opportunities for the integration of individuals with I/DD (Lemon and Lemon, 2003):

- Public, cooperative, and private subsidized housing with legislation to ensure that an adequate amount of subsidized housing be dedicated specifically to individuals with disabilities.
- Affordable and accessible public transportation systems with legislation that guarantees that outlying areas be serviced with alternative transportation services as opposed to leaving certain rural areas without transportation services.
- Guaranteed employment projects that provides support to community-based entrepreneurial projects that target individuals with I/DD and/or legislation that requires employers to hire a certain percentage of individuals with disabilities.
- Incorporation legislation that allows community groups to develop innovative community projects that provide housing solutions for individuals with I/DD that do so in collaboration with individuals with I/DD and their caregivers.

It is essential that a broad perspective on community supports and public services be examined. Advocates should focus on initiatives to expand existing services and advocate for required legislation to continue to provide more equitable independent living options to individuals with I/DD.

Main Themes Related to Supporting Independent Living

Self-Determination and Choice Making

Choice making is an essential element of the self-determination movement (Wehmeyer, 2002), person-centered planning (Holburn & Vietze, 2002), and the Quality of Life approach (Stancliff, 1997, 2001). Specific housing choices for individuals with I/DD may include: 1) the choice to move out of a housing situation if the individual is unhappy, 2) the choice of roommates (if any), 3) the type of residence, and 4) the location of the residence (Stancliff et. al., 2011). The notion that individuals with I/DD should have opportunities to choose where, how, and with whom they live is widely endorsed but commonly denied. Research has shown that individuals with I/DD rarely choose where and with whom to live (Heller, Miller, & Factor, 1999; Lakin et al., 2008; Wehmeyer & Metzler, 1995). A recent study showed that 55% of individuals with I/DD do not choose where they live, 32% participate in the decision making process with support, and only 12% choose where to live without assistance. When examining the choice of living companions, 59% had no choice, and only 21% chose with whom to live without help (Stancliffe et al., 2011). Despite the fact that fewer individuals with I/DD are living in institutions and other group settings than ever before, since 1990 there has been only a 6% increase in individuals independently choosing where to live and 12% increase in choosing with whom to live (Wehmeyer & Metzler, 1995).

Individuals with I/DD are often restricted in their choice-making opportunities because of a lack of effective social networks (Mansell & Beadle-Brown, 2004). However, there is a very fine line between a supportive social network that enables choice making and a controlling social network that oppresses individual choice. Often, there is no clear distinction between the choices of the individual with I/DD and the choices of their family members. Case managers and administrators often accept the preferences of family members as representative of the preferences of the individual with I/DD (Wiesel & Fincher, 2009). It must be noted, however, that self-determination does not simply mean that individuals with I/DD always make their own choices without input or information from others. These individuals often benefit from the support from others during the decision-making process to assist them in making informed decisions as opposed to impulsive choices (Luckasson et al., 2002).

Individuals with I/DD may be limited in their choice making options related to where and with whom to live because of long waiting lists for residential services (Wiltz, 2007). Before individuals with I/DD ever visit potential homes or meet potential roommates, they are commonly placed on waiting lists (Davis, 1997). Polister (2002) analyzed how these waiting lists are managed and found that the factors considered when moving people off of waiting lists into residential accommodations include length of time on the waiting list, emergencies, risks in current living situations, severity of disability, potential service benefits, and age of care taker. Unfortunately, the individual's choice was not a considered factor.

Individuals with low support needs often have more available choices than individuals with high support needs (Fitzpatrick & Pawson, 2007; Stancliffe et al., 2011). Individuals living in their own home or an agency-operated apartment are more likely to have opportunities to choose where and with whom to live than those living in a group home (Stancliffe et al., 2011). Community living environments that are more individualized with fewer residents are associated with more opportunities for choice making (Burchard, Hasazi, Gordon, & Yoe, 1991; Stancliffe, 1997; Stancliffe & Abery 1997; Stancliffe, Abery, & Smith, 2000; Stancliffe & Keane, 2000; Wehmeyer & Bolding, 1999). Individuals in supported living have more opportunities to choose where and with whom to live and also tend to rate higher in other areas of quality of life than those living in group homes (Emerson et al., 2001; Howe, Horner, & Newton, 1998).

Choice making is one aspect of self-determination. Self-determination also consists of the individual setting their own goals and evaluation their progress towards meeting those goals. According to Wehneyer, self-determination entails "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference" (Wehmeyer, 1996, p.18). Research shows that individuals with I/DD who have greater self-determination skills also have a greater quality of life (Lachapelle et al., 2005; Wehymeyer & Schwartz, 1998). Thus, those who provide supported living services need training related to enhancing the self-determination skills for individuals with I/DD.

Person-Centered Planning

An important focus when supporting individuals with I/DD is to use person-centered planning protocols. This provides opportunities for individuals to share their dreams and set goals with their support teams so that a plan can be developed to assist the individuals in achieving the goals identified (Wigham et al., 2008). Several outcome studies have found that person-centered approaches can result in the individuals having greater choice, increased contact with friends and family, and more community participation (Holburn et al., 2004; Robertson et al., 2006). While goal setting and developing a plan is the basis of person-centered planning, a recent study demonstrated that the success of individuals with I/DD in achieving the goals they set often relies on how much assistance they get from support staff (McConkey & Collins, 2010). Individuals who provide independent living support services need training to understand how to involve people with I/DD when making housing plans, but they also need to develop expertise in setting up appropriate levels of supports to ensure the individuals can achieve their goals and continue to increase their independence through the supports provided.

Needs/Social Mix/Choice

Mainstream social housing allocations are made with three main considerations: 1) the financial needs of the individuals 2) the social mix of residents focusing on diversity of income levels and race), and 3) consumer choice (Wiesel, 2011). These same considerations should be made for individuals with I/DD, however, needs, social mix (diverse mix of residents), and choice entail more complex considerations for those with I/DD than other mainstream recipients of social housing. Needs is not simply a financial issue, but an issue of the independent living needs and supports the individuals will require. Social mix is not only related to income levels and race, but it is related to the mix of individuals with different levels of impairments associated with their disabilities and the social mix with individuals without disabilities. Choice entails not only the location and type of residence, but, in some cases, it also involves the choice of roommates who are compatible with the individual. Wiesel (2011) argues that an over-emphasis on any one of these considerations is problematic for the following reasons:

- When need is the main focus for housing allocations, there is a risk of having a crisis-driven system in which individuals with the most severe independent functioning and/or behavioral needs have priority over allocations than those with less support needs.
- When social mix becomes a main priority, individuals with I/DD lose the options to make roommate choices.
- When choice is the main focus without consideration of needs and mix, people with higher levels of needs may not have access to the supports and services they require due to inflexible funding structures and/or individuals with the highest level of needs may experience minimal social mix.

Unfortunately, there is no formula for how we should weigh the importance of needs, social mix, and choice. However, it is essential that decisions for social housing be made with carefully consideration of all three of these factors to ensure the most appropriate allocations are made.

Housing Accommodations

An additional barrier faced by individuals with I/DD who also have physical impairments is the lack of housing options that provide the necessary accommodations they need for independent living. Lakin and Stancliffe (2007) describe a variety of accommodations to consider when examining ways to promote independent functioning:

- Physical modifications such as ramps and specially designed kitchens and bathrooms.
- Technologies such as alerting systems and one-touch phones.
- Modified supports such as periodic phone call check-ins, training in independent living skills, or living with a companion without a disability.
- Careful selection of environments such as choosing housing near shops, family, and/or work to decrease travel demands.

It is essential to determine what accommodations can be put in place to allow an individual with I/DD to live as independently as possible without necessitating full-time supervision and care.

Housing Funding Sources for Individuals with I/DD

It continues to be a challenge to cover the cost of providing independent and integrated living options for individuals with I/DD. This section that follows provides an overview of federal and state funding sources available to individuals with I/DD to support housing costs including Medicaid and community-based waiver programs, the National Council on Independent Living (NCLI) , and the Section 8 Houser Choice Voucher Program.

Medicaid and Home and Community-Based Waivers

In 1965, the Medicaid program began to provide medical care for low income Americans. Initially, funding for individuals with disabilities was exclusive to those residing in institutions. Any funding for individuals in their own home or community based housing was limited to primary medical needs, such as doctor visits and hospital stays. Long-term care was only available for skilled nursing facilities (SNF) for individuals aged 21 and older. Due to the high costs of nursing care facilities, and public criticism that Medicaid favored institutionalization, the government began to focus on cost effective methods such as home health services (see: http://aspe.hhs.gov/daltcp/reports/primer.htm).

In the 1980's, demand increased to fund individuals to stay at home or move out into the community. Congress approved the 1915(c) waiver program in 1981, which allowed states to provide services for individuals to avoid institutionalization. These services were not previously provided under Medicaid. Examples of waiver services included case management, homemaker, home health aide, personal care, sdult day health habilitation. and respite care. In order to meet the demands of their citizens, many states expanded their programs to include home and community-based housing. In the early 1990's states began to issue Home and Community Based Services (HCBS) waivers under 1915(c) (see http://www.pascenter.org/documents/PASCenter_HCBS_policy_brief.php).

In 1999, the Supreme Court decided the *Olmstead v. L.C.* case. The case involved two women with developmental disabilities living in Georgia (Lois Curtis and Elaine Wilson). It was found that these women would be best served in the community instead of in an institutional setting. The state refused to move them into the community. Atlanta Legal Aide filed suit against the Georgia State Commissioner of Human Resources (Tommy Olmstead). The resulting Olmstead decision declared that persons with disabilities have a right to live in the community. The Court stated that the institutionalization of people is working under the assumption that they are not capable or worthy of public life, and individuals who were restricted to life in an institution faced isolation and limited social, family, work, and educational experiences and opportunities for independence. The Olmstead decision supports the right of persons with disabilities to leave institutions if they could benefit from life in the community. It challenged the government to develop and provide more opportunities through community-based services. The Olmstead ruling provided guidance for states regarding Title II of the ADA. It clarified the ADA "integration mandate" through the assertion that states had an obligation to ensure Medicaid-eligible persons did not experience discrimination by remaining in institutions if they would be better served in the community. If a person was unable to benefit or was not equipped to live out in the community, the Americans with Disabilities Act (ADA) would not prevent them from residing in an institution. Olmstead also found that state responsibility to provide community based treatment was not limitless (see http://aspe.hhs.gov/daltcp/reports/primer.htm).

The Olmstead ruling prompted states to create formal plans for more community integration. While there has been some guidance from the Centers for Medicare and Medicaid Services (CMS), there is a great amount of variation from state to state. States face a number of obstacles when it comes to community integration, including funding, labor shortages, and the lack of affordable housing (see http://www.balancingincentiveprogram.org/sites/default/files/Thomson_Reuters_2011LTSSExpenditures_Final.pdf).

The Home Care Financing Administration (HCFA) approved 242 waiver programs in 2000. States may offer multiple numbers of waivers. In 1998, the average cost per waiver participant was $14,950. The average cost of Home and Community Based waiver services for an individual with developmental disabilities was $29,353. The average cost of HCBS waiver program for seniors was only $5,362. Spending on long care community-based services has increased from

$17 billion in 1999 to $52 billion in 2009. In 2009, more than half of all Medicaid recipients received care in a community setting. However, there is still a greater demand for community-based services. In 2009, 1.6 million individuals remained in institutions while awaiting community-based services (see http://www.pascenter.org/documents/PASCenter_HCBS_policy_brief.php#c2). Presently, 28 percent of long-term care Medicaid spending is directed toward services for in home and community based services. The states have great flexibility when it comes to waiver services. Residential benefits and services may be offered through the states' standard Medicaid program or through home and community-based waiver programs. States may offer a variety of different programs to meet the needs of consumers. Due to the fact that states have extreme flexibility when it comes to Medicaid, there are fifty different states with fifty different Medicaid programs. Forty-eight states operate over 300 waivers. In 2009, 45 percent of all Medicaid spending on long term care was from HCBS services. This percentage varies from state to state (see http://www.hhs.gov/asl/testify/2010/06/t20100622a.html).

The National Council on Independent Living

The NCIL is a membership organization founded in 1982, and it operates on the premise that people with disabilities know what they want and know what is best for them. They believe that individuals with disabilities have a right to live in the community, and deserve equal rights and opportunities. Individuals with all types of disabilities have a common struggle and they have more political power as a group. NCIL represents individuals with disabilities, Centers for Independent Living (CILs), Statewide Independent Living Councils (SILCs), and other organizations that advocate for the rights of people with disabilities throughout the United States (see http://www.ncil.org).

NCIL has two types of membership. The individual annual membership fee is $35, with a reduced fee of $10 for individuals under the age of 26. The dues may be negotiable if there is a financial hardship. Organizational memberships are based on the organization's annual budget, not including pass-through funds. Membership fees for a Center for Independent Living (CIL), Statewide Independent Living Council (SILC), or other organization with an annual budget between $100,000 and $200,000 would cost $286 per year. An organization with an annual budget between $900,000 and $1,000,000 would pay fees of $1,573 per year. Member benefits include voting rights to select board members, opportunities to join committees, action alerts for critical issues, reduced fees for the NCIL Annual Conference, and access to training sessions (see http://www.ncil.org).

NCIL provides a directory for Statewide Independent Living Councils (SILCs). There are currently 56 SILCs nationwide. SILCs work with state agencies to develop and implement independent living plans for its citizens. They are consumer controlled, and the majority of the voting members are individuals with disabilities who are not employed by a CIL or a state agency. SILCs are responsible for monitoring and evaluating federally mandated state plans for Independent Living (see http://www.ncil.org/about/aboutil/). Members are typically appointed by the Governor of each state, and most have disabilities and/or are knowledgeable about disability advocacy. SILCs are not for profit organizations (501 (c) 3). SILCs promote the independent living philosophy throughout the state and provide support and technical assistance to the

Centers for Independent Living (CILs). They promote the philosophy that all individuals have a right to live independently in society with self-determination and peer support.

NCIL provides a directory for Centers for Independent Living (CILs). Currently there are 403 CILs in the United States (see http://www.ilru.org/html/publications/directory/SILC.html). According to Section 702 of the Rehabilitation Act of 1973, a Center for Independent Living means it is a, "…..consumer-controlled, community-based, cross-disability, nonresidential private nonprofit agency that is designed and operated within a local community by individuals with disabilities and provides an array of independent living services" (see http://www2.ed.gov/programs/cil/index.html). Individuals with disabilities make up 51% of the staff and 51% of the Board of Directors. CILs provide four core services including information and referral independent living skills training, individual and systems advocacy, and peer counseling (see www.ncil.org).

CILs are committed to being consumer controlled and including individuals across all disabilities. In order to qualify for federal funding for CILs, states must establish a Statewide Independent Living Council (SILC). States must also establish a statewide independent living plan approved by their SILC chairperson and the state director of Vocational Rehabilitation. Grant funding for CILs is based on population. The federal government oversees the awarding of grant funds. If the amount of state funding for the CILs exceed federal amounts, then the state may apply to oversee the awarding of all grant funds the following year. Currently, only three states manage their own grant money (see http://www2.ed.gov/programs/cil/index.html).

Section 8 Houser Choice Voucher Program

The Section 8 Housing Choice Voucher Program is a federal program for assisting very low-income families, the elderly, and people with disabilities to afford housing in the private market. Participants are able to find their own housing, including single-family homes, townhouses and apartments. Housing choice vouchers are administered locally by public housing agencies (PHAs). The PHAs receive federal funds from the U.S. Department of Housing and Urban Development (HUD) to administer the voucher program.

An individual or family that is issued a housing voucher is responsible for finding a suitable housing unit of choice where the owner agrees to rent under the program. Rental units must meet minimum standards of health and safety, as determined by the PHA. A housing subsidy is paid to the landlord directly by the PHA on behalf of the participating family or individual. The family or individual then pays the difference between the actual rent charged by the landlord and the amount subsidized by the program. Under certain circumstances, if authorized by the PHA, a family may use its voucher to purchase a modest home (see http://portal.hud.gov/hudportal/HUD?src=/topics/housing_choice_voucher_program_section_8).

Unfortunately, the wait list for this housing voucher program is extremely long, and they often close waiting lists if there are more individuals and families on the list than can be helped in the near future. Also, PHAs may establish local preferences for selecting applicants from its waiting list. For example, PHAs may give a preference to a family who is (1) homeless or living in substandard housing, (2) paying more than 50% of its income for rent, or (3) involuntarily displaced. Families who qualify for any such local preferences move ahead of other families and individuals on the list that do not qualify for any preference. Each PHA has the discretion to establish local preferences to reflect the housing needs and priorities of its particular community.

Conclusion

Fortunately, there has been a general trend of increased inclusion of individuals with I/DD related to independent living in communities across the nation and more thoughtful consideration of quality of life indicators when comparing different housing options. Likewise, there has been a more focused effort on person-centered planning and building self-determination skills of individuals with I/DD as they are more involved in identifying their unique strengths and needs, setting goals for themselves, evaluating their own progress towards meeting their goals, and they have many more choice-making opportunities related to their living options than in the past. Unfortunately, concerns remain in regards to meeting the varied needs of individuals with I/DD to support an increasing trend towards higher rates of independent living for this population. Lakin and Stancliffe (2007) discussed how the Medicaid scrutiny and cost-containment initiatives continues to pose a threat to sustaining and improving housing supports since Medicaid is a primary funding source for these efforts. There continues to be a great deal of competition and long waiting lists for housing supports considering the varied needs of individuals with I/DD, the positive move towards more community inclusion, and the steadily increasing ageing population. Another area of concern is research showing that individuals with more severe disabilities have less favorable outcomes on quality of life indicators than those with mild disabilities (Perry & Felce, 2003). This suggests that there needs to be a greater emphasis on providing a better quality of services and supports for those with more significant disabilities to enable them to experience a quality of life at least comparable to those with mild disabilities. To continue the progression towards equality in housing and independent living for individuals with I/DD advocates need to think creatively, pursue legislation to provide flexibility in funding for housing supports, develop initiatives to improve the training provided to staff who provide supported living services, and encourage the use of evidence-based practices when teaching independent living skills to youth and adults.

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