

# **Aging with Intellectual and Developmental Disabilities: Trends and Best Practices**

**Prepared by:**

Laura Jackson, M.P.A., Coordinator, Center on Aging & Developmental  
Disabilities

Tom McVeigh, M.S., Director of Program Development

Robin Rust, M.P.A., Consultant

Christy Miller, B.A., Research Assistant

**UMKC- Institute for Human Development**

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## Executive Summary

This report was initially published in 2007 by the University of Missouri-Kansas City Institute for Human Development at the request of the Missouri Division of Developmental Disabilities to describe service trends and to identify promising practices. The report has been updated in 2015 with current demographic data, by incorporating current literature and to reflect changes in policy at the national level that have impacted trends in supports for individuals with intellectual and developmental disabilities. In addition, the report is updated to reflect progress toward five recommendations in the 2007 report.

As a result of improved health care, individuals with intellectual and developmental disabilities (I/DD) are living longer than in past decades. While there is no specific data on the numbers of older individuals with I/DD, using currently accepted prevalence rates, which range from 1.49% to 1.58% (Larson, et al., 2001), demographic data from the United States Census Bureau, and data from the Division of Developmental Disabilities on actual numbers of people seeking services, a reasonable estimate may be made of the number of Missourians with I/DD. But more importantly, an estimate may be made of the numbers of people not currently linked to the state DD system who may potentially seek services in the near future as family and other informal caregivers themselves age and become unable to support their family member with I/DD due to their own age-related disability, entry into a nursing facility, or death.

Prior to the mid-20<sup>th</sup> century, public funding for individuals with I/DD was primarily limited to large institutions. In 1972, in response to deplorable conditions in institutions, Public Law 92-223 authorized federal funding through Medicaid for Intermediate Care Facilities for Individuals with Developmental Disabilities, establishing standards for services, requiring a treatment focus, and ensuring state maintenance of prior funding (Agranoff, 2013). This set the stage for an institutional bias in the Medicaid program that has taken several decades to reverse. In 1967, 194,560 individuals resided in 165 state I/DD facilities (U.S. Department of Health, Education and Welfare, 1972). Since 1968, however, the number of people residing in these facilities has declined by an average of 5% annually (Braddock, 2013).

Significant policy changes at the federal level have pushed the trend for supports for individuals with I/DD toward community inclusion. In 1981, Congress amended Title XIX of the Social Security Act (Medicaid) adding Section 1915(c) authorizing home and community-based services (HCBS) as an alternative to care in an institution. These programs are also commonly known as “waivers” as states may seek approval from CMS to waive certain requirements of the Medicaid program, such as the requirement that services be available statewide, and comparability of services. The waiver of comparability enables a state to target HCBS to certain groups, by age, diagnosis, or type of disability.

Most states, Missouri included, began seeking approval from CMS for HCB waivers during the 1980s. Today all 50 states operate HCB waivers, and most states have several waivers serving more than one target population. Although federal funding for HCB services became available in 1981, an institutional bias continued in the Medicaid program until a landmark Supreme Court Decision in 1999. The institutional bias was evidenced by the amount of funding for all long-term supports and services (LTSS) for institutional care, which in many states has been greater than 50% until just recently.

In June, 1999, the Supreme Court held in *Olmstead v. L.C.* that unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the Americans with Disabilities Act of 1990.

In the decade following the Olmstead Supreme Court Decision, Congress has authorized a variety of funding initiatives to compel states to reduce the institutional bias in long term supports and services (LTSS), including but not limited to the following:

- Real Choice Systems Change Grants, enabling states to make fundamental systems changes to reduce reliance on institutional care and increase access to HCB supports.
- Aging and Disability Resource Centers, also known as “No Wrong Door) systems, intended to streamline access to LTSS.
- Money Follows the Person: Authorized under the Deficit Reduction Act in 2005, MFP enables states to receive enhanced federal Medicaid match for individuals moving from nursing facilities and ICF/IID facility to the community.
- Balancing Incentives Program: Authorized under the Patient Protection and Affordable Care Act in 2010, BIP enables states to receive enhanced federal funding for all HCB services. The primary goal of BIP is to push states to “rebalance” all funding for LTSS so that greater than 50% of funding is for HCB services.

While trends in supports for individuals with I/DD have moved away from large publically operated facilities to HCB supports, a similar trend toward decreasing size of community settings offering residential supports has been taking place. In the late 1970s, almost half of all individuals with community-based residential supports lived in congregate settings serving 7-15 people, but by 2005 that number had decreased to just over 15%. At the same time, the proportion of individuals in settings with three or fewer individuals has increased to over 53% of the total (Lakin & Stancliffe, 2007).

Another significant trend in the provision of residential supports for people with I/DD has been from agency-provided housing toward supports in one’s own home, through what is commonly known as individualized supported living. Most states, Missouri included, have experienced an increase in the proportion of individuals receiving residential supports, who share a residence with three or fewer housemates. In this arrangement, the home must be owned, leased or rented by at least one household member or a family member. The Money Follows the Person program provides enhanced federal funding only when individuals transition from institutions to a home shared by four or fewer individuals, owned, leased or rented by at least one of the household members or family.

Trends in Missouri by and large reflect those at the national level. Missouri, like many states, was already on a trajectory prior to the 1999 Olmstead Supreme Court decision to reduce the numbers of people served in state habilitation centers (Missouri’s name for state operated ICF/IID facilities). Between 2000 and late 2014, Missouri decreased the numbers residing in the state facilities from over 1300 to fewer than 420. Only four of the state’s original six habilitation centers are still in operation, with plans to close a third center by end of 2015.

Federal regulations published by CMS that became effective in March of 2014 are expected to have a significant impact on the manner in which residential supports are structured for individuals with I/DD. While the new federal rules do not place limits on the size of congregate residential settings, nor do the rules prohibit provider-owned housing, the rules establish new requirements for characteristics of these settings.

## Overview

The alarm has been sounding for some time now about the rapid aging of America's population and the capacity of our communities and service systems to handle the changes. By 2030, the number of people over 65 is expected to reach 73 million, over 20% of our population. Compare this with 2010, when senior citizens made up just 13% of the population (Harvard Joint Center for Housing Studies (JCHS), 2014). Included in this estimate are the nearly 900,000 older adults with intellectual and developmental disabilities (I/DD) in the United States, who are expected to number 1.4 million by the year 2030 (Factor, Heller, & Janicki, 2012).

Most older adults with I/DD require some kind of long-term supports and services, and most receive the bulk of this care from family members, often parents who are themselves aging (Factor, Heller, & Janicki, 2012). Together with the estimated 70% of older adults without I/DD who will eventually need some kind of long-term care, this represents an enormous challenge for families, communities, and service systems right now and in the coming decades (JCHS, 2014).

This report will explore the considerable overlap in service and support needs for older adults in general and older adults with I/DD, as well as important differences in the specific needs and concerns of aging individuals with I/DD and their families. It will provide analysis of current practices and policies with implications for future policy decisions and resource allocations, along with targeted recommendations for Missouri's aging and I/DD service systems.

The framework for this report is a movement known as Aging in place, which has become a predominant theme shaping housing and other policies that relate to the needs of older adults in the United States. The Centers for Disease Control defines aging in place as "the ability to live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level." Aging in place approaches, used in both aging and disability fields, allow individuals to continue living in the community setting of their choice and provide for any necessary assistance through a customized combination of formal and informal supports. This approach benefits both individuals, who overwhelmingly wish to age in their homes, and governments, who find savings in home-and-community-based care rather than institutional care (Chan, et al., 2012).

*Aging in place: allows individuals to continue living in the community setting of their choice and provides any necessary assistance through a customized combination of formal and informal supports.*

Aging in place is understood to encompass not only residential needs, but the full range of physical, functional, and psychosocial health concerns that contribute to successful aging for all people, with and without disabilities. Accordingly, this report reviews housing policy and practice in a larger context of choice, quality of life, and self-determination for our aging population.

Two primary challenges face individuals, families, communities and systems; the challenges experienced by individuals aging with I/DD and those experienced by their caregivers. These challenges are highlighted throughout this report. In fact, as one examines community supports for older individuals with I/DD it is important to examine the balance between their needs and the capacity of their care providers to meet these needs.

## Demographics: U.S. and Missouri

As noted above, senior citizens will make up an increasing proportion of our population in the coming years. In Missouri, this figure is expected exceed national averages, with nearly 1.4 million senior citizens, 25% of the population, by 2030 (Missouri DHSS, 2012). These changes are due in part to the large number of aging baby boomers but also to greater longevity; medical and nutritional advances continue to drive life expectancy higher. Today the average life expectancy in the U.S. is 78.8 years, up from 75 years as recently as 2006. At this rate of increase, Americans, on average, can be expected to live to 88 by mid-century (CDC, 2014; Easterbrook, 2014).

Individuals with I/DD have experienced a more dramatic increase in lifespan than the population as a whole. The average life expectancy of people with I/DD was 22 years in 1931 but now approaches 70 for most people with I/DD and 60 for those with the most severe disabilities (Bigby, 2002; Bittles & Glasson, 2010). The rate of increase suggests that for most people with I/DD, life expectancy will approach that of the general population within a few decades.

No specific census data exists on the number of older persons with I/DD, and thus we can only rely on estimates. There were an estimated 850,600 adults with I/DD age 60 and older in the US in 2012. Experts predict this number will reach nearly 1.4 million by 2030 when the last of the baby boom generation reaches age 60 (Factor, Heller, & Janicki, 2012).

Similarly, we can only estimate the number of aging Missourians with I/DD but rates likely follow national trends.

- Missouri's population in 2013 was 6,044,214
  - Using the currently accepted prevalence rate of 1.58% for I/DD, Missouri's population of individuals with DD is estimated at 95,497.
  - Nationally, 71% of people with I/DD live with family caregivers. (Braddock et al., 2013; Braddock, Hemp, & Rizzolo, 2008). Using that statistic, 67,802 people with I/DD in Missouri live with family caregivers.
  - An estimated 25% of these family caregivers are over the age of 60

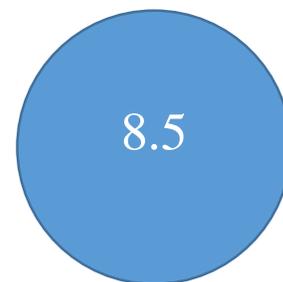
Significantly, just an estimated 28% of adults with I/DD in the U.S. are connected with any formal I/DD service system (Bigby, 2007). In Missouri, the overall figure is slightly higher, at 36%, but remains strikingly low for older adults (Missouri DHSS, 2014). As of October, 2014, Missouri's Division of Developmental Disabilities serves just 1,098 of an estimated 14,038 Missourians with I/DD over the age of 65. These figures have enormous implications for both aging and disability service systems, which may find demand for services further outstripping resources as the baby boomers age and as family caregivers die or become incapacitated, leaving many older people with I/DD without needed supports.



Missouri adults over 65 with I/DD



Adults over 65 served by MO Division of DD



% of adults over 65 with I/DD receiving services

## **Federal and State Policy: Milestones on the Path to Inclusion**

As Missouri considers how best to develop and implement aging in place strategies that meet the needs of families and individuals, it is useful to review the legal, political, and social shifts that underlie today's priorities. A few key court decisions and pieces of legislation have both shaped and reflected the national trend toward greater independence and self-determination for people with disabilities.

### **1965: Medicaid**

Title XIX, the Medicaid program, provides health-related coverage to low-income individuals and/or families and to people with disabilities. It is operated by the Centers for Medicare and Medicaid Services (CMS). In 1972, Public Law 92-223 added Intermediate Care Facilities for Individuals with Developmental Disabilities to the Medicaid program.

### **1981: Home and Community-Based Services**

The Omnibus Budget Reconciliation Act (OBRA) of 1981 amended Medicaid to allow home and community-based services (HCBS) under Section 1915(c) as an alternative to care in an institution. These programs are known as "waivers," as CMS may waive certain requirements of the Medicaid program for states pursuing HCBS expansion. States applying to operate HCBS waivers must ensure that:

- the cost of services in the community does not exceed the cost of care in an institution
- people who receive community services meet the level of care required in the institution
- waiver participants' health and safety is not compromised in the community

Home and community-based services may be offered at the option of a state and states may limit participation in these programs and establish waiting lists. The OBRA of 1981 also added personal care as an optional state plan service.

### **1990: Americans with Disabilities Act**

The ADA prohibits discrimination and ensures equal opportunity for persons with disabilities in employment, state and local government services, public accommodations, commercial facilities, and transportation.

### **1999: *Olmstead* Decision**

In *Olmstead v. L.C.*, the court held that unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the Americans with Disabilities Act and that public entities must provide community-based services to persons with disabilities when:

- (1) such services are appropriate
- (2) the affected persons do not oppose community-based treatment
- (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity (U.S. Department of Justice, Civil Rights Division).

This landmark decision significantly increased access to home- and community-based services for people living in institutions, as well as those still in the community.

### **2000-2010: Funding Initiatives to Promote Community Living**

In the decade following the *Olmstead* Decision, Congress authorized a variety of funding initiatives to compel states to reduce the institutional bias in long term supports and services (LTSS). These include:

- Real Choice Systems Change Grants: Assist states to shift long-term care from institutions to home and community-based services. ([www.Medicaid.gov](http://www.Medicaid.gov), Real Choice Systems Change)
- Aging and Disability Resource Centers (ADRCs): Bridge state aging and disability service systems to create a person-centered, community-based environment to streamline access to long-term services.
- Money Follows the Person (MFP): Gave states federal funding to support individuals transitioning from institutions to community living. The Patient Protection and Affordable Care Act of 2010 (ACA) expanded and extended the program.
- Balancing Incentives Program (BIP): Provides enhanced federal funding to states for all home and community-based services. The primary goal of this funding is to “rebalance” spending by increasing the level of spending on HCBS services to exceed 50% of all LTSS costs for the state.
- Health Home: Authorized in the ACA, health homes provide comprehensive care management, care coordination and health promotion, comprehensive transitional care including following up from inpatient and other settings, patient and family support, referral to community and support services, and use of health information technology to link services.

#### **2014: New HCBS Regulations**

In January of 2014, the Centers for Medicare and Medicaid Services published final regulations implementing the new community options authorized under the Deficit Reduction Act of 2005. The new regulations are an important step toward full community inclusion. In summary, the new regulations clarify requirements that HCB services:

- Be integrated in and support access to the greater community, provide opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources
- Ensure the individual receives services in the community to the same degree of access as individuals not receiving Medicaid HCB services

### **Trends in Residential Settings and Policies: U.S. and Missouri**

Over the past several decades a great deal of information has been collected and synthesized concerning residential services for people with I/DD. Clear trends have emerged regarding where people with I/DD live and how they are supported to live there:

- Community living vs. institutions
- Separation of residential and support services
- Smaller community settings
- Homes of one’s own vs. agency housing

#### **Trend: From Institution to Community**

The Americans with Disabilities Act and other initiatives described above have been part of a steady movement toward community inclusion for people with disabilities. Nationally, the number of people with I/DD living in large state institutions peaked in 1967 at 194,650. By 2011 that number had fallen to 29,574. As of 2012, 14 states had completely shut down state-operated I/DD institutions.

A number of federal and state policies prevent unnecessary admission to nursing homes and increase access to community living options. Since 1987, federal law requires that individuals with I/DD or mental illness (MI) be screened prior to admission to a nursing facility, if the nursing facility will be seeking Medicaid reimbursement for the service. The result of this prescreening is that an individual with I/DD or MI will not be admitted to a nursing facility simply on the basis of their disability. Subsequent changes to federal regulations have strengthened the requirements for nursing facilities to offer information about returning to the community to all residents whose nursing care is covered by Medicaid.

### *Benefits of Home and Community Based Services*

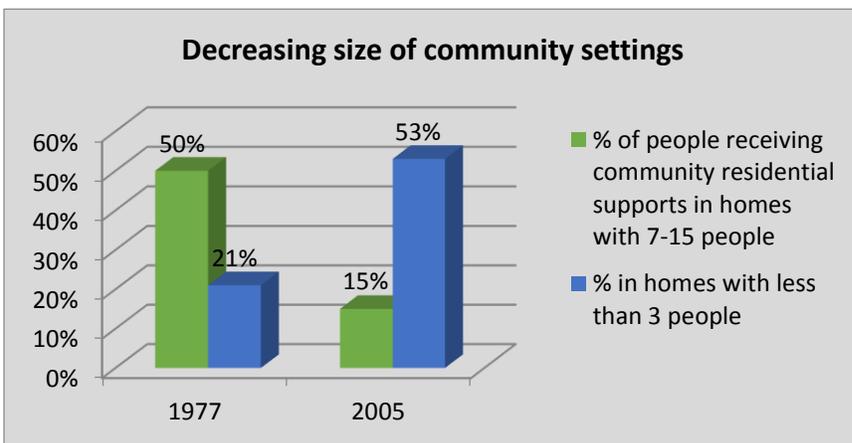
**Improved quality of life:** Research shows that individuals with I/DD have “greater personal freedom, more participation in social activities, more frequent associations with family and friends when living in the community rather than institutional settings” (Lakin & Stancliffe, 2007, p.152). In addition, longitudinal studies demonstrate a strong correlation between community living and improved functional skills, which results in greater individual independence

**Cost effectiveness:** States applying to operate HCBS waivers must ensure that the average per capita Medicaid cost for individuals participating in the waiver will not exceed the average per capita Medicaid cost for institutional settings. Research indicates that most waivers in fact produce cost savings. A 2011 analysis of HCBS waivers found “significant direct financial savings to Medicaid long-term care programs” amounting to \$57 billion nationally for \$25 billion invested (Harrington, Ng, & Kitchenor, 2011). In Missouri, an evaluation of the Partnership for Hope HCBS waiver shows similar benefits, with about \$7 million in state and county spending on the waiver generating over \$22 million in value added to the state’s economy (Institute for Human Development, 2014).

One explanation for the cost effectiveness of HCBS is that institutions face growing “fixed costs” even as residential populations decline; state institution populations have been shrinking dramatically, but the operating cost per person has actually risen 65% (Braddock, 2013).

### **Trend – Decreasing Size of Community Settings**

As more people with I/DD receive residential supports in the community, the size of community residential settings has also been shrinking. Between 1997 and 2005, a marked change occurred in the number of individuals living in very small settings (Lakin & Stancliffe, 2007). This trend has continued as better outcomes for individuals and cost savings of smaller settings become apparent.



**Figure 1: Between 1977 and 2005, the percentage of people in larger homes fell while the percentage of people in homes with less than 3 people rose.**

**Cost effectiveness:** Nationally, the cost of care by residential setting decreases with the size of the facility. 2011 financial data reported by Braddock (2013) showed the following average annual cost of care by residential setting for individuals with developmental disabilities:

Table 1: Cost of Care by Residential Setting	
State operated institutions, 16+	\$220,119
Public ICF/ID, <16	\$126,262
Private ICF/ID, 16+	\$89,060
Private ICF/ID, <16	\$85,485
Non-ICF/ID, 16+	\$39,200
Supported living	\$26,258

With substantial, growing and often unmet demand for supports, the cost-effectiveness of residential services is highly relevant to policy makers at both national and state levels. Even though it costs less to support an individual in the community than in an institution, the rapidly increasing number of older adults with I/DD, combined with increasing life

expectancies, will place great stress on state agencies charged with allocating resources and providing services to individuals and their family caregivers.

**Federal HCBS Regulations:** The new HCBS regulations do not place limits on the size of provider-owned community-based congregate living settings, but rather, establish new requirements for characteristics of these settings. Provider owned or controlled residential settings must ensure:

- Residents have privacy in their sleeping or living unit;
- Units have lockable entrance doors, and only the individual and appropriate staff have keys to the doors as needed;
- Individuals sharing units have a choice of roommates;
- Individuals have the freedom to furnish and decorate their sleeping or living unit with the lease or other agreement;
- Individuals have freedom and support to control their schedules and activities and have access to food at any time;
- Setting is physically accessible to the individual.

The new rules were effective in March, 2014. States with existing HCB services (including state plan and waivers) are required to submit a transition plan to CMS no later than March, 2015 describing how the state will ensure all HCB services will be in full compliance with the rules within five years. In many states, some providers of residential services may not be able to meet these requirements, and larger congregate residential settings that have the impact of isolating the individual from the community may be phased out.

The trend data on size of community settings is relevant to state agencies and policy makers who must allocate resources and provide services in ways that meet government regulations, respect individuals' rights and desires for independence and choice, and ensure an adequately trained workforce.

## Trend – Supported Community Living

A third trend in residential supports is supported community living, in which people control and choose where they live, who they live with, and the services needed to achieve their desired life outcomes. Increasingly, individuals with I/DD are choosing to rent or own their own homes. The number grew from 13% (40,881 people) in 1995 to over 24% (101,143 people) in 2005 (Lakin & Stancliffe, 2007). The policy shift from agency-controlled housing to individually-controlled housing is grounded in the self-determination movement, which represents a fundamental shift in power for people with disabilities. As Lakin and Stancliffe note:

Living in one's own home changes the dynamics of service-delivery, because the home is not dependent on a continuing relationship with a service provider. It establishes an easily understood status, in which the person controls who enters their home. Specific living arrangements and the amount and arrangements of paid and natural supports are designed differently for each individual, based on decisions among competing priorities as with other citizens (e.g., the cost of housing against other spending options (p.154).

**Benefits of Supported Living:** Quality of life research shows that **individual well-being increases as living arrangements become smaller and more normalized** (Lakin & Stancliffe, 2007). In a review of 33 years of studies on supported living, researchers found consistent evidence that individuals moving from institutions to supported living make substantial gains in adaptive behavior skills (Larson, Lakin, & Hill, 2013). Supported living is also associated with better outcomes on measures including:

- Self-determination
- Autonomy
- Satisfaction
- Independence
- Physical and social integration
- Community participation
- Personal well-being (Lakin & Stancliffe, 2007)

In addition, research demonstrates a positive correlation between choosing one's own home and housemates and outcomes on safety and freedom from abuse and neglect (Gardner & Carran, 2005).

**Self-Directed Services and Individualized Budgets:** In recent decades, states have experimented with self- or family-directed and individualized budget service models that allow people to choose and manage their own services, including hiring and paying support staff. These models align well with aging in place practices and have been shown to improve quality of life as well as benefits including:

- fewer unmet needs,
- better utilization of services,
- reduced caregiving burden for family members
- better outcomes for caregivers and individuals and
- decreased out of home placement.

A 2014 inventory of self-directed long-term supports and services programs found that nationwide most states have at least one self-directed program and that 60% of programs target more than one population – older adults, adults with I/DD, adults with physical disabilities, and others. Only a few of the 212 identified programs targeted just one population such as the elderly or people with I/DD (Sciegaj et al., 2014). **This reflects the growing emphasis on interagency and cross-discipline collaboration when it comes to supports and service programs for a range of populations.**

#### *Policy Implications of Research on Self-Directed Services and Individual Budgets*

**Need for Flexible Options:** Both a 2007 Kaiser Commission report and a 2013 literature review on self-directed supports for older adults found lower enrollment for older people than for younger beneficiaries. This is partly attributed to many older adults’ hesitation to take on budgeting and hiring tasks for all their services .

Instead, older adults may wish to manage a budget for just one or two home- and community-based services but stay with traditional services for other needs. When beneficiaries have flexibility in the number and type of services they choose to direct, evidence indicates they are more able and willing to participate (Spillman, Black & Orman, 2007).

**Need for Participant Support:** Assistance with hiring, training, supervising, and paying is a key program element shown to affect older adults’ continued involvement. CMS requires states to include systems for supporting beneficiaries in developing and managing their budgets and obtaining needed services; older adults may require ongoing support and assistance in order to achieve successful outcomes .

#### **Trends and Policy in Missouri**

Missouri has aggressively pursued opportunities to take advantage of federal matching funds for home and community-based long term supports and services for individuals with I/DD. Missouri was one of the first states electing to add personal care to its Medicaid state plan in 1982, and that same year also implemented one of the nation’s first HCB waivers, targeting individuals age 65 and over. Missouri’s first waiver for individuals with I/DD was implemented in 1988, and subsequently four more waivers for individuals with I/DD have been implemented.

All five Missouri waivers serving individuals with I/DD now include self- and family-directed supports, and as of late 2014 over 1,000 individuals have chosen to self-direct or designate a family member to direct supports on their behalf. These options also allow family members to provide support (excluding spouse, parent of a minor child and legal guardian), a policy that enhances choice and flexibility.

#### *Missouri’s HCBS Waivers for Individuals with I/DD*

**Comprehensive waiver:** Implemented in 1988, this waiver specifically targets individuals with I/DD who require residential supports. Residential supports include:

- group homes,
- host homes
- individualized supported living, which enables people who own or rent a home to share living space with up to 3 housemates.

Individualized supported living is currently the most widely used type of residential support in Missouri. The waiver allows room and board for a live-in care-giver, enabling flexibility in designing shared living options. The waiver serves all ages, but is most appropriate for adults with more intense support needs who do not have a natural support system. The Comprehensive waiver will serve up to 8610 individuals by June, 2015.

**Waiver for children with I/DD:** Implemented in 1995, this waiver serves children through age 17. The waiver excludes parental assets and income and enables children who would not otherwise be eligible for Medicaid (called MO HealthNet in Missouri) to remain at home with HCB supports and to access the full array of MO HealthNet state plan benefits. Upon reaching age 18, youth who still require HCB supports and who will remain eligible for MO HealthNet under another category of assistance are seamlessly transitioned to the waiver most appropriate for their needs. The Waiver for Children with I/DD will serve 366 children by September, 2015.

**Community support waiver:** Also called the “Support” waiver, and sometimes referred to as an “in-home” waiver, this waiver offers the same array of services as the comprehensive waiver **excluding residential supports**. While the waiver has an annual spending limit, the limit may be exceeded on a case-by-case basis with approval from the local Division of DD Regional Office. The spending limit is \$28,495 during state FY2015 but is automatically adjusted by the CPI inflation factor annually. This flexibility enables individuals with extensive support needs to remain at home with family or other natural supports. Implemented in 2000, this waiver will serve 1851 individuals by June of 2015.

**Autism Waiver:** Implemented in 2009, this waiver serves children ages 3 through 18 with autism spectrum disorders. Upon reaching age 19, youth who continue to need HCB supports are transitioned seamlessly to another waiver most appropriate for their needs. The autism waiver will serve 175 children and youth during state FY 2015.

**Partnership for Hope:** Implemented in 2010, this waiver is available in 100 of Missouri’s 114 counties and the City of St. Louis. Initially called the “Prevention Waiver,” it targets people with I/DD who might not otherwise be able to access other HCB waivers due to prioritization criteria, which is based on available funding.

This waiver is a unique partnership with local county DD service organizations, and the non-federal share of the cost of services is split equally between the state DD authority and the local DD authority, also called Senate Bill, or SB 40 Boards. The Partnership for Hope waiver includes the same array of services as the Community Support Waiver, as well as dental services for adults. Adult dental care was removed from Missouri’s state Medicaid plan due to lack of funding in 2005. The service was included in the state FY2015 budget but funding is

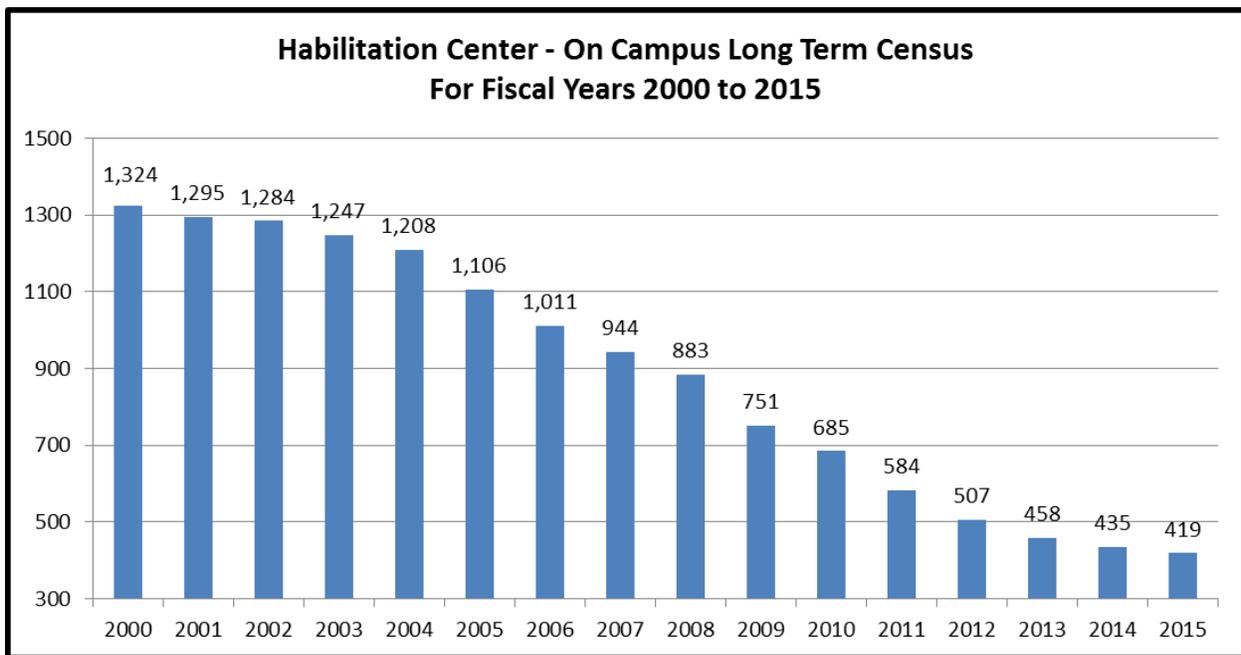
*The premise of the Partnership for Hope waiver is to provide supports to people before they are in crisis, so they can remain more independent and not only delay entry into a facility, but delay the need for more costly home and community-based supports.*

currently in restriction due to uncertainty that state revenue will be sufficient to cover the service and ensure a balanced state budget. The Partnership for Hope waiver has capacity to serve 3125 individuals by September of 2015. At the request of the Division and the Missouri Association of County DD Services, the UMKC Institute for Human Development began a five year evaluation of Partnership for Hope in 2012. A current report is posted at this link: <http://dmh.mo.gov/docs/dd/PFH-threeyearreport.pdf>.

For a comprehensive chart of services available under Missouri HCB waivers for individuals with I/DD follow this link: <http://dmh.mo.gov/dd/progs/waiver/services.htm>

### *Deinstitutionalization and Money Follows the Person in Missouri*

Missouri, like many states, was already on a trajectory prior to the 1999 Olmstead Supreme Court Decision to reduce the number of individuals receiving services in state institutions for individuals with I/DD, called habilitation centers in Missouri. Prior to 1980, Missouri had over 5,000 individuals residing in state habilitation centers, but by the late 1990's had reduced the number to around 1500. As of late 2014 Missouri has fewer than 420 individuals residing in state habilitation centers. Only four of the state's original six habilitation centers are still in operation, with plans to close a third center by the end of 2015.



**Figure 2: Decline in individuals with I/DD living in state habilitation centers 2000-2015.**

Missouri was one of the first states to apply for Money Follows the Person in 2006, receiving approval from the Centers for Medicare and Medicaid Services to begin program operation and claiming of enhanced federal funds beginning in late 2007. The target population for Missouri's MFP program is individuals with I/DD, individuals with I/DD who also have a diagnosis of mental illness, individuals with disabilities, and individuals who are elderly. While Missouri had already been assisting individuals to transition from facilities, the MFP program has provided additional federal funds enabling Missouri to better identify individuals wishing to move from facilities and to build a better infrastructure for supporting individuals returning to communities.

As of early 2015, A total of 324 individuals with I/DD have moved to the community from habilitation centers since the inception of MFP, and 59 have transitioned from nursing facilities. Of these, 58 individuals 60 and over have moved from habilitation centers, and 12 individuals aged 60 and over from nursing facilities. The oldest individual to move from a habilitation center was aged 95 in 2011, and age 81 from a nursing facility in 2013.

### *ADRCs and Other Rebalancing Initiatives in Missouri*

In 2008 Missouri was awarded both an Aging and Disability Resource Center grant and a Person-Centered Hospital Discharge Planning Grant jointly funded by the Center on Disease Control and the Administration on Aging. Both projects were conducted as pilot demonstrations in an 18-county region in Northwest Missouri. Target populations were people who are aging, people with disabilities including developmental disabilities, and family caregivers.

The ADRC brought together aging and disability partners in an unprecedented collaboration to create a networked, multi-entry system for public education, information and referral, and options consulting regarding options for community living. It was publicly launched under the name Show Me Options in 2011.

The Person-Centered Planning arm of the project developed an integrated hospital discharge planning system that works with the ADRC to improve outcomes for patients leaving the hospital either for home or for a nursing facility, to ensure that discharge planning is person-centered, and to reduce hospital readmission rates.

#### *Primary products and outcomes of the ADRC project:*

- A coordinated system of information and access for all adults with disabilities and older adults seeking long-term support in NW Missouri.
- A successful model for cross-system collaboration, documented in a Replication Toolkit;
- A comprehensive Options Consulting training curriculum for use by other regions seeking to create an ADRC;
- A Red Flag tool developed for use by hospital discharge planners and ADRC Options Consultants;
- A set of criteria/standards developed by a statewide committee to guide the establishment of future ADRCs in Missouri.

### *Balancing Incentives in Missouri*

Missouri was one of the first three states in the nation to apply for the Balancing Incentives Program (BIP) funding in 2012. Missouri's program is called Missouri Community Options and Resources, and was fully implemented in October of 2013. Missouri has achieved the **three primary goals** of BIP by implementing:

- a single point of entry/no wrong door system
- a web-based core standardized assessment
- conflict-free case management.

Most importantly, Missouri "moved the needle" on funding for long term supports and services, achieving the goal of rebalancing funding during 2014. As of the end of 2014, Missouri spends 57% of all LTSS funding on HCB services.

### *Health Homes*

Missouri was the first state in the nation to obtain CMS approval on a state plan amendment for health homes in late 2011, implementing the program in January of 2012. Missouri offers two health home programs, described briefly below:

- Primary Care Healthcare Home: Providers include community health centers (also known as federally qualified health centers) and other health care systems. The target population is individuals with two or more chronic conditions including asthma/COPD, developmental disabilities, diabetes, heart disease, obesity and tobacco use.
- Community Mental Health Center Health Care Home (CMHC): Providers include CMHCs and affiliated agencies. The target population is individuals with serious mental illness and individuals with a mental health condition and at least one other chronic condition including developmental disabilities, substance abuse, diabetes, heart disease, overweight, and tobacco use. The CMHC program has saved approximately \$2.9 million in avoided costs (ED utilization, inpatient hospitalization) since implementation (2013 CMHC Progress Report).

### **Family Support Community of Practice**

Missouri is the lead state in a national Community of Practice on Lifespan Supports for Self-Advocates and their Families. This five-year initiative is funded by AIDD and administered by the National Association of State Directors of Developmental Disabilities Services. The core project team includes the UMKC IHD and the Human Services Research Institute. Anticipated outcomes of the project include:

- State and national consensus on a national framework and agenda for improving support for families with members with I/DD.
  - Enhanced national and state policies, practices and sustainable systems that result in improved supports to families.
- Enhanced capacity of states to replicate and sustain exemplary practices to support families and systems.

## **Bridging the Gap: Aging in Place Policy and Practice**

The expectation of the aging baby-boom generation to receive supports in their own homes or other least-restrictive settings has created nation-wide planning challenges to meet the residential service needs of this “new” aging population (U.S. Health Resources and Services Administration, 2006). Whether people with I/DD who are aging live alone, with family, or live in shared housing where residential services are provided through a home and community-based program, appropriate supports to enable them to age in place and avoid relocation will be critical.

Current research and best practices for aging in place can inform Missouri’s efforts to plan, implement, and evaluate strategies to meet the needs of aging individuals with I/DD and their families. This research identifies challenges and barriers to aging in place as well as elements of successful models.

*Aging in place has emerged in response to the changing expectations and preferences of older adults, both with and without disabilities.*

Aging in place is the clear preference of older adults, with and without I/DD. Traditional cost-benefit analysis suggests that aging in place does cost less than institutional living – HUD estimates that nursing home costs are at least three times higher than non-institutional long-term care options - but most experts also recognize a broader set of benefits that occur when older adults get to choose where they live. For individuals, these include greater independence, stronger social networks and decreased isolation, more community participation, and better physical and mental health. For instance, evaluation data from a 2008 Aging in Place initiative in Missouri found better outcomes related to depression,

cognitive function, and activities of daily living for older adults receiving services at home than for those in nursing homes (HUD, 2013).

Evidence also shows that older adults who live in the community can make economic contributions as consumers, employees, and volunteers (Stanford Center on Longevity, 2013). And even though family members provide the bulk of caregiving for older adults living at home, there will increasingly be workforce opportunities as the baby boomers age and as people with I/DD outlive family caregivers. Finally, many indicators for successful aging in place – walkable communities, affordable and accessible housing, transportation, safe streets, a variety of retail and recreation options, accessible public spaces – also benefit other community members, the environment, and the local economy.

Public policy at federal, state, and local levels, as well as private and non-profit sector initiatives, now addresses the aging in place movement. The federal Aging in Place initiative, part of the 2006 Older Americans Act reauthorization, provided grants to communities, including one to Catholic Charities of Kansas City-St. Joseph, to explore aging in place strategies. In addition to the I/DD supported living initiatives described earlier, a range of public and private strategies now exist, such as Naturally Occurring Retirement Communities and Communities for All Ages projects. These can and should fully include individuals with I/DD and their families. The demand for such initiatives has also spurred participation from the homebuilding, real estate, mortgage, insurance, and design industries, whose professionals can now become Certified Aging in Place Specialists.

### **Aging in Place Indicators for Success**

A recent research summary from the Stanford Center on Longevity (2013) outlines key community-level indicators for successful aging in place. Although many of the elements of aging in place are interrelated and interdependent, policies that support the specific components can be identified. Together with information about the needs of older adults with I/DD, this list of indicators offers a helpful framework for considering policy and practice decisions in Missouri.

*“True independence is more than simply living outside an institution”*  
*HUD report on Aging in Place*

### **Variety of Affordable, Accessible Housing Options**

A range of options – single homes, apartments, assisted living – is associated with keeping seniors in the community. Many older adults live in older homes which can be expensive to maintain and modify. Communities need zoning and building guidelines that allow for modifications, provide subsidies/incentives to modify, require universal design for new construction, and relax codes to allow more units of independent-living senior housing.

### **Transportation Options**

Especially for individuals with I/DD, who usually don’t drive, transportation can be a major barrier to aging in place. Older adults in general also require affordable, accessible transportation options so they can easily leave home to participate in community life. Senior discounts, expanded public transportation, non-profit services specifically for older people, use of volunteers, and other alternatives can help, although rural areas face unique challenges that still await innovative policy solutions.

### ***Walkable Neighborhoods***

For older adults and individuals with I/DD, being able to walk to the grocery store, a coffee shop, the pharmacy, or a friend's house allows greater independence and promotes a healthy lifestyle. Walkability is associated with greater physical activity and better health for older adults and the general population. It also correlates with higher property values and economic growth and stability. Policies such as Complete Streets offer guidelines to create mixed-use, safe, walkable neighborhoods.

### ***Safe Neighborhoods***

Research shows that older adults with disabilities have more social interaction when they feel safe in their community. Fear of crime and violence inhibits physical and social activity, which can lead to health problems and functional decline. In addition, emergency preparedness plans need to specifically include both older adults and those with I/DD.

### ***Health Care***

An estimated 80% of Americans over 65 live with at least one chronic condition such as hypertension, heart disease, diabetes, or arthritis (Stanford Center on Longevity, 2013). Without easy access to appropriate health care, older people with health issues are at greater risk for institutionalization. In addition, the functional decline associated with chronic disease increases caregiver burdens, another threat to aging in place.

Aging individuals with I/DD experience many of the same health problems as the general aging population. However, they also experience certain conditions, either inherent or preventable, at higher rates and with elevated risk for negative consequences. For instance, research has shown that aging adults with I/DD have a higher incidence of death or disease from conditions including thyroid disease, respiratory disease, intestinal obstruction, hypertension,, diabetes, obesity, reduced mobility, poor dental health, and osteoporosis (Haverman, 2010, Rimmer et al., 2010). The health disparities experienced by people with I/DD are attributed in part to higher rates of obesity and poor general fitness (Rimmer, et al., 2010), which makes it all the more important to have safe, walkable environments that can promote healthy lifestyles.

### *I/DD and Dementia*

The onset of dementia can further complicate age-related health changes for adults with I/DD. Dementia is a prevalent cause of continued institutionalization or movement to institutions for older adults with and without I/DD. Recent research has informed guidelines and best practices to promote aging in place for people with I/DD who show signs of dementia.

The National Task Group on Intellectual Disabilities and Dementia Practices (NTG), for instance, issued detailed guidelines for addressing the needs of both individuals and families throughout the stages of dementia. Their recommendations and those from other researchers include:

- Adhere to principles of person-centered care and self-determination
- Where possible, change the environment rather than moving the individual
- Develop a dementia-capable workforce that can meet the changing needs of both individuals and family caregivers
- Train and support family members to keep individuals living at home as long as possible
- Adapt homes for safety, security, and comfort as cognitive abilities change
- Promote collaboration across aging and disability service systems to ensure that dementia services are available, appropriate, and affordable
- Use the evidence-based “staging model” developed for use in general dementia care (Jokinen, Janicki, Keller, McCallion, Force & NTG, 2013; Janicki, McCallion, & Dalton, 2000).

The Stanford aging in place research calls for an adequate supply of health care providers trained in the needs of older people and located conveniently, transportation to help people get to appointments, and plenty of health information produced using health literacy best practices that target the changing vision, cognitive abilities, and other needs of older adults.

There is also an acknowledged need for aging in place initiatives to focus on health education strategies and person-centered self-management programs that specifically target and include people with I/DD. Research shows that older people with I/DD are less likely to have access to health promotion and preventive health services, which contributes to complex health conditions, morbidity, and loss of independence (Hahn, 2014; Factor Heller, & Janicki, 2012). These disparities have not gone unnoticed by policymakers and practitioners, although there is still work to be done. The Center for Disease Control and Prevention’s Healthy People 2020 calls for greater inclusion of people with disabilities in health promotion efforts and in all aspects of community life and participation (CDC, 2012).

As the goals, funding streams, and infrastructure of aging and disability systems become increasingly integrated, such inclusive health promotion and prevention strategies will ultimately benefit all aging individuals, regardless of disability status.

### *Community Supportive Services*

Evidence suggests that home-and-community-based services (HCBS) increase the likelihood of aging in place. States’ efforts to rebalance long-term care spending toward HCBS and away from institutions have had an impact on aging in place for both the general population and individuals with I/DD; unmet needs for in-home services are associated with poor health and increased risk of nursing home placement. Aging in place research suggests that access to HCBS also reduces caregiver burden. Research also finds that older adults and their families, including those with I/DD, are not always aware

of available services and how to access them, indicating a need to more effectively provide information and help people navigate service systems.

### ***Social Integration and Community Participation***

Social interaction promotes physical and mental health for older adults, with and without disabilities. The Stanford aging in place report cites evidence that “older adults who are socially isolated are at risk for a number of negative outcomes, including depression, chronic illness, and mortality” (p. 21). Policies that support walkability, mixed use communities, neighborhood safety, and accessible recreation and cultural activities can also support the social integration of people with disabilities and older adults. In addition, communities have experimented with programs and interventions that bring together different generations in community service or other activities. Strong, broad social networks make life richer for everyone; they can also make it easier for adults with long-term care needs to find help with daily or occasional needs and tasks, which can relieve pressure on both family caregivers and public service systems (Stanford Center on Longevity, 2013; HUD, 2013).

Social networks and supports are critical for individuals across the lifespan and increasingly so for individuals aging with I/DD and their aging family caregivers (Simplican, Leader, Kosciulek, & Leahy, 2015; Amado, Stancliffe, McCarron & McCallion, 2013). These can be formalized supports and services or naturally occurring support networks between family members and friends. It is critical to ensure these social support networks are in place or maintained to promote healthy aging and increase quality of life.

### **Caregiving Issues**

The health and well-being of family caregivers has begun to command more attention from policy makers, community organizations, and agencies. Because these family members provide an enormous amount of care, estimated at economic worth of over \$450 billion annually, they are a critical part of the web of informal supports making it possible for so many older people to age in their homes (AARP, 2011). A few statistics illustrate the magnitude of the issue:

- Currently there are an estimated 65.5 million family caregivers in the United States, 43.5 million of whom care for someone over 50 (NCA, 2012).
- Among people providing care to someone over the age of 65, the average age was 63 in 2009 and continues to rise (AARP, 2011).
- Among caregivers over the age of 60, 1.15 million care for an adult with I/DD (Factor, 2005).
- In Missouri, an estimated 590,000 family caregivers provide informal care valued at over \$6 billion annually (Missouri DHSS, 2012).

Older adults with I/DD and their caregivers face unique challenges and complexities. Not only must they plan for a future in which aging parents may no longer be able to care for their aging child with I/DD, but the stresses on family members caring for aging loved ones with I/DD have been shown to be especially acute. By their mid-60s, parents of adults with I/DD, compared to parents of adults without a disability, reported lower marital stability, reduced leisure time, higher limitations in parental activities of daily living, and lower health related quality of life” (Williams & Perkinson, 2012, p. 150). Studies also illustrate poorer mental health for parents caring for an adult child with I/DD (Alzheimer’s Association, 2011; Williams & Perkinson, 2012).

There is a great need to assess and meet the needs of aging caregivers for people with I/DD. Failure to receive needed services, including respite, training, and other caregiver-targeted supports, contributes to early or unnecessary out-of-home placements for people with I/DD.

For example, there is a recognized need to train caregivers how to recognize and respond to age-related changes in health, adaptability, and cognition. This includes how to physically adapt the home, how to tailor social and recreational opportunities to changing needs/abilities, and how to provide health and behavioral support in safe and appropriate ways. For families dealing with dementia, caregiver training and support are especially critical to keeping older adults at home with a higher quality of life. Several training programs and curricula have been developed for both formal caregivers and family members of people aging with I/DD, including some that are specific to dementia (Jokinen et al., 2014; Janicki, McCallion, & Dalton, 2002).

As these aging caregivers themselves increasingly require some forms of long-term supports and services, the demand on the aging and disability service networks is potentially overwhelming. Experts worry about a backlog of service needs developing as family caregivers die or become unable to provide the same level of care, especially since so many older adults with I/DD are not currently connected to any formal system of supports.

### Life Care Planning

Improved planning is a key to improved supports for both individuals and caregivers. Especially for the many families who have not been connected to state or local service systems, there is a need for help with future planning related to housing, finances, personal assistance, and quality of life, among other issues. Future planning for individuals and family members has “significantly contributed to families completing a letter of intent,

*Despite progress in recognizing caregiver needs, the need for improved caregiver support will be of increasing concern as more and more individuals choose to care for their aging family member at home.*

developing a special needs trust (a trust which protects government and disability benefits), and taking action on residential planning” (Heller, et. al., 2004, p.2) It has also been shown to produce other benefits such as “decreased caregiver burden, increased choice-making of individuals with disabilities and increased discussion of plans with individuals with disabilities” (Heller & Caldwell, 2005; Heller et al., 2007). However, state agencies and federal programs are not consistently able to prioritize future planning when they allocate funds and resources and develop programs.

## Current Challenges

### Capacity of Service System to Meet Growing Demand

As the baby boom generation ages and as lifespan continues to lengthen for people with I/DD, the capacity of state service systems to meet their needs is increasingly strained. In addition, a lack of data on the exact numbers of older people with I/DD in Missouri, their service needs, and the amount of unmet need creates planning and allocation difficulties for state agencies.

While some states have experienced reductions in service funding for people with I/DD, Missouri has been fortunate to have received increased levels of funding annually. The Division of Developmental Disabilities budget for community programs for state fiscal year (SFY) 2015 (July 2014 through June 2015) is \$827 million, which includes funds to eliminate the waiting list for in-home HCB supports. This total also includes funds moved from the nursing facility appropriation in the Department of Social

Services to the Division of DD budget to cover the increased costs for people transitioning from nursing facilities to the community. The FY16 budget includes a request for new funds to serve new people who are added to the waiting list, as waiting lists are not static and new people are added almost daily.

The needs of family caregivers put further pressure on a service system that is not fully equipped to provide the training and support services that can help families care for aging loved ones as long as possible. As described in previous sections of this report, thousands of family members provide the bulk of care for aging relatives, and as these caregivers themselves get older, demand for aging and disability services will swell.

People with I/DD who are working but are approaching retirement age, including those working in sheltered workshops, will add pressure to the system. Many of these individuals may already be participating in a HCB waiver, however upon retirement many will need increased levels of support. In Missouri, over 6800 individuals work in sheltered workshops and the median age is 41.2 years.

Our service system also faces workforce challenges related to the supply and adequate preparation of formal caregivers. Research indicates that professionals working in both home health and in residential settings need targeted training in the age-related changes, including all phases of dementia, that affect the care needs of individuals with I/DD. These include screening for dementia and other conditions, understanding drug interactions, and adapting the physical and social environments.

## **Progress Toward Policy and Practice Goals in Missouri**

In 2007, at the request of the Missouri Division of Developmental Disabilities, the Institute for Human Development (IHD) compiled a comprehensive literature review and analysis of best practices related to residential and community supports for older adults with I/DD. That report concluded with a set of policy and practice recommendations, which are presented here along with a summary of progress toward each.

In January 2015, IHD and the Division convened an Aging and DD Advisory Council, bringing together a range of experts and stakeholders to consider current opportunities and challenges and determine goals and steps for moving forward statewide. This newly convened council will use the current report and other resources to make policy and practice recommendations and plans.

### **2007 Recommendations and Current Status**

#### **1. Aging in Place**

***Recommendation: Identify and enhance statewide policies that support individuals to “age in the place” of their choice.***

The Partnership for Hope Waiver, implemented in 2010, has significantly enabled people to age in place. As of late 2014, this waiver has served over 3,000 individuals whose needs may safely be met with \$12,000 or less in HCB services, avoiding the necessity of residential supports.

Expansions and enhancements to the Community Support waiver, including increases to the number of people who may be served, a relaxing of the restrictions around the annual spending cap, and the addition of services such as assistive technology have also significantly enabled people to age in place.

## ***2. Joint Planning between the Divisions of DD and Senior and Disability Services***

***Recommendation: Continue collaborative planning to improve access to services and supports for older individuals with I/DD and their aging family caregivers.***

The development, implementation and operation of Missouri Community Options and Resources have significantly enhanced interagency coordination across the entire LTSS spectrum in Missouri. This includes clarifying protocols for coordinating services for individuals eligible for both DMH/DD and DHSS services.

Development of a new ADC waiver and transition from state plan ADHC to ADC or DD day supports improved interagency collaboration; however, there remain opportunities to improve communication and coordination across systems both locally and at the state level.

## ***3. Choice in Housing and Other Support Options***

***Recommendation: Conduct demonstrations of best retirement and support planning practices for older persons with I/DD.***

In 2012, the Division of Developmental Disabilities established a Housing Plan with a mission to develop quality, affordable, accessible housing for people with disabilities in safe locations where they can access support services, transportation, employment, and recreation throughout their lifespan. The Division works in partnership with the Missouri Inclusive Housing Development Corporation.

The Division has also trained Community Living Coordinators at Regional Offices, added a Host Home option to the Comprehensive waiver, and established new protocols for shared living.

## ***4. Training and Resource Implications Resulting from Age-Related Changes***

***Recommendation: Identify resource and training needs and conduct training and provide access to resources that meet these needs.***

Providing formal and family caregivers with the training they need to understand aging-related changes and its processes is considered a best practice. Progress in this area has included:

- New MO HealthNet state plan Primary Care Health Homes and Community Mental Health Center Health Care Homes were launched in 2012.
- Individual Service Plan (ISP) Guidelines updated in 2013.
- Training on person-centered planning and ISP development provided by local Targeted Case Management agencies and made available through Department of Mental Health “E-learning” system.

## ***5. On Going Research and Needs Assessments***

***Recommendation: Conduct a needs assessment and develop a plan of action related to the needs of older individuals with developmental disabilities in Missouri.***

Research sponsored by MACDDS with a grant from the Missouri Foundation for Health in 2008 led to the development and implementation of the Partnership for Hope waiver. Ongoing evaluation of this waiver continues to provide valuable information about the service needs of individuals with I/DD and their families. However, a needs assessment specific to aging individuals with I/DD has not been conducted; such research is still necessary to inform a plan of action.

## **Conclusion**

The future holds challenges for Missouri's system of supports and services for people who are aging with developmental disabilities and their families. While much progress has been made to enable people with intellectual and developmental disabilities to live productively in their homes and communities, the demographic trends are clear there will be an increased need for services as people with I/DD are living longer. Through the leadership of the UMKC Institute for Human Development, in partnership with state agencies, community service providers, people with I/DD and their families, advocates and other professionals will collaborate on a plan to assess needs and current system capacity, and to develop, implement, and evaluate new ideas and promising practices to address the challenges.

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