

Housing and Independent Living for Individuals with Intellectual Disabilities

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Chapter 1

Literature Review

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. 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. 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 chapter includes a review of the literature related to housing options and independent living for individuals with I/DD.

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 the following position statement related to housing for individuals 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. Providers should honor individual choices and preferences.
- 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. Institutional settings and large congregate living arrangements are unnecessary and inappropriate for people with I/DD, regardless of type or severity of disability.
- Affordable housing options must be available to people with I/DD, 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 I/DD receive their fair share of all local, state, and national housing resources.
- 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 I/DD have the right to be free from housing discrimination, and there must be robust education, outreach, and enforcement of that right. People with I/DD must have opportunities comparable to those of people without disabilities to rent or buy their own homes (<http://aaidd.org/news-policy/policy/position-statements/housing#.UrIBQSivSJg>).

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 we do not lose sight of what individuals with I/DD should have access to when it comes to housing and community living as we deal with the ongoing challenges of existing options. The following literature review will share information about the different housing options currently available for individuals with I/DD, essential themes related to supporting independent living of individuals with I/DD, and research-based practices that can be utilized to prepare individuals with I/DD for successful independent living to the maximum extent possible.

Housing Options

In the literature on housing options for individuals with I/DD there are a variety of terms used to describe the options available such as dispersed housing, group homes, supported living, clustered housing, village communities or intentional communities, residential campuses, family housing, and out-of-family housing. 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.) 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 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 (Krauss, Seltzer, & Goodman, 1992; Lunskey & Benson, 1999; McConkey, Naughton, & Nugent, 1983). A recent study in England 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 (Felce, Perry, & Kerr, 2011).

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. In a recent study examining the housing and support needs of aging individuals with I/DD, many parents who provided family housing and support reported that because their adult child had always been cared for at home, they had not acquired the independent living skills necessary to increase their choices of accommodation and support when the time came that the family could no longer support the individual (Shaw, Cartwright, & Craig, 2011).

Clustered Housing

Simply put, clustered housing means that individuals with I/DD are grouped together to live in close vicinity to one another. There are three types of clustered housing: cluster housing, village communities, and residential campuses. Cluster housing typically 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 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 (Cox & Pearson, 1995; Segal, 1990). 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. A study conducted in England in 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 (Emerson, 2004). In general, the literature shows that dispersed housing offers a better quality of care and quality of life than clustered housing (Mansell, 2006).

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. 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).

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. 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 individual indicated that there 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:

1. 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.
2. 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.

3. 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.

In a follow-up study that examined the relationships between individuals with I/DD living in group homes and their neighbors (van Alphen, Dijker, van den Borne, & Curfs, 2010), several themes were identified:

1. 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.
2. 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.
3. The high turnover of residents may deter neighbors from establishing relationships with residents since they may not stay in the home for very long.
4. 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:

- a) 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.
- b) 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.

c) 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 non-disabled 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 indicated that paid staff that support individuals in supported living arrangements place a greater emphasis on social inclusion

than staff that work in group homes or in day programs (McConkey & Collins). 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 to this day, 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 resulting 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. 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):

- a) Public, cooperative, and private subsidized housing with legislation to ensure that an adequate amount of subsidized housing be dedicated specifically to individuals with disabilities.
- b) 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.
- c) 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.
- d) 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. 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 (Wehmeyer & Metzler, 1995; Heller, Miller, & Factor, 1999; Lakin et al., 2008). 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 much 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; Wehmeyer & Bolding 1999; Stancliffe & Keane 2000; Stancliffe, Abery, & Smith, 2000). 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 (Howe, Horner, & Newton, 1998; Emerson et al. 2001).

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. Research shows that individuals with I/DD who have greater self-determination skills also have a greater quality of life (Lachapelle et al., 2005; Wehmeyer & 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, 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:

- a) 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.

b) When social mix becomes a main priority, individuals with I/DD lose the options to make roommate choices.

c) When choice is the dominant focus without much 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:

a) Physical modifications such as ramps and specially designed kitchens and bathrooms.

b) Technologies such as alerting systems and one-touch phones.

c) Modified supports such as periodic phone call check-ins, training in independent living skills, or living with a companion without a disability.

- d) 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.

Teaching Independent Living Skills

To increase the development of independent living skills for individuals with I/DD, there are a variety of evidence-based teaching approaches to incorporate into educational experiences from youth to adulthood. First and foremost, however, it is imperative to focus on providing opportunities for children, adolescents, and adults with I/DD to develop a variety of daily living skills. Often times, caregivers report that they help their child with most activities of daily living or even do the tasks for them without focusing on increasing the child's independence. This can be due to the challenges with raising a child with I/DD, time constraints, stress, and lack of training on how to teach daily living skills to increase the child's independence. Dr. Lou Brown, one of the leading advocates for the inclusion of individuals with severe disabilities and promoters of teaching independent functioning skills says, "We have to stop retarding our children." This may be a harsh statement, but it speaks the message loud and clear. In order for individuals with I/DD to truly become independent as possible, caregivers, educators, and service providers must commit to setting independent functioning goals and using evidence-based teaching practices to promote the development of independent living skills.

Task Analysis

Task analysis is a common instructional approach to teaching independent living skills. This entails breaking a task down into sequential steps and then teaching the steps using one of three chaining procedures: forward chaining, backward chaining, or total task presentation. With forward chaining, you teach the individual the first step of the task, the second step, and so on. Backward chaining involved first teaching the last step, second to last step, and so on. Total task presentation presents all steps every time the task is performed gradually increasing the individual's independence throughout the task.

Pictorial Representations

Using pictorial instructions presented on cards is an effective strategy for teaching chained tasks to individuals with intellectual disabilities (Johnson & Cuvo 1981; Wacker, Berg, Berrie, & Swatta, 1985; Bergstrom, Pattavina, Martella, & Marchand-Martella, 1995). The pictures serve as cues to remind the individual to complete each step of an independent living task. It is usually necessary to combine the use of the pictorial instructions with prompting and fading procedures and positive reinforcement when the individual is first acquiring a new skill (Pierce & Schreibman, 1994). Pictorial representations can also be implemented using computers instead of cards (Lancioni., Van den Hof, Boelens, Rocha, & Seedhouse, 1998). Computer software and apps on tablets are viable options for individuals that have difficulty physically handling cards or need reminders that this instructional technology can provide to remain on task (Lancioni & O'Reilly, 2002).

Time Delay

Time delay is another evidence-based practice for teaching independent living skills to individuals with I/DD (Schuster, Gast, Wolery, & Guiltinan S, 1988; Schuster &

Griffen, 1991). This involves providing a certain amount of time for an individual to respond before providing a prompt. There are two types of time delay that can be used: constant time delay and progressive time delay (Collins, 2007). With constant time-delay, for the first session the instructor uses a 0-second time delay by providing the prompt immediately following the opportunity to respond. Then for each successive session, the instructor increases the time delay to a fixed amount of time (ex. three seconds). With progressive time-delay, the instructor gradually increases the time delay by first starting with 0-second time delay during the first session, 1-second time delay during the second session, and so on. This strategy ensures that the individual is successful by providing prompts if there is not a correct response, but also prevents prompt dependency by using a time delay to encourage a response without a prompt. Combining the time delay strategy with pictorial representations can be effective for individuals who need visual supports (Griffen, Wolery, & Schuster, 1992).

Systematic Prompting and Fading Procedures

When focusing on teaching independent living skills to individuals with I/DD, it is essential to ensure that people do not become dependent on prompts from educators, caregivers, and service providers. One way to decrease prompt dependency is to systematically fade any prompts that are used during skill acquisition phases on learning. There are two ways to fade prompts: most-to-least prompting and least-to-most prompting. Regardless of the method, the first step in fading prompts is to establish a prompt hierarchy. With most-to-least prompts, the instructor first uses the highest level of prompting on the hierarchy and then gradually moves to lesser degrees of prompting until eventually the individual responds without prompts. With least-to-most prompting, the

instructor begins with the lowest degree of prompting and increases the amount of prompts if the individual does not respond.

Video Based Instruction

Independent living skills can also be taught using video based instruction (Rayner, Denholm, & Sigafoos, 2009; Rehfeldt, Dahman, Young, Cherry, & Davis, 2003; Sigafoos et al., 2005). This entails showing the individual a video of the target skill(s) being demonstrated in the natural environment and then providing opportunities for the individuals to imitate the skill(s) observed in the video (Mechling et al., 2005). This type of instruction provides the visual supports that many individuals with I/DD require, allows them to focus on examining the task without being distracted by other environmental factors, and can reduce their reliance on prompts. There are four ways to use video based instruction: basic video modeling, video self-modeling, point-of-view video modeling, and video prompting (Franzone, & Collet-Klingenberg, 2008). Basic video modeling involves videoing someone other than the individuals performing the skill and having the individual watch the video so that the skill can then be imitated. Video self-modeling is used to record the individual demonstrating the skill and having the individual watch him/herself performing the skill so the skill can then be imitated in the natural environment. This requires “behind the scenes” prompting and editing so the video watched by the individual shows an uninterrupted, unprompted demonstration of the skill. Point-of-view video modeling is when the video is recorded from the perspective of the individual. Thus, the individual is simply watching the task be performed as opposed to watching someone perform the task. For example, when teaching how to wash dishes using point-of-view video modeling, the video would

simply show someone's hands performing each step of the task. Video prompting involves breaking a task into steps and recording each step with pauses so the individual may attempt the step before viewing subsequent steps.

Computer-Based Intervention

Computer-based instruction is a promising intervention strategy for teaching daily living skills to individuals with I/DD (Ramdoss, Lang et al. 2012; Ramdoss, Mulloy et al. 2011). The computer presents visual and audio stimuli related to the target skill and allows the individual to interact with the program using touch screens, trackballs, switches, keyboards, or scanners (Mechling, Gast, & Barthold, 2003). This allows the use of specific reinforcement contingencies, corrective feedback, and tailored prompting hierarchies (Higgins & Boone 1996; Mechling, PrI/DDgen, & Cronin, 2005).

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) discuss 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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Chapter 2

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 chapter 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, and the Section 8 Houser Choice Voucher Program. The chapter concludes with an overview of policies and procedures used in selected states to allocate funding for housing supports and services.

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 (<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
- Adult day health habilitation
- 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)

(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 out 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 decisions 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 (<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 (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 (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 (<http://www.hhs.gov/asl/testify/2010/06/t20100622a.html>).

The National Council on Independent Living

The National Council on Independent Living (NCIL) is a membership organization founded in 1982. NCIL 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 (<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.

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 (<http://www.ncil.org/about/aboutil/>). Members are typically appointed by the Governor, 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 (<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” (<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:

- Information & referral
- Independent living skills training

- Individual and systems advocacy
- Peer counseling

CILs are committed to being consumer controlled and including individuals across all disabilities (www.ncil.org). 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 (<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.

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. For more information on the Section 8 Housing Choice Voucher Program visit:

http://portal.hud.gov/hudportal/HUD?src=/topics/housing_choice_voucher_program_section_8.

Overview of State Level Housing Supports for Individuals with IDD

While there are not drastically different policies and available options when it comes to housing supports across the nation, each state may have some unique difference in policy or may have residential options not offered in other states. An overview of how some states are currently providing access to housing supports is provided. A more detailed review of supports and services available in South Carolina is provided since this research was funded by College Transition Connection, a South Carolina organization

that works with select colleges and universities in South Carolina to design, create and fund transition and post-secondary opportunities for young adults with intellectual disabilities (<http://collegetransitionconnection.org/>).

South Carolina

The South Carolina Department of Disabilities and Special Needs (SCDDSN) is the state agency that plans, develops, coordinates and funds services for South Carolinians with intellectual and developmental disabilities (<http://ddsn.sc.gov/Pages/default.aspx>). SCDDSN works with other state agencies to coordinate, arrange for and deliver services to eligible individuals. SCDDSN provides services through contracts with local service-provider agencies. Many of these agencies are called Disabilities and Special Needs (DSN) Boards, and they serve every county in South Carolina. There are also approximately 60 other qualified service providers available in many locations around the state.

Eligibility and Person-Centered Planning. Each local DSN Board serves as the initial entry point into the SCDDSN system. The DSN Board will first conduct a screening and send an eligibility packet to SCDDSN. The eligibility process should not take more than ninety days. Once a person becomes eligible for SCDDSN services, it is determined what level of service coordination the individual will receive, based upon the assessed needs. There are two levels of services. Level I services provide active, ongoing supports and Level II services provide intermittent assistance as needed.

A service coordinator then works with the individual and his/her family and friends to develop a person-centered plan to address the needs identified and to monitor the implementation of the plan. The purpose of the person-centered plan is to give

individuals and their families the power to use the resources allocated to them in a way that makes sense to them. There are two types of person-centered plans: basic plans and life plans. With the basic plans, goals are set and a plan is developed that identifies the services and supports the individual wants and needs and available resources are utilized to select who will provide these services. Life plans are different in that the goal of the plans is to prioritize and identify important goals and preferences for an entire lifetime. The service coordinator will look at both immediate and long-term goals. Selected meeting participants will be responsible for working with the individual to monitor the life plan. Regardless of which person-centered plan is being used, if the individual is not satisfied with the services and supports he or she is receiving, another qualified provider can be selected.

Once the person-centered plan is developed, individuals may then choose from the SCDDSN directory of service providers (<https://app.ddsn.sc.gov/public/directory/landing.do#>), which lists all the organizations and agencies qualified to provide service. For housing services, individuals select providers under residential habilitation. In order to be listed in the directory, a provider must meet all federal, state and SCDDSN requirements for quality and safety. After service providers are selected, service coordinator oversight and monitoring must occur at least monthly for the first 2 months and then at least quarterly. Information gathered during monitoring may lead to a change in the service, such as an increase or decrease in services authorized, change of provider, or a change to a more appropriate service.

Residential Habilitation Services. There are four different types of residential habilitation services: supported living programs (SLP), community training homes

(CTH), intermediate care facilities (ICF), and regional residential centers. With SLP services adults live in apartments, duplexes or single-family houses and receive support as needed. Currently there are 71 SLP settings in South Carolina with 43 different providers, and they are the least restrictive environments. There are two types of supported living programs: SLP-I and SLP-II. With SLP-I, the staff may stop by a few times a week as needed, and they are also available by phone. In SLP-II settings, staff is on site 24 hours.

Community training homes (CTH) provide personalized care and training with no more than 4 people living in a house. There are two types of community training homes: CTH-I and CTH-II. In CTH-I homes, private citizens open their houses to individuals with disabilities. They are trained and the house must pass all inspections and be qualified & licensed as a CTH-I. CTH-II homes have employees who provide care in a state licensed house that is owned or rented by a provider organization. Statewide, there are currently 128 CTH-I homes with approximately 4 people in each home. There are 674 CTH-II homes with approximately 4 people in each home making this the largest type of residential setting in South Carolina.

Intermediate care facilities (ICF) are structured residential environments where individuals receive 24-hour care, supervision, training, and recreation. There are currently 71 individuals in ICF residences.

Regional Residential Centers provide 24-hour care and treatment for individuals with the most complex, severe disabilities. Currently there are 745 residents in these centers. The locations are: Columbia, Florence, Clinton, Summerville, and Hartsville. SCDDSN directly oversees the operation of these facilities, which are managed by a

facility administrator.

Waivers. Prior to 1981, the Federal Medicaid program paid for services to SCDDSN consumers with intellectual and developmental disabilities only if that person lived in an institution. In 1981 the Social Security Act was amended to allow states to offer Medicaid funding for long-term care services when those services are provided in the person's home or community. This became known as the Home and Community Based (HCB) Waiver or Medicaid Waiver option.

Community Supports Waiver. The South Carolina Department of Health and Human Services (SCDHHS) is the state agency responsible for all Medicaid funding. Since 1991, SCDHHS and SCDDSN offer the Community Supports Waiver as an option for individuals with intellectual disability or related disabilities to choose to receive care at home rather than in an Intermediate Care Facility for Persons with Intellectual Disabilities (ICF/I/DD). Although the individual may choose to receive care at home, he/she must require the degree of care that would be provided in the ICF/I/DD. The purpose of the Community Supports Waiver is to offer opportunities for individuals to self-direct certain services if they choose. Available services available with the Community Supports Waiver include:

- Personal Care I/II
- Adult Day Health Care (ADHC)
- ADHC Nursing
- ADHC Transportation
- Respite Care
- Environmental Modifications

- Medical Equipment, Assistive Technology and Appliances
- Incontinence Supplies
- Private Vehicle Modifications
- Behavior Support Services
- Day Activity Services
- Career Preparation Services
- Community Services
- Employment Services
- Support Center Services
- In-Home Support
- Personal Emergency Response System

For more information on the Community Sports Waiver go to:

<http://ddsn.sc.gov/about/directives-standards/Documents/attachments/738-01-DD%20-%20Attachment%204b%20%28Revised%20050911%29.pdf>.

Intellectual Disabilities/Related Disabilities (I/DD/RD) Waiver. In addition to the Community Supports Waver, as of March 2011, housing rehabilitation services may be funded through South Carolina's Intellectual Disabilities/Related Disabilities (I/DD/RD) Waiver. Services available through this waiver include:

- Personal Care I/II
- Residential Habilitation
- Environmental Modifications
- Private Vehicle Modifications
- Specialized Supplies, medical equipment, and assistive technology

- Incontinence Supplies
- Prescriptions Drugs
- Respite Care
- Audiology Services
- Adult Companion Services
- Nursing Services
- Adult Dental and Vision
- Adult Day Health Care (ADHC)
- ADHC Nursing
- ADHC Transportation
- Adult Attendant Care
- Behavior Support Services
- Psychological Services
- Career Preparation
- Employment Services
- Day Activity
- Community Services
- Support Center Services
- Personal Emergency Response System

For more information on the I/DD/RD Waiver go to:

<http://ddsn.sc.gov/providers/Medicaidwaiverservices/mrrd/Documents/Default/WaiverInformationSheet.pdf>.

Funding allotments. SCDDSN uses a funding level system for the waivers. The

money is disbursed based on the needs of the individual. Needs are determined by assessments. For example those who qualify for ICFs receive approximately \$70,000-73,000 per year. Those who qualify for CTH-II receive \$27,000 per year. Those who qualify for CTC-I receive \$20,000 per year. Those who qualify for SLP receive \$15,000 to \$16,000 per year. When individuals qualify for a waiver, they are set up with a checking account. Money from the waiver is dispersed into the account, which is then monitored by the state and independent organizations. The bills are paid from the account and the remainder is for the individual to spend as he or she wishes. The individual's account balance cannot exceed \$2,000, or their eligibility for Medicaid and assistance could be at risk. If an individual has a full time job or other sources of income, he or she may make alternative financial arrangements, such as a pooled trust or Medicaid trust fund. It is important to note that waivers that provide residential habilitation services do not cover the costs of room and board. The waiver covers the care, skills, training and supervision services provided to individuals in a non-institutional setting. Room and board is typically paid for by Supplemental Security Income (SSI) checks or earned income. SSI is a federal program that provides monthly financial payments to persons with disabilities who have limited income. An individual who meets the eligibility criteria for SSI can receive monthly payments up to \$710 for the 2013 program year. Married couples (with no children), where both spouses are eligible for SSI, can receive up to \$1,066 per month. Many states have programs that provide financial supplements to individuals who receive SSI. Individuals with a deceased or retired parent may qualify for more money. The level of funding varies from state to state.

Waiting lists. The unfortunate reality is that simply being eligible for waiver

programs does not guarantee that an individual will be a recipient. Saying that there are long waiting lists would be an understatement. As of August 2013, there were over 4,431 individuals on the I/DD/RD waiver waiting list and 3,869 individuals on the Community Supports waiver waiting list.

To add to this overwhelming wait list barrier to accessing funds, when a slot does become available for the I/DD/RD waiver, top priority goes to critical cases. Individuals on the critical cases list include those who are in imminent danger, have an immediate need for direct care or supervision, have recently lost a primary caregiver or are at imminent risk of losing a primary caregiver, or are ready for discharge or have recently been discharged from a hospital and need services immediately to prevent readmission. At any given time throughout the year, there may be 40 to 50 people on the critical waiting list.

Here is another harsh reality: When an individual has an opportunity to be moved off of a waiting list and access funding, the individuals must accept a placement where space is available. It is not uncommon for an individual to have to move to a different city or region of the state moving away from relatives, friends or employment because there are so few housing options.

The Babcock Center. The Babcock Center is the largest private provider of community services for people with severe lifelong disabilities in South Carolina. They currently serve approximately 800 individuals. Mary Duffie started the program in 1967 by providing daycare to preschool children with disabilities. In 1971, she found a man and a woman with disabilities living in a chicken coop and realized the need for housing for adults with disabilities. The Babcock Center launched South Carolina's first

community residential services for adults with I/DD. In the late 1970s, the agency obtained funding to construct smaller, more home-like residences in local neighborhoods.

Prospective residents must first register with SCDDSN. They must specify that they wish for the Babcock Center to be their service provider. They have a waiting list, the length of which changes on a daily basis. Most openings occur when someone passes away. According to the center, they have fifty-nine facilities housing approximately 400 residents. They have thirty, four bedroom community training homes. The CTH homes have mid-level staff 24 hours a day. That staff provide help as needed and independent living skills training. They have two intermediate care facilities (ICF) with twenty residents in each facility. They also have two apartment buildings with on-site staff to provide medication when scheduled and transportation when needed. In general, staff checks in on them on a weekly basis. For more information about the Babcock Center visit: <http://www.babcockcenter.org/>.

Tri Development Center of Aiken County. The Tri-Development Center offers career preparation services. Examples include career exploration, safety and advocacy skills. Employment services with supervision and training are available to residents in group or community settings. Job coaches are available to assist with on the job training and time management skills. Day programs are provided in facility-based settings. They may include games and crafts as well as communication and social skills activities. Residents in day programs are taught self-determination and self-advocacy skills. Community services expose residents to community resources and participation. Community services may occur in the facility or out in a natural setting. The Tri-Development Center offers prevention services and self-advocacy group meetings. The

Tri Development Board of Aiken County has thirty-two residential facilities that house 179 individuals. These are described below.

- **SLP-II.** The Tri Development Center has twenty single bedroom apartments in the SLP II category, called the Aiken Apartments. One staff member is on site 24 hours a day. Rent is paid based on income and the remainder is subsidized by the US Department of Housing and Urban Development. Staff members provide training in areas such as daily living skills, taking medications, scheduling appointments, maintaining sanitary living environments, interpreting medical information, and assisting with development of interpersonal skills. Many of the residents work at various jobs throughout the community. The S.C. Department of Health and Environmental Control conduct licensing inspections.
- **SLP-I.** There are thirteen residents who live on their own in apartments located throughout the community who receive SLP-I services. These individuals need limited supervision and supports. Staff members are available to assist as needed in areas such as money management, transportation, shopping, understanding medical information, reading mail, etc. Emergency response is also available.
- **ECTH.** They have eight homes with ten residents total for enhanced community training homes (ECTH-I). The ECTH-I model is similar to an enhanced foster care program for adults. Contracted caregivers live in a private home with one or two individuals with disabilities. These homes receive licensing inspections annually which are conducted by the S.C. Department of Health and Environmental Control.
- **CTH.** Tri Development has twenty-three CTH-II homes with three to four

residents each. Residents in CTH-II homes receive independent living training.

This training may include cooking, hygiene, and home organization. Some CTH-II homes have shift staff while others have live-in caregivers.

- **ICF.** Tri Development has four intermediate care facilities (ICF) with eight residents in each. They teach individuals basic care and feeding skills at this facility. Care is 24 hours a day. ICF residents have individualized programs for skill development for possible movement to a less restrictive environment.
- **Community Residential Care Facilities.** There are two community residential care facilities with sixteen residents total. Those living in a community residential care facility cannot require nursing, unless it is on a very short time period. Day services and vocational programs are offered through other Tri-Development locations.

For more information about the Tri Development Center of Aiken county visit:

<http://www.aikentdc.org/>.

United Cerebral Palsy. United Cerebral Palsy (UCP) of South Carolina began in 2003 and is a charter affiliate of the national United Cerebral Palsy organization. They offer programs for persons with cerebral palsy and other developmental disabilities including autism spectrum disorder, Down syndrome, spina bifida, traumatic brain injury, and physical and intellectual disabilities.

UCP currently serves ninety individuals in thirty-two locations. They have twenty SLP slots, five CTH-I homes, and nineteen CTH-II homes. UCP has their own internal interest bearing consumer fund account for their residents. These accounts have no fees. They have only two individuals with outside bank accounts. Approximately 50% of their

residents work at least part time; however, most are employed in sheltered workshops for below the minimum wage. For more information about UCP community living supports visit: <http://www.ucpsc.org/programs/community-living-options>.

York County DSN Board of Disabilities. York County DSN provides residential services to 156 individuals in twenty-five programs. It began in 1980 and is a private 501(c)3 organization. The Board is made up of eleven volunteer members appointed by the Governor. There is a representative for each of the seven districts in York County. York County DSN has one, twenty-unit SLP-II with 24-hour on site staff support. Eighteen residents live in an SLP-I setting with staff available as needed. They have twenty CTH-II homes with four individuals in each home. They have four community residential care facilities with eight individuals in each.

Most residents work at Horizons or through Vocational Rehab. Horizons Industries provides the day services for residents. It is comprised of the York and Rock Hill Work Activity Centers. Each center offers support services, day activities, career preparation, and employment services. The employment services include group employment through a mobile work crew or enclave, or individual employment through job coaches or resume support. The York County DSN Board foundation operates Mulligan's Thrift store. The store provides training for community employment. For more information about York County DSN visit:

<http://www.yorkdsnb.org/services/residential/>.

ABLE of South Carolina. ABLE serves approximately 600 people. More than fifty percent of the staff at ABLE have a disability. They do not have any physical residences. They do not provide housing; only referrals. The staff provides consumers

with Independent Living Plans. Currently, they do not have a formal follow up system. They are completely consumer driven providing one-on-one and group advocacy training, systemic community information and referral connection, peer support two times a month in person and online, and independent living skills training. For more information about ABLE of South Carolina visit: <http://www.able-sc.org/>.

University of South Carolina Supportive Community Living Initiative. The Supportive Community Living Initiative provides individuals with developmental disabilities supports to become active members of their communities. It provides technical assistance in exploring creative housing opportunities. This program supports the acquisition of leadership and self-determination skills. It acts as a liaison between community partners, county agencies, and state agencies. The program provides person-centered planning support and resource information to assist individuals in employment and housing. The program does not provide any physical residences or direct support in homes or in employment. The Supportive Community Living Initiative is founded on the idea that a combination of financial supports through various agencies combined with an individual's community work income can make independent living possible. Community based employment is promoted. The program offers assistance in the navigation of a number of financial resources including, but not limited to, Individual Development Accounts (IDA), Section 8 vouchers, food stamps, Social Security Income, subsidized housing, HUD/SCSHFA down payment assistance, and grants for assistive technology. They assist approximately eight to ten people at a time. Typically, they provide support and resources to individuals already receiving services from SCDDSN. For more information about the Supported Community Living Initiative visit:

http://uscm.med.sc.edu/supported_living/index.asp.

Centers for Independent Living (CILs). There are six Centers for Independent Living (CILs) in South Carolina including: Coastal Disability Access in Conway, Disability Action Centers in Columbia, Greenville, Disability Resource Centers in Charleston, Disability Solutions in Hartsville, and Walton Options for Independent Living in North Augusta. For contact information for each center visit:

<http://www.virtualcil.net/cils/query-iandr.php?state=sc>.

Comparison to AAIDD Housing Position Statement. If the housing supports for individuals with I/DD in South Carolina were compared to the AAIDD position statement (<http://aaIDDd.org/news-policy/policy/position-statements/housing#.UrNR1yivSJh>), there would be substantial discrepancies between what housing options should be available for individuals with I/DD and the realities that exist in South Carolina. More options must become available for choosing where and with whom they live and housing that reflects their personal preferences and styles. Individuals with I/DD should have more opportunities to interact with people without disabilities. Adults with I/DD should receive the supports they need to transition out of the family home when they wish to do so. According to the 2012 Accountability Report, SCDDSN serves over 32,000 people with disabilities. 85% of those served live at home, compared to the national average of 56%. According to the AAIDD housing position statement, 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. Additionally, affordable housing programs must be expanded and funded to eliminate long waiting lists, and public policies must ensure that individuals with I/DD receive their fair share of all local, state, and national

housing resources. For these changes to be made, the state of South Carolina needs strong advocates and leaders who will work towards removing the barriers that exist for individuals with I/DD to access appropriate housing supports.

California

California has 21 regional centers with more than 40 offices located throughout the state that serve individuals with developmental disabilities and their families. Independent living programs are monitored by regional centers. They provide and coordinate support services for individuals in independent living settings. They focus on functional skills training for adults who generally have basic self-help skills. As of December 2013, the California Department of Developmental Services provides services for 265,104 individuals through 21 regional centers. All regional centers are nonprofit, private corporations. They contract with the Department of Developmental Services. Due to a key mandate (Section 4620) from the 1969 Lanterman Act, the state of California determined that regional service centers would be the best way to serve consumers. California concluded that state agencies were unable to best meet the individual needs of people with developmental disabilities, and private, non-profit agencies were better equipped to operate regional centers. In 1998, an amendment to the Lanterman Act stated that an advocacy coordinator should be assigned to each of the 21 regional centers. Advocacy coordinators could not serve on any of the regional service center boards, in order to avoid any conflicts of interest (<http://www.dds.ca.gov/RC/home.cfm>).

Eligibility is determined at no cost, and individuals are assigned a case manager or service coordinator. A person-centered approach is used to determine the best possible level of care for individuals with developmental disabilities. This is called the Individual

Program Plan (IPP). Family and regional staff are actively involved in the planning process (<http://inlandrc.org/service-providers/>). The regional centers provide ongoing support and monitoring of services. All service providers must go through a vendor approval process, which includes license verification at the regional center level. Only approved service providers receive reimbursements from the state (http://www.dds.ca.gov/Rates/Vendor_Process.cfm).

The regional centers offer a variety of residential options, including Supported Living Services, State Operated Centers, Community Care Facilities, Intermediate Care Facilities, and Family Home Agencies (<http://inlandrc.org/wp-content/uploads/2013/09/7-52-Rate-Determinations.pdf>). Supported Living Services (SLS) include services for adults who have chosen to own or lease a home in the community. SLS may provide supports for moving, independent living skills, and emergency preparedness. There are currently 3,960 residents served by SLS. A Supported Living Services Standardized Assessment Questionnaire is used to determine the type and duration of supports (http://www.dds.ca.gov/SLS/docs/DDS_SLS_StdAssmtQuestionnaire.pdf).

California currently has four state developmental centers (DCs). Fairview, Lanterman, Porterville, and Sonoma are licensed as Intermediate Care Facilities and hold certifications as Skilled Nursing Facilities (SNF). California also has a Community Facility (CF) in Riverside County. As of February 26, 2014, the total population for California Developmental Centers and State Operated Community Facilities was 1,325. Each DC has its own distinct vision and core values. Agnews Developmental Center opened in 1885 in the Bay area as a home for individuals with mental illness. In 1972 the

center transitioned to serve only those with developmental disabilities. The facility closed to residents in 2009, through the Agnews Closure Plan as part of a statewide effort to transition as many residents as possible into the community. Admission into one of the DCs requires a PCP and must include activities that address community involvement, education, and vocational skills. A court order is required, and the PCP team must determine that the DC is the most appropriate residential setting. California is committed to transitioning as many DC residents into the community as possible, through the Developmental Center Initiative (<http://www.dds.ca.gov/DevCtrs/Home.cfm>).

The Fairview Developmental Center in Costa Mesa, is the newest DC facility, which opened in 1959. The center's population was 2,622 in 1967. They currently have 322 residents and 1,500 employees as of January 29, 2014. The facility has a swimming pool, library, an animal farm, and a golf course. Fairview has four distinct residential programs: Acute Care, Nursing and Specialized Medical Needs, Behavioral and Psychiatric Support Services, and Social and Positive Behavior Development. Fairview Family and Friends is a nonprofit organization that helps Fairview residents receive benefits that may be over the Fairview budget. (<http://www.dds.ca.gov/Fairview/Index.cfm>).

The Porterville Developmental Center opened in 1953, and is located near the Sierra Nevada Mountains. In 1957, they had over 2,600 residents. Today, the center houses 412 residents and employs 1,300. In 2009, the center completed an expansion program for 96 residents. The center has recreational complexes, a hospital, a police station, and a fire station. Porterville has its own water supply and power plant. A number of their residents require services in a secure area, and have been determined by a court to

be unable to stand trial, and/or present a danger to themselves or others.

(<http://www.dds.ca.gov/Porterville/Index.cfm>).

The Sonoma Developmental Center is located in northern California and is the oldest of the DCs. In 1884 they started with 148 residents. They now have 463 residents. They have a campground, post office, petting farm, plant nursery and a swimming pool. In 2008 they developed an Advocacy Rights and Opportunities (ARO) program

(<http://www.dds.ca.gov/Sonoma/Index.cfm>).

Lanterman opened in 1927 under the name Pacific Colony. It is located in Pomona, CA. At its peak in 1946, the facility housed over 1,900 residents in a building with the capacity for 1,512. Lanterman has a campus-like environment with standard services such as specialized care, independent living programs and activities, as well as vocational training at the Day Training Center (DTAC). Lanterman has a music therapy program, camp cabins, petting zoo, and an equestrian program. They also have Main Street USA which is a, "...simulated city built to assist clients who have difficulty integrating and using community services." In 2010, the state of California announced that Lanterman would start the closure process. At that time it had 401 residents and 1,280 employees. As of December 25, 2013, Lanterman's residential population was 103

(<http://www.dds.ca.gov/Lanterman/Index.cfm>).

Community Care Facilities provides 24-7 non-medical residential care. Each facility has a designated service level. Service Level I is limited and provides supervision for individuals with no major behavior issues. Service Level II includes care, supervision and training when needed for individuals with no behavioral issues. Service Level III provides care, supervision and ongoing training for individuals with acute needs. Service

Level IV provides services to individuals with the most severe needs. This level is subdivided into nine levels for staffing designation. In January 2014 the monthly reimbursement rates ranged from \$1,003 to \$5,159 depending on service level (<http://www.dds.ca.gov/LivingArrang/CCF.cfm>). Currently, 11,660 residents are served in Community Care Facilities.

California has four types of Intermediate Care Facilities that provide 24-hour residential services. ICF/DD serves individuals with developmental disabilities who have recurring, intermittent skilled nursing needs. ICF/DD-H provides 24-hour care, health and habilitation services to no more than fifteen residents. The residents must not be in need of continuous skilled nursing care. ICF/DD-N provides 24-hour care for up to fifteen medically fragile individuals. Developmentally Disabled Continuous Nursing Care (DD-CNC) provides 24-hour care in community based residential homes to medically fragile individuals. DD-CNC waiver participants must be Medi-Cal eligible and without a communicable disease. This waiver helps people stay in the community while receiving continuous skilled nursing care (<http://www.dds.ca.gov/ICF/Home.cfm>).

Family Home Agencies (FHA) began in 1996, and they oversee private residences to care for up to two individuals with a developmental disability. The FHA agency, family members at the approved homes, and the community, all help to support the resident. The FHA is a private, non-profit agency, which contracts with local regional centers to approve, monitor and support the residences. The FHA is also responsible for matching residents to the residences. Currently, 592 California residents are served by FHAs. The average monthly cost for FHA services is \$4,722, and the average annual cost is \$53,849 (<http://www.dds.ca.gov/LivingArrang/FHA.cfm>).

Georgia

Georgia provides services to individuals with I/DD through the Department of Behavioral Health and Developmental Disabilities (DBHDD). There are six regional offices. Each region has an intake and evaluation team who will determine eligibility. DBHDD provides support to people with developmental disabilities. DBHDD serves people of all ages with the most severe and likely to be long-term conditions. They offer family support including respite care and home and community-based waivers. There are several different types of waivers for individuals with I/DD. The New Options Waiver (NOW) provides supports to people who do not need 24-hour care. It was designed for people with disabilities who live with family members or in their own home. There is a limit of \$25,000 a year for services under the NOW Waiver. This waiver is for people who need less intensive services and supports. The Comprehensive Supports Waiver (COMP) was designed for people who need a full range of out-of-home services or intensive in-home services. The COMP Waiver is also used for people who are transitioning out of institutions into community living. According to a Georgia Department of Health January 2012 Snapshot report, there were over 12,000 individuals with the NOW and COMP waivers at the end of 2011. There are approximately 7,000 individuals on the NOW and COMP Waiver waiting list in 2013.

The Money Follows the Person (MFP) program helps individuals transition out of ICFs. They must have lived in the ICF for at least 6 months to be eligible for the program. After 365 days of “transition services” the individual in the MFP program will move to another waiver or state service. MFP recipients may also qualify for peer community supports, household furnishings, household goods and supplies, moving

expenses, utility deposits, rent deposits, roommate match, transportation, equipment and supplies, and vehicle adaptation.

Due to a DOJ lawsuit, Georgia has agreed to halt all state hospital facility admissions due only to a developmental disability. Georgia also must create 600 waiver slots for individuals presently in the state hospitals so that they may reside in community settings. They must create 400 waiver slots for individuals with I/DD to remain in the community (Americans With Disabilities Settlement). In 2012, 168 individuals with developmental disabilities were transitioned out of state hospitals and into the community.

Kentucky

Kentucky has recently increased their support for individuals with disabilities to be successful in the community. The Kentucky Division of Developmental and Intellectual Disabilities contracts for services through the 14 Regional Boards and other qualified private providers. They have two branches; the Supports for Community Living Waiver Branch, and the Community Support Branch (<http://dbhdid.ky.gov/ddid/>). The Community Support Branch oversees the 14 Regional Community Mental Health/Intellectual Disability Centers (CMHCs). The Supports for Community Living Waiver Branch provides services that help participants to live and work in the community. The waiver provides residents with an alternative to institutions. Some services include Adult Day Training, Community Living Supports, Residential Supports, Respite and Supported Employment.

The Supports for Community Living Branch Waiver added SCL2 Waiver services in January of 2014. SCL2 waiver services include Community Access, which helps

waiver participants be more involved in their community using natural supports.

Environmental Accessibility Adaptation Service has a lifetime limit of \$8,000, and includes modifications for homes. Community Transition aids individuals moving from an institution to their own home. The maximum amount is \$2,000 and includes items such as furniture, initial utility fees, and essential kitchen and bath items. Natural Supports Training provides education for community members providing unpaid support for individuals transitioning into the community. The maximum amount is \$1,000 per plan of care year. Shared living is for residents living in their own home with an unrelated caregiver. The caregiver receives up to \$600 per month for room and board in lieu of a salary. Other SCL2 waiver services include, day training, occupational therapy, person-centered coaching, personal assistance services, physical therapy residential supports, respite, speech therapy, transportation clinical and therapeutic services.

The Michelle P. Waiver is a home and community based waiver program for Medicaid eligible persons who want to remain in their own home. The services are nonresidential, and are a mix of services from the Supports for Community Living Waiver (SCL) and the Home and Community Based Services Waiver (HCB). Waiver services are limited to 40 hours per calendar week.

Montana

Montana is home to approximately 18,000 individuals with a developmental disability. In 2012, there were 750 people on the wait list for services with the Montana Developmental Services Division. Priority is given to those who qualify from a crisis screening, or needs basis. Priority is also weighed based on the amount of time on the list. The Developmental Service Division provides services through 65 private, non-profit

firms. They are currently serving 2,700 individuals. Once selected, individuals have a cost plan built based on need. The waiver will pay for supports only. SSI pays the remaining amount for room and board. People usually have \$40 to \$50 remaining from that amount to use at their discretion. They have 5 regional offices and their goal is to give individuals the maximum amount of autonomy in the most natural environment possible. The Montana Developmental Center is the sole state run institution. They have 45 residents and provide 24-hour care. Other individuals with developmental disabilities live with service providers or family members

(<http://www.dphhs.mt.gov/dsd/ddp/index.shtml>).

Oklahoma

Oklahoma is divided into three separate areas for services for individuals with disabilities. The website (www.OKDHS.org) is unique because it lists providers by area along with relatively current vacancy listings. The vacancies include male or female openings and the type of accepted waiver. Oklahoma has two main types of waivers: Community and In-Home Supports. In 2012, the state of Oklahoma announced the closure of both of their large-scale institutions. Oklahoma has struggled with the accommodation of the transition of these individuals due to funding, and the fact that there are already over 7,000 on an existing waiting list.

Texas

Texas offers five types of residential services for adults intellectual and developmental disabilities. Home and Community Based Services (HCS) are for individuals who live with family members or their own apartments or homes. Some may reside in group homes. Residential assistance such as day habilitation, vocational support,

skilled therapies, and behavioral support are provided on a case-by-case basis. In order to qualify for HCS, individuals must first qualify for care in an ICF. ICFs provide 24 hour residential and habilitation services. The home size may range from six to more than 100 people. Intellectual and Developmental Disabilities Community Services provide day habilitation and community support to individuals out in the community. State Supported Living Centers (SSLC) offer 24-hour residential care. The Texas Home Living Program (TxHmL) provides support to individuals living at home or with family members.

All of the Texas programs require that income and resources may not exceed specific limits. Consumer Directed Services (CDS) may be used in conjunction with HCS and TxHmL. CDS allows for individuals to hire their own family, friends, or neighbors and set wages for those employees based on a personal budget. Texas also provides a relocation service for individuals who want to leave an institution to move in with a family member.

Virginia

In 2012, the state of Virginia and the Department of Justice (DOJ) reached a settlement agreement that resulted in the closing of all but one of their five training centers. All individuals who meet the criteria for a documented I/DD waiver wait list must be discharged with an individualized support plan for transition into the community. There is a great emphasis on consumer choice and community living with four general options: in-home residential supports, sponsored residential services, group home residential services, and community ICF homes.

In-home residential supports are designed for individuals living in a family home or in a home or apartment provided by a family member. These in-home supports enable

people to thrive in their own community by delivering individualized care. They may include independent living skills. Sponsored residential services are supports given in a sponsor's home. These homes are licensed, approved and evaluated by the Virginia Department of Behavioral Health and Developmental Services (DBHDS). No more than two people may receive residential services in one home. Group home residential services offer 24-hour supervision to individuals in a licensed, community based home. Unless an individual is a part of the Money Follows the Person (MFP) Project, there is no limit on the size of the group home. Community ICF/I/DD homes are typically for four to twelve individuals and provide intensive training and 24-hour supervision.

Virginia has an Individual and Family Support Program (IFSP) designed to assist individuals on the waiting list for the intellectual disability (I/DD) or developmental disability (DD) Medicaid waivers to access short-term resources, supports, and services that will help them remain in their own community homes. Families must reapply each year and the maximum amount is \$3000 per year.

Virginia also has micro-boards. They are made up of family and friends the individuals with an intellectual disability. The micro-board purchases a house for several individuals with a disability. The house must have a common area and each person must have a separate bedroom. The Virginia Development Housing Authority (VHDA) aids micro-boards with funding, flexible financing, types of mortgages and education for non-profit status. These micro-boards are gaining popularity. They are successful because individuals are able to choose their housemates and for the most part, the location of the home.

Currently Virginia has forty community services boards (CSB). The CSB is the

entry point for services and waiver waiting lists. Currently there are over 7,000 individuals on the waiver waiting lists. With no additional slots, they expect that the list will be 8,000 by the end of 2014. The list grows by about 900 each year (The ARC of Virginia, 2013). The service boards are increasingly moving away from being residential service providers as private companies fill the void. Medicaid reimburses on an hourly rate. Currently it is \$15.00 an hour for residential habilitation and \$19.00 per hour for in home services. According to the Alexandria service board, host families are becoming increasingly popular. This program is very similar to foster care.

Summary

There is still much work to be done to increase the use of consumer-driven approaches for housing supports with funding provided directly to people with disabilities and their families as opposed to service providers and organizations. There also needs to be a shift towards fully utilizing natural supports as opposed to relying on paid staff to meet all of the independent living needs of individuals with I/DD. Instead of focusing on paid staff providing care giving services, there needs to be a paradigm shift that encourages paid staff to identify and develop the capacities of natural supports that will increase opportunities for independence. Supports should follow the individuals in settings where they desire to be as opposed to supports being bound to a particular location.

Chapter 4

Residential Facilities and Services Throughout the Country

This chapter provides an overview of selected residential facilities and services for individuals with I/DD across the county. The residential facilities described are for information purposes only and are not included as recommendations. In fact, Dungeness in Wisconsin recently made the news due to a federal OSHA probe into one of their homes. According to the July 27, 2013 Baraboo News Republic Report, a 26 year-old man with a developmental disability was being kept in a small, padded cell intended for solitary confinement. All individuals and their support teams must carefully consider all options and make informed decisions when it comes to something as important as living environments.

Anaconda Work and Residential Enterprises (AWARE)

AWARE is the largest, private non-profit service provider of residential living in Montana. AWARE was started in 1976 by concerned parents. They currently employ over 700, and serve 120 individuals. Services include early head start, transportation, child advocacy, mental health, and disability services. Their headquarters are in Anaconda, MT with a population of around 9,000. They have 19 group homes. Four homes are unlicensed congregate living homes with support. AWARE provides supportive living support to approximately 45 individuals in their own home or apartment (<http://www.dphhs.mt.gov/qad/healthcarefacilitieslist/communityhomes.pdf>). Only five are private pay. The average cost plans for residents range from \$38,000 to over \$200,000 per year.

A number of residents are employed outside of AWARE. AWARE contracts with a number of local businesses to set up mobile work crews, enclaves and supported employment. AWARE provides case management services to coordinate community, medical, and residential services for the individual. There is an ongoing waiting list for residential homes. While waiting, individuals may qualify for targeted case management and supported employment (<http://www.aware-inc.org/index.html>).

Annandale Village

Located in Suwanee, Georgia, Annandale Village offers a 54-acre campus-like environment for individuals with I/DD. They offer both a residential and day only program. They have the capacity for 108 people and they currently have 94 residents. Dr. and Mrs. Maxwell Berry started Annandale Village in 1969. Their daughter had a developmental disability and they wanted her to have a quality life not offered in an institution. They modeled Annandale Village after the design of Canfield Villages in

Europe. Currently, Annandale has nine homes ranging from independent apartments to the Amy Somers Center for Continued Care and the D. Scott Hudgens Center for Skilled Nursing, formerly known as assisted living centers. They have approximately 105 employees.

The cottages provide residents with 24-hour care and supervision. They may have private or shared bedrooms and the bathrooms are dormitory style. Four to eight people may live in a cottage. Semi-independent apartments offer residents a private bedroom and Jack and Jill style kitchen and bathroom. A staff member is available from 4:30 pm until midnight, and nightly security is available. Residents in the semi-independent apartments do their own housekeeping and laundry. Independent apartments have private bedrooms, kitchens, bathrooms and living areas. HUD clients (Section 8) receive \$523 off of the residential fees but must make less than \$16,000 per year in earnings or benefits. The Amy Somers Center for Continued Care offers semi-private rooms with a shared living area. Two staff members provide 24-hour care.

The cost for the residential programs range from \$3,116 to \$3,565 per month. Seventeen residents have the NOW waiver. They limit the number of residents with the waiver to seventeen individuals or revenue of \$250,000 per year, because they are subject to another accreditation if they go over that particular amount. Residents' SSI monthly payments range from \$400 to \$1000.

Fifteen residents are employed off campus. 70% of all residents are employed on campus in either a workshop or enclave. Residents also volunteer at a local animal shelter and camp for children with disabilities. For more information about Annandale Village visit: <http://annandale.org/>.

California Mentor

California Mentor has 17 locations, and is one of the largest California service providers for people with disabilities. Services are based on an Individualized Service Plan (ISP). ISP services may include 24-hour home-based supervision, life skills development, advocacy services, community integration and family support. California Mentor adult services include:

- Family Home Agencies (FHA)
- Day programs
- Independent living (BrI/DDges)
- Supported living
- College programs
- Employment services
- Specialized residential home

California Mentor Independent Living Services (Bridges) assists individuals with a move. A Living Transition Profile is created with input from the individual and their family, friends, professionals, and California Mentor staff. The move may be from a family home with parents or from a group home. The support is temporary until an individual decides that assistance is no longer necessary, or they decide to receive services through the Supported Living Program. Bridges helps people find places to live, navigate public transit, and locate roommates. As the individual gains more independence, Bridges methodically removes the unnecessary support (<http://72.3.230.197/about-us/the-mentor-network>).

The California Mentor Supported Living Program aids individuals who choose to

live independently in their own home or apartment. California Mentor provides personalized support on an hourly basis and a 24-hour on call emergency nurse. Examples of support may include transportation, shopping, household maintenance and cleaning, and money and time management. Supported Living participants have access to California Mentor social events such as concerts, classes and trips.

California Mentor offers two types of college programs. College to Career (C2C) is a partnership with Harbor Regional Center, Long Beach City College, and Hope, Inc. Students receive academic and independent living support based on their ISP while living in an off-campus apartment. They may choose from over 100 courses of study. California Mentor also offers College Support. College Support is a program designed to aid students with disabilities at the community college level.

California Mentor provides Specialized Residential Homes through a partnership with Loyd's Liberty Homes (statewide ICFs), and Cornerstone Living Skills. They provide community-based and residential support services and ICFs. Cornerstone Living Skills has homes located in Santa Rosa, CA.

California Mentor FHA creates personalized partnerships between host families and individuals with disabilities. They are responsible for the approval process of the homes as well as ongoing education, monitoring, and support. The California Mentor FHA program provides specific, personalized supports including:

- Medication management
- Clinical supports
- Optional day programs
- Community integration

- Advocacy services
- Behavioral supports
- 24-hour, on call support from CA Mentor

For more information about California Mentor visit: <http://www.ca-mentor.com/>.

Casa de Amma

Ralph and Eleanor Leatherby started Casa de Amma in 2004. They were dismayed by the limited options available in California for their son, Doug. They felt that the larger institutions were too big and impersonal and the smaller group homes would be too isolating, with limited opportunities for social growth. Casa de Amma began with the goal of promoting independence while allowing individuals, 21 or older, with complex learning or mild disabilities to belong to a larger community.

There are 35 apartments furnished by the residents. The building has a common dining and recreational center. Casa de Amma residents have an individualized support plan including personal and social goals that address interpersonal skills, social event planning, and dating. Additionally, daily living and work goals include finding employment, job support, personal finances, and household cleaning. Health and well-being goals encompass medication and medical appointment management, healthy living choices in nutrition, and exercise.

(<http://casadeamma.org/programs/vocationalcommunity.html>).

Casa de Amma charges \$45,209 per year for rent, water, gas, and trash services. Breakfast is included seven days a week and dinner is six nights a week. Residents are responsible for their daily lunch, cleaning, and dinner on Saturday nights. They also pay for their own electric utilities, phone, cable, and Internet service. \$10,000 is due when the

resident moves in. \$5,000 of that amount is non-refundable

(<http://casadeamma.org/programscost.html>).

Casa de Amma currently has 13 individuals on a waiting list. These 13 individuals are already approved for funding. Another six have pending applications. Due to the fact that Casa de Amma is not vendored through a state regional center, residents must attain self-vendorization funding approval. Self-vendorization was made possible by the Lanterman Act. Approximately 70-75% of Casa de Amma's residents have been approved for 50-100% of the annual cost via self-vendorization. The remaining amount is the responsibility of the family or fundraising.

Casa de Amma loses approximately one resident a year due to an out-of-state move. Most of the time a move is because a resident wishes to be closer to family members. They have 15 full-time staff and 10 part-time staff members. There is always one staff member on duty at night. Most of the residents are involved in meaningful activities at least three days a week. This may include full or part-time employment, volunteer activities, or school. Only two residents are presently not involved in the minimum amount of meaningful activities. For more information about Casa de Amma visit: <http://casadeamma.org/>.

The Center for Independent Futures

The Center for Independent Futures (CIF) is a non-profit organization founded in 2002 by two parents. After navigating the system of disabilities in Illinois and finding it to be confusing and difficult, they decided to assist other parents with the process of accessing products and services for their young adult with intellectual or developmental disabilities. With over 20 years of personal experience with the Illinois school and

disability systems, Kay Branz and Jane Doyle decided to educate other parents of young adults with disabilities to promote independence and community integration. The Center for Independent Futures is unique due to their association with Planned Lifetime Advocacy Network (PLAN). PLAN is a Canadian consulting company providing memberships for parents of individuals with disabilities. The memberships include advocacy and estate planning workshops. They closely follow the Toward Independent Living and Learning, Inc. (TILL) model. TILL promotes independence within a community. TILL offers residential, vocational, and support services for individuals with disabilities in Southern New Hampshire and Eastern Massachusetts. The Center for Independent Futures uses their Independent Living Readiness Inventory to determine client readiness, placement, and needs. A trained consultant uses interviews and observation to determine an individual's independent living skills.

The Center for Independent Futures serves over 100 individuals, and offers Community Living Option (CLO) Residences, Community Living Option (CLO) Family Partnerships, Network and Family Coaching, and a Life Tools Camp. There are four CLO residences located in Evanston, IL. Each has one Community Builder staff member. The staff member fosters independent living skills and provides night time support if necessary. The CLO Family Partnership is a monthly meeting made up of families with individuals with disabilities. Meetings provide resources, support and education. Technical assistance at meetings are provided by TILL, PLAN, and Northwestern University.

The Center for Independent Futures also offers Life Tools Camp. Since it is not unusual for many young adults to transition from their family home to a residence

without proper training and support, the Life Tools Camp provides multiple opportunities for campers to practice independent living skills. They offer two-week day camps with optional overnight experiences. Day camps are from 10 a.m. to 3 p.m. for \$1,700.

Overnight camp is \$300 per two-night stay. All campers must complete the Independent Living Readiness Inventory as a part of the camp application process, and pay a \$500 fee.

Repeat campers are encouraged. Camp fees and activities include:

- Meal preparation
- All meals and activities
- Money management
- Transportation
- Household chores
- Social skills
- Parent orientation
- A personalized learning plan
- An exit consultation
- A Life Tools Portfolio (breaks skill building into practical units)

For more information on the Center for Independent Futures visit:

<http://www.independentfutures.com/>

Dungarvin

Dungarvin is a national organization consisting of fifteen privately owned companies operating in thirteen different states. They provide support to 2,100 individuals. Each state organization offers different services. Their residential program is flexible with some individuals living in their own apartment or home with or without

roommates. Dungarvin staff members assist with meal preparation, medical assistance, transportation, and independent living skills when needed. Dungarvin also has group homes located throughout the community. Three to five residents occupy the homes with live in staff 24 hours a day.

The Dungarvin Residential program of Oregon serves 101 individuals with I/DD. Fifteen are children. Fifty-five people participate in their full time residential program. One individual is in the supportive living program in an individual apartment. Support staff comes as needed. Fifty-four people live in community living homes throughout Portland. Room and board is \$552.70 per month. Residential habilitation services are determined by the SIS scale, which is then translated into tier one through seven. Tier one is \$470 per month and tier seven is \$10,000 to \$15,000 per month in support money. They have one private pay resident. Currently there is only one vacancy. Thirty-seven of their full time residents are in some type of supportive employment, and most make at least minimum wage.

In-home services are offered only in Minnesota and Ohio. Services are provided to an individual residing with his or her family or in his or her own living environment. Due to the broad range of abilities, the in-home services vary. The person and the family design the level of support and service that is needed in collaboration with Dungarvin.

Home Host Services are available in Oklahoma, Colorado, and Utah. Here the individual may live with a non-related individual, guardian, or spouse. Host Home providers are independent contractors, and they assist with skill development and community involvement.

Dungarvin provides case management services in Minnesota to support people in

their goal of living in the community as independently as possible. Dungarvin's hourly supports provide staffing only when a person needs assistance. Staff members are scheduled to be on-site to assist an individual according to his or her personal needs and goals. In some instances, staff may only drop by to assist with medication needs or financial assistance. In others, staff may be scheduled for longer time periods to assist with additional daily living skills. For more information about Dungarvin visit:

<http://www.dungarvin.com/>.

The Good Neighbor Village

The Good Neighbor Village is a non-profit organization located outside of Richmond, Virginia with three full time employees and eighteen residents. Several families came together to start the village in 1987. They currently have three cottages located on 43 acres of land. The Good Neighbor Village hopes to eventually have capacity for 60 individuals. Each cottage has separate bedrooms and residents take turns helping the house supervisor prepare meals. Light housekeeping tasks are expected and residents are all able to care for themselves. There are no day programs or activities. The Good Neighbor Village is solely a private pay facility and does not accept waivers. The cost is \$2,350 per month and it includes room, board, utilities, and basic cleaning services. For more information about the Good Neighbor Village visit:

<http://www.goodneighborvillage.org/>.

Home of Hope

Home of Hope is located in Vinita, Oklahoma. Their residential programs include community supports, group homes, and ICF homes. They have received four HUD grants for over \$1 million to build three person homes. Currently Home of Hope serves 176

residents, eighty-eight of these residents are in the Community Supports program living in their own home or apartment. Most Community Supports residents are on a class action waiver that has allowed them more choices in their living arrangements. Another group of residents are on an ITS or in-home waiver with Title 9 support. There are also residents on a community waiver. Currently there are three private pay residents. A private pay resident will pay approximately \$140,000 per year. Home of Hope currently has eighty-six individuals in thirteen ICF homes. For more information about Home of Hope visit: <http://www.homeofhope.com/>.

HopeTree Developmental Disabilities Ministry (DDM)

In 1992, HopeTree Family Services established the Developmental Disabilities Ministry (DDM) to provide homes for adults with intellectual disabilities. They have seventeen group home locations throughout the state of Virginia serving eighty-three residents. HopeTree is able to choose from a list of potential applicants based on financial qualifications and personalities. Residents must be a good fit for the home as it is essential that the residents get along on a personal level. Most of the newer homes have three to four residents. The residents live in small homes throughout the community with private, single occupancy bedrooms. Common areas are for staff members and other residents. Room and board along with habilitation services are approximately \$40,000 for private pay individuals. Fifteen percent are private pay. 80% of their funding is through Medicaid. They maintain strong ties with churches and rely heavily on the help of local ministry partners who have identified the need for Christian services for adults with intellectual disabilities in their communities.

The HopeTree goal is to create a Christian environment in which adults with

intellectual disabilities can experience the most complete life possible. HopeTree also provides short-term respite care, and in-home residential support services. Currently they have 15 people receiving in-home services. This is for individuals who do not want or need 24 hour care. HopeTree is continuing to expand the DDM program by adding more group homes and new services on a regular basis.

Residents attend churches within their communities and are encouraged to work and volunteer. In the event that these daily activities are not available or workable for a resident, other daily activities will be developed. Each resident has his or her own personalized plan with goals that are reviewed on a regular basis. DDM staff members plan daily activities (crafts and social games). Transportation is provided or arranged by DDM staff. The DDM staff manages medical needs and appointments. All residents must have medical care that can be provided by outpatient services only. For more information about HopeTree DDM visit <https://hopetreefs.org/developmental-disabilities-ministry/> .

The Jewish Foundation for Group Homes

The Jewish Foundation for Group Homes (JFGH) is a nonprofit organization dedicated to the independence and community inclusion of individuals with disabilities, regardless of faith or creed. JFGH's programs support more than 200 individuals in over 70 sites throughout the Washington D.C Metropolitan area. JFGH serves individuals over the age of 18 with intellectual and other disabilities. They have several residential options for their residents. The Group Home and Alternative Living Unit (ALU) Program has twenty-three homes with four to six residents in each. JFGH provides 24-hour care and assistance. The Henry and Alice Greenwald Community Supported Living Arrangements (GCSLA) Program provides supports to individuals in their own homes. They may

provide transportation, medical monitoring, chore support, and recreational activities as well. The Mary and Charles Oshinsky Apartment (OAP) Program is for independent adults with disabilities who may need, “drop-in” assistance with chores, transportation or money management. For more information about the JFGH visit: <http://www.jfgh.org/>.

“Just” People, Inc.

“Just” People, Inc. is a private not for profit agency in Atlanta, Georgia that provides a variety of support services to adults with developmental disabilities, mental illnesses and head injury. Becky Dowling started the program in 1995 after her work with individuals with I/DD in separate settings. “Just” People, Inc. serves individuals who do not need bathing, feeding and dressing supports. Their consumers have the ability to live in an apartment without live-in staff but need staff available for daily or weekly support. There is staff on property overnight to provide support in case of emergencies.

“Just” People, Inc. serves 180 individuals with I/DD in their residential services program. They have 2 town home complexes: Village Walk and Burns Walk. These are 30 unit, two bedroom, and two and a half bath town homes in gated communities. Staff and support are available as needed. The Community Living program is a part the residential services. These clients live at home. “Just” People, Inc. provides individualized services such as transportation, medication monitoring, job training and support as well as independent living skills training. About half of their residents are private pay. The other half uses a combination of SSI, food stamps, and waivers. The cost for a town home unit is \$2300 per month. SSI, Medicaid waivers, and food stamps are used to cover much of the cost. The town homes have a waiting list, but those on the waiting list are typically a part of the Community Living Program while they wait for an

opening. For more information about “Just” People, Inc. visit:

<http://www.justpeople.org/>.

Marbridge

Marbridge is an organization that provides residential supports in Texas. It includes four communities on nearly 200 acres thirteen miles outside of Austin, Texas. They serve over 240 individuals over the age of eighteen. They employ about 175 full-time staff members. The average stay ranges from eight to eighteen years. The four communities provide different levels of care. The Villages consist of fourteen cottages and a community center for meals and events. Most residents have jobs outside of the Marbridge campus. Each cottage has a large bedroom divided into four semi-private zones. The shared living rooms have a large entertainment center. The Ranch provides its residents with daily structured activities. There is 24-hour supervision for about seventy individuals. The Villa provides 24-hour skilled nursing care. They have approximately seventy to eighty residents at any given time, and over half of the full time staff works in the Villas. The Bridges is the medical recovery and rehabilitative care site. Many residents come to the Bridges to recover and then return home.

Marbridge offers residents an Individual Program Plan (IPP) and a comprehensive training program to develop skills for community or campus based employment. These training programs follow a semester schedule to reflect a college campus environment. They offer electives in art, gardening, ceramics, choir, scrap booking, fabric art, photography and other subjects based on interests. The grounds include recreation rooms, computer labs, an art studio, a chapel, a pool, a cardio gymnasium, a softball field, an outdoor amphitheater, an activities pavilion, equestrian activities, and walking trails.

They also have approximately fifteen horses for lessons. Additionally, Marbridge residents are offered off campus experiences including deep-sea fishing, attending professional athletic events, local festivals, museum visits, dining and shopping, and vacations to places like Disneyworld, the Caribbean, and the Grand Canyon.

Marbridge uses the term, “tuition” to describe their fee schedule. The tuition includes training and education along with functional academics and room and board. They do not accept Medicare or Medicaid waivers. Most of the residents use some form of SSI or SSDI benefits towards the tuition cost. The Ranch and Village costs approximately \$3000 or more per month. The Villa can be \$3500 for a semi-private room. Some types of transportation are included in these fees. Marbridge residents are extremely active in the Special Olympics. There are usually extra costs associated with the travel to the Special Olympic events. Many residents are season ticket holders to professional and college sporting events in Austin. Transportation costs to these events are extra. There is currently no waitlist for females. For more information about Marbridge visit: <http://www.Marbridge.org/>.

The Mission Project

Three concerned families started The Mission Project in 2004 in Mission, Kentucky to “establish and maintain support structures for persons with developmental disabilities to enable them to live independently in a safe environment with the opportunity to engage in meaningful work, social interaction with peers, educational opportunities, physical activities, training and recreation.” The Mission Project is a 501(c) 3 not-for-profit corporation. The project receives grant money and holds three fundraisers per year. One event is the Kentucky Derby Gala. The mission statement is,

“The Mission Project participants live in their own apartments and receive support from state licensed service providers. It is not required that all Mission Project participants use the same service providers. They contract on an individual basis. Services are paid for by a combination of Medicaid Waivers, family income and special needs trusts. They measure their success by a modified version of the Supports Intensity Scale. Parents or caregivers measure the type of support needed, the frequency of the monitoring, and the daily support time.

All residents of the Mission project are expected to work or volunteer in the community at least four hours per month. The Mission Project requires a substantial amount of family support. It is mandatory for each participant with a disability to have a parent or a family member on the Mission Project Board. Attendance at board meetings is a necessity, as well as active participation in fundraising events and an annual financial contribution.

The Mission Project has ten core values:

- Safety
- Employment
- Continuing education
- Physical fitness
- Social activities
- Parental input
- Increasing independence
- Continuity with a “successor plan”
- Opportunities for travel

- Service to the community

The Mission Project provides residents with social activities, coordination, vans for transportation, as well as a 24-hour support and emergency line staffed by volunteers. They have an annual trip through the Mission Project Travel Club. Currently there are two Mission Project programs. Mission Project I has 18 participants and no openings. Mission Project II began with the support from the board members in Mission Project I. They currently have 9 participants. For more information about The Mission Project visit: <http://www.themissionproject.org>.

Park Lawn

Park Lawn is a non-profit organization in Oak Lawn, Illinois. It was founded in 1955 by parents. In 1968, Park Lawn was able to use state funding to expand its staff and facilities. In 1972, they added adult services and eventually vocational workshops and residential homes. They currently offer three types of residential facilities. Park Lawn Center provides 24-hour care for forty residents. Residents have an integral role in planning recreational activities. Park Lawn Homes have fifteen residents, and they are involved in meal planning and preparation as well as housekeeping. There are daily social and recreational activities. Community Integrated Living Arrangements (CILA) are single family homes. Park Lawn has eight single-family homes in five cities. The residents make the majority of the housekeeping and meal decisions. They prepare their own meals and are responsible for household chores. They also have a say in the household budget. Staff provides guidance when needed. CILA also provides support for individuals living with family members or independently. For more information about Park Lawn visit: <http://www.parklawn.com/>.

Rescare

ResCare serves 60,000 people in 43 states, Canada and Puerto Rico. They have approximately 16,000 people in their residential program. Their services include residential, home care, workforce, pharmacy, and education and training. Their residences range from large residential centers with ninety-nine individuals to homes or apartments with only one resident. Due to its large size, ResCare often takes specialty cases by request of the federal government or a state. ResCare is also active in mergers and acquisitions of existing providers. They successfully lobbied for food stamp eligibility for their residents. Originally food stamp recipients could not choose a for-profit provider. Last year ResCare grossed \$1.6 billion in revenue and they net about 2 cents on the dollar. According to ResCare, they take special care to provide quality residences in safe neighborhoods. This tends to increase their costs associated with the residences. Due to recent cost-cutting trends in Medicaid reimbursements, ResCare is concerned about being able to maintain their current quality of care. In order to provide homes with specific accommodations, ResCare spends approximately \$8000 more on average than a traditional family home. ResCare currently has only two private pay residents. Private pay residents are extremely rare and tend to have exceptional circumstances. In one case an individual's father passed away, leaving the individual approximately \$55,000. The resident lost Medicaid eligibility for a few months due to the increase in funds. There were not enough funds to stay on private pay for more than a few months. This individual used their funds and then was able to be Medicaid eligible once more. Another private pay case was an insurance claim payment for an individual with TBI. Medicaid reimbursement can range anywhere from an average daily rate in

Louisiana of \$89 to \$97 per day, to Indiana's average daily rate of \$190. High intensity cases can have an average daily rate of \$450 per day. For more information about

Rescare visit: <http://www.rescare.com/>.

Services for Independent Living

Services for Independent Living (SIL) is a non-profit CIL located in Columbus, Missouri. They are non-residential, cross-disability, community based, and consumer-driven serving seven counties. They are a vendor for In-Home Services through state disability agencies, the Department of Veterans Affairs, Veterans Home Care, and private pay. SIL offers four core services to support independent living:

- Advocacy
- Independent Living Skills Training
- Information and Referral
- Peer Support

SIL provides In-Home Services for personal care, household chores, respite care, and authorized nursing visits to individuals with disabilities and the elderly. These services aid individuals so that they may live independently in the community. Consumer Directed Services (CDS) enables individuals to hire and train their own attendants. They must be at least 18 years old, Medicaid eligible, and able to make their own healthcare decisions. SIL acts as a fiscal agent, administers background checks, and maintains a database of eligible attendants. Attendants must be at least 18 years old, and cannot be the spouse of the individual. The Missouri Department of Health and Senior Services manages statewide CDS programs. Most of their consumers are referred by a government agency through a screening and assessment for services. There is a face-to-face

assessment as the last step where the number of hours and types of needs are determined. Currently, they serve 160 people through CDS and 15 people through In-Home Services. Two individuals are using Veterans Affairs funds, and the rest are funded through government waivers. They do not have anyone currently using private funds. For more information about Services for Independent Living visit: <http://www.silcolumbia.org/>.

Specialized Housing, Inc.

Specialized Housing, Inc started in 1983 to support adults with disabilities to live in their own residential home out in the community. They recognized that group homes and rental homes were subject to landlords. Rentals lacked the opportunity for autonomy for citizens with disabilities. Specialized Housing, Inc provides supportive housing services to New England and greater Boston area residents in their own home. They work with residents to plan meals and coordinate medical appointments and medicine. They assist in training for household chores as well as participation in recreational and community events and opportunities. For more information visit: <http://specializedhousing.org/>.

St. Louis Life

St. Louis Life was built in 2007, and is located in a master planned community of Winghaven in O'Fallon, Missouri. Winghaven is a community with single-family homes, recreational complexes, walking trails, golf, a spa, library, retail shops and restaurants. They also have medical buildings and an urgent care facility. St Louis Life is a residential program for individuals with developmental disabilities between the ages of 19-35. Their residents must be able to live independently, self-medicate when necessary, and are willing to be involved in meaningful activities (work or volunteer) at least 20 hours a week. They have two buildings: the Commons and the apartment complex. The

Commons has a library, computer lab, recreational room, staff offices, and a common dining area. The apartment complex next door has sixteen, 650 sq. ft. units with kitchens and private baths.

The St. Louis Life staff members help residents to make medical appointments, facilitate employment and volunteer opportunities, and provide job coaching and support. While the staff does not provide skilled nursing support, they are available to assist residents in communicating with medical professionals. Staff members monitor Internet usage and provide weekly transportation to local grocery stores. Transportation to church or spiritual services is available upon request. Residents must have their own personal cell phones on them at all times for communication and safety. Staff members encourage community integration and social interactions. They plan monthly cultural and recreational outings as well as an annual trip. These extra curricular activities are at an extra charge to the resident. The annual fee for residents is \$42,000. This includes a single, 650 sq. ft. apartment (equipped with an emergency call button) with utilities and 14 meals (breakfast and dinner) per week. Transportation, employment placement and coaching, and 24-7 staff support are also included. There is a \$75 non-refundable application fee. For more information on St. Louis life visit: <http://www.stlouislife.org/>.

Target Community and Educational Services, Inc.

In 1983, a group of concerned parents voiced two main concerns to Dr. Donald Rabush, a professor of Special Education at McDaniel College in Maryland, regarding the supervision of their children with developmental disabilities in supported living environments. They noted a high staff turnover rate, as well as a lower level of education amongst staff members. Dr. Rabush and the parents formed a partnership that eventually

became Target Community and Educational Services, Inc., a 501 (c)(3) nonprofit organization. Its mission is to “.... enhance the lives of children and adults with intellectual and developmental disabilities through quality, community-based residential,

Target Community and Educational Services, Inc. is governed by a volunteer Board of Directors with over 200 employees. There are six major components to their program:

- The Autism Waiver Service Coordination
- Community Living
- Community Supported Living Arrangements
- Day Habilitation
- Supported Employment
- Post-Secondary Education

The Community Living Program is comprised of the Alternative Living Unit (ALU) Program and the Apartment Program. The nine ALU homes each have three residents with intellectual and developmental disabilities. All residents have their own bedroom, and graduate students from the Master of Science in Human Services Management program at McDaniel College serve as Community Living Managers to provide support (<http://www.mcdaniel.edu/graduate/your-plan/academic-programs/m.s.-in-human-services-management>). Support is available 24 hours a day seven days a week, and each resident has an individualized schedule that supports independent living.

The Community Supported Living Arrangements (CSLA) program serves approximately 50 individuals with intellectual or developmental disabilities that live at home or with family members. Drop-in services and support are provided on an individual basis for 20-30 hours per week. Assistance includes help with household

chores, shopping, transportation, money management, and other independent living skills. There is an emphasis on community involvement. Staff members facilitate involvement in local recreational activities. Some CSLA hours are paid for through private pay; however, most are through Maryland Developmental Disabilities Administration (DDA) hours. Clients are awarded a certain number of DDA support hours depending on the individual need determined by the DDA. Needed hours can range from 5 to 80 hours per week.

The Target Community and Educational Services, Inc. apartment program started in 1997 in Rockville, MD. Its goal was to provide higher-functioning individuals with private living environments. There are currently four Community Living managers providing 24-7 on site supervision for seventeen residents in nine apartments. Most of the residents in the apartment program are employed in the community. They may need assistance with household chores, transportation, managing finances, or medical appointments. For more information about Target Community and Educational Services, Inc visit: <http://www.targetcommunity.org/>.

Chapter 5

Independent Living Assessment and Intervention Resources

This chapter provides an overview of formal independent living assessment tools that can be used with adults with intellectual and developmental disabilities. A description of how each assessment is administered, the areas assessed, and how the assessment can be used is provided. Links for ordering each assessment tool is included following each description. The chapter also includes goal setting, instructional planning, and progress monitoring tools.

Independent Living Assessment Tools

BRIGANCE® Transition Skills Inventory (TSI)

The BRIGANCE® Transition Skills Inventory (TSI) is a criterion-referenced assessment tool covering a broad range of knowledge and skills important for successful

transition into adult life. The assessment methods include observation, performance though oral response, written response, or physical response, and interview. There are four domains: Academic Skills, Post-Secondary Opportunities, Independent Living, and Community Participation. The assessment helps teams to determine present levels of skills and abilities, set appropriate goals, and monitor progress. The Independent Living domain includes the following skill areas: food, clothing, housing, money and finance, health, and travel and transportation. The table below gives more specific information about the skills assessed in the housing domain:

Housing Skills	Description
Housing Resources	Focuses on the individual's ability to understand where to look and what to look for when seeking housing
Tenant Agreement/Lease	Focuses on the individual's ability to understand and fill out a tenant rental/lease agreement
Supplemental and Related Lists/Skill Sequences	<ul style="list-style-type: none"> • Abbreviations in housing ads • Features of housing (ex. size, price, location, amenities, utilities, maintenance, limitations, parking, storage) • Resources for finding housing (ex. newspaper, internet, realtor, family and friends, apartment guides) • Tenant rights • Tenant responsibilities • Parts of a housing budget • Housekeeping • Home repairs • Household tools/devices

Another valuable resource is the BRIGANCE® Transition Skills Activities manual. This includes age-appropriate lesson plans and activities aligned directly to the assessments found in the BRIGANCE® Transition Skills Inventory (TSI). For ordering information for the BRIGANCE® Transition Skills Inventory (TSI) and supplementary

materials visit:

http://www.curriculumassociates.com/products/detail.aspx?title=brigtsi#additional_nav.

Supports Intensity Scale™ (SIS)

The Supports Intensity Scale™ (SIS) is a norm-referenced, valid, and reliable instrument designed to determine the pattern and intensity of an individual's support needs (Thompson, Bryant, Campbell, Craig, Hughes, et al., 2004). It was designed to assess support needs, determine the intensity of needed supports, monitor progress, and evaluate outcomes. This tool allows the planning process to shift from fixing or changing the individual to identifying and designing supports to increase independence and community participation.

The assessment entails a semi-structured interview with at least two respondents who know the individual well. The assessment considers support needs related to personal competence, behavioral support needs, medical support needs, and the number and complexity of settings and life activities. There are three dimensions of intensity used to indicate the supports an individual may need including frequency, daily support time, and type. Frequency examines how often support is needed (ex. less than monthly, monthly, weekly, daily, hourly). Daily support time examines what amount of time is devoted to provide support on the days it is needed (ex. no time, less than thirty minutes, more than thirty minutes to less than two hours, two hours to less than four hours, four hours or more). Type of support examines the nature support needed (ex. no support, monitoring, verbal or gestural prompting, partial physical assistance, full physical assistance). The SIS has three sections: Section 1 (Support Needs Scale), Section 2 (Supplementary Protection and Advocacy Scale), and Section 3 (Exceptional Medical

and Behavioral Support Needs). The tables below give an overview of what activities and supports are assessed in each section:

Section 1: Support Needs Scale				
<p>Home Living Activities (using the toilet, laundry, preparing/eating food, housekeeping, dressing, personal hygiene, operating home appliances)</p>	<p>Community Living Activities (transportation, recreation, using public services, visiting others, community participation and interaction, shopping, accessing buildings)</p>	<p>Lifelong Learning Activities (interacting with others in learning activities, participating in educational decisions, using problem solving strategies, using technology for learning, accessing educational settings, learning functional academics, health skills, self-determination skills, and self management strategies)</p>	<p>Employment Activities (receiving accommodations, learning and using job skills, interacting with co-workers and supervisors, task completion with speed and quality, changing job assignments, seeking information and assistance)</p>	<p>Health and Safety Activities (taking medication, avoiding health and safety hazards, obtaining health care services, ambulation, accessing emergency services, maintaining a nutritious diet, physical health and fitness, and emotional well-being)</p>

Section 2: Supplemental Protection and Advocacy Scale
<p>Protection and Advocacy Activities (self advocacy, managing finances, protecting self from exploitation, obtaining legal services, exercising legal responsibilities, making choices and decisions, advocating for others)</p>

Section 3: Exceptional Medical and Behavioral Support Needs	
<p>Medical Supports Needed (Respiratory care, feeding assistance, skin care, seizure</p>	<p>Behavioral Supports Needed (Externally directed destructiveness, self-directed</p>

management, dialysis, ostomy care, lifting/transferring, therapy)	destructiveness, sexual, tantrums, wandering, substance abuse, mental health treatment)
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For SIS ordering information, visit: <http://aaidd.org/sis/order#.U3oigFhdXnI>.

Checklist of Adaptive Living Skills (CALs)

The Checklist of Adaptive Living Skills (CALs) (Morreau & Bruininks, 1991) is a criterion-referenced, valid, and reliable assessment with approximately 800 specific adaptive behaviors related to self-care, personal independence, and adaptive functioning in leisure, work, community, and residential environments. CALs is used for determining the needs of individuals, setting instructional goals, and monitoring progress. The person responding to the questions should know the individual well. For each behavior listed, the responder would simply check the items that the individual is able to perform independently (performs the skill well at least 75% of the time without being reminded to do so). It is optional for the responder to indicate what level of prompting is needed for the skills the individuals is not able to perform independently to set appropriate goals and monitor progress. There are four broad domains with a variety of skills modules included in each domain. Below is a table that gives an overview of the domains and skills modules.

Broad Domains	Skills Modules
Personal Living Skills	<ul style="list-style-type: none"> • Socialization • Eating • Grooming • Toileting • Dressing • Health Care • Sexuality
Home Living Skills	<ul style="list-style-type: none"> • Clothing Care • Meal Planning and Preparation • Home Cleaning and Organization

	<ul style="list-style-type: none"> • Home Maintenance • Home Safety • Home Leisure
Community Living Skills	<ul style="list-style-type: none"> • Social Interaction • Mobility and Travel • Time Management • Money Management and Shopping • Community Safety • Community Leisure • Community Participation
Employment Skills	<ul style="list-style-type: none"> • Job Search • Job Performance and Attitudes • Employee Relations • Job Safety

For ordering information, visit:

<http://www.riversI/DEpublishing.com/products/cals/index.html>

The Assessment of Functional Living Skills™ (The AFLS™)

The Assessment of Functional Living Skills™ (The AFLS™) (Partington & Mueller, 2012) is an assessment, skills tracking system, and curriculum guide used to promote independence at home, school, and in the community. The focus of the AFLS is on essential, practical, everyday skills of daily living that, if mastered, prevent the individual from needing someone else to do these things for him or her. AFLS has four protocols: Basic Living Skills Assessment, Home Skills Assessment, Community Participation Skills Assessment, and School Skills Assessment. Regardless of which protocol is being used, information is obtained from three sources: interviewing caregivers who regularly interact with the individual, observing the individual in particular situations, and the formal presentation of tasks to the individual to determine competence with specific skills.

The AFLS is a criterion-referenced assessment that assists with setting goals for intervention. Each protocol consists of a variety of functional skills that are scored using a set criteria to rate the individual on a 0-2 scale or 0-4 scale depending on the target skill. Teaching companions for each assessment protocol are currently being developed. These will include task analyses, teaching suggestions, and prompting strategies for each skill included in the assessment. Below is a table that gives an overview of the skills assessed in each assessment protocol.

Basic Living Skills Assessment	Home Skills Assessment	Community Participation Skills Assessment	School Skills Assessment
Self-management, basic communication, dressing, toileting, grooming, bathing, health, safety, and first aI/DD, nighttime routine	Meals at home, dishes, clothing and laundry, housekeeping and chores, household mechanics, leisure, kitchen, cooking	Basic mobility, community knowledge, shopping, eating in public, money, phone, time, social awareness and manners	Classroom mechanics, meals to school, routines and expectations, social skills, technology, common knowledge, core academics, applied academics

It is important to note that the AFLS™ is not a norm-referenced assessment and has not been tested for validity or reliability. For ordering information, visit: <https://rhu014.veracore.com/sv5fmsnet/OeCart/OEFrame.asp?Action=NEWORDER&cmunenodseq=&FromFav=&PmSess1=247530&pos=AFLS01&v=3>.

Free Online Independent Living Inventories

There are informal independent living inventories available online at no cost. These are typically not instruments that have documented validity and reliability, but can be useful for informal use and/or for getting ideas when designing original assessment tools to meet the specific needs of the individuals being served. Below is a table that

provides links to free online independent living inventories along with a description of what is included in each assessment.

Name of Inventory	Link	Description
Life Skills Inventory: Independent Living Skills Assessment Tool (Washington State Department of Social and Health Services)	http://www.dshs.wa.gov/pdf/ms/forms/10_267.pdf	Includes a variety of items under the following categories: <ul style="list-style-type: none"> • Money Management/Consumer Awareness • Food Management • Personal Appearance and Hygiene • Health • Housekeeping • Housing • Transportation • Educational Planning • Job Seeking Skills • Job Maintenance Skills • Emergency and Safety Skills • Knowledge of Community Resources • Interpersonal Skills • Legal Skills • Pregnancy Prevention/Parenting and Child Care
Taft College Transition to Independent Living Program Skills Inventory	http://www.taftcollege.edu/tcwp/til/wp-content/uploads/2010/09/TIL_skills_inventory_sheet.pdf	Includes a variety of items under the following categories: <ul style="list-style-type: none"> • Household • Personal Care • Safety Skills • Money Management • Social Skills • Travel • Vocational

Ecological Assessment

It is often necessary to use informal assessment methods that take place within natural environments using ecological assessment to fully understand the skills and abilities an individual has and needs for specific independent living contexts. When using ecological assessment, the assessor documents the skills needed within a particular

environment/context and observes the individual during naturally occurring routines and activities to identify skills needed to increase independence. For example, an assessor can document the skills needed to use the laundry equipment in an individual's apartment using a task analysis approach. Then the individual is observed while the assessor documents which steps of the task analysis the individuals performed independently while doing laundry and which steps required assistance from others. Based on these ecological assessments, goals and objectives can be written for specific independent living contexts.

Goal Setting and Progress Monitoring Resources

This section provides tools for goal setting and progress monitoring. The table below can be used to document an individual's present level of skills and abilities, goals and objectives related to essential skills needed for successful independent living, and supports the individual will need to achieve the outcomes set. Teams can delete skill areas that are mastered or not applicable for a particular reason. The information related to present levels and abilities could be gathered using the assessment tools described in the previous section.

Skill Area	Present Level of Skills and Abilities	Long-term Goal(s)	Short-term Objectives	Supports Needed
Researching Affordable Housing Options				
Accessing Available Funding for Housing and Supported Living				

Making Housing Choices				
Meal Planning, Meal Preparation, and Eating				
Budgeting and Paying Bills				
Home Maintenance				
Home Cleaning and Organization				
Clothing Care				
Operating Home Appliances				
Home Safety				
Home Leisure				
Personal Hygiene				
Dressing				
Toileting				
Health Care				
First Aid				
Living with Roommates				
Accessing Support as Needed				

Once goals are set, progress-monitoring procedures must be used to ensure individuals are making strides towards achieving their goals. Self-monitoring tools can be used for a variety of skill areas. Below are some sample self-monitoring templates that can be used weekly, bi-monthly, monthly, quarterly, semi-annually, or annually:

Objective	I can perform this skill independently	I can perform this skill with very little support I ask for from others.	I can perform this skill when I have help from others for some of the steps.	I can perform this skill when others help with most or all steps.

Objective	I Mastered This	I Am Near Mastery	I Require Some Assistance	I Require Significant Amounts of Assistance

Instructional Resources from the National Secondary Transition Technical Assistance Center (NSTTAC)

The National Secondary Transition Technical Assistance Center (NSTTAC) provides sample lesson plans that can be used to address a variety of life skills including: leisure skills, social skills, self-determination skills, problem solving, self-awareness, self-advocacy, independent living, money, grocery shopping, home maintenance, meal planning and preparation, restaurant skills, safety skills, self-care skills, and functional reading and math skills. The website that hosts these lesson plans is:

<http://www.nsttac.org/content/student-development-0>. Below is a table that gives an

overview of specific lesson plans related to independent living and housing with links to those lessons.

Topic	Link
Problem Solving to Complete an Independent Living Task	http://www.nsttac.org/sites/default/files/assets/pdf/31.pdf
Grocery Shopping	http://www.nsttac.org/sites/default/files/assets/pdf/49.pdf http://www.nsttac.org/sites/default/files/assets/pdf/50.pdf http://www.nsttac.org/sites/default/files/assets/pdf/51.pdf http://www.nsttac.org/sites/default/files/assets/pdf/52.pdf
Home Maintenance	http://www.nsttac.org/sites/default/files/assets/pdf/LP_TeachingSweepingTableWashing.pdf http://www.nsttac.org/sites/default/files/assets/pdf/53.pdf http://www.nsttac.org/sites/default/files/assets/pdf/54.pdf http://www.nsttac.org/sites/default/files/assets/pdf/55.pdf http://www.nsttac.org/sites/default/files/assets/pdf/56_85.pdf http://www.nsttac.org/sites/default/files/assets/pdf/McDonnellandMcFarland1988laundromat.pdf
Safety	http://www.nsttac.org/sites/default/files/assets/pdf/63b.pdf http://www.nsttac.org/sites/default/files/assets/pdf/63c.pdf http://www.nsttac.org/sites/default/files/assets/pdf/WarningLabel.pdf http://www.nsttac.org/sites/default/files/assets/pdf/FireSafety.pdf http://www.nsttac.org/sites/default/files/assets/pdf/CookingFires.pdf

	http://www.nsttac.org/sites/default/files/assets/pdf/LessonPlanOReilly1990homesafety.pdf
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NSTTAC also provides resources on evidence-based practices for improving independent living outcomes of individuals with disabilities. Visit <http://www.nsttac.org/content/nsttacdcdt-fact-sheets> to access these resources. One of the documents entitled *Improving Post-School Independent Living Outcomes: Evidence-Based Secondary Transition Predictors*, and it can be found at this link: http://www.nsttac.org/sites/default/files/assets/pdf/NSTTAC-DCDT_Fact_Sheets/FactSheetIndependentLiving081909.pdf. This document shares research related to four main areas that improve independent living outcomes for students with disabilities including: inclusion in general education, paid work experience, self-care skills, and support networks. The Evidence Based Practices in Transition link (<http://www.nsttac.org/content/evidence-based-practices-secondary-transition>) provides a review of several effective practices for teaching independent living skills including: task analysis/chaining, computer-assisted instruction, constant time delay, progressive time delay, least-to-most prompting, most-to-least prompting, simultaneous prompting, response prompting, self-monitoring, and video modeling.

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