

Medicaid Residential Options for People with Autism and other Developmental Disabilities

By

Robin E. Cooper, M.S.S.W.
December 2012

NASDDDS

National Association of State Directors of Developmental Disabilities Services

115 Oronoco Street, Alexandria, VA 22314
Tel: 703-683-4202; Fax: 703-684-1595
Web: www.nasdds.org

Table of Contents

Centers for Medicare & Medicaid Services and Residential Services	3
Interaction of the ADA/Olmstead and Medicaid	3
Medicaid Financing Options for Residential Services	4
Home and Community-Based Services	10
CMS Policy Guidance on HCBS	10
Incentivizing Home and Community-Based Services	14
Financing Residential Services	16
1915(i) State Plan Home and Community-Based Services	20
Other Medicaid Financing Options	23
Non-Medicaid Public Financing for Residential Services	24
State Examples of ASD-Specific Programs	27
Autism Specific Waivers	28
Medicaid HCBS that Support Living Arrangements for Individuals with ASD	33
Conclusion	40

Support for this product development came from a cooperative agreement from the National Institute on Disability and Rehabilitation Research, U.S. Department of Education (#H133B080005) and a contract from the Minnesota Department of Human Services (#H5532310) with the Research and Training Center on Community Living (RTC) at the Institute on Community Integration, University of Minnesota.

Centers for Medicare & Medicaid Services and Residential Services

Interaction of the ADA/Olmstead and Medicaid

How the American Disabilities Act (ADA), the Olmstead decision, and Medicaid financing of institutional and home and community-based services (HCBS) interact is often a source of confusion. How can federal regulations, at the same time, both permit *and* challenge the use of institutional and segregated services for individuals with intellectual disabilities? As we will see below, Medicaid regulations do permit (but do not necessarily promote) the use of Medicaid funding for institutional settings as well as congregate day and vocational programs. But it is critical to remember that Medicaid is a *financing* option and the Olmstead decision stands above and apart from Medicaid financing regulations. The Olmstead decision is overarching — and actually is in force *regardless* of the source of public funding. The settings covered by Olmstead could be financed by Medicaid or state or local dollars — or other federal programs. Olmstead is about the right to the most integrated setting — *regardless of financing options*. Medicaid financing for HCBS can be a powerful tool in assuring compliance with Olmstead, providing the major source of financing for home and community-based services for our nation. But states can legally use Medicaid to finance settings that may not comply with Olmstead — even though they comply with Medicaid regulations. Again, when states use settings that congregate or segregate individuals with disabilities — regardless of what funds those settings — Olmstead comes into play. As noted above, Olmstead enforcement is not confined to only residential settings. DOJ has noted in two recent actions that the reliance on congregate, segregated day programs also is a violation of Olmstead, thus the decision is relevant not only to where people live, but to what they do during the day.¹ The Virginia findings letter expressly noted, "As a means of preventing institutionalization, the commonwealth should...provide integrated day services, including supported employment. The commonwealth should move away from its reliance on sheltered workshops." In the Oregon action, in June 2012 DOJ issued a findings letter, "concluding that Oregon is violating the ADA's integration mandate in its provision of employment and vocational services...the department found that the state of Oregon plans, structures, and administers its system of providing employment and vocational services to individuals with intellectual and developmental disabilities in a manner that delivers such services primarily in segregated sheltered

¹ See: The U.S. Department of Justice, Civil Rights Division findings letter, February 10, 2011, "Investigation of the Commonwealth of Virginia's Compliance with the American's with Disabilities Act and of Central Virginia Training Center."

workshops rather than in integrated community employment settings, causing the unnecessary segregation of individuals in sheltered workshops that are capable of, and not opposed to, receiving employment services in the community ."² States would be well advised to consider *all settings* that segregate or congregate individuals with disabilities as potentially not comporting with the Olmstead Decision and the ADA.

Fundamentally, the Centers for Medicare and Medicaid Services (CMS) approval and financing of a setting does not constitute approval or agreement regarding compliance with the requirements under Olmstead. CMS can and does approve and finance settings that may not meet the requirements of the Olmstead decision and may be found out of compliance with Olmstead in DOJ actions. Thus Medicaid and Olmstead can appear to be on separate tracks. But in reality CMS guidance has supported the Olmstead decision since its inception, beginning with the State Medicaid Directors (SMD) Olmstead letter #1 in 1998 up to and including recent guidance on home and community-based character issued in the recent NPRM on home and community-based services. These letters and regulations, along with other CMS guidance, are discussed below.

Medicaid Financing Options for Residential Services

We focus on Medicaid because it is the single largest source of long-term supports to individuals with intellectual and developmental disabilities (I/DD), including individuals with ASD.³ In 2009, Medicaid accounted for 75.5 percent of the spending for long-term supports for individuals with I/DD. Only 14.8 percent of spending is other state (and local funds).⁴ There are other public supports such as Supplemental Security Income (SSI) and Supplemental Security Disability Income (SSDI) — which provide income to individuals with I/DD and can cover some living expenses, but these sources only account for 9.6 percent of the overall spending for individuals with I/DD.⁵ Medicaid provides financing for residential supports through a variety of options, including institutional services through the intermediate care facility for individuals with intellectual disabilities (ICF/ID) and HCBS options such as 1915(c) HCBS waiver,

² DOJ Findings Letter, June 2012, found at www.ada.gov/olmstead/olmstead_cases_list2.htm#oregon-findltr.

³ We focus on the Medicaid program because although Medicare does offer some coverage of institutional services, typically it is short-term coverage related to an illness, not long-term care associated with life-long disabilities. We are aware that many individuals with ASD are dual-eligibles — that is both eligible for Medicare and Medicaid — but it is Medicaid that provides funding for long-term community and institutional services.

⁴ Braddock et al., *The State of the States in Developmental Disabilities 2011*, University of Colorado, and AAIDD, 2011, p. 26.

⁵ *Ibid.*, p. 27.

the 1915(i) State Plan HCBS and other authorities such as the 1115 waiver option.⁶ Medicaid is a state-federal partnership, with the states required to provide "matching" funds. The federal government adds funding to this "match" at a rate that varies between 50 percent and 75 percent depending on the economic situation of each state. What this means is if a state Federal Medical Assistance Percentage (FMAP) is 50 percent, the state pays half the bill for Medicaid services and the federal government pays half. Thus states must have the availability of matching funds if they plan to open up new Medicaid services or programs such as 1915(c),(i), or others discussed below.⁷

It is also important to clarify what is meant by "residential" services. Traditionally this term refers to "out-of-home" settings, typically controlled by a provider (either an individual such as a foster home provider or agency). This definition includes group living arrangements and foster settings for both adults and children. But the definition of residential services has broadened. Residential supports can also occur in an individual's own home — that is a place either owned or leased by the individuals (or their representative). Residential services may be "relationship" based — perhaps a mutually shared living arrangement between an individual with a disability and someone agreeing to provide support, including in many states, family members.⁸ And, as more and more individuals continue to live at home with their families, supporting individuals within the family setting is increasingly important. An expanded interpretation of residential services allows for more options and individualization of services and is in keeping with an approach that supports customized situations for individuals — something that is particularly critical for individuals with ASD who may have highly individual needs that require significant individualization of supports and services.

This report focuses on publicly financed residential services — that is those supports and services offered through state and federal programs such as Medicaid, SSI, state residential supplement programs, and housing and urban development. We are well aware that there are many private pay programs for individuals with ASD but we have limited the scope of this paper to publicly funded programs. Information on private pay options is available through a multitude of web resources.

⁶ For a comprehensive overview of all Medicaid home and community-based services, see: *Understanding Medicaid Home and Community Services: A Primer, 2010 Edition*, found at www.medicaid.gov/mltss/docs/primer10.pdf.

⁷ A good description of FMAP can be found at aging.senate.gov/crs/medicaid6.pdf. 2012 FMAP percentages can be found at www.federalregister.gov/articles/2010/11/10/2010-28319/federal-financial-participation-in-state-assistance-expenditures-federal-matching-shares-for.

⁸ See, Cooper, Robin, *Caring Families...Families Providing Care: Using Medicaid to Pay Relatives Providing Support to Family Members with Disabilities*, NASDDDS, June 2010.

As will be discussed in more detail below, the national trend is that more individuals with I/DD, including individuals with ASD, live at home with their families. Currently 55.9 percent of all individuals served through the HCBS waivers live with family — and in five states 70 percent or more of the individuals served live with family.⁹ A study done by Easter Seals in 2008 indicated that this holds true for individuals with ASD, at least for those under 30 who have finished high school. The study found that 79 percent of individuals with ASD who have finished high school and are under the age of 30 live at home with their parents (as opposed to 32 percent of young adults without ASD).¹⁰

In discussing how individuals with ASD are supported where they live, the issue of individuals living at home with families in greater numbers must be addressed if we are committed to assuring a full life in the community for individuals with ASD. Expanding the interpretation of residential supports to the concept of supporting individuals wherever they live opens up many more possibilities in service and support design that is in keeping with person-centered practice. And supporting individuals with ASD requires more than residential supports to assure that the situation fully supports the individual — other services such as employment supports, self-advocacy opportunities, positive behavioral supports, environmental modifications, and assistive devices may be critical factors in assuring the person's success in community living.

Institutional Services. The Medicaid program was signed into law by President Lyndon Johnson in July 1965.¹¹ The very first set of benefits covered under Medicaid (called the Medicaid State Plan) included health care service such as physician services, inpatient and outpatient hospital services, lab and x-ray, and skilled nursing facility services. Although state participation in the Medicaid program was voluntary, once states signed on, a specific set of services — including skilled nursing facility services — were mandated. That meant, in order to participate, the state had to offer these services. States could also elect to cover a set of "optional" services such as speech and language therapy, physical therapy, and nursing services.¹² In 1971 CMS added an optional service, called intermediate care facilities, including those that specifically served individuals with intellectual disabilities, now known as intermediate care facilities for

⁹ Larson et al., *Residential Services for Person with Developmental Disabilities: Status Through 2010*, RTCCL, Institute on Community Integration/UCEDD, Table 2.9, p. 86.

¹⁰ Easter Seals, *Living with Autism Study*, Harris Interactive, 2008. Found at www.easterseals.com/explore-resources/living-with-autism/study.html.

¹¹ For a definitive history of Medicaid and services to individuals with I/DD, see, Gettings, Robert, *Forging a Federal-State Partnership: A History of Federal Developmental Disabilities Policy*, AAIDD, NASDDDS, 2011.

¹² See: www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Medicaid-Benefits.html.

individuals with intellectual disabilities (ICFs/ID).¹³ Although ICFs/ID is not a mandated service, all 50 states and the District of Columbia have included this service in their Medicaid coverage.¹⁴

CMS defines ICFs/ID as institutions and further clarifies that an ICF/ID is an, "establishment that furnishes (in single or multiple facilities) food, shelter, and some treatment or services to four or more persons unrelated to the proprietor."¹⁵ While the more common notion of institution is a larger facility, smaller ICFs/ID that more closely resemble community group homes are also classified as institutions due to the licensing category. Throughout this paper, we generally use the term institution to mean the larger, congregate settings that serve a greater number of individuals as CMS does make certain licensing distinctions between smaller ICFs/ID, commonly known as "community ICFs" and the larger settings. ICF/ID, like all Medicaid State plan services is an entitlement as long as the individuals meets eligibility for entrance into the setting and has "medical necessity" for the service.

Eligibility for ICF/ID services is set in federal statute and requires that an individual have a need for what CMS terms "active treatment." Active treatment is defined as an "aggressive, consistent implementation of a program of specialized and generic and treatment services."¹⁶ While states have the authority to define the need for ICF/ID services the statute does require that in addition to the need for active treatment, the need for services must come from the person's intellectual disability or related condition.¹⁷ Related conditions are described in statute as, "... severe, chronic disability that meets all of the following conditions and is attributable to:

(1) cerebral palsy or epilepsy or, (2) any other condition, other than mental illness, found to be closely related to mental retardation because this

¹³ These facilities were originally called ICFs/MR — for mental retardation—and the term still appears in federal statutes. But CMS notes that, "Federal law and regulations use the term "intermediate care facilities for the mentally retarded." CMS prefers to use the accepted term "individuals with intellectual disability" (ID) instead of "mental retardation."

¹⁴ One state, Oregon, has no licensed ICF/ID beds in their entire state. All individuals are served in the community. But Oregon has to keep the option of ICF/ID in their Medicaid State Plan as this is required in order to operate the 1915(c) HCBS waiver. If an individual demanded an ICF/ID, Oregon would provide for this by contracting with another state.

¹⁵ 42 CFR 435.1009.

¹⁶ 42 CFR 483.440(a).

¹⁷ Persons with related conditions defined at 42 CFR 435.1009. The definition of related condition is primarily functional, rather than diagnostic, but the underlying cause must have been manifested before age 22 and be likely to continue indefinitely. Related conditions have included developmental disabilities which are defined in P.L. 101-496.

condition results in impairment of general intellectual functioning or adaptive behavior similar to that of mentally retarded and requires treatment or services similar to those required for these persons, (b) it is manifested before the person reaches the age of 22, (c) it is likely to continue indefinitely (d) and results in substantial functional limitations in three or more of the following areas of major life activities: (1) self-care; (2) understanding and use of language; (3) learning; (4) mobility; (5) self-direction; (6) capacity for independent living."¹⁸

If states choose to include individuals with related conditions, some individuals with ASD who do not have intellectual impairments may still meet the adaptive functioning definition of having a related condition and thus potentially meet eligibility for ICF/ID (and HCBS waiver) services.

Although CMS calls the service ICF/ID, states may choose to offer the service to individuals who have a developmental disability or related condition — and who may not have an intellectual disability. Thus there is a possibility that individuals with ASD who do not have an intellectual disability may qualify for ICF/ID services if their state uses the expanded definition for eligibility. States have broad discretion in crafting their eligibility for ICFs/ID. States may choose not to include individuals with related conditions, confining eligibility to individuals who have intellectual disabilities, or to include some but not all of the related conditions cited in the definition above. The inclusion of the "related conditions" as a component of the state's eligibility criteria has implications for individuals with ASD who do not have an intellectual disability or who do not meet the functional criteria used to define a developmental disability. In some states these individuals are not be eligible for ICF/ID services, which means they cannot be admitted to these settings. This type of eligibility restriction also has implications for Medicaid financed HCBS for individuals with ASD as eligibility for the 1915(c) HCBS waivers is directly linked to eligibility for an ICF/ID.¹⁹

As noted earlier, ICFs/ID must provide active treatment and furnish services on a 24/7 basis. ICFs/ID can and do provide supports to individuals to attend programs outside of the facility such as supported employment and community-based activities , if the facility operator is willing to purchase or provide these services. While many of the

¹⁸ 42 CFR 435.1009.

¹⁹ For a state-by-state description of eligibility for the ICF/ID (and HCBS waiver) eligibility, see: Zaharia and Moseley, *State Strategies for Determining Eligibility and Level of Care for ICF/ID and Waiver Program Participant*, Rutgers Center for State Health Policy, July 2008.

larger ICFs/ID provide "in-house" programs, throughout the country some ICFs/ID do provide for residents to attend day and vocational programs outside of the facility.

Although still a Medicaid covered service reliance on institutional settings has declined markedly over the past two decades. As of 2010, states provided ICF/ID services to 43,310 individuals in state and privately operated in settings that serve 16 or more individuals. In 2001 this figure was 78,607 individuals.²⁰ As of 2012,

- 12 states no longer have state-operated ICFs/ID with more than 16 beds,
- 7 states no longer have anyone in either a public or private facility greater than 15 beds,
- 15 states have less than 200 individuals in large ICFs/ID, and
- 20 states have no large private ICF/ID settings.

And with recent DOJ actions in states such as Georgia, Texas, Virginia, and Illinois (who have large numbers of individuals in ICFs/ID), we expect continued declines in the use of these types of settings.

"Community" ICFs/ID. Although the original ICF/ID rules were written with large facilities in mind, states were interested in developing smaller living arrangements which did not quite fit within the regulations issued for large settings. By 1981, CMS developed new guidance covering the operation of settings with fifteen beds or less.²¹ This led to many states developing smaller settings. According to the University of Minnesota's most recent report on residential services, there are nearly 4,000 ICFs/ID nationally that have between 1-6 beds and close to 2,000 settings that serve 7-15 individuals. Most of these settings are concentrated in a few states, with only five states accounting for 75 percent of the individuals served in setting licensed for 1-6 individuals and 8 states accounting for 80 percent of the individuals served in settings licensed for 7-15 individuals. Reliance on these "community" ICFs/ID has lessened, with the number of individuals served in these settings essentially flat since 2001. Presently 11 states have none of these types of facilities and nine states have fewer than 100 individuals served in these settings.²² These "community" ICFs/ID still must operate within a very specific set of federal regulations — including staffing ratios, specific personnel requirements and a host of health and safety requirements. While clearly intended to assure the health and welfare of individuals in the settings, these

²⁰ The data on ICFs/ID are from, *Residential Services for Person with Developmental Disabilities*, University of Minnesota ICI reports from 2001 and 2011. All reports can be found at rtc.umn.edu/risp/main/.

²¹ Gettings, 2101, pp. 79-80.

²² All data taken from *Residential Services for Person with Developmental Disabilities*, reports from 2001 and 2011. All reports can be found at rtc.umn.edu/risp/main/.

regulations may add to the cost of services, while not affording as much flexibility as states' own regulations in the design, staffing and "customization" of these community group living arrangements.

Home and Community-Based Services

Medicaid provides financing for home and community-based — non-institutional — residential services through a number of options. The 1915(c) home and community-based services waiver and the 1915(i) State Plan Home and Community-Based Services option afford states the ability to cover a wide-array of residential services. Other State Plan options, 1915(j) State Plan Self-Directed Personal Care, and 1915(k) Community First Choice can provide for personal care services to assist individuals to live in their own homes. And the 1115 research and demonstration waivers also may be an avenue to extend residential services to individuals with ASD. Other programs such as Money Follows the Person (MFP) and the Balancing Incentive Payment (BIP) program offer states increased federal financing to move people from institutional settings to home and community-based services, while 1915(k), Community First Choice (CFC) incentivizes the use of home-based personal care. We focus on the 1915(c) and (i) options as these provide the broadest array of services and can include out-of-home residential services, while touching on the other programs.

CMS Policy Guidance on HCBS

Olmstead Letters. After the issuance of the Olmstead decision, CMS offered a series of State Medicaid Director (SMD) letters providing states with guidance on using the 1915(c) HCBS waiver (described in detail below) to support the Olmstead decision.²³ Beginning in July 1998 and most recently in May 2010, CMS issued a series of letters advising states on using Medicaid in meeting the requirements of the ADA and the Olmstead decision. In these letters CMS provided states with ideas on how to use the HCBS authorities to provide HCBS to assist individuals living in institutions to move to the community and encourage integrated community settings. Through these Olmstead letters CMS clarified a variety of policies that assisted states to move individuals to the community, among them:

Olmstead Letter, July 29, 1998 reminded states of recent Olmsted enforcement actions in three cases and urged states to, "in recognition of the anniversary of the ADA, to strive

²³ Letters can be found at www.medicaid.gov/Federal-Policy-Guidance/Federal-Policy-Guidance.html#Search and in the Accompanying Materials to the 1915(c) HCBS waiver application found at www.hcbswaivers.net.

to meet its objectives by continuing to develop home and community-based service options for persons with disabilities to live in integrated settings."

Olmstead Letter No: 1, January 14, 2000 laid out the requirements of the Olmstead decision and the interaction of Medicaid with the Olmstead decision, noting, "Medicaid can be an important resource to assist States in meeting these goals."

Olmstead Update No: 2, July 25, 2000 was a series of questions and answers on how CMS and the Department of Health and Human Services were working on assisting states to comply with the Olmstead decision including advice about required Olmstead plans and who is affected by these plans.

Olmstead Update No: 3, July 25, 2000 offered states a variety of new policies around the 1915(c) HCBS waiver that afforded states options to assist individuals to move to community settings including providing Medicaid funding for transition services such as security deposits, first and last rent payments and other costs associated with individuals moving from institutions to the community; providing for payment of a personal assistance retainer to cover the costs of retaining personal care workers while an individual is hospitalized or otherwise temporarily absent from a HCBS waiver program; clarified that habilitation services — including supported employment — is available to all HCBS waiver participants regardless of disability, based on the plan of care along with other provisions providing more flexibility for states.

Olmstead Update No: 4, January, 10, 2001 provided states with detailed guidance on a number of technical questions regarding limits on numbers served, access to services and establishing target groups with an emphasis on providing, "...guidance and support to States in their efforts to enable individuals with disabilities to live in the most integrated setting appropriate to their needs, consistent with the Americans with Disabilities Act (ADA)." The letter also detailed how the HCBS waivers interact with State Plan requirements under the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) mandate that requires states to afford access to all mandatory and optional State Plan services for children.

State Medicaid Director letter # 10-008, Community Living Initiative, May 20, 2010 marking the 20th anniversary of the ADA, CMS reaffirmed their commitment to upholding the requirements of the ADA and provided states with information on all the authorities available to states through the Medicaid program to assist them to uphold the ADA, including technical assistance from CMS and information on a variety of options from housing to HCBS waivers.

Collectively these letters affirm and clarify CMS policies regarding the use of Medicaid to uphold the tenets of the ADA and Olmstead. This guidance offers encouragement to states to move away from institutional services and instead use the HCBS waiver program and other HCBS options to support individuals with disabilities.

Home and Community-Based Character. Each of the Medicaid HCBS authorities comes with specific requirements on eligibility, scope of services, quality management and other requirements. But one provision, the "community-based character" for living arrangements, applies to *all* Medicaid funded home and community-based services, including those under 1915(c), (i), (j), (k) and 1115 waivers. In a Notice of Proposed Rulemaking (NPRM) issued May 3, 2012 (and building on an earlier version of the rule issued in 2009), CMS proposed a series of characteristics that would act as a "test" against which a determination would be made if a setting truly is a community setting. While these rules as of this writing are not final, CMS has increased their review of settings states intend to (or currently do) cover under the various home and community-based options. As proposed in 42 CFR 441.530, the characteristics that would establish a setting as comporting with home and community-based character are:

- (i) The setting is integrated in, and facilitates the individual's full access to, the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, in the same manner as individuals without disabilities.
- (ii) The setting is selected by the individual from among all available alternatives and is identified in the person-centered service plan.
- (iii) An individual's essential personal rights of privacy, dignity and respect, and freedom from coercion and restraint are protected.
- (iv) Individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact are optimized and not regimented.
- (v) Individual choice regarding services and supports, and who provides them, is facilitated.
- (vi) In a provider-owned or controlled residential setting, the following additional conditions must be met. Any modification of the conditions, for example, to

address the safety needs of an individual with dementia, must be supported by a specific assessed need and documented in the person-centered service plan:

- (A) The unit or room is a specific physical place that can be owned, rented or occupied under another legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord tenant law of the State, county, city or other designated entity;
- (B) Each individual has privacy in their sleeping or living unit:
 - (1) Units have lockable entrance doors, with appropriate staff having keys to doors;
 - (2) Individuals share units only at the individual's choice; and
 - (3) Individuals have the freedom to furnish and decorate their sleeping or living units.
- (C) Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time;
- (D) Individuals are able to have visitors of their choosing at any time; and
- (E) The setting is physically accessible to the individual.

The regulation indicates what settings are *not* considered to meet the HCBS character, including:

- (i) A nursing facility;
- (ii) An institution for mental diseases;
- (iii) An intermediate care facility for the mentally retarded;
- (iv) A hospital providing long-term care services; or
- (v) Any other locations that have qualities of an institutional setting, as determined by the secretary.

The proposed regulation also goes on to state that:

The Secretary will apply a rebuttable presumption that a setting is not a home and community-based setting, and engage in heightened scrutiny, for any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment, or in a building on the grounds of, or immediately adjacent to, a public institution, or disability-specific housing complex.

While this last statement perhaps leaves some room for states to present arguments on establishing residential services in conjunction with institutional services, CMS has presumptively taken the stance that these types of arrangements do not constitute home and community-based character, while leaving room for states to make arguments to the contrary. Interestingly, CMS did make a ruling about the development of HCBS waiver-funded group homes on the grounds of a Missouri state institution serving individuals with I/DD. CMS, in a letter signed by Donald Berwick, CMS administrator, indicated they would not fund group homes on the grounds of the institutions under Missouri's 1915(c) waiver, noting:

42 CFR 441.300 permits states to offer HCBS that individuals need in order to avoid institutionalization. However, Missouri proposes to add capacity through this waiver amendment to serve individuals living on the grounds of an institution which provides inpatient institutional treatment, a setting which is segregated from and with restricted access to the larger community. Under the proposed amendment, Missouri would not provide services that permit individuals to avoid institutionalization, but would serve individuals in an institutional setting. This waiver amendment does not meet the requirement of the regulation.

Collectively this guidance points to assuring that individuals have opportunities to be present and participate in their communities — while also affording protections and opportunities for choice and control over their lives. Clearly, CMS proposed regulations are in line with the Olmstead decision, thus in developing residential service, states, families, developers, and providers would be well advised to incorporate this guidance when developing and designing residential supports for individuals with ASD.

Incentivizing Home and Community-Based Services

CMS, in addition to offering states guidance on the development of residential services, has made investments in helping states shift service delivery away from institutional services. Two programs, the **Money Follows the Person** (MFP) initiative and the **Balancing Incentives Payment** (BIP) program, provide states with increased federal funding in exchange for making effort and investments in increasing HCBS, while simultaneously reducing reliance on institutional services. To date, 43 states plus the District of Columbia participate in the Money Follows the Person Initiative which has resulted in almost 12,000 individuals moving from institutional services to the community — with \$4 billion federal funding available. As of 2010, 1,075 individuals

with intellectual and developmental disabilities have been served through MFP.²⁴ Although data are not specific as to which populations within the I/DD community have been served, given that these are transitions from institutions it is likely individuals with ASD are included.²⁵

Eight states have applied for and received authorization for BIP — which provides these states with an increase in federal funding for all HCBS through September 30, 2015. BIP is intended to encourage more investment in HCBS and reductions in the use of institutional services — that is, a rebalancing of the service system toward community services. The increase becomes available to a state once they apply during the first full day of approval of their application after October 1, 2011. CMS has made \$3 billion dollars available during this period and programs will be approved until all funds are committed — but the last date of application for states is August 31, 2015. CMS provides states with either a 2 percent or 5 percent increase on all HCBS the state provides — the amount of the increase depends on where a state is in rebalancing. The less "balanced" the larger the FFP increase. So far, based on CMS calculations one state qualifies for the 5 percent increase while others are eligible for the 2 percent increase. Expenditures for Medicaid LTSS provided only in integrated settings that are home and community-based and therefore not provided in institutions are eligible for the increase including:²⁶

- HCBS under 1915(c) or (d) or under an 1115 Waiver
- State Plan home health
- State Plan personal care services
- State Plan optional rehabilitation services
- The Program of All-Inclusive Care for the Elderly (PACE)
- Home and community care services defined under Section 1929(a)
- Self-directed personal assistance services in 1915(j)
- Services provided under 1915(i)
- Private duty nursing authorized under Section 1905(a)(8) (provided in home and community-based settings only)
- Affordable Care Act, Section 2703, State Option to Provide Health Homes for Enrollees with Chronic Conditions

²⁴ Irvin, Carol et al., *Money Follows the Person 2010 Annual Evaluation Report, Final Report*, Mathematica Policy Research, October 7, 2011, pp. 3-7.

²⁵ Information on MFP can be found at www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Balancing/Money-Follows-the-Person.html.

²⁶ More information about BIP is found at www.balancingincentiveprogram.org/faqs.

- Affordable Care Act, Section 2401, 1915(k) — Community First Choice (CFC) Option

A third option that incentivizes HCBS is the **Community First Choice (CFC)** State Plan Option under 1915(k) of the Social Security Act. States can elect to include in their State Plan the option to provide self-directed personal care services. States must cover certain required services including assistance in accomplishing activities of daily living, instrumental activities of daily living, and health-related tasks through hands-on assistance, supervision, and/or cueing. Additionally, the state may choose to provide transition costs such as rent and utility deposits, first month's rent and utilities and purchase bedding, basic kitchen supplies, and other necessities required for transition from an institution. Further, states may "provide for expenditures relating to a need identified in an individual's person centered plan of services that increase independence or substitute for human assistance, to the extent that expenditures would otherwise be made for the human assistance."²⁷ As examples of this last type of expenditure, CMS offers non-medical transportation and microwaves.

The CFC option is open to individuals who meet an institutional level of care and have a need for personal care services. These services can be critical to assuring an individual can remain in their own or family home and would be available to individuals with ASD if they have a need for personal care and meet the level of care (LOC) requirements. If state elects to offer this benefit under 1915(k), as long as they receive an increase of 6 percentage points in Federal Medical Assistance Percentage (FMAP) on all of CFC services and supports.

Financing Residential Services

1915(c) Home and Community-Based Services Waiver. In 1981, President Reagan proposed and Congress passed a new option under 1915(c) of the Social Security Act, the Home and Community-based services (HCBS) waiver program.²⁸ Until 1981, Medicaid funds for long-term supports were available only for hospital and institutional services. Medicaid-funded supports (other than "acute care" — health and medical services) were not available to individuals with disabilities who lived in the

²⁷ *Federal Register*, Vol. 77, No. 88 / Monday, May 7, 2012 / Rules and Regulations, p. 26829.

²⁸ Congress also passed the "Katie Beckett waiver" (which became the TEFRA option) which allowed children who were eligible for a Medicaid card when hospitalized to retain Medicaid eligibility for health and medical services while living at home. The option was named for Katie Beckett who had been living in a hospital until this option passed, allowing her to get needed health and medical services at home and in the community.

community — in their own homes, their family home or other settings not licensed as ICFs/ID. This was known as the "institutional bias" — that is Medicaid was biased toward institutional care and did not provide for supports and services to assist individuals to live in the community. For individuals with ASD or I/DD, the only way to get long-term support was to enter ICF/ID.

Under the 1915(c) provisions states can apply to CMS for permission to use funding that otherwise would have been used for individuals to live in institutions for home and community-based services. States apply for a waiver of the regulations that had confined the use of Medicaid funds to institutional services. In order to obtain permission for the waiver, states must apply to CMS filling out an extensive application that details the populations served, covered services and a host of assurances regarding the health and welfare of individuals served. The waiver application and accompanying manual can be found at 157.199.113.99/WMS/help/35/appOnlineHelp.html#pageOne.jsp.

HCBS Waiver Eligibility. Waiver eligibility has three aspects: (1) Medicaid eligibility, (2) level of care, and, (3) targeting criteria. First, the person must be eligible for Medicaid services under the state Medicaid plan. Second, eligibility for the HCBS waiver requires the person must meet what is termed the "level of care" for institutional services. This means that the individual would qualify for institutional services in a Medicaid funded setting *but for the provision* of home and community-based services. This level of care is the eligibility criteria used to ascertain if the person qualifies for Medicaid reimbursed institutional care. The criteria used, and the methods to determine eligibility, are developed by each state and approved by CMS. And third, the individual must belong to a specific identified recipient population, usually called the target group that the state sets for each waiver. Target groups usually define some characteristics of the group such as age, diagnosis, condition, and/or risk factors. States have broad latitude in defining the target population for a waiver. For example, some states may choose to have several waivers for various groups such as elderly, medically fragile children, brain injury, AIDS/HIV positive individuals. A state could choose to design a waiver program that specifically serves individuals with ASD — and in fact, as we will describe later, nine states have done so. (A recent University of Minnesota Policy Brief also details the types of waivers and services states offer that explicitly support individuals with ASD using the HCBS waiver authority.)²⁹

²⁹ University of Minnesota, Research and Training Center on Community Living Institute on Community Integration, *A National Review of Home and Community-based Services (HCBS) for Individuals with Autism Spectrum Disorder*, Policy Research Brief, December 2011, Vol. 21, No. 3.

As long as the members of the target group in each waiver application are eligible for Medicaid and qualify for institutional services in a Medicaid funded setting based on establishing need for an institutional level of care, they can be eligible for community residential and other services) services under the HCBS waivers. One caveat with the HCBS waiver is that states can cap the number of individuals served and can cap the total amount of the benefit — that is they can put limits on individual services and can limit the overall dollars spent for any one individual. This means that states can have waiting lists for entrance into the HCBS waivers if they have reached the cap on the number of individuals for whom there is services funding. But states can amend their waivers at any time to increase the numbers served, as long as the state is able to provide the matching funds needed to serve these individuals.

Individuals with ASD can be eligible for HCBS waiver services as long as they meet the level of care criteria set by each state and any targeting criteria the states sets within their waivers *and* there is an available "slot" — that is the state has not reached the cap set on the number of individuals the state expects to serve given available funding. Residential services could be available as long as the state elects to cover those services in the waiver. As noted earlier, states have a fair amount of discretion in setting the eligibility criteria. And because eligibility for the HCBS waiver is directly linked to eligibility for institutional care (in this case eligibility for an ICF/ID), how states determine eligibility for ICFs/ID will determine if individuals with ASD are included in the state's HCBS waiver program. Some states require that individuals with ASD have an intellectual disability in order to meet entrance criteria to ICF/ID services. This same restriction would then apply to the HCBS waiver eligibility. Other states have broader definitions of eligibility, including "related conditions" which could mean a set of functional impairments that do not include intellectual disability, thus a broader range of individuals with ASD could potentially qualify for the HCBS waiver programs. As an example, Virginia has two HCBS waiver programs — one for individuals with intellectual disabilities and a second program for individuals with developmental disabilities but who do not have an intellectual disability, thus individuals with ASD who do not have an intellectual disability may qualify for services under one of Virginia's waiver programs.³⁰ This is also the case in Pennsylvania.

Covered Services. Services must be provided under an individual plan of care approved by the state (or their designated agency or organization), with oversight from the state Medicaid agency. The types of services offered under the waiver are at states' discretion with a few, minor limitations. This permits states to design and offer a wide-array of services tailored to the specific needs of the individuals served. Services typically include residential and in-home supports, vocational training such as pre-vocational

³⁰ Information on Virginia's waivers found at www.dbhds.virginia.gov/ODS-MRWaiver.htm.

and supported employment services, respite, personal care, day programs, and housing and environmental modifications. States cover other services such as transportation, therapies, drugs and medical supplies, crisis intervention, counseling and behavioral intervention. The states can define their own services and limit or expand the services menu as they see fit. The HCBS regulation does require that an individual use their Medicaid card for any services covered in the state Medicaid plan. The HCBS waiver also cannot cover any services that are otherwise available to the person through the public schools or through vocational rehabilitation agencies, nor can it cover room and board costs.

For individuals with ASD the HCBS waiver program can provide a multitude of options for residential services. The waiver can cover "traditional" services such as group homes or adult foster care — and can provide residential services to children as well. But because states have the option to develop their own services definitions, the waiver affords an opportunity to design customized supports and services that can be tailored to meet the needs and preferences of all individuals served, including individuals with ASD. Because states also establish the provider qualifications and payment rates or services, this allows states to develop highly specialized services that may require staff trained in supporting individuals with ASD or consultation services to assure the living arrangement meets the specific needs of the person with ASD. The HCBS waiver can provide what is called a "live-in caregiver" payment — that is the waiver can cover the costs for room and board for a live-in caregiver — another option that could support an individual with ASD to live in their own home with the support of a live-in caregiver. These and other options are discussed in more detail in a later section.

Individuals also have the option for **self-directed services** (or have a guardian or representative direct services on their behalf). Self-directed options afford individuals a high degree of choice and control over services. The individual or representative may have the authority to hire, train, evaluate, and fire individual workers practices that offer excellent opportunity to customize the support provided to the person with ASD. A 2009 report indicated that about 36 states offered some form of self-directed services or were planning implementation for the immediate future.³¹ Although we do not have current data, self-directed options have continued to expand with states such as Ohio recently developing a self-directed HCBS waiver.

³¹ Larson, Sheryl, Editor, *Implementation of Consumer-Directed Services for Persons with Intellectual or Developmental Disabilities: A National Study*, Policy Research Brief, Vol. 20, No. 1, Research and Training Center on Community Living, University of Minnesota, January 2009.

Other ASD specific services could include therapies such as applied behavioral analysis or other positive behavioral supports specifically designed to assist individuals with ASD. The waiver could cover environmental modifications that allow for the customization of the person's living arrangement — sometimes a critical element in the success of the living arrangement. For example, an individual with ASD may be disturbed by certain kinds of lighting or textures in carpeting or other surfaces. Changes that make the individual's home less disturbing can fall under environmental modifications and can be covered under the HCBS waiver. The HCBS waiver affords states considerable latitude in designing residential (and other) services that can be highly specialized and customized for individuals with ASD. We explore some of these options in a later section.

1915(i) State Plan Home and Community-Based Services

Originally proposed in 2007, amended in 2010 and again in 2012, 1915(i) offers states the option to include a wide-range of home and community-based services as a State Plan Option 1915(i) is not a waiver like 1915(c) — it is an optional set of benefits states can choose to add to their Medicaid State plan. The intent of 1915(i) is to offer the same types of home and community-based services that can be covered under the 1915(c) waivers to populations *that do not meet the level of care criteria for institutional services*. 1915(i) effectively "decouples" institutional eligibility from eligibility for HCBS. While states can include populations that meet institutional level of care, the entrance criteria for eligibility for services under 1915(i) must be less stringent than those for institutional eligibility. 1915(i) is typically referred to as State plan HCBS in CMS materials and the application itself is called an iSPA, (i State Plan Amendment). CMS has a draft format available to use when applying for a 1915(i). To date eight states have approved 1915(i) programs, but none yet specifically target individuals with ASD. One state has an iSPA in development targeting children with autism.

In terms of individuals with ASD, under 1915(i), the decoupling of institutional level of care criteria from eligibility for HCBS potentially opens up services to individuals with ASD who do not meet eligibility for other HCBS options such as the waivers. States could craft a 1915(i) SPA that targets individuals with ASD and could offer highly specialized services including residential supports to this population. States routinely report that individuals with ASD cannot qualify for their HCBS waiver — yet need the types of supports and eservices available under the HCBS waiver authority. 1915(i) offers a potential way to use Medicaid financing for this group, particularly those who cannot meet an institutional level of care. Eligibility for 1915(i) is based on meeting: (1) Medicaid eligibility, (2) target group if the state chooses to target, and, (3) needs-based

criteria. In order to be eligible for 1915(i) services, the individual must meet all applicable criteria.

Medicaid Eligibility Groups for 1915(i). In terms of Medicaid eligibility groups, states must include Individuals that are in an eligibility group covered under the state's Medicaid State plan, and who have income that does not exceed 150 percent of the federal poverty level (FPL). Individuals with incomes up to 150 percent of the FPL who are only eligible for Medicaid because they are receiving 1915(c) waiver services may be eligible to receive services under 1915(i) provided they meet all other requirements of the 1915(i) State plan option. The state can choose to provide 1915(i) for individuals who qualify for Medicaid under the state's the medically needy options. The state may opt to include only those whose income is up to the SSI limit or can also choose to include individuals who have income up to 300 percent of SSI and meet the eligibility requirement for institutional services. These individuals must meet the states' level of care requirements for eligibility for HCBS under 1915(c), 1915(d), or 1915(e) or an 1115 waiver.³² These individuals do not have to be *receiving* services under an existing section 1915(c), (d) or (e) waiver or section 1115 waiver but do have to be eligible for a waiver. It is at the states discretion as to whether or not they use this expanded Medicaid eligibility for individuals who meet an institutional level of care.

Target group. Although 1915(i) is an entitlement to all eligible, states have the *option* to target the benefit to specific groups — much like the 1915(c) waivers. States do not have to target the benefit and can just use the needs-based criteria (described below) as the basis for eligibility (in addition to of course Medicaid eligibility). Because states can target, 1915(i) offers states the option to waive comparability if they use this optional targeting feature. This means that the benefit does not have to equally available to all individuals and can be made available to a specific group within the larger Medicaid eligible population.

CMS has advised states that targeting criteria are things such as age, diagnosis, condition, or specific Medicaid eligibility group (as defined above). Using targeting, states can choose to define the group or groups that 1915(i) covers. This ability to target the program means that states can craft a benefit specifically intended for individuals with ASD. And the state can further refine the group served but setting needs-based criteria that relate to individuals with ASD.

³² 1915(c) is the HCBS waiver program, 1915(d) is the "model" HCBS waiver limited to 200 participants, and 1915(e) is for children with AIDS.

Needs-Based Criteria. Key to the provision of services under 1915(i) is the requirement to establish needs-based criteria that are less stringent than the state's criteria for eligibility for institutional services. As noted earlier, the intent of 1915(i) is to break the link between eligibility for HCBS and eligibility for institutional services (as is required under 1915(c)). The statute does not explicitly define needs-based criteria, but CMS has proposed (in the NPRM) to define, "needs-based criteria as describing the individual's particular need for support, regardless of the conditions and diagnoses that may cause the need."³³ Additionally, the statute does not define "stringency" but the NPRM indicates, "The requirement is simply that there be a differential between the threshold of need for the State plan HCBS benefit as compared to the threshold of need for institutional services."³⁴

Defining the needs-based criteria is perhaps the most challenging and essential step for developing a 1915(i) SPA. While needs-based criteria are not defined in the statute, CMS guidance in the NPRM suggests that functional status — that is capacity to perform Activities of Daily Living (ADLs) may be one basis for establishing needs-based criteria. CMS also notes that Instrumental Activities of Daily Living (IADLs) or the need for cuing may also be a basis of needs-based criteria as well as specific risk factors.³⁵ The use of IADLs is of importance for individuals with ASD — as IADLs can include social communication and skills such as managing finances, using a phone or shopping for groceries. Individuals with ASD who may not have intellectual impairments or personal care needs may very well need support in maintaining social relationships or performing activities such as shopping in public — thus the use of the needs-based criteria — rather than the institutional level of care criteria — can open this benefit to individuals with ASD who do not qualify for other HCBS options.

It is important to understand that 1915(i) becomes an entitlement to all those who meet eligibility. Unlike the 1915(c) HCBS waiver program, states cannot cap the number of individuals served under 1915(i), nor put dollar caps on the total amount of services individuals receive, although there can be utilization caps on individual services and of course a limited service "menu." Because 1915(i) is an entitlement, crafting the target group and needs-based criteria are important to assure the benefit goes to the intended group in order that the state be able to manage the funding for the benefit.

³³ NPRM, May 3, 2012, *Federal Register*, Vol. 77, No. 86 / Thursday, May 3, 2012 / Proposed Rules, p. 26367.

³⁴ NPRM, p. 26368.

³⁵ The 1915(i) statute references section 7702B(c)(2)(B) of the Internal Revenue Code of 1986 for the definition of ADLs. ADLs are usually defined as: bathing, dressing, eating, toileting, mobility and transferring. IADLs often include: preparing meals, performing ordinary housework, managing finances, managing medications, using the phone, shopping for groceries, and getting around in the community.

Covered Services under 1915(i). 1915(i) allows coverage of any or all the types of services permitted under 1915(c) — thus states can cover residential and home-based services under 1915(i) and can design services specific to the population of individuals with ASD. As with the 1915(c) waiver, services under 1915(i) may be self-directed.

Other Medicaid Financing Options

The **1115 Research and Demonstration** waiver option allows states flexibility in crafting their Medicaid programs. States can ask for waivers of existing regulations in order to expand eligible populations, add new services, or use Medicaid funding in ways that are efficient and effective but not "permissible" under the regular rules. States such as Arizona, Vermont, and Wisconsin use the 1115 authority in order to operate their Medicaid long-term supports and services programs, including services to individuals with I/DD (and ASD). **1915(j)** offers states the option to provide consumer-directed personal care services, including permitting states to provide cash to recipients to purchase services. And the "regular" state plan can cover a number of optional services that may be of use to individuals needing residential supports such as homemaker chore services and personal care for individuals living in their own homes.

Within the context of the Medicaid State Plan, **Early Periodic Screening, Diagnosis, and Treatment (EPSDT) services** may provide some ASD specific treatment services for children. EPSDT requires states, "...to provide comprehensive services and furnish all Medicaid coverable, appropriate, and medically necessary services needed to correct and ameliorate health conditions," for children up to age 21.³⁶ Although there has not been any definitive ruling from CMS as to what ASD specific services EPSDT must cover, based on litigation and fair hearings in at least three states, coverage of applied behavioral analysis has been mandated. Other states have chosen to cover this service without any legal challenge, while others look to the 1915(c) and in one state potentially 1915(i) as vehicles to deliver ASD-specific therapies under Medicaid. These therapeutic interventions may be essential for children to remain in either the family home or other residential settings and thus may be a critical part of in the success of the child's community placement.

Non-Medicaid Public Financing for Residential Services

Before the advent of the HCBS waiver program, states did pay for residential programs with "pure" state and local dollars, meaning this funding was not used as match for

³⁶ See: www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-Periodic-Screening-Diagnosis-and-Treatment.html.

federal funds. Today, only 12.9 percent of all spending for services for individuals with I/DD are "pure" state funds, that is funds not used as match to draw down Medicaid financing or used as supplemental payments to SSI recipients.³⁷ As discussed above, states mainly fund residential supports through Medicaid. But Medicaid does not cover the costs of room and board, so individuals must rely on other resources to cover those residential costs.

Room and Board Payments. Medicaid can finance the supports and services for individuals with ASD needing residential services, but Medicaid does not cover room and board costs for individuals living in the community.³⁸ Medicaid does not cover any costs associated with housing such as rent or mortgage payments or any "board" costs — that is the cost of food and personal needs such as clothing or toiletries. Individuals must pay their room and board costs out of their personal income, using resources such as Supplemental Security Income (SSI), Social Security Disability Income, pensions, trusts, or earnings. Some states provide for supplements to assist individuals to cover the costs of room and board.

State Supplemental Assistance. According to the Social Security Administration, as of 2011, 28 states provided state funded supplemental assistance to individuals receiving SSI/SSDI.³⁹ This assistance is in the form of state funds intended to help individuals cover their housing and other costs. As an example, the 2001 Minnesota Legislature allowed for a **Minnesota Supplemental Aid (MSA)** special need allowance for disabled individuals who are under the age of 65, otherwise eligible for MSA, relocating into the community from an institution or are eligible for State Plan services or home and community-based waivers do not have housing, and are determined to be "shelter-needy," defined as having total shelter costs exceed 40 percent of gross income (for example, 40 percent of \$674 SSI equals \$270). The applicant must have submitted an application to Housing and Urban Development (HUD) for a housing voucher (see below). The subsidy is \$200 a month (\$2,400 per year) until a HUD housing voucher is granted. The state is looking to de-bundle housing from services in their group living

³⁷ Braddock et al., *State of the States in Developmental Disabilities 2013: The Great Recession And Its Aftermath* (Preliminary Edition, 12th Annual Coleman Institute Conference), Department Of Psychiatry And Coleman Institute University Of Colorado and Department Of Disability And Human Development University Of Illinois At Chicago, November 2, 2012, Figure 15, p. 36.

³⁸ For individuals served in ICFs/ID, Medicaid does cover room and board costs. Individuals do contribute their SSI toward these costs, but Medicaid can cover the difference in cost between the SSI amounts and actual room and board costs. This is not the case for community living arrangements.

³⁹ According to a 2011 report from the Social Security Administration, 28 states provide some type of supplementation. Information can be found at www.socialsecurity.gov/policy/docs/progdesc/ssi_st_asst/2011/index.html.

arrangements so people have the ability to move out and to their own place. The background for this program is that the state realized that the housing voucher waiting list was many years long and they wanted to create opportunities for people at home and those in group arrangements. In **Pennsylvania**, for FY 2009-2010, the average "gross" room and board amount was \$14,573 per year for individuals living in group homes. Pennsylvania requires individuals to contribute 72 percent of their SSI toward their room and board costs (with the remainder used as an allowance for person needs — 72 percent of SSI payment is \$5,820 annually). The net average for the State funded room and board supplement to providers is \$8,753 per person per year for people living in small (1-4) group homes. For individuals with ASD seeking residential services it is worthwhile to ascertain if the state provides room and board supplements — and if these are extended to more than just group living arrangements. The availability of these supplements clearly can be essential in making the residential situation possible. These housing supplements are paid from state funds. Unfortunately not all states provide housing supplements, thus it can be difficult for individuals with limited income to find affordable housing.

Housing Rental and Purchase Programs. The federal department of Housing and Urban Development (HUD) has a variety of programs administered through local housing authorities that provide housing assistance to individuals with disabilities.⁴⁰ In past years it has been difficult for individual with disabilities to gain access to housing vouchers that help defray the cost of rent. Not enough vouchers were available — and waiting lists sometimes stretched years — and often were even closed to new applicants. CMS, again in conjunction with their support of the Olmstead decision, has partnered with HUD in making more housing funds specifically available to non-elderly disabled individuals — and in settings that are not "disability-specific." HUD has offered new funding options that support individuals in settings that are integrated — meaning in housing that also supports more than just individuals with disabilities.⁴¹

The Section 811 Supportive Housing for Persons with Disabilities program provides funding to develop and subsidize rental housing with the availability of supportive services for very low-income adults with disabilities. The Frank Melville Supportive Housing Investment Act offered states new opportunities to develop thousands of new permanent supportive housing units. The new programs include:

⁴⁰ See: HUD's website on vouchers for individuals with disabilities at portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/programs/hcv/ned.

⁴¹ A complete description of these programs can be found in a CMS informational bulletin: *New Housing Resources to Support Olmstead Implementation*, Cindy Mann, Director, Center for Medicaid and CHIP Services (CMCS), June 18, 2012.

- Incentives to leverage other sources of capital for 811 units, such as the federal Low-Income Housing Tax Credits, HUD HOME funds, and bond financing,
- The Project-Based Rental Assistance (PRA) intended to assist State and local governments to, "systematically create integrated supportive housing units within affordable rental housing developments." This funding opportunity invites and encourages state Housing Finance Agencies (HFA) or other appropriate housing agency to establish integrated supportive housing units for non-elderly persons with disabilities in affordable rental housing developments, and,
- Public Housing Authority (PHA) Housing Choice Vouchers specifically intended for use by non-elderly disabled individuals providing support to, "very low-income families to lease or purchase safe, decent, and affordable privately owned rental housing."

For those individuals with ASD seeking residential services in a home they either wish to rent or own, working with the local housing authority can be a path to affordable, sustainable housing. Local housing authorities can be found through:

www.housingvoucher.org or www.phada.org/ha_list.php. In California, the Association of Regional Center Agencies spearheaded a multifaceted housing initiative worth reviewing. They have initiatives that range from creating trusts to financing construction — and provide many excellent ideas on how to create more affordable, high quality housing for individuals with I/DD including working very closely with local housing authorities. Information can be found at arcanet.org/initiatives/housing/index.html.

Some housing authorities are willing to work with families that may wish to donate a home, providing a permanent residential setting for a family member. Through the California "Legacy Homes" program families can work with housing authorities to donate housing.⁴² And many states have housing agencies that assist individuals with finding affordable housing, including assistance to purchase a home. For example, Wisconsin offers assistance through an agency called Movin' Out — and Connecticut through their "Home of Your Own" program. These are two examples of programs that can assist individuals with disabilities, including individuals with ASD to find housing suited to their needs that is financially sustainable.⁴³

⁴² For an example of this California program see: arcanet.org/new-day/wp-content/uploads/2012/10/Presentation-Mary-Eble-.pdf or www.northbayhousingcoalition.org.

⁴³ Connecticut see: www.chfa.org/Homeownership/for%20Homebuyers/Homebuyer%20Mortgage%20Programs/HomeOfYourOwnProgram.aspx; Wisconsin see: www.movin-out.org.

Insurance Mandates. According to the National Council of State Legislatures (NCSL), as of 2012, 39 states enacted legislation requiring insurance coverage for services to individuals with autism. While most of these regulations relate to children, it appears that about 10 states enacted regulations under mental health parity principles that include treatments for adults with autism. The services are therapeutic interventions and do not cover residential services, but coverage of therapies may be essential to an individual's success in a residential program.⁴⁴

State Examples of ASD-Specific Programs

State Autism Departments. Massachusetts, Missouri, Pennsylvania, and South Carolina have each formally constituted a distinct unit that is responsible solely for overseeing and/or providing services to people with autism. Massachusetts has an Autism Division in its Department of Developmental Services (which is part of the Executive Office of Health and Human Services) that oversees the autism waiver program. Missouri established the Office of Autism Services to lead program development for children and adults with autism spectrum disorders including establishing program standards. Pennsylvania's Bureau of Autism Services, part of the Department of Public Welfare, develops and manages services and supports to enhance the quality of life of adults living with Autism Spectrum Disorders (ASD) and to support their families and caregivers and providing technical assistance to other Department of Public Welfare (DPW) offices and government agencies. (Services to children with autism are managed through other government agencies.) South Carolina's Autism Division in the Department of Disabilities and Special Needs provides consultation, training and evaluation services for families of individuals with autism, and the professionals working with them.

Although most states do not have a distinct department or division dedicated to autism services, many individuals with ASD are served through the programs generally available to individuals with I/DD, as long as they meet the eligibility criteria for services. And many of the states' I/DD programs do include services that are specifically intended to support individuals with ASD.⁴⁵ For example, Wisconsin's Children's Long-Term Support Waiver includes a service titled, "Intensive Treatment Services for Children with Autism" specifically targeted to children with ASD. Illinois in their Children's Waiver has done the same thing. Waivers serving adults frequently provide

⁴⁴ *Insurance Coverage for Autism*, NCSL, August 2012, found at www.ncsl.org/issues-research/health/autism-and-insurance-coverage-state-laws.aspx.

⁴⁵ See: *A National Review of Home and Community-based Services (HCBS) for Individuals with Autism Spectrum Disorders*, Policy Research Brief December 2011, Vol. 21, No. 3.

intensive behavioral supports that are of assistance to individuals with ASD. So while these states do not have a separate ASD waiver or program, they do afford specialized services to individuals with ASD. States, although they may not have autism-specific programs, often make explicit commitments to assuring that individual with ASD will be served through their I/DD programs. For example, Virginia has created both regional and statewide collaborative organizations to assure individuals with ASD get the supports and services they need. Virginia expressly tracks how many individuals with ASD are served in their HCBS waivers to assure that individuals with ASD are getting access to HCBS services. A quick Internet search reveals that states including Alabama, Iowa, New Jersey, New York, and Wisconsin, among many others have established Autism Councils or Committees to assure attention and access to services for individuals with ASD.⁴⁶

Autism Specific Waivers

Autism-Specific 1915(c) HCBS Waivers. Currently, 11 states have specific HCBS waivers targeted to individuals with ASD. (Nebraska has an approved autism waiver but it is not operational as yet.) These states are Arkansas, Colorado, Kansas, Maryland, Massachusetts, Missouri, Montana, North Dakota, Pennsylvania, South Carolina, and Utah. Indiana had a separate waiver for individuals with autism but recently merged this waiver into their community integration and habilitation waiver, including the same services that were available under their previous autism waiver. Wisconsin's children's waiver specifically covers intensive behavioral supports for children with autism, but this waiver includes other children as well. New York also has a children's waiver that expressly includes children with autism but it also includes children with I/DD as well.

As can be seen from the chart below these programs — with the exception of Pennsylvania — focus exclusively on children and do not provide residential services out of the family home. Pennsylvania's waiver provides a full range of services to adults including residential habilitation. Residential programs are provided in Community Homes (Group Settings) and Family Living Homes. Pennsylvania requires that these providers complete training developed by the Bureau of Autism Services regarding services for people with autism spectrum disorders as part of becoming qualified to serve individuals under this waiver.

⁴⁶ Information on Wisconsin's program is found at www.dhs.wisconsin.gov/children/clts/waiver/family/eligibility.htm. Information for New York is found at www.opwdd.ny.gov/opwdd_community_connections/autism_platform.

The autism waivers focus on children really means that states use their other HCBS waivers serving individuals with I/DD as the vehicle to provide residential services to individual with ASD. All 50 states and the District of Columbia have HCBS waivers that serve adults — and all of them provide some type of non-family based living supports — whether in group living arrangements, foster homes, shared living and supported living in individuals' own homes.

Many states have providers that specialize in serving individuals with ASD. While these providers are covered under the states' "regular" I/DD program, case managers and family organizations are often aware that certain providers have experience and expertise in serving individuals with ASD. So even when states do not specifically create separately identified waiver or other programs for individuals with ASD, providers with specific expertise in this population may be available within the services system. In seeking information about states' programs, individuals would be advised to start with the state agency responsible for services to individuals with I/DD.⁴⁷ A list of all state agencies can be found at www.nasdds.org/MemberAgencies/index.shtml. Other websites provide state-by-state information. For example, the Easter Seals Society has dedicated a website to state-by-state profiles offering information on state programs for individuals with autism. These profiles can be found at www.easterseals.com/site/PageServer?pagename=ntlc8_autism_state_profiles. Other sites such as Autism Speaks (www.autismspeaks.org/family-services/resource-guide) and the Autism-PDD Network (www.autism-pdd.net/resources-by-state.html) also offer state-by-state information on programs and services for individuals with ASD.

⁴⁷ A list of all state agencies can be found at www.nasdds.org/MemberAgencies/index.shtml. Other websites provide state-by-state information. For example, the Easter Seals Society has dedicated a website to state-by-state profiles offering information on state programs for individuals with autism. These profiles can be found at www.easterseals.com/site/PageServer?pagename=ntlc8_autism_state_profiles. Other sites such as Autism Speaks (www.autismspeaks.org/family-services/resource-guide) and the Autism-PDD Network (www.autism-pdd.net/resources-by-state.html) also offer state-by-state information on programs and services for individuals with ASD. These and many other resources on the web are available to seek information on ASD programs state-by-state. CMS commissioned a paper that profiles nine states' approaches to autism services which can be found at www.cms.gov/apps/files/9-State-Report.pdf. The paper, titled, *Report on State Services to Individuals with Autism Spectrum Disorders (ASD)*, Centers for Medicare & Medicaid Services (CMS) ASD Services Project, Subcontract No. S-10 CMS-33 No. 2, *Final Report*, April 1, 2011, profiles the following states: AZ, CA, CT, IN, ME, MO, NM, PA, and WI.

Table 1 AUTISM-SPECIFIC HCBS WAIVERS

State	Population Served	Residential Services (not family home)	ASD-specific services (Requires autism-specific provider qualifications)	Other services covered
Arkansas	Children 18 months to 7 years	None	One-to-one treatment up to 30 hours/week; includes individualized strategies shown to be effective with children with autism	
Colorado	Children with autism ages 0-6	None	Behavioral Therapy	
Kansas	Children with autism ages 0-5	None	Consultative clinical & therapeutic services (autism specialist) Intensive individual supports Respite (under direction of autism Specialist) Interpersonal communication therapy Parent support and training (peer-to-peer)	Family adjustment counseling
Maryland	Individuals with autism ages 1-21	Residential habilitation	Family training Intensive individual support Therapeutic integration	Respite Environmental accessibility adaptations Adult life planning
Massachusetts	Birth-8	None	Expanded Habilitation Education (in-home Services) Family Training	Respite Community Integration Homemaker Individual Goods &

			Behavioral Supports & Consultation	Services Home & Vehicle Modifications Adaptive Aids Speech Therapy Occupational Therapy Physical Therapy
Missouri	Individuals with autism ages 3-18	None	Behavior analysis	In-home respite Personal assistant Environmental accessibility adaptations Out of home respite Specialized medical equipment and supplies (adaptive equipment) Support broker Transportation
Montana	Children with autism spectrum disorder and adaptive behavior deficits aged 15 months to 7 years	None	Children's autism training Program Design and Monitoring	Respite Case management Adaptive Equipment/Environmental Modifications Extended State plan: OT, PT, Speech Transportation Individually directed goods and services
North Dakota	Birth-4	None		In home supports Intervention coordination Environmental mods Equipment and supplies
Pennsylvania	Age 21 and above	Residential habilitation	Behavioral specialist services	Job assessment/finding, Supported employment Transitional work services

				Day habilitation Supports coordination Therapies Assistive technology Community inclusion Community transition Environmental mods Family counseling Family training Respite
South Carolina	Children with autism ages 3-10	None	Early Intensive Behavioral Intervention (EIBI)	Case management
Utah	Children ages 2-6th birthday	None	Intensive Individual Support – Consultation Services Intensive Individual Support – Direct Services	Respite Financial Management Services Case Management (Administrative Function)

Note: Nebraska has an approved waiver for children with autism that has not as yet been implemented.

Medicaid HCBS that Support Living Arrangements for Individuals with ASD

As we have noted, the 1915(c) HCBS waiver and 1915(i) options under Medicaid are the most likely sources of financing for community residential services for individual with ASD. What services are available and how they are designed and delivered is very much at state option. While most states would not specifically label residential options as targeting individuals with ASD, states could require specialized expertise from providers when serving this population or incorporate design features that support individuals with ASD when developing residential resources. And the individuals' person-centered plan should of course specifically address any needs relating to the person's ASD, including specific supports that may be needed wherever the person lives.

Like services to all individuals with I/DD, services to individuals with ASD include a long history of congregate settings. These have ranged from state and private

congregate settings including large institutions, residential schools and smaller settings such as "intentional communities," "cluster housing," "campus-based" housing and autism "farms." While some of these approaches are intended to offer highly specialized services to support individuals with ASD in safe and secure environments, the national trends described earlier are clearly moving away from congregate, segregated, disability-specific settings to customized, more individualized services. We are aware that some state agencies have received requests for funding of residential programs expressly designed for individuals with autism, including congregate settings in a rural areas and the development of cluster and/or campus-type housing — that is multiple houses in close proximity sharing staff. Given DOJ guidance, these settings may not comport with the Olmstead ruling — and also may not comport with CMS's eventual regulation on home and community-based character. Given CMS focus on community character and DOJ focus on most integrated setting, states would be well-advised to put new resources into developing provider expertise in serving individuals with ASD in smaller, more individualized options.

A recent report titled, "*Advancing Full Spectrum Housing: Designing for Adults with Autism Spectrum Disorders*" provides a comprehensive overview of current trends in supporting individuals with ASD.⁴⁸ This report lays out the variety of housing options currently in use by individuals with ASD and provides advice on the design of optimal residential programs for individuals with ASD. The report provides a framework and challenges providers and developers to think through critical issues in supporting individuals with ASD. These design principles include:

- Ensure Safety and Security
- Maximize Familiarity, Stability and Clarity
- Minimize Sensory Overload
- Allow Opportunities for Controlling Social Interaction and Privacy
- Provide Adequate Choice and Independence
- Foster Health and Wellness
- Enhance One's Dignity
- Achieve Affordability
- Ensure Durability
- Ensure Accessibility and Support in the Surrounding Neighborhood

The report goes on to give specific advice in each of these areas with great attention to detail — even to things like landscaping and specific materials in construction that can

⁴⁸ Ahrentzen, Sherry, and Steele, Kim, "*Advancing Full Spectrum Housing: Design for Adults with Autism Spectrum*," Arizona State University, the Herberger Institute School of Architecture and Landscape Architecture, and the Stardust Center for Affordable Homes and the Family, 2009.

affect the well-being of individuals with ASD. These principles can be applied to any residential setting, but again in keeping with national trends and best practice the report advises, "*Adults with ASDs vary in the amount of personal space needed to feel comfortable. What the adult with ASDs perceives as crowded may not be what architects and designers typically perceive [21]. If there are to be roommates, a total of two or three individuals seems to be optimal in terms of sharing space and minimizing disruption. More than six adults in the same living unit may appear crowded, and residents may begin to be disturbed by competing stimuli and lack of space [27].*"⁴⁹

As noted earlier, states have wide latitude in crafting the array of supports and services covered under their HCBS waivers. States can craft their own definitions of any service — and can propose new and innovative services that do not appear in existing CMS guidance. With any of these services, states could specify provider competencies and experience needed to qualify to serve individuals with ASD. These qualifications can be part of state regulation, the state waiver application — or more flexibly, designed into the person's individual support plan as part of the person-centered planning process. Customizing the person's supports should be part of solid individualized planning. If the person-centered plan truly attends to what is important to and for the individual, residential supports can be tailored to meet the individual's needs and preferences.

Group Living Arrangements. Typically known as group homes, these settings are operated by a provider (individual or agency) that owns and controls the physical property and provides the staff support on a 24/7 basis. The CMS proposed definition defines these settings as, "Round-the-clock services provided in a residence that is NOT a single family home or apartment."⁵⁰

These settings range widely in size, with some states limiting group living arrangement to a maximum of three individuals while others permit much larger settings. These settings are typically licensed and subject to specific state statutory requirements on the physical plant and staffing. Data from 2010 indicated that of all individuals served in the HCBS waiver, 27.5 percent lived in some type of residential facility — that is a provider controlled setting with multiple residents.⁵¹ If a provider controlled setting does not work for the person with ASD, typically the individual must move and seek a

⁴⁹Ibid., p. 24.

⁵⁰ Definitions taken from the *proposed* HCBS waiver taxonomy that CMS is working on with state partners that will allow for cross-state comparisons of services and thus could create a national data set on services. This is still in progress, so any definitions are only proposed at this time.

⁵¹ Larson, 2010, p. 122.

new place to live, which can cause significant stress and disruption particularly for individuals with ASD who may need predictable, stable relationships and routines.

As noted above, group living arrangements may be challenging for individuals with ASD. Making customized accommodations to house routines or even the physical setting can be critical to success. Based on the individual's preferences and the capacity to match the person with the setting, group living is certainly one option for residential services.

Foster Homes. The proposed CMS Taxonomy defines a foster home as, "Round-the-clock services provided in a single family residence where one or more people with a disability live with a person or family who furnishes services." Again, like group homes, the residence belongs to the provider. Foster homes — often called host homes or adult family homes — can be a viable alternative for individuals with ASD again as long as the setting is specifically matched to the individual's needs and preferences. Moving into a place that potentially has established rules and routines may be challenging — thus careful planning and program design — along with ASD-specific training and support to the provider — are essential for success.

Shared Living. Shared living is not a specific model or "placement" type; rather it is an approach to supporting an individual based on a relationship. It is an, "... arrangement in which an individual, a couple or a family in the community share life's experiences with a person with a disability."⁵² Shared living is predicated on making a "match" between the individual providing support and the compensated person supported. Shared living may build from existing relationships — or may be developed through a process of individuals getting to know each other over time — and making the commitment to share their lives. Careful matching plus on-going support for the providers are essential elements for successful shared living. Shared living can occur in many settings but it is somewhat typical that the individual moves into the home of the person(s) providing support. This means a deep study of the impact on all members of the household and establishing clear, mutual understanding of each person's responsibilities and house "rules." Maine, Pennsylvania, Rhode Island, and Vermont — among other states — have successfully used this model to provide stable, long-term, cost-effective supports for individuals with highly specialized needs.⁵³

Supported Living. In the proposed taxonomy CMS has chosen to define supported living as, "Round-the-clock services provided in a person's home or apartment where a

⁵² Cooper, Robin, *Shared Living Guide*, NASDDDS, May 2011, p. 12.

⁵³ See: Cooper, *Shared Living Guide* for descriptions of shared living.

provider has round-the-clock responsibility for the person's health and welfare." Many states current definitions include less than 24-hour support — and states have flexibility in how they choose to define services. But the key characteristic of supported living is that *the home is controlled by the individual* or their representative — not the provider of services. This allows the individual to change providers or support staff without having to move — creating far less disruption to the person than having to move from a provider-controlled setting if the situation is not suitable. Supported living affords the opportunity to completely design the intensity and type of supports to match needs and preferences. Support can range from assistance with personal needs to training to assistance to access community activities. And many states permit self-directed option in supported living services, giving the individual (or their representative) a high degree of choice and control over the services — including the option to hire, train, evaluate, and fire the person(s) providing support. Individual in supported living may also benefit from other services such as **assistance with chores or homemaker services** for individuals who are unable to do tasks such as cooking for themselves.

Family Home-Based Services. As noted earlier, many more individuals with I/DD, including those with ASD, are living at home with their families. And this trend is expected to continue given the fiscal pressures states are facing along with shortages of direct support workers. Particularly for adults, states are looking at ways to support families to support their adult children in the family home — while also assuring that the individual is afforded an adult life. There are a variety of other supports to assist the person while living in the family home **including personal care, respite, skills training (habilitation), and community integration assistance**, all of which can assure that the individual has an adult life — while still living at home.

Live-in Caregiver. The HCBS waiver (and thus 1915(i) also) allows states to apply to make payments for rent and food expenses of an unrelated live-in caregiver.⁵⁴ *This is intended for someone who is living in the home (owned or rented) of the individual –not in the caregiver's home.* Under this provision the participant covers the costs of rent and food and is reimbursed for these costs. This approach may work well for individuals who may not need a lot of supports — or it can be paired with other payments to the individual for the provision direct support which can be compensated under personal care or other services. This situation is sometimes referred to as a "paid roommate" and may work well for individuals who wish to share their lives, bringing someone into their own home. This option affords individuals a high degree of choice and control. It

⁵⁴ *Application for a Home and Community-Based Waiver [Version 3.5]: Instructions, Technical Guide and Review Criteria*, January 2008, CMS, pp. 266-267.

is not a provider agency sending someone — but is an arrangement based on a mutual decision to share lives.

Community Transitions Services. CMS defines Community Transitions Services as, "...non-recurring set-up expenses for individuals who are transitioning from an institutional or another provider-operated living arrangement to a living arrangement in a private residence where the person is directly responsible for his or her own living expenses."⁵⁵ Therefore this service is only available to individuals moving into their own homes from an institutional setting — not to individuals moving into provider controlled, owned or operated settings. The expense cannot include room and board — but can include fees for setting up utilities or security deposits. General expenses for establishing a basic household are allowable and can include:

- security deposits that are required to obtain a lease on an apartment or home;
- essential household furnishings and moving expense required to occupy and use a community domicile, including furniture, window coverings, food preparation items, and bed/bath linens;
- set-up fees or deposits for utility or service access, including telephone, electricity, heating and water;
- services necessary for the individual's health and safety such as pest eradication and one-time cleaning prior to occupancy;
- moving expenses;
- necessary home accessibility adaptations; and
- activities to assess need, arrange for and procure need resources.

For individuals establishing a home in the community, this can be an essential service — but in order to cover these costs the state must explicitly include this service in their HCBS waiver application. For individuals with ASD, the ability to purchase furnishings may assist an individual with sensitivities to textures or provide or environmentally friendly cleaning services for individuals who may have olfactory sensitivities.

Environmental Modifications. Called Home Accessibility Adaptations in the HCBS waiver application, environmental modifications are defined as, "Those physical adaptations *to the private residence of the participant or the participant's family*, required by the participant's service plan, that are necessary to ensure the health, welfare and safety of the participant or that enable the participant to function with greater independence in the home."⁵⁶ While the services definition goes on to note that states can cover things

⁵⁵ *Ibid.*, p. 166.

⁵⁶ *Ibid.*, p. 162

like grab bars, ramps, widened doorways or the installation of special electrical systems to support medical needs, states have the capacity to modify this definition to include adaptations for individuals with ASD that will assist them to live more independently or assure their safety and welfare.

Adapting the environment for an individual with ASD may be essential to their comfort and success. Changing lighting, textures, or soundproofing or safety adaptations such as intercoms and alarms can add to the success of the residential setting. The work of George Braddock in customizing individual's homes to maximize their independence and safety is worth reviewing.⁵⁷ As his approach notes, "The right physical environment can fundamentally change the relationship between a person and his / her supports. The right physical environment can support a person to live a more integrated life."

One emerging area of environmental adaptations is **remote or electronic monitoring**. Both Indiana and Ohio offer this service under their HCBS waivers for individuals with I/DD, including individuals with ASD. Indiana defines this services as, "... the provision of oversight and monitoring within the residential setting of adult waiver participants through off-site electronic surveillance. Also included is the provision of stand-by intervention staff prepared for prompt engagement with the participant(s) and/or immediate deployment to the residential setting."⁵⁸ In Ohio, remote monitoring "...means the monitoring of an individual in his or her residence by staff using one or more of the following systems: live video feed, live audio feed," motion sensing system, radio frequency identification, web-based monitoring system, or other device approved by the department."⁵⁹ Both states developed extensive protocols to assure thoughtful and appropriate use of monitoring that rests on the full informed consent of the individual (and/or their legal representative), and assure individual rights to privacy.⁶⁰ Some states report the use of electronic monitoring has increased independence for some individuals, allowing them to spend time in their homes without direct support workers on-site.⁶¹

⁵⁷ See: gbcchs.com.

⁵⁸ *DDARS Waiver Manual*, 2012, Manual, Section 10.9, Electronic Monitoring, state of Indiana, www.in.gov/fssa/files/Part_10_-_Service_Def.pdf.

⁵⁹ Ohio Administrative Code 5123:2-9-35 Home and community-based services waivers — remote monitoring and remote monitoring equipment under the individual options and self-empowered life-funding waivers, codes.ohio.gov/oac/5123%3A2-9-35.

⁶⁰ Ohio: test.mr.state.oh.us/training/documents/Assessment-remotemonitoringfinal.pdf and doddportal.dodd.ohio.gov/INF/finditfast/publications/Documents/IO%20Waiver%20Handbook,%20New%20Rev.%207-15-11.pdf ; Indiana: *DDARS Waiver Manual*, 2012, Manual, Section 10.9, Electronic Monitoring, state of Indiana, www.in.gov/fssa/files/Part_10_-_Service_Def.pdf.

⁶¹ Sites to look at are www.waisman.wisc.edu/soundresponse/support.php and www.simply-home.com.

Assistive Technology. CMS defines assistive technology as, "assistive technology device means an item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of participants."⁶² The definition also includes training to use the device both for the individual and those supporting him or her. Individuals with ASD may particularly benefit from the inclusion of this service into state HCBS waiver programs. States may have been reluctant in the past to purchase tablets and computers for individuals, but with emerging research, many states agree that computer/tablet/smart phone based applications can be of significant benefit to individuals. Applications that assist individuals to ride a bus independently, cook, manage their home (locking doors, turning out lights) — can help individuals to need less hands-on support. Some devices can be programmed to "cue" individuals through tasks — which may provide the individual a greater sense of control than being cued by another person.⁶³ Coverage of assistive devices can include needed evaluations and assessments to ascertain which devices are best suited to the individual — matching the person, device, and program is of course critical to a positive outcome.

In terms of individuals with ASD, there has been an explosion of applications on the iPad and other tablets and computers. While research is just emerging, some anecdotal evidence indicates that some individuals may benefit from these applications, but the use and applications must be customized to the needs, skills, and goals of the individuals and based on careful assessment of the capacity of the person and the intended goals in using the device. States may want to devise planning protocols in order to make decisions about what assistive devices are allowable (or more easily, what is not allowable)

Other Supportive Services. We would be remiss if we did not note how critical other supports are to the success of residential or home-based services. Employment supports, opportunities to engage socially with peers, positive behavioral supports, and self-advocacy involvement are all elements of successful life in the community. All these types of support can be covered under Medicaid — through the HCBS waiver programs, or through other options such as 1915(i).

⁶² *Application for a Home and Community-based Waiver [Version 3.5]: Instructions, Technical Guide and Review Criteria,* January 2008, CMS, p. 165.

⁶³ For a look at how technology has created independence for individuals see: www.colemaninstitute.org, www.ablelinktech.com and www.ablelinktech.com/index.php?id=21.

The ability to work means income — a way to help offset the considerable costs of a home or apartment — and of course provides self-esteem, purpose, and relationships in our lives. At present, 19 states have official **employment first initiatives**, intently focusing effort on employing individuals with I/DD (and ASD). An additional 14 states have other significant employment initiatives underway. An employment first approach to life planning presupposes that in our society work is a valued outcome — and makes employment a priority.⁶⁴

Conclusion

The tenets of the ADA, affirmed by the Olmstead decision, afford individuals the right to live in the most integrated setting. Medicaid offers a wide-array of programs, supports, and services that can assist individuals with ASD to have full and productive lives as members of their communities. And states have considerable flexibility and latitude in designing the supports and services. Medicaid clearly is a key resource for financing individualized and customized services to individuals with ASD. And guidance from CMS clearly promotes community inclusion and integration as key elements of services to individuals with disabilities, making Medicaid a powerful tool in developing residential — and other services — for individuals with ASD.

⁶⁴ See: State Employment Leadership Network, *Employment First Resource List* at seln.info/components/com_wordpress/wp-content/uploads/2012/08/emp_first_resources_2012.pdf.