Housing and Support Options

for

People with Intellectual

and Developmental Disabilities

Introduction

In January of 2013, the Coleman Foundation awarded funding to the collaboration of Ray Graham Association, Clearbrook, and Aspire to research innovative housing and support models with potential for implementation in Illinois for persons with intellectual and developmental disabilities (IDD). Representatives from these three provider agencies in suburban Chicago focused on researching options that could:

◆ Address the critical need to create community-based, cost effective housing models in Illinois

◆ Seek solutions which decrease reliance on state funding

◆ Lead to the development of alternative home ownership structures

◆ Honor an individual's right to choose a home which affords the opportunity to live a fulfilling and productive life in the community

Throughout 2013, the collaboration partners gathered information and data from a variety of sources including interviews with national experts and leaders in the field of service design and delivery, as well as visiting several provider agencies in Wisconsin, Michigan, and Oregon. Research also included arranging presentations from housing developers, attendance at housing seminars and technology conferences, and the review of published documents and reports from national associations and researchers which highlighted service trends for people with IDD. The collaboration partners met monthly to examine its research results and identify further sources of information that might benefit the project.

One original goal of this project was to identify implementation-ready residential model(s) that the Coleman Foundation could share with provider agencies for replication across Illinois. As research of innovative residential models progressed, it became apparent that there was not one specific 'best practice' that should be replicated across the state, but rather, many viable options that offered the flexibility needed to develop services that are truly person-centered.

Several common themes and trends presented themselves repeatedly throughout the research, interviews, and tours conducted during this project:

◆ Person-centered planning that encourages choice in where to live and with whom and promotes the level of self-direction desired by the individual
◆ Individualized budgets which allow for support that is flexible and changes over time
◆ Property ownership by entities other than the service provider resulting in a separation of housing from supports
◆ The use of independent Support Brokers who are responsible for completing the assessments and interviews that lead to establishing individualized budgets
◆ Flexible Medicaid waivers which include expanded menus of services from which to choose such as different levels of support in a variety of residential settings, flexible day service and

employment options, community guides, assistive technology, remote monitoring, and non-medical transportation

◆ Some of the 'best' of best practices in housing and support options for people with IDD does not yet transfer easily to large-scale system change. The challenge of moving from typical practice toward best practice and then taking best practice to scale remains. However, service providers and states are beginning to use approaches which have been successful on a small scale to inform their decisions on service design, funding, and systems change. (Best Practice, Expected Practice, and the Challenge of Scale, Michael W. Smull, Mary Lou Bourne, and Helen Sanderson)

To highlight additional trends and practices identified during their research, the collaboration partners used the following grid format to organize housing and support options for consideration. This grid is a modified version of one originally developed during a collaboration between the Center for Independent Futures and the Housing Opportunity Development Corporation. By using this grid as a planning tool, individuals and organizations assisting persons with IDD will be able to select information from each of the categories to customize housing and supports based on person-centered needs and desires. The concepts in the grid are presented as options to be discussed and considered during person-centered planning and are not intended to be mutually exclusive.

Housing and Support Options for People with I/DD

Housing Options				Support Options		
I want to live with:	I want to live in:	The property I live in is owned by:	My home life is directed by:	My support is provided by:	My level of support is:	My support is funded by:
• Myself • Family • Roommate • Group	• House, Condo, Apartment • Family Home • Shared Living Arrangement • Group Home • ICF/IID • State Operated Housing	• Me • Family • Roommate • Landlord • Agency • Housing Corporation • State	• Me • Family • Roommate • Agency • State	• Assistive Technology • Family/ Friends • Roommate • Volunteers • Neighbors • Paid staff	• Case Management Only • Part Time • Full Time	• Me • Family • Government Programs/ Entitlements

Adapted from the work of Housing Opportunity Development Corporation and Center for Independent Futures.

Housing Options

I want to live with:

Myself – Family – Roommate - Group

For persons with or without disabilities, choosing with whom to live should be influenced by personal preference. When considering whether to live alone, with family, with a roommate, or with a group of unrelated people, persons with IDD should consider their personal preference and the pros and cons of each of these living options. For example, some people prefer the quiet and control of one's personal space that is usually associated with living alone while others may enjoy the socialization and shared responsibility that can occur when living with others. Cultural influences may also contribute to a person's decision to live with a family member or in a setting outside of the family home.   In 2011, 16% of persons with IDD in the United States lived alone or with a roommate, while 72% lived with family member(s)(Braddock, David. *State of the States in Disability Services*. 2013).   Regardless of a person's current living arrangement, the person-centered planning process should consider what the person with IDD desires in the short- and long-term. In recent years, the size of group living settings has been decreasing yet the decision to live alone or with others should be driven primarily by personal preference as there is no right or wrong option suggested by field trends or the opinions of service providers or other professionals.

I Want to Live In:

House, Condo, Apartment

Approximately 16% of individuals with IDD live alone or with a roommate in a private home or apartment rented or owned by the individual (Braddock, 2013). Individuals with IDD may rent a home or apartment with combination of earned income, Supplemental Security Income (SSI), vouchers or subsidies through the U.S. Department of Housing and Urban Development (HUD). While most persons with an SSI level income are eligible for federally funded Housing Choice Vouchers (administered locally by public housing agencies), they are subject to long waiting lists.

Family Home

Nationally, the majority (72%) of persons with IDD are living in their family home and receiving care from family members (Braddock, 2013).

Shared Living Arrangement

In Illinois, approximately 2.5% of persons with IDD receiving Community Integrated Living Arrangement (CILA) funding from Illinois Department of Human Services live in a host family setting (IDHS Developmental Disabilities Reports, website, 2013). Host family, or shared living, is an arrangement where one or two persons with IDD live with unrelated person(s) who are under contract with a provider agency to provide needed supports and services. This type of living arrangement and funding has been an available CILA option in Illinois for several years but its use has increased in recent years as an alternative to the larger group home model.

There are numerous examples of provider agencies across the country that have developed this model with much success. Organizations such as Options in Community Living (http://www.optionsmadison.com/) in Madison Wisconsin, Choicess (http://choicess.com/wp/) in Arcadia California, Avenues Supported Living Services (http://www.avenuessls.org/) in Valencia California, and L'Arche (http://www.larcheusa.org/) are considered leaders in shared living arrangements. Each of these providers has had much success in providing highly individualized supports within small, community-based settings for persons with all levels of IDD.

Group Home
Community-based group homes have been a common type of living arrangement for people with IDD nationally beginning in the 1970s. As of December 2012, approximately 8200 persons with IDD lived in group homes of up to eight persons in Illinois (IDHS website, 2013). Nationally, the trend for several years has been moving toward smaller settings with single bedrooms, with 23% living in group homes with 7 or 8 beds in 2011 (Braddock, 2013). Comparatively, 54% of persons living in group homes in Illinois are living in homes with 7 or 8 beds (IDHS website, 2013). Although many Illinois providers find it cost prohibitive to operate group homes with less than 6 individuals, enhanced rates and incentives are being offered to providers willing to develop group homes with four or less single bedrooms for persons leaving state operated facilities and Intermediate Care Facilities for Individuals with Intellectual Disabilities.

Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID)
This type of residential option offers medical care, rehabilitation, and active treatment for persons with intellectual disabilities within a licensed setting. In Illinois, approximately 6300 persons with intellectual and developmental disabilities lived in ICF/IID settings, representing a 5% decrease since July 2008 (IDHS website, 2013). For persons desiring a less restrictive living option, or perhaps not needing the level of medical care afforded in an ICF/IID setting, transitioning to living in the community has been difficult in the past because the funding is typically not transferable between these two types of residential options. On July 28, 2005 however, the Ligas v. Hamos lawsuit was filed on behalf of adults with developmental disabilities residing in private, state-funded Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) who choose to move to community-based services or settings and on behalf of adults with developmental disabilities residing at home who are seeking community-based services or settings. (IDHS website, 2013). As of September of 2013, 519 persons living in ICF/IIDs had moved to less restrictive living settings. This exceeded the requirement in the consent decree that one-third of the eligible class members move by December of 2013 (Records, Tony. *Ligas vs. Hamos - Second Annual Report of the Monitor*. September 30, 2013).

State Operated Housing
State operated developmental centers, formerly referred to as institutions for persons with disabilities, have been downsizing since the 1970s. In 1977, 149,892 persons with IDD resided in state operated facilities nationally, compared to only 29,574 in 2011, representing an 80% decrease during this 34 year period (Braddock, 2013). The trend toward developing less restrictive, community-based living options for people with IDD continues today. Nationally, 14 states have no state operated developmental centers and many others are moving to close their remaining facilities. In Illinois, two state operated

facilities have closed since 2010, leaving seven open facilities as of December 2013, one of which is scheduled to close in 2014. Approximately 1800 persons with IDD reside in state operated facilities in Illinois which represents a 29% reduction since 2007 (IDHS website, 2013).

This downsizing effort is due in large part to Illinois' Rebalancing Initiative. Illinois, along with 42 other States and the District of Columbia have implemented the Pathways/Money Follows the Person (MFP) Demonstration Program which has the primary focus of increasing the use of Home and Community-Based Services (HCBS) and reducing the use of institutionally-based services. It is also intended to eliminate barriers and mechanisms in State law, State Medicaid plans, or State budgets that prevent or restrict the flexible use of Medicaid funds to enable Medicaid-eligible individuals to receive long-term care in the settings of their choice. As of May 2012, the Illinois Pathways/MFP Program has assisted 533 individuals with transitioning to the community. (MFP website, 2013) The average cost of providing care in a state operated facility in 2011 was approximately $220,000, while the current average cost in Illinois to provide community-based CILA services was approximately $53,000 in 2012 (Braddock, 2013).

The Property I Live in is Owned By:

Individual
Many individuals with IDD rely on federal entitlements or benefits as their primary income source and thus find home ownership difficult to achieve. Organizations such as Community Vision, Inc. in Portland Oregon (http://www.cvision.org) have developed programs to provide one-on-one counseling for people living with disabilities to develop individualized plans for working toward home ownership. Community Vision's Homeownership Independence Program empowers people with disabilities and families with 80% annual median income (AMI) or less (established by HUD) to purchase a home in the community of their choice. The fixed mortgage payment offers independence, stability, security from rent increases, and the pride of being part of a community.

Family
Some families may have the means to own the home where an individual lives alone or with roommates. In some cases, the family may own or donate the home while supports are provided by organizations. Partnerships of this type between families and agencies allow for stable housing for the individual with IDD while extending the funding received from external sources for the individual.

Roommate
Persons with IDD may choose to rent in a property owned by an unrelated roommate. Although the roommate owns the home, the person with IDD may receive supports from family or paid supports, or from the roommate through a host family or shared living agreement.

Landlord
Rental properties are available in most communities and can offer persons with or without disabilities flexibility in terms of budget, location, and other preferences.   Renting also allows for a shorter term commitment compared to home ownership. Low income persons may be able to receive subsidies or make use of various state and federal vouchers to help pay their housing costs. Additionally, persons with disabilities have fair housing rights and may not be discriminated against when renting a property. Finally, although a typical landlord may rent a property to anyone in the community, some rental

properties are owned by family members or other private investors for the sole purpose of renting to persons with IDD whom they know.

Agency

Property that is owned directly by a non-profit service provider agency is currently the most prevalent ownership model for group homes in Illinois. In addition to the increased flexibility of providing living arrangements to meet the individual needs of persons with IDD, many agencies find that owning property can contribute to the organization's long-term financial stability. Conversely, services and housing being provided by separate entities is becoming more common nationally. While having services and housing provided by the same entity may be the most efficient model, separating them may offer more choice for the individual with IDD.

Some organizations have addressed the need for affordable housing for persons with IDD by purchasing buildings or apartment complexes and then offering affordable rents, considered to be 30% or less of a person's income. The Center for Independent Futures (http://www.independentfutures.com/) in suburban Chicago has had success with this model. Additionally, this organization is developing an implementation plan that will identify potential financial, legal, ownership, and support options for housing to guide other grass roots groups to develop affordable housing despite the constraints of limited state/federal funding and regulatory requirements.

Housing Corporation

As organizations continue their efforts to assist persons with IDD to live full lives in their communities, they are looking for alternatives to purchasing and maintaining housing such as the group home model used commonly in the past. Limited access to capital, as well as the need to closely manage financial risk during uncertain economic times, have led to the development of several types of partnerships between organizations providing support services and a variety of housing developers.

One such company that purchases and renovates properties for persons with disabilities is Scioto Properties (http://www.scioto.com/). Scioto retains ownership of the property and offers the support provider agency a few different lease options based on varying degrees of operating and maintenance responsibility. Advantages for the support agency include not needing to commit financial resources to owning real estate and freeing up the provider's staff by using Scioto's team of housing professionals to ensure appropriate selection, negotiations, inspections and closing of the properties.

Other provider agencies are partnering with housing developers who focus specifically on the development of affordable housing units for low- and moderate-income households. These developers, such as the Housing Opportunity Development Corporation in the northern Chicago suburbs (http://hodc.org/), typically focus both on housing development and property management. One large national housing developer, Mercy Homes (https://www.mercyhousing.org/) and its regional center serving Illinois and Wisconsin, Mercy Homes Lakefront (https://www.mercyhousing.org/lakefront), have extensive experience with housing development for underserved and impoverished populations and have the ability to handle every aspect of affordable real estate development including project

financing, community outreach and planning, construction management, property management and asset management.

By working closely with local, state, and federal agencies such as the Illinois Housing Development Authority and the U.S. Department of Housing and Urban Development, these housing development organizations are able to increase the affordable housing stock for limited income individuals including those with IDD.

Partnerships between provider organizations and housing developers are well-developed in many other states. The Community Housing Network (CHN) in southeast Michigan (http://www.communityhousingnetwork.org/) develops affordable housing opportunities for people with disabilities and has created the Housing Resource Center which connects people to vital programs and services to prevent them from becoming homeless, or to help them with a variety of other housing needs. Although CHN is primarily an affordable housing developer and property management company, they also have a strong focus on directing people to other resources that might be needed to achieve and maintain stability in other life areas as well. Additionally, CHN employs some people receiving housing support services as office and support workers within the organization. In Wisconsin, Movin' Out (http://movin-out.org/), housing counselors assist people with disabilities and their families throughout Wisconsin to match up housing which is affordable and attainable given their specific situation and their desires. Movin' Out makes use of all available HUD resources and services include housing development, housing counseling, and education in the areas of both home ownership and home rental.

Another partnership to note is Home First Illinois (http://www.iff.org/resources/content/2/4/documents/HFI%20Overview.pdf), a joint program launched by IFF and Access Living. Home First Illinois' purpose is to develop integrated, accessible, and affordable homes, providing permanent, community-based housing to people with disabilities. Through this initiative, IFF develops, owns, and manages homes that will remain permanently affordable to very low-income people with disabilities.

State
Within the past 30 years, most states have been shifting away from owning and operating large residential settings for persons with IDD. Comparatively, many states no longer own any state-operated facilities whereas Illinois operated seven such settings serving 1,800 individuals as of the end of 2013 (DHS). Although the cost of providing services in this type of setting is significantly higher than the cost of community services, this model is designed to provide intensive clinical services for persons with significant medical or behavioral needs.

Direction

My Home Life is Directed By:

Individual – Family – Roommate – Agency – State
One key consideration while exploring and evaluating housing and support options available to the person with IDD is the level of self-direction they desire within their home. The desired level of autonomy and decision making authority within a home is also a matter of personal preference and can be influenced by a number of factors. Decisions such as what to eat for dinner, which day to do the laundry, and how to arrange the furniture may be influenced by how many people are sharing the setting and who owns the setting. Although many people, with and without disabilities, want full direction and responsibility within their home, this should not be presumed in all cases. Some persons may desire to direct all personal and household decisions themselves while others may prefer that others living in the home, a provider agency, or the home owner share this responsibility. For example, people who choose to live in an apartment setting understand that they will have limited opportunity to direct decisions related to property maintenance and landscaping. Additionally, persons may choose a more structured living arrangement, with others directing much of the home life and daily routines while they are learning the skills they need to live in a more independent, self-directed living arrangement. Similar to the decision of with whom to live, the level of self-direction desired within the home is a matter of personal preference and individual needs.

Support Options

My Support is Provided By:

Assistive Technology
Many organizations committed to assisting people with IDD to live as independently as possible are employing a variety of technology solutions. While these solutions can be expensive, and only 1% of Medicaid waiver dollars are currently spent on recipient technology (Braddock, 2013), many states and individual organizations recognize the potential impact of the use of technology for increasing independence of persons with IDD and in some cases, decreasing the need for full-time paid supports. Some examples of organizations using or providing innovative technology solutions include:

The Waisman Center, located in Dane County Wisconsin, is part of University of Wisconsin Center for Excellence in Developmental Disabilities and provides the Sound Response and Night Owl monitoring systems.   Sound Response (http://cow.waisman.wisc.edu/soundresponse.html) is a system of supports that enables individuals who require occasional overnight assistance to live more independently. It involves a centrally located monitoring site connected to residences through a variety of electronic sensing devices. Each home has the necessary monitoring equipment to meet the needs of each individual. When an emergency arises, Sound Response staff is able to physically respond within five minutes. Night Owl Support Systems (http://nightowlsupportsystems.com/aboutus.html) is based on

the same technology and systems as Sound Response and is currently available in other states beyond Wisconsin.

Other nationally recognized companies providing remote monitoring include Rest Assured (http://restassuredsystem.com/) and Sengistix (http://sengistix.com/). Systems may involve sensors, cameras, or a combination of both. Support needs that can be monitored remotely include sleep monitoring is being used to support needs in the areas of sleeping habits, elopement, CPAP usage, repositioning and medication schedules, biometrics, as well as monitoring a host of activities of daily living such as cooking, dressing appropriately, and leaving home on time.

Imagine!, an organization providing services for persons with cognitive disabilities in the Denver, Colorado area, has taken their years of research in the area of assistive technology and developed SmartHome (http://imaginesmarthomes.org/about.htm). The technology systems available within the SmartHome are designed to enhance the quality of life within the home and the community, augment the effectiveness of caregivers, and provide cost and energy savings. Web based communication and individual prompting mechanisms, such step-by-step instructional software for preparing meals, reduce the need for continuous supervision within the home.   Daily tasks can be automated to allow caregivers to spend more time with each consumer. Software for online medication prompting and tracking and the analysis of staff activity through sensor feedback to increase awareness and accountability is also part of SmartHome technology in use.

AbleLink Technologies (http://www.ablelinktech.com/) headquartered in Colorado Springs, Colorado, offers mobile, desktop, and cloud-based solutions focused on increasing the independence of people with traumatic brain injuries, cognitive disabilities, as well as the aging population. AbleLink's product offerings include Visual Impact and WayFinder. Visual Impact provides easy step-by-step multimedia instructions for self-directed learning including preparing meals and other important self-care activities. WayFinder uses GPS-based personalized audio and visual cues to support independent travel via bus systems and on foot. With WayFinder, specific travel routes can be created and activated from the GPS location. Then, users receive customized audio and visual instructions to prompt them through route navigation.

Provider groups and state associations are also actively pursuing ways to incorporate technology solutions to supplement the services and supports already available to persons with IDD. The September 2013 Technology Summit, held in Carmel Indiana, included representatives from state associations and service providers from Illinois, Indiana, and Ohio. Discussions and presentations at the summit focused on solutions already working in these states, as well as ideas for furthering necessary funding and system changes. One resource highlighted was the Illinois Assistive Technology Program (http://www.iltech.org/about.html) which promotes the availability of assistive technology services and programs. Additionally, since the affordability of assistive technology is often an obstacle, this program also serves as a clearinghouse of assistive technology funding options.

Finally, another group, the Coleman Institute for Cognitive Disabilities (http://www.colemaninstitute.org/), within the University of Colorado, is acknowledged as a national

leader in advancing the use of technology for, and by, persons with cognitive disabilities. The Institute coordinates an annual conference which brings together experts and advocates for sessions highlighting current practices and potential technology solutions. The 2013 conference highlighted the Declaration of the Rights of People with Cognitive Disabilities to Technology and Information Access. National leaders presented innovative technology solutions (http://www.colemaninstitute.org/institute-annual-conferences/2013-conference/2013-conference-agenda). Additionally, the Coleman Institute administers the State of the States in Disabilities Services Project (http://www.stateofthestates.org/) which offers longitudinal information and state profiles on service access and funding for persons with a variety of disabilities and living situations.

Family/Friends

Approximately 72% of estimated 4.9 million persons with IDD in the United States live with a family caregiver and 57% of service funding is directed toward supporting persons in their family home (Braddock, 2013). Additionally, approximately 88% of persons being awarded Medicaid waiver funding in Illinois are choosing in-home supports rather than 24-hour group home supports (IDHS website, 2013).

Roommate

One support model observed in many other states relies on roommates for all, or part, of the support needed by the individual with IDD. This model may resemble the traditional shared living arrangement discussed earlier in this paper or may be directed by the person with IDD (or family) to include a formal agreement with a roommate to provide support(s) in exchange for room, board, and/or other compensation.

In their 2011 Shared Living Guide, Robin Cooper, Kara LeBeau, and Nancy Thaler, (National Association of State Directors of Developmental Disability Services) focus on creating the opportunity for people with developmental disabilities to have a home and share everyday life with others. Building on the experiences of states, the guide explains the service system components necessary to develop and sustain shared living and is especially useful for persons who are interested in arranging and directing their own in-home support services.

Volunteers

Many organizations have developed volunteer programs to supplement the supports provided by paid staff. This use of volunteers offers a cost-efficient way to extend private/public funds as well as enabling organizations to offer a higher wage to their paid staff. Angels' Place (http://angelsplace.com/index.html) based in Southfield, Michigan, relies on over 1,000 volunteers who contribute their time by working with individuals with disabilities in their homes and during community activities, and providing all of the needed maintenance within the homes.   JARC (http://www.jarc.org/), also based in Michigan, has a well-developed volunteer program to supplement their paid supports. Volunteer opportunities are available for teens, individuals and families, as well as corporate and community groups interested in supporting persons with IDD in a variety of ways based on individual need and interest.

Neighbors

Many organizations direct their efforts toward fostering community connections in order for people with IDD to become integral members of their communities rather than just participating in community activities. The report Best Practice, Expected Practice, and the Challenge of Scale, available through the NASDDDS, focuses on connecting, building relationships and natural supports, and having a coherent strategy that moves people away from service life and toward community life.

Making Community Connections (MCC), an initiative of JARC in Michigan supports people with disabilities to be OF the community, not just IN the community. This means that they are not merely bystanders but appreciated, acknowledged and accepted by other community members. The MCC program facilitates connections between people with and without disabilities which occur in a variety of community settings, activities and clubs.

Another growing example of neighbors connecting with neighbors is time banking. The Dane County TimeBank (http://danecountytimebank.org/) in Wisconsin is a network of over 2,000 individuals and organizations who exchange services and skills to build community and capacity. In time banking, services are exchanged include helping neighbors cover basic needs, skilled services and skill building, and other creative connections. Persons with IDD benefit from this type of exchange by not only receiving support or assistance in specific areas, but of having the opportunity to build natural supports and connections and give back to their communities in a variety of ways.

Paid Staff

The second most prevalent support model, after supports provided by family members, are those supports provided by paid staff. These support staff may be employed by service provider agencies such as in the traditional group home model and are hired and trained to meet the needs of persons with IDD as well as meeting licensure and regulatory requirements. Paid staff may also be employed directly by the person with IDD or family as seen with personal assistants through the Illinois Department of Rehabilitation Services (IDRS) Home Services Program or personal support workers through various Medicaid waivers. Certainly hiring one's own support staff offers the highest degree of self-direction yet also presents the challenge of recruiting and retaining qualified persons while meeting all applicable state and federal employment laws.

My Level of Support Is:

Case Management Only

A person with IDD may only need or desire limited support in the form of case management services. Case management support could include assistance with maintaining benefits and referral to services to meet needs in the areas of transportation, employment, education, and health and safety. Typically, a case manager does not provide personal supports, but rather, serves as a liaison and advocate ensuring that the person with IDD is aware of, and can access, supports as needed.

Part-Time

Part-time supports may be desired by persons with IDD who are semi-independent in their homes and communities and only require assistance with certain activities of daily living or in certain situations. Part-time supports could include personal care at certain times of the day, assistance or training on cleaning, shopping, meal preparation, laundry, budgeting and money management, as well as assistance with accessing social networks and community activities.

Full-Time

Full-time supports benefit those persons with IDD who require ongoing assistance with all or most activities of daily living or those whose level of physical or cognitive functioning requires continuous supervision to ensure the person's health and safety.

My Support is Funded By:

Individual – Family

In some cases, persons with IDD or their families are able to pay for their own supports; either with personal earnings, family financial resources, or funds from a special needs trust.   Typically however, private payment for support services is cost prohibitive for most persons with IDD and their families.

Government Programs/Entitlements

Home and Community-Based Services (HCBS) waivers were first authorized to allow federal Medicaid funds to be used for services other than medical care. Although waivers are optional, most states have one or more approved waivers which allow them to determine how many persons may receive services as well as providing flexibility in the selection of services within the dollar cap. Nationally, there were over 627,000 waiver participants in 2011, 18,000 of which received services through one of Illinois' nine waivers. One of Illinois' waivers, the Adult HBS waiver, saw a 47% increase in the number of recipients, between 2008 and 2013, closely mirroring the increases experienced in other states. HCBS waiver funding comprised 49% of the national spending on services for people with IDD in 2011. (DHS website, 2013)

Although Illinois compares to other states in its utilization of Medicaid waivers, it differs in two key areas; per capita spending and flexibility of services offered within the waivers. In 2011, HCBS waiver spending averaged $90 per capita nationally while only $44 per capita in Illinois (Braddock, 2013). Additionally, allowable services authorized within Illinois' waivers offer less options and flexibility than some other states. Although all states' waivers have predetermined caps on spending, states such as North Carolina, Kentucky, Georgia, Vermont, Connecticut, Washington, Ohio, and Indiana offer flexibility and a wider variety of services to their waiver recipients.

Findings and Next Steps

Research on innovative housing and support models by the collaboration of the Ray Graham Association, Clearbrook, and Aspire organizations yielded a wide variety of successful practices in use across the United States. Although no single model was identified as a best practice and

implementation-ready for use in Illinois, the following specific trends were noted to be gaining momentum in many parts of the country over the past few years:

- ◆ Person-centered planning – although the concept of personalized supports is not new, there is an increasing expectation that supports for persons with IDD offer a high degree of choice and result in individualized support plans which are flexible and based on an individual's changing needs over time.
- ◆ Smaller settings – movement away from group homes of 6-8 individuals to settings with 1-3 persons, each with his/her own bedroom. The shared living model often promotes a smaller, individualized setting and is prevalent in many states.
- ◆ Housing options – increasing use of models where services and housing are provided by separate entities. Additionally, persons with IDD and their families are increasingly accessing vouchers or other funding already available from local, state, and federal sources to own or rent their own homes or turning to housing development agencies for housing supports, rather than receiving housing as part of their over-all service provision.
- ◆ Technology – the continued expansion of the types of technology supports available within the home and community for persons with IDD increases the potential impact on independence and quality of life factors while decreasing, or at least supplementing, the need for paid supports.
- ◆ Community connections – ongoing funding constraints are leading to an increased focus on the use of volunteers and networks such as time banks to supplement paid supports.
- ◆ Flexible waivers – many states have structured their Medicaid Home and Community-Based Services (HCBS) waivers to offer an increasing degree of flexibility in the selection of services within the pre-set dollar cap. With approximately half of the funding for persons with IDD in the United States coming through Medicaid waivers, efforts to expand the types of allowable supports authorized within these waivers continue.

To highlight the trends and practices identified during its research, the collaboration partners developed a grid to organize the various housing and support options for consideration.   By using this grid as a planning tool, individuals and organizations assisting persons with IDD will be able to select information from each of the categories to customize housing and supports based on person-centered needs and desires. The concepts in the grid are presented as options to be discussed and considered during person-centered planning and are not intended to be mutually exclusive.

The three collaboration partners plan to apply information learned through this Coleman research project to enhance the housing and/or support services offered by their organizations during the coming year.

References and Further Reading

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Pathways to Community Living – Money Follows the Person. Retrieved from http://www.mfp.illinois.gov/ December 2013

Credits

- Chas Moseley – National Association of State Directors of Developmental Disabilities Services/Virginia
- Susan Perlik – Community Alternatives Unlimited/Illinois
- Scott Shepard – Avenues Supported Living/California
- Cathy Ficker Terrill – The Council on Quality and Leadership/Maryland
- Lilia Teninty – Human Services Research Institute/Oregon
- Joe Wykowski – Community Vision, Inc./Oregon

Conferences/Webinars:

- Technology Summit 2013 – Indiana
- Time Bank Exchange webinar – TASH
- Coleman Institute Annual Conference 2013 – Colorado
- TASH Conference 2013 - Chicago

Site Visits:

- Community Vision, Inc. – Oregon
- Dane County Department of Developmental Disability Services – Wisconsin
- Movin' Out – Wisconsin
- Options in Community Living – Wisconsin
- Waisman Center – University of Wisconsin
- Angels' Place – Michigan
- Community Housing Network – Michigan
- JARC – Michigan
- On My Own – Michigan

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Housing and Support Options for People with I/DD

Housing Options				Support Options		
I want to live with:	**I want to live in:**	**The property I live in is owned by:**	**My home life is directed by:**	**My support is provided by:**	**My level of support is:**	**My support is funded by:**
• Myself • Family • Roommate • Group	• House, Condo, Apartment • Family Home • Shared Living Arrangement • Group Home • ICF/IID • State Operated Housing	• Me • Family • Roommate • Landlord • Agency • Housing Corporation • State	• Me • Family • Roommate • Agency • State	• Assistive Technology • Family/ Friends • Roommate • Volunteers • Neighbors • Paid staff	• Case Management Only • Part Time • Full Time	• Me • Family • Government Programs/ Entitlements

Adapted from the work of Housing Opportunity Development Corporation and Center for Independent Futures.