Study on Housing with Supports for Children with Severe Autism

Disability Services Division

January 2013

Legislative Report

Minnesota Department of **Human Services**

For more information contact:

Minnesota Department of Human Services

Disability Services Division

P.O. Box 64967

St. Paul, MN 55164-0967

(651) 431-2400

This information is available in alternative formats

to individuals with disabilities by calling

(651) 431-2400.

TTY users can call through Minnesota Relay at

(800) 627-3529.

For Speech-to-Speech, call

(877) 627-3848.

For additional assistance with legal rights and protections for equal access to human services programs, contact the agency’s ADA coordinator.

Minnesota Statutes, Chapter 3.197, requires the disclosure of the cost to prepare this report. The estimated cost of preparing this report is $150,000.

Printed with a minimum of 10 percent post-consumer material. Please recycle.

Table of Contents

I. Executive summary

This report was completed to address a requirement by the Legislature to study housing with supports for children with severe autism. DHS chose to contract with the University of Minnesota's Research and Training Center on Community Living, Institute on Community Integration to complete the study. DHS contracted with the Institute on Community Integration for several reasons, including:

- Their role in coordinating the Minnesota Leadership Education in Neurodevelopmental and Other Related Disabilities, which is an interdisciplinary training program that responds to the needs of children with Autism Spectrum Disorders (ASD), other neurodevelopmental and related disabilities, and their families, by bringing together faculty, staff and students from twelve disciplines across the University of Minnesota.
- The Research and Training Center on Community Living's experience with research on residential services, including the National Residential Information Systems Project, which, for the past twenty year, has collected and disseminated annually national and state statistics on public and private residential services, Medicaid program utilization and expenditures.
- Their role as a University Center for Excellence in Developmental Disabilities. The mission of University Centers for Excellence in Developmental Disabilities is to serve as liaisons between the academic expertise of institutions of higher learning and service delivery systems so as to positively affect the lives of individuals with developmental disabilities and their families by increasing their independence, productivity and integration into communities.

The study completed by the Institute on Community Integration is included in this report. DHS developed recommendations and an implementation plan, as required by the legislature, based on the results of the comprehensive study.

The study completed by the Institute on Community Integration included the following:

- Information on residential service trends for people with autism, including Minnesota and national trends.
- Case study summaries for a variety of housing with supports for children with autism, both within Minnesota and nationally. These included community-based settings, treatment facilities, institutions and campus-based models.
- Stakeholder input, including advisory council recommendations and key stakeholder interviews.
- An analysis of federal policy and initiatives related to residential services.
- Examples of ASD-specific residential services in other states.

- An analysis of the impact and implication of current Minnesota initiatives.
- Summary of the findings and recommendations.

Based on the information provided in the study, DHS is recommending the development of home and community-based services to specifically support children with severe autism. Some development can occur within existing resources. This will involve a multi-pronged approach, which will include:

- Supporting families to keep children in their family home, whenever possible.
- Developing capacity with a pool of home and community-based services providers who are able to support children with severe autism, using identified criteria that are important to the success of services, as determined by the results of the study. There are options to do this both within existing resources and with additional funding.
- Providing technical assistance from the state, or other sources identified by the state, at all phases of development.

Another option that can be explored is the use of intermediate care facilities for people with developmental disabilities to support children with severe autism, using identified criteria that are important, as determined by the results of the study. This will likely require additional funding, although steps will be taken to evaluate options to do this within existing resources.

II. Legislation

2012 Laws of Minnesota, chapter 247, Article 4, Section 50:

AUTISM HOUSING WITH SUPPORTS STUDY.
The commissioner of human services, in consultation with the commissioners of education, health, and employment and economic development, shall complete a study to determine one or more models of housing with supports that involve coordination or integration across the human services, educational, and vocational systems for children with a diagnosis of autistic disorder as defined by diagnostic code 299.0 in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). This study must include research on recent efforts undertaken or under consideration in other states to address the housing and long-term support needs of children with severe autism, including a campus model. The study shall result in an implementation plan that responds to the housing and service needs of persons with autism. The study is due to the chairs and ranking minority members of the legislative committees with jurisdiction over health and human services by January 15, 2013.

III. Introduction

The Department of Human Services (DHS) contracted with the University of Minnesota's Research and Training Center on Community Living, Institute on Community Integration to complete a study on available options on housing with supports for children with severe autism. The report produced by the Institute on Community Integration in included in Section IV of this report, which follows this introduction.

The authorizing legislation required that the study include an implementation plan that responds to the housing and service needs of people with autism. To respond to this requirement, DHS has included Sections V and VI on recommendations and an implementation plan, based on the results of the study information compiled by the Institute on Community Integration. The recommendations and implementation plan follow the complete report from the Institute on Community Integration.

The readability level of the study included in this report is higher than what is typical for DHS products. In an effort to retain the integrity of the study, DHS did not make substantive changes to the study to address the readability concerns. We apologize for any inconvenience this may cause.

Residential Services for Individuals with Autism:

Considerations for Minnesota

Submitted by

The Research and Training Center on Community Living

Institute on Community Integration, University of Minnesota

December 31, 2012

Table of Contents

Acknowledgements

The authors wish to thank the following for their contributions to this project:

Community Advisory Council Members
This was a time-limited group and we asked them for a lot of information in a very short amount of time. Each member contributed with intention and commitment. A list of Advisory Council members is included in Appendix D.

Key Stakeholders
Through a lengthy interview, these individuals were candid and thoughtful about their own personal experiences. They shared their stories and ideas with passion and sincerity to support Minnesotans with autism so they are able to access residential services appropriate to their individual needs.

Truven Health Analytics
Truven Health Analytics conducted the data analyses presented in these reports at the request of the Minnesota Department of Human Services and the research team.

The Minnesota Department of Education
The Minnesota Department of Education provided the research team with information on the students in Minnesota with autism who have been served in out-of-state educational programs. Staff from the Minnesota Department of Education also provided the research team with education-related questions for the site visit protocol.

The Center for Advanced Studies in Child Welfare at the University of Minnesota
The Center for Advanced Studies in Child Welfare at the University of Minnesota's School of Social Work provided data on children with autism who are served in residential treatment programs through the child welfare system in Minnesota.

Report Authors (listed alphabetically)
The Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota:
Anab Gulaid, M.P.A.
Jen Hall-Lande, Ph.D.
Amy Hewitt, Ph.D.
Barb Kleist, J.D.
Tim Moore, Ph.D.
Derek Nord, Ph.D.
Christen Opsal, M.A.
Joe Timmons, M.A.

National Association of State Directors of Developmental Disability Services:
Robin E. Cooper, M.S.S.W.
Charles R. Moseley, Ed.D.

I. Introduction and Background

Statement of Purpose

This report presents the findings of a study funded by the Minnesota Department of Human Services and conducted by the University of Minnesota's Research and Training Center on Community Living, Institute on Community Integration concerning residential services for individuals with autism spectrum disorders (ASD)—primarily those considered "severe" or with the most challenging behaviors. The study came about as part of a bill passed in April 2012 by the Minnesota Legislature. The language from the bill is as follows:

The commissioner of human services, in consultation with the commissioners of education, health, and employment and economic development, shall complete a study to determine one or more models of housing with supports that involve coordination or integration across the human services, educational, and vocational systems for children with a diagnosis of autistic disorder as defined by diagnostic code 299.0 in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). This study must include research on recent efforts undertaken or under consideration in other states to address the housing and long-term support needs of children with severe autism, including a campus model.

The study shall result in an implementation plan that responds to the housing and service needs of persons with autism. The study is due to the chairs and ranking minority members of the legislative committees with jurisdiction over health and human services by January 15, 2013.

The purposes of the study were to:

- identify how children and adults with ASD are currently served in Minnesota with regard to residential, educational, and employment services;
- identify residential providers in Minnesota that serve children and adults with ASD;
- identify national residential service trends for children and adults with ASD nationally;
- identify recent activities, priorities, and decisions of the U.S. Department of Justice and Centers for Medicare and Medicaid Services regarding congregate care;
- identify characteristics of campus/segregated specialized residential services for children and adults with ASD in Minnesota and nationally;
- identify community non-institutional and non-segregated models of residential services for people with ASD in Minnesota and nationally; and
- establish criteria for a "model" residential program that serves people with ASD with input from an advisory panel of stakeholders within Minnesota.

The purposes of the study came from the understanding that many families in Minnesota have found it difficult or impossible to access appropriate residential services for their children with autism and related severe behaviors. Often, these families end up in one crisis situation after another and their children move from one unstable placement to another; they even sometimes end up in programs outside Minnesota, far from home. In this study, researchers gathered and reviewed data from sources inside and outside of Minnesota with the goal of informing policymakers about effective residential services for this population.

Summary of Study Methods

This research study used mixed methodological approaches allowing for both qualitative and quantitative approaches. It generated new data and used existing data sources when appropriate. Key data collection methods included:

- an analysis of existing data on residential services delivered to Minnesotans with ASD, characteristics of the children and adults with ASD receiving residential services, and characteristics of places where people with ASD are receiving residential services;
- in-depth interviews with key stakeholders;
- on-site case studies in various models of residential services for people with ASD, both in Minnesota and out-of-state;
- a structured focus group process with key stakeholders to provide input on the characteristics of effective residential services for children, youth, and adults with ASD;
- a review of the literature related to residential services for children and adults with ASD; and
- a review of federal policy and state initiatives and their implications for residential services for people with ASD in Minnesota.

Population

Autism spectrum disorders (ASD) comprise a range of behaviorally defined developmental disabilities including Asperger's syndrome and pervasive developmental disorder—not otherwise specified. ASD characteristics include communication difficulties, social interaction challenges, and repetitive or stereotypical patterns of behavior (American Psychiatric Association, 2000). Between 2002 and 2006, the Centers for Disease Control and Prevention noted a 57% increase in the prevalence of ASD among eight-year-olds; it is now estimated that 1 in 88 children in the U.S. has a diagnosis of ASD (Centers for Disease Control, 2012). The prevalence of ASD among adults is less well documented (Hall-Lande & Hewitt, 2010), due in part to changes in diagnostic procedures—it is believed that many adults have undiagnosed ASD and/or were diagnosed with some other disability (e.g., developmental disability, intellectual disability) as children.

This study focused on residential services for children, youth, and adults with severe functional limitations in the three cardinal features of autism: 1) failure to develop communicative language, 2) failure to develop interpersonal interactions, and 3) failure to develop adaptive skills (i.e., being limited to a narrow range of repetitive and stereotyped actions and interests) and who have co-occurring challenging behavior.

Research Questions

To achieve the goals of the study, the researchers generated these research questions:

1. What are effective characteristics of residential services for children, youth and adults with ASD?
2. What residential services are currently provided to Minnesotans with ASD?

3. What are the similar and different attributes of campus, farm, group home, supported living and self-directed models of residential services for people with autism have severe functional limitations?
4. How do U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services and U.S. Department of Justice actions influence the future of residential services for Minnesotans with ASD?
5. What do various stakeholders in Minnesota identify as characteristics of effective residential services for children, youth and adults with ASD that have severe functional limitations?

II. Residential Service Trends: Considerations for People with Autism

Residential services for individuals with intellectual and developmental disabilities, including people with ASD, have evolved over the last 50 years with the advancement of research, technology, and advocacy movements related to people with intellectual and developmental disabilities.

Institutions were once the primary out-of-home residential option for individuals with intellectual and developmental disabilities; few of them promoted a return to one's community. Today, more options exist that promote individualized services, community integration and lifelong learning. Many decades ago, Minnesota made a commitment to close its large state institutions. It has been a national leader in this effort. While there are no longer any state-run institutions in Minnesota designated for individuals with intellectual and developmental disabilities, some people with intellectual and developmental disabilities and ASD remain in state-run institutions for people with mental illness. Additionally, there are still some large non-state-run institutional facilities licensed as intermediate care facilities for people with developmental disabilities.

Institutions are typically defined as large, state-operated or private, residential facilities that provide facility-centered residential services to 16 or more residents (Larson, Ryan, Salmi, Smith & Wuorio, 2012). Multiple research studies and investigations on institutions report that such large congregate settings are characterized by an environment of care that can marginalize people with disabilities, inhibit their integration within society, foster dependence, and create a culture of abuse and neglect that victimizes individuals with intellectual and developmental disabilities. As a result, significant efforts have been made over the years by parents and other advocates to close institutions in Minnesota and across the country. In the last half century, states operated 354 large state intellectual and developmental disabilities facilities and special intellectual and developmental disabilities units in psychiatric facilities but in the late 1970s, many states began to close their large institutions. In fiscal year 2010, 160 of those facilities remained open. States reported their intention to close 21 more large state intellectual and developmental disabilities facilities between 2010 and 2014 (Larson et al., 2012).

Another way of looking at this: in 1977, 84% of individuals with intellectual and developmental disabilities lived in residences of 16 or more people; only 8.2% lived in residences with 6 or fewer people. By 2010, those numbers had almost reversed—75.5% lived in residences with 6 or fewer people. The role of the state as a residential service provider also steadily declined between 1977 and 2010, with 63% of all residential service recipients living in state-operated residential settings in 1977 but only 9.2% in 2010 (Larson et al., 2012). More recently, smaller community residential settings have become the norm for most individuals who do not live with their families. Community residential settings include a greater variety of residential options and thus increase choice for individuals with intellectual and developmental disabilities and their families.

Residential Settings Funded by Medicaid

A recent study of outcomes of services for people with intellectual and developmental disabilities noted that 10.6% of people who receive residential services funded by Medicaid are people with ASD (Hewitt et al., 2012). Medicaid-funded residential services include intermediate care facilities for people with developmental disabilities and Medicaid home and community-based services. Home and community-based services residential arrangements include living with family members, in a residential facility, in a home owned or leased by a person with intellectual and developmental disabilities, with a host or foster family, or in some other type of supported setting.

In fiscal year 2010, nationally, there were 6,514 intermediate care facilities for people with developmental disabilities and 592,070 people with intellectual and developmental disabilities receiving home and community-based services, compared to 1,833 people who were admitted to large (16+ residents) state-operated intellectual and developmental disabilities facilities in 37 states in fiscal year 2010. The average size of an intermediate care facility for people with developmental disabilities in the U.S. in 2010 was about 13 residents, compared to 186 residents in 1977. The number of people receiving home and community-based services in 2010 was more than 6.5 times the number living in intermediate care facilities for people with developmental disabilities. In fiscal year 2010 in Minnesota, 29 individuals with intellectual and developmental disabilities were living in the last state institution (the Minnesota Extended Treatment Options program, which has since closed), and 1,758 individuals were living in intermediate care facilities for people with developmental disabilities. Of these 1,758, 401 were living in intermediate care facilities for people with developmental disabilities with 16 or more residents and 15,353 were receiving home and community-based services (Larson et al., 2012).

Costs of Residential Services- Nationally, in fiscal year 2010 the average annual per resident expenditures were $229,220 in state-operated facilities with 1-6 residents, $211,335 in facilities with 7-15 residents, and $195,275 in facilities with 16 or more residents. Medicaid expenditures per average daily participant are much higher for people in intermediate care facilities for people with developmental disabilities than for home and community-based services recipients. Total federal and state expenditures for intermediate care facilities for people with developmental disabilities services in fiscal year 2010 were $12.87 billion, with an average expenditure per resident of $146,999. Expenditures for Medicaid home and community-based services recipients were $26.3 billion, with a recipient average of $44,396 per year. The average per diem expenditures for the last institution in Minnesota in fiscal year 2010 was $850.83. Minnesota expenditures for intermediate care facilities for people with developmental disabilities services in fiscal year 2010 were $169,111,403, with an average annual resident expenditure of $96,497.

Minnesota home and community-based services expenditures were $998,020,576 in fiscal year 2010, with an average of $66,127 per year per recipient (Larson et al., 2012).

Experiences and Models of Residential Services Used by People with ASD- According Resnik & Blackbourn (2009), of the people with ASD between the ages of 19 and 30, 79% lived at home, 12% lived in supported residences, 4% were living independently, 3% lived in other residential locations and 2% lived in supported residences. These results are consistent with more recent research that used data from a national random sample of adult service users in developmental disabilities services in 19 states. These data found that 10.6% of residential service user of home and community-based services and intermediate care facilities for people with developmental disabilities were people with a diagnosis of ASD (Hewitt et al., 2012).

Since most adults with ASD live with their parents, little is known about their demographics and outcomes. The limited research suggests a relationship between the type and quantity of services received and the quality of life experienced by adults with ASD (Renty & Roeyers, 2006). Adults with ASD tend to have poor outcomes (Billstedt, Gillberg, & Gillberg, 2005; Howlin, Goode, Hutton, & Rutter, 2004), probably due to their lifelong challenges with communication, social relationships, social interactions, employment, and independence (Howlin, Mawhood, & Rutter, 2000; Lawer, Brusilovskiy, Salzer, & Mandell, 2009). There are also service access issues for people with ASD that can negatively affect their quality of life. While 10.6% of the adults who receive formal developmental disability services have a label of ASD (Hewitt et al., 2012), it is also likely that many adults with ASD who do not have an intellectual disability are not receiving services.

For this report, residential out-of-home models for individuals with intellectual and developmental disabilities generally fall into one of four categories:

1. **Transitional models** are temporary residential care settings that offer short-term placements with the intent of transitioning individuals back to their original living arrangement or to an arrangement that will be more permanent. Transitional placements are generally intensive inpatient centers which evaluate and treat individuals with severe behavior disorders. Other options for transitional programs, generally for higher functioning individuals with ASD, include life skills training and/or college support programs.
2. **Group home models** are smaller, more typical homes in a community residential neighborhood. The number of residents in group homes ranges from 1 to 15. Group homes generally have overnight staff. They are designed to integrate individuals into the community and to provide easy access to community services. Residents of group homes usually have goals to increase their independence through instruction and training on self-help (e.g., bathing, dressing, grooming); daily living skills (e.g., meal preparation, laundry, housecleaning, home maintenance, money management, hygiene, appropriate social interactions); social interaction; and appropriate behavior.
3. **Supported living models** are programs in which the individual or family owns or rents a dwelling for the individual and services are brought into his or her home. Emphasis is placed on supporting the individual needs and desires of the resident. These models typically are not staffed overnight but can be.
4. **Campus or farm models** combine residential living arrangements with education and employment opportunities either on campus, on a farm, or in the community. These

> living arrangements consist of a variety of single-family homes, apartments, and multi-unit dwellings and residents often work in supported employment or customized employment situations. Staff provide training on self-care, home-care, vocational skills, and socialization. These programs can be located in rural, suburban or urban areas.

As noted above, many individuals with intellectual and developmental disabilities live with family members and methods of external support for them can vary considerably.

III. Current Residential Services for People with ASD in Minnesota

To understand the extent of residential services accessed by individuals with ASD in Minnesota, the following section describes the types of services children, youth, and adults ASD receive, based on data from the Department of Human Services, the Minnesota Department of Education and the Center for Advanced Studies in Child Welfare.

Minnesota Department of Human Services

The Department of Human Services (DHS) maintains a number of data sources that provide details regarding characteristics of children and adults with ASD receiving services as well as information about the services accessed. These data sources span the 2006 to 2010 calendar years and include the Medicaid Management Information System, MAXIS, screening and assessment data and residential service provider data. Unless otherwise noted, a person was identified as having an ASD if they had a diagnosis code beginning with 299. (These analyses were conducted and associated tables developed by Truven Health Analytics upon request from the study team.)

Characteristics of People with ASD Receiving Services A total of 17,454 people receiving DHS services were identified as having ASD in 2010 (see Table 1). Fifty-eight percent of all service recipients with ASD were 17 years old or younger, 39% were ages 18-64 years, and 3% were 65 and older. A major type of service provided are long-term supports and services, defined as participation in a 1915c waiver or Alternative Care, or receipt of Personal Care Assistance, Private Duty Nursing, Intensive Residential Treatment Services, Adult Rehabilitative Mental Health Services, Children Therapeutic Services and Supports, Assertive Community Treatment, Rule 5 services, or a Consumer Support Grant. Of this group, a total of 10,020 received long-term supports and services, constituting 9% of the 111,636 total recipients of long-term supports and services. Across age groups, children ages 0-5 were least likely to receive long-term supports and services (39.4%) and adults ages 18-20 were most likely to receive long-term supports and services (66.3%).

Table 1: People with ASD in CY2010, by Age and Use of Long-term Supports and Services (LTSS)

Age Group	ASD Receiving LTSS (n)	ASD Not Receiving LTSS (n)	Total with ASD	Percent of Total ASD Receiving LTSS
0-5	808	1,245	2,053	39.4%
6-17	5,163	2,847	8,010	64.5%
18-20	841	428	1,269	66.3%
21-64	2,898	2,577	5,475	52.9%
65 +	310	257	567	54.7%
Missing		1	1	0.0%

Age Group	ASD Receiving LTSS (n)	ASD Not Receiving LTSS (n)	Total with ASD	Percent of Total ASD Receiving LTSS
Total	10,020	7,355	17,375	57.7%

Note: This data excludes 79 people flagged with an ASD diagnosis but with no claims data for CY2010.

Based on the race of the individuals with ASD who received services in 2010, there were differences in the age of the service recipients. Tables 2 and 3 present these demographics for individuals receiving services through LTSS and non-LTSS means. As shown on Table 2, across age groups there was little variation in LTSS representation among those identified as Asian, Native American, and Hawaiian and Pacific Islander. A greater percentage of children with ASD identified as Black and African American, being of two or more races, or race unknown received LTSS than did adults of the same racial background. Conversely, children with ASD identified as White made up the greatest percentage of LTSS service recipients across all age groups, but a greater percentage of adults received LTSS than children.

Table 2: Racial Distribution of LTSS Recipients with ASD: CY2010

Race	Ages 0-5	Ages 6-17	Ages 18-20	Ages 21-64	Ages 65+
Asian	3.5%	3.4%	3.4%	3.5%	3.9%
Black/African-American	21.0%	12.3%	7.3%	7.7%	10.6%
Native American	1.6%	2.1%	1.8%	1.3%	0.6%
Hawaiian/Pacific	0.1%	0.1%	0.1%	-	-
Two or more races	6.3%	3.5%	1.4%	0.3%	-
Race unknown	8.2%	5.6%	4.3%	1.8%	1.9%
White	59.0%	72.1%	81.5%	85.4%	82.9%

The racial distribution of non-LTSS services recipients show that individuals with ASD identified as White make up the highest percentage of recipients across all ages, followed by those identified as Black/African American (see Table 3). A greater percentage of children with ASD identified as Native American, two or more races, or race unknown received non-LTSS services than did adults of the same racial background, whereas a greater percentage of adults identified as White received non-LTSS service than children.

Table 3: Racial Distribution of Non-LTSS Recipients with ASD: CY2010

Race	Ages 0-5	Ages 6-17	Ages 18-20	Ages 21-64	Ages 65+
Asian	4.6%	4.0%	7.2%	4.2%	4.3%
Black/African-American	15.4%	13.8%	15.4%	14.6%	6.6%
Native American	3.5%	3.7%	1.6%	2.1%	-
Hawaiian/Pacific	-	0.1%	0.2%	0.1%	-
Two or more races	7.1%	4.6%	0.9%	0.8%	-
Race unknown	6.8%	5.5%	3.3%	2.8%	3.5%
White	62.6%	67.7%	71.0%	75.2%	85.6%

Comparing the racial distribution of people with ASD receiving LTSS and non-LTSS services to state population demographics (all ages), a few noticeable differences arise (see Tables 2, 3, and 4). First, it appears that people with ASD identified as Black/African American made up a larger percentage of service users than would be expected based on state demographics. Specifically, they were considerably overrepresented in LTSS services among ages 0-17 and 65 and older and non-LTSS services across all years except 65 and older than they are in the state population (all ages).

Similarly, considerably more people identified as Native American ages 0-17 were represented in non-LTSS services and considerably more people identifying as two or more races ages 0-17 were represented in LTSS and non-LTSS services than would be expected based on state demographics. Conversely, those with ASD identified as White were considerably underrepresented in the 0-17 age group of LTSS services and 0-64 age group of non-LTSS services, compared to the state's demographic composition.

Table 4: Minnesota Population Racial Demographics – U.S. Census 2010

Total MN Population	Native American	Asian	Black or African American	Native Hawaiian - Other Pac. Islander	Some Other Race	Two or More Races	White
5,303,925	1.1%	4.0%	5.2%	0.0%	1.9%	2.4%	85.3%

Source: Office of the State Demographer (2011).

Residential Services and Supports. The nature of this study required a focused assessment of residential services funded by DHS. The first stage in this process was to assess the utilization of residential services for people with ASD in the 2010 calendar year, regardless of severity of ASD or residential service providers serving the population. To provide a comprehensive assessment of services provided, this analysis included services formally defined as residential as well as services and therapies not explicitly defined as residential but often provided as a home-based service or provided to directly improve an individual's ability to function in their home.

Table 5: Waiver Recipients with ASD Receiving Residential Services in CY2010, by Age

Age Group	Number Receiving Residential Services	Percent of all Waiver Recipients with ASD
0-5	1	0.1%
6-17	140	7.5%
18-20	191	10.2%
21-64	1,445	77.0%
65+	100	5.3%
Total	1,877	

Note: Waiver recipients with residential services defined as Elderly Waiver, Community Alternative Care, Community Alternatives for Disabled Individuals, Developmental Disabilities, and Brain Injury participants coded as living in a congregate setting and with at least one claim for customized living, residential care, supported living services, or foster care.

Tables 5 and 6 present information on individuals with ASD who received residential services provided by a waiver residential provider or intermediate care facility for people with developmental disabilities. A total of 1,877 individuals with ASD received waiver residential service and 290 received intermediate care facilities for people with developmental disabilities services. Similar usage patterns exist across age groups: nearly 75% percent of all Waiver residential service and users of intermediate care facilities for people with developmental disabilities obtain the service between ages 21-64 and approximately 20% receive services between the ages of 0-20. Note that these groups are not mutually exclusive: over the course of a year an individual could have a waiver residential services claim and a claim for an intermediate care facility for people with developmental disabilities

Table 6: Individuals with Autism Spectrum Disorder Using Intermediate Care Facilities for people with Developmental Disabilities (ICF-DD) in CY2010, by Age

Age Group	Number with ICF/DD Claims	Percent of all ICF/DD recipients with ASD
0-5	1	0.3%
6-17	28	9.7%
18-20	31	10.7%
21-64	221	76.2%
65+	9	3.1%
Total	290	

Truven also conducted an analysis of residential providers serving people with ASD. Results showing waiver and intermediate care facilities for people with developmental disabilities that serve the largest population of people with ASD (as identified on screening documents) can be seen on Tables 7 and 8. It was found that there were many more waiver providers serving people with ASD than intermediate care facilities for people with developmental disabilities. In total, 559 waiver providers served people with ASD compared to 120 intermediate care facilities for people with developmental disabilities. Five providers were found to serve people with ASD in both waiver and intermediate care facilities for people with developmental disabilities:

1. Hiawatha Manor Inc.
2. Laura Baker Services Assoc.
3. Riverview Services Inc.
4. Mount Olivet Rolling Acres
5. Renville County Community Residential

Table 7: Residential Providers Serving the Greatest Number of People with ASD

Name	Individuals with ASD served
REM Hennepin Inc.	30
Zumbro House Inc.	31
Habilitative Services Inc.	36
Community Living Options Inc.	41
Partnerships for MN Futures	42
Divine House Inc.	44
Dungarvin MN LLC	47

Waiver providers also served more people with ASD on average (3.5 people) than intermediate care facilities for people with developmental disabilities providers (2.5 people). Table 7 lists seven waiver providers which serve 30 or more people with ASD. Table 8 lists the intermediate care facilities for people with developmental disabilities serving five or more people with ASD.

Table 8: ICF-DD Serving Five or More People with ASD

Name	Individuals with ASD served
Harry Meyering Ctr. Inc.	5
Riverview Services Inc.	5
REM SW Srvs. Marshall B	5
People II	7
Northeast Residence II	8
Hiawatha Manor Inc.	8

Name	**Individuals with ASD served**
Lake Owasso Residence	8
Laura Baker Services Assoc.	12
Shingle Creek Option	15
Vasa Children's Home	15
Mount Olivet Rolling Acres	30

These data regarding Minnesota provider capacity to serve people with ASD should be used with extreme caution as the provider codes used were not synthesized based on overall provider and very likely indicate numbers served by one site or a few sites only (many organizations in Minnesota have divisions or sub-corporations). Additionally, the screening document used may not adequately identify ASD diagnoses. There are known providers of services to people with autism (including some in which we conducted site visits) that did not show up in this analysis. Further analyses are needed to be able to accurately report which Minnesota providers serve significant numbers of people with ASD as well as the severity of the symptoms these individuals have. What this data does show is that there are many Minnesota providers who serve individuals with autism; it provides insight into the capacity of Minnesota to use existing providers to serve this targeted group of individuals.

Personal Care Assistance services are intended to support people in their homes and communities. As shown on Table 9, a total of 4,508 people with ASD had personal care assistance claims in 2010. The vast majority of personal care assistance service users (82%) were under 18. As a percentage of recipients of long-term services and supports with ASD in the age groupings, the majority of individual's ages of 0-5 and 6-17 use personal care assistance services, whereas approximately 20-33% of adults with ASD use personal care assistance services.

Table 9: PCA Use in CY2010 by LTSS Recipients with ASD

Age Group	**Number with PCA Claim**	**% of LTSS Recipients with PCA Claim**	**Total ASD Receiving LTSS**
0-5	591	73.1%	808
6-17	3,094	59.9%	5,163
18-20	277	32.9%	841
21-64	472	16.3%	2,898
65+	74	23.9%	310
Total	4,508	45.0%	10,020

Table 10 presents the usage of physical, occupational, and speech therapies by individuals with ASD in 2010. Usage differences did not exist across Fee-For-Service and managed care services status. The table shows low usage of these three therapies overall and across each age group, ranging from 2.1-3.9% of all people with ASD. The average number of units of therapy used across ages was 23.3 for physical therapy, 67.6 for occupational therapy and 24.8 for speech therapy.

Table 10: Therapy Use by Individuals with ASD in CY2010

Age Group	# with PT claims	%with PT claims	Average units of PT	# with OT claims	% with OT claims	Average units of OT	# with ST claims	% with ST claims	Average units of ST
0-5	29	1.4%	30.2	175	8.5%	71.6	239	11.6%	24.1
6-17	100	1.2%	26.2	386	4.8%	73.4	354	4.4%	25.8
18-20	16	0.0%	5.2	9	0.0%	30.9	3	0.0%	13.0
21-64	203	3.7%	20.9	97	1.8%	42.8	21	0.4%	19.4
65+	17	3.0%	39.9	3	0.5%	8.7	0		N/A
Total	365	2.1%	23.3	670	3.9%	67.6	617	3.6%	24.8

Notes: Fee-for-Service and Managed Care combined; Percentages based on 17,374 individuals identified with ASD in 2010; PT = physical therapy, OT = occupational therapy, ST = speech therapy.

More in-depth analysis was conducted to assess the residential service use of people with severe autism. Specifically, the research team sought to determine where people with severe autism receive residential services. The severity of autism is not explicitly identified in DHS assessment and screening processes. As a result, to isolate this subpopulation for analysis, the research team was required to operationalize the term "severe autism." The attributes of those identified as having severe autism included having a developmental disability, communication limitations, behavioral challenges, and an inability to toilet oneself. Due to the use of different screening documents that approached these categories differently, it was necessary to key proxies to approximate the barriers. Therefore, an individual was deemed to have severe autism if they had a developmental disability diagnosis and each of the three impairments or challenges, as defined by the screening document (see Table 11).

Table 11: Definitions of Severe ASD Domains by Screening Document

Domain	Long-Term Care Screening	Development Disabilities Screening
Severe communication deficit	Any noted communication impairment	Appreciable limitation in receptive or expressive communication
Challenging behavior	History of behavioral symptoms or a need for 24-hour supervision due to cognition, orientation, or behavioral issues	Moderate to very severe rating in any one of the 10 behavioral scales
Toileting/self-care	Any need for assistance in toileting	Requiring self-care support (inability to toilet was not an available flag)

Table 12 presents residential service usage for people with severe autism receiving DHS services in 2010. In total, 538 people received residential services. The vast majority (*n* = 426 or 79% of the total) were ages 21-64. Approximately 12% (*n* = 64) of residential service recipients were under 18. Of all identified waiver residential recipients with ASD, 22.7% were identified as having severe autism, whereas 37.6% of all people with ASD receiving intermediate care facility for people with developmental disabilities services were identified as having severe autism.

Table 12: Waiver and ICF-DD Individuals with "Severe ASD" Receiving Residential Services in CY2010, by Age

Age Group	# with Severe ASD Waiver	% of ASD Waiver with Severe ASD	# with Severe ASD – ICF-DD	% of ASD ICF-DD with Severe ASD
0-5	1	100%	0	0
6-17	51	36.4%	12	42.9%
18-20	31	16.2%	6	19.4%
21-64	337	23.3%	89	40.3%
65+	7	7%	2	22.2%
All ages	427	22.7%	109	37.6%

Note: Percentages based on a total of 1,877 individuals with ASD receiving waiver residential and 290 receiving ICF-DD services.

Child Welfare Data – Private Out-of-Home Placement

A recent survey of child welfare recipients in Minnesota was conducted by the Center for Advanced Studies in Child Welfare at the University of Minnesota and the Council of Child Caring Agencies to better understand the experiences of children in private out-of-home placements in Minnesota. It captured data on a total of 938 children in the child welfare system (the full report, "Minnesota Adoption Disruptions Autism Report," is available in Appendix H). Of this group, 76 (8%) were diagnosed with ASD. A total of 78.9% of the children with ASD in child welfare were white, 13.2% identified as two or more races excluding Native American, and 2.6% were Black or African American and two or more races including Native American. Sixty-seven percent of children with ASD were ages 13-18; 22% were ages 0-12.

Of the children with ASD in private child welfare placements, over 50% were diagnosed with disruptive behavior disorder, 43% were diagnosed with a mood disorder, and 33% were diagnosed with anxiety disorder. Child welfare recipients have a number of additional disability diagnoses; however, the prevalence of these diagnoses is considerably lower (see Appendix H). These disabilities are not mutually exclusive.

Table 13 presents information about where children with ASD are placed in the private child welfare system. About 90% of children with ASD in child welfare were placed in residential treatment or treatment foster care. Nearly two-thirds of children with ASD were placed by court order or voluntarily by counties due to mental health concerns. Finally, 75% of all children with ASD placed in private child welfare were placed by county agencies.

Table 13: Child Welfare Placement of Children with ASD (N = 76)

Current Placement Type	#	%
Residential treatment	38	50.0
Group home	7	9.2
Treatment foster care	31	40.8
Legal Authority for Placement		
Court order	28	36.8
Juvenile justice	10	13.2
Voluntary by county – mental health	24	31.6
Voluntary by parent – mental health	14	18.4
Mental health – other	0	0.0
Missing	0	0.0
Placing Entity		
County agency (7-county metro)	38	50.0
County agency (out-state)	19	25.0
Tribal agency	0	0.0
Other state agency	12	15.8
Parent private placement	7	9.2
Missing	0	0.0

Minnesota Department of Education Data

Many Minnesota children with ASD receive residential education services out-of-state. Minnesota Statute (Out-of-State Tuition; Minnesota Statute 125A.79, Subd.8) indicates that if the student is placed by the courts or human services there are funds to assist the districts with the costs of education. If the district places the child in an out-of-state residential program, then the district is responsible for the total cost of the education. Room and board are eligible for a transportation reimbursement and healthcare and treatment services are eligible for state aid as a contracted student placement.

Table 14 shows out-of-state educational placements as identified by the Minnesota Department of Education during fiscal years 2011 and 2012. A total of 38 students with ASD were placed in out-of-state placement in fiscal years 2011 and 2012. Approximately two-thirds of students in 2012 were between 1st and 9th grade, whereas 28% were that age in 2011. The average percent of school year that a student was placed out-of-state school is also shown in Table 14. In addition, across all out-of-state placements of students with ASD in 2012, 50% or less of their annual education was provided in a state other than Minnesota. Information about children with other disabilities placed outside of Minnesota was not provided, so it is not possible at this time to determine what percentage of all children from Minnesota placed in out-of-state educational programs are children with a diagnosis of ASD.

Table 14: Education Out-of-State Placement and Schooling of Students with ASD by Grade, FY 2011 and 2012

Grade	# FY 12	% of total FY 12	Average % of school year FY 12	# FY 11	% of total FY 11	Average % of school year FY 11
1 to 6	15	39%	31%	9	28%	34%
7 to 9	10	27%	51%	13	0%	29%
10 to 12	11	31%	41%	0	41%	48%
Early childhood	2	6%	50%	1	3%	100%
Total	38			38		

IV. Case Study Summaries

A key component of this research included on-site case studies of various models of residential services serving people with severe autism both within Minnesota and out-of-state. Case studies began in August, 2012 and continued through the end of the year. These included programs of various designs such as campus, farm, group home and supported living models. The sites chosen were drawn from a number of suggestions from key stakeholders and conversations with other providers. The primary selection criteria for inclusion were that they served children or youth with severe autism and that autism was the primary diagnosis for a majority of the residents receiving services. Eight site visits were made, four in Minnesota and four out of state. The sites visited included:

Alternatives for People with Autism
Brooklyn Park, MN
http://afpwa.org/

Camphill Special School and the Transition Program at Beaver Farm
Glenmoore, Pennsylvania
http://www.camphillspecialschool.org/index.php

Chileda
La Crosse, Wisconsin
http://chileda.org/

Fraser
Twin Cities Metro Area, MN
http://www.fraser.org/

The Homestead
Altoona, IA
http://www.thehomestead.org/

The New England Center for Children
Southborough, Massachusetts
http://www.necc.org/

Private Residence
Twin Cities Metro Area, MN

REM Heartland Minnesota
Southern, MN
http://www.remminnesota.com/welcome.aspx

Two or three researchers were present for each site visit. Visits lasted 90 minutes to 5 hours (depending on size) and researchers generally talked to administrative staff, toured grounds and buildings, engaged with direct service staff who were around, and observed, when possible, programming activities.

The research team developed a draft site visit protocol to be used to interview key staff at each site (see Appendix C for the protocol). The Minnesota Department of Human Services and the ASD Advisory Council reviewed the draft protocol on two occasions and it was piloted in two site visits. Following the pilot phase, refinements were made to the final protocol that included shortening the length and focusing the items. Observational and interview data were collected during each of the site visits. Verbal responses were captured on the protocols by the research team. In addition to using site visit protocols, researchers wrote field notes to reflect their observations and experiences. Four members of the research team reviewed and coded the data to identify themes and key points of information which are reported in the summary below. After the site visits were completed, additional follow up questions were asked of providers by phone or email to verify or clarify specific information.

Alternatives for People with Autism

Brooklyn Park, MN
http://afpwa.org/

Overall Structure and Funding of the Organization

The mission of Alternatives for People with Autism is to create community living options for people with autism and to demonstrate the feasibility of these options so that people with autism may realize dignity, opportunity and growth. Alternatives for People with Autism is a non-profit, community-based residential program providing progressive services to adults with autism and moderate to profound intellectual disability. It was started 30 years ago by a small group of parents who had children with severe autism and were raising them at home because the only other option was institutionalization.

Alternatives for People with Autism's main residence is an intermediate care facility for people with developmental disabilities and is licensed for 15 adults ages 18-60 with severe ASD and intellectual disabilities. The individuals who receive services live in 3 suites, each with 5 bedrooms, a living room, dining room, kitchen with access to a large deck, and fenced backyard. The suites are designed for individuals who receive services to age in place. Each resident has their own bedroom. Three of the individuals who receive services are females and 12 are males. The individuals who receive services have an average per diem of $330/day. Currently, 1 of Alternatives for People with Autism's residents is a person of color.

Alternatives for People with Autism also have a waiver site licensed to serve three people with an average per diem of $345/day. Both the intermediate care facility for people with developmental disabilities and the waiver site are licensed by DHS. Other funding comes from residents' wages and Social Security benefits. Alternatives for People with Autism does not engage in formal fundraising; however, they do receive cash donations and in-kind contributions. In the past they have received some grant funding. The primary source of general operating funds is federal Medicaid and state Medical Assistance programs.

Administration and Staffing

Alternatives for People with Autism has 66 personnel, full- and part-time; this includes a director, three licensed staff (registered nurse, social worker, and psychologist), three consultants (registered dietician, pharmacist, and occupational therapist), and 60 non-licensed staff, most of whom are living skills instructors (i.e., direct support workers). Alternatives for People with Autism does not employ certified behavior analysts or assistant analysts; they use consultants for Applied Behavior Analysis from the University of Minnesota.

Alternatives for People with Autism's primary targets for staff recruitment are college students who completed 44 undergraduate credits. Current recruitment venues include the University of Minnesota and other local colleges. They seek students who are majoring in psychology, special education, occupational therapy, and related academic disciplines. For full-time staff (program manager, program coordinator, and shift leader), Alternatives for People with Autism requires a 4-year degree in a related field. Currently, many of Alternatives for People with Autism's full time staff are Qualified Intellectual Disability Professionals (formerly known as Qualified Mental Retardation Professionals).

Alternatives for People with Autism does not track annual staff turnover; however, the board reviews staffing needs at its monthly meetings. Turnover of part-time staff is more common than among full-time staff. The employment of college students is intentionally built into the staffing model at Alternatives for People with Autism to allow for an ongoing supply of engaged and energized employees and to reduce incidents and caregiver fatigue/burnout. Part-time staff view their work as a first step in their career. Alternatives for People with Autism's investment in intensive staff training is considered a "benefit" for new staff.

Program Managers earn $37,000 to start; Program Coordinators earn $32,000 to start; non-licensed staff earn $13.56/hour if they do not have a college degree and $13.86/hour if they do. Alternatives for People with Autism did not provide salary data for their registered nurse, social worker and psychologist. Full-time staff receive health care, dental, vacation time and sick leave. Alternatives for People with Autism does not have a pension or retirement plan. Part-time employees do not receive benefits.

At Alternatives for People with Autism, the first 90 days of employment is considered orientation and is an intensive training period. Staff receive a minimum of 10 days of intensive training including completing an Introduction to Behavioral Psychology course. Each employee receives specific training on each resident—an intensive 5-day, everything you need to know about each resident training. Staff are assigned/scheduled to only work with one group of 5 individuals who receive services. Alternatives for People with Autism is always recruiting and often has at least 5 strong applicants for every open position.

Alternatives for People with Autism's board of directors has 6 members who generally serve long terms; many are parents of adults with severe autism. Board members provide consultation to the organization (for example, one former board member was an architect who designed the original building). Other board members provide expertise in finance and employment/human resources. The board receives and reviews a print-out on every resident at the annual meeting. It focuses on the individuals who receive services' needs and how to meet them.

Residential Supports and Services across the Lifespan

Alternatives for People with Autism is located in a suburban neighborhood surrounded by single-family homes, townhomes and apartments. It is near walking trails and within walking distance to a grocery store and other retail. There are two buildings on the property. One building contains the 15-bed intermediate care facility for people with developmental disabilities in the upper level. The lower level of the building contains a large room used for gross motor activities and group celebrations/activities, a sensory room, a wood shop, and administrative offices. The second building is a single family home licensed as a home and community-based services waiver program for 3 individuals. This home has 3 bedrooms and has been used to provide respite and personal care assistance for individuals before they turn 18. A security system monitors residents who receive services in both buildings via cameras and door alarms to alert staff when someone has left and for protection of the vulnerable adults living at the Alternatives for People with Autism's homes.

Alternatives for People with Autism's residential services are focused on skill development (rather than caretaking). The role of the staff is to teach and assist residents to develop skills to be as independent as possible. The program is modeled on the concept of lifelong learning. Programs and services are individualized, including time in the community with either 1:1 or 2:1 staff-to-resident ratio. Alternatives for People with Autism has two vans for use to access community activities and events.

Alternatives for People with Autism defines "supports across the lifespan" to mean "aging in place." The suites are designed for individuals who receive services to age in place and have been recently remodeled to include ramps, an elevator, accessible bathrooms and a security system. The average length of stay for a resident is 20 years.

Alternatives for People with Autism do not currently provide services to individuals under 18 but has in the past. They are currently working with one individual who is transition-age and is attending a school-based transition program.

When an opening in a residence occurs, a posting is put on the Metro Crisis Coordination Program website and they then get referrals from case managers. Initially referrals are screened for age and diagnosis. Potential candidates for openings are brought to Alternatives for People with Autism's admissions committee to determine who is the best fit and who they are most interested in pursuing for the opening. Alternatives for People with Autism expects to serve people who have some of the most challenging behaviors in the state and they screen out those who do not need the level of staff support Alternatives for People with Autism provides. After getting information from social workers, the director sets up at least two site visits to meet the individual and their family and to observe interactions with staff and the current individuals who receive services.

Educational, Transition, and Employment Supports and Services

As a residential provider, Alternatives for People with Autism is mandated to coordinate programming with the day treatment and habilitation programs where individuals who receive services go during the day. When needed, Alternatives for People with Autism will send staff to the day treatment and habilitation programs to do training on a behavior program for an individual. Each resident is required by law to have an interdisciplinary team and Alternatives for People with Autism collaborates with the day treatment and habilitation providers to form that team. Alternatives for People with Autism doesn't track the employment or daytime outcomes of individuals who receive services who attend day treatment and habilitation programs; however, they do track communication, primarily related to behavior interventions, with day program staff via their record keeping software called Computer-Aided Person to Person Services.

Currently, one resident is in a community public school transition program and Alternatives for People with Autism works with the school to coordinate educational programming. That individual is expected to continue to receive residential supports and services from Alternatives for People with Autism after the school transition program is completed.

Clinical Interventions and Approaches

The major focus of interventions at Alternatives for People with Autism is developing skills. They believe everyone can learn. They also focus on helping individuals develop more skillful communication and better choice-making with the aim of supporting as independent of a life as the individual desires or is capable of. Each resident has annual goals for community integration, independent living and food preparation. Choice is integrated into each individual's program and families are encouraged to participate in setting annual goals.

To measure progress, Alternatives for People with Autism developed a software program called Computer-Aided Person to Person Services that provides a systematic, consistent way to track training outcomes of residents. Each residential suite has a computer kiosk that staff access to record and track data. Each resident has a customized Computer-Aided Person to Person Services profile designed specifically for them. Staff follow certain steps to be sure training to support residents (such as doing laundry, cleaning one's room, money management, and taking medication) are completed the same way every time for consistency. Staff can print out and refer to a list of steps to be sure each is followed as well as bring data to outside meetings such as medical appointments. An individual's Computer-Aided Person to Person Services data is reviewed weekly, quarterly, and annually. The goal is to make decisions based on current data, not historic data and not anecdotal information.

By implementing the Computer-Aided Person to Person Services system, Alternatives for People with Autism has seen a decrease in time spent taking and recording data to only about 6 minutes per hour. According to Alternatives for People with Autism leadership, this increases the amount of time available for direct support and interaction with the individuals who receive services. Alternatives for People with Autism are currently working on making Computer-Aided Person to Person Services accessible on tablets and smart phones. Some individuals who receive services enter their own data into the Computer-Aided Person to Person Services kiosk.

Alternatives for People with Autism has a Registered Nurse on staff and all employees are trained in medication administration. Alternatives for People with Autism approaches outside medical providers positively and tries to find and use providers who are willing to work with individuals who have challenging behaviors. Alternatives for People with Autism shares behavior tracking data with the doctors to provide support for treatment and/or medications.

Alternatives for People with Autism reported that being proactive and staying current on each person's needs is one of their greatest challenges, as is maintaining priorities due to changing behavior and staffing needs. Another challenge or barrier is working the reimbursement systems within the state when it comes to employment or medical emergencies. For example, staff goes with residents to support them if they have to go to the hospital even though funding for residential services is cut off when an individual is admitted. Other challenges mentioned by Alternatives for People with Autism leadership include access to services for individuals who are on the waiting list, decrease in dental services coverage for residents, annual costs increasing but not getting cost of living increases, and reduction in resources that may lead to reduction of staff.

Support to and Inclusion of Families

Alternatives for People with Autism encourages family involvement. Family members with guardianship status are given an access code to the residence and can visit at any time. Alternatives for People with Autism also provides staffing and support for individuals who receive services when they go to their family's home. Some families actively participate in treatment plan development, others do not. Alternatives for People with Autism maintains regular communication with families by phone, email, or through written reports related to Computer-Aided Person to Person Services data. Families can call any time to find out how their family member is doing (one parent calls every day).

Alternatives for People with Autism asks families about their traditions so they can learn and try to incorporate them into the individual's plan. As individuals who receive services and their parents age, Alternatives for People with Autism tries to be flexible and accommodating by providing staff support for outings and other family gatherings. Aging parents and the availability of funding to support regular contact/visits with family are considered a challenge because funding decreases also affect Alternatives for People with Autism's ability to provide support to families.

Some families want to participate in behavior interventions in their home during visits, and some do not want interventions at home. Alternatives for People with Autism will provide training to families who request it.

Alternatives for People with Autism hosts events for families to meet each other and visit. Alternatives for People with Autism supports each individual's spiritual needs and finds alternatives if the person served is not able to be at church during regular hours. For example, Alternatives for People with Autism hosted a bar mitzvah for one resident and supports another resident in annual Christmas Eve candle lighting. They also support individuals who receive services in attending choir rehearsals as well as inviting pastors from local churches to visit people at Alternatives for People with Autism.

Research Team Observations

The Alternatives for People with Autism living suites were clean, small and homey. They had somewhat of a dorm feel. The common rooms each had a living room, kitchen and eating area with tables. The bedrooms were painted different colors and seemed tailored to individuals. The newly remodeled bathrooms looked nice and were designed with accommodations for individuals with physical limitations. There is a large fenced yard that offers privacy and security while allowing access to the outdoors.

Only one resident was home and observed receiving services. The physical environment was accessible. Each suite had a lot of windows and natural light. There is an elevator to access suites upstairs from the ground floor. Door alarms and security cameras are installed. There was not a lot of clutter in each of the three living areas. There is no noticeable "staff desk" other than the computer kiosk which was not conspicuous in the suite. APA has a sensory room as well as a larger activity room with a swing, bikes and some large cushions. The residents also have access to the rest of the building including the staff break room and workshop on the lower level.

Notable features of the program:

- Alternatives for People with Autism actively supports the learning and skill development of all individuals who receive services. They utilize a software program called Computer Assisted Person-to-Person Service to track training outcomes for each individual to maximize their growth and learning. The people who receive services through Alternatives for People with Autism grow and learn new skills.
- Alternatives for People with Autism successfully recruits part-time staff from local colleges and usually hires individuals who are majoring in human service fields. They are able to manage their staffing needs and purposefully hire people with a high level of skill.
- Alternatives for People with Autism provides intensive initial and ongoing training for all staff including training in positive behavior supports.
- Alternatives for People with Autism is located in a suburban residential neighborhood with a large yard. It is convenient to walking trails, dining, a grocery store and other retail.
- Alternatives for People with Autism encourages strong family involvement. Families are encouraged to visit anytime and are invited to residential events throughout the year.
- Alternatives for People with Autism pays attention to the aging of the individuals who receive services and their aging parents and promote an “aging in place” model of residential services.
- Alternatives for People with Autism is governed by a small and long-term Board of Directors that includes several parents of children with severe autism.

Other notes:

- Alternatives for People with Autism has no plans for expansion beyond current licensed capacity.

Camphill Special School and the Transition Program at Beaver Farm

Glenmoore and Phoenixville, Pennsylvania
http://www.camphillspecialschool.org/index.php

Overall Structure and Funding of the Organization

Begun in 1963, Camphill Special School's mission is to create wholeness for children and youth with intellectual and developmental disabilities through education and therapy in extended family living so that they may be better understood and their disabilities moderated, that they may more fully unfold their potential, and that they may more fully and meaningfully participate in life. Camphill Special School provides services to children with many types of intellectual and developmental disabilities and a significant number of Camphill Special School's students have classic autism.

Camphill Special School is a Waldorf school and a Pennsylvania Approved Private School for children with intellectual and developmental disabilities. They are part of the worldwide Camphill movement and the only Camphill residential community in North America for children. They offer residential and day academic and prevocational programs as well as therapeutic care for children in grades K-12 well as the Transition Program at Beaver Farm for young people ages 18-21. The international Camphill movement is based on the principles of Anthroposophy, the philosophy of Rudolf Steiner that seeks to integrate spirit, body and soul. Steiner formulated the concept of curative education, which includes the arts as healing and educational forces, and his influence is felt in Camphill Special School's adapted Waldorf curriculum.

Camphill Special School has two program sites. The larger site, for the younger students, is set in a rural area west of Philadelphia and is made up of 10 homes, a school building, and several other buildings (administration, maintenance, shop/crafts, convocation, etc.) that serve approximately 55 residential students and an additional 33 day students ages 5-19. The smaller site, about 10 miles away, is for the older students—the Transition Program at Beaver Farm; it has 3 homes and several farm buildings and serves 20 students aged 18-21. Camphill Special School and the Transition Program at Beaver Farm do not serve any children from Minnesota although several parents from Minnesota have visited the program. Both of these locations have a village feel to them with several purposefully designed buildings. Approximately 13% of Camphill Special School's residents are individuals of color and 38% are female.

Camphill Special School is funded primarily by referring school districts. Tuition is $36,500 for a 10-month school year; students go home for winter break and summers. Residential students pay an additional $32,500. Occupational therapy, physical therapy and speech therapy are $88/hour. Students who need a 1:1 aide are charged an additional $197/day. Some financial aid is available for families who are not supported by their home district. Many school districts have been reluctant to agree to fund the residential component of the program due to the additional costs and filling residential spots has been difficult in recent years.

Administration and Staffing

Camphill Special School has an atypical but effective staffing model. First, they have no executive director; management is done through a council comprised of responsible resident coworkers (approximately 30) that have worked at Camphill Special School for 3 years or more, led by an executive committee of 7-8 senior resident coworkers with a minimum of 7 years of Camphill experience. Second, most of the staff in the residences are “volunteers” who are referred to as co-workers (many from Europe); they live and work in the homes for no hourly pay. These volunteers do receive benefits, however, such as room and board, healthcare and tuition vouchers for school for their children. These individuals also include interns of many kinds: students on a gap year, AmeriCorps participants and others who want the experience of the Camphill Model. There are 80 or so of these volunteers at the 2 campuses. Camphill Special School also has 50 paid staff: therapists, teachers, aides, maintenance and administrators.

Both paid staff and volunteers are recruited online and through print media both in the U.S. and Europe. Camphill Special School has a partnership with a Prescott College in Arizona that can lead to a bachelors of arts degree in “Curative Education” that is free to the Camphill Special School volunteer if he or she commits to 6 years of work at Camphill Special School. Staff who wish to pursue special education teacher certification can do so at a local university.

Students in the Curative Education Program serve as residential volunteer coworkers and receive benefits that include room and board, a monthly stipend, health insurance and participation in the Camphill School of Curative Education and Social Therapy. The curriculum includes academic and artistic coursework; supervised practice in childcare, education and therapy; and the experience of community life.

These students can get a Paraprofessional Certificate, an intermediate credential awarded to those who complete the first two years of the program and an additional one-year internship in an assistant capacity. Other students, over four years, receive a Diploma in Curative Education, which is recognized by the International Curative Education and Social Therapy Council. Its holders are entitled to use the professional designation ‘Certified Curative Educator’.’ Students also can receive undergraduate credit through Excelsior College and complete a bachelor’s degree with Prescott College (Arizona) during a fifth year of work and study.

Residential Supports and Services across the Lifespan

Camphill Special School and the Transition Program at Beaver Farm incorporate “family living” as a major component of their model. Every house at Camphill Special School and the Transition Program at Beaver Farm is different and neither setting feels institutional from the outside or the inside. Most of the homes are quite large and accommodate 10 or more people (family volunteers and the students who live in them). The furnishings are functional and each house we visited was warm and inviting.

Residential students build upon their classroom learning with the support of a house team trained to address their specific individual needs. A close relationship among education staff, house parents, volunteers, interns and each student’s parents is expected at Camphill Special School. Everyone communicates and collaborates for the physical and emotional wellbeing, communication needs and growth of the child. The house parents, often a couple who are long-term, experienced members of the Camphill Movement, oversee all aspects of life in the houses and supervise resident volunteers and interns, who have direct responsibility for care of the students in the homes. The volunteers and interns come from all over the world to work with the students and often are enrolled in the Camphill School of Curative Education and Social Therapy. Each house contains two or three groups of children who share rooms. The volunteers in the homes often also work some in the school and the children eat meals in their assigned homes. The relationship between the house family, educational staff, other volunteers and the children is a key to the success of the Camphill Special School and the Transition Program at Beaver Farm.

Children who are non-ambulatory and children with other severe physical disabilities are considered on an individual basis to determine if Camphill Special School is most appropriate to meet their needs. All children must be deemed potentially capable of integration into Camphill Special School's village setting. It is located in a rural setting and the outdoors is a significant component of the instructional milieu. Children with significant mobility support needs would likely have a difficult time accessing this environment. Parents or guardians must be willing to make the required personal involvement with the school's staff and programs as well as with their own child. This includes families who live farther away.

Children go home on holidays and in the summer. The length of time a child remains at Camphill Special School varies. Some children have been there for 14 years; others stay only a year or two. Ultimately, once a child has passed school and transition age, they have to move on to a different program. Some move to adult-focused Camphill programs in the area.

Educational, Transition, and Employment Supports and Services

Because the students who attend Camphill Special School have a very wide range of intellectual functioning, staff members tend to be flexible in their approach to academics. The Waldorf philosophy stresses hands-on learning; for most of the students, this seems to be appropriate. Camphill Special School uses other Waldorf approaches such as "looping": teachers continuing with a class from one year to the next throughout the elementary and middle school grades. Other teachers may be responsible for special subjects, but close relationships develop between classroom teachers/assistants and students, providing a kind of consistency and stability rare in other settings. Camphill Special School also emphasizes dramatic, visual, musical and movement arts. Practical skills such as woodworking, weaving, sewing and gardening are integrated with traditional academic subjects. Camphill Special School assigns students to classes according to chronological age and they participate in age-appropriate educational programming as well as with small group and individualized instruction that addresses each child's needs and abilities. Utilizing the adapted Waldorf curriculum, Camphill Special School strives for a comprehensive understanding of each child as capable of learning, accomplishment, social interaction and social relationships.

Students in the elementary and middle grades participate in trips to museums, concerts and plays. Birthdays and special occasions are celebrated in houses and classrooms. Depending on individual interests and availability, some students become members of local Special Olympic teams, such as basketball, swimming or softball.

High school students are grouped according to their chronological ages, enabling both age-appropriate educational experiences and age-appropriate social interaction. Students in grades 9-12, ages 14-18, participate daily in a prevocational program designed to develop skills and attitudes that enhance their social development and allow them to participate in meaningful cooperative work. Working individually or in small groups, students rotate through various prevocational crews including the school store, household activities, gardening, landscaping, weaving, sewing, woodworking, maintenance, life skills and stable and animal care.

Each year students in the high school elect student council officers and representatives from each grade. The student council meets with its faculty advisor to discuss student issues and concerns and to suggest and plan activities. Student council-sponsored activities have included a dance benefiting Hurricane Katrina victims and the Camphill Special School Prom.

Camphill Special School understands that adolescents with developmental disabilities encounter the same challenges that typical teenagers face surrounding issues of privacy, personal space, sexuality, relationships, and sometimes, abuse; they support students in these areas of concern so that they can feel comfortable with themselves. They have designed a comprehensive educational program about these issues, not only for students but also for parents and school staff.

The Transition Program at Beaver Farm guides students, through community work and living, from school into adult life. The Camphill Special School vision is to provide a safe place and an encouraging environment for students to explore this transition. The Transition Program at Beaver Farm offers prevocational experiences, opportunities to learn life skills, academic support and therapies.

In the Transition Program at Beaver Farm, as a group, students, staff, volunteers and interns operate a biodynamic farm, a method of organic farming. Biodynamics is a holistic system that works to bring about healing and balance to soil, with the goal of producing healthier plants and animals. No artificial or chemical pesticides or herbicides are used. Currently, the Transition Program at Beaver Farm produces all the beef, pork, chicken and eggs that are used by Camphill Special School. Camphill Special School is not a self-sustaining environment; nearly all of its food (besides that produced at the Transition Program at Beaver Farm) is purchased at local stores.

The school programs are compliant with special education laws and each student has an individual education plan that is monitored by special education teachers and the local school district.

Clinical Interventions and Approaches

Camphill Special School does not rely heavily on formal clinical interventions such as applied behavioral analysis, though the staff appears knowledgeable about these approaches. Its Waldorf focus and its sensory therapies are its primary interventions. Individuals who receive residential services and students have regular access to physical therapy (including massage therapies), occupational therapy, speech, recreation (including horseback riding), and artistic and Anthroposophical therapies (including Therapeutic Eurythmy—expressive movement and music therapy). Therapies are provided in a variety of settings on campus including in the residential homes.

The daily and annual rhythms of life are important aspects of community at Camphill Special School. The staff feels that the predictability of waking up, attending school, performing household chores, working on a prevocational crew, having a music lesson, meeting a friend for free play time and going to sleep, all with established routines and expectations, provide children with a secure sense of the world around them. The philosophy at Camphill Special School holds that consistency is not only an aid in discipline, but also encourages creativity.

The outdoor space seems to be used as a means for addressing challenging behavior. Children and staff take walks and use the outdoors as a place to focus energy and to explore. Additionally, healthy eating and nutrition are key components of life at Camphill Special Schools. The food is prepared in the homes and is made of natural and healthy ingredients (for example, at the Transition Program at Beaver Farm, millet burgers and squash soup were being prepared for lunch.)

Support to and Inclusion of Families

Camphill Special School and the Transition Program at Beaver Farm support the inclusion of families into their programs and do require a certain amount of involvement, particularly when it comes to transitions (summer, winter break, and when moving from one site to another). Students at both sites seemed to come from a variety of racial and cultural backgrounds and the staff/volunteers are comfortable supporting cultural diversity. Camphill Special School also has a diversity fund designed to provide tuition support for minority students whose families lack sufficient personal and/or government resources to attend the school. If families visit, they can spend the day with their children at school and in their home; most families stay in a hotel in a nearby town.

Research Team Observations

Camphill Special School and the Transition Program at Beaver Farm have been around for over 58 years and are built on the Camphill model that embraces lifelong learning and the Waldorf educational philosophy. Its residences are in rolling hills and rural areas and consist of large homes that have a “big-family” feel to them. At least nine people live in each residence and meals are a big part of the day for all. Since many of the volunteer (and some paid) staff are from Europe, there is an international feel to all components of the organization. The essence of the model is the belief in the human capacity and spirit and the desire live as a village with each member providing his/her own unique contributions.

Notable features of the program:

- The fact that the school closes in the summer and for the winter holidays requires that families remain an integral part of the child’s life. Camphill Special School and the Transition Program at Beaver Farm encourage this in many ways.
- One of the primary components and success of the Camphill Special School and the Transition Program at Beaver Farm is the overwhelming life commitment made by many of the staff and volunteers through the Camphill movement. These are individuals who are committed to learning and to the children that receive services through the Camphill Special School and the Transition Program at Beaver Farm. The love and relationships observed and shared is evident in their purpose and through the work they do.
- Camphill Special School and the Transition Program at Beaver Farm use many creative ways to overcome staffing difficulties. The use of volunteers at this level is an innovative model that benefits from a large infrastructure that Camphill International has developed over several decades. However, this model would be extremely difficult to replicate and very few Camphill programs exist in the U.S.
- Camphill Special School has an interesting governance structure with no executive director but rather an executive council comprised of responsible resident coworkers (approximately 30) that have worked at Camphill Special School for 3 years or more, led by an executive committee of 7-8 senior resident coworkers with a minimum of 7 years of Camphill experience.
- College students have many incentives to work or volunteer at Camphill Special School and the Transition Program at Beaver Farm. No- cost degrees through Prescott College and teacher certification through local colleges are a key method used to recruit long-term employees.
- Students/individuals who receive services spend a lot of time outdoors at Camphill Special School and the Transition Program at Beaver Farm. There are animals at the farm that supply some of the meat, poultry and dairy products used at the Transition Program at Beaver Farm and Camphill Special School. There are horses at each site and Hippotherapy is an integrated part of programming.
- The Waldorf model of education includes a great deal of hands-on and practical activities that supplement other educational and clinical interventions.
- Camphill Special School has a diversity fund to provide tuition support for minority students whose families lack sufficient personal and/or government resources to attend Camphill Special School.
- Therapies (including occupational therapy, physical therapy, speech and recreation) are very commonly incorporated into students’ days. Formal clinical approaches (like applied behavioral analysis) are not used at Camphill Special School or the Transition Program at Beaver Farm.

Other notes:

- Camphill Special School relies exclusively on school districts as the major source of funding. The combined cost of the educational and residential program, although competitive, is contrary to the policy of Least Restrictive Environment enforced by many school districts. The residential service component of the Camphill Special School program is not funded by residential service options in Pennsylvania.

- Camphill Special School does fundraising, hosts an annual benefit, and relies heavily on its affiliation with the international Camphill movement.
- Camphill Special School and the Transition Program at Beaver Farm generally have openings for students/individuals who receive services each fall.

Chileda

La Crosse, Wisconsin

http://chileda.org/

Overall Structure and Funding of the Organization

Chileda's motto is "Unlocking Potential." Its goal is to provide supports and services to individuals who are unable to receive services elsewhere. Chileda says "yes" to families who have been told "no" in other settings.

Chileda began in 1973 as a small residential school serving students with multiple disabilities in Stevens Point, WI. In 1990, it moved to La Crosse and, along the way, began to work more with students with significant behavior issues. Today, all students served by Chileda have significant behavior issues and most have significantly low cognitive functioning. The focus of Chileda's program is to help young people ages 6-21 increase their communication, social, and independent living skills through positive behavior supports. It does this in a campus setting—a school adjacent to four modern-looking duplexes in the city.

Chileda is funded primarily by school districts, county and state agencies, and occasionally, families. The average daily rate is approximately $167,775/year ($460/day). Who pays depends on the state the student comes from—some states require the school district to pay everything; some are less directive and funding may come from more than one source. Chileda is not a licensed Medicaid provider—state dollars for residents come through the child welfare system for residential treatment programming. One-third of Chileda's students come from Wisconsin, others come from several states with the majority from Illinois, Iowa, and Minnesota. A few come from as far away as Texas and California. Approximately 24% of Chileda's residents are individuals of color and 32% are female.

Most are referred by county case managers or school district special education programs. Some are referred by social workers, attorneys or advocates. On rare occasions, families refer and self-pay. Half of Chileda's students have been in foster care; the guardianship status of Chileda students covers the whole spectrum. Chileda enrolls students with histories of significant aggression including self-injury, property destruction, spitting, hair pulling, etc. Chileda generally does not enroll students with a criminal history or extreme sexual behaviors.

Chileda's programs are generally not long-term. Some individuals stay for only a 90-day assessment program. Most others stay for an average of a year, but some stay as long as three years. The expectation is that all students will transition back to their home community and most do this within a year or two.

Administration and Staffing

Chileda employs approximately 230 people: 20 are managers or administrators, 20 are certified teachers or therapists, and 190 are non-licensed direct support workers. About 80 staff are full-time, including nearly all the administration and licensed staff. The rest are part-time (less than 30 hours/week). The school runs year-round. Chileda recruits unlicensed staff primarily through existing employees or through the three local colleges. Licensed staff are recruited somewhat more widely. Most of the management are recruited and promoted from within the agency. Chileda's turnover rate is very low for this kind of work: 20% or less, primarily unlicensed staff, many of whom are students and/or part-time workers. The licensed management staff are stable.

Chileda pays a competitive wage for full-time employees. Non-licensed employees receive $9.50/hour to start. Some long-term unlicensed staff earn up to $20.00/hour but recently implemented policies will narrow this wage range in the future. Some of the licensed staff (therapists) are contracted through Mayo Health System. Chileda provides traditional health/life/vacation benefits to full-time staff. They also match up to 4% of an individual's salary of a 401(K) contribution.

Chileda's biggest staffing challenges involve turnover (since all work with students is relationship-based) and the difficulty of finding full-time staff willing to work second shift in the residential program sites.

Residential Supports and Services across the Lifespan

Chileda's campus consists of a school building and 4 duplex houses on about an acre of land in an urban setting. Each of the 8 units has 5 bedrooms, one of which is a double. Each unit is single-sex and grouped by age (occasionally the age grouping policy is waived if there are personality conflicts in a residence). The 2 sides of each duplex are connected by a staff office with windows that look into the 2 living areas and a time-out room. The houses are grouped around a fenced-in courtyard with basketball hoops, swings, playground equipment and benches. There is also a small hill for sledding in the winter. The housing units have an open kitchen/dining/living area surrounded by the bedrooms and bathrooms. They are roomy and each has a television, couches, games, books, etc. There is little on the walls but staff informational bulletins or schedules. The rooms are thus somewhat stark and bare in presentation.

Three staff work third shift in each duplex and stay awake all night. More staff work second shift and coordinate activities held in the residences and certain areas of the school building. The kitchens are used minimally for some meals (and training activities) but daily meals come on trays from the local hospital by truck three times a day.

Chileda can serve up to 42 children and an additional 20 day school students. In fall 2012, 37 children received residential services and 15 day school students were enrolled. They also have the capacity to provide respite care for a few individuals when the residence is not full.

Chileda is a temporary placement for children and the goal of the residential services component is to get the children back in their home communities. One of the greatest challenges Chileda faces is how long it can take local communities to develop appropriate residential services for the children at Chileda. Typically children who live at Chileda have not been able to find appropriate residential services in their local community.

Educational, Transition, and Employment Supports and Services

Chileda uses "Structured TEACCHing" throughout the day and into the evening for individuals who receive services (see below). Each student has an individual education plan that is usually developed in collaboration with the home district and family members. Since the goals for most students focus on behavior, socialization, and communication skills, actual work on academics is given less time during the day.

In the school, Chileda's students are generally grouped by age (so students often spend a lot of time during the day with their housemates). Academic progress is measured through individual education plan goals, reviewed at regular intervals. Each of the 8 "homerooms" is led by a licensed special education teacher who monitors academics. Only a small percentage of Chileda students receive general education credit for coursework.

Chileda uses the intervention approach called "Structured TEACCHing" (aka TEACCH), which is based on understanding the learning characteristics of individuals with autism and the use of visual supports to promote meaning and independence. TEACCH services are known for their flexible and individualized support of individuals with ASD and their families.

The principles of Structured TEACCHing include:

- Understanding the culture of autism
- Developing an individualized person- and family-centered plan for each client or student, rather than using a standard curriculum
- Structuring the physical environment
- Using visual supports to make the sequence of daily activities predictable and understandable
- Using visual supports to make individual tasks understandable

It was clear that every Chileda staff person knew this approach and used it. Visual cues were posted in every room and teachers and staff were observed implementing these approaches.

Generally Chileda strives to use only positive behavior approaches. Careful attention is paid to the environment in which the children receive instruction and attempts are made to remove other children from potential harm and use the environment to ameliorate difficult behavioral situations. Children are redirected to sensory quiet rooms where they can take a break. Time-out rooms exist and are sometimes used in the school and residences. These rooms have doors in them and tape on the floor of the room to indicate to the student in what area they need to remain while in the room (this enables the staff to see the student). These rooms are equipped with cameras that project an image outside of the room for the staff to monitor the student.

Chileda provides academic instruction in basic math and reading, handwriting, time and money management skills, human sexuality, health and nutrition, social and coping skills, domestic skills, basic science, and self-determination.

Chileda depends on home district planning to determine an individual's "transition." Fundamentally, transition at Chileda means transitioning back to the home district; this process doesn't focus on the transition from adolescence to adulthood in the traditional sense. All supports are provided by organizations in the home district and Chileda does not stay involved after a student leaves. Chileda does communicate with various group homes in the home districts if the student is headed to one to promote a smoother transition. Some older students (i.e., students with more skills) get more exposure than others to community living. If appropriate, shopping, bus travel, mobility skills, etc. are taught. One of the reported changes for Chileda is that they cannot do as much as they would like to facilitate services after discharge with families or other caregivers. They also report that they struggle with unrealistic expectations of some families and of county/school district staff regarding student outcomes.

Chileda conducts outside consulting through “Chileda University” which was created to meet training needs within the community by offering general and customized workshops for parent groups, schools and service providers. Chileda employees also provide individualized consultation to address specific behavioral challenges within a variety of settings. Training and consultation topics include Autism Spectrum Disorders, Attachment Disorders, Supporting Individual Rights to Self-Advocacy, Creating Visual Systems to Promote Independence, Risk Management and Social Skills Strategies.

Clinical Interventions and Approaches

Chileda does not conduct diagnostic assessments for ASD; if these services are needed, they contract with local community practitioners. They do perform specific assessments for speech/language, occupational therapy and physical therapy needs and they observe and record signs and symptoms of illness and mental health/behavioral issues. Typically a student will arrive at Chileda with assessment information provided by their home district.

Chileda uses a number of formal and informal functional behavioral assessments which drive positive behavior support plans and the TEACCH approach. All staff receive training in positive behavior supports and licensed staff and administrators regularly pursue continuing education. Both the school and the residences have padded time-out rooms with cameras and monitors.

Behavior plans are developed using proactive principles including positive reinforcement and antecedent control. In addition, Chileda’s education and recreation departments have developed supports to assist individuals in developing appropriate social skills in various environments. Because many behavioral occurrences are likely the result of an individual’s limited communicative abilities, licensed speech and language professionals assist in identifying and addressing communications needs.

Chileda uses Nonviolent Crisis Intervention training through the Crisis Prevention Institute. All employees document the frequency, duration and intensity of interfering behaviors, at all hours, to assist in identifying behavioral trends. This data is used to track progress toward behavioral goals and objectives and monitor the effectiveness of interventions.

Chileda uses all licensed staff— nursing, speech/language, occupational therapy, physical therapy, behavior specialists, special education staff, and resident supervisors—in the assessment process. Regularly scheduled team meetings are held to plan and look at data on individual students.

Chileda has formal relationships with Franciscan Skemp/Mayo Health System and Gundersen Lutheran Health System. Students receive services from professionals who practice at these organizations and professionals from both organizations collaborate with Chileda staff.

Support to and Inclusion of Families

Chileda has three case managers who are the point people in connecting with families. Families are encouraged and expected, whenever possible, to participate in pre-entry planning and ongoing evaluation meetings by phone/Skype, email, or in person. Some families want a lot of contact (daily) which can be difficult due to caseload size; others want communication weekly or every other week. Families are invited to participate in quarterly meetings in person or by phone/Skype. Families are also given monthly behavior updates. Chileda does limited amounts of co-treatment training (with families) related to social skills. Through phone calls, Skype, and visits, family members are encouraged to reinforce the social behaviors that students are learning at Chileda.

Chileda supports visits from family members but is not set up for “activities” with family members on campus and there is no housing for family members. Informally, they work with families during visits. Chileda had tried to foster family connections but found it difficult to get positive outcomes. Family members are not allowed to volunteer or participate regularly in program activities.

Research Team Observations

Chileda is a large organization that serves and supports individuals with ASD throughout the Midwest. It runs a school that is located on campus in a modern, clean and brightly lit building. Its classrooms and gymnasium felt like a regular school but there were indicators throughout that this was a segregated program (e.g., time out rooms, special gym equipment, picture schedules everywhere). The residences were modern, clean and comfortable although the “offices” between duplex units looked much like observation posts. There are modern kitchens in each residence but you get the impression that they are not used much since meals are brought in to the school by the local hospital’s commissary.

The residences surround a central courtyard (and the side of the school) and high, opaque fences keep the children inside the campus grounds. The courtyards are pleasant and have some playground equipment. There is not a sense that the program is connected to the neighborhood; the campus is in an area with a lot of office buildings and a large nursing home. It is a few blocks away from any single-family homes and there are no parks in the area.

The staff in the school (the residences were empty when we visited) seemed very engaged and dedicated. Most of the management staff we met with had been at Chileda for a long time and the administration of the organization was stable. All of the staff knew the program intervention and modeled its use throughout the visit. Student works of art are posted throughout the school and the hallways are brightly lit and colorful.

Notable features of the program:

- The student-to-staff ratio is very low and the staffing is reasonably stable. This makes it possible to develop relationships quickly and to sustain them while the child is at Chileda.
- There is a single designated treatment and intervention approach that is intense and consistently used; it extends into the evening and weekends. Data is used to monitor progress and identify needed interventions.
- Training and education are valued and provided at Chileda. All staff are trained to use crisis prevention, positive behavior support, and the TEACCH method. Continuing education and upgrading skills is valued and modeled by management.
- Chileda is an integrated education and residential campus model. Since the school is adjacent to the residences, it is used every evening and on weekends for art, recreation and related activities. The space is specifically designed to meet the needs of children with severe challenging behavior.
- Chileda's goal is to transition students back to their home districts. This program is short term in duration and most children experience success with learning more appropriate social skills, reducing challenging behavior and developing new functional skills while at Chileda.
- The program is not Medicaid-funded. Education, child welfare and local community dollars are used to fund these services.
- The program serves children from many states and will provide services to children who have been unable to find appropriate services in their local communities.
- Chileda offers respite services to local families.

Fraser

Richfield, MN
http://www.fraser.org/

Overall Structure and Funding of the Organization

Fraser is Minnesota's largest and most comprehensive provider of autism services. They provide healthcare, residential, and education programs to children and adults with more than 60 types of mental and physical disabilities. Fraser serves more than 9,000 individuals and delivers more than 1,000 evaluations for autism and developmental disabilities statewide each year.

Fraser offers an array of housing and in-home support options for people with disabilities in the Twin Cities metropolitan area. It owns 26 group homes and 5 apartment buildings, as well as coordinates client-controlled apartments in the community. Fraser also provides personal care assistance for many children and adults who live in their own homes or apartments. Many residents in these programs have ASD; 17 of the residences also focus on mental health issues and 14 of them focus on developmental disabilities. Approximately 20% of the people they serve have severe autism; 90% of their in-home services are provided to individuals with ASD.

Fraser's mission is to make a meaningful and lasting difference in the lives of children, adults and families with special needs. They accomplish this by providing education, healthcare and housing services. Their vision is a world where all people have equal opportunity and choice to realize their dreams to live, work, learn and play as members of the community.

Fraser began as a school for children with disabilities in the founder's home in 1935. The founder, Louise Fraser, had a daughter who was deaf. Ms. Fraser was trained as a teacher and had a talent for working with the "more difficult" students. Over the years Fraser has grown steadily and increased its reach and services. It now provides services and supports in these areas:

- Evaluations
- Autism (Children)
- Autism (Teens & Adults)
- Emotional/Behavioral
- Therapy/Rehabilitation (Children)
- Housing
- Home and Community Supports
- Case Management
- Childcare/Pre-School
- Workshops for Families and Professionals

Service recipients come from all over Minnesota but most are from the Twin Cities metropolitan area. County case managers primarily make referrals to Fraser for residential services but some referrals are also made by families, agencies and schools. Fraser is licensed to provide housing in 4 counties (Hennepin, Dakota, Anoka and Ramsey).

Fraser's programs are funded through numerous sources. For this profile, we are focusing on county support through developmental disability services and waivers. Each client receives a set allocation of $867 per month through Group Residential Housing funding, which is a state-funded income supplement program that pays for room-and-board costs. Each client also receives an individual waiver allocation that supports programming. At the Fraser site visited, the average waiver allocation was $280 per day, which supports a 3-to-4 staff-to-client ratio and awake overnight staffing.

The specific program at which the site visit was conducted was a small group home located in the Twin Cities Metro. This program serves 4 young adults (1 female and 3 males, ages 17-20). Two of the residents moved in when they were 7 and 8 years old. All have severe limitations of functioning related to communication, repetitive behavior, social skills and challenging behavior. All of them also have significant medical conditions. None of the current residents are individuals of color but Fraser works with families of all backgrounds and supports residents of color in many other program sites.

Administration and Staffing

Fraser employs over 740 people. In group homes, a house supervisor hires and trains staff and oversees the operation of the home (at the home we visited, there were 12 staff total). A number of direct care staff float among the group homes and provide additional staffing as needed. The house supervisors and division managers all have college degrees (in human services or related fields). The rest of the staff in group homes have high school education or above and are recruited through online applications and job fairs (Fraser has 4 recruiters, with one dedicated to staffing the group homes full-time). Wages in the group homes range from $10.50-$13/hour. Full-time employees receive benefits including health and dental, vacation and retirement. Direct service turnover in the residential division was 32% last year.

Fraser staff undergoes a great deal of training during their first year. All staff learn about crisis and behavioral interventions, first aid and cardiopulmonary resuscitation, and medical management. In the context of their new assignment, they also learn about autism, mental health and developmental disabilities. New staff shadow current staff for several weeks followed by ongoing supervision and coaching.

Other Fraser staff that may support residents in group homes include nurses, occupational therapists, physical therapists, speech therapists, music therapists, mental health and behavior specialists.

Residential Supports and Services across the Lifespan

To move into a Fraser group home, the individual must have a diagnosis of a developmental, cognitive or other disability with a waiver from the county of financial responsibility. The Fraser residential management team reviews all referrals to determine the appropriateness of placement in the homes that have openings.

The specific home in which the site visit was conducted was initially developed around the individuals who lived there. The home is in a suburban residential neighborhood. It was nicely furnished and looked like a typically decorated home with artwork displayed (although bolted or attached with Velcro to the walls). Each individual had his/her own bedroom specifically tailored to meet their individual likes and interests. There is a sensory room that is used for individual sensory needs and therapeutic activities at the request of the residents or upon encouragement from staff. The backyard is spacious and fenced in with places for the residents to sit, run, swing and move around.

On-site staff develops and manage day-to-day services to help each person participate in the community at his/her highest ability. Family, friends and a receptive community play a large part in helping each person to achieve their goals. Time in the community is critical; for example, residents can become members of the local YMCA. Fraser makes a lifelong commitment to serve the residents as long as these services continue to be the best option for them and their needs can be met with available resources. Other services may include:

- Day Treatment
- Behavioral Aide Services
- Case Management
- Skills Training
- Therapy Services
- Behavioral Interventions
- Employment Skills and Job Supports
- Group Social Skills Training
- Transition Services

Adolescents in group homes who complete public school may continue in housing services (and usually do).

Educational, Transition, and Employment Supports and Services

All residents of school age continue in public school programming, usually until they turn 21. Fraser staff support individual education plan goals and attend school planning meetings. School and group home staff communicates routinely. Residents also receive supports as they transition to day training and habilitation programs in the area.

Clinical Interventions and Approaches

Fraser performs diagnostic evaluations for ASD that include a combination of interviews, standardized testing and clinical observation. Fraser takes a team approach, with parents actively involved in the evaluation process so that they understand their child’s diagnosis. Following the child’s evaluation, clinicians and parents review the results together. A report that summarizes the findings and recommendations is also given to parents.

For younger children, Fraser provides a menu of treatment options including behavioral interventions tailored to the level and needs of each individual and his/her family. Behavioral interventions are integrated into daily activities along with psychological, medical, rehabilitation, educational and social communication strategies. Interventions are delivered at Fraser’s center-based locations, as well as in the home.

Fraser provides pediatric therapies and comprehensive rehabilitation services for children with motor and sensory dysfunction, decreased functional and developmental skills, feeding and swallowing difficulties and speech and hearing issues. Their rehabilitation department provides evaluation, consultation, and treatment services based on the strengths and challenges of each child. Their pediatric therapists collaborate with parents, caregivers, teachers and mental health professionals to maximize results.

Fraser supports mental health services for children whose parents or caregivers have concerns about their developmental, behavioral and/or emotional wellbeing. They serve children (from infants to age 18) with a variety of mental health diagnoses. The program also provides services which help parents evaluate and build their own skills they can use to support their children.

Support to and Inclusion of Families

All along the way, families are actively encouraged to participate in planning. In residential settings, family members are invited to individual planning meetings as well as events at the home or in the community. Families are also encouraged to meet other families and to provide input on issues related to the living situation. At the program where the site visit was conducted, a parent was present during the site visit. This parent is active on the Fraser Board of Directors and parent council. Within this particular program the parents get together routinely and often contribute in-kind as well as material items for the home. For example, they recognize the staff who works in the home by organizing social events like a summer picnic and they recently helped to purchase YMCA memberships for the residents.

Fraser communicates with families through planning meetings and regular reports on each resident. Fraser's residential division publishes a quarterly newsletter that also goes out to families. Fraser staff is aware of the diverse nature of Minnesota families and try to meet specific needs with regards to culture, food, religious practices, and language.

Fraser provides a number of resources to families including workshops on topics such as:

- What's Next? Understanding an Autism Diagnosis
- Autism Spectrum Disorders 101
- Asperger's Disorder: Understanding the Diagnosis
- Look and Learn: Use of Visual Tools
- Executive Function: Tools and Strategies
- Supporting Siblings of a Child with Special Needs
- Transition Considerations for Individuals Interested in Post-Secondary Training
- Transitioning to Adulthood: An Overview

Research Team Observations

Fraser services and supports are comprehensive and can meet the needs of individuals from birth to old age. This is an organization that can bring to scale many activities for clients at many developmental stages. Fraser housing services are focused on individuals with developmental disabilities but their expertise in many areas of ASD provides many supports across all age ranges.

Notable features of the program:

- Fraser supports transition from adolescence to adulthood on many levels including housing, clinical supports, employment, and education.
- Children and adolescents are never required to move out of a home due to their age. People served can "age in place" and the program evolves with them.
- Fraser programs aim to move individuals to less restrictive environments as much as possible.
- Families who use Fraser services often do so for decades. The organization does many planned and purposeful things to engage and include families. Family members are included in many activities and can provide input on home management issues.
- Fraser staff has extensive experience with evaluation and diagnostic activities and provide services in more than one location.
- Fraser staff work to establish collaborative relationships with county and school personnel.
- Fraser housing services include supporting individuals and families in crisis.

Other notes:

- Fraser has long waiting lists for many of its services. It has limitations for growth that are financial in nature and impacted by state and local policies.
- Fraser employees who serve as case managers cannot freely refer their clients to other Fraser programs—state rule protects against conflicts of interest but at times also infringes on families' preferences.

The Homestead

Altoona, IA
http://www.thehomestead.org/

Overall Structure and Funding of the Organization

The Homestead provides a variety of services and supports for children and adults with autism. Through their residential and community services, they seek to enrich the lives of people with autism through work, play and community. They say that their programs work not only to help people with autism adapt to mainstream society, but also to help mainstream society better adapt to people with autism. The Homestead provides specialized assistance and training in order to maximize access to social, educational, vocational and family activities. With that individualized support, individuals learn to more effectively communicate, develop relationships with those around them and lead more fulfilling lives. The Homestead works toward these goals by providing solutions through community services for children, youth and adults. In addition, The Homestead provides consulting and training services to families and agencies across Iowa.

The Homestead was founded in 1991 by parents and professionals who recognized the need for a provider agency with a specific focus on providing services for people with autism. The founders believed that services for children and adults with autism lagged behind those for people with other disabilities and that in most states, people with autism have few residential or vocational options available. The founders researched other programs around the country and talked with experts in the field of autism, including Bittersweet Farms (Whitehouse, Ohio) and the Carolina Living and Learning Center (Chapel Hill, North Carolina). As a non-profit organization, The Homestead set about to create a model program for Iowans with autism. Those early efforts have grown into a collection of varied programs focused on meeting the needs of people with autism. Today, The Homestead serves children and adults in a wide variety of campus- and community-based settings.

The Homestead provides these services:

- Supported Community Living and/or Respite for Children: Support is provided for children ages 3-18 while living in the home of parent/guardian;
- Youth Home: Residential services for children ages 5-18 in Altoona, Iowa; licensed as intermediate care facility for people with intellectual disabilities facility;
- Consultation: Training is provided to individuals, families, agencies, and organizations in a variety of teaching techniques and services aimed at serving people with autism. Training is conducted by experienced professionals and may include, but is not limited to, autism specific training, program consultation, individual assessments, Applied Behavioral Analysis programming, and creating an organization or department to support people with autism;

- Campus Residential Services: Residential services for adults (ages 18 and older) in one of 6 four-bedroom homes at its Pleasant Hill location; licensed as an intermediate care facility for people with intellectual disabilities facility;
- Supported Community Living for Adults/Daily: Support is provided around the clock to adults (ages 18 and older) living in an apartment or home within the Greater Des Moines area (Participants in this program are matched with 1-3 roommates who also require supported community living);
- Supported Community Living for Adults/Hourly: Support is provided to individuals (ages 18 and older) who live alone and only need a few hours per day of support, or individuals still living with parents/guardians;
- Children's Autism Project: Applied Behavior Analysis support for children, ages 3-8, in the autism clinic setting; sessions are held 5 days/week for 2.5 hours/day

Currently The Homestead serves approximately 35 children in their applied behavior analysis program, 8 youth in their group home, and 24 young adults at the Pleasant Hill Farm. In the past they have not served individuals from Minnesota. There are 60 adults in the supported community living programs. The Homestead does not keep demographic data on race or gender.

The individuals who receive services from The Homestead come from all over Iowa, but mostly from the central part of the state. Referrals come from school districts, parents and non-profit and state agencies. Funding comes from school districts, counties and Medicaid funding. The campus residential setting receives some revenue through the sale of produce, flowers and Christmas wreaths, but these activities are reported to be barely break-even ventures. Some fundraising is done as well. The Homestead is reimbursed up to $320/day through Medicaid funding and from around $200 to $450/day for waivered services (the majority of services are not home and community-based services).

Administration and Staffing

The Homestead has 228 staff including 200 full-time employees. This includes about 35 administrators and licensed staff. The rest, direct support workers, earn an average of $10.50/hour. The Executive Director reported that being able to recruit staff at this wage is a significant challenge. Full-time staff receive health insurance, dental, vision, and long-term disability benefits. Employees also receive an 8% match for a retirement account and 19 days of paid time off per year to start.

Finding qualified non-licensed staff is very difficult; this is one reason why the Homestead is not interested in expanding its residential programming but instead is expanding early intervention and applied behavior analysis services.

Parents were part of the founders of the Homestead and some serve actively as board members or volunteers.

Residential Supports and Services across the Lifespan

The Homestead has two residential settings, one for adolescents and adults and one for children. In 1994, The Homestead opened the first of 6 four-bedroom homes on 80 acres of farmland in Pleasant Hill, Iowa (east of Des Moines). Twenty-four men and women live and work at The Homestead's campus residential program. Each of the 6 homes offers private bedrooms that are decorated to the taste of the individual, a common living area, kitchen and dining room. Each of the homes on the campus was built slightly differently from the others in an effort to make them easily identifiable by the people who live in the home. In general, the homes resemble the architecture of a barn. Homestead staff work around the clock to meet the needs of individuals with autism by helping them gain the skills necessary to complete daily chores, grooming, planning and participating in recreational activities and leisure, and communication. Individuals served by this program also receive assistance and support with vocational and educational opportunities.

The campus residential program is home to a working farm operation located on 80 acres of land. This program location is on a busy highway and there are no fences. Individuals who receive services participate in paid work opportunities at this location, helping to grow fruit and vegetables that are sold to community members through the organization's consumer supported agriculture program. Homestead staff work the farm with the individuals who receive services and also support residential living 24 hours a day. It has been a challenge to find direct support workers who are good at supporting people with autism and also good at farming. Typically there are two associates for every four individuals who receive services during waking hours and one for every four individuals who receive services during the overnight hours. The farm program is licensed as an Intermediate Care Facility for People with Intellectual Disabilities.

Individuals who receive services on the campus farm stay for a long time—there is one resident who has been there since it opened. As a result, they have few openings (approximately one every three years). The Homestead does provide supports in the community for higher functioning adults in group homes or individual apartments and some people who once lived on the farm site have moved into the community over the years.

In 2003, an eight-bed duplex was opened in Altoona to better meet the needs of children with autism who need intensive supervision and support. This home has both private and semi-private bedrooms and includes a sensory room that provides a variety of interactive experiences for the children. While living at the home, children receive individualized teaching on daily residential, recreational, educational, social, and communication skills. As children grow older, they may also participate in some vocational programming.

All children living at the youth home attend school in the Southeast Polk School District or in Des Moines Public Schools. Transportation to and from schools are coordinated with the school district. The home is staffed 24 hours a day when the children are present. Typical staffing patterns are 1 associate to 2 children during waking hours and 1 staff to 4 children during sleeping hours. The program is also licensed as an intermediate care facility for people with intellectual disabilities.

Educational, Transition, and Employment Supports and Services

The Homestead does not have an educational program for the individuals who receive services in the group home. This is provided by local school districts. Group home staff participates in planning activities in the schools.

At the campus farm setting, individuals who receive services are provided with transition supports and vocational training primarily through farm labor. Some individuals who receive services do have work experiences and part-time jobs off campus.

Clinical Interventions and Approaches

The Homestead Children's Autism Project provides one-on-one, direct Applied Behavior Analysis services for children with autism. The intervention is a comprehensive learning system for each child that surrounds them with a collaborative team. The program includes training for the family, allied professionals, and peers closely supervised by trained specialists. Staff focuses on communication and interaction skills and behavioral interventions.

Each child is enrolled for intensive services up to 5 days a week (up to 20 hours) and each session is individualized to the needs and readiness of the individual child. The ultimate result is to lead the child to be reinforced by learning. Currently, services are available in morning, afternoon, and after school.

Each child participating in the Children's Autism Project is required to have at least one family member or significant other designated to ensure the services are carried out in the home and community. The family contact receives instruction on the core principles of ABA and their specific application to their individual child and family. Families receive a maximum 2.5 hours of training/week; instruction is provided both individually and in groups.

Family training may include monitoring the implementation of strategies in the home or community, review of video recordings, self-assessments and competency-based instruction. In addition to the individualized services provided to each child and their family, the Children's Autism Project trains allied professionals to serve children in other community settings. Consultation is available through the Children's Autism Project for families and agencies unable to access direct services due to location or funding.

At the campus farm program, elements of positive behavior support and TEACCH are used as an intervention model. The environments are not cluttered, have visual cues throughout and provide opportunities for privacy. There are no specific environmental modifications/adaptations designed specifically for people with autism. Each home is alarmed so that staff gets a signal if a person leaves their home.

Support to and Inclusion of Families

The Homestead involves parents as much as possible and expects families to be actively involved in applied behavior analysis early intervention activities especially. The group homes do not accommodate families for overnight visits but do encourage regular family visits. The campus farm setting is not set up for overnight visits but they also encourage families (and community members) to participate as volunteers or to visit most any time. The organization no longer organizes family events.

Research Team Observations

Most of the Homestead's growth focuses on early intervention and applied behavior analysis services, despite their belief that residential programming is needed by many Iowans with autism. The high cost and the difficulty of finding residential staff make The Homestead administration reluctant to try to expand their relatively small-scale housing availability. The residences they do have are well designed and maintained. Staffing is provided around the clock and safeguards are in place to ensure safety of the individuals who receive services. The group home for children provides services and support similar to other group homes. All of the Homestead staff has autism-specific training as well as training on positive behavior interventions and TEACCH.

The campus farm model is intriguing in its scope and the variety of job tasks available. The Homestead administration admits that farming is difficult work and that sensory and health issues arise for individuals who receive services at this location. The weather, allergens, equipment noise, monotonous work and many other things often cause problems for people with ASD and related health conditions. The cost to run the farm component of the program is high and the sale of produce and flowers does not offset these costs. The equipment, land, and many buildings located on the campus farm are added costs.

Notable features of the program:

- Parents founded the program and are active on the Homestead board.
- Individuals who receive services on the campus farm stay for long periods of time (some through adulthood) and openings in this program are rare.
- The products produced at the farm are sold to community members through the program's consumer support agriculture activity, although the farm component of the program is a financial drain.
- The residential services for children are designed to promote reintegration into the family home.
- The Homestead provides a wide variety of supports for children, youth and adults with autism/ASD and is viewed by the community as experts in these services.
- Families are encouraged to participate in all the Homestead programming. Participation is mandatory for those families receiving applied behavior analysis—family members receive 2.5 hours of training/week.
- The Homestead promotes the idea of individuals living in the community with their families or in more independent settings with part-time supports (personal care assistance).

Other notes:

- There is a shortage of beds for children with autism in Iowa but the Homestead is not in a position to provide more services.

- The campus farm model, while meeting client needs, is expensive to operate and the executive director reported that it would likely not be possible to replicate as a new non-profit activity (as funding for residential services now exists in Iowa).

The New England Center for Children

Southborough, Massachusetts
http://www.necc.org/

Overall Structure and Funding of the Organization

The New England Center for Children is a private, nonprofit autism research and education center dedicated to transforming the lives of children with autism worldwide through education, research and technology. The New England Center for Children's vision is to be a global leader in the provision of effective, evidence-based educational services for the millions of underserved children with autism around the world and their families.

The New England Center for Children has a day school in suburban Boston with 235 students ranging in age from 3-22 years. The New England Center for Children also provides housing and residential training for 120 of these students in group homes and apartments in nearby communities. All students at the school have developmental disabilities and most of them have ASD. The New England Center for Children also provides applied behavior analysis supports to dozens of other students in their homes or local schools. Approximately 15% of their residents are individuals of color and 17% are female.

Most New England Center for Children residential students come from New England, primarily Massachusetts and Connecticut, but others come from as far away as California (The New England Center for Children has no students from Minnesota). Day students live within an hour of the center. Referrals to the New England Center for Children are generally made by school districts, county agencies or parents.

The New England Center for Children provides three levels of support in its residential programs depending on the behavior challenges of the individual. For most children—those who do not exhibit self-injurious or destructive behavior—the staff support ratio is typically 1:2 or 1:3 (staff to children). In the intermediate settings—children who need more supports but are unlikely to exhibit self-injurious or destructive behavior—the ratio is closer to 1.5:1. In the "severe" settings—children who are prone to self-injury and other severe challenging behaviors—students live in a specially designed four-unit apartment building in a residential neighborhood close to the Southborough campus with a 1:1 ratio.

The New England Center for Children uses a rolling admissions process; most openings are the result of students aging out of the program and occasionally from younger students making enough progress to return to their home district. Generally, residential students are admitted based on the type of space available in the residence. The admissions process includes a review of records submitted by the family and/or school district, including the current individual education plan, the most recent individual education plan progress report, recent assessments (medical, communication, psychological), a diagnostic report, the New England Center for Children application, immunization record and last physical exam and a copy of the applicant's health insurance card.

The New England Center for Children is funded primarily by referring school districts. Besides funding from school districts, the New England Center for Children has a large development effort that raises operating and capital development funds. The school is licensed as a "private school supported by public funds." Out-of-state students may be funded by state or county funding rather than from school districts. Yearly tuition is $97,000 (intensive day services w/1:1 staffing – all our day students); yearly room and board runs from $104,900 to $209,000 depending on the supports needed by the individual. (All figures are rounded)

Administration and Staffing

All New England Center for Children staff (except overnight residential staff) have college degrees, usually in a related field like psychology or special education. The New England Center for Children recruiters go to many college career fairs in the region when seeking new hires. All academic staff are called "teachers" even though they may not be certified teachers at the time of hire. The New England Center for Children has partnered with two local colleges, Simmons College and Western New England University, to offer on-site graduate study at the New England Center for Children – the New England Center for Children subsidizes the tuition with these program for all staff without certification to attain master's degrees to become certified applied behavior analysis providers and/or certified special education teachers (this is considered part of the fringe benefit package available to employees). The New England Center for Children employs a number of physical therapists, occupational therapists, speech and language therapists, nurses, and other medical specialists. The New England Center for Children also offers many internships and field placements for college students.

The New England Center for Children has a comprehensive in-house training program for educational staff. New staff undergoes a rigorous three-week orientation and learn about autism, interventions, crisis management, and protective approaches to aggressive behaviors. New staff also spends many hours shadowing experienced staff and then are shadowed themselves. All training curriculum has been created by New England Center for Children staff and is not available to the public. All staff is oriented to applied behavior analysis theory and a lot of time is spent training staff to document interventions.

Upper management at the New England Center for Children makes a salary that is typical of or a little higher than those in similar settings. Supervisors make up to $48,000/year and certified staff starts at $34,000 and can make up to $48,000. Overnight staff starts at $13/hour; longstanding staff may make $20/hour.

Residential Supports and Services across the Lifespan

The New England Center for Children has 15 residential settings, including a building that could be considered an apartment building with 4 large units. Each building or unit has 5-9 individuals who receive services. Some of the individuals who receive services without behavior challenges share a room; the rest have their own room. All settings, except two (that with the youngest children and the adult home), are segregated by gender and are open year-round. The New England Center for Children does not provide respite care. Educational staff work Tuesday-

Saturday or Monday-Friday; they drive to the homes of their students each morning (except Sunday) and ride in vans to school with the individuals who receive services. Students go to school 6 days a week. Teachers also work part of the second shift. The rest of second shift and third shift are handled by non-licensed staff. There is always at least one staff member awake in all settings.

All the residential settings are in suburban or rural areas outside of Boston. Typical of this part of the country, there are few sidewalks and narrow, curvy roads. The homes all have living areas and kitchens. The homes have backyards so residents can spend time outdoors. Individuals can go on excursions to parks, stores, or other community settings during the school day or evenings.

While in their residences, students focus on independent living skills, leisure interests, recreation, and community activities, as well as practicing skills learned at school. The New England Center for Children teachers work with the students both in school and at the residence, further emphasizing consistency and the feeling of safety and ultimately contributing to the success of the instruction. All students in the New England Center for Children’s residential programs participate in its comprehensive healthcare program. The average stay at the New England Center for Children is 7.7 years. The shortest is 1 year. The longest is 16 years.

Supervision of evening and night staff is extensive. Supervisors that travel (by car) to each residence throughout the night and residence staff are monitored in many ways to make sure they are awake and that they have on-call support when appropriate. The various living areas in the apartment building are all connected by hallways and support for crisis situations appears to be well planned.

Individuals who receive services that are able are expected to participate in the upkeep of their home. Cleaning, cooking and shopping are common activities. Some of the older individuals who receive services have paid employment in the school (a few are employed in the community) and they take on more responsibility as they develop more skills. Breakfast and dinner are eaten at each student’s residence. Lunch is eaten in the school’s cafeteria.

Nurses and/or nurse practitioners are always on duty. Contract physicians/specialists provide support for individuals who have seizures, psychiatric problems, dental and nutrition needs, and a myriad of other healthcare issues. The New England Center for Children also has relationships with the police and fire departments of the communities in which the school and residences are located so that public safety offices can be sensitive to the needs of the students in stressful situations.

Medical staff at the school provides “conditioning” activities for students who are anxious about dental or medical procedures. Students are required to have health insurance that covers healthcare expenses from local providers. The New England Center for Children makes sure that a full range of medical and dental services are available at all times.

Educational, Transition, and Employment Supports and Services

The New England Center for Children is funded to serve individuals from 18 months to 22 years old—i.e., those that are covered by Individuals with Disabilities Education Act. Students at the New England Center for Children are generally grouped by age. Some of the students in the older groups are in classroom settings that lead to high school credit. Many students, because of their intellectual disability, are not in "for credit" classes but spend most of their days working on communication skills, independent living skills, occupational and physical therapy, recreation and physical education, and socialization.

Beginning at age 16, discussion about transition plans begins and parents are advised about options for adult services. Except for the one group home, the New England Center for Children does not provide any supports or services to those over 22. The New England Center for Children does have a career development center and many students get involved in that early on; at age 14, some students with less significant disabilities can get "working papers" from the state and have opportunities for part-time employment, both paid and volunteer. Some of these students have paid jobs in the school doing clerical work or working in food service or maintenance. The New England Center for Children has relationships with several local employers that lead to work experiences. For example, Sun Life Insurance has hired New England Center for Children students for clerical work and one graduate has been working there full-time for a number of years. At age 22, students tend to return to their home communities and get involved with adult service providers for day habilitation and residential services.

Clinical Interventions and Approaches

The New England Center for Children's curriculum is based on the principles of applied behavior analysis. According to New England Center for Children staff, applied behavior analysis is "the application of information about learning and motivation to help people with everyday problems. It provides scientifically-derived interventions to overcome the learning and communication deficits and behavioral excesses of individuals with autism and other developmental disabilities… [it is] based on positive reinforcement, to teach skills across a student's day: at home, in the residence, at school, and in the community." The New England Center for Children employs over 100 certified Board Certified Behavior Analysts and serves as a setting for dozens of internships every year.

For students with the most difficult challenges, the ultimate goal of the New England Center for Children intensive instruction is to decrease their dangerous and severe behaviors and increase their capacity to function and communicate independently. In this way, these students can be prepared to move on to less restrictive settings and enjoy an improved quality of life.

The New England Center for Children's priority is to assess all functions of a child's behaviors and develop treatment plans to increase their abilities to interact successfully with the people in their environment, so that resorting to dangerous behaviors is unnecessary. This plan stresses the development of functional communication skills, identifying and establishing preferred activities and reinforcements, and teaching the child to become competent in many self-care, leisure and daily living skills so that they experience repeated success. For students with less difficult challenges, the goals are similar but individualized based on input from the home district, parents and others.

Nearly all assessments of current students are done in-house using measures developed at the New England Center for Children and based primarily on applied behavior analysis principles. All professional staff are involved in assessments and all teaching staff have a background in applied behavior analysis, special education, or both. Occasional outside consultants are used to support individuals with the most intractable behaviors.

Functional behavioral assessments are conducted and interventions based on applied behavior analysis principles are used daily. Positive behavior support plans are strength-based and reinforcements are used throughout the day and evening for most students. The New England Center for Children does use time-out rooms in the school and the residences—these are small rooms with padding and a window in the door. There is an electronic lock that only operates when a staff person has his or her hand on the switch; this ensures that no one can be in the time-out room without being observed the whole time.

Support to and Inclusion of Families

The New England Center for Children involves parents as much as possible; they develop team/parent communications and expect collaborative development of individual education plans. Additionally, parents receive training in applied behavior analysis and parents and siblings may join support groups at the New England Center for Children. The New England Center for Children does outreach to out-of-state families and arranges Skype calls between students and families. The New England Center for Children offers parent workshops and information sessions in the local area and sponsors an annual parents' night.

The New England Center for Children's residences does not accommodate families for overnight visits but do accommodate family visits on a regular basis.

The New England Center for Children supports families from minority backgrounds; it will provide interpreters for families who do not speak English and will, when possible, accommodate special diets based on cultural or religious beliefs.

Research Team Observations

The New England Center for Children is a large organization that serves and supports individuals with autism throughout the Northeast region. Its school is large and modern; its facilities do not feel institutional but rather like any other school. Its pool, gymnasium, cafeteria and classrooms are clean and well maintained. Student works of art are posted throughout the school and the hallways are brightly lit and colorful.

The residences we visited (four in total) were pleasant and homey. Furniture was solidly built but comfortable and each residence's kitchen felt "family-like." All the residences we visited were in residential, suburban neighborhoods and except for the on-site parking spaces, seemed to fit into the neighborhood well.

The staff at the school seemed engaged and dedicated. All the management staff interviewed had been at the New England Center for Children for many years and the administration of the organization seemed stable.

Notable features of the program:

- The New England Center for Children teaching staff work at both the school and the residences; they also ride to school on the New England Center for Children's vans with their students. Their involvement in these settings appears to give a great deal of continuity to students' days.
- The New England Center for Children employs over 100 certified Board Certified Behavior Analysts and serves as a setting for dozens of internships every year. Most staff have four-year degrees.
- The New England Center for Children provides services to many children who have severe self-injurious and aggressive behavior.
- The school is a large building that has many modern features including the pool and gymnasium. School goes on six days a week.
- Nearly all students spend time in the warm therapeutic pool at the school several times per week.
- The New England Center for Children's connections with local colleges is strong and most professional staff continue their education during their tenure at the New England Center for Children.
- The New England Center for Children attracts professionals from all over the country and internationally to visit and do research with its students.
- The New England Center for Children has opened a school in Abu Dhabi to provide services and supports for children in that country. Residential services are planned as well.
- The residential settings for all students are located in real neighborhoods and are not isolated facilities.
- For individuals who have the skills to work outside of the school, the New England Center for Children has built interesting partnerships with local employers.

Other notes:

- The school itself is on a busy highway and there is not much opportunity for students to venture outside except to the playgrounds on campus.
- As in many rural neighborhoods, the homes we visited have no sidewalks and taking a walk in the neighborhood seemed unsafe because of traffic.
- There are no commercial areas adjacent to the school or the homes that were observed.

Private Residence

Twin Cities Metro, Minnesota

Overall Structure and Funding of the Residence

The Minnesota Department of Human Services has a service option for individuals with disabilities funded through the Home and Community Based Waiver Program called Consumer Directed Community Supports which gives persons more flexibility and responsibility for directing their services and supports, including hiring and managing direct care staff.

The family on which the case study is based has used Consumer Directed Community Supports funding for about 10 years—most of which is used to fund supportive personnel. The individual who receives this service is now an adult but when he began receiving this service he was a youth. By using Consumer Directed Community Supports, this family has been able to keep their son in the family home his whole life. Their home is a duplex with a residence upstairs and one downstairs; currently the son lives on the first level (with staffing and technology support) and the parents live upstairs. By using Consumer Directed Community Supports, this family has hired a number of employees to engage their son through the day and to take him into the community for a number of developmental and volunteer activities. The services provided in this home are delivered by paid staff and non-paid family members. On average each week staff provide 50 hours of service and family members provide the rest including overnights.

Administration and Staffing

The individual receives approximately $65,000 per year through Consumer Directed Community Supports (if he were on the straight waiver, he may be eligible for $85,000 per year with more restrictions on what services he could access). He also receives Supplemental Security Income (approximately $698/month), Sheltered Needy funds (approximately $391/month), and a small amount of food stamps due to his special diet.

Families that use Consumer Directed Community Supports funding must have a fiscal agent to handle payroll and related processes. This particular family does the hiring and then uses Lifeworks, a non-profit organization in the area in the role of fiscal support agent. Typically, this individual has 4 or 5 staff throughout the week, all of whom work part-time. Some staff are college students; some are older. Most have worked for this family for 2 to 3 years. They generally make $12.00 to $15.00 per hour depending upon experience but they don't receive benefits. The family tries to hire people who have been in the field or who are studying human services in some fashion. All those who are hired are expected to actively participate in their son's community activities, implement behavior support and work on educational goals; no one is hired to be a "caretaker."

One of the individual's parents receives wages through the Consumer Directed Community Supports for service coordination (about 10 hours per week). The service coordination includes staff scheduling, staff training, setting up activities, coordinating health and specialty care, and attending planning meetings with county staff and others. As the use of this integrated residential support model goes forward, the family is looking for ways to increase staff time and have considered having live-in help for overnights.

Residential Supports and Services across the Lifespan

The individual who receives services in this program has autism, an intellectual disability, hearing loss, and is legally blind. He requires 24-hour supervision and support. He communicates through a few phrases that he repeats and he makes vocalizations and he does not read. He has a lot of strengths and participates in a number of activities in the community on a regular basis. He participates in yoga and a drumming class; he goes to a health club and works out with a personal trainer; he is part of a friendship group and volunteers at a local restaurant and a local non-profit; he also walks the family dog most days, visits a senior center once a month, and does some recycling and shredding for a local organization.

The staff support the individual in all these activities with coaching, transportation and monitoring behaviors. The personal trainer has worked with him for a long time and he is willing to spend time with the support staff to ensure the individual is safe when he exercises or swims.

While at home and in the community, this individual does display what many people would consider challenging behavior. He has occasional meltdowns, loud outbursts, can become physically aggressive (in the right circumstances) and he has a history of property destruction (which require home and environmental modifications). His family and his support team have a philosophy that the community has a responsibility to accept and engage the individual even though he does not always behave the way most people in the community do. When he is in the community, he's set up for success; other than medical appointments, he rarely goes to activities he doesn't enjoy (no grocery store or running errands, rarely attending meetings with his mother, etc.). When he's in the community, it's to do an activity that he typically enjoys, and staff always bring items to ensure success (snack, beverage, IPad, music).

The family and staff report many examples of how over time the community has grown to know this individual. On a recent trip to a local community program the individual was having a difficult day (loud yelling, refusing to move off of the floor) and a child at the program was overheard saying, “That’s XXX’s mom; he is still learning how to use his words.” This was a powerful example of community inclusion for this individual.

This family house has a number of electronic alarms and monitoring equipment that they use to watch their son and, to an extent, the staff. There are cameras in most of the rooms and alarms on all doors (even interior doors to ensure he is not wandering the house without someone nearby). Information from the alarms and cameras can be accessed remotely from a personal computer during times when the family is out of town or away from the home. Certain items are locked (such as the refrigerator) but other items are not—years ago, almost everything was locked. There is also an intercom in place so communication between units in the duplex can be maintained.

The individual who lives in this home has significant dietary restrictions and the kitchen is set up to keep all foods with gluten separated from the rest of the items that the person is allowed to eat.

Educational, Transition, and Employment Supports and Services

This individual attended school in the local district until he was 21. He had, by and large, a good educational experience and some years were better than others. Since then, all training and support has been provided by his parents and his hired staff. The family considered a day training and habilitation program (they toured several) but they never found one that they thought could meet his needs; there were always questions about food and diet, consistent staffing throughout the week, physical activities, and engaging him all day long (the individual will "wait" until he is given choices for activities).

Clinical Interventions and Approaches

Because of the nature of the individual's disabilities, his parents have always used a combination of clinical interventions to increase his independence and to limit his challenging behaviors. Some of these have elements of Applied Behavior Analysis. Overall, they have tried to reinforce positive behavior and to ignore or pay little attention to negative behavior. Calling attention to negative behavior often just leads to more negative behavior. They have also focused on improving his ability to communicate and have used the PECs system of picture boards to teach him to communicate. He now has an iPad that he primarily uses for educational name recognition games (and to encourage use of his hearing aids). Eventually this tool may be used more for his communication.

For activities, the staff use the PECs calendar with pictures on it to show him what events are planned for the day. The individual is given options on a regular basis. Over the years, his ability to pay attention to an activity has slowly increased. During his school years, 5 to 10 minutes were usually his limit. He is now able to do some things for 20-30 minutes (such as name recognition games on the iPad). The individual is now also much less likely to become physically aggressive than during childhood and adolescence.

The individual's health is quite fragile and he spends time with a lot of medical specialists throughout the year. Managing this regimen is difficult because (since he became an adult) there is not a single place he goes to for his care; he now receives specialty services at many clinics instead of one special needs hospital.

Support to and Inclusion of Families

In this service option the family has ultimate involvement and control. Within set parameters and a given budget allocation, they make all of the decisions related to their son's care. This family is planning for the future and sees their current program as building that future where their son will have his own home (the lower duplex) and his services can be managed either by their other adult children or a future service provider. One day staff may occupy the upper level of the duplex. This family has long been involved in the ASD community and other disability advocacy groups; they have long advocated for other families to be able to access services and supports on a broader scale. They appreciate the fact that developing a residential service plan like they have for their son is not for every family but they also believe that more families could do something like this if the system promoted it.

Research Team Observations

The individual's home is large and homey—it is set up for a lot of space dedicated to the individual's in-home activities. There is a sensory room with some exercise equipment and he has anytime access to the kitchen, dining room, living room and bedroom. The dog also has free range inside and appears to be a well-adjusted companion for him.

The security to keep this person inside is elaborate and works well. The family's plan to allow him more of his own "space" is moving slowly but his family discusses openly that there is a lot of planning needed to take each step forward. Everything has taken years to teach their son but this provides him an opportunity to grow and learn. While he will likely always require 24-hour support, this family is working toward figuring out how he can be less dependent upon them and planning for an eventual future where they may not be able to provide support.

Notable features:

- The family has developed an individual program based on the needs of their son. In this program they are seen as the experts and they direct the team that delivers the services and supports. That said, they also have all of the responsibility of monitoring and supervising the program.
- Interestingly under the Consumer Directed Community Supports model, the individual received a smaller allocation of resources than they would receive if a licensed service provider delivered the same services. This difference would be more than enough to offset the costs of an employee benefit package or to reduce the number of hours the family is expected to provide.
- This individual has a program plan that all staff are expected to follow. The staff who work with this individual develop their own routines with him based on the time of day they work. Incorporated in his routines is the opportunity for him to have some options for activities.
- The family designs, coordinates and delivers training to the staff to meet the specific needs of their son. When a new staff is hired on they receive a training wage and do some shadowing of either other employees or the family.
- Staff tend to stay two years or more—well above average for the retention rate for direct support. The staff earn on average slightly more per hour in wages but none have access to paid time off, health or other benefits and they all work part-time.
- The individual is integrated into his community by design and family persistence. He enjoys physical activity and does well when he is exercising or swimming. He has gone to the same health club for many years and other members know his name and encourage him to do well.

- This individual spends time each day in the community and his control of his behaviors while in the community seems to have increased year by year.

REM Heartland

Southern Minnesota
http://www.remminnesota.com/welcome.aspx

Overall Structure and Funding of the Organization

REM Minnesota is a statewide provider of community supportive living residences located in over 50 counties. Its mission is to offer adults, children, young people and their families innovative, quality services and supports that lead to growth and independence, regardless of the physical, intellectual or behavioral challenges they face. REM Minnesota's philosophy emphasizes partnerships – with those they serve and their families, their employees and the communities in which they work – in an effort to help people shape the direction of their own lives in community-based settings. Its services include 24/7 community supportive living, semi-independent living services, in-home/hourly services, housing with services, intermediate care facilities, and respite care. REM Minnesota was founded in 1967 and was one of the first community-focused providers as deinstitutionalization in Minnesota occurred. In 2003, REM programs became a part of the Mentor Network.

REM Minnesota offers:

- Expertise in assessing, supporting and serving individuals with cognitive, emotional, medical and/or physical challenges.
- Leveraged use of existing community resources to avoid duplication and control costs.
- Improved quality of life for individuals served.
- Individualized approaches and flexible options.
- Cost-effective solutions with demonstrated outcomes.

Their goal is for individuals to gain: better access to community resources, increased participation in community life, greater personal choice, improved adaptive living skills and greater overall life satisfaction.

The specific program at which the site visit was conducted was a small group home located in southern Minnesota that is a part of the REM Heartland regional program. REM Heartland serves 289 individuals, 17 of which have ASD; of these individuals 8 have severe symptoms of autism. This program serves 3 young men who have autism, two of whom have verbal communication skills, fairly good self-preservation skills, and go to day programs. The other resident communicates through vocalization or assistive devices and requires hand-over-hand assistance for most self- and home-care tasks. This individual also has a history of self-injury and aggression, and prior to moving into the home was in a crisis placement for about a year. At the time of admission, his aggression or self-injury behaviors were occurring hourly. Since the time of admission, the individual's aggressive and self-injury behaviors have reduced to once every other day.

The home itself has been open for less than a year. When the program first opened, it served only one individual and then, after many months and stabilization for the initial individual, two additional individuals moved into the home. One of the residents is a person of color.

The home is a split-level house with two bedrooms and a living area on the upper floor, a kitchen and dining room on the main floor, and a bedroom and living area on a lower level. There is also a basement for storage that is kept locked. Some physical modifications were made to the home after REM purchased it. A solid wall was erected between the dining area and the upper living area to prevent anyone from jumping over the top. Barriers prevent the sliding glass doors from being opened easily and the home is alarmed to indicate if anyone has left the house. Televisions in the living areas and the bedrooms have protectors on them to prevent damage.

Administration and Staffing

REM and REM Heartland specifically run a multitude of programs. The specific program site in which this case study was conducted is a Home and Community Based Services program (Waiver) funded by Medicaid. When this site opened and for the period in which only one person was living in the home, the daily rate for service was approximately $728 and the county also paid $850 for room and board (the equivalent to Group Residential Housing because the individual was a minor). Each time an individual was added to the home, this daily rate was adjusted as were the staffing patterns. At the time of the site visit the daily rate was roughly $450 (plus monthly Group Residential Housing for the adults and an equal amount paid by the county for the minor).

At the time of the site visit 9 staff worked at the program with 2-3 staff on duty in the home all of the time. There is one program coordinator/supervisor who works varied direct support hours throughout the daily schedule to supervise all of the staff/shifts and manage the program. When the program first opened, the location had been purchased from another provider and the supervisor of that program came to work for REM Heartland as the supervisor of this new program. Additionally, several staff from the intermediate care facility for people with developmental disabilities in town operated by REM Heartland moved over to the new program on a temporary basis to bring their experience to the new program. Some of these staff stayed and others eventually went back to work at the intermediate care facility for people with developmental disabilities. During the first year of this new program, the turnover rate was about 75% (compared to a 40% average in the regional program). All direct support workers at this program have to be over 21 and are fingerprinted because the program serves minors.

The program consults with a board certified behavior analysis paid for by the county and their Director of Quality Assurance does crisis behavioral support as needed for the program. Additionally, for the initial individual who moved into this program, the crisis placement staff did a lot of consulting and support with REM prior to and immediately following admission.

Wages vary depending upon the position an employee works in the program, but employees who work in this program make on average about $1.50 more per hour than if they worked in another program run by the regional program. To start, direct support workers earn $10.60/hour if they are working an awake shift and $7.25/hour for asleep hours. The program coordinator/supervisor earns $14.25/hour. REM Heartland offers a robust benefits package for its employees, a cafeteria plan with levels of health insurance from which employees can choose as well as paid time off, dental, vision and short- and long-term disability. Full-time benefits are offered to employees who work 30 hours or more a week.

REM provides a robust training program to its employees. Within the first 60 days of employment all direct support workers receive 60 hours of training including basic training on topics such as rights, Vulnerable Adults Act and Rule 40. Additionally, in programs where individuals have autism, the staff attend a 10-hour training specific to autism developed by REM. This ASD training is broken down into four sessions that provide an overview of autism and interventions effective in working with people with autism. Seven employees within REM Heartland are considered ASD specialists and teach this training program.

The greatest challenges the program faces with regard to personnel is “finding the right people and grabbing their heart” so they see the potential in everyone served within this program. This is extremely difficult when you are trying to find staff who work with youth and adults who have severe challenging behavior and autism. One strategy the program uses to retain staff is to ensure that after each and every behavioral incident they debrief with all of the staff to learn from the incident and to support one another.

Residential Supports and Services across the Lifespan

When REM Heartland develops a new residential program, it is developed with the people in mind and with the hope that they will live in the home for a lifetime. REM Heartland is committed to people being able to stay in their homes and modifying services and staffing based on the changing needs of the individual. REM Heartland typically receives referrals for people needing services from various counties. The staff work hard to understand the unique needs of the individual in need of services and make a determination if they have an opening or can develop a new program to meet the person’s identified needs and desires.

A key component of residential services for this company is that they are delivered in the community and that the individuals who live in the programs have opportunities to be included in their communities. REM Heartland direct support workers know that community integration takes time, especially for people with significant behavior and sensory challenges; yet being in the community is a priority for everyone served in this program. Within this program they have been working with the individual who has the greatest support needs to go to a local park and walk each day, attend horseback riding therapy, ride a tandem bike in the neighborhood, and other activities designed to grab his attention and keep him busy throughout the day. He requires 1:1 staff most of the time and occasionally 2:1 but community integration is a priority and the staff are trained to desensitize individuals to new experiences.

General desired outcomes of residential services for all people who receive REM Heartland services are that they are happy, have increased independence and a meaningful life, and that their families are happy with the services provided. Each individual has an individualized support plan which includes learning goals and objectives.

Individual preferences related to nutrition and other interventions are respected and honored by REM Heartland. Currently they make every attempt to avoid serving processed foods at the request of one of the families.

Educational, Transition, and Employment Supports and Services

Two individuals who live in this program have completed their educational programming and are now in day programs at a local day training and habilitation center. The younger individual currently receives one hour of home-based education from a teacher in a local school district 3-4 days a week. When the teacher arrives, the residential program provides staff there with the teacher during instructional time. Instruction occurs in the lower level living area and the teacher is on one side of a counter and the student is on the other side. The iPad and NovaChat are used during instruction. This individual has an individual education plan and the goal is to be able to desensitize him to being able to go to the school location at least part of the day. The residential staff report a close working relationship with the school and the individual teacher. The local school district is responsible for meeting his educational needs as required by the Individuals with Disabilities Education Act.

Clinical Interventions and Approaches

For individuals with challenging behavior, an individualized behavior program is developed.

REM Heartland does internal assessments such as the Woodvale to assess independent living skills, sensory and interest inventories, and a sexuality assessment. REM program staff also conduct functional behavioral assessments prior to the development of a behavior plan to assist in identifying the purpose or function of observed challenging behavior. When an individual has a behavior program each behavior incident is documented and behaviors are charted to enable staff to identify triggers (e.g., staff present, time, location, medication changes). Additional efforts are made to monitor the use of any psychotropic medication. Routine and specialty health services are provided by community professionals.

Ongoing interventions are designed for:

- Person-Centered Orientation in Planning and Service Delivery
- Community Inclusion and Socialization
- Integration of Health Care Services
- Coordination of Services
- Personal Safety
- Respect for Individual Rights and Dignity of Risk
- Vocational and Educational Supports

Support to and Inclusion of Families

REM Heartland knows and embraces the need for families to be involved in the lives of their family member with a disability. From the very beginning of service provision it is REM Heartland's approach to have an open-door policy, to encourage open and honest communication, and to support family members in coming to the home or to support the person they serve in going to their family’s home. Many REM Heartland programs sponsor summer picnics, potlucks, or other similar activities in which family involvement is welcomed. Family members are not encouraged to be formal volunteers within the program but they are welcome in the program at any time. Staffed are trained to embrace, support, and work with family members.

Research Team Observations

The services provided for these young men have been evolving since the residence opened. The home itself seems well set up to meet the needs of its residents. The staff has support from REM Heartland administration that seems very willing to respond to the challenging issues ongoing in the home.

Notable features of the program:

- This organization was able to customize a new small community program to meet the needs of a person with extreme challenges due to his autism.
- Community integration is a priority and the staff in this program work hard to make it happen for each person served.
- This organization was able to work effectively with a county to develop a financial model that enabled the program to be built around an individual with significant challenges and then evolve the program over time to be a less expensive model. This transition was done in less than a year.
- The program has a specific training program related to autism and all staff who work with individuals with this diagnosis are required to complete it. They also have designated staff members with a specialty in ASD who are available to assist and train others.
- The program effectively uses assessment, program planning and data analyses to work successfully with individuals with significant behavior challenges by reducing incidents over time.
- The program provides a pay differential for employees who work in homes where people have significant challenging behavior or other support needs. This strategy, along with utilization of long-term staff with experience in the beginning of program implementation, enabled them to endure an initially high turnover rate.
- The program has an open approach to working with and embracing families of the individuals they serve.
- Home modifications and technology are used to ensure safety.

Emerging Themes across Case Studies

1. Each residential program that was visited had unique characteristics with strengths and stated challenges. No two programs were alike. Each of the service providers had over 18 years of experience in delivering services to children, youth and adults with autism. Many did not start out as autism specific service providers but over time they developed an expertise in serving this population. Some intended to expand their services to serve individuals with autism; others had no intentions for program expansion.

2. The residential programs had different philosophical approaches to service delivery and, each program seemed to live by their philosophy and mission which drove their services. Each program was committed to finding and capitalizing on the gifts, strengths and capacities of the individuals they served. They believed that the children, youth and adults they served were able to learn and they viewed their principle role as teachers and skill developers.

3. Every provider we visited had specific strategies and approaches to attract and keep well-trained management, supervisory and direct support employees. All but one offered benefit packages and most (though not all) offered wage differentials or paid higher than average wages for long- term services and supports in their area. Most had relationships with local colleges or universities and purposefully recruited students with academic interests in areas like special education, psychology or social work.

4. The providers visited were committed to staff training and offered on-going and continuing education training beyond that required by state regulation. Each had either developed their own proprietary training program specific to serving people with autism or they used a combination of training materials they developed or that were developed by others. Many encouraged their employees to continue in post-secondary educational programs and provided opportunities for on-site practicum learning.

5. Of the programs visited, none used the exact same intervention approach to teach new skills or reduce unwanted targeted behavior. However, all used principles of Applied Behavior Analysis, positive behavior support, communication training and/or environmental modification. Each program and their staff were observed as being well-versed in their selected intervention approach or strategy and it appeared to be consistently implemented and modeled by the management/administrative staff as well.

6. Programs that were more recently developed tended to address environmental concerns such as lighting and sensory rooms and they incorporated larger indoor and outdoor spaces in which children could wander and explore without fear of elopement. All but one of the programs had made modifications to ensure that people would not be able to leave the program location without an alarm sounding and these programs also had modified television sets (typically bolted to walls and encased in thick Plexiglas), curtains and wall hangings (either not present or adhered with Velcro) to prevent them from being damaged or used to harm others. Two programs used home monitoring and

sensor technology in order to observe individuals and staff from a remote location and one used monitoring technology to view children in time-out rooms.

7. Residential programs that were larger in size and located in more rural areas tended to offer fewer opportunities for the individuals served to engage and interact with their communities.

8. The campus model residential programs were time limited and children were typically there on a short-term basis (typically 1 – 4 years) until they could return to their home community. These programs were viewed as transitional in nature. Smaller programs that served fewer than 6 people were able to serve a child or young adult throughout their lifetime if the individual and family chose this as a permanent place of residence. These smaller programs tended to be more individualized. The physical location was designed with the individual in mind from the beginning and service provision was customized to meet the individual resident's needs.

9. Children and young adults in each residential program received special education services that appeared compliant with the provisions of the Individuals with Disabilities Education Act. The residential services and educational staffs had routine communication and worked to implement similar intervention strategies when possible. In the larger, more congregate programs residential staff often worked at least part time during the day with the children while en route to/from school or at the school itself.

V. Stakeholder Input Regarding Residential Services

Advisory Council

A part of this study included the facilitation of a short-term structured advisory group process to provide input and opinions on the effective characteristics of residential services for children, youth and adults with autism. Ultimately, a 39-member Advisory Council was assembled by the Minnesota Department of Human Services. Members of this group came from two sources. Ten of the members were asked to participate by study staff based on their involvement in related projects and policy initiatives. The other 29 members were selected after the Minnesota Department of Human Services sent an open request to stakeholders to submit a Statement of Interest to join the council to support the objectives of this project. Forty-six individuals applied for these spots. The 16 applicants who were not selected were invited to participate in stakeholder interviews.

The Advisory Council was comprised of parents, clinicians, county workers, advocates, service providers, educators and employees of Minnesota's Departments of Education, Health, and Employment and Economic Security. All participants had personal and/or professional experience in working with children, youth or adults with autism and their families—many of the parents on the council also work in the field.

The Advisory Council was asked to participate in a series of meetings and conference calls over the course of 11 weeks this fall. The meetings and calls were facilitated by the research team and were also attended by DHS staff.

Table 15: Stakeholder Advisory Council Membership by Stakeholder Type

	Metro	Out-State	Ethnic Minority
Parents	13	4	3
Clinicians	5	1	
Residential Service Providers	4	1	
Advocates	12	2	2
State or County Staff	7	2	
Educators	4		
Attorneys	2		

Note: some members fit more than one category.

Strategies Used to Ensure Diverse Stakeholder Perspectives

The Minnesota Department of Human Services and the project staff worked to ensure that diverse perspectives were gathered as a part of the stakeholder advisory process. The make-up of the Advisory Committee used a matrix of various perspectives to plan for and assemble the Advisory Council (see Table 15). Once convened the members had the opportunity to share with project staff their ideas for adding to the diversity of perspectives gathered. This process identified 41 individuals and 20 referrals to organizations and clinics. These suggestions included several organizations that serve people who are Native American, Somali, Hispanic, African American, Asian Pacific or Hmong. This process also yielded suggestions to include more practitioners with a behavior analysis or psychiatric background. Intention was used in identifying the additional stakeholders from these recommended sources for the participants in the key stakeholder interviews interview through the survey process.

Methodology

Research team members facilitated three Advisory Council meetings on October 16, November 13 and December 11, 2012. Full council meetings were held on Tuesday afternoons in the metro area. In between meetings, two Residential Services Workgroup conference calls were held on October 23 and November 20 and members had the opportunity to respond to follow up questions via on-line surveys. These three strategies were used in combination to ensure that stakeholders had ample opportunity in various formats to provide input. Overall participation was good across these three methods, see Table 16 for an overview of the meeting, call and survey participation. Each meeting and call was structured to include introductions of participants, review of the charge of the Council, updates on other components of the study, and a facilitated discussion to answer “key questions” pertaining to the research questions. The public was invited to attend or listen in to all sessions—there were approximately 10-12 guests at each of the meetings. Throughout the process Advisory Council members discussed the following topics:

1. Effective characteristics of residential services for children, youth and adults with ASD who have severe challenges in the cardinal characteristics of ASD (communication, repetitive behavior/restricted interests, socialization) and co-occurring challenging behaviors.
2. Gaps and/or overlaps in the provision of residential services to children and youth with ASD who have severe challenges.
3. Ensuring that residential services recommendations are consistent in the context of other DHS initiatives such as Minnesota’s Olmstead Plan, Rule 40 changes, Reform 2020 and Quality Commission.
4. Menu of options DHS should consider for serving children, youth and adults who have severe challenges in the cardinal characteristics of ASD (communication, repetitive behavior/restricted interests, socialization) and co-occurring challenging behaviors.

Table 16: Stakeholder Advisory Council Participation by Stakeholder Type

	Meetings			Workgroup Calls		On Line Surveys		
	10/16	11/13	12/11	10/23	11/20	10/19	11/17	12/20
Parents	16	10	11	4	3	Surveys were answered anonymously		
Clinicians	6	4	4	2	2			
Providers	4	4	3	3	2			
Advocates	13	9	11	2	4			
State or County Staff	9	7	8	5	5			
Educators	4	4	3	2	2			
Attorneys	2	2	2	2	2			
Total Participants	36	24	29	18	17	27	12	10

Stakeholder Advisory Council Input on Effective Characteristics of Residential Services

It is important to note that the role of the advisory council was to respond and discuss specific questions designed to solicit input from the various stakeholders about effective residential services for people with ASD. The time limited nature of this process did not allow for use of a consensus process, therefore the input described in this report does not represent group consensus. When possible, it identifies themes that emerged in stakeholder input.

Through the first meeting, conference call, and survey, Council members were asked to identify clear characteristics of effective residential services for individuals with ASD and to identify specific characteristics that would address the needs of individuals with “severe” autism. Participants were also asked to describe a model residential program for children and youth with the most significant autism.

Council members expressed varying perspective about whether or not strong residential support exists for individuals with ASD. Some of members talked about how some group home providers do not specialize in ASD and that there isn’t any specific program model that is serving this population well in Minnesota. At the same time, other members voiced strong support for existing community-based organizations that they identified as providing good supports to people with autism. The descriptions of effective residential services included the following characteristics:

- *Safe, Purposeful, Functional and Accessible Space* - Council members indicated that individuals needed to have their own bedroom and that the physical environment needed to be designed so that there were different spaces that accommodated the varied needs of the people who lived in the program at different times. The geographic location should be carefully selected to ensure there is as little unexpected noise as possible and that there was enough space for people to spend time outside without danger. Effort to ensure natural light, good air quality and to provide additional calming and sensory spaces was recommended. Some members mentioned the desire to integrate nature into the environment and program area. Others reported the need to have amenities available on site for the children who cannot go out into the community (e.g. swimming pools, hair-cuts, horses). Some reported the need to have sensory therapy rooms, swings and other playground equipment. When possible some stakeholders felt that it was important to make available hippo-therapy. Stakeholders discussed that rural or suburban locations could work provided the people had access to the community.

- *Careful Attention to Who Lives in the Residential Program Council*- Members discussed the importance of having a limited number of people living in same space and ensuring that housemates were selected based on similar needs and interests.

- *Highly Trained Staff who Have Specialized Skills in ASD*-Participants identified the need for a high ratio of staff to residents and that the staff who work in the program need to have specialized training and experience in working with people with autism. The staff of the program also needs to really know and understand the individuals who receive services and that they have a clear picture of each individual's history, needs and strengths.

- *Family Engagement and Active Involvement*- Members expressed an interest in integrated programming models where program staff and parents actively work together to develop services and support. Ideally there would be guest accommodations for parents to visit and stay overnight.

- *Strong Teams Based, Collaborative and Well-Coordinated Programming and Services* Members spoke of the need for a team approach to address resident needs and to have specialized case managers who truly understand the dynamics of autism. Members felt that having someone in charge of coordinating activities (e.g. recreation, medical appointments) and programming was important. The significance of community education and involvement was also mentioned and this included training police and firefighters in the area. Conversation also addressed the need for involvement of the neighborhood, non-traditional supports and a combination of informal and formal supports to complete the circle of care.

- *Effective Clinical and Teaching Approaches* - Members discussed the value of using effective clinical interventions and community support services such as behavior analysts, nurses, and occupational therapists to address the clinical and sensory needs of the individuals with autism served in the program. Members identified the need to include supports that are integrated with learning and education; with an emphasis on communication modes, highly individualized scheduling, rich opportunities to incorporate interests of each child and a focus on employment and use of technology.

- *Focus on Health and Nutrition*- Members mentioned the need for staff to focus on client nutrition and to provide healthy food options at all times. Some brought up the need for biomedical inputs and nutrition education for families and staff. There was not agreement on where medical treatment should be delivered (in the residential program or available in the community) but all members agreed that being able to attend to the medical and health related issues was important.

- *Prevent the Need for Out-of-Home Placements* -Participants discussed the need to focus on getting services to these children and their families early so that services can be delivered in the family home and families can stay together. However, members agreed that it is not always possible and that a certain portion of children with ASD will need out of home placement.

Gaps and Needs in Current Minnesota Residential Services

Through the second Advisory Council meeting, follow up call and survey, members were asked to provide input on the current gaps in residential services, perceived causes and emerging remedies. They were also asked to provide comment on whether or not campus or farm residential models should be made available to individuals with autism in Minnesota. The following themes emerged:

- *Access and Funding*- According to members, there is currently not enough access to high quality residential services for children, youth and adults with autism in Minnesota. The moratorium on intermediate care facilities for people with developmental disabilities new development and the home and community based services developmental disabilities waiver make it nearly impossible to design individualized residential programs. Members discussed the need for state policies that will eliminate waiting lists for people with autism (and other developmental disabilities). Members also discussed that there is not equality in the type and availability of residential services depending on where in the state you live.

  They discussed the need for greater consistency across counties and the need for a fair, transparent, accountable process for selection for placement and equitable funding for all families in need. Members reported the need for greater flexibility in creating new models of housing that correspond to licensing requirements and the ability to integrate intellectual and developmental disabilities and mental health services in one program model or other more flexible blended or braided funding allocation methods. Members also brought up the need to develop funding that addresses all aspects of an individual’s treatment plan; current models all inclusive per diem rates that result in specialized services often getting omitted from treatment plans.

- *More Options and Greater Support for Families*- Members discussed that families often have no or few choices in terms of where their children (or siblings) receive out of home placements. They reported that a greater number of choices that were specifically equipped and skilled at serving children with autism and co-occurring challenging behavior needed to exist. Members also identified the need to include more education to families about access to services, assessments, options and community resources. Providing opportunities for families to learn about and address cross-county inconsistencies was discussed. Additionally, members discussed the need for parents and siblings to have support across the lifespan.

- *Residential Services that Ensure Safety and Attend Environmental Needs* - In the current system, if people are lucky, they are offered an existing "slot" or available bed in an existing group home. Members discussed how this prevents the development of new housing options that integrate a holistic environmental model with good design principles (i.e. sensory integration) and the use of assistive technology. Members indicated that there is a need for physical environments that are developed or modified specifically to meet the needs of people with autism. These efforts should include attention to lighting, available space/locations for different people to go to for quiet time, available swings and other sensory resources and to ensure environments that eliminate the opportunity to flee.

- *Person Centered Planning and Services to Match (across the Lifespan)* - Members identified the need to intervene early with children with autism and to get support to their family early. This support needs to be focused on skill training (as opposed to caretaking). Understanding and planning for the needs of children and youth before they are in crises is recommended. Effective transition planning that focuses on meeting residential needs across the lifespan is important. Advisors brought up the lack of residential programs that are truly based on person centered planning approaches that are designed to meet the individual needs of children, youth and adults with autism. They discussed that taking a true person centered approach would allow for the integration of leisure and life and would allow for consistent coordination among providers, specialists, educators, parents and siblings. Another gap identified by the members was a focus on individual long term (life course) planning. Often planning is limited to the specific service delivered, one year at a time.

- *Trained Professionals and Direct Support Workers* - Members discussed a persistent gap in having enough qualified and trained professionals in Minnesota who are Board Certified Behavior Analyst trained or have other needed expertise and skills in occupational therapy, speech therapy, dietician/nutritionists and medical specialties to address the needs of Minnesotans with autism. These professionals need to be able to conduct ongoing assessment, use appropriate intervention protocols and evaluate of client needs and client outcomes. Members discussed a pervasive lack of access to such expertise in Minnesota, especially in Greater Minnesota and within culturally diverse communities. Additionally, members discussed the need for direct support workers (Personal Care Assistants too) to have training/competence in positive behavior supports and to have better staff to client ratios in residential programs. Certification in statute for Board Certified Behavior Analysts was discussed.

Members also reported the need to include training on autism for staff at all levels and recommended that state funding/support of training be available. Members identified the need for there to be high levels of oversight to ensure qualifications of staff that support children, youth and adults with autism. Additionally on-going continuing education and follow-up training was seen as important because often staff only get trained upon hire and then no additional training is provided that catches them up with information and skills development on new treatment approaches or interventions. Members discussed the need to develop a core list of competencies (similar to the College of Direct Support) and to provide training to staff using evidence-based ASD specific training. Other topics recommended by members were person centered planning and treatment models and training to address issues of culture and diversity. Members suggested that ASD residential programs needed to pay attention to retention and turnover of their employees and that training standards needed to be developed.

- *Programmatic Focus on Skills Development* - Members affirmed that residential services for people with autism must focus on skill development and learning. Members discussed the reality that many current residential programs are simply about caretaking and the staff are not trained to expect and teach new skills. Children, youth and adults with autism need to have access to residential services where the focus is on teaching and learning.

- *Focus on Nutrition and Health* - Residential providers need to be skilled and qualified to meet the ongoing nutrition and health needs of the children, youth and adults with autism that receive services. This means they need to know about, respect and implement special dietary needs as prescribed by a physician or requested by parents/guardians. Providers need to ensure that all staff are adequately trained to meet these needs and nutrition and health specialist services must be made available.

- *Culturally Responsive and Integrated Services* - Members discussed a gap in cultural supports and trained interpreters for families that do not speak English throughout the service delivery system, Additionally, members discussed the need for independent living skills training circles of support that include members form the individual’s community with a focus on cultural competence. Families in diverse communities need more proactive services to address needs before crisis. It was also discussed that there currently is no data gathered or reported in Minnesota on children and youth with autism who are aging out of youth services from immigrant populations.

- *Ongoing Oversight, Quality Assurance and Evaluation of Services* - Members discussed a lack of data analyzed and reported on a regular basis from state agencies regarding children, youth and adults with autism. They also discussed a gap in high level oversight of current autism services and the need to develop policies to ensure quality practices statewide and to have more state involvement in quality control related to residential services for people with autism.

- *Campus and Farmstead Model Programs* - Members did not agree on whether or not there was a need to develop campus or farmstead model residential services for children, youth and adults with autism in Minnesota. Members expressed a wide variety of views on these models. Some expressed strong opinions against using a campus or farmstead model. Some identified these models as a step backward toward institutionalization and described with passion the effort over the past 30 years to free people from institutional settings. Another perspective was that isolating young people will not prepare them in life and is not consistent with a social justice model because it is segregation.

Conversely others reported that segregated programs might work if they are used for short amounts of time—not for years and years. The Minnesota Life College model was brought up as a transitional program in Minnesota where kids live in town homes, have a buddy system and attend school in the local district (it should be noted that this program does not serve children with severe autism). Others spoke very highly of campus and farmstead models of residential programs and reported that they felt these models provide opportunities for people to be with other people like themselves, to have freedom to move around on a grounds that is safe and where all of the medical, nutrition and educational services are available to them right there in one place.

Among these perspectives was that families, if they were better supported, wouldn't feel the need to access segregated model residential services for their children. During these conversations members did agree whatever models are used, the main point is that more residential services are needed in Minnesota for children, youth and adults with autism and the current system is not sufficient to meet the safety and transition needs of children with severe autism. Access is just not available to these families who have children that need services—this results in many families and children in crisis.

Residential services options that should be available to Minnesota families who have children with severe or classic autism

The final stakeholder meeting and follow up survey focused attention on the types of services and support that should be made available to individuals with severe autism in Minnesota and their families. These are identified below and organized around a slightly modified version of a framework document provided to Advisory Council members at the initial meeting called, *Principles of Effective Practices in ASD across Intervention Programs and Services*.

A compilation of the ASD Advisory Council survey responses can be found in Appendix F.

1. **Residential Services Include Active Family Involvement Using an Integrated Model**
    - Residential programs that integrate family into planning, treatment-setting, decision-making, and provide families with flexibility and a welcoming environment need to be made available. Families need to be seen and respected as experts on their children and are included in behavioral supports, interventions and trainings.
    - In-home supports are always available with enough programming and staffing (direct care and clinical) to meet the needs of the child and family. All staff who deliver in home services have expertise and training in supporting children, youth and adults with "severe" autism.

- Timely and immediate access to in-home or out-of-home respite care, both short term and longer term, are available to children with autism in Minnesota and their families when these services are available. Respite providers have expertise in working with children, youth and adults with autism as well as their families.
- Families have 24/7 access to their child and the program services as needed and desired.
- Services include healthy, nutritious meals and programming to address individual dietary needs and preferences of the individual and their family traditions.
- Crisis supports to assist in reducing challenging behavior (e.g. self-injury, aggression, property destruction, extreme social withdraw) are immediately available when needed and as necessary include respite services (in- or out-of-home). Expanded mobile crisis service teams using Minnesota State Operated Community Services model are available and used proactively when problems initially emerge.
- Residential services are person/family directed to provide ultimate customization and flexibility. This includes control over how allocation of resources is spent.
- County agencies have clear criteria for eligibility and supportive referral programs to help families or individuals apply for and access services.
- Child welfare agencies understand the context and reality of having a child with severe autism and every effort is made to support the family in finding appropriate residential services (in-home or out-of-home). Every effort is made to maintain parental rights and avoid removal of children with autism from their parents.

2. **Residential Services are Person Centered and Individualized to the Unique Needs of the Individual with Autism**
    - Provide autism “specialty homes” with physical plant and clinical programming that is unique to the needs of children, youth and adults with severe autism.
    - Person Centered Plans that focus on the lifespan are required and fully implemented in all residential services.
    - The development of new residential programs and a more flexible approach to residential service development exists so that many more options are available to children, youth and adults with autism. These exist to avoid “plugging” people into any available residential settings just because an opening exists knowing that that service is unlikely to meet that person/family’s needs.
    - The system ensures that funding allocation is equitable for all levels of family income and irrespective of the county in which an individual/family lives.
    - Program models that honor individual preferences and needs across all areas of life including but not limited to: geographic location, housemates, environment, nutrition, clinical intervention approach, health and wellness are available.
    - Policies that ensure that individualized communication, behavioral and social skills interventions are available to people who receive residential services throughout their lives. Providers of these specialized services have training and expertise in autism.
    - Family supportive services and funding exist to allow family access and opportunities participation in child’s care (including transportation and housing when appropriate).

3. **Residential Services Include Environmental Designs that are Safe, Purposeful, and Offer Functional Space**

- ASD specific environments that are sensory adapted to meet the needs of residents with autism are available.
- Housing is built to attain certification from the Leadership in Energy and Environmental Design; this means that structures are environmentally friendly.
- Residential services that eliminate the use of environmentally toxic products are available.
- Smart Home Technology (technology used to monitor the environment and the people within) is used as an option when appropriate to support observation, safety and independence.
- More flexibility in the design of space by allowing new programs to be developed around the individual needs is developed.
- Kitchen preparation areas in residential services are able to accommodate dietary needs specific to the individual (e.g. gluten free, kosher, organic, vegan).

4. Residential Services Include Staff that are Highly Trained and Specialized in Autism Spectrum Disorders

- Qualified autism residential providers are available who can create proper behavioral and social intervention plans for the individuals who receive services.
- Residential programs train and integrate families into clinical interventions and treatments.
- Supervisors who work in residential programs have a 4 year degree in a related field and experience in working with individuals with autism, developing and implementing behavioral interventions and data analyses.
- A standardized certification in autism services exists for all practitioners who work in residential services that support children, youth and adults with autism/ASD.
- Processes for “on the spot feedback” and problem solving related to staff interactions and the opportunity to reflect and debrief challenging situations so they can become more infrequent are incorporated and used in residential services.
- Residential programs have collaborative relationships with public safety offices and provide these community members with training on autism/ASD.

5. Residential Services are Data Driven with Frequent, Ongoing Assessment

- Assessment processes are conducted for the individual served, including functional behavioral, health and wellness preferences, and transition. These assessments take a holistic approach to the individual and are multi-disciplinary.
- Specific outcomes of residential services are developed in collaboration with the individual, family, provider, other specialists and community members and the progress toward these outcomes is routinely monitored.
- An independent evaluation process exists through which an external entity monitors the quality of the residential services being provided. This process should include multiple stakeholder perspectives.

6. Residential Services are Culturally Responsive and Inclusive

- Ensure programs are culturally responsive to meet the needs and preferences of individual residents with autism and their families.

- Develop and make available professional interpreters for non-English speaking families.
- Residential service providers exist that are from various cultural and linguistically specific communities.
- Flexible models of services are available to meet the cultural preferences of children, youth and adults and their families (e.g. host families, shared living, community approaches to services).
- Data exists that routinely identifies who receives what types of residential services based on demographic information including race, ethnicity and linguistic identification.

7. **Services Promote Skill Generalization**
   - Allow the first focus to be skill building in the family home including behavioral supports.
   - Provide funding for family education and training.
   - Place more emphasis on early intervention.
   - Promote services that are holistic by designing care plan to grow skills in behavior, mental health, physical health, life skills, leisure skills, spirituality and family integration.
   - Promote services that use community settings for training (library, mall, YMCA) so that skills can be practiced in multiple environments.

8. **Services are Geographically Accessible**
   - Funds for residential services are allocated to support individuals not providers.
   - Residential services options are available in the same area as family members so that visitation and planning meetings are convenient.
   - Remove the moratorium on group homes limits so that services can be made available throughout the state.

9. **Services Address Transition, Employment, Education and Other Service Needs Across the Lifespan**
   - Develop holistic approach using collaborative relationships with community organizations, schools, employers and governmental agencies.

10. **Services Expand Natural Support Systems**
    - Continue holistic approach and reach out to neighbors, volunteers, extended family members, and religious organizations
    - Provide more coverage for personal care assistance and ensure that PCAs are trained specifically to meet the needs of people with autism with a focus on training and skill development and not caretaking.

Key Stakeholder Interviews

In-depth, structured interviews were conducted with 21 key stakeholders to examine effective residential service options for children and adults with severe autism. The Protocol for Autism Residential Services Study Key Stakeholder Interviews was developed by University of Minnesota and Minnesota Department of Human Services staff in conjunction with the members of the ASD Advisory Council; a copy of this Protocol is located in Appendix B. A Detailed Summary of Stakeholder Residential Services Interviews is located in Appendix E.

The questions in the interview focused on experiences providing and receiving residential services; characteristics of effective residential services; model residential programs for children youth and adults; effective practices involving families; culturally responsive residential services and supports; supports across the lifespan; barriers to meeting the long-term residential needs of individuals with autism; and improving access to effective residential supports for children youth and adults with Autism. A summary of the stakeholder perspectives are listed. Interviews were conducted by telephone. Interviewees were sent an email in advance of the interview explaining the purpose and they were provided with a copy of the questions to be asked.

Roles and Characteristics of Stakeholders Interviewed

When asked to identify their roles related to people with autism, 12 stakeholders identified their role as a parent, 8 stakeholders identified their role as a service provider, 3 stakeholders identified role as advocacy/parent organization and 2 stakeholders indicated other as their role (a few stakeholders indicated that they had more than one role). Of the 12 stakeholders who identified themselves as parents, they reported an aggregate of 8 children with classic/severe autism and 6 with diagnosis of Asperger's or ASD (not severe). The age range of the children included 8 school age children between the age of 3-17 and 6 young adult children ages 18-27.

Highlights Emerging from Stakeholder Interviews

Three key themes emerged from the interviews when stakeholders were asked to share their experiences—impact on families, navigating service system, and funding for services.

Impacting Families - In sharing their experiences, parents reported the stress caused by having to wait for services especially when families are in crisis. In more than one reported situation, the wait was more than two and a half years after the family was in crisis. Nearly all of the parents indicated that unless they got to a crisis point they could not access residential services. Even after they were in crisis, some had to deal with a lack of crisis beds, putting a further strain on already frayed situations. Longer term, these experiences led to all manners of family problems including severe financial troubles, divorce, depression, and, in at least one situation, suicide.

Some parents reported social isolation because they are often unable to take their children out of the home and their children require 24 hour supervision. Parents reported health issues due to fatigue, stress and lack of sleep. Additionally many had experienced trauma and physical injury.

Most were financially strained. In many situations, extended family was not present, available or willing to assist.

Parents whose children were receiving residential services also shared challenges—poor communication from staff, lack of accountability in training and teaching the children skills, lack of staff trained specifically to work with children with severe autism, and hostility toward parents who wanted to stay involved with their children were reported frustrations. For families receiving in-home services, the lack of privacy and lack of respite services was reported to contribute to strained relationships among family members.

Navigating Service System - Trying to find appropriate residential services that specifically address the needs of children, youth and adults with severe/classic autism was reported as extremely difficult. Stakeholders cited examples that included counties offering only limited out-of-home residential options and families having to try to find services on their own. Parents and other stakeholders reported an increased need for out-of-home residential services as the child with severe autism got older and their behavior became more difficult to manage; yet the opportunity to plan for such services so they would be available when needed did not occur. Stakeholders also indicated that because of the lack of out-of-home residential services, parents have to travel long distances to visit their children who are at residential programs outside of Minnesota.

Stakeholders identified lack of coordination of services as a challenge and cited instances where temporary out of home placement jeopardized school enrollment; transition programming was ineffective in addressing employment needs; county staff that were poorly paid and not trained to provide effective programs and interventions specifically for individuals with autism; and service providers having difficulty including parents and guardians as part of the team.

Funding for Services - Funding of residential services and supports for children and adults with autism was another theme that emerged from these interviews. Stakeholders expressed concerns about the lack of transparency and accounting of the cost for providing residential services children outside the family home in all settings (e.g. state operated, crisis, private provider or consumer directed community support). All stakeholders discussed the impossibly long waiting list for a home and community based services waiver and how the moratorium on building new residential services restricted children and families form being served. Stakeholders shared with the interviewer's stories about many children, youth and adults who need services and on waiting lists and how their families are sometimes falling apart. The inability to blend funding sources when a child is in a group home (for example, not allowing parents insurance to cover medications) was also a reported challenge.

Key Characteristics of Effective Residential Services

In the interviews, stakeholders were asked to identify characteristics of effective residential services. Comments emerged into the following categories. These are identified below organized around a slightly modified version of a framework document provided to Advisory Council members at the initial meeting called, *Principles of Effective Practices in ASD across Intervention Programs and Services*.

1. Family-Focused Services

Several stakeholders identified characteristics of effective residential services that were family centered:

- Service providers encourage family involvement.
- Families and guardians are expected to be actively involved on child’s support team.
- Parents are actively involvement and have opportunity to serve on board.
- Parents have input regarding what goes on and doesn't go on in the group home.
- Services are individualized and reflect the choice, desire and culture of the family.
- Parents are welcome and visit on a regular basis.
- Opportunities available for all family members to be involved.
- Service provider nurtures a good relationship between staff and families.

2. Person Centered Based on the Unique Needs of the Individual with Autism

Several stakeholders identified the characteristics of residential services that are person centered and individualized:

- Stakeholders work together to determine what's best for the child using person centered planning.
- Services are individually tailored and might include therapeutic interventions, increase independence skills or personal skills.
- Funding allows for individualized services that can be customized to the needs of people with severe/classic autism, not a one size fits all model.
- Families understand and are involved in person centered planning.

3. Safe and Purposefully Designed Environments

Stakeholders emphasized the need to consider the specific needs of children and adults with severe autism when planning and designing residential supports. Suggested features include:

- Settings are small and in a neighborhood that is centrally located in community.
- Settings have an open floor plan that is intuitive to what has to happen in the space, no fluorescent lighting, comfortable, and predictable.
- Areas that encouraged socialization are found in every home.
- Individual spaces are provided for each child and are safe and home-like.
- Home modifications include specific sensory, lighting, and safety locks.
- Some children would benefit from a campus or ranch in a non-urban or rural setting.
- Large outdoor spaces are available for individuals to safely explore and roam.
- Space can be divided into units of private rooms with appropriate sensory tailored to the individual including physical motor activities.
- Private rooms are designed with low lighting.
- Multiple spaces are available with different textures and lighting that is secure.
- Calming space is available in each home.
- Safe rooms are available with padding on walls and hard surfaces for kids that are self-injurious.
- Technology is installed such as alarms at the door and multiple devices in every room with schedules so kids would have access wherever they were in the home.

4. Highly Trained Staff Who and Specialized in Autism Spectrum Disorders

In responding to questions about effective characteristics and models of residential services for children and adults with autism, stakeholders identified the need for specialized staff training and credentials specific to autism. Key characteristics identified include:

- Staff, caregivers and supervisors need to have extensive training on autism.
- Staff need to understand the sensory aspects to autism to support auditory and visual needs of individual.
- Staff should encourage growth and learning and include caregivers in learning different philosophies and methods of treatment.
- Staff has individualized training with professional guidance along with supervision.
- Staff have courses in psychology, family psychology and ongoing continuing education units to stay current on best practices and that ensure staff understanding of complexities and stress of family of child with autism.
- Staff have a minimum of a two year degree and training in positive behavior supports.
- Staff have specific training using social stories and identifying most effective technique to address particular problem.
- Staff have competency-based training that includes training from an occupational therapist and speech language pathologist to address sensory needs, training from a behaviorist to address behavioral needs, and training from a nutritionist to address dietary needs.
- Staff have a passion to work with children and adults with autism.

5. Data Informed

Stakeholders did not identify the need for services to be data driven with frequent, ongoing assessment directly, however several stakeholders identified that effective residential services include extensive training for staff and families that is customized to meet the needs of the individual based on comprehensive planning. Stakeholders also identified specific program features including:

- Staff review goals and individual progress on an annual basis.
- Staff conduct quarterly meetings with families to share progress.
- Staff use behavior plans to track an individual’s progress in residential program.

6. Culturally Responsive and Inclusive

Overall stakeholders shared the belief that culturally responsive residential services and supports should be provided in Minnesota; however stakeholders varied in their experience with residential services and supports that were culturally responsive. Notable comments from stakeholders regarding culturally responsive residential services and supports included:

- It is important to learn about an individual’s culture, beliefs such as attending church, specific food considerations or dietary needs related to culture or ethnicity.
- Culturally responsive residential services and supports should be culturally diverse and mixed; staff should be culturally appropriate and matched to clients; one example is an adult day care center specifically for Somalis.
- One stakeholder shared an experience in which the residential program in which their child received services was multi-cultural including residents who are Somali, Latino and African American the staff in this program was also described as being culturally diverse

and they work to honor children's cultural customs and preferences in collaboration with the family.

7. Focused on Building Skills and Learning

Stakeholders talked about the need to emphasize teaching and learning in residential programs. Their comments are summarized below.

- Programming has to be team-oriented and consistent across providers such school, therapies, and medical; some group homes do a good job of integrating school programs with programming at home.
- Basic behavior interventions are ideal; a lot of behavior intervention focuses on attention seeking and not looking at the why of behavior.
- It is useful to measure the impact of intensive behavior programming in group homes with regular behavioral assessments.
- We should promote the use the individual service plans to identify programming needs such as physical activity that is age and developmentally appropriate, individualized dietary and nutrition, and occupational therapy/physical therapy/Speech for sensory integration needs.

8. Geographically Accessible

When responding to questions about effective characteristics of residential services, several stakeholders identified geographic accessibility as an important feature in residential services for allowing family involvement. Several stakeholders commented specifically on geographic accessibility in relation to the type of residential program including:

- Location of a campus should allow families to visit 2-3 times per week.
- Proximity of group home should be located in family’s community so they can visit regularly.
- If the location of farm or ranch is in a rural area, it should not more than 1½ hour drive from family.

9. Transition, Employment, Education and Other Service Needs across the Lifespan

Stakeholders varied in their interpretation of “supports across the lifespan” and shared several ideas regarding how to provide services and supports across the lifespan. Stakeholder comments included:

- Ongoing support is needed so individuals can become as productive as possible and make contributions during their life. A person with autism has different needs; some are able to learn things like cooking, others need hand over hand support in nearly every aspect of life.
- Age and developmentally appropriate programming is available that develops and changes as that individual grows (one example provided is that Applied Behavior Analysis might work for a child at age 6; however at age 15, the child’s needs are different especially medical, dental and hygiene needs; the learning never stops).
- Implement models that create more collaboration like a shared community with multiple families working together. Use community-type settings with families together that have similar needs and engage in congregate care.
- Agencies are interested in programs that serve childhood all the way to adulthood in group setting noting that kids in group homes need more structure.

10. Use and Rely on Natural Support Systems
Several stakeholders made references in their responses to the need for residential services that are connected to the community and include regular community outings. The concept of natural supports was most prominent in stakeholder responses related to cultural responsive residential services and supports and the need for individuals to be connected to their cultural and religious communities. Other stakeholder comments relating to natural supports included:

- Maintaining family connections is important. Siblings also need to be included,
- Effective services should include opportunities for individuals to stay connected with their church and practice their faith.

VI. Federal Policy and Initiatives Related to Residential Services

Overview of the Americans with Disabilities Act and the Olmstead Decision

Since the Americans with Disabilities Act was signed into law in 1990, the Act has resulted in positive changes in the lives and aspirations of people with disabilities across each of its four main policy goals: ensuring equality of opportunity, full participation, independent living and economic self-sufficiency. Improvements in architectural design and construction, transportation, and communication accessibility brought about by the Americans with Disabilities Act have enabled people with disabilities to experience greater independence and increasing levels of inclusion, employment and community participation (P.L. 110-325).

The preference in federal policy for home- and community-based services for persons with disabilities was advanced by the U.S Supreme Court's ruling in 1999 in the case of Olmstead et al. v. L.C. et al. (527 U.S. 581 Amended 2008 (P.L. 110-325)). The Olmstead Decision established that the unnecessary segregation of people with disabilities in institutions is a form of discrimination under Title II of the Americans with Disabilities Act of 1990 and set the responsibility of states to provide services to individuals with disabilities within "the most integrated setting" appropriate to their needs.

An executive order signed by President Bush in 2001 launched the "New Freedom Initiative" affirming the nation's commitment to the provision of publicly financed community-based services and supports to individuals with disabilities fostering independence and community participation. The federal government's commitment to assure the right of people with disabilities to live, work and receive services in community settings was renewed by President Obama when he declared 2009 to be "The Year of Community Living" and directed the Department of Justice and other federal agencies to "vigorously enforce the civil rights of Americans with disabilities" by ensuring the implementation of the Olmstead Ruling as a top priority (Department of Justice, 2012).

The Olmstead Ruling: Key Provisions and Implications

Among the most noteworthy outcomes of the Americans with Disabilities Act to date have been changes in the delivery of publicly financed services and supports that occurred in the Olmstead Decision. The ruling stated "that public entities must provide community-based services to persons with disabilities under three conditions when: (a) such services are appropriate; (b) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity" (U.S. Department of Justice, 2012).

The Supreme Court noted that its finding "reflects two evident judgments." First, "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life." And second, that "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment" (U.S. Department of Justice, 2012).

The Supreme Court's Olmstead Ruling requires states to develop comprehensive working plans to end unnecessary segregation of individuals currently living in segregated programs and to furnish supports to individuals on waiting lists at a "reasonable pace" with the goal of integrating individuals with disabilities into mainstream society to the fullest extent possible.

Each state must develop an "Olmstead Plan" that provides the framework through which it intends to comply with its obligation to ensure people with disabilities have access to opportunities to live, work, and receive supports in integrated settings. The plan is to provide an assessment of the state's current efforts to ensure individuals with disabilities receive services in the most integrated settings appropriate to their needs, identify policies and practices that may hinder the movement of people and services from segregated to integrated settings, and the steps necessary to address waiting lists and other related policy goals. The plan must describe the state's commitments to expand integrated opportunities according to a reasonable timeframe and include measurable goals, specify the resources necessary to meet those goals, and identify the groups of people with disabilities who are to be covered by plan activities.

Guidance from the Department of Justice Civil Rights Divisions suggests that plans should include specific commitments for each group of individuals with disabilities who are receiving segregated services and be able to demonstrate that progress toward effectively meeting its goals. It is important to note that states may use alternative strategies that accomplish the goals of an Olmstead plan. As of 2010, 26 states had written Olmstead plans while 18 states had published alternative strategies. Seven states were reported to have neither an Olmstead plan nor an alternative response to Olmstead (District of Columbia, Florida, Idaho, New Mexico, Rhode Island, South Dakota and Tennessee). (See the PAS Personal Assistance Center's website for a listing of state Olmstead Plans at http://www.pascenter.org/olmstead/olmsteadcases.php).

States are obligated to comply with the American with Disabilities Act's integration mandate and may be found in violation of the Act if the state funds, operates or administers its programs and services to individuals with disabilities in a way that results in their unjustified segregation or exclusion from society through its: (a) direct or indirect operation of facilities, programs or services; (b) financing of the delivery of services in private facilities; or (c) because it promotes or relies upon the segregation of individuals with disabilities in private facilities or programs through its planning, service system design, funding choices, or service implementation practices.

The integration mandate obligates states to:

- Furnish supports and services to individuals with disabilities in integrated settings that offer choices and opportunities to live, work, and participate in community activities along with individuals without disabilities at times and frequencies of the person's choosing.
- Afford choice in their activities of daily life and the opportunity to interact with non-disabled persons to the fullest extent possible.
- Provide individuals with an assessment of their needs and the supports necessary for them to succeed in integrated settings by professionals who are knowledgeable about the variety of services available in the community.
- Enable people with disabilities to make informed choices about the decision to reside in the most integrated settings by furnishing information about the benefits of integrated settings, facilitating on-site visits to community programs and providing opportunities to meet with other individuals with disabilities who are living, working and receiving supports in integrated community settings, with their families, and in other arrangements.
- Protect people with disabilities from the risk of institutionalization resulting from service or support reductions or reconfigurations as a result of state funding reductions through the provision of support alternatives that do not result in institutionalization.

Integration Mandate Prevails It is important to note that a state's obligation to comply with the Americans with Disabilities Act integration mandate are independent and separate from any regulations or requirements of Medicaid programs under Title XIX of the Social Security Act. A state could, for example, decide to address its wait list for developmental disabilities services by increasing placements in Medicaid funded institutional intermediate care facilities for people with intellectual disabilities and expanding the use of segregated institutional programs for all people with autism. This approach would not necessarily run afoul of Medicaid financing or operational guidelines but would violate the Americans with Disabilities Act's integration mandate by unnecessarily segregating people through the lack of more integrated support options and by providing certain services only in segregated settings.

Requiring the state to change its policy would not be considered a "fundamental alteration." Similarly, under Section 1915(c) of the Social Security Act states are allowed to place a cap on the number of eligible individuals with disabilities they will serve through their home and community based Medicaid waiver programs. While consistent with Medicaid regulations, the presence of such a cap does not remove the obligation of the state under the Americans with Disabilities Act to serve individuals with disabilities in the most integrated settings appropriate to their needs.

Conditions under Which Olmstead Applies The provisions of the Americans with Disabilities Act under the Olmstead decision apply to people of all ages with all types of disabilities. Under Title II of the Americans with Disabilities Act, an individual with a disability is "qualified" if he or she meets the eligibility requirements for receiving services or participating in the public program or activity. On an operational level, the Olmstead decision has been interpreted by the Department of Justice to apply to people with disabilities who receive services from segregated institutions or settings, as well as those who are at risk of institutionalization as a result of the lack of the availability or accessibility of publicly funded services and supports in the community. The definition of a segregated setting encompasses: "(1) congregate settings populated exclusively or primarily with individuals with disabilities; (2) congregate settings characterized by regimentation in daily activities, lack of privacy or autonomy, policies limiting visitors, or limits on individuals' ability to engage freely in community activities and to manage their own activities of daily living; or (3) settings that provide for daytime activities primarily with other individuals with disabilities" (U.S. Department of Justice, 2012).

Enforcement of the Olmstead Integration Mandate Enforcement of the Olmstead integration mandate is a central priority of the Obama Administration and a focus of the Year of Community Living initiative launched in 2009. Department of Justice officials note that the Olmstead Ruling encompasses more than requiring that people with disabilities move out of institutions and that enforcement efforts have been organized around three broad goals designed to ensure that people with disabilities have the services and supports that they need to live and thrive in the community. Focus is on ensuring people with disabilities: (a) have opportunities to live life like people without disabilities; (b) have opportunities for integration, independence, recovery, choice and self-determination in all aspects of life – in the settings in which they live, the activities that occupy their time during the day, their work, and in their access to the community; and (c) receive quality services that meet their individual needs (Perez, 2012).

In carrying out its responsibilities to ensure compliance with the Americans with Disabilities Act and the Olmstead Ruling, the Department of Justice utilizes an array of administrative and legal tools, including: (a) direct investigations of state policies and practices; (b) the preparation and issuance of Findings Letters reporting on the results and conclusions of their investigations, leading to; (c) Settlement Agreements with states on an acceptable course of action to bring illegal policies and practices into compliance with the Americans with Disabilities Act; and (d) litigation for system reform. The Department of Justice additionally offers technical assistance and guidance to states on Olmstead requirements and expectations, and provides information and materials for interested parties on its website, www.ada.gov/olmstead.

By 2010, the U.S. Department of Justice had brought, intervened in, or participated as an amicus or interested party in Olmstead litigation in an increasingly large number of states nationwide. Since that time, actions brought by the Civil Rights Division has expanded to over 40 matters in 25 states (see the Civil Rights Division website, at http://www.ada.gov/olmstead/index.htm). The initial focus of Olmstead enforcement was on enabling people with disabilities who were unnecessarily segregated in institutions to receive needed services and supports in the most integrated community settings appropriate to their needs. In recent years, however, enforcement patterns have expanded to include the extent to which the availability, quality and responsiveness of existing publicly funded community based service delivery systems protected individuals with disabilities from unnecessary segregation. This trend can be seen in the language and focus of the comprehensive settlement agreements that the Department of Justice entered into with states during the past several years.

For instance, the Department of Justice settled with the state of Georgia in October 2010 to resolve the complaint that Georgians with developmental disabilities and individuals with mental illness were being unnecessarily and unconstitutionally institutionalized and subjected to conditions that would harm their lives, health and safety in violation of the Americans with Disabilities Act and the U.S. Constitution. The agreement requires Georgia officials to change policies and to take a number of very specific operational steps to ensure people with developmental disabilities and those with mental illness receive appropriate services in the most integrated settings appropriate to their needs. Regarding people with developmental disabilities, Georgia agreed to take several significant actions including:

- End all admissions to state-operated institutions by July 1, 2011 and transition all individuals to the most integrated setting appropriate to their needs by July 1, 2015.
- Expand its home and community based waiver program to serve at least 1,100 individuals with developmental disabilities in the community to: (a) furnish supports to people in their own or their family's homes, (b) provide family supports to 2,350 families, (c) create 6 mobile crisis teams to all communities, and (d) establish 12 crisis respite homes.

The emphasis on states’ establishment of a community based service delivery infrastructure in the Department of Justice’s enforcement activities was underscored in a landmark settlement with the Commonwealth of Virginia aimed at ending the unnecessarily institutionalization of people with intellectual and developmental disabilities throughout its service delivery system. In the Department of Justice’s correspondence to Virginia, and in the subsequent settlement with the state (U.S. v. Virginia - 3:12CV059 (E.D. VA 2012)), the Department of Justice cited a number of “systemic failures” in the Commonwealth’s service delivery system “causing unnecessarily institutionalization” throughout the system including:

- The failure to develop a sufficient number of community-based institutional alternatives, especially for people with complex needs.
- The failure to use available resources to expand community services and re-align existing resources to prioritize investments in non-institutional settings.
- The presence of a flawed process for discharge planning that identified discharge barriers, individual’s needs, and services necessary to meet those needs.
- The failure to develop sufficient numbers of services in the community to meet waiting lists and address the needs of persons at immediate risk of institutionalization.
- The failure to develop the crisis response and respite capacity necessary to prevent people with disabilities in crisis from being institutionalized due to the lack of alternatives (Perez 2011).

As noted above, the obligation of states to furnish services to individuals with disabilities in the most integrated settings applies to individuals with disabilities receiving all types of public support not just those living in segregated institutional settings. The Department of Justice’s Olmstead enforcement activities have extended beyond publicly operated institutional facilities to include people receiving public supports that result in their inappropriate and illegal segregation in privately owned and operated nursing homes, day programs, and other facility based alternatives. A summary of Olmstead litigation activities in the 12 U.S. Circuit Courts of Appeals is available from the Department of Justice’s website at http://www.ada.gov/olmstead/olmstead_enforcement.htm.

State Operated Facilities The Department of Justice Civil Rights Division has issued Findings Letters and have been involved in Settlement Agreements regarding people with disabilities who are living in, or at-risk of entering state-operated facilities in several states including:

- *US v. State of Georgia* expanding community services and supports for over 1,000 people in state intellectual and developmental disabilities facilities and on waitlist for services.
- *US v. State of Virginia* resulting in the broad expansion of community support options for more than 4,200 people with intellectual and developmental disabilities in state and private facilities and on the state's waitlists.
- *Department of Justice's Findings Letter State of Mississippi* identifying violations on behalf of adults & children in public and private developmental disability facilities and concluding that the state is violating the Americans with Disabilities Act's integration mandate in its provision of services to adults and children with developmental disabilities and mental illness by unnecessarily institutionalizing persons with mental illness or developmental disabilities in public and private facilities and failing to ensure that they, as well as people on wait lists for services, are offered a meaningful opportunity to live in integrated community settings consistent with their needs.
- *US v. State of New Hampshire* (Lynn v. Lynch) addressing the needs of people with mental illness who reside in or are at risk of entering the state psychiatric hospital and state-operated nursing facility for people with mental illness.

Private Facilities The Civil Rights Division has intervened to prevent the unnecessary segregation of people with disabilities in private facilities receiving public support.

- Nursing Homes and Private Facilities
    - Texas - Intervention in Steward v. Perry, the Department of Justice was granted a request to intervene in a pending lawsuit against the state alleging violations of Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act for unnecessarily segregating individuals with developmental disabilities in nursing facilities. The intervention addressed the needs of thousands of people with intellectual and developmental disabilities in and at-risk of entering private nursing homes in the state with the Arc of Texas as an organizational plaintiff.
    - Virginia - Investigation regarding children with developmental disabilities in nursing homes, relief was included in the VA agreement (see above).
    - Florida – Findings Letter issued in September 2012 concluded the State of Florida was violating the Americans with Disabilities Act's integration mandate in its provision of services and supports to children with medically complex and medically fragile conditions. The Department of Justice found that the State of Florida plans, structures, and administers a system of care that has led to the unnecessary institutionalization of children in nursing facilities and places children currently residing in the community at risk of unnecessary institutionalization.
    - New York – The Department of Justice intervened in DAI v Cuomo regarding people with mental illness living in adult homes in New York City who were seeking integrated supported housing and community supports.

- Private Intermediate Care Facilities: A Statement of Interest was issued in private litigation.
- Day Programs and Services: Civil Rights Division activities have made it clear that the provisions of the Americans with Disabilities Act and the Olmstead Ruling are not limited to the settings where people live but also apply to the supports and services that people with disabilities receive during the day.
    - Oregon - Lane v. Kitzhaber Statement of Interest and, Findings Letter concluding that the State of Oregon violates the Americans with Disabilities Act's integration mandate in its provision of employment and vocational services because it plans, structures, and administers employment and vocational services for individuals with intellectual and developmental disabilities primarily in segregated sheltered workshops rather than in integrated community employment settings. This causes the unnecessary segregation of individuals in sheltered workshops that are capable of, and not opposed to, receiving employment services in the community. The Department of Justice recommended that the State implement remedial measures, including the development of sufficient supported employment services to enable those individuals unnecessarily segregated, or at risk of unnecessary segregation, in sheltered workshops to receive services in individual integrated employment settings in the community.
    - Virginia - Settlement of US v. State of Virginia and Olmstead settlements in Delaware, North Carolina and Georgia resulted in expansions of supported employment & integrated day activities in each of those states.
- Community Services
    - Delaware – Settlement of US v. State of Delaware US v. DE resulting in the expansion of community services for over 3,000 people with mental illness residing in or at risk of entering state psychiatric hospitals and private Institutes for Mental Disease facilities. The settlement also expanded access to assertive community treatment services, crisis services, and supported employment, intensive case management, peer and family supports. The settlement expanded the availability of integrated scattered site housing, rental vouchers and subsidies and assurance that housing complexes would have no more than 20% people with disabilities in residence.
- At Risk Cases: in a significant number of instances the Department of Justice Statements of Interest filed in support of private plaintiffs have included reference to practices and policies that result in the unnecessary segregation of individuals with disabilities as a result of:
    - State cuts to critical services without individualized assessments of impact or an exceptions process for those with special conditions or treatment needs.
    - Policies requiring people with disabilities to enter an institution to move to top of a waiting list for community services rather than being furnished with services in an integrated setting in the first instance.
    - Provisions limiting the delivery of needed services to persons living in an institution but not in the community.
    - State budgetary reductions to critical community mental health services supporting private litigation in California to prevent cuts to services for people

with mental illness who had been determined to be at risk of out-of-home placements without those services.
  - The lack of intensive, community based and "wrap-around" services for children with mental/behavioral health conditions.

Interaction of the ADA/Olmstead and Medicaid

How the Americans with Disabilities Act, the Olmstead decision and Medicaid financing of institutional and home and community-based services 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? 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 Olmsted 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 home and community-based services can be a powerful tool in assuring compliance with Olmstead. 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.

The national trend is that more individuals with intellectual and developmental disabilities, including individuals with autism, live at home with their families. Currently 55.9% of all individuals served through the home and community based services waivers live with family—and in five states 70% or more of the individuals served live with family (Larson et.al, 2012). A study done by Easter Seals (2008) indicated that this holds true for individuals with autism, at least for those under 30 who have finished high school. The study found that 79% of individuals with autism who have finished high school and are under the age of 30 live at home with their parents (as a opposed to 32% of young adults without autism).

Medicaid Funded Institutional Services

The Centers for Medicare and Medicaid Services defines intermediate care facilities for people with intellectual disabilities as institutions and further clarifies that an intermediate care facility for people with intellectual disabilities 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 (42 CFR 435.1009)". While the more common notion of institution is a larger facility, smaller intermediate care facilities for people with intellectual disabilities that more closely resemble community group homes are also classified as institutions due to the licensing category. Intermediate care facilities for people with intellectual disabilities, like all Medicaid State plan services is an entitlement as long as the individuals meets eligibility for entrance into the setting an has “medical necessity” for the service. Intermediate care facilities for people with intellectual disabilities must provide active treatment and furnish services on a 24/7 basis. Intermediate care facilities for people with intellectual disabilities 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 larger intermediate care facilities for people with intellectual disabilities provide “in-house” programs, throughout the country some 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 services in intermediate care facilities for people with intellectual disabilities 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 (Larson et.al, 2012). As of 2012:

- 12 states no longer have state-operated intermediate care facilities for people with intellectual disabilities 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 intermediate care facilities for people with intellectual disabilities, and.
- 20 states have no large private intermediate care facilities for people with intellectual disabilities settings.

And with recent Department of Justice actions in states such as Georgia, Texas, Virginia and Illinois (who have large numbers of individuals in intermediate care facilities for people with intellectual disabilities), we expect continued declines in the use of these types of settings.

There are nearly 4,000 intermediate care facilities for people with intellectual disabilities 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% of the individuals served in setting licensed for 1-6 individuals and 8 states accounting for 80% of the individuals served in settings licensed for 7-15 individuals. Reliance on these “community” intermediate care facilities for people with intellectual disabilities 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 (Larson et.al., 2012). These “community” intermediate care facilities for people with intellectual disabilities still must operate within a specific set of federal regulations—including staffing ratios, specific personnel requirements and a host of health and safety requirements.

Medicaid Funded 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 and the Balancing Incentive Payment program offer states increased federal financing to move people from institutional settings to home and community-based services, while 1915(k), Community First Choice incentivizes the use of home-based personal care. A focus on the 1915(c) and (i) options is included in the following sections as these provide the broadest array of services and can include out-of-home residential services, while touching on the other programs.

Home and Community-Based Character

Each of the Medicaid home and community-based services 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 issued May 3, 2012 (and building on an earlier version of the rule issued in 2009), the Centers for Medicare and Medicaid Services 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, the Centers for Medicare and Medicaid Services 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:

1) 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.
2) The setting is selected by the individual from among all available alternatives and is identified in the person-centered service plan.
3) An individual's essential personal rights of privacy, dignity and respect, and freedom from coercion and restraint are protected.
4) Individual initiative, autonomy and independence in making life choices, including but not limited to, daily activities, physical environment, and with who to interact are optimized and not regimented.
5) Individual choice regarding services and supports, and who provides them, is facilitated.
6) 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:

    i) Units have lockable entrance doors, with appropriate staff having keys to doors;
    ii) Individuals share units only at the individual's choice; and
    iii) 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 home and community-based services character, including:

1) A nursing facility;
2) An institution for mental diseases;
3) An intermediate care facility for the mentally retarded;
4) A hospital providing long-term care services; or
5) 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, The Centers for Medicare and Medicaid Services 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, the Centers for Medicare and Medicaid Services did make a ruling about the development of home and community-based services waiver-funded group homes on the grounds of a Missouri state institution serving individuals with intellectual and developmental disabilities. The Centers for Medicare and Medicaid Services , in a letter signed by Donald Berwick, the Centers for Medicare and Medicaid Services 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, the Centers for Medicare and Medicaid Services 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 The Centers for Medicare and Medicaid Services, 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* initiative and the *Balancing Incentives Payment* program, provide states with increased federal funding in exchange for making effort and investments in increasing home and community-based services, 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 Money Follows the Person. Although data are not specific as to which populations within the intellectual and developmental disabilities community have been served, given that these are transitions from institutions it is likely individuals with ASD are included. Eight states have applied for and received authorization for Balancing Incentives Payment—which provides these states with an increase in federal funding for all home and community-based services through September 30, 2015. The Balancing Incentives Payment is intended to encourage more investment in home and community-based services and reductions in the use institutional services—that is, a rebalancing of the service system toward community services.

A third option that incentivizes home and community-based services is the *Community First Choice* 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 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 (Medicaid Program, 2012)" As examples of this last type of expenditure, the Centers for Medicare and Medicaid Services offers non-medical transportation and microwaves. The Community First Choice option is open to individuals who meet an institutional level of care and have a need for personal care services.

Financing Residential Services

Medicaid - 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 waiver program. Under the 1915(c) provisions states can apply to the Centers for Medicare and Medicaid Services 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.

1915 (c) 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 home and community-based services 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 the Centers for Medicare and Medicaid Services. 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.

Individuals with ASD can be eligible for home and community-based services 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 home and community-based services waiver is directly linked to eligibility for institutional care (in this case eligibility for an intermediate care facility for people with intellectual disabilities), how states determine eligibility for intermediate care facilities for people with intellectual disabilities will determine if individuals with ASD are included in the state’s home and community-based services waiver program. Some states require that individuals with ASD have an intellectual disability in order to meet entrance criteria for intermediate care facilities for people with intellectual disabilities. This same restriction would then apply to the home and community-based services 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.

1915 (c) 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 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.

For individuals with ASD the home and community-based services 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 home and community-based services 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.

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 home and community-based services waiver. The home and community-based services waiver affords states considerable latitude in designing residential (and other) services that can be highly specialized and customized for individuals with ASD.

Medicaid - 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 home and community-based services. 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 home and community-based services in the Centers for Medicare and Medicaid Services materials and the application itself is called an iSPA, (i State plan amendment). The Centers for Medicare and Medicaid Services 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 home and community-based services potentially opens up services to individuals with ASD who do not meet eligibility for other home and community-based services options such as the waivers. States could craft a 1915(i) state plan amendment 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 home and community-based services waiver—yet need the types of supports and eservices available under the home and community-based services 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.

1915(i) Eligibility 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% of the federal poverty level. Individuals with incomes up to 150% of the federal poverty level 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 Supplemental Security Income limit or can also choose to include individuals who have income up to 300% of Supplemental Security Income and meet the eligibility requirement for institutional services. These individuals must meet the states' level of care requirements for eligibility for home and community-based services under 1915(c), 1915(d), or 1915(e) or an 1115 waiver. 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 haves 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.

1915(i) 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.

The Centers for Medicare and Medicaid Services 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.

1915(i) Covered Services 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.

Medicaid - 1115 Research and Demonstration Waiver - This 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 intellectual and developmental disabilities (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* services may provide some ASD specific treatment services for children. Early Periodic Screening, Diagnosis and Treatment 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. Although there has not been any definitive ruling from the Centers for Medicare and Medicaid Services as to what ASD specific services Early Periodic Screening Diagnosis and Treatment 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 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 home and community-based services waiver program, states did pay for residential programs with “pure” state and local dollars, meaning this funding was not used as match for federal funds. Today, only 12.9% of all spending for services for individuals with intellectual and developmental disabilities are “pure” state funds, that is funds not used as match to draw down Medicaid financing or used as supplemental payments to Supplemental Security Income recipients. 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.

VII. State Examples of ASD-Specific Residential Services

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 ASD and to support their families and caregivers and providing technical assistance to other Department of Public Welfare 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 intellectual and developmental disabilities, as long as they meet the eligibility criteria for services. Many of the states' intellectual and developmental disabilities programs do include services that are specifically intended to support individuals with ASD. 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 intensive behavioral supports that are of assistance to individuals with ASD. So while many states do not have a separate ASD waiver or program, they do fund specialized services to individuals with ASD. States, although they may not have autism-specific programs, often make explicit commitments to assure that individuals with ASD will be served through intellectual and developmental disabilities programs. For example, Virginia has created both regional and statewide collaborative organizations to ensure that individuals with ASD get the supports and services they need. Virginia expressly tracks how many individuals with ASD are served in their home and community-based services waivers to verify that individuals with ASD are getting access to home and community-based services.

Home and Community Based Services (HCBS) Waiver across States

As the prevalence of ASD diagnosis continues to rise, demand for waiver supports and services is expected to grow and will likely present significant policy challenges. State home and community-based services programs face lengthening waitlists and funding cuts. The 1915(c) waiver program functions as a "capped entitlement." States have the authority to limit the number of people enrolled in their waiver programs. While many states would like to increase the numbers of individuals served, declining state revenues and expanding Medicaid rolls have stifled growth. The mounting population of youth and young adults with ASD who are leaving school with substantial support needs increase the demands on an already-stressed service system. Those demands will increase in the coming years as the growing number of young people identified with ASD in early childhood progress through school and into the adult services system.

A review of statewide ASD policy indicated a significant need for additional funding to meet the diverse needs of individuals with ASD and their families. Funding limitations were consistently cited as a primary obstacle in the provision of specialized ASD services. Historically, people who have an ASD have been expensive to support due to the nature of their needs and states have been challenged to develop comprehensive, well-coordinated systems to support individuals with ASD.

Data for this section of the report was provided from the *Policy Research Brief: A National Review of Home and Community Based Services (HCBS) for Individuals with Autism Spectrum Disorders* (Hall-Lande, Hewitt, Moseley, 2011). The data on children's waivers was updated in December 2012 using the Easter Seals state autism profiles resource guide (http://www.easterseals.com/site/PageServer?pagename=ntlc8_autism_state_profiles), and linking to the websites, reports, and plans of state task forces, councils, and working groups therein. The review of state policy around waiver services revealed that all 50 states and the District of Columbia reported serving people with intellectual disabilities under one or more of their section 1915(c) or section 1115 Medicaid Waiver programs. The waivers in most states used broad categories when describing who was targeted for services in their comprehensive home and community-based services waiver, such as, "serves individuals with Developmental Disabilities, Intellectual Disabilities, Mental Retardation, etc."

Although many states serve people with ASD under their primary home and community-based services waiver, not all states explicitly included ASD as a specific related-conditions clause. At the time of this review, 40 states and the District of Columbia listed ASD as a related clause or explicitly included ASD in the definition of people served under the state's home and community-based services waiver for people with intellectual disabilities. Most states indicated that individuals with ASD were included in one or more of their home and community-based services programs for persons with intellectual and/or developmental disabilities (the latter sometimes referred to as "related conditions").

A growing number of states reported having ASD-specific waivers for children. For the purposes of the current study, Autism Waivers for Children were defined as ASD specific waivers serving the approximate age span of 0-21. Although many states serve children with ASD under the broad developmental disabilities waiver, those states were not included under Autism Waivers for Children category in Table 17. At the time this data was collected, 11 states offered ASD-specific waivers for children. As shown in Table 17, Arkansas, Colorado, Kansas, Maryland, Massachusetts, Missouri, Montana, Nebraska, North Dakota, South Carolina (Pervasive Developmental Disorder waiver), and Utah had ASD waivers specific to children. Connecticut had submitted a plan for ASD waivers. Two states, Indiana and Pennsylvania, had ASD waivers that specifically served adults in 2010. However, Indiana's Autism Waivers have been recently combined into a new Community Integration and Habilitation Waiver.

Eligibility under home and community-based services Waiver An analysis of eligibility standards for home and community-based services programs provided both consistent themes and variability across states. All states established that in order to be eligible to receive services under the home and community-based services waiver program, the individual would otherwise need long-term care in a nursing home or other institutional setting. Individuals with ASD also having a diagnosis of intellectual disability qualified for home and community-based services in each state. In terms of specific disability eligibility criteria, the majority of states used cognitive ability scores (i.e., IQ), functional limitation scores, or a combination of both to qualify for home and community-based services waiver services. Broad eligibility criteria such as diagnosis from a qualified professional (e.g., psychologist, physician and psychiatrist) or "meets DSM-IV criteria for disability" was also common in the eligibility language.

Functional skill deficits were another common component of eligibility across states. The majority of states listed deficits in functional/adaptive skills (language/communication, learning, mobility, self-direction, capacity for independent living) as an aspect of eligibility. The standard across states was three or more functional needs to meet state eligibility criteria. Intelligence quotient (IQ) was a more complicated construct as it related to state eligibility criteria.

For the majority of states that explicitly included IQ level as a component of eligibility criteria, the stated allowable IQ score had to be a standard score of 70 or below. A few states offered tiered IQ eligibility criteria with a different IQ cutoff point for related disabilities such as ASD. For example, a few states, such as Florida, have one IQ requirement for people with intellectual disabilities (59 or less) and another threshold (69 or below) for people with secondary conditions such as ASD. Some states, such as Georgia, indicated that persons with listed conditions other than intellectual disabilities qualify if they need similar types of services as persons with intellectual disabilities. Most states included more general terminology related to eligibility criteria, such as "[has a] diagnosis from a qualified professional" or "meets DSM-IVR criteria for mental retardation or ASD." A few states used internal assessments or eligibility screeners for inclusion in the home and community-based services waiver.

ASD-Specific Waivers An analysis of ASD-specific waivers revealed that specific eligibility requirements were: (a) the diagnosis of an ASD by a qualified professional (licensed psychologist or physician) and (b) Medicaid income eligibility requirements. In these programs, IQ was not specified as a component of eligibility criteria (although for 1915(c) waivers, they also had to meet institutional level-of-care criteria). For children's ASD Waivers, some states included financial eligibility statements, such as parents' income (e.g., Colorado), while other states excluded parental income (e.g., Maryland). All children's Waivers included eligibility for the diagnosis of ASD, but some states explicitly stated in policy that they extended services to children with Asperger's syndrome, Pervasive Developmental Disorder-Not Otherwise Specified and/or developmental disability. Diagnosis by a qualified professional such as a psychologist or pediatrician was required on all ASD children's waivers.

Services Provided Through ASD-Specific Waivers An analysis of services provided in the children's ASD waivers reveals a focus on specialized needs of children with ASD, including intensive, in-home behavioral therapy (e.g., Applied Behavior Analysis), speech therapy, occupational therapy, social skills training, and children's respite care. When comparing adult ASD waivers to non-specific developmental disability waivers, there appears to be some overlap in the services and supports provided. For example, common services listed under the specific adult ASD waivers included adult day services, respite services, behavioral support, family training, environmental modification, and employment supports. Pennsylvania providers of support under the adult ASD waiver are required to complete ASD-specific training and meet specific standards related to ASD. Clinical and behavioral supports, as well as technical assistance, were also made available to enrolled providers under the waiver program. Additionally, the services provided had to be established as effective for people with ASD.

ASD Waivers for Children are a Growing Trend

A growing trend across states was the development of specific waivers for children with ASD. Several states have ASD-specific waivers predominantly for children, and others indicated plans to develop one. The impetus to develop these seemed to be in response to multiple factors, including growing demand, extensive waiting lists and research confirming a critical window of intervention effectiveness during the early childhood years. Since most children with ASD do not receive a diagnosis until after 3 years of age, access to service is needed quickly. The development of ASD-specific children's waivers helps to address this issue by providing more direct and expedient access to services for children with an ASD diagnosis.

A review of children's ASD waivers across states revealed both similarities and differences in state policy. A common component of state children's waivers included a diagnosis of ASD and some states extended eligibility to other or broader disability categories such as Pervasive Developmental Disorders. Family support, Applied Behavior Analysis and intensive behavioral interventions were commonly identified services and supports in these programs across states. However, there were relatively wide variations in the ages covered under the children's waivers. Some states exclusively targeted the early childhood window (birth to age 5). Other states extended the age range from birth to age 21. Although specific age ranges for eligibility varied across states, all children's ASD waivers targeted children from birth to age 3. This policy is consistent with the growing body of research indicating that early childhood (birth to age 5) is a critical period for the effectiveness of behavioral, language, and other related therapies and interventions (Courchesne & Pierce, 2005; Dawson et al., 2009; Ozonoff & Cathcart, 1998). This policy focus on early intervention and effective supports might help the next generation of people with ASD fare better in the world of employment, community and independent living.

Not only were the states with ASD waivers for children part of a growing policy trend, states without ASD-specific children's waivers consistently indicated both the growing need and/or strong desire to develop specialized programs for children with ASD. A few states indicated that they were in the preliminary planning stages of a children's ASD waiver, and many other states indicated that they hoped to develop a children's program in the future. Current funding limitations were consistently cited as an obstacle to developing these waivers.

Table 17. Status of home and community-based services waivers across States (2012)

State	Autism Related Clause	Autism Waiver for Children	Autism Waiver for Adults

State	**Autism Related Clause**	**Autism Waiver for Children**	**Autism Waiver for Adults**
Alabama			
Alaska	X		
Arizona	X		
Arkansas	X	X	
California	X		
Colorado	X	X	
*Connecticut			
Delaware	X		
DC	X		
Florida	X		
Georgia	X		
Hawaii			
Idaho	X		
Illinois	X		
*Indiana	X		
Iowa			
Kansas	X	X	
Kentucky			
Louisiana	X		
Maine	X		
Maryland	X	X	
Massachusetts	X	X	
Michigan			
Minnesota			
Mississippi	X		
Missouri	X	X	
Montana	X	X	
Nebraska	X	X	
Nevada	X		
New Hampshire	X		
New Jersey	X		
New Mexico	X		
New York	X		
North Carolina	X		
North Dakota		X	
Ohio	X		
Oklahoma			
Oregon	X		
Pennsylvania	X		X
Rhode Island	X		

State	Autism Related Clause	Autism Waiver for Children	Autism Waiver for Adults
*South Carolina	X	X	
South Dakota			
Tennessee			
Texas	X		
Utah	X	X	
Vermont	X		
Virginia	X		
Washington	X		
West Virginia	X		
*Wisconsin	X		
Wyoming	X		

*Notes: Connecticut currently has submitted a plan for ASD waivers. Indiana's Autism Waivers have been recently combined into a new Community Integration and Habilitation Waiver. Nebraska has an approved autism waiver for children. However, they are currently waiting on a private donation match and have not been able to implement. South Carolina has a Pervasive Developmental Disorder Children's waiver. Initial data from Policy Research Brief: A National Review of Home and Community Based Services (HCBS) for Individuals with Autism Spectrum Disorders (2011). Data on children's waivers was updated in December 2012 using the Easter Seals state autism profiles resource guide.

Medicaid HCBS that Support Living Arrangements for Individuals with ASD

The 1915(c) home and community-based services waiver and 1915(i) options under Medicaid are the most likely sources of funding 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. The individuals' person-centered plan should, of course, specifically address any needs relating to his or her ASD, including specific supports that may be needed wherever the person lives.

Like services to all individuals with intellectual and developmental disabilities, 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.

In addition to the advocacy in Minnesota, some other 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 the Department of Justice guidance, these settings may not comport with the Olmstead ruling—and also may not comport with the Centers for Medicare and Medicaid Services' eventual regulation on home and community-based character. Given the Centers for Medicare and Medicaid Services focus on community character and the Department of Justice 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"* (Ahrentzen and Steele, 2009) provides a comprehensive overview of current trends in supporting individuals with ASD. 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 gives specific advice in each of these areas with great attention to detail—even to things like landscaping and specific materials in construction that can 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 that

> 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. 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 (Ahrentzen and Steele, 2009)**.**

As noted earlier, states have wide latitude in crafting the array of supports and service s covered under their home and community-based services waivers. States can craft their own definitions of any service—and can propose new and innovative services that do not appear in existing Centers for Medicare and Medicaid Services 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 Centers for Medicare and Medicaid Services proposed definition defines these settings as, “Round-the-clock services provided in a residence that is NOT a single family home or apartment.”

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 home and community-based services waiver, 27.5% lived in some type of residential facility—that is a provider controlled setting with multiple residents (Larson et. al., 2012). If a provider controlled setting does not work for the person with ASD, typically the individual must move and seek a new place to live, which can cause significant stress and disruption particularly for individuals with ASD who may need predictable, stable relationships and routines.

Foster Homes The proposed Centers for Medicare and Medicaid Services 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.” 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.

Supported Living - In the proposed taxonomy the Centers for Medicare and Medicaid Services has chosen to define supported living as**, “**Round-the-clock services provided in a person's home or apartment where a 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.

Family Home-Based Services - Many more individuals with intellectual and developmental disabilities, 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 home and community-based services waiver (and thus 1915(i) also) allows states to apply to make payments for rent and food expenses of an unrelated live-in caregiver. *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 is not a provider agency sending someone—but is an arrangement based on a mutual decision to share lives.

Community Transitions Services The Centers for Medicare and Medicaid Services 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." 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 home and community-based services 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 home and community-based services 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." While the services definition goes on to note that states can cover things 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.

One emerging area of environmental adaptations is remote or electronic monitoring. Both Indiana and Ohio offer this service under their home and community-based services waivers for individuals with intellectual and developmental disabilities, including individuals with ASD. 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.

Assistive Technology The Centers for Medicare and Medicaid Services 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," 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 home and community-based services 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.

Other Supportive Services **-** Other supports may be critical to the success of residential or home-based services. Employments 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 home and community-based services waiver programs, or through other options such as 1915(i).

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 intellectual and developmental disabilities (including 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.

VIII. Context and Implications of Minnesota State Initiatives

Minnesota Department of Human Services Olmstead Planning

Minnesota does not currently have an Olmstead Plan. However as a requirement of a settlement agreement reached in 2011 (related to a class action lawsuit against the State of Minnesota Department of Human Services [DHS] in the U.S. District Court by three former residents of the Minnesota Extended Treatment Options program) DHS was mandated to establish an "Olmstead Planning Committee." The Olmstead Planning Committee was charged with making public recommendations as to the establishment of a State Olmstead Plan by October 5, 2012. By June 5, 2013, the state and DHS are mandated to develop and implement a comprehensive Olmstead Plan that uses measurable goals to increase the number of people with disabilities receiving services that best meet their individual needs and in the "most integrated setting." The Olmstead Planning Committee submitted its report to DHS on October 23, 2012.

The Olmstead Planning Committee developed a Vision and Principles Statement as a component of their plan recommendations that are intended to guide DHS in the development of the Minnesota Olmstead Plan. The stated mission of the Minnesota Olmstead Plan as recommended by the Olmstead Planning Committee is that the plan "will empower and support people with disabilities of all ages and abilities to live with dignity and independence in the most integrated setting consistent with their own preferences and based upon their own choice. The intended outcome of the plan is to expand, strengthen and integrate high quality and effective systems of community-based services and supports that are person-centered, individually-directed, and adequately funded" (Olmstead Planning Committee, 2012). The Olmstead Planning Committee plan recommendations can be found at: http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=opc_home

The Olmstead Planning Committee report included a number of recommendations and goals related to services and support for people with disabilities in Minnesota. The Olmstead Planning Committee recommendations and goals focused on a number of areas relevant to residential services for children, youth and adults with autism, including: community based services and supports, state plan Medicaid services, where people live, where people work, and how to measure community integration. Many of these goals and recommendations are similar to information provided by stakeholders in this study. The Olmstead Planning Committee recommendations and goals that appear to be most highly related to this study are identified below and certainly need to be taken into consideration when authorizing, planning and developing residential services for children, youth and adults with autism/ASD.

Related Recommendations (taken from Olmstead Planning Committee 2012):

- The State should develop a process to ensure that there is enforcement of consumer choice by all providers including but not limited to case managers as well as service providers.
- Evaluate and consider adding the following services to the Medicaid state plan: 1) an inter-agency employment initiative which should include a DHS state plan service under 1915(i) to add a broad employment supports service for all people with disabilities who need services to get and keep employment. This should include the aspects of IPS, autism specific

employment supports, family stabilization services and other supported employment services that can be covered by Medicaid; 2) caregiver-family education and supports, including respite services.

- Develop regional crisis services to assure the provision of assessment, triage and care coordination so that persons with disabilities receive the appropriate level of care in the most integrated setting.
- Expand consultative services and make them available state-wide through the use of telepresence (the provision of services via encrypted video conferences using the Internet and computers/video screens and sound capabilities to communicate back and forth between a remote location and a central location).
- Support workforce development for public and private providers. Development should include a short-term training component for existing professionals that achieves competency in the areas of positive behavioral supports and person-centered planning and thinking. It should also include.
- Use a long-term strategy to develop a sufficient number of individuals with advanced training and competencies in treatment for individuals with developmental disabilities, people with mental illness and co-occurring chemical dependency issues and other clinical complexities.
- Establish and communicate to every individual with a disability his/her (monthly or annual) budget for housing and services. This budget amount will assist an individual to make informed choices on services and supports similar to a budget for a person without a disability.
- This individualized budget approach will require establishing a state-wide methodology for accurately assessing the cost per service/support. The current plan is for MnCHOICES to be the methodology for calculating individualized budgets.
- The waiting lists for the developmental disabilities waiver and community alternatives for disabled individuals waiver must be tracked, monitored and the Plan must contain a plan to reduce waiting lists. The state should consider a systematic method of reducing waiting lists in keeping with the spirit and intent of the Olmstead decision.
- The state should implement an outcome measurement process that gathers specific outcome indicators related to the populations included in the plan about the quality of their lives in the community. This measurement process should gather data across several areas of life domains including health, safety, well-being, employment, social relationships, home, satisfaction with services and supports, choice and control, and inclusion/integration. It should provide comparative analyses opportunities across programs, populations and in comparison with other similar states.
- The data gathered to monitor community integration and the outcomes experienced by people who have been integrated should be easily accessible to the general population and should provide comparisons of the progress made in Minnesota over time and in comparison with other similar states. Annual progress should be reported.

Related Goals (taken from Olmstead Planning Committee 2012):

- Increase the availability and access to integrated community settings in order to ensure that all people with disabilities have the ability to live in the most integrated setting possible.

- Reduce the number of persons with disabilities residing in nursing homes and intermediate care facilities for people with developmental disabilities by 2,000 individuals over a five year time period through Money Follows the Person.
- Establish a minimum reduction of 5% over the next five years in adult foster care beds and housing with services establishments. The money saved from reducing less integrated bed capacity should not be part of a budget reduction exercise but rather be reinvested into an array of existing or new and enhanced services.

Reform 2020

In 2011, the Minnesota Legislature directed DHS to reform Medical Assistance, Minnesota's Medicaid program, to achieve better outcomes for people with disabilities, seniors and other enrollees. Federal approval will be sought so the state can make changes in the areas of community integration and independence, improved health, reduced reliance on institutional care, attainment of housing and employment and reduced use of services that are less effective. This initiative is called Reform 2020. Detailed information about this initiative can be found at: http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=dhs16_166654

The Reform 2020 waiver proposal is a comprehensive package incorporating many of the key components of the overall reform initiative. On Nov. 21, 2012, DHS resubmitted the waiver proposal to the Center for Medicare and Medicaid Services. The Center for Medicare and Medicaid Services has held a 30-day federal comment period from Dec. 5, 2012 through Jan. 6, 2013.

Some components of Reform 2020 have significant implications on residential services for people with autism. The effort to redesign Home and Community-based Services provides a new conceptual framework that focuses services on bolstering community and family support and using intensive support models only when absolutely necessary. Among the goals of Reform 2020 that are relevant to residential services for people with autism and the information heard form stakeholders throughout this study are: 1) improving individual outcomes for people who currently have high costs and cross-systems needs that are not well-managed, 2) providing better informed individual decision making about long term services and supports, 3) promoting lifelong person centered planning, 4) improving transitions from one program to another, 5) getting low cost, high-impact services to people in need earlier, 6) focusing on home and community-based services as an entitlement instead of institutional care, and 7) decreasing the reliance on more costly services (institutional).

Another implication of Reform 2020 is the recommended change from Personal Care Attendant Services to Community First Services and Support. This proposed change would allow this service to be more flexible and include additional activities such as teaching, coaching, prompting and providing home modifications and the use of technology to replace human supervision. It also includes the opportunity to develop provider standards to promote the hiring of staff with appropriate skills. Additionally, eligibility would be based not only on functional activities of daily living needs but would also include challenging behaviors. Community First Services and Support would be offered in traditional service provider models but also through self-direction. Lastly, Reform 2020 includes provisions specifically related to services for children with ASD that are coordinated with medical and education services and provide early intensive behavioral interventions.

Money Follows the Person

The Money Follows the Person Initiative is a grant to the Minnesota Department of Human Services, funded in 2011 that allows the state to draw additional federal dollars to support people with disabilities and elderly Minnesotans who currently live in institutional settings to move into the community. This grant targets people with intellectual and developmental disabilities, mental health diagnoses, brain injury and the elderly. Over the next 4-5 years a plan will be put in place to move hundreds of people from institutional or congregate care facilities into community programs.

When thinking about residential services and supports for people with autism there may be an opportunity to re-focus opening intermediate care facilities for people with developmental disabilities "beds" in certain programs that may close the create a transitional program specific for people with autism that are in crisis. It will also be important to ensure that this does not result in target number of community placements required of the grant being difficult to meet.

Intermediate Care Facilities for People with Developmental Disabilities and Home and Community-Based Services Adult Foster Care Moratoriums

In 2009, the Minnesota Legislature authorized a moratorium on the growth of adult and child corporate foster care limiting capacity at 14,156. This means that new growth is not permitted unless all of the individuals meet hospital level of care (meaning they otherwise would be in an acute care hospital) or an exception is made by DHS. The development of new corporate foster care sites specifically for people with autism is currently not permitted unless there is an open bed or the individual meets hospital level of care. The ability to create any type of group residential setting for people with autism (that draws any federal matching resource) will likely require an exception or lifting of these restrictions put in place related to the moratoriums.

Rule 40 Task Force and Pending Changes

Rule 40 is a law in Minnesota that requires providers of services to people with intellectual and developmental disabilities to limit the use of aversive and depravation procedures when addressing programmatic needs of people with intellectual and developmental disabilities who have challenging behavior. This current law requires the development and approval of Rule 40 plans whenever these types of procedures are used. In 2012, the Rule 40 Advisory Committee was formed as part of a class action legal settlement (the Jensen settlement) involving individuals served at Minnesota Extended Treatment Options within the State Operated Services division of the Department of Human Services (DHS). The committee's purpose was to study, review and advise DHS on how to modernize Rule 40 to reflect current best practices in the treatment of challenging behavior (e.g., aggression, self-injury, destruction) in light of increased restrictions on the use of restraint and seclusion procedures in the Jensen settlement. The advisory committee met monthly between January 2012 and December 2012, with more frequent subcommittee meetings from July-September. The advisory committee consisted of 16 people representing counties/lead agencies, family members, independent experts, Minnesota DHS, Minnesota Disability Law Center, Minnesota Governor's Council on Developmental Disabilities, parents, plaintiffs' counsel, providers, and self-advocates.

A draft report of the advisory committee's recommendations will be available in early 2013. The recommendations will highlight the need for the updated rule to act as a guide for person-centered positive support strategies rather than a list of prohibited techniques. A manual will accompany the new rule and further specify requirements for person-centered positive supports, staff training, monitoring, reporting and oversight. In brief, the draft recommendations will include universal person centered planning, the use of positive support strategies that have an evidence base, frequent data-based treatment evaluations for each individual, and efficient access to additional experts in service disciplines not yet represented on the treatment team when data indicate insufficient progress. The recommendations will also clarify the definition of emergency, permit manual restraints in case of emergency only and prohibit mechanical restraint and seclusion.

Implementation of recommendations will require changes in licensing requirements for services providers, changes in current staff training, and may impact the availability of residential services to support individuals with intellectual disabilities who need intensive residential services. It is the intent of the committee to provide for sufficient staff training opportunities so service providers are well-trained and well-supported as they address the new requirements, and the committee recognizes the scope of the effort required to do this effectively and sustain new practices to realize the ultimate goal of culture change throughout the service system. These recommendations will be applicable to any residential service program for Minnesotans with autism.

IX. Summary of Findings and Implications

This final section of the report summarizes the findings of this study across the various methodologies used to obtain information. This summary is intended to inform decision making related to residential services for children, youth and adults with autism; especially those with the most severe autism. This summary includes information gathered from stakeholders regarding residential services for people with autism but it is not a consensus report of stakeholder input. Instead it is a summary of findings from stakeholders (the ASD Advisory Council and Key Stakeholder interviews), case studies, the review of national policy and initiatives, and from the literature.

Is There a Need for Autism Specific Housing?

Autism-specific housing is a growing topic of interest especially with the rise in children being diagnosed with ASD and the current population of children with ASD growing older and transitioning into adulthood. Many states are currently trying to respond to advocacy efforts promoting (and refuting) the need for ASD specific residential services. Some families advocate for segregated ASD specific programs while some families want integrated community programs. Nearly every state has waiting lists for long-term services and supports, including residential services and this is certainly true in Minnesota. Many families are struggling as they wait for much needed services and supports.

Families who have children with severe functional limitations due to ASD often have difficulty in keeping jobs; can have limited opportunities for socialization friends and family due to social isolation; may be sleep deprived because their children are up all night; and may encounter frequent injury such as bites, bruises, hair pulled out of their heads and even broken bones. Many of these families experience trauma regularly and are struggling to make it from one day to another. These difficulties often lead to divorce, broken families, poverty or bankruptcy, mental illness, drug and alcohol abuse, and suicide. Even in these crisis situations, families wait for services.

During this study, we have found that some families are happy with the services they receive while others are extremely unhappy and frustrated. Based on information obtained in the course of this study, access to services and supports is very uneven from family to family and from community to community in Minnesota. This inequity and inconsistency in family experiences should be of great concern to policy makers and policy advocates in Minnesota. Services ought to be provided consistently and access should be available no matter the situation the family is in or in the community in which they live—the services need to be provided by trained, committed and caring professionals who have the knowledge, skills and ability to deliver the right kinds of support at the right time. The debate remains as to what types of service settings should be funded and made available.

As has been identified in earlier sections of this report, residential services and living arrangements of people with autism vary in size, model and type and they are generally designed for individuals with disabilities other than autism (Van Bourgondien & Elgar, 1990). There is little research available but what exists indicates a growing demand for residential services for children, youth and adults with autism, as well as the development of strategies for assuring the quality of these programs (Van Bourgondien & Schloper, 1990). One only has to look at the growing prevalence of autism and subsequent collected data in the United States to see this growing demand for residential services.

Autism is considered a developmental disability but there are unique attributes of individuals who have autism: deficits in communication and social skills, restricted and repetitive behaviors, sensory deficits, and, often, significant behavioral challenges. Treatment and care needs to be specialized for individuals with autism with an emphasis placed on communication, social interaction and positive behavioral intervention to teach new skills. There are many different perspectives on whether or not people with ASD require separate housing with specialized support services or if current residential services can and do meet their needs. There are identified advantages of ASD-specific housing as well as disadvantages.

Individuals with autism often present with certain challenges that require specific interventions that attend to communication approach, sensory integration, sleep disturbance and challenging behavior. For some individuals with autism, challenging behaviors make all aspects of daily living difficult. One advantage of ASD-specific housing options is that people with autism receive interventions that are consistent and work with minimizing or reducing their challenging behavior. Staff can be trained to implement consistent interventions and approaches and environmental modifications can be developed to prevent such challenges.

In a review of several studies, Mahan and Kozlowski (2011) identified several effective strategies used to support individuals with ASD in residential services. These include: 1) differential reinforcement for adults with comorbid ASD and intellectual disabilities, 2) the use of a mixture of differential reinforcement, response cost, and relaxation, and 3) non-contingent reinforcement combined with response cost.

Other studies have shown effective outcomes for people with ASD when specific interventions are used by residential staff. For example, the Autism Program with a Structured Method (PAMS) model was used over a four year period and showed significant changes in stereotypic behavior and communication (Gerber, Besserom Robbiani, Courvoisier, Baud, Travore, Blanco, Giroud & Carminati, 2011). Additionally, in a study of the use of the Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) psycho-educational model showed an increase in visual structure used by staff and a related increased residents' use of skills independently (Van Bourgondien, Reichle & Spencer, 2003). ASD specific programs can allow for physical environments that best meet the sensory needs of the individual such as using space to develop specific sensory integration rooms, quiet rooms, modified lighting, fencing and other environmental modifications that are designed for people with ASD.

There are also important reasons why clustering people with ASD together in the same residential program may not be an effective approach. Even though grouping may aid in simplifying program development, staff training and implementation, it may also lead to additional challenges for staff. According to Van Bourgondien and Schopler (1990), grouping can lead to higher staff turnover due to a decrease in morale by attempting to treat and serve some of the most difficult individuals through one program. Additionally, individuals with autism who are together in one location may not have the benefit of seeing appropriate behavior modeled for them by others when they are only around people who exhibit similar behavior.

It is also important to remember that clustering children and youth with a label of autism/ASD together in one program does not mean that the children will have the same needs. The autism spectrum includes children with very different needs. Additionally if everyone in a program has autism and co-occurring challenging behavior it may be more difficult to provide enough staffing support to ensure that all people in the program get opportunities for community inclusion and participation.

Campus and Farmstead Model or Community-Based Model

Another decision point that many states are facing based on strong advocacy efforts is whether or not to build campus or farm model autism-specific residential programs. Stakeholders in Minnesota have different opinions about these program models. On the one hand many stakeholders feel that campus and farm models promote segregation and are a step backward from the decades-long efforts to rid Minnesota of institutional programs. These stakeholders have strong beliefs (supported by the research community) that segregation in large programs leads to a greater risk of abuse and neglect, social isolation and poorer outcomes in areas such as community integration, choice-making, friendships and social relationships, and employment (HSRI, 2012). On the other hand many stakeholders express strong support for this model. Many among this group have had poor experiences in Minnesota with community-based residential services. They believe that segregated campus or farm models actually give their family members greater safety, freedom and more opportunity to learn. These stakeholders embrace the model that if all services (education, employment, health, specialist and residential) are provided at the same site it can result in more consistent programming and will make it easier for family coordination and communication.

For this study we visited both campus/farm models as well as community-based models of residential services in Minnesota and outside of Minnesota. In all models, we saw effective programming and characteristics of programs that the research team felt worked well in that setting. We saw people with severe autism having their needs met effectively in a site that served only one person and in sites that served over 50 individuals. Community-based providers in Minnesota were observed running effective services as was the one campus model we observed in state. The capacity to develop and run effective services for children with autism seems to exist in Minnesota, however, funding for expansion and access to these services does not.

A number of stakeholders that we interviewed or talked with during site visits and stakeholder meeting throughout this study had children who had been placed out of state in a short term transitional program at some point and were now back in Minnesota receiving community based services. Most of these families were satisfied with the community services their child was now receiving, some were not. They all shared many challenges in getting access to their child's current residential services placement. Most reported that they had experienced frustration, silo-driven uncoordinated services and ineffective or ill-informed county case managers. The culminating effect of their experiences could easily be understood as trauma.

Providing Residential Services to Children, Youth and Adults with Autism in the Current National and Minnesota Context

Stakeholder input and experience is not the only consideration that needs to be made with regard to the development of residential services for children, youth and adults in Minnesota. Federal and state policy, litigation and existing initiatives also need to be understood and considered when making these decisions. As this report identified, the Centers for Medicare and Medicaid Services will certainly allow campus/farmstead models to be built and funded as intermediate care facilities for people with developmental disabilities programs. That said, the Department of Justice very likely would make these same programs targets because of inconsistencies with the intent of the Olmstead Decision under the Americans with Disabilities Act. Just because the Centers for Medicare and Medicaid Services allows for it, does not mean it will not be a violation of the Olmstead Decision; this places the state at risk of a Department of Justice enforcement action.

More importantly there are several new options related to home and community-based services and the Affordable Care Act that bring new opportunities for states to develop and integrate effective lifelong services for people with autism. These opportunities emphasize early and proactive intervention as well as opportunities to provide services and supports to families through specialized services targeted to specific groups of high-risk individuals. These opportunities need to be maximized.

There is a high intent and desire to maximize federal participation in the funding of residential services for people with autism. Medicaid is the primary vehicle through which federal dollars can be used to pay for residential long-term services and supports. States certainly have options to fund 100% of these programs but that makes them twice as expensive and in times when states (including Minnesota) are facing budget deficits year after year, using state funding without federal match to develop services does not make fiscal sense and these programs would still be under the jurisdiction of the Department of Justice. Options also exist to create programs that are totally private pay although without public dollars there is no public oversight for these programs and that presents significant risk for the individuals who receive the services because there is little oversight and accountability.

In Minnesota there are numerous state initiatives and activities in various stages of development that have significant implications for the decisions that the Department of Human Services makes in response to the demand for residential services for people with autism. The eventual implementation of an Olmstead Plan will hold the state to certain benchmarks and targets related to community-based services. Efforts to build larger congregate settings that are institutional in nature (more than 6 people) will have to comply with identified community benchmarks and will be subject to oversight not only under the Jensen/Minnesota Extended Treatment Option class settlement agreement but also the Department of Justice. Efforts under the Money Follows the Person initiative may provide opportunities to target or transform existing services in Minnesota toward individuals with autism. This may be possible as intermediate care facilities for people with developmental disabilities are reduced in size or closed and converted to home and community-based services programs. Reform 2020 also offers opportunity to target preventative and proactive supports to families who have children with autism when these children are very young, hopefully preventing the need for some to require long-term intensive residential services as youth and adults.

Realistically, the moratorium on new intermediate care facilities for people with developmental disabilities and adult licensed foster care under home and community-based services may need to be lifted in order to meet the needs of these families who either have their children living in other states, placed in programs ill-equipped to meet their needs, or living in programs too far away for family involvement. Certainly placing children with severe autism and significant behavior support needs in programs not tailored to meet their needs (typically because it is the only place with an open bed at the time placement needs to occur) is not working for many individuals with autism and their families in Minnesota. Many children require that environments and programs be built around them to meet their specific needs and right now the moratorium is likely preventing such programs from being developed. If other services funded under home and community-based services are going to be effective at supporting this population they need to provide enough resources to offer 24 hour awake supervision (as required) and intensive staffing support, clinical intervention support and specialist services to meet the needs of children, youth and adults with autism.

Clearly there is capacity in Minnesota to develop and implement residential services for people with severe autism. Several of the case studies conducted in this study were completed in provider organizations in Minnesota that were delivering effective community residential services to children with severe autism. One was a consumer directed community support program developed and managed by a family. Not all of the Minnesota providers studied wanted to expand but some would and they had the capacity to expand if funding and approval to expand were provided. The moratorium and lack of sufficient county and state support and resources to provide services were identified as the single largest barriers to the expansion of residential services for people with severe autism by these Minnesota providers.

Characteristics of Effective Residential Services

The stakeholder input, case study observations, information from the literature and the federal policy and initiatives portions of this report lend themselves to the following considerations as effective residential services for people with autism. Irrespective of the model or funding stream used to deliver residential services, these considerations must be made.

Accessible, Available and Funded Statewide In order for residential services to be effective, they have to exist. They also have to be available to children, youth and adults and their families at the time they need the services. There are currently large and growing waiting lists for families who have children with autism in Minnesota. Many of the families whose children are currently getting services are not getting effective services or have experienced tremendous challenges in getting effective services to meet their child's needs. Some have bounced from one ineffective program to the next because the program was not designed to meet their specific needs. There are families in need of out of home residential services to meet the needs of their children with severe autism in Minnesota and these services are not being provided. Many families have to drive out of state or over four hours to visit the children because the only services made available to them were far from their local community.

Active Family Involvement Using An Integrated Model- Providers must partner with families and view families as experts on their child's needs. Family members need to be trained on interventions used and included as active participants in all planning. Programs need to be available in locations near the family so that families can be active partners in an integrated service approach. When families are geographically separated it is difficult for the child and the family because they rarely get to see one another.

Focus on Learning, Skill Development and Generalization Children, youth and adults can learn throughout their lifetime. Residential services need to focus on teaching, skill developmental and the generalization of these skills from various environments (e.g. school, home, community). While there does not appear to be a universally used or desired intervention approach to teach new skills and address challenging behavior related to autism, specific intervention approaches need to be selected and utilized in the residential program and all staff need to understand and implement these intervention approaches to ensure success.

Person Centered and Individualized to the Unique Needs of the Person- Every child with autism is unique and their families are unique. Each has a unique context and life experience. Their services need to be tailored to meet their needs and to address their needs in the context of their family and community situations. Service providers must be flexible and willing to adapt their programs to meet the needs of each individual. Authentic person centered planning that is designed to identify the strengths, gifts, challenges and aspirations of the person in the context of their family and community need to be ongoing evolving tools that are used to guide and define the services and support that children with autism receive.

Culturally Responsive and Inclusive Residential programs need to meet the needs children and families from diverse communities. Staff within these programs must be able to communicate with the individuals and their family members using the person's preferred language and are responsive to the individual's cultural traditions and needs. Religious beliefs are respected and the residential provider works with the individual and family to ensure that opportunities to express beliefs and worship are made available. Food and cooking preferences are honored. Residential services are provided near the individual's community and community members are engaged as requested. When possible, some staff ought to be from the same cultural backgrounds of the children, youth or adults served in the program.

Residential Environments are Safe, Purposeful and Offer Functional Space There are important environmental adaptations and considerations that are needed for children, youth and adults to live effectively in their physical environment. Many children, youth and adults with autism have sensory challenges and lighting, sound and textures need to be modified to ensure maximum ability to navigate and exist within the environment. Individuals with autism need their own bedrooms. Additionally, children, youth and adults with autism need to live in homes where there are rooms in which they can retreat to relax and calm down; these rooms often are equipped with swings and other tools to address sensory needs. Children, youth and adults who have severe challenging behavior need environments that are carefully constructed so that they cannot use things in their environment to harm themselves or others. Additionally having plenty of room to wander and walk without being able to flee is important for many of these individuals. When children are placed into existing programs/homes that are not adapted to their needs, failures in these placements often occur.

Highly Trained and Specialized Staff - Staff that work in residential services for children, youth and adults with autism must have expertise in supporting people with autism. Additionally they must have expertise in supporting people with challenging behavior and have practice in preventing, de-escalating, gathering data about and monitoring progress related to challenging behavior. Staff need to have an understanding about and be able to provide necessary intervention related to the sensory challenges experienced by people with autism as well as other treatments such as special diets. Staff need supervision and training beyond that which is typically required for residential services staff. They must be required to have specialized training related to autism, challenging behavior, communication, social interaction, human development and working with families.

Program Interventions are Data Driven and Use Frequent, Ongoing Assessment Residential service programs need to develop and implement data driven monitoring of individual learning and behavior support programs to assess their effectiveness. This data needs to be charted and presented so that family members and other practitioners (e.g. medical doctors, psychologists, teachers) can understand and learn from them. These programs should include monitoring of the use of psychotropic and other medications as well as dietary changes and other holistic intervention approaches that are used.

Plan for, Address and Fund Services That Integrate Transition, Employment, Education, Mental Health and Other Service Needs across the Lifespan - The service system is fragmented. Stakeholders provided rich details about how difficult it is to bridge various services for their children with autism, including: early intervention, education, residential, crisis intervention, community support, mental health and transition/vocational. Efforts need to be made to minimize this fragmentation for families who have children with severe autism. Integrated funding models through demonstration that are pooled to provide 24/7/365 services including the full menu of treatments needed should be explored to increase effectiveness, improve access and create efficiencies.

Expand and Use Natural Support and Other Community Systems Communities need to better understand and be supported to participate in the growth and development of children with autism and their families. This includes fire and safety officers, public programs such as libraries, community gyms, after school programs and extended families. Case managers and support coordinators need training and support to build strategies for these supports in individual support and education plans.

Conclusion

This comprehensive report on residential services for people with autism provides the Department of Human Services with an opportunity to critically examine the menu of residential services in Minnesota for people with autism**.** The voices of stakeholders in Minnesota on these issues are passionate and driven by their experiences and knowledge. These issues are complex especially since every individual with autism is unique with his or her own strengths, needs and preferences. Minnesota must ensure that services are more than adequate and that each family can access supports so they remain healthy and intact. We have an understanding of what works; we also have an understanding of the depth of these unmet needs. Strategically addressing gaps and focusing resources to provide greater residential options are achievable goals—ones that Minnesota stakeholders are willing to get behind and work towards.

Appendices

A. References

B. Protocol for Autism Residential Services Study Key Stakeholders Interviews

C. Protocol for Autism Study Residential Program Site Visits

D. Autism Spectrum Disorder Advisory Council Membership Roster

E. Detailed Summary of Stakeholder Residential Services Interviews

F. ASD Advisory Council Survey Responses

G. NASDDDS Report: *The ADA, Olmstead and Medicaid Residential Options for People with Developmental Disabilities*

H. *Minnesota Adoption Disruptions & Dissolutions: An Examination of Child Outcomes in Private Out-of-Home Placements*

Appendix A

References

Ahrentzen, S. and Steele, K., (2009). "*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.

American Psychiatric Association (2000). *Diagnostic and statistical manual of mental disorders (IV-text revision).* Washington, DC: Author.

Billstedt, E, Gillberg, C. and Gillberg C. (2005). Autism after adolescence: population-based 13- to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders*, 35(3), 351-360.

Centers for Disease Control and Prevention (2012). *New data on autism spectrum disorders*. Retrieved from the CDC – New Data on Autism Spectrum Disorders http://www.cdc.gov/features/countingautism/

Easter Seals (2008). *Living with Autism*. Retrieved from the Easter Seals' Living with Autism Study http://www.easterseals.com/site/DocServer/Study_FINAL_Harris_12.4.08_Compressed.pdf?docID=83143

Gerber, F, Bessero, S, Robbiani, B, Courvoisier, D. S, Baud, M. A, Traore, et al. (2011). Comparing residential programmes for adults with autism spectrum disorders and intellectual disability: Outcomes of challenging behaviour and quality of life. *Journal of Intellectual Disability Research*, 55, 918-932.

Hewitt, A., Stancliffe, R. J., Sirek, A.J., Hall-Lande, J., Taub, S., Engler, J., Bershadsky, J., Fortune, J., and Moseley, C.R. (2012). Characteristics of adults with autism spectrum disorder who use adult developmental disability services: Results from 25 US states. *Research in Autism Spectrum Disorders* 6 (2):741-751.

Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*, 45, 212-29.

Howlin, P., Mawhood, L., & Rutter, M. (2000). Autism and developmental receptive language disorder—a follow-up comparison in early adult life. II: social, behavioral, and psychiatric outcomes. *Journal of Child Psychology and Psychiatry*, 41, 561–578.

Larson, S.A., Ryan, A., Salmi, P., Smith, D., and Wuorio, A. (2012). *Residential Services for Persons with Developmental Disabilities: Status and trends through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Lawer, L., Brusilovskiy, E., Salzer, M.S., & Mandell, D.S. (2009). Use of vocational rehabilitation services among adults with autism. Journal of Autism and Developmental Disorders, 39, 487-494.

Mahan, Sara & Kozlowski, Alison M. (2011). Adults with autism spectrum disorders. Matson, Johnny L [Ed], Sturmey, Peter [Ed]. *International handbook of autism and pervasive developmental disorders*. New York, NY, US: Springer Science + Business Media, US; pp. 521-538.

Medicaid Program; Community First Choice Option; Final Rule. *Federal Register,* Vol. 77, No. 88, (Monday, May 7, 2012), page 26829.

Office of the State Demographer (2011). *Minnesota population by race and Hispanic origin.* Minnesota Department of Administration, Office of Geographic and Demographic Analysis Division.

Olmstead v. L.C., 527 U.S. at 600-01 and 607

Renty J, Roeyers H. (2006). Quality of Life in High-Functioning Adults with Autism Spectrum Disorder: The Predictive Value of Disability and Support Characteristics. Autism 10(5):511-524.

Resnik, D. and Blackbourn, J. (2009). *Opening doors: A discussion of residential options for adults living with autism and related disorders.* Retrieved from http://www.autismcenter.org/documents/openingdoors_print_042610_001.pdf.

Perez, T.E. (2011). Letter to Governor Robert McDonnell Re: Investigation of the Commonwealth of Virginia's Compliance with the American's with Disabilities Act and of Central Virginia Training Center.

Perez, T.E. (2012). *Olmstead enforcement update: Using the ADA to promote community integration*. Testimony before the Senate Committee on Health, Education, Labor & Pensions, United States Senate. Retrieved from http://www.help.senate.gov/imo/media/doc/Perez3.pdf.

U.S. Department of Justice (2012). *Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C*. Retrieved from http://www.ada.gov/olmstead/q&a_olmstead.pdf.

Van Bourgondien, Mary E & Schopler, Eric. (1990). Critical issues in the residential care of people with autism. *Journal of Autism and Developmental Disorders*, 20, 391-399.

Appendix B

Protocol for Autism Residential Services Study Key Stakeholders Interviews

Name of interviewer(s):

Name of Key Informant(s):

Primary stakeholder perspective(s):

Parent *Service Provider* *Advocacy/Parent Organization* *Other*____________

Informant Contact Information:

Date of Interview:

Location of interview:

Residential Services Background

On April 28, 2012, Governor Dayton signed into law Chapter 247, H.F. No. 2294. One provision of the act is Article 4, Sec. 5: the Autism Housing with Supports Study:

The commissioner of human services, in consultation with the commissioners of education, health, and employment and economic development, shall complete a study to determine one or more models of housing with supports that involve coordination or integration across the human services, educational, and vocational systems for children with a diagnosis of autistic disorder as defined by diagnostic code 299.0 in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). This study must include research on recent efforts undertaken or under consideration in other states to address the housing and long-term support needs of children with severe autism, including a campus model.

The study shall result in an implementation plan that responds to the housing and service needs of persons with autism. The study is due to the chairs and ranking minority members of the legislative committees with jurisdiction over health and human services by January 15, 2013.

In August, 2012, The Research and Training Center on Community Living (RTC) at the University of Minnesota’s Institute on Community Integration received a contract from the Minnesota Department of Human Services to coordinate this study. (The RTC conducts a wide range of research, training, and technical assistance and dissemination projects related to community supports under its center grant and related project funding. The RTC is a designated

Rehabilitation Research and Training Center on Community Living and Employment of Persons with Intellectual and Developmental Disabilities.)

Study Approach: This study will be guided and supported by a stakeholder advisory group. It will involve the use of mixed research methods (quantitative and qualitative). Existing data regarding services delivered characteristics of children and adults served and providers will be analyzed. Additionally in-depth interviews with key stakeholders, Directors of Developmental Disability Services in multiple states, key personnel of various types of ASD service providers (including segregated and community models) will be conducted. Lastly on-site case studies and observations will be conducted in both segregated and community models of services. A final report will be provided to DHS on December 1, 2012 for their review and approval.

Study Activities: There are seven key tasks to be completed in this study:

1. Identify how children and adults with Autism Spectrum Disorder are currently served in Minnesota with regard to residential, educational and employment services.

2. Identify residential providers in Minnesota that serve children and adults with ASD.

3. Identify national residential service trends for children and adults with developmental disabilities including ASD in the United States

4. Identify U.S. Department of Justice and Centers for Medicaid and Medicare Services recent activities, priorities and decisions regarding congregate care

5. Identify characteristics of campus/segregated specialized residential services for children and adults with ASD in Minnesota and nationally.

6. Identify community non-institutional and non-segregated models of residential services for people with ASD in Minnesota and nationally.

7. Establish criteria for a “model” residential program that serves people with ASD with input from an advisory panel with of stakeholders within MN.

Study personnel are conducting site visits and structured interviews at several organizations (both inside and outside of Minnesota) that provide some combination of residential, educational, social, vocational, and/or independent living services and supports to individuals with ASD. This information will be combined with data from structured interviews with key stakeholders in the state of Minnesota to inform the findings of this study. These key stakeholders include parents and family members, direct service providers, agency administrators, legislators, and other advocates.

Interview Protocol

1. Please describe your role(s) related to people with autism.

2. What are your experiences in providing or receiving services from residential service provider (in-home or out of home) for individuals with autism? Please describe. Probe for the following: (timeline, location(s), description(s), type of program, services delivered, funding, philosophy toward reducing or treating challenging behavior, impressions (positive and negative), outcomes, barriers and limitations). How were outcomes measured? Were programs strengths based?

3. Please describe the characteristics of effective residential service or support for people with ASD? Is this the same for people across (at all levels of) the spectrum? What are similarities and differences?

4. Can you describe what a model residential program for children, youth and adults with the most significant autism might look like? Probe for: (settings/physical plant, clinical interventions, funding, staffing, educational components, location(s), philosophy/approach toward challenging behavior, culturally specific considerations/supports, target outcomes.) What credentials would you expect staff to have in such a program?

5. Can you describe your experiences with individuals' food allergies or special nutritional planning that have impacted how services were provided?

6. Do effective residential supports exist in MN for people with "severe/classic" autism (severe challenges in the cardinal characteristics of ASD (communication, repetitive behavior/restricted interests, socialization) and co-occurring challenging behavior)? Why or why not? If they do exist who are effective residential support providers and what makes them effective?

7. What are your experiences and thoughts with regard to congregate care models of residential services for people with autism? (These have been called campus models, farms or planned communities.) Is this a model the Department of Human Services should develop in Minnesota?

8. Please describe what you consider effective practices for <u>involving families</u> in residential services and supports for their family members with ASD. Probe for: culturally specific considerations/supports, planning, team building, clinical intervention, staff training and family education.

9. Please describe what you see as culturally responsive residential services and supports? How do we ensure culturally responsive residential services and supports in Minnesota? Please describe experiences you have had with efforts that organizations have made to be an inclusive setting for families from diverse backgrounds (cultural, racial, economic, religious, etc.).

10. Please tell us what the term "supports across the lifespan" means to you. How can we provide services and supports to individuals with ASD across the lifespan? Do we

provide these lifespan services now? Why? Why not? How are residences structured to protect vulnerable children? How are services constructed to meet developmental levels? What are the barriers and what needs to change?

11. Please describe what you perceive to be the most significant barriers related to supporting the long-term residential needs of individuals with ASD (across the spectrum).

12. Are there additional barriers specific to people with “severe/classic” autism (severe challenges in the cardinal characteristics of ASD (communication, repetitive behavior/restricted interests, socialization) and co-occurring challenging behavior)?

13. What needs to happen in Minnesota to be able to provide effective residential support to people with ASD (across the spectrum)? Please describe.

14. Are there additional things that need to happen in order to provide effective residential services to people with “severe/classic” autism (severe challenges in the cardinal characteristics of ASD (communication, repetitive behavior/restricted interests, socialization) and co-occurring challenging behavior)? Please describe.

15. What are your policy recommendations to improve access to effective residential support for children, youth and adults with ASD?

Appendix C

Protocol for Autism Study Residential Program Site Visits

Name of Interviewer(s):

Name of Key Informant(s):

Role of Key Informant(s):

Contact Information:

Date of Site Visit:

Location:

Background and Introduction

On April 28, 2012, Governor Dayton signed into law Chapter 247, H.F. No. 2294. One provision of the act is Article 4, Sec. 5: the Autism Housing with Supports Study:

The commissioner of human services, in consultation with the commissioners of education, health, and employment and economic development, shall complete a study to determine one or more models of housing with supports that involve coordination or integration across the human services, educational, and vocational systems for children with a diagnosis of autistic disorder as defined by diagnostic code 299.0 in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). This study must include research on recent efforts undertaken or under consideration in other states to address the housing and long-term support needs of children with severe autism, including a campus model.

The study shall result in an implementation plan that responds to the housing and service needs of persons with autism. The study is due to the chairs and ranking minority members of the legislative committees with jurisdiction over health and human services by January 15, 2013.

On August 21, 2012, The Research and Training Center on Community Living (RTC) at the University of Minnesota's Institute on Community Integration received a contract from the Minnesota Department of Human Services to coordinate this study. (The RTC conducts a wide range of research, training, and technical assistance and dissemination projects related to community supports under its center grant and related project funding. The RTC is a designated Rehabilitation Research and Training Center on Community Living and Employment of Persons with Intellectual and Developmental Disabilities.)

Study Approach: This study will be guided and supported by a stakeholder advisory group. It will involve the use of mixed research methods (quantitative and qualitative). Existing data regarding services delivered characteristics of children and adults served and providers will be analyzed. Additionally in-depth interviews with key stakeholders, Directors of Developmental Disability Services in multiple states, key personnel of various types of ASD service providers (including segregated and community models) will be conducted. Lastly on-site case studies and observations will be conducted in both segregated and community models of services. A final report will be provided to DHS on December 1, 2012 for their review and approval.

Study Activities: There are seven key tasks to be completed in this study:

1. Identify how children and adults with autism spectrum disorder are currently served in Minnesota with regard to residential, educational and employment services.

2. Identify residential providers in Minnesota that serve children and adults with ASD.

3. Identify national residential service trends for children and adults with developmental disabilities including ASD in the United States

4. Identify U.S. Department of Justice and Centers for Medicaid and Medicare Services recent activities, priorities and decisions regarding congregate care

5. Identify characteristics of campus/segregated specialized residential services for children and adults with ASD in Minnesota and nationally.

6. Identify community non-institutional and non-segregated models of residential services for people with ASD in Minnesota and nationally.

7. Establish criteria for a “model” residential program that serves people with ASD with input from an advisory panel with of stakeholders within MN.

To complete Tasks 1, 2, 3, 5, and 6, study personnel are conducting site visits with structured interviews at several organizations (both inside and outside of Minnesota) that provide educational, social, vocational, and/or independent living services and supports to individuals with ASD.

At these site visits, RTC staff with the support of Minnesota DHS staff will use the following protocol to gather information about the qualities, characteristics, context and outcomes of residential programs that offer an array of services and supports to individuals with ASD. This information will be summarized and used to inform key policy makers and elected officials in Minnesota.

Protocol

The site visit/structured interview will look at an organization's

1. Overall structure and funding
2. Administration and staffing
3. Residential supports and services across the lifespan
4. Educational, transition, and employment supports and services
5. Clinical interventions and approaches
6. Supports to and inclusion of families

1. Overall Structure and Funding of the Organization

Please describe for us the structure of your organization.

1. What is the overall mission and purpose of your organization?
2. When did your organization begin? What are your organization's developmental roots/history?
3. How many individuals do you serve? Please describe the people that your organization serves (ages, race/ethnicity/socio-economic status, disability label, guardianship status)
4. Where do your participants come from? What are your referral sources?
5. Do you currently serve anyone from the state of MN? If so how many and from what counties?
6. Can you describe the characteristics of the people who receive your services?
7. We are interested in residential services and supports for people with "severe/classic" autism (severe challenges in the cardinal characteristics of ASD (communication, repetitive behavior/restricted interests, socialization) and co-occurring challenging behavior). Of the students/participants that you serve, how many would be considered individuals with "severe/classic" ASD?
8. Please describe your admissions process.
9. How are you funded? What is your annual budget? Where does your funding come from? How are you licensed (what state agency?) Are there cost sharing provisions that involve families?
    - Residential
    - Educational
    - Employment
    - Family Support
    - Other

2. Administration and Staffing

Please describe for us how your organization is staffed.

a) How many total personnel do you employ? __________

b) Of this total approximately how many are:
   - o Administrators/Managers _________
   - o Direct service clinical (licensed)__________
   - o Direct service supervision and support (non-licensed) ________
   - o Certified behavior analysts or assistant analysts? _________

c) How do you recruit new staff? Describe the processes you use to find new employees? What are your recruitment sources?

d) What kind of credentials do you look for to fill positions? Please describe the various licenses and certifications you require for your staff in the following position:
   - o Administrators/Managers
   - o Supervisors
   - o Direct service clinical (licensed)
   - o Direct service supervision and support (non-licensed)

e) What is your annual turnover rate? (How many of the staff who were working at your organization on January 1 of any year were still there on Dec 31 of that same year?) Do you gather and report turnover rate to administration and board? If so, how and what is done with this information? Please describe.

f) Can you describe staff wages and benefits? What are the approximate average wages of the personnel in the following categories:
   - o Administrators/Managers
   - o Supervisors
   - o Direct service clinical (licensed)
   - o Direct service supervision and support (non-licensed)

g) What benefits do your employees receive? (vacation, sick, health insurance, dental, disability, life) Do all employees receive these or are there differences by job classification. Please describe.

h) What is your staff training program like? How much training does your staff receive and when do they receive it? Topics? Re-training? In-house, outside training etc…? Are there any particular training curricula that you use with your personnel? How is their competency measured?

i) Are your staff a part of organized labor? A labor union? If so which one?

j) What are your greatest challenges and barriers regarding personnel – staff recruitment, retention and training?

k) Can you tell us about your board? What is its size and scope of responsibility? How are Board members recruited? What kinds of expertise do they bring to your organization?

3. Residential Supports and Services across the Lifespan

a) Please tell us about residential services. Describe the program setting(s) and explain how it is staffed. What are your eligibility criteria? Do all of your participants live here? If they do not live here where do they live? Do you provide respite care? Are you open year round?

b) Please tell us what the term “supports across the lifespan” means to you. Do you provide these lifespan services now? Why? Why not?

c) How are residences structured to protect vulnerable children?

d) How are services constructed to meet developmental levels?

e) What is done to meet cultural and spiritual needs of residents?

f) What is your overall goal for your residential services program? What is the average length of stay? The shortest? The longest?

g) What are the treatment outcomes and life outcomes you are hoping for related to the people who are in your residential program? How do you measure these?

h) What strategies do you use to ensure that the people who live here are active and engaged in their community life?

i) What strategies do you use to promote social engagement, social inclusion and friendships?

j) Please describe ways in which you respect and promote cultural differences? How do you provide services and supports that are culturally responsive to the person and his/her family?

k) Please describe how the individuals who receive your residential services are active in home life (e.g. cooking, cleaning, maintaining the home). How are individual dietary needs met?

l) What actions do you take to ensure safety? How are night and weekend staff monitored?

m) How do you use technology in the residence (both for record keeping and for assistive communication)?

n) What are the greatest challenges and barriers do you face in your residential program?

4. Educational, Transition, and Employment Supports and Services

Please tell us how your organization supports students/clients in educational and employment services.

a) Briefly tell us about your organization's education planning process. Describe how you assess participants for placement in the educational components of your program. What educational models or interventions are used? What is the evidence base for this?

b) Describe how your educational programming reflects the intent and spirit of IDEA 2004. Describe how Free Appropriate Public Education (FAPE) is assured. What processes are in place to assure family involvement in planning and progress monitoring as well as protections of parental and student due process rights?

c) What are the roles of student's resident school district, the providing school district, IEP/IFSP Team, residential staff, student, parents, county, medical providers in placement, service coordination, ongoing programming, progress monitoring and transition planning?

d) Describe how your organization works collaboratively with state agencies, county workers, school districts, other community based organizations/ professionals to ensure the highest quality services and supports are available to your participants/clients.

e) When a student is from another geographic area, how do the local agencies interact and engage with the same professionals from the student/individual's home community?

f) How do you incorporate vocational development and career planning?

g) Do you have relationships with area employers or community organizations for work experience, job shadowing, mentoring or other reasons?

h) Briefly describe what transition means to your organization. What supports are available as individuals leave your program? Where do your participants go after they turn 21?

i) What types of outcomes do you expect in educational and vocational domains?

j) What difficulties or barriers do you face in the service areas of education, transition and employment? Describe difficulties or barriers you face when it comes to service coordination and collaboration with outside agencies or organizations.

5. Clinical Interventions and Approaches

a) Please tell us about how your organization approaches diagnostic assessments for ASD. How are participants' needs assessed in your program? Are there standardized tools used? If so what ones? Who is involved in the assessment process? Are they on staff or outside consultants?

b) Are functional behavioral assessments used and, if so, do they drive the formation of individualized positive behavior support plans? What interventions do you use when individuals present challenging behaviors?

c) Describe medical services and supports you provide for your participants.

d) Describe mental health services and supports you provide for your participants.

e) Describe how your organization meets the medical needs of participants.
f) Please tell us what clinical interventions or models of programming support for which your organization is known. Describe the evidence base of these interventions or models.
g) How has this model or approach evolved over time?
h) How does your organization balance the desire of families to use varied methods and approaches to intervention and treatment of autism?
i) How is individual and programmatic data collected and used in making clinical decisions?
j) What are your greatest challenges and barriers in the area of clinical intervention?

6. Support to and Inclusion of Families

a) Describe the expectations that your organization has for including family members in planning (including behavior plans and treatment decisions)?
b) How is communication between your organization and families facilitated and maintained?
c) Describe the efforts your organizations have made to be an inclusive setting for families from diverse backgrounds (cultural, racial, economic, religious, etc.)
d) Do you provide training or co-treatment opportunities for parents either at your organization or in their home? If so please describe
e) Are there activities designed for families to meet each other, share experiences and support one another?
f) Are family members encouraged to volunteer or participate in program activities with their loved ones or with others?
g) What are your greatest challenges and barriers experienced in the area of family support?

Participant Observation Notes (qualitative impressions and observations made by the researcher)

What are your overall impressions of the site? Things you saw and felt that were positive? Things you saw that were perhaps troubling?

What was the nature of interactions that you observed between staff and the people with ASD who were receiving services? How did these feel to you – describe?

What was the physical environment like?

How does the organization address sensory integration into daily life for the residents? Describe lighting, access to outdoors, safety issues. Does it feel like a home?

What were your perceptions of the staff that you saw and with whom you interacted?

Other things of interest that were observed.

Appendix D

Autism Spectrum Disorder Advisory Council Membership Roster October – December 2012

Name	Role/Organizational Affiliation
Idil Abdull	Parent and Somali American Autism Foundation
Delores Alleckson	Rice Institute for Counseling and Education
Mike Amon	Alternatives for People with Autism
Jean Bender	Parent and The Arc of Minnesota
Barb Dalbac	Minnesota Department of Health
Amy Dawson	Autism Advocacy and Law Center, LLC
Amy Esler	Amplatz Children's Hospital, University of Minnesota
Paris Gatlin	Caregiver and The Arc Greater Twin Cities
Sheryl Grassie	Parent and End of the Spectrum
Kara Hall Tempel	Minnesota Department of Education
Diane Halpin	Lionsgate Academy
Anne Harrington	Celebrate the Spectrum
Anne Henry/Bud Rosenfield	Minnesota Disability Law Center
Carey Hodapp	Meeker County
Nancy Houlton	UCare
Jami Hughes	Alliant Behavioral Pediatrics
Kim Kang	Autism Society of Minnesota
Ginny Kistler	Parent
Peggy Kunkel	REM Minnesota
Traci LaLiberte	Center for Advanced Studies in Child Welfare, University of Minnesota
Istahill Malin	Parent
Kathryn Marshall	Minnesota Autism Center
Don McNeill	Parent and PACER
Bruce Nelson	Association of Residential Resources of Minnesota (ARRM)
AJ Paron-Wildes	Parent
Pat Pulice	Fraser
Teri Sanders	Residential Services, Inc.
Nancy Schussler	Behavioral Dimensions
Margaret Semrud-Clikeman	Pediatric Neurology, University of Minnesota
Phil Sievers	Minnesota Department of Education
Denise Steans	Washington County
Mike Stern	Parent and Governor's Council on Developmental Disabilities
Brad Trahan	Parent and ASD State Task Force
Laurie Wabner	Creative Care Resources
Abbie Wells-Herzog	Minnesota Department of Employment and Economic Development
Rich Yudhishthu	Parent
Cary Zahrbock	Medica Behavioral Health
Andrea Zuber	Ramsey County
Timothy Zuel	Hennepin County

Appendix E

Detailed Summary of Stakeholder Residential Services Interviews

1) **Please describe your role(s) related to people with autism.**
   - Parent of a child, age 25 with Asperger's. Also a leader of a small autism advocacy organization.
   - Parent of a young child, age 8, with severe autism. Also, works with parent organization that is focused on autism and is involved with housing legislations.
   - Clinical service provider. Provides individual clients and families for individual and family therapy. Also, consultant to educational institutions and community-based groups working with youth with autism.
   - Parent of a child, age 16 with autism.
   - Parent of two adult children on the spectrum where one child is characterized as very high functioning and the other child is low.
   - Parent of a child, age 27, who is on the spectrum. Parent is also professional who screens people with autism and decides qualification of county services.
   - Parent of a child, age 15, who has autism. Also, an advocate for insurance coverage for early intervention services for children with autism both in Minnesota and in another state.
   - Parent of a child, age 21, who on autism spectrum. And, professional in special education area and has been working in the field for over twelve years.
   - Parent of a child, age 14, with autism.
   - Parent of a child with autism and is also a clinician working with children on the autism spectrum.
   - Parent of two children on the autism spectrum where one child has Asperger's and the other child as more severe autism. Parent is also advocate for a non-profit group that advocates for more residential options.
   - Service provider with a broad base of experience working with people with autism and their families for 20 years including as an advocate, advisor, care giver and administrator.
   - Service provider who is a director supervising programs for people with various disabilities.
   - Service provider who is developing an autism specific program for adults over age 21 at a non-profit that provides supported employment and day training and habilitation for adults with disabilities. Currently works as a service innovation manager working on curriculum development for all over learning advocacy, vocational, and creative arts.
   - Attorney in private practice who works with people with special needs. Assists families with establishing guardianships and supplemental needs trusts and has a younger brother with a developmental disability.
   - Service provider who is a county supervisor for children with disabilities using the CADI Waivers with a focus on reviewing eligibility requirements for programs, psychological testing and case management for children with autism. Also conducts training for staff and for county vendors who provide services to individuals with disabilities.
   - Parent of a child with severe autism, currently living at a provider home.

- Parent of a child, age 15, with autism who went into residential placement over a year ago.
- Service provider/innovation coach who is an autism specialist at a local school district with students, teachers, parents and paraprofessionals and students with autism ages 6-18 to use technology such as iPads in a level 4 setting.
- Service provider who has worked as a case manager for children with developmental disabilities and currently supervises social workers who place children with developmental disabilities into corporate foster care and residential treatments.

2) **What are your experiences in providing or receiving services from residential service provider (in-home or out of home) for individuals with autism? How were outcomes measured? Were programs strengths based?**

Parents Perspective

- Child is currently living in family home; and parents are looking for options for him perhaps in a semi-independent type of housing arrangement. Child needs some support, someone to check on
- Child received two years of services in day intensive early intervention program at a service provider. This program didn't address needs in the home. Then child participated in an intensive early intervention in-home program through a different service provider. Provider worked with parents to help child. At young age, child moved into a provider home because of highly destructive behaviors. This was not a good experience due concerns about programming and staff behavior. Currently child is living in a crisis home with several other kids, while waiting for a new group home to open.
- Child is currently at out- of- state congregate model residential program, where child is making progress toward goals and parent has seen staff in the program use child’s strengths to overcome weaknesses using clear and consistent consequences and rewards. Before going to the out of state residential program, child was in provider home and it was disaster because staff did not have the training to work with kids and more specifically skills to work with kids with autism.
- Child has had in-home respite care previously about 6-9 hours a week which was helpful but not enough. Currently child has a behavior therapist.
- Child received PCA for many years as a child. At 21, child was able to get a DD Waiver through the County and used funds to attend residential Service program
- Spouse is adamant about keeping Child at home.
- Child is in out of state program. Previously, child went to respite care where the duration of visits varied and gave the family a much needed break.
- Child is currently living in out of home placement. Prior to that parent hired people they reported was wonderful however the program was not fully funded. Child was one of the first children to get in-home Waive and parents kept him at home to 1:1 services. Since moving to out of home placement, parents report that child has lost all his language skills. While parents believe they have one of the best service providers out there, there are issues with the condition of the place and quality of programming.
- Child has had PCA services; however as child grew older parents needed to consider moving child out of the family home because increased medical needs. Child is currently

living in provider home placement that is designed specifically to teens with autism; however parent would like child to live in campus model.
- Child was at segregated out of home residential placement setting, and now is in out of home provider that is paid for by Waiver. Parents report can finally have a life now with child not at home.

Service Provider Perspective

The majority of the service providers interviewed do not provide residential services to children and adults with autism; however several did comment on their experiences working with individuals who were living in residential settings including:

- Many patients in residential settings, group homes, younger children often in crisis homes.
- Lack of services is unbelievably acute for crisis services. Very severely impaired kids that need 1-2 or 4-6 week respite away from home that are non-hospital based and beds never seem to be available.
- Families are reluctant to agree to medication changes rather they want to first address issue of behavior as a response to staff changes.
- Services are individually tailored and might include therapeutic interventions, increase independence skills, or per Child skills.
- Don’t provide residential services but we work with clients who live in group homes. In general a lot of residential providers have a lot to learn about serving people with autism. For example, doing better job at matching people's needs when matching people living together.
- Instead of an IEP meeting, we have a yearly meeting that includes family, individual, group home staff to review annual goals and outcomes for individual.
- We like to use the Developmental Disability Waiver so services can be received in the individuals’ family home. We have provided services under a foster care model; however prefer group home model or independent living services for apartment living. We have noticed residential services are moving away from congregate care model.
- We don't provide residential services--we work with students to receive them, but don't go into their homes unless it is for a meeting. We do work with group homes quite closely. Big issue is the availability of placement. We see a lot of individuals in crisis and there is no space for them so they are on waiting lists and families are under stress dealing with their kid’s behavior. The high turnover in group home staff is very hard for the children. Constant change and having to re-train staff is difficult and we see increase in challenging behaviors when there is new staff. Kids become aggressive towards staff and families when their residential life is always changing. On the positive side we are seeing that kids are able to be on task for longer amounts of time and they can communicate better using the iPad for communication. We are seeing a variety of benefits for using technology.

3) Please describe the characteristics of effective residential service or support for people with ASD? Is this the same for people across (at all levels of) the spectrum? What are similarities and differences?

Stakeholders identified the following characteristics of effective residential services:

Staffing

- Staff, caregivers and supervisors need to have extensive training as to what autism is. They need to get to know the kids individually.
- Staff should have broad training and education on what practices are out there and learn to be flexible and adaptable.
- Staff needs to understand the sensory aspects to autism to support auditory and visual needs of individual.
- Staff should be proactively thinking about what a child needs for comfort, well-being, to be happy with choices to avoid boredom.
- Staff should encourage growth and learning and include caregivers in learning different philosophies and methods of treatment--this would really help.
- Being able to maintain staffing that is stable with minimal turnover is important, especially for kids who struggle with change and transitions.

Programming

- Individualized programming that is person-centered.
- Programming has to be team oriented and consistent across providers. Some group homes do a good job of integrating school programs with programming at home.
- Basic behavior interventions are ideal a lot of behavior intervention focuses on attention seeking and not looking at the why of behavior.
- Intensive behavior programming in group homes with regular behavioral assessments
- Use the individual service plans to identify programming needs such as physical activity that is age and developmentally appropriate, individualized dietary and nutrition, OT/PT/Speech for sensory integration needs.
- Meaningful community involvement, not driving around in car or only taking kids to the park when people are not around.
- The needs of individuals across the spectrum can be different; some individuals might require more adaptation than others.

Setting

- Smaller residential settings in the community that is designed to engage and meet the needs of the family.
- Ensure the environment is adaptable and can be modified to meet specific needs of individuals with autism.
- Allow for different options to address needs of individual family units.
- Match individual with peers that have similar needs and with a provider that has the skills and expertise to address autism specific needs.
- Teach independent skills. With the exception of one, in group homes, people are not trained; instead, they are babysitting.
- Communication.
- Effective communication between school and family.
- Communication between everyone is imperative.

4) Can you describe what a model residential program for children, youth and adults with the most significant autism might look like? What credentials would you expect staff to have in such a program?

Interviewees had different ideas when it came to describing a model residential program. Some indicated that the setting should be small and in a neighborhood that is centrally located in community and include:

- The physical setting of home would have an open floor plan that is intuitive to what has to happen in the space, no fluorescent lighting, comfortable, and predictable.
- Every home would have areas that encouraged socialization.
- Each kid would also have their own individual spaces that would be safe for them.
- Home modifications to include specific sensory, lighting, and safety locks
- Each staff person is trained on that person's routine

Others interviewees reported that they prefer a campus or ranch setting of a moderate size serving 10-20 individuals in a non-urban or rural setting that is close enough for families to visit 2-3 times per week and includes a lot of outdoor space for individuals to safely explore and roam. Other features of the campus model include:

- Space divided into units of private rooms with appropriate sensory tailored to the individual including physical motor activities.
- All services including therapies, academics etc. at the one site would reduce a lot of anxiety when we need to take these kids to appointments.
- Intervention services such as ABA etc. on site.
- Behavioral therapists have to be seen by a PhD level trained behavioral therapist.
- Four houses with four residents living in each house provides a built in community with peers and staff where they will have more social and community interaction than they would have in a typical group home in town.
- A campus model is the best for kids with severe classic autism where all their needs can be met. Close enough to see him 2-3 times per week.

Other identified features of a model residential program include:

Space/Setting

- Private rooms with low lighting.
- Adapt the environment and provide multiple spaces with different textures and lighting that is secure.
- Provide calming space in each home.
- Kids that are self-injurious need safe rooms with padding on walls and hard surfaces.
- Utilize technology such as alarms at the door, multiple devices in every room with schedules so kids would have access wherever they were in the home.

Programming/Outcomes

- Intervention services such as ABA provided on-site.
- Specific routines that are built around each individual’s day to provide familiarity and eliminate anxiety.

- A holistic approach with dietary needs, sensory needs, OT/Speech, access to a pool for physical activity.
- Positive reinforcement that includes therapeutic play.
- Strong understanding of accommodating dietary needs such as providing soy-free, gluten free meals options within the group home's budget.
- Sensory equipment is available and technology such as an iPad is used for communicating needs.
- Behavioral therapy training to help family not let child get away with behaviors. Model to family how to work with child.

Cultural Considerations

- Important to learn about an individual's culture, beliefs such as attending church, specific food considerations or dietary needs related to culture or ethnicity.
- There are providers who are Hmong, Hispanic and Karen. Case managers and staff have been hired by some counties and service providers who come from different cultures.

Staff credentials and training include:

- Staff has individualized training with professional guidance along with supervision.
- Staff has taken courses in psychology, family psychology and ongoing CEU's to stay current on best practices and ensure staff understanding of complexities and stress of family of child with autism.
- Staff has a minimum of a two year degree and training in Positive Behavior Supports including how to set up someone's routine and follow it.
- Staff has specific training in autism such as using social stories, identifying most effective technique to address particular problem.
- Staff has competency-based training that includes training from an Occupational Therapist and Speech Language Pathologist to address sensory needs, training from behaviorist to address behavioral needs and training from a nutritionist to address dietary needs.
- Staff has a passion to work with children and adults with autism.
- Staff is younger and has energy to work with kids.
- Staff has ability to communicate and work with families.
- Staffing ratios to ensure no staff abuse.

5) Can you describe your experiences with individuals' food allergies or special nutritional planning that have impacted how services were provided?

Stakeholders shared a range of perspectives and experiences with food allergies or special nutritional planning including:

Parents Perspective

- A lot of individuals with autism are on gluten free diets. Behavior is directly correlated with their diet, so this is very important especially in people who are nonverbal. If people are in pain and can't verbalize it, then they act out.
- More severe child never needed gluten free.

- Our child had major GI issues and we went on a gluten/casein free diet, within six months big changes. If you have medical issues like gastrointestinal pain then all the behavioral therapies are a waste of time until you've addressed the underlying medical needs.
- Kids with autism tend to have fixation with food. My child has to eat everything plain. No casseroles.
- We just have to monitor food consumption so we have to watch that so child isn't over-eating.
- We went through diet therapy and the group home won't follow the gluten free special diets that we used to treat bowel disease using nutritional supplements; however Medicaid stopped covering, so we now pay the $500/month for nutritional supplements. We have an excellent protocol; however it won't be paid for by Medicaid.

Service Provider Perspective:

- When screening people with autism, almost all have food allergies along the way, however allergies have been different across individuals with autism.
- It is limited other than to ensure we are meeting our license requirement. We have dietitian and a policy for special diets. We are required to develop nutrition plan that works. For individuals on the spectrum we strive to be flexible and see how we can accommodate special needs of the family.
- We would be aware of what allergies are and we would monitor the lunch that they bring, we don't provide food services we have all that documented on someone's risk management plan and we would follow that to make sure they are getting what they are and are not supposed to have.
- We have a lot of experience with gluten free diets. The case managers' work to make sure the food meets the child's needs such as peanut allergies, access to refrigerator, casein-free etc.
- If a student has a very specific dietary need and their diet is compromised, we do see spikes in behavior. Parents make notes, and so we try and identify what is causing behavior. Because family homes and corporate foster cares are licensed, they need a doctor's note to consider the dietary needs. The cost of food in meeting everyone's dietary needs could be cost prohibitive.

6) Do effective residential supports exist in MN for people with "severe/classic" autism (severe challenges in the cardinal characteristics of AASD (communication, repetitive behavior/restricted interests, socialization) and co-occurring challenging behavior)? Why or why not? If they do exist who are effective residential support providers and what makes them effective?

Stakeholders shared mixed responses to this question with half of the responses indicating that no effective residential supports exist in Minnesota citing examples of individuals who moved out of state in order to receive services or whose children are receiving services outside of Minnesota. Notable comments shared by stakeholders include:

- People I know have ended up moving out of state to get housing for their children. Personally I know of three families that have moved out of Minnesota in order to get residential services. I think there are some effective residential supports in Minnesota but there are not enough.

- CCP (Cooperating Community Programs) do seem to be one of the better MN options. They use a person centered approach and are based in St. Paul. I think they have a better understanding of the autism spectrum as a whole.
- No exposure to residential facilities that are effective however Meridian Crisis Services does good job of communicating with family and following through with OT services.
- No. We lag behind states like Massachusetts and Wisconsin. We don't have residential treatment center or group homes that are monitored well enough. We are getting better, but when child is attacking parents, you call crisis center, but they aren't used to this type of situation because usually it is vice versa. Parent’s end up calling everyone and no one knows what to do or how to handle situation so they end up bringing child to emergency room about every three days which costs state lot of money.
- No. The group homes in our area may do a little remodeling but they are not significantly different and are not designed to address behavioral challenges like breaking windows or overflowing the bathtub. The house needs to be significantly different than your average group home. I have a friend who placed her child in a group home and he broke a window and now it is boarded up because the group home hasn’t replaced it. Safety is a huge issue. Workers are supposed to be monitoring rooms at night but this child has got beaten up at night. They are not providing the adequate supervision and seem to get away with a lot. I'm also told the parents had to sign a document saying they would never sue. My child is still living at home for this reason--I haven't found anyone who is satisfied with group homes when putting their children in one.
- It's expensive to have a child with autism living in your home. Holes in walls, broken windows--common expenses that are not getting reimbursed. One parent must be home at all times which cuts your finances in half, and then there are the supplements are costly. It's very expensive.
- Parent thinks we do a great job with 70-80% of population with autism referring to MN College life. When there are challenging, co-occurring behaviors, there is not really an effective program such as young guys with sexuality issues. If they do exist, there is extreme shortage.
- No. I don't think there are group homes set up that understand children with autism and different aspects of their disorder. A lot of children don't have safety awareness and group homes that I've seen don't have a level of understanding of these children's needs. Staff does not have enough training--high turnover rates. Don't understand challenging and dangerous behavior and importance of safety. For example, drowning is the leading cause (or 2nd) of death of kids with autism.
- No and I know this because I could not find it anywhere. Parent believes the underlying cause for lack supports for people with severe autism is because they are largely a hidden population. Parents with kids with severe autism are not out and about in the community because we are pretty isolated in our own home.
- Absolutely. There are smaller service providers such as New Directions in White Bear that are phenomenal.

- I think they do exist. They are combined and intertwined with other programs. They might not be specific or designed that way but many of service providers are effective such as REM and Fraser.
- I would say not, I don't know a lot about children and youth services for adults I know that adults are kicked out of group home because of behavior
- Yes, I visited some three years ago. We looked at facilities in the area owned by No Place Like Home, Meridian, REM and Community Involvement Programs.
- Not in Minnesota, at least not programs like Chileda. We feel fortunate to have Child in a group and its close. Child is also in a really good school she likes. People in the house are similar to child developmentally. We are lucky staff have a lot of energy and find ways to have fun with child. Child thrived in Chileda and is quite happy in group home now. child is now toilet trained and having child in a group home is nice because we can visit.
- Absolutely not. Many group homes require parents to use chemical restraints before they will accept child. We were told by our social worker that due to a moratorium on group homes, our child will be coming back home when child turns 18 because they need the juvenile beds. There are not enough juvenile beds for children and not good choices for children with autism. Children with autism are being housed in hospitals. If you refuse a placement for whatever reason, you go to the bottom of the list. The current providers don’t have a clue about working with kids with severe autism.
- We do have some really good homes, and it really boils down to the staff. There are homes we have worked with that have amazing staff who build strong relationships with the kids. We do have houses where there is less of a bond between staff and kids and there is higher turnover.
- Yes. There are group homes that serve individuals with severe autism. However, we don’t have enough crisis residential treatment facilities for all disabilities. We need to help parents and educate them how to find what works for their child.

7) What are your experiences and thoughts with regard to congregate care models of residential services for people with ASD? (These have been called campus models, farms or planned communities.) Is this a model the Department of Human Services should develop in Minnesota?

Stakeholders were split in their experiences with congregate care model for residential services for people with ASD and equally split on whether the Department of Human Services should develop congregate care models of residential services for people with autism with several Stakeholders reported that they did not have enough experience to comment on whether this is a model DHS should develop in Minnesota. Stakeholder comments supporting a congregate model of residential services included:

- I like programs like child’s Ranch and while they don't work for everyone, they are good because they focus on the community as a whole. Most of these types of programs support social skills training, vocational coaching, medication management, etc. I think the Department. of Human Services should develop this in Minnesota making sure the program includes social skills training, OT, and PT, and is available to Elementary age students and adolescents with autism.

- Absolutely believe DHS should develop these in Minnesota. Unsure whether parent would place child there based on his/her personal gains in current setting but other kids with more behaviors may benefit from congregate care with everything in one place. Parent only toured Chileda but feels this is a good model for children with severe autism and has heard good reports from other families whose children have been there.
- For severely autistic children, Chileda model would work. While it looks like an institution, it does offer structure. Children need more structure at first, so congregate model may be a good initial approach and then send residents into community group homes after they make more progress. DHS should develop this model in Minnesota. In a sense it would be ideal to have a little town that is like a little campus with activities. They could still do productive things without having to go out in society where they may be shunned. Not that this is right. The program could also have an exam room where people could be seen once a month by a Doctor to address medical needs as well as provide for educational needs, vocational training and activities. There are so many things that cannot be provided in a group home. When talking about the severely disabled, one stop shopping is the best option for them. Minnesota could have a model like this and make it feel less like an institution by taking residents out into communities and helping others.
- Minnesota Life Program is a campus model and most of people who live there are disabled. It is racially diverse. People pay market rent for apartments and there is no section 8. It is a place where people can get over training and help with learning daily living skills that is integrated with larger community.
- I think DHS should work in concert with non-profits to develop such models. While the state doesn't have the capacity, it should have oversight. No one should have total control. Examine current models that work including those that are corporate owned, parent owned, owned by non-profits, and state owned. State involvement is important. Room for improvement in current system.
- Big believer that child would benefit from this type of model. Likes the idea of children working on farms. Child was most cooperative when “working," "pushing," etc. to get child through from point A to point B. Labor needs to be in balance with other activities. The more parents are involved the better. Location should be no more then 1 ½ hours from parents to limit travel and maximize participation of all family members.
- Yes DHS should consider a congregate care model in a smaller residential setting where individuals have an opportunity to engage in daily living to gain specific skills.
- Chileda as a congregate care model offers consistency throughout the day, environment and staff which makes people living there more comfortable.
- I like the idea of congregate care that includes a comfortable setting amongst peers where they have some freedom to do what they want. While the state calls these institutions because they are isolated without integration and are exclusionary, I favor, because for individuals who live there, it is their peer group and may be most comfortable to them.
- Congregate care model is ideal because these kids thrive there. They can do things, be productive. They need the structure. They could do assembly, grow things--they could help the economy and contribute to society.

- I think the terminology being used is giving the wrong impression; the congregate care is not what they are looking for. I've seen the farms and the kids learn things. I think it gives parents options. DHS should consider these models.

Stakeholders’ comments against DHS using congregate care model to develop services included:

- Philosophically I don't believe in grouping but some individuals have much more significant needs. I am against anything that looks like an institution, Staff at Chileda has good training but I don't think we need to be building more of these. We'd like to see all institutions closed. We could serve them better in the community and improve their quality of life. The administrative cost of the institutions really drives up the overall cost of providing services.
- I am generally opposed to them at every level. We have tried them forever. I see the largest setting as no more than four individuals. If larger, then they learn each other’s bad behaviors. We wouldn't send our regular children to such a facility. Going to a larger place doesn't mean better programming and mystifies the world of autism. Those people go there. It's their problem. Time and time again in the larger places, the kids with bad behavior get all the attention because negative attention is at least attention. They don't understand why they aren’t' with their families any more. I have not seen one model that works and I know how hard it is to work with children with severe autism.
- Creating a new congregate care model would be contrary to what we have been doing. To support that I have to see how and where it might be more beneficial than providing services in a community setting. Beyond access, need to look at cost effectiveness. It might be step back. We have gotten really away from that. We need to get into less restrictive settings if we can. I don't think will work and getting people out of institutions is my philosophy.
- No, DHS should not consider congregate care model. It is institutionalizing and big buildings.
- When you start talking about segregated communities on farms or away from world, it’s my experience that individuals with autism lose skills.

8) Please describe what you consider effective practices for involving families in residential services and supports for their family members with ASD.

Stakeholders shared similar considerations for effective practices for involving families that centered around four themes-clear and consistent communications, training for families and staff, team approach and family support. Stakeholder comments in each of these areas included:

- Clear and Consistent Communication.
- Cordial communication and asking for parent input is the key.
- Inform family of happenings and what's changing, any issues or concerns, etc.
- At my provider, family is involved by getting weekly advisory emails from support person at school that is specific to child, various input on condition of apartment and status of child, this is in addition to quarterly meetings to check on progress.
- Availability of interpreters to communicate with families from different cultures.

- Communication is consistence and is part of the service provider’s routine and protocol.
- Families want to be listened to and not be considered a nuisance when they ask questions or share concerns.
- Clear communication is important. Families need to be incorporated with the child’s planning, and clinical interventions.

Training for Families and Staff

- Families need training such as a life coach to work with the family so they can work on supports together with the staff.
- Staff training is especially important for learning how to support individuals and their families who are people from different cultures.
- Be respectful of culturally specific considerations and family cultural beliefs
- Develop cultural understanding with staff.
- Families should be involved in training with staff.
- Great success with families using skill-building modeling approach

Team Approach

- Planning together about what steps are and what goals should be. This model also works well with school programs.
- Start with where family is at and use a solution-focused approach.
- One model is to have the family stay at group home until staff and individual child is comfortable.
- I'd like to see a model where families could come and stay for a week in a guest house and be included in the daily programs.
- Start with the expectation that all families participate in general programing. Whether it is once a month helping make a meal with residents or some other activity where the family involvement would continue on a regular basis.
  Families should be as involved on all levels including school, afterschool programs etc. This is critical.
- Important to honor family traditions are i.e. Christmas, Jewish and integrate these traditions into the home.
- Right now you have a system where they set up meetings when you move to group home and you meet with social worker, provider and school all separately. They should create an effective team and being able to delegate responsibilities to different people on the team. Right now the group says they will take care of all the medical stuff and does things without parent's permission. Building a team to meet once a month to see who's going to do what and how to best serve the client to make the best possible outcome.
- Depends on how long child has been in residence. If it is within the first year, including the family is especially important to let staff know what has worked in the past and where there may be potential pitfalls.

Family Support

- Family invited for family night or inviting them to come and participate in different activities at the house.

- I would like to see more groups for parents to talk about their experience and their grief. Sibling support groups as well. My sense is that the healthier the family, the better the kids will do.
- On a holiday, have staff go home with kids to their families to allow opportunity for family and provider to work together.
- Families should be allowed to be involved as little or as much as they want. That should be up to the person running the place. I think most families would love to come see their children in a place they fit in and thrive in.
- Group homes need to encourage visitations. Most group homes are respecting of parents. It is a learning process and can't happen immediately. Families need help in how to best build relationship with group homes. Some parents are extremely involved and the relationship could be good or bad and others are hands off. Effective parents are onboard. In terms of cultural considerations, it is important that providers are aware of parent's role as driver.

9) Please describe what you see as culturally responsive residential services and supports? How do we ensure culturally responsive residential services and supports in Minnesota? Please describe experiences you have had with efforts that organizations have made to be an inclusive setting for families from diverse backgrounds (cultural, racial, economic, religious, etc.).

Overall Stakeholders shared the belief that culturally responsive residential services and supports should be provided in Minnesota; however Stakeholders varied in their experience with residential services and supports that were culturally responsive. Comments from Stakeholders regarding culturally responsive residential services and supports included:

- "We have to--especially with autism and the Somali community. We need to understand their culture--we don't want those children to be left out. We may end up spending more money if we don't learn about working with these other cultures down the road because they may need services lifetime from the state. I personally don't get as many Somali cases since they are classic autism cases, but we are open to working with everyone. We need to gain their trust."
- In a campus model I'd have a chapel outfitted for their needs such as soft chairs not benches. I think multi-denominational group homes typically do not provide transportation to religious services.
- Culturally responsive residential services and supports should be culturally diverse and mixed. Staff should be culturally appropriate and matched to clients. One example is an adult day care center specifically for Somalis.
- Trying to create more common connections across diverse groups. Should be more exposure to diversity so they know who to interact cross-culturally. Environments where children can share and exchange diversity.
- Somali and Hispanic cultures may have issues with shame by placing child in a residential setting versus current home. Restructuring of services may be necessary.
- We have to work together to figure out what's best for the child using person centered planning to look at the whole person. Residential should be responsive to cultural needs. Listening to families and avoiding stereotypes and bigotry. I think the cultural considerations can be written right into individual service plans.

- During the intake services provider should ask about religious preference and how important/significant it is to implement certain practices which could also be expanded to address food related considerations.
- For every culture we have there is a novel look at autism. We would work with that provider to get staff in to match the cultural needs. For example we would have a Hmong child receive services from a Hmong foster care provider. We work with other community organizations to help families from other cultures access services such as Medical Assistance so they can access the Waiver.
- My child’s residence is multi-cultural; he has roommates that are Somali, Latino and African American. The staff is also culturally diverse and they work to honor children's cultural customs and preferences. An example is because one child is Muslim, they don't serve pork. They don't take kids to church; this is the families’ responsibilities. My child hasn't been taken to church by group home, only goes when he is at home. The multi-cultural aspect has been one of the best parts of my child's group home.
- A couple kids we have are Somali. It would be nice to have a Somali person in the house to help with cultural or language barriers. Group home staff of other cultures may handle things differently than a family from a specific culture.
- Culture is not an issue. Social workers assist families from other cultures and work with interpreters for families who need them.

10) Please tell us what the term “supports across the lifespan” means to you. How can we provide services and supports to individuals with ASD across the lifespan?

Stakeholders varied in their interpretation of “supports across the lifespan” and shared several ideas regarding how to provide services and supports across the lifespan. Stakeholder comments included:

- I think we do provide services and supports to some across the lifespan and we are getting better at early childhood intervention and schools are definitely working to improve in this area.
- Means services across whole lifespan and involving families. Even if children are nonverbal, they can still understand language and are receptive to communication so it is important to work with children on communication and general learning throughout their life. To provide supports across the lifespan we need to create relationship with someone who is checking in on life skills, residence, workplace, etc. Parents' goals are to live longer than children so they can continue to manage and provide supports for their children.
- Lifespan of child. Continue to give support through community and should always have supports so if they need speech, OT, cognitive training, or a job, there are avenues in which parents can find these supports and put them in action.
- I don't think services across the lifespan exist now. We have a large number of people with autism just entering adulthood and the world is not ready for them yet. Children born in the early 90's need ongoing support so they can become as productive as possible and make contributions during their life. A person with autism has different needs, my older child has cooking and organizational needs. Some kids with autism just have social skill needs--they have education, but can't get through an interview for a job they are qualified for because of their lack of social skills. They will need marriage

counseling if they get married because they lack relationship and social skills. These are examples of supports across the lifespan.

- Supports across the lifespan means there will be a program in place for child after parent's demise. This requires age appropriate programming that develops and changes as that individual grows. For example, ABA worked wonders for our child at age 6; however at age 15, child needs are different especially medical, dental and hygiene needs. The learning never stops.
- I don't think supports across the lifespan are structured to protect vulnerable children. It's a cliff; children are well taken care of until they leave school. They are not really ready to be adults because they can’t take care of themselves and they don't get the skills training they need to live independently.
- Model that creates more collaboration, a shared community with multiple families working together. Community-type setting with families together that has similar needs and engages in congregate care.
- Developmentally appropriate programs that address issues across the lifespan. Service needs for those that are older are dramatically different. Services are not adequate for high functioning adults and older children. Seems easier to find services for individuals who are lower functioning but the older your child gets and the higher functioning they are the harder it is to get services.
- Minnesota is imperfect but they do okay and are improving. People with disabilities are using their voices and are being heard. Self-advocacy is vital and important. Major deficits in programming exist and cuts in funding have hurt people who are living longer.
- It’s a fractured system where services are divided by age categories for children services are age 1-18 and adult services are age 18-65.
- Intervention from diagnosis/pre-diagnosis all the way until somebody dies. Giving families the information lots of different times about what they can expect in the future.
- Birth to death. We provide services to individuals as they age. Children's workers until they are 21 then we transition to another case manager for adult services. One area we are working on is retirement. The challenge we have with congregate setting is losing control and can't ensure that vulnerable children are always safe.
- We'd (parents) all like to go to our grave knowing our children would be cared for the rest of their lives. One place that includes vocational services would be idea. Moving is hard on them.
- No, we don't provide services across the lifespan because the needs of the kids are not being met. Children are vulnerable and need protection. On example of this was when our child’s door lock was turned around for a whole week and resulted in him being locked in his room whenever his door was shut. New services being proposed still lack checks and balances. I think it's left up to the parents and there could be better checks and balances.”
- Support across the lifespan is not just the support kids receive when they are young and in school. It goes beyond there. Kids get a lot of support from birth to 21, but after that supports are much harder to access. Families have to jump through more and more hoops to get support unless it is an emergency situation. We have some supports across the lifespan now but they are not enough. There are not enough beds for kids with autism in crisis and the next biggest need that is not being met is mental health.

- Agencies are interested in programs that serve childhood all the way to adulthood in group setting noting that kids in group homes need more structure.

11) Please describe what you perceive to be the most significant barriers related to supporting the long-term residential needs of individuals with ASD (across the spectrum).

Stakeholders indicated that the most significant barriers to supporting the long term residential needs of individuals with ASD included:

Funding

- It always boils down to money. Lack of funding for appropriate residential services and training to access what the individual needs.
- Funding in the infrastructure. One--mindset that by establishing these autism communities, we are returning to the days of institutionalization. It's frustrating to me because I thought the whole point of deinstitutionalization was to provide a better quality of life. I think people are too focused on the meaning of that word. Bad institutions were bad because they were not run correctly and didn't focus on the needs of the people. People need to look at what is best for this group of people. Many people with developmental disabilities need the social aspect of being a part of a community. For my child, it doesn't matter; the social need isn’t as great.
- Lack of flexibility of how funding can be used.
- Current Model of the 4 bed group home is becoming an outdated and expensive model.
- I am shocked when I hear providers receive $450/day for some residents to be in group homes. I question what justifies that much money. I have a child with severe behavioral issues that would make it very difficult to hire someone to be with him--but you can do a lot with that much money.

Understanding Autism

- We need more Person-Centered Planning to work with the entire family. We need to be providing social skills training and more OT and PT, not just medical and medication interventions.
- The government and their misunderstanding of autism spectrum. They think they should be at home, or that they should be in the least restrictive community. That is the worst thing for them. That's joke to think they could live in the least restrictive setting--these kids need structure and constant supervision.

Access and Availability of Services

- Acute shortage of appropriate housing.
- Lack of availability of appropriate sites for individuals. Fewer options when they are younger.
- Some providers are not willing to take on those with really high behaviors. These are the ones that are hardest to place.
- There is no one place to go that gives a parent all options. Need a disability planner to assist parents in understanding different service options and then assist with accessing services.

- There is no unified programing. Social services are usually denied. There should be a unified case management role that will look at all aspects of services, I don't think it is a lack of money; it is allocation of services not done effectively. Consolidate services into single centers of excellence or organizations and connect families with someone that is a true case manager that understands what resources are available and how to access them.

Stakeholders identified additional barriers specific to people with "severe/classic" autism including:

- Campus model definition is a barrier, there is a distinct difference between older people on the spectrum and younger people on the spectrum and this is a barrier when evaluating new service models.
- Lack of person centered planning.
- Inadequate care in group homes serving children with severe/classic autism.
- Difficulty in getting behavioral programs in place because of all of the paperwork.
- Simplification of the requirements around use of restraints to better address behavior needs.
- Lack of consensus among different groups and organizations focused on autism. All autism groups need to meet and come to an agreement as to how we can provide them with the best quality of life.
- I have seen residences where the most severe live in group homes and behavior challenges get less dramatic. So many things will set off a person but as they get older, things are less frantic. They seem to do better when their needs are being met, and are in close contact with their families. Closeness with families is critical and technology can people live in the community.
- Trying to figure out how they can be supported the best, don't know if they fit into the existing model of knowledge and education on how to best support that person.
- Behavior plans are very important. We have specialized staff that have a lot of crisis training and are very proactive. More education for staff so they understand how to alleviate crisis before they happen. Need to evaluate current crisis home services and increase use of sensory rooms. As the State looks at removing use of restraints under Rule 40, alternatives like sensory rooms will be needed.
- Limited options for residential when turns 18.

12) What needs to happen in Minnesota to be able to provide effective residential support to people with ASD (across the spectrum)?

- Need more supports for families, more residential places available, and more quality residential places. There is a shortage of residential options for children with more severe autism. Parents often way beyond crisis level when seek residential services.
- Reduce barriers to innovation. Allow funding for pilot projects and practices that don't have a lot of hard data.
- Need better support structure for families that includes how to get help especially when in a crisis.
- Need children's group homes, need a place that is safe, structured, and successful for a child. Important to keep child in home, but doesn't work for all families.

- Need research to show how this is affecting siblings and stress of family and family functioning.
- Look at more clear definition of what autism really is instead of looking at severity level.
- Address budget deficit and lack of funding for expanding services.
- Need to have a complete and open debate and discussion among all the parties. Not everyone wants to live in integrated housing. People who fight segregation should consider more options. Money follows the person. More choices, more options. More discussion and debate is needed.
- Need to listen to families and have them help create the model. Give funding to families who can create models. Start small in clusters before expanding.
- Priority by legislature should funding service innovation that matches different levels of disability rather than limit innovation through cuts and over-regulation. We need the ability to try new things.
- Current service model can't be sustained with current funding. Need to look at different models of support and figure out how to do it.
- Service contracts with service providers are moving from County to State. The State will need to ensure that providers are keeping up with trends and new practices.
- The government needs to realize what's needed and then implement those things such as lifting the ban on creating more group homes and consider larger settings like Chileda as a model.
- More staff training, communication and collaboration between service providers and families.
- End Moratorium on creating new group homes.

Stakeholders shared additional things that need to happen in order to provide effective residential services to people with “severe/classic” autism including:

- More residential places and more quality services specific to the needs of children with severe autism and challenging behaviors.
- Funding sources should allow for more variance in backgrounds and credentials of staff in different programs and services.
- Public campaign to inform people that having larger groups does not mean that we are trying to go back to institutionalization. Public education to show that there is a way to bring people together to create an inclusive model that requires family involvement to maintain community to community that will not bring us back to institutionalization.
- Money is an issue and drives a lot of decisions. Acknowledge the fact this problem is not going away. In a few years, there is a going to be a crisis in terms of an increase in the number of kids with severe/classis autism needing placement. A lot of people see the value of establishing autism homes to meet the specific needs for children with severe/classic autism. It will help if people are educations about what we are asking for. They also need to know the sense of urgency. Sometimes keeping kids home with their family is not the best situation. There needs to be more education overall on severe autism. There are successful models around the country and in other countries that we could look to as models.
- We should seriously look at the whole profit structure of group homes. This has been a problem. Consider other models such as co-ops, client owned residences where they or

their agents run the place using nonprofits to provide supports. Flexible funding for individualized services is needed such as OT, PT, speech, yoga, Tai chi, recreation none of which involves negative behavior or punishment.

- Making accessible support specific to autism available statewide and include services that can supplement residential services.
- Funding needs to be directed to the individual needs of the person and rather than the current per diem model where providers get a daily per diem such as $95 per day to provide residential services to an individual.
- Schools should be required to come up with lunches to address kid's nutritional needs.
- More emphasis and resources directed at training staff on the specific needs of children and adults with severe/classic autism.

13) What are your policy recommendations to improve access to effective residential support for children, youth and adults with ASD?

- Policy makers need to look the statistics in the schools where we have according to stakeholder "450,000 in school that has autism." This is a disability that needs different intervention than others.
- More residential options and more awareness of options currently available.
- Funding for innovation. Strengthening connections of private sector within community particularly in area of supporting for employment.
- Show legislators what is happening in families and homes. People don't understand costs - family and friends leave you, you are isolated. Personal items get destroyed that families have to cover costs for. Recommend that families not only receive assistance for services or housing, but also destruction of per child property. Put money towards creating better processes of support and crisis centers. This may cost more up front, but save money in long run.
- I think one policy that is a problem is that when a child reaches 18 they must leave the group home. If they start as a teen they should be able to stay in that home. As residents age, the label of the home could change. The people could stay together as a family and not be forced to move around. The label of the home would change not the people in it.
- Budget is so imperative to whole issue. Right now, way too much of discussion is driven by lobbyists at legislature that want to keep group home model and continue down road they have taken last 4 years. They need to redo services. Misspending dollars because of lobbyists.
- Need to listen to families and parents who have children who are suffering. They need lived experiences to understand what families are going through. Have this conversation with policy makers to build legislation. More adequate and quality resources, service delivery, time frame. Constant checking in on how things are progressing. Needs to be more action and less talking.
- Lift moratorium on developing new group homes.
- Specific training on autism for people working with our kids.
- State needs to allow autism communities and not consider them institutions, a campus setting, farm, or school can be more cost effective.
- Early intervention should start right away. Save money later on. Kids that have early interventions leap from being severely autistic to being Asperger's like.

- Get rid of for profit housing and go back foster provider model for families.
- Current state formula for rate setting is lower than what we provide and doesn't allow for quality staff at that rate.
- I think the state is kind of doing the best that they can. They have to consider both higher functioning and lower functioning kids and can't be discriminatory. I would like to see them more open to these congregate models. I don't think this is a bad thing. I think the state is looking at these things as they did a long time ago not as new interpretations of them.
- Lift the moratorium. With that in place, nobody can do anything and families are stuck.
- Don’t allow group home providers to require chemical restraints in order to serve child integrating therapy options at school and home (family or group) Sensory integration needs must be provided for.
- Require transparency, all the costs should be laid out for parents to review. Currently, group homes won't provide explanation of benefits or Medicaid statements School district bills Medicaid for the aid, the group home has signed off on this for my child without my consent.
- Mandatory training on autism to a certain level of competency with a regular competency check-up to ensure using current best practices are used since these can change over time.
- Remove the moratorium.

Appendix F

ASD Advisory Council Survey Responses

Advisory Council Members were given the opportunity to provide additional responses to key questions in three online surveys. Below is a compilation of responses received to key questions. The responses below are from those council members who chose to respond to the survey. Not all council members responded.

Survey 1

In the first online survey, council members were asked to identify additional characteristics of effective residential services that were not identified during the ASD Council meeting discussion.

What are additional characteristics of effective residential services?
High priority on community integration. Increase independence in all aspects of the consumer’s life. Providers must develop a strong professional work environment for their staff and at the same time provide a relaxed home-like environment for the people we serve. Highly organized (communication with other agencies, parents/guardians, medical personnel.)
I wasn't on the call for this part. I'd say there needs to be a skilled team of behaviorists, psychologists and SLP's on staff who can conduct good functional behavior analyses and collect ongoing data on efficacy. And there needs to be a focus on well-being--individualizing for each person to bring them opportunities to do things that make them happy, stimulated, and engaged with the community. Oh, and FUNDING. Residential services need infinitely more funds.
I think people gave excellent feedback to this question. It was very informative to me, as a residential service provider. I would add that an effective residential service provider must also have good knowledge of resources in their area, as well as easy access to these services. For us, some services have been difficult to obtain for our clients at time - for dental appointments; we have clients that must be transported 2.5 - 3.5 hours away in order to receive dental care. This has also been nearly an issue with psychiatric care. Psych doctors can be very scarce, especially in rural areas (even just in Duluth), and very often, parents want someone who has a lot of familiarity with or is "specialized" in autism spectrum disorders. Finding psych doctors who use the Huggins model can be difficult. We are lucky in Duluth to have access to a lot of great providers - I can only imagine how difficult it would be in rural areas to find good psych doctors, medical doctors, dentists, schools or work programs. Access to appropriate and safe transportation. Geographic location of the residential program - is it soothing, is there constant noise or lights outside, can the person go outside safely, neighbors, etc.
The ability to choose the residential setting that best fits the person with ASD's needs, interests, abilities and preferences.
I think pretty much everything I would recommend was mentioned in that meeting, however, I don't remember if anyone mentioned having quality programs and skill development opportunities to be integrated with housing options.
Two unique characteristics I would like to emphasize are a functional environment and well-trained staff. First, the surroundings need to be tailored for the individual (water, sensory room, swings inside and outside, large shower facility, safety, protection from elopement, privacy for the disrobing client, quiet area). Second, the staff needs to be well-trained in managing classic autism. Correct restraints and means for de-escalating situations. There should be opportunities for continuation of training.
I mentioned freedom from ABUSE, but it would be helpful to define what that is when dealing with challenging behaviors: this can range from restraints to aversive to neglect.

I felt there was a disconnect between what could be considered an effective residential service and some very basic assumptions. For example, one person offered that the individuals be safe in their environment, where to me that would seem to be very, very basic. It was hard to wrap my head around the fact that some individuals were talking about self-determination and some were talking about being safe in the residence. I also don't know if anyone mentioned access to the community.
I am a psychiatric NP and have also had training by the Medical Academy of Pediatric Special Needs which offers a bio medical approach to the treatment of various aspects such as behaviors associated with Autism. This also requires special dietary concerns such as GF/CF. My adult child did quite well when they was at home where this type of diet was prepared for them. However, when adult child transitioned to independent living, this was too difficult for them to manage on own which adversely affected health and level of function. Unfortunately, residential services in Minnesota are not well versed in this area of need. Additionally, there needs to be more education in terms of sensory needs. I frequently find individuals on the spectrum who are placed in foster homes that supposedly have knowledge of Autism; however the individual's sensory needs are frequently overlooked. Examples: Peers wearing strong scented perfumes, burning scented candles in the rooms, using strong scented cleaning solutions. A fear that I frequently hear from parents is the lack of training and monitoring of support staff at these facilities. Our children are vulnerable which is a concern to parents. I frequently see staff who look like they just left their gang activities prior to coming to work. On several occasions I have encountered staff who have taken the liberty to educate the client about sexual things. Again, inappropriate. These young clients need professional therapy as they transition, in a proactive manner, not reactive following an unfortunate event.
From the child welfare perspective I represent I think that a well-integrated treatment plan/discharge plan and ongoing communication is essential. My intent here is that it is inclusive of the bio parent, responsible caregiver AND/OR a substitute care provider. Agencies often will work with the foster parent that the child/youth will be discharged to but not include the parent. This is a tremendous gap. Caregivers should ALL be included, at least at some level.
Assessing and teaching self-help imitation skills also having leisure and special activities to that specific child/youth and adults,
Positive Behavioral Supports and Person Centered Planning
-Comprehensive, behaviorally based treatment model that is comprised of individualized goals that target skills deficits in areas of cognitive, social, personal/daily living, play/leisure, language, fine/gross motor areas, reduction of problem behaviors or stereotyped, repetitive and/or restricted patterns of behavior. -Data based measurement system to determine progress towards goals and/or the need for goal revision -Requirement of presence of onsite Board Certified Behavior Analyst who possesses the skills necessary to appropriately develop behavior support plans. -Functional assessment and functional analysis of problem behavior by qualified professional with board certification in behavior analysis (BCBA) with functionally derived interventions that evaluate environmental variables that trigger and maintain the problem behavior and seek to teach socially acceptable replacement behaviors.-Parent/caregiver training in behavior management techniques to sustain treatment gains and ensure consistency across environments -Adequate supervision and training of direct care staff by Board Certified Behavior Analyst-Crisis Management/prevention training-Emphasis on quality of life, functional independence and functional communication, and access to appropriate leisure activities that are sensitive to ethnic, linguistic and cultural variables -Yearly psychological standardized testing evaluation to provide standardized measure of treatment progress, update functioning and diagnosis and obtain treatment recommendations.-Review of treatment plan every 90 days, renew treatment plan at 6 month intervals, monthly progress review, weekly direct supervision of client by licensed professional with board certification to monitor progress or changes needed to treatment, required on site BCBA present at least 30 hours weekly for quality assurance to ensure agencies don't hire consultants to come monthly for cost control purposes but yet still meet the state's requirement but at the expense of quality and appropriate treatment oversight.
Opportunity is what I expressed - And let's make this clear, while Federal Law says anyone living in a

group home of four or more individuals must be classified as an "Institution" - it is very clear that these are NOT institutions. I understand that "term" must be used to receive Medicaid dollars, etc., but effective residential services are just that - Programming, Recreation, a solid quality of life for these individuals! DHS even understands and recognizes the importance of making this a clear message. I just would like to see this same understanding across this area of study.
Special program practices or features should be available for young children (<8 ?) to enable the parent/child bond to remain strong; different options might be available for these families, such as an overnight suite in the group home, or greater in home support so residential not needed, such as a "live-in nanny".
On site management of staff and/or video cameras.
A range of options is important to meet individual needs and preferences. Any model should provide opportunities to move between more restricted/segregated settings and community settings as needs change.
Individualized - there cannot be one model program that fits any one group of people. We can wrap individualized supports around anyone. Then use employment, neighborhoods, support networks, circles of support, communities, to help them live a rich, included life. One person at a time. Holistic - look at the person's whole range of needs, their circle of support, the type of outcomes they want for their lives and support all of that. Not just one component of it. Incorporate employment, family, friends, all into the residential side of things. Use a strength-based approach and focus on what the person’s unique gifts and talents are - capitalize on that to help them achieve all that's possible. Have high expectations of folks and their circles of support. Empower people and their families to be the drivers of everything. Don't over support - allow people to move back and forth between levels of support depending on where there are at in their life "the right service at the right time.”
Environmental design!Focus on choice and quality of life.Treatment options.English as a first language staffing.A LARGE # OF EYES to limit the opportunity for abuse.Accountability.
Safety and freedom from abuse/neglect. Well-coordinated educational and residential components of the setting.

Survey 2

In the second online survey, council members were asked to respond to questions focused on identifying effective residential services in Minnesota and their thoughts and or opinions on congregate care models**.**

Do effective residential supports exist in MN for children and adolescents with “severe/classic” autism? Why or why not? If they do exist, what makes them effective?
Yes. What makes them effective is the ability of the service provider to be able to develop a highly individualized support plan that is very specifically tailored to the needs of each individual. The provider must have access to good functional behavior assessments, outside agencies or professionals who can help with assessments (psychiatrist, behavior analyst and occupational therapist) and developing a good support plan. Modifications may also have to be done to the home in order to accommodate an individual. For example, appropriate/soothing lighting, extra stimuli for individuals who may need more sensory input, reduced stimuli for individuals who are overwhelmed by too much sensory input.

General child welfare professional is prepared to assess this at the time of placement and therefore they can't effectively advocate for a child with severe autism on their caseload.
They are limited and do not meet the demand.
This remains a mixed bag. The funding seems to always be in jeopardy, and the parental fee makes the matter challenging. Classic autism comes with many intangible costs that are not often recognized, like inability of the parents to work full hours, the need for additional assistance for simple tasks like grocery shopping, running errands, being able to drive safely and finding PCA help within the current regulatory constraints (who wrote these uninformed rules anyway?). Effective housing for children and adolescents has the same problem with hidden costs that are not covered. Ultimately, the family is responsible for covering those costs, which makes the residential support only one piece of the overall budget. In many cases, it is not economically feasible to use the residential supports because not enough funding in the family budget is available to cover the intangibles.
I am not aware of residential supports in central MN. Some group homes may claim to offer these services however as a provider I frequently find that direct care staff are poorly trained and not well monitored. Example: Last week I had an 18 year old Asperger's patient who had previously been in trouble due to his involvement in porn on the internet. He is now band from using the internet, but his PCA brought him copies of Penthouse and Playboy magazines.
They do exist but they are small, individualized, max 4 people, and usually have strong parental leadership to make them great.
No, I don't think we have any good residential programs here and quite frankly it is even scary to think that our children might need them. I for one would like my son to not have autism to the point of needing residential support, but rather become a productive member of society that lives independently.
Yes, I believe some do exist in MN. There are many variables that impact this success. First, I believe it needs to be a cooperative effort with parents, providers and county people working together. Too often the county is not able or willing to support the ongoing challenges presented with some of these individuals, they are just looking for a provider to do the service, keep the kids safe and parents happy, and when either one of those expectations aren't met they are quick to judge and blame. The services for these very special needs kids/adolescents requires the creativity, flexibility and thinking that "we are all in this together." Having just mentioned flexibility, this is an area that also requires attention, whether that is in the physical plant, which requires extra space for the unique needs of these kids, access to a variety of sensory supports and materials/equipment, and access to good OT services. Funding the service is also an issue, the residential provider's ability to pay the direct support staff enough money is limited, and the ability to pay for qualified oversight of employed Specialists such as BA or other skilled individuals to be present while the DSP is working to help guide them in best practices application. What makes certain services effective is that all or most of the issues mentioned above are managed/facilitated by a strong leader of a provider who is creative, has the ability to lead outside of the box and is effective in rallying everyone on the IDT around their vision and has a true understanding of the unique needs of these individuals.

Why are we only focusing on "severe/classic," and what does that mean? Researchers don't have consensus on that, so how is MDH defining it? There are not effective supports for individuals across the autism spectrum. There is not adequate funding, and there is not an array of options to address the needs of the population. A minority of individuals with autism qualify as "severe," and I would argue there are at least residential facilities available for them, although they are often not appropriate for the needs of adults with ASD who might have problem behaviors that are different from individuals with other disabilities. There is nothing even available for an adult who is verbal, might have mild delays or no learning delays but has adaptive skill or mental health reasons that they cannot live independently. Funding seems to be dependent on IQ, and the majority of people with ASD don't have intellectual disability.
There are a few effective residential supports that exist. Children and adolescents require intervention as well as care so the traditional “care” model is not effective. Those that work have, higher staff ratios and highly trained staff who understand the process of learning and how to integrate it with daily living. Additionally, families and community that are involved over time increase the effectiveness.
Experiences and thoughts regarding congregate care models of educational and residential services for children and adolescents with autism (These have been called campus models, farms or planned communities.)
I think that it can sometimes work well to have an individual’s home and day training run by the same organization. This way, transition times can be well managed, and individualized plans and risks can be very well planned out and uniform - greater consistency, I guess. I could see this working well, especially because so many of the people we serve who have autism are very frightened/anxious when there are new faces, and it can take several months until they get used to new staff. Having a congregate care model could also help with consistency among staff, I'd imagine.

I believe that campus models are, in general, not a good practice for individuals with autism. I believe that if one examines the reasons that people would support them, their reasons are an indication of the inadequacy of the current system, and not an endorsement of the model. For example, some individuals of the campus model support it because they want their adult children to be "safe" and to have access to services. Some services might be to just get a haircut, get a meal or watch a movie, in a place where their needs are met and their behaviors are understood. However, these models create isolation between individuals with autism and the greater community at large. This isolation makes individuals with autism an easy target to "forget." By having individuals in the community, we keep the community aware of the need. I believe it is much easier to vote for spending cuts for people who are out on farms instead of living next door. This contact with the greater community also has more of a chance of fostering an awareness of autism and paving the road for acceptance. As more people encounter individuals with significant disability in their everyday journeys, it would seem that we would, as a society, increase the tolerance for people who are different from the main stream.For the individuals themselves, it would seem that if we truly support individuals with having authentic self-determination that can ONLY happen in an authentic setting. Again, my major point is that the proposal for campus models stems not from their inherent worth as a model, but rather as a response to the inadequacy of the current system. I believe it would better to work to improve community-based services, than to sequester these individuals away from society.Currently, I work in a school for students on the autism spectrum. These students represent most of the range of the disability. For our students with the least cognitive disability and the greatest behavioral flexibility, the model is effective in helping these students to nurture their social skills and provide them with opportunities for leadership and participation that would very likely not be available in a mainstream setting. However, if our school only served individuals who are the most greatly impacted by the disorder, these benefits would NOT be recognized. Our school is an adolescent safe harbor as we prepare our students, not for more isolation, but rather, to function in a neurotypical world. At our school they learn to self-advocate and participate in activities where they practice their emerging skills in a supportive environment. No one is suggesting a campus model for these individuals; it is only being suggested for more significantly disabled individuals.
I worry that congregate care is really institutionalizing our kids, with a different name. All people do better in integrated settings. I worry that by grouping all our kids with ASD together we are headed back to the dark ages.
Congregate care models have the feel of institutional settings with a different name. We need to be careful before reverting back to the use of institutions. We found in the past that institutional/congregate housing actually cost more and was more difficult to manage with bad outcomes for the clients. Classic autism usually needs 24/7 supervision and congregate care models suggest that not enough staff (the most significant costs in a care budget) will be available to provide one-to-one care. If enough staff is being used, then why go to congregate models? There will not be enough savings to make a change to congregate beneficial.
I think congregate care models are desperately needed. This could serve as an excellent supportive transition to independent adult living for some on the spectrum as well.
I do not feel qualified to respond to this question.
One of the biggest issues with larger facilities is that if you go more than 10 people you have a hard time meeting person centered goals because of regulations. Regulations are hard to get around when creating unique environments for special individuals. We see this roadblock for memory care patients in senior living right now.
Again, this is depressing because we want our kids to recover from autism, but I understand the need and would support those now going through this and their views.

My initial reaction is that I am not in support of it, having been witness to the deinstitutionalization of the state hospitals and the difference it made in people’s lives when they had the opportunity to experience life in their community. My belief is that we learn and grow through our life experiences and if those experiences become limited we limit our growth. However, the sensory processing challenges faced by some of the more severe/classic individuals might better be met using this model. On the other hand we are learning so much through research on a daily basis I can’t help but believe that we will be become better able to meet these sensory challenges in the near future without isolating these kids.
I have a little experience with some projects in development. I think we need to investigate new models like these, but they need to be researched carefully. Just because it's new doesn't mean it's effective. I imagine success of these programs will be dependent on the characteristics, experience, training and expertise of staff, much like our existing intervention services. We definitely need more diverse options for adults.
Ideally, we will find a compromise that acknowledges families’ preferences and still maintains community (and federal) standards. At the very least, a campus setting should incorporate rigorous external oversight to ensure that services are not delivered in an institutional manner.

Survey 3

In the third online survey, council members were asked identify what they think are the most important residential support options.

Please identify the three most important residential services options for Minnesota families who have children with severe Autism.
person-centered, family integration, rehabilitation
Full Family Foster Care (specific to families with Teen parents and a child with autism. Needing intensive assistance in home). Accessibility with close proximity for families to remain involved
Remembering that residential services don’t have to be a “building or place,” but rather should happen wherever the person lives (with family, with roommates, in own apartment/ townhouse/home: 1. Respite for caregivers and families. 2. Individualized, person and family-centered holistic in-home supports that include an employment component and support for families to develop a rich informal support network of people who are able to also help provide support. 3. Early intervention services in the home, to give families & people support to learn how to communicate & relate effectively and be lifelong (not just “early”).
The campus-type model would be most valuable. Many people with severe, classic autism are functional in certain ways. My child can follow directions, clean tables, do laundry, recycle, stack, roller-skate and much more but child doesn't function well in public. The reason is because child won't leave when it is time to go or child will leave when is isn't time to go. This may sound like a simple thing but it isn't. If it is time to go but child doesn't want to, child lies down in the street, sidewalk or anywhere, and won't move. This is something that could be dealt with in a safe, cloistered setting. And at the same time, child could be contributing to a community with child’s functional behaviors. I know there are others like my child.
Stay at home with family, Group home, Apartment or home with staff
I do not have enough subject matter expertise to provide input on this survey question.
Funding for housing, care and supervision of individuals, access to proper assessment of problem behavior by a board certified behavior analyst to preserve placement, funding for transportation to access services in community needed (ex: medical, speech or other professional services).
1. Availability 2. Cost Effective

3. Parent and Culture Friendly (driven)
1. Home and community based options (expand existing or add more to state plan for greater access) 2. Short term crisis stabilization (in home or out of home) 3. Appropriate out of home options once all other supports have been tried. i.e., a continuum of individualized service options
That exists? Or that should exist? Right now most children and adults are told there are no options.
I believe these residential services set up today with uneducated PCA's as the primary care givers is a mistake. I like the idea of a larger setting where there is more supervision for staff and residents. Having an RN or LPN in the facility will cut down on neglect, med errors and lack of understanding to the Autistic person. Sensory rooms are great. And staff meetings involving family and resident.
I believe these residential services set up today with uneducated PCA's as the primary care givers is a mistake. I like the idea of a larger setting where there is more supervision for staff and residents. Having an RN or LPN in the facility will cut down on neglect, med errors and lack of understanding to the Autistic person. Sensory rooms are great. And staff meetings involving family and resident.
1. Availability 2. Cost Effective 3. Parent and Culture Friendly (driven)
The most important option continues to be care at home. This is the most cost effective means for supporting the family. However, that means that the support should involve well-trained and available PCA services. This makes economic sense. A short term housing alternative requires that someone pays for another roof, retrofit the home for classic autism behaviors, maintain the physical facility and supply the same staff. At the home with sufficient PCA support, the cost is lower and the family preserved. This means that many of the current PCA payment rules need to be changed so that families can actually use the service. For example, current rules preclude payment to a PCA for overnight care when the child is sleeping; completely ignoring that classic autism involves sporadic sleep patterns. How do we pay someone for an hour here and there when the child is awake at 2 am, but tell them that they are off the clock if the child sleeps for 45 minutes? The second most important service option is a place for short term respite care. At the moment, the cost is running about 600 dollars per day. This can be understandable when recognizing that the house might not be used every day, yet the cost of maintaining the home is constant. Most families will want respite on the weekends, and the house may be partially or completely empty during the school week. However, this type of alternative would help the extended family get some rest from the daily (and nightly) struggle with classic autism behaviors. These types of houses are in short supply. Another option that might be more cost effective is a “day program” where the child may go when school is out. This residential facility would be more akin to a school site, but acknowledges that the family needs the break during the daylight hours. This would allow the family an opportunity to run errands, get to the grocery store, mow the lawn, clean the house and have a typical day while the child is in a safe environment. I expect that the costs would be lower because it would not be necessary to hire overnight staff, and the location might be a school site that is already retro-fitted to be safe. Residential options do not necessarily have to include overnight stay to be helpful for the family.
Remembering that residential services don’t have to be a “building or place”, but rather should happen wherever the person lives (with family, with roommates, in own apartment/townhouse/home: 1. Respite for caregivers and families. 2. Individualized, person and family-centered holistic in-home supports that include an employment component and support for families to develop a rich informal support network of people who are able to also help provide support. 3. Early intervention services in the home, to give families & people support to learn how to communicate & relate effectively and be lifelong (not just “early”).

Appendix G

The ADA, Olmstead and Medicaid Residential Options for People with Developmental Disabilities

By

Robin E. Cooper, MSSW, Director of Technical Assistance and
Charles R. Moseley, Ed.D., Associate Executive Director

Prepared for

University of Minnesota Research and Training
Center on Community Living

December 2012

NASDDDS

National Association of State Directors of Developmental Disabilities Services

113 Oronoco Street, Alexandria, VA 22314
Tel: 703·683·4202; Fax: 703·684·1395
NASDDDS Web site: www.nasddds.org

Table of Contents

Section I

Section II

The Americans with Disabilities Act and the Olmstead Ruling

The preference in federal policy for home and community based services for persons with disabilities was advanced by the U.S Supreme Court's ruling in 1999 in the case of Olmstead et al. v. L.C. et al. (527 U.S. 581 Amended 2008 (P.L. 110-325)). The Olmstead Decision established that the unnecessary segregation of people with disabilities in institutions is a form of discrimination under Title II of the Americans with Disabilities Act of 1990 (ADA) and set the responsibility of states to provide services to individuals with disabilities within "the most integrated setting" appropriate to their needs. An executive order signed by President Bush in 2001 launched the "New Freedom Initiative" affirming the nation's commitment to the provision of publicly financed community-based services and supports to individuals with disabilities fostering independence and community participation. The federal government's commitment to assure the right of people with disabilities to live, work and receive services in community settings was renewed by President Obama when he declared 2009 to be "The Year of Community Living" and directed the Department of Justice (DOJ) and other federal agencies to "vigorously enforce the civil rights of Americans with disabilities" by ensuring the implementation of the Olmstead Ruling as a top priority.1

The Americans with Disabilities Act of 1990

Background. The Americans with Disabilities Act (ADA) was signed into law by President H. W. Bush on July 26, 1990. The landmark legislation was passed by Congress to "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities"[2] Noting that the historical isolation and segregation of people with disabilities continued to be "a serious and pervasive social problem,"[3] Congress acted to prohibit such discrimination by any public entity through the enactment of legislation that ensured that no qualified individual with a disability would, "… by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."[4]

---

[1] U.S. Department of Justice. Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C. Accessed from http://www.ada.gov/olmstead/q&a_olmstead.pdf. November 2012.

[2] 42 U.S.C. § 12101(a)(2).

[3] 42 U.S.C. § 12101(b)(1).

[4] 42 U.S.C. § 12132.

The framework of the ADA was built upon several major pieces of legislation that were passed by the U.S. Congress during the 1960's and 1970's including the Civil Rights Act of 1964, the Voting Rights Act of 1965, the Civil Rights Act of 1968, and the Rehabilitation Act of 1973.

- The Civil Rights Act of 1964 prohibited discrimination by entities receiving public funds, employers, public facilities and others based on race, religion and national origin but did not specifically identify people with disabilities as a protected class.

- The Voting Rights Act of 1965 protects the rights of minorities to vote in elections but did not ensure the rights of people with disabilities.

- The Fair Housing Act, Title VIII of the Civil Rights Act of 1968, includes provisions that prohibit discrimination on the basis of race, religion, national origin and sex in the sale and rental of housing, but it was not until 1988 that the Act was amended to afford protections to people with disabilities and families with children.

- Section 504 of the Rehabilitation Act of 1973 prohibits discrimination on the basis of a disability towards otherwise qualified people with disabilities by recipients of federal financial assistance. The legislation represents the first time that people with disabilities as a group were identified as a separate class – rather than as separate diagnoses.[5] No protections, however, were afforded for people with disabilities from discrimination by employers, by public accommodations in the private sector, by publicly funded programs and by those providing federal financial assistance.

Although each of these measures addressed significant civil rights issues, and had some impact on people with disabilities, none were specifically designed nor intended to address the barriers to full inclusion faced by people with disabilities in U.S. society. In its review of the need for legislation in this area Congress noted several national research findings on the status of people with disabilities in the U.S., and the challenges they faced in fully accessing and participating in the mainstream of community life. Congress found that over 50 million Americans had one or more physical or mental disabilities, and the prevalence rate was increasing as the nation's population grew. It was also noted that discrimination on the basis of a person's disability existed throughout American society in housing, public accommodations, education, transportation, communication, recreation, health services, voting, and access to public services. Furthermore, in contrast to the experiences of individuals who faced discrimination on the basis of race, color, sex, origin, religion, or age, people with disabilities were not as a class generally covered by existing civil rights legislation and often had no remedy in the law to redress such discrimination. Congress noted that the continuing existence of unfair and unnecessary discrimination and prejudice denied people with disabilities the opportunity to compete and pursue opportunities on an equal basis with the non-disabled population, and that the costs of discrimination in terms of

---

[5] Mayerson, A. (1992) The History of the ADA: A Movement Perspective. Disability Rights Education and Defense Fund, Berkley CA.

national expenditures resulting from unnecessary dependency and unproductiveness reached the billions of dollars.

Defining Disability. Coverage under the ADA is provided to individuals with disabilities who meet the three-part definitional criteria included in the Act. Under the ADA an individual with a disability is defined as a person who: (a) has a physical or mental impairment that substantially limits one or more major life activities; or (b) has a record or history of such an impairment; or (c) is perceived or regarded as having such an impairment.[6]

The phrase "major life activities" is defined as the ability to carry out key activities or functions such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working. The determination of "impairment" and the extent to which the impairment substantially limits a major life activity is made on an individual basis. The determination is not related to the presence or absence of a particular condition but rather to the impact that the condition or impairment has on the person and his or her ability to function in society. The extent to which an impairment "substantially limits" a major life activity is based on the conditions, manner or duration under which the life activity can be performed by the individual as compared to others in society.

Structure. The ADA prohibits discrimination on the basis of disability in the areas of employment, public services provided by state and local governments, public services operated by private entities, transportation, certain commuter authorities such as AMTRAK and telecommunications. The Act is divided into three titles.

Title I Employment. Employment provisions apply to private employers, state and local governments, employment agencies, and labor unions. Title I prohibits discrimination against "qualified individuals with disabilities" in all employment practices, including job application procedures, hiring, firing, advancement, compensation, training and other terms, conditions, and privileges of employment. Title I additionally covers recruitment, advertising, tenure, layoff, leave, fringe benefits, and all other employment-related activities.[7]

Title II - Public Accommodations by State and Local Governments. Title II covers programs, activities, and services of public entities and is divided into two subtitles. Subtitle A provides protections from discrimination on the basis of disability to people with disabilities in the services, programs, or activities of all State and local governments and extends the prohibition of discrimination on the basis of disability established by section 504 of the Rehabilitation Act of 1973, to all activities of State and local governments, including those that do not receive Federal financial assistance. Subtitle B clarifies the requirements of section 504 for public transportation entities that receive Federal financial assistance and extends coverage to all public entities that provide public transportation, whether or not they receive Federal financial assistance.

---

[6] 29 CFR Section 1630.2(g): Disability. 76 FR 16980 Page 16980

[7] About the Americans with Disabilities Act of 1990 (ADA) Martin County Florida http://www.martin.fl.us

The Title II regulations require public entities to "administer services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."[8] The preamble discussion of the "integration regulation" describes "the most integrated setting" is one that "enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible . . . .[9]"

Public entities are required under Title II to conduct a self-evaluation of current policies and practices and must ensure that individuals with disabilities are not excluded from services, programs and activities because of building inaccessibility. The "program accessibility" standard does not require that public entities must make each of their existing facilities accessible. Covered entities may ensure access by modifying existing facilities, building or acquiring new facilities, relocating programs or services utilizing alternative sites or approaches to service delivery.

In order to receive protections under Title II, a "qualified" individual with a disability must meet the essential eligibility requirements for receiving or participation in services or programs furnished by a public entity with or without: (a) reasonable modifications to a public entity's rules, policies, or practices; (b) removal of architectural, communication, or transportation barriers; or (c) provision of auxiliary aids and services.[10]

Title III Public Accommodations by Private Business. A "public accommodation" refers to a privately operated entity that owns, leases, leases to, or operates a place of public accommodation. Title III prohibits discrimination on the basis of disability in all public accommodations operated by private businesses including, but not limited to hotels, restaurants, theaters, retail stores, museums, libraries, parks, private schools, and day care centers and other such entities. Places of public accommodation are required to remove barriers in existing facilities where it is "readily achievable," that is, where it can be "easily accomplished and able to be carried out without much difficulty or expense." Such readily achievable modifications include making structural changes to provide access around a few steps via a ramp or other means, lowering sinks in bathrooms, repositioning telephones and other adjustments of this nature. Public accommodations may need to make alternative changes if the physical removal of a barrier is not possible or practicable such as furnishing direct assistance to people with disabilities to help them access items that are located on high shelves that are out of their reach, or assistance in finding items in stores.

The Olmstead Ruling: Key Provisions and Implications

Since the ADA was signed into law in 1990 the Act has resulted in positive changes in the lives and aspirations of people with disabilities across each of its four main policy goals: ensuring equality of opportunity, full participation, independent living and economic self-sufficiency.

---

[8] 28 C.F.R. § 35.130(d) (the "integration mandate").

[9] 28 C.F.R. Pt. 35, App. A (2010)

[10] The Americans with Disabilities Act Title II Technical Assistance Manual

Improvements in architectural design and construction, transportation, and communication accessibility brought about by the ADA have enable people with disabilities to experience greater independence and increasing levels of inclusion, employment and community participation.

Among the most noteworthy outcomes of the ADA to date have been changes in the delivery of publicly financed services and supports that occurred as a result of the U.S. Supreme Court's Decision in Olmstead v. L.C. in 1999. The case involved two women diagnosed with mental illness and developmental disabilities receiving voluntary treatment at a psychiatric unit in the state-funded Georgia Regional Hospital. In spite of the fact that their medical treatment had concluded and state mental health professionals had determined that each person was ready to move to a community-based setting, the women were not permitted to leave the facility. The two women brought suit against the state under the ADA for their release from the hospital. In June, 1999 the Supreme Court determined that the unjustified segregation of persons with disabilities constitutes discrimination and is in violation of Title II of the ADA. In this decision the Court ruled that individuals with mental disabilities have the right to live in the community rather than in institutions and "that public entities must provide community-based services to persons with disabilities under three conditions when: (a) such services are appropriate; (b) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity."[11]

Integration Mandate and States' Obligations. The Supreme Court noted that its finding "reflects two evident judgments." First, "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life." And second, that "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement and cultural enrichment."[12] The Court held that to comply with the ADA's integration mandate, public entities must make "reasonable accommodations" to their policies, procedures or practices when necessary to avoid such discrimination. The obligation to make reasonable modifications may be excused only where the public entity demonstrates that the requested modifications would "fundamentally alter"

The Olmstead decision interprets public entities' obligations under Title II of the ADA and the parameters through which qualified individuals with disabilities are not subjected to discrimination, denied benefits or excluded from participation in services, programs or activities of a public entity.

---

[11] U.S. Department of Justice. Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C. Accessed from http://www.ada.gov/olmstead/q&a_olmstead.pdf November 2012.

[12] *Olmstead v. L.C.*, 527 U.S. at 600-01 and 607

its service system. [13] The Supreme Court's Olmstead Ruling requires states to develop comprehensive effectively working plans to end unnecessary segregation of individuals currently living in segregated programs and to furnish supports to individuals on waiting lists at a "reasonable pace" with the goal of integrating individuals with disabilities into mainstream society to the fullest extent possible.

Olmstead Plan. A state's Olmstead Plan provides the framework through which it intends to comply with its obligation to ensure people with disabilities have access to opportunities to live, work, and receive supports in integrated settings. The plan should provide an assessment of the state's current efforts to ensure individuals with disabilities receive services in the most integrated settings appropriate to their needs, identify policies and practices that may hinder the movement of people and services from segregated to integrated settings and the steps necessary to address waiting lists and other related policy goals. The plan must describe the state's commitments to expand integrated opportunities according to a reasonable timeframe and include measurable goals, specify the resources necessary to meet those goals, and identify the groups of people with disabilities who are to be covered by plan activities. Guidance from the DOJ Civil Rights Divisions suggests that plans should include specific commitments for each group of individuals with disabilities who are receiving segregated services and be able to demonstrate that progress toward effectively meeting its goals. It is important to note that states may use alternative strategies that accomplish the goals of an Olmstead plan. As of 2010, 26 states had written Olmstead plans while 18 states had published alternative strategies. The remaining seven states were reported to have neither an Olmstead plan nor an alternative response to Olmstead (DC, FL, ID, NM, RI, SD, TN).[14] (See the PAS Personal Assistance Center's website for a listing of state Olmstead Plans at http://www.pascenter.org/olmstead/olmsteadcases.php).

States are obligated to comply with the ADA's integration mandate and may be found in violation of the Act if the state funds, operates or administers its programs and services to individuals with disabilities in a way that results in their unjustified segregation or exclusion from society through its: (a) direct or indirect operation of facilities, programs or services; (b) financing of the delivery of services in private facilities; or (c) because it promotes or relies upon the segregation of individuals with disabilities in private facilities or programs through its planning, service system design, funding choices, or service implementation practices.[15]

---

[13] 28 C.F.R. § 35.130(b)(7).

[14] Ng, T., Wong, A., & Harrington C. (April 2012). Home and Community-Based Services: Introduction to Olmstead Lawsuits and Olmstead Plans. National Center for Personal Assistance Services University of California at San Francisco.

[15] 28 C.F.R. § 35.130(b)(1)

The integration mandate obligates states to:

- Furnish supports and services to individuals with disabilities in integrated settings that offer choices and opportunities to live, work, and participate in community activities along with individuals without disabilities at times and frequencies of the person's choosing.
- Afford choice in their activities of daily life and the opportunity to interact with non-disabled persons to the fullest extent possible.
- Provide individuals with an assessment of their needs and the supports necessary for them to succeed in integrated settings by professionals who are knowledgeable about the variety of services available in the community.
- Enable people with disabilities to make informed choices about the decision to reside in the most integrated settings by furnishing information about the benefits of integrated settings, facilitating on-site visits to community programs and providing opportunities to meet with other individuals with disabilities who are living, working and receiving supports in integrated community settings, with their families, and in other arrangements.
- Protect people with disabilities from the risk of institutionalization resulting from service or support reductions or reconfigurations as a result of state funding reductions through the provision of support alternatives that do not result in institutionalization.

<u>Integration Mandate Prevails</u>. It is important to note that a state's obligations to comply with the ADA integration mandate are independent and in addition to and separate from any regulations or requirements of Medicaid programs under Title XIX of the Social Security Act. A state could, for example, decide to address its wait list for developmental disabilities services by increasing placements in Medicaid funded institutional ICF/ID facilities and expanding the use of segregated institutional programs for all people with autism. This approach would not necessarily run afoul of Medicaid financing or operational guidelines but would violate the ADA's integration mandate by unnecessarily segregating people through the lack of more integrated support options and by providing certain services only in segregated settings. Requiring the state to change its policy would not be considered a "fundamental alteration." Similarly, under Section 1915(c) of the Social Security Act states are allowed to place a cap on the number of eligible individuals with disabilities they will serve through their home and community based Medicaid waiver programs. While consistent with Medicaid regulations, the presence of such a cap does not remove the obligation of the state under the ADA to serve individuals with disabilities in the most integrated settings appropriate to their needs. To comply in this example, the state may need to submit a waiver amendment to increase the numbers served or take additional steps to reduce its reliance on segregated support alternatives. As above, it is doubtful that such an action would be considered a fundamental alteration of the state's program.

Conditions Under Which Olmstead Applies

The provisions of the ADA under the Olmstead decision apply to people of all ages with all types of disabilities (see definition of eligible disabilities above[16]). Under Title II of the ADA, an individual with a disability is “qualified” if he or she meets the eligibility requirements for receiving services or participating in the public program or activity. On an operational level, the Olmstead decision has been interpreted by DOJ to apply to people with disabilities who receive services from segregated institutions or settings, as well as those who are at risk of institutionalization as a result of the lack of the availability or accessibility of publicly funded services and supports in the community. The definition of a segregated setting encompasses: “(1) congregate settings populated exclusively or primarily with individuals with disabilities; (2) congregate settings characterized by regimentation in daily activities, lack of privacy or autonomy, policies limiting visitors, or limits on individuals’ ability to engage freely in community activities and to manage their own activities of daily living; or (3) settings that provide for daytime activities primarily with other individuals with disabilities.”[17]

Given the broad interpretation of the scope of the Olmstead Ruling it is difficult to identify the total number of individuals that are covered under the Act’s provisions. In 2001, the Government Accounting Office noted that the implementation of the Olmstead Ruling was taking place in the context of expanding numbers of aging baby boomers and individuals with disabilities, and that the full extent of the population covered by the Ruling was unclear. [18] The estimation of the total numbers of individuals to whom the Act applies remains challenging in 2012. Existing data on persons with disabilities receiving public supports in institutional and community programs nationwide suggests that the Act could be expected to cover approximately 37,853,991 individuals in 2010. This number is based on the following:

- Approximately 1,499,279 people with disabilities resided in institutional settings in 2010. This estimate includes 1,385,251 in nursing facilities, [19] 31,101 people with developmental disabilities in state institutions, 25,927 individuals with developmental disabilities living in

---

[16] A person with disability under the ADA is defined as a person: (a) with a physical or mental impairment that substantially limits one or more of an individual’s major life activities, (b) with a record of such an impairment, or (c) who is regarded as having such impairment. 42 U.S.C. §12102(2).

[17] U.S. Department of Justice. Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C. Accessed from http://www.ada.gov/olmstead/q&a_olmstead.pdf November 2012.

[18] General Accounting Office Testimony Before the Special Committee on Aging, U.S. Senate. (September 24, 2001). Long Term Care: *Implications of the Supreme Court’s Olmstead Decision are Still Unfolding* by Kathryn Allen.

[19] C. Harrington, H. Carrillo, M. Dowdell, P. Tang, and B. Blank. Table 4, "Nursing, Facilities, Staffing, Residents, and Facility Deficiencies, 2005 Through 2010," Department of Social and Behavioral Sciences, University of California, San Francisco.

publicly funded private residential facilities with greater than 15 beds,[20] and 57,000 people in state mental health facilities.[21] Researchers have long used 15 beds as the size or capacity criteria separating institutional from community based settings. While this benchmark may facilitate the gathering and reporting of data across states, the figure is arbitrary and makes little sense when placed against the Olmstead integration mandate requiring public entities to support individuals with disabilities in the most integrated settings appropriate to their needs. Including the numbers of persons with disabilities residing in settings of between 4 and 15 beds would significantly increase the total. Furthermore, it is important to note that the provisions of the Olmstead Ruling also apply to people living in community settings and with families who might be at risk of institutionalization.

- Approximately 36,354,712 individuals with disabilities ages 5 years and over lived in the community in 2010. Based on a total U.S. population of 304,287,836 this yields a prevalence rate of 11.9%. The range among states was between California with 3,640,092 individuals with disabilities and Wyoming, with 65,570 individuals with disabilities. The state with the highest prevalence rate was West Virginia at 18.9 percent; Utah had the lowest prevalence rate, 8.5 percent.[22]

Enforcement of the Olmstead Integration Mandate

Enforcement of the Olmstead integration mandate is a central priority of the Obama Administration and a focus of the Year of Community Living initiative launched in 2009. Department of Justice officials note that the Olmstead Ruling encompasses more than requiring that people with disabilities move out of institutions and that enforcement efforts have been organized around three broad goals designed to ensure that people with disabilities have the services and supports that they need to live and thrive in the community. Focus is on ensuring people with disabilities: (a) have opportunities to live life like people without disabilities; (b) have opportunities for integration, independence, recovery, choice and self-determination in all aspects of life – in the settings in which they live, the activities that occupy their time during the day, their work, and in their access to the community; and (c) receive quality services that meet their individual needs.[23]

---

[20] Larson, S.A., Ryan, A., Salmi, P., Smith, D., and Wuorio, A. (2012). Residential Services for Persons with Developmental Disabilities: Status and trends through 2010. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

[21] Ibid. General Accounting Office Testimony

[22] Institute on Disability. (2011). American Community Survey. In 2011 Annual Disability Statistics Compendium: Disability Statistics and Demographics Rehabilitation Research and Training Center. University of New Hampshire.

[23] Thomas E. Perez Assistant Attorney General Civil Rights Division Department Of Justice Before The Senate Committee On Health, Education, Labor & Pensions United States Senate Entitled:

In carrying out its responsibilities to ensure compliance with the ADA and the Olmstead Ruling, DOJ utilizes an array of administrative and legal tools, including: (a) direct investigations of state policies and practices; (b) the preparation and issuance of Findings Letters reporting on the results and conclusions of their investigations, leading to; (c) Settlement Agreements with states on an acceptable course of action to bring illegal policies and practices into compliance with the ABA; and (d) litigation for system reform. DOJ additionally offers technical assistance and guidance to states on Olmstead requirements and expectations, and provides information and materials for interested parties on its website, www.ada.gov/olmstead.

Samuel Bagenstos, Principal Deputy Assistant Attorney General of the Department of Justice Civil Rights Division, noted in remarks to the University of Cincinnati in 2010, that the U.S. Department of Justice had brought, intervened in , or participated as an amicus or interested party in Olmstead litigation in an increasingly large number of states nationwide. Since that time, actions brought by the Civil Rights Division has expanded to over 40 matters in 25 states (see the Civil Rights Division website at http://www.ada.gov/olmstead/index.htm)

The initial focus of Olmstead enforcement was on enabling people with disabilities who were unnecessarily segregated in institutions to receive needed services and supports in the most integrated community settings appropriate to their needs. In recent years, however, enforcement patterns have expanded to include the extent to which the availability, quality and responsiveness of existing publicly funded community based service delivery systems protected individuals with disabilities from unnecessary segregation. This trend can be seen in the language and focus of the comprehensive settlement agreements that the DOJ entered into with states during the past several years.

Georgia. DOJ settled with the State of Georgia, for example, in October 2010 to resolve the complaint that Georgians with developmental disabilities and individuals with mental illness were being unnecessarily and unconstitutionally institutionalized and subjected to conditions that would harm their lives, health, and safety in violation of the ADA and the U.S. Constitution. The agreement requires Georgia officials to change policies and to take a number of very specific operational steps to ensure people with developmental disabilities and those with mental illness receive appropriate services in the most integrated settings appropriate to their needs. Regarding people with developmental disabilities, Georgia agreed to take several significant actions including:

- End all admissions to state-operated institutions by July 1, 2011 and transition all individuals to the most integrated setting appropriate to their needs by July 1, 2015.

“Olmstead Enforcement Update: Using The Ada To Promote Community Integration” Presented On

- Expand its home and community based waiver program to serve at least 1,100 individuals with DD in the community to: (a) furnish supports to people in their own or their family's homes, (b) provide family supports to 2,350 families, (c) create 6 mobile crisis teams to all communities, and (d) establish 12 crisis respite homes.[24]

The state agreed to enact similar reforms for people with mental illness agreeing to serve 9,000 individuals with serious and persistent mental illness in the community who are "currently served in State Hospitals; frequently readmitted to State Hospitals; frequently seen in emergency rooms; chronically homeless and/or being released from jails or prisons." Furthermore, the state agreed to:

- Establish a range of community services and supports including: 22 Assertive Community Treatment teams; 8 Community Support teams to provide services in individuals' own homes; 14 Intensive Case Management teams; 45 Case Management service providers; 6 Crisis Services Centers; 3 additional Crisis Stabilization Programs; 35 community-based psychiatric beds; and an array of mobile crisis teams, crisis apartments, supported housing, supported employment, and peer support services.

- The agreement also provides for a State-wide quality management system for community services. [25]

Virginia. The emphasis on states' the establishment of a community based service delivery infrastructure in DOJ's enforcement activities was underscored in a landmark settlement with the State of Virginia aimed at ending the unnecessarily institutionalization of people with intellectual and developmental disabilities throughout its service delivery system. The DOJ's broad based approach to the enforcement of the Olmstead integration mandate is outlined in the letter from Thomas Perez, Assistant Attorney General of the DOJ Office of Civil Rights to the Governor of Virginia reporting the department's findings of the Investigation of the Commonwealth of Virginia's Compliance with the American's with Disabilities Act and of Central Virginia Training Center dated February 10, 2011. In this correspondence, and in the subsequent settlement with the state,[26] DOJ cited a number of "systemic failures" in the Commonwealth's service delivery system "causing unnecessarily institutionalization" throughout the system including:

- The failure to develop a sufficient number of community based institutional alternatives, especially for people with complex needs.

---

[24] United States v. Georgia Civil No. 1:10-CV-249-CAP October 2010 Settlement Agreement fact sheet.

[25] Ibid. United States V. Georgia above.

[26] U.S. v. Virginia - 3:12CV059 (E.D. VA 2012)

- The failure to use available resources to expand community services and re-align existing resources to prioritize investments in non-institutional settings.

- The presence of a flawed process for discharge planning that identified discharge barriers, individual's needs, and services necessary to meet those needs.

- The failure to develop sufficient numbers of services in the community to meet waiting lists and address the needs of persons at immediate risk of institutionalization.

- The failure to develop the crisis response and respite capacity necessary to prevent people with disabilities in crisis from being institutionalized due to the lack of alternatives.[27]

DOJ entered into a comprehensive settlement agreement with the State of Virginia designed to make sweeping changes in the state's service delivery system for persons with disabilities. The state agreed over the next ten years to expand the 1915(c) Medicaid waiver program in order to: (a) move 800 individuals with IDD from state training centers to community programs, (b) furnish supports to 3,000 adults and youth with intellectual disabilities who on the state's "urgent" waitlist and/or are being served in private institutions, and (c) provide program supports to 450 adults and youth with developmental disabilities currently being served in private institutions. Additional provisions of the settlement call for the development of comprehensive and coordinated strategies to ensure families of children and adults with disabilities have access to resources, supports and services; the development of mobile crisis teams, community-based crisis stabilization and respite services, and a 24 hour 7 day per week crisis hotline. Under the settlement, the state also agreed to expand: the availability of integrated housing supporting people in their own homes, in small settings of four or fewer individuals with disabilities, or with their families; access to integrated employment and day activity opportunities under the 1915(c) Medicaid waiver and institute an employment first policy; improve access to case management and provide enhanced case management for people with complex needs, who are experiencing crisis living in congregate settings and are being discharged for state training centers.[28]

Other States. As noted above, the obligations of states to furnish services to individuals with disabilities in the most integrated settings applies to individuals with disabilities receiving all types of public support not just those living in segregated institutional settings. DOJ's Olmstead enforcement activities have extended beyond publicly operated institutional facilities to include people receiving public supports that result in their inappropriate and illegal segregation in

---

[27] Thomas E. Perez (2011). Letter to Governor Robert McDonnell Re: Investigation of the Commonwealth of Virginia's Compliance with the American's with Disabilities Act and of Central Virginia Training Center (see http://www.ada.gov/olmstead/olmstead_cases_list2.htm#va).

[28] See the Department of Justice, United States v. Commonwealth of Virginia at www.justice.gov/crt/about/spl/virginia-ada.php for the settlement agreement, fact sheet, complaint and investigative findings.

privately owned and operated nursing homes, day programs, and other facility based alternatives. A summary of Olmstead litigation activities in the 12 U.S. Circuit Courts of Appeals is available from the Department of Justice' website at http://www.ada.gov/olmstead/olmstead_enforcement.htm.

State Operated Facilities. The DOJ Civil Rights Division has issued Findings Letters and involved in Settlement Agreements regarding people with disabilities who are living in, or at-risk of entering state-operated facilities in several states including:

- *US v. State of Georgia* expanding community services and supports for over 1,000 people in state IDD facilities and on waitlist for services (see above).

- *US v. State of Virginia* resulting in the broad expansion of community support options for more than 4,200 people with IDD disabilities in state and private facilities and on the state's waitlists (see above).

- *DOJ's Findings Letter State of Mississippi* identifying violations on behalf of adults & children in public and private DD facilities and concluding that the state is violating the ADA's integration mandate in its provision of services to adults and children with developmental disabilities and mental illness by unnecessarily institutionalizing persons with mental illness or DD in public and private facilities and failing to ensure that they, as well as people on wait lists for services, are offered a meaningful opportunity to live in integrated community settings consistent with their needs.

- *US v. State of New Hampshire* (Lynn v. Lynch) addressing the needs of people with mental illness who reside in or are at risk of entering the state psychiatric hospital and state-operated nursing facility for people with mental illness.

Private Facilities. The Civil Rights Division has intervened to prevent the unnecessary segregation of people with disabilities in private facilities receiving public support.

- *Nursing Homes and Private Facilities*

    i. Texas - Intervention in Steward v. Perry, DOJ was granted a request to intervene in a pending lawsuit against the state alleging violations of Title II of the ADA and Section 504 of the Rehabilitation Act for unnecessarily segregating individuals with developmental disabilities in nursing facilities. The intervention addressed the needs of thousands of people with IDD in and at-risk of entering private nursing homes in the state with the Arc of Texas as an organizational plaintiff.

    ii. Virginia - Investigation regarding children with DD in nursing homes, relief was included in the VA agreement (see above).

   iii. Florida – Findings Letter issued in September 2012 concluded the State of Florida was violating the ADA's integration mandate in its provision of services and supports to children with medically complex and medically fragile conditions. DOJ found that the State of Florida plans, structures, and administers a system of care that has led to the unnecessary institutionalization of children in nursing facilities and places children currently residing in the community at risk of unnecessary institutionalization.

   iv. New York – DOJ intervened in DAI v Cuomo regarding people with mental illness living in adult homes in New York City who were seeking integrated supported housing and community supports.

- *Private Intermediate Care Facilities.* Statement of Interest was issued in private litigation.

- *Day Programs and Services*. Civil Rights Division activities have made it clear that the provisions of the ADA and the Olmstead Ruling are not limited to the settings where people live but also apply to the supports and services that people with disabilities receive during the day.

   i. Oregon - Lane v. Kitzhaber Statement of Interest and, Findings Letter concluding that the State of Oregon violates the ADA's integration mandate in its provision of employment and vocational services because it plans, structures, and administers employment and vocational services for individuals with IDD primarily in segregated sheltered workshops rather than in integrated community employment settings. This causes the unnecessary segregation of individuals in sheltered workshops that are capable of, and not opposed to, receiving employment services in the community. DOJ recommended that the State implement remedial measures, including the development of sufficient supported employment services to enable those individuals unnecessarily segregated, or at risk of unnecessary segregation, in sheltered workshops to receive services in individual integrated employment settings in the community.

   ii. Virginia - Settlement of US v. State of Virginia and Olmstead settlements in Delaware, North Carolina and Georgia resulted in expansions of supported employment & integrated day activities in each of those states.

- *Community Services*.

   i. Delaware – Settlement of US v. State of Delaware US v. DE resulting in the expansion of community services. for over 3,000 people with mental illness residing in or at risk of entering state psychiatric hospitals and private Institutes for Mental Disease (IMD) facilities. The settlement also expanded access to ACT services, crisis services, and supported employment, intensive case management, peer and family supports. The settlement expanded the availability of integrated scattered site housing, rental vouchers and subsidies and assurance that housing complexes would have no more than 20% people with disabilities in residence.

- *At Risk Cases.* In a significant number of instances the DOJ Statements of Interest filed in support of private plaintiffs have included reference to practices and policies that result in the unnecessary segregation of individuals with disabilities as a result of:
    i. State cuts to critical services without individualized assessments of impact or an exceptions process for those with special conditions or treatment needs.
    ii. Policies requiring people with disabilities to enter an institution to move to top of a waiting list for community services rather than being furnished with services in an integrated setting in the first instance.
    iii. Provisions limiting the delivery of needed services to persons living in an institution but not in the community
    iv. State budgetary reductions to critical community mental health services supporting private litigation in California to prevent cuts to services for people with mental illness who had been determined to be at risk of out-of-home placements without those services.
    v. The lack of intensive, community based and "wrap-around" services for children with mental/behavioral health conditions.

Conclusion

The Olmstead Ruling in 1999 established that the unnecessary segregation of people with disabilities in institutions is a form of discrimination under Title II of the Americans with Disabilities Act of 1990. In this decision, the Supreme Court reviewed the definition of disability under the ADA and clarified the relationship between the presence of a particular physical or mental condition and the extent to which such an "impairment" substantially limits major life activities. The Olmstead Ruling established the role and responsibilities of states and public entities with respect to their obligations under Title II of the ADA to ensure that eligible individuals with disabilities receive public services within "the most integrated setting" appropriate to their needs. The Olmstead integration mandate provides a framework through which qualified individuals with disabilities are not subjected to discrimination, denied benefits or excluded from participation in society through the delivery, provision or funding of services, programs, or activities by a public entity.

The provisions of the ADA as interpreted by the Olmstead Ruling are comprehensive and apply to all services and supports furnished or funded by or through public entities. In the distant past, publicly financed services were provided in facility-based programs, segregated away from society. Since that time service delivery methods, designs and strategies have changed significantly in response to individual and family advocacy, progressive legislation at the federal and state levels, improved instructional and support methodologies and a growing understanding of the deleterious impact that segregation and exclusion from society has on the lives of individuals with disabilities. Although service delivery approaches have changed, reflecting a greater emphasis on integrated community based services, federal funding mechanisms and states' systems of support for people with disabilities have continued to be anchored in traditional service models that result in unnecessary segregation of individuals with disabilities and their exclusion from society. The passage of the ADA and the Olmstead Ruling recognizes in law the obsolescence of traditional non-integrated approaches and provides a broad system change framework for public entities to follow to improve service delivery and the lives of people receiving supports and carry out Congress' "comprehensive national mandate for the elimination of discrimination against individuals with disabilities."[29]

---

[29] 42 U.S.C. § 12101(b)(1).

Annotated References

1. About the Americans with Disabilities Act of 1990 (ADA) Martin County Florida Martin County, Florida ADA web page http://www.martin.fl.us/portal/page?_pageid=352,830377&_dad=portal&_schema=PORTAL

2. DOJ website on Olmstead: http://www.ada.gov/olmstead/index.htm.

    - DOJ Website on ADA enforcement and Technical Assistance materials: http://www.ada.gov/publicat.htm

    - DOJ website on Litigation and Enforcement: http://www.ada.gov/olmstead/olmstead_enforcement.htm.

3. Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C. U.S. Department of Justice Civil Rights Division http://www.ada.gov/olmstead/q&a_olmstead.pdf

4. Olmstead: Reclaiming Institutionalized Lives (August 2003). National Council on Disability. Accessed from the NCD website November 2012. http://www.ncd.gov/publications/2003/Aug192003.

    In this report, the National Council on Disability (NCD) assesses the nation's response to the United States Supreme Court's decision in *Olmstead* v. L.C., 527 U.S. 581 (1999) that the unjustified institutionalization of people with disabilities is a form of discrimination. NCD examines the Federal Government's implementation efforts and the strategies states and key stakeholders are using to (1) develop consensus on a coordinated action plan, (2) identify and commit the necessary resources for community-based service options, and (3) sustain collaborative action toward creating real choice for people with disabilities living in institutions.

5. Ng, T., Wong, A., & Harrington C. (April 2012). Home and Community-Based Services: Introduction to Olmstead Lawsuits and Olmstead Plans. National Center for Personal Assistance Services University of California at San Francisco. For a state by state summary of Olmstead lawsuits see http://www.pascenter.org/olmstead/olmsteadcases.php).

6. U.S. Equal Employment Opportunity Commission Fact Sheet on the EEOC's Final Regulations Implementing the ADAAA. http://www.eeoc.gov/laws/regulations/adaaa_fact_sheet.cfm

7. The Americans with Disabilities Act Title II Technical Assistance Manual. The Americans with Disabilities Act Title II Technical Assistance Manual Covering State and Local Government Programs and Services. http://www.ada.gov/taman2.html#II-1.3000.

   This technical assistance manual addresses the requirements of Title II of the Americans with Disabilities Act, which applies to the operations of State and local governments. This manual presents the ADA's requirements for state and local governments in an easily accessible format providing a focused, systematic description of the ADA's requirements.

The Centers for Medicaid and Medicare Services (CMS) and Residential Services

Interaction of the ADA/Olmstead and Medicaid

How the 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 Olmsted 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.[30] 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 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 ."[31] States would be well

---

[30] See: The US 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".

[31] DOJ Findings Letter, June, 2012, found at: http://www.ada.gov/olmstead/olmstead_cases_list2.htm#oregon-findltr.

advised to consider *all settings* that segregate or congregate individuals with disabilities as potentially not comporting with the Olmstead Decision and the ADA.

Fundamentally, 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. [32] In 2009, Medicaid accounted for 75.5% of the spending for long term supports for individuals with intellectual and developmental disabilities. Only 14.8% of spending is other state (and local funds). [33] There are other public supports such as Supplemental Security Income (SSI) and Supplemental Security Disability Income (SSDI)—which provide income to individuals with intellectual and developmental disabilities and can cover some living expenses, but these sources only account for 9.6% of the overall spending for individuals with intellectual and developmental disabilities.[34] 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, the 1915(i) State plan HCBS and other authorities such as the 1115 waiver option.[35] 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%-75% depending on the economic situation of each state. What this means is if a state Federal Medical Assistance

---

[32] 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-eligible—that is both eligible for Medicare and Medicaid—but it is Medicaid that provides funding for long-term community and institutional services.

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

[34] Ibid., p. 27.

[35] 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: http://www.medicaid.gov/mltss/docs/primer10.pdf

Percentage (FMAP) is 50%, 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.[36]

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.[37] 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.

As will be discussed in more detail below, the national trend is that more individuals with intellectual and developmental disabilities, including individuals with ASD, live at home with their families. Currently 55.9% of all individuals served through the HCBS waivers live with family—and in five states 70% or more of the individuals served live with family.[38] 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% of individuals with

---

[36] A good description of FMAP by the Congressional Research Service can be found at: http://aging.senate.gov/crs/medicaid6.pdf. 2012 FMAP percentages can be found at: https://www.federalregister.gov/articles/2010/11/10/2010-28319/federal-financial-participation-in-state-assistance-expenditures-federal-matching-shares-for.

[37] See, Cooper, Robin, *Caring Families…Families Providing Care: Using Medicaid to Pay Relatives Providing Support to Family Members with Disabilities,* NASDDD, Inc. June, 2010.

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

ASD who have finished high school and are under the age of 30 live at home with their parents (as a opposed to 32% of young adults without ASD).[39]

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 devises 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.[40] 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.[41] 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 individuals with Intellectual Disabilities, ICF-IDs.[42] Although ICF-ID is not a mandated service, all fifty states and the District have included this service in their Medicaid coverage. [43]

---

[39] *Easter Seals', Living with Autism Study*, Harris Interactive, 2008. Found at: http://www.easterseals.com/site/PageServer?pagename=ntlc8_living_with_autism_study_home.

[40] For a definitive history of Medicaid and services to individuals with intellectual and developmental disabilities, see, Gettings, Robert, *Forging a Federal-State Partnership: A History of Federal Developmental Disabilities Policy*, AAIDD, NASDDDS, 2011.

[41] Medicaid.gov – Medicaid Benefits at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Medicaid-Benefits.html

[42] 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."

[43] 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

CMS defines ICF-IDs as institutions and further clarifies that and 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. “ [44] While the more common notion of institution is a larger facility, smaller ICF-IDs 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 ICF-IDs, 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 an 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.”[45] 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. [46] 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 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.” [47]

1915(c) HCBS waiver. If an individual demanded an ICF-ID, Oregon would provide for this by contracting with another state.

[44] 42 CFR 435.1009

[45] 42 CFR 483.440(a)

[46] 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.

[47] 42 CFR 435.1009

> 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 ICF-IDs. 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.[48]

As noted earlier, ICF-IDs must provide active treatment and furnish services on a 24/7 basis. ICF-IDs 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 larger ICF-IDs provide "in-house" programs, throughout the country some ICF-IDs 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. [49] As of 2012,

- 12 states no longer have state-operated ICF-IDs 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 ICF-IDs, and
- 20 states have no large private ICF-ID settings

---

[48] 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/MR and Waiver Program Participant*, Rutgers Center for State Health Policy, July, 2008.

[49] The data on ICF-IDs are from, *Residential Services for Person with Developmental Disabilities*, University of Minnesota ICI reports from 2001 and 2011. All reports can be found at: http://rtc.umn.edu/risp/main/.

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

"Community" ICF-IDs. Although the original ICF-ID rules were written with large facilities in mind, states were interested in developing smaller living arrangement s 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. [50] 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 ICF-IDs 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% of the individuals served in setting licensed for 1-6 individuals and 8 states accounting for 80% of the individuals served in settings licensed for 7-15 individuals. Reliance on these "community" ICFs-DD 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.[51] These "community" ICF-IDs 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 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.

---

[50] Gettings, 2101, p. 79-80.

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

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.[52] 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 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

---

[52] Letters can be found at: http://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.

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 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 who 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 intellectual and developmental disabilities. 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.[53] Although data are not specific as to which populations within the intellectual and developmental disabilities community have been served, given that these are transitions from institutions it is likely individuals with ASD are included.[54]

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 in intended to encourage more investment in HCBS and reductions in the use 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% or 5% 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% increase while others are eligible for the 2% 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:[55]

- 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)

---

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

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

[55] More information about BIP is found at: http://www.balancingincentiveprogram.org/faqs.

- Affordable Care Act, Section 2703, State Option to Provide Health Homes for Enrollees with Chronic Conditions
- 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."[56] 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 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.[57] 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 community—in their own homes, their family home or other settings not licensed as ICF-IDs. 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 intellectual and developmental disabilities, the only way to get long term support was to enter ICF-ID.

---

[56] Federal Register /Vol. 77, No. 88 /Monday, May 7, 2012 /Rules and Regulations, page 26829.

[57] 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.

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: www.hcbswaivers.net.

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.) [58]

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

---

[58] 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.

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 ICF-IDs 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.[59] 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 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.

---

[59] Information on Virginia's waivers found at: http://www.dbhds.virginia.gov/ODS-MRWaiver.htm

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.[60]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.

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.

---

[60] 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.

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.

<u>Medicaid eligibility groups for 1915(i).</u> 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% of the Federal Poverty Level (FPL). Individuals with incomes up to 150% 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% 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. [61] 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 haves 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.

<u>Target group.</u> Although 1915(i) is an entitlement to all eligible, states have the <u>*option*</u> 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.

---

[61] 1915(c) is the HCBS waiver program, 1915d 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."[62] 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."[63]

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. [64] 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.

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.

---

[62] NPRM, May 3, 2012, Federal Register, Vol. 77, No. 86 / Thursday, May 3, 2012 / Proposed Rules, p. 26367.

[63] NPRM, p. 26368.

[64] 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.

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 intellectual and developmental disabilities (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.[65] 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 federal funds. Today, only 12.9% of all spending for services for individuals with intellectual and developmental disabilities are "pure" state funds, that is funds not used as match to draw down Medicaid financing or used as supplemental payments to SSI recipients.[66] As discussed above,

---

[65] Medicaid.gov – Early and Periodic Screening, Diagnostic, and Treatment at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-Periodic-Screening-Diagnosis-and-Treatment.html

[66] 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.

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.[67] 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. [68] 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% of gross income (for example, 40% 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 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 09-10, the average "gross" room and board amount was $14,573 per year for individuals living in group homes. Pennsylvania requires individuals to contribute 72% of their SSI toward their room and board costs (with the remainder used as an allowance for person needs. 72% 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

---

[67] For individuals served in ICF-IDs, 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.

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

arrangements. The availability of these supplements clearly can be essential is 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.[69] 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.[70]

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:

- 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: Low Income Housing Voucher at

---

[69] HUD's Web site on vouchers for individuals with disabilities: http://portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/programs/hcv/ned.

[70] 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.

http://www.housingvoucher.org/ or the Public Housing Authorities Directors Association at http://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 intellectual and developmental disabilities including working very closely with local housing authorities. Information can be found at the Association of Regional Center Agencies Housing Initiative website: http://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. [71] 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.[72]

Insurance Mandates. According to the National Council of State Legislatures, 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.[73]

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

---

[71] For an example of this California program see a presentation available on the Association of Regional Center Agencies website at: http://arcanet.org/new-day/wp-content/uploads/2012/10/Presentation-Mary-Eble-.pdf or the North Bay Housing Coalition website: http://www.northbayhousingcoalition.org/.

[72] Connecticut Housing Finance Authority Home of Your Own Program: http://www.chfa.org/Homeownership/for%20Homebuyers/Homebuyer%20Mortgage%20Programs/HomeOfYourOwnProgram.aspx; Wisconsin Movin' Out, Inc.: http://www.movin-out.org/

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

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 individual s with ASD are served through the programs generally available to individuals with intellectual and developmental disabilities, as long as they meet the eligibility criteria for services. And many of the states' intellectual and developmental disabilities programs do include services that are specifically intended to support individuals with ASD.[74] 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 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 intellectual and developmental disabilities 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.[75]

Autism-Specific 1915(c) HCBS Waivers. Currently nine states have specific HCBS waivers targeted to individuals with ASD. These states are Colorado, Kansas, Maryland, Massachusetts, Missouri, 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

---

[74] 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.

[75] Information on Wisconsin's program is found at the Wisconsin Department of Health Services Children's Long-Term Support Waivers web page: http://www.dhs.wisconsin.gov/children/clts/waiver/family/eligibility.htm. Information for New York is found at New York State Office for People with Developmental Disabilities Autism Platform web page: http://www.opwdd.ny.gov/opwdd_community_connections/autism_platform

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 intellectual and developmental disabilities 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.

The autism waivers focus on children really means that states use their other HCBS waivers serving individuals with intellectual and developmental disabilities 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" intellectual and developmental disabilities 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 intellectual and developmental disabilities.[76] A list of all state agencies can be found at the National Association of State Directors of Developmental Disabilities website:

---

[76] A list of all state agencies can be found at the National Association for State Directors of Developmental Disabilities Services (NASDDDS) web page: http://www.nasddds.org/MemberAgencies/index.shtml. Other web sites provide state-by-state information. For example, the Easter Seals Society has dedicated a Web site to state-by-state profiles offering information on state programs for individuals with autism. These profiles can be found at Easter Seals 2012 State Autism Profiles: http://www.easterseals.com/site/PageServer?pagename=ntlc8_autism_state_profiles. Other sites such as Autism Speaks Resource Guide (http://www.autismspeaks.org/family-services/resource-guide) and the Autism-PDD Network Autism Resources by State (http://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: http://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, WI.

http://www.nasddds.org/MemberAgencies/index.shtml. Other web sites provide state-by-state information. For example, the Easter Seals Society has dedicated a Web site to state-by-state profiles offering information on state programs for individuals with autism. These profiles can be found at: http://www.easterseals.com/site/PageServer?pagename=ntlc8_autism_state_profiles. Other sites such as Autism Speaks (http://www.autismspeaks.org/family-services/resource-guide) and the Autism-PDD Network (http://www.autism-pdd.net/resources-by-state.html) also offer state-by-state information on programs and services for individuals with ASD.

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**
Colorado	Children with autism ages 0-6	None	Behavioral Therapy	None
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 & 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 Behavioral Supports & Consultation	Respite Community Integration Homemaker Individual Goods & Services Home & Vehicle Modifications Adaptive Aids

Table 1 AUTISM-SPECIFIC HCBS WAIVERS				
				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
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

Table 1 AUTISM-SPECIFIC HCBS WAIVERS				
				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)

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 intellectual and developmental disabilities, 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.[77] 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

---

[77] 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.

- 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 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 seem 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]***.**[78]

As noted earlier, states have wide latitude in crafting the array of supports and service s 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."[79]

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% lived in some type of residential facility—that is a provider controlled setting with multiple

---

[78] Ibid., p. 24.

[79] 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.

residents.[80] If a provider controlled setting does not work for the person with ASD, typically the individual must move and seek a 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."[81] 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.[82]

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 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*

---

[80] Larson, 2010, p.122.

[81] Cooper, Robin, *"Shared Living Guide",* NASDDDS, Inc., May, 2011, p. 12.

[82] See, Cooper, "*Shared Living Guide*" for descriptions of shared living.

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 intellectual and developmental disabilities, 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.[83] *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 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."[84] 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

---

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

[84] *Ibid*., p. 166.

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." [85] While the services definition goes on to note that states can cover things 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.[86] 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 adaptation s is **remote or electronic monitoring**. Both Indiana and Ohio offer this service under their HCBS waivers for individuals with intellectual

---

[85] Ibid., p. 162.

[86] http://gbcchs.com/

and developmental disabilities, 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." [87] 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." [88] 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.[89] 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. [90]

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." [91] 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

---

[87] DDARS Waiver Manual, 2012, Manual, Section 10.9, Electronic Monitoring, State of Indiana, http://www.in.gov/fssa/files/Part_10_-_Service_Def.pdf.

[88] 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, http://codes.ohio.gov/oac/5123%3A2-9-35

[89] Ohio Assessment for Remote Monitoring: http://test.mr.state.oh.us/training/documents/Assessment-remotemonitoringfinal.pdf and Individual Options Waiver Handbook: https://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, http://www.in.gov/fssa/files/Part_10_-_Service_Def.pdf

[90] Some sites to look at are the Waisman Center Sound Response web page: http://www.waisman.wisc.edu/soundresponse/support.php and Simply Home at http://www.simply-home.com/.

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

individual a greater sense of control than being cued by another person.[92] 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 is 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 on 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. Employments 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).

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 intellectual and developmental disabilities (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.[93]

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

---

[92] For a look at how technology has created independence for individuals see: The Coleman Institute for Cognitive Disabilities at http://www.colemaninstitute.org/, AbleLink Technologies at http://www.ablelinktech.com/ and AbleLink Technologies Intellectual and Developmental Disabilities Solutions at http://www.ablelinktech.com/index.php?id=21

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

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.

V. DHS recommendations

The first priority for DHS is to provide necessary supports that allow children to live at home with their families; however, DHS recognizes that there is a need for different housing arrangements for some children. To address this need, DHS recommends building upon current efforts to improve the availability of housing with supports in the community for people with autism. As shown through this study, it is important that any housing with supports for children with severe autism address key features, including:

- Active family involvement in decision-making, planning and provision of the treatment
- Focus on learning, skill development and generalization
- Services that are person centered and individualized to the unique needs of the person
- Culturally responsive and inclusive services
- Residential settings that are safe, purposeful and offer functional space
- Highly trained and specialized staff
- Program interventions that are data driven and use frequent, ongoing assessment
- Expanded use of natural support and other community systems

The housing with supports could include supports provided through home care services, home and community based services waivers, including in family homes or licensed settings, and in intermediate care facilities for people with developmental disabilities.

Under the home and community based services waivers, the supports can be provided in any setting that meets the definition of home and community based settings, as defined in statute[94], including a child's family home, or a licensed foster care setting. During the 2012 session, legislation passed which required DHS to identify and work with counties to find capacity and locate providers to support children and adults with autism in foster care settings where the license holder does not reside (e.g., corporate foster care)95. DHS recommends development of service providers, in partnership with counties, that can provide the key features identified above in a variety of housing settings, including a child's family home, licensed family foster care homes, licensed foster care settings where the license holder does not reside (i.e., corporate foster care), and intermediate care facilities for people with developmental disabilities. When providing the support in a child's family home or a licensed family foster care home, an important component of the support is respite for the family, in order to provide an opportunity for that

---

[94] Minnesota Statute 256B.492

[95] 2012 Laws of Minnesota, Chapter 247, Article 5, Section 7 (see Appendix X)

family to have a break from the care of the child. The development of the support options will include a plan for periodic evaluation to determine if the supports provided are the most effective for the people living there.

If an existing small intermediate care facility for people with developmental disabilities is interested in changing their support model to address the key features identified above, DHS will provide technical assistance to that facility. Additional funding, beyond what is available through current resources, may be required to support the transition of the facility to serving children with severe autism.

Additional funding or legislative approval will be necessary to create certain options for housing with supports for children with severe autism. These options include:

- Providing the opportunity for existing intermediate care facilities for people with developmental disabilities to change their model of service to support children with severe autism. In most situations, changing the service model will require that current residents of the facility move In these situations, a planning process for each person would allow them choice about where they live and services they receive. Additional funding is required to provide home and community based services waivers as people leave the intermediate care facility since these costs likely cannot be absorbed within the available limits on the growth of the developmental disabilities waiver.
- Developing a new intermediate care facility for people with developmental disabilities. The development of a new facility would require that the commissioner make an exception to the moratorium, as authorized in MN Statute 252.291, subd. 2. See the Appendix for this section of statute, which includes the criteria for an exception to the moratorium. This would require funding for the new facility.
- Providing a rate adjustment to encourage existing intermediate care facilities for persons with developmental disabilities to change their support model to support children with severe autism. Funding is needed for the rate adjustments.
- Creating an exception to the moratorium on foster care where the license holder does not reside (i.e., corporate foster care), as well as an exception to the capacity reduction required by the 2012 legislature. This exception would apply to homes licensed to provide services through the home and community based services waivers.

Additional home and community based service funding may be required if persons currently not receiving home and community based services are prioritized to receive services in addition to the current allocation criteria and growth limits in place for the home and community based service waivers.

VI. Implementation Timeline

In the fall of 2012, DHS sent a foster care needs determination survey to counties and tribes that included two questions on whether the county or tribe was interested in receiving assistance from DHS in developing foster care home for people with autism. 40 counties and tribes indicated an interest in receiving assistance.

Using this information, DHS will commit to the following timeline:

Activity	Estimated Timeline
Select the counties or tribes to participate in a pilot project to serve children with severe autism using home and community based services waiver funding.	By February 15, 2013
Assist identified counties with obtaining the necessary foster care capacity, within the existing capacity limitations.	By February 28, 2013
Working with identified counties, develop measurable outcomes for services.	By March 31, 2013
Issue Request for Proposals, in collaboration with identified counties, to find qualified providers of home and community based services (in-home and residential) who can meet the key features identified in Section VI.	By March 31, 2013
Notify existing intermediate care facilities for people with developmental disabilities of the opportunity and technical assistance available to change their support model to service children with severe autism, and solicit response by facilities who may be interested.	By April 30, 2013
Assist identified counties with selecting qualified	By May 15, 2013

Activity	Estimated Timeline
providers of home and community based services.	
Work with identified counties and selected providers to finalize an evaluation plan	By May 31, 2013
Provide any necessary technical assistance to counties, providers, and others	Throughout the process
Determine whether changes need to be made to the recommendations or implementation timeline, and report changes to the 2014 legislature. This will involve working with a stakeholder group on housing with supports	By November 30, 2013
Determine appropriate criteria for provider autism certification	By November 30, 2013

VII. Appendix

2012 Laws of Minnesota, Chapter 247, Article 5, Section 7:

FOSTER CARE FOR INDIVIDUALS WITH AUTISM.

The commissioner of human services shall identify and coordinate with one or more counties that agree to issue a foster care license and authorize funding for people with autism who are currently receiving home and community-based services under Minnesota Statutes, section 256B.092 or 256B.49. Children eligible under this section must be in an out-of-home placement approved by the lead agency that has legal responsibility for the placement. Nothing in this section must be construed as restricting an individual's choice of provider. The commissioner will assist the interested county or counties with obtaining necessary capacity within the moratorium under Minnesota Statutes, section 245A.03, subdivision 7. The commissioner shall coordinate with the interested counties and issue a request for information to identify providers who have the training and skills to meet the needs of the individuals identified in this section.

Minnesota Statutes, 252.291

Subd. 2.**Exceptions.**

(a) The commissioner of human services in coordination with the commissioner of health may approve a newly constructed or newly established publicly or privately operated community intermediate care facility for six or fewer persons with developmental disabilities only when:

> (1) the facility is developed in accordance with a request for proposal approved by the commissioner of human services;
>
> (2) the facility is necessary to serve the needs of identified persons with developmental disabilities who are seriously behaviorally disordered or who are seriously physically or sensorily impaired. No more than 40 percent of the capacity specified in the proposal submitted to the commissioner must be used for persons being discharged from regional treatment centers; and
>
> (3) the commissioner determines that the need for increased service capacity cannot be met by the use of alternative resources or the modification of existing facilities.

(b) The percentage limitation in paragraph (a), clause (2), does not apply to state-operated, community-based facilities.