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Meeting the Needs of Youth with Autism Spectrum Disorder: A Survey of Service Delivery Systems

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I. Introduction

The Center for Public Representation has recently prepared two Q&As addressing the nature and treatment of Autism Spectrum Disorder (ASD).¹ This Fact Sheet is the third installment in this series of technical assistance resources designed to raise critical questions and suggest possible strategies to address the service needs of youth with ASD.

There are a wide variety of public and private benefits available to youth with ASD, administered and funded through a complex network of state and federal service systems. Given the critical nature of these services, fiscal constraints faced by state governments, and continued expansion of the Medicaid program, it is increasingly important to understand how various service delivery models can be combined to offer the broadest possible service array, while delivering care in accordance with clinical and administrative best practices.

II. Meeting the Needs of Youth with ASD

Since 2007, the Centers for Disease Control (CDC) and National Health Statistics Reports have documented continued increases in the prevalence of ASD, attributable in large part to the diagnosis of previously unidentified children and youth.² In 2006, the Harvard School of Public Health estimated that it costs

¹ The first Q&A (May 2013) discusses the implications of diagnostic changes to DSM V. The second Q&A (June 2013) provides an overview of evidence-based treatment interventions for youth with ASD.

² The most recent CDC National Health Statistics Report on Autism Spectrum Disorder can be found at <http://www.cdc.gov/nchs/data/nhsr/nhsr065.pdf>.

\$3.2 million dollars to care for one individual with Autism over his or her lifetime, and that it costs society an estimated \$35 billion each year to care for all individuals with Autism.³ Given these costs, and the growing number of affected individuals, many states are considering how to deliver needed services with the greatest efficacy, flexibility and economy.

Despite the recent decision by the American Psychiatric Association to utilize the single definition of ASD,⁴ the population of children and adolescents carrying this diagnostic label is far from homogeneous. Rather, youth with ASD can demonstrate a wide variety of strengths and needs with dramatically different levels of functioning. Often they present with a complex and inter-related set of symptoms and co-morbid conditions, including cognitive and developmental delays, communication disorders, mental illness, repetitive and maladaptive behaviors, sensory integration difficulties and learning disabilities. As such, they present a challenge to any potential service system, calling for a range of services and intensity in treatment interventions.⁵

III. Vehicles for the Delivery of Services to Youth with ASD

A. Early Intervention (EI)

1. Overview

The early intervention program for infants and toddlers with disabilities is a federal grant program disseminated to states and administered by the U.S.

³ This study, conducted by Michael Ganz, Assistant Professor of Society, Human Development and Health at Harvard School of Public Health is described in the book *Understanding Autism: From Basic Neuroscience to Treatment* (CRC press, 2006) in a chapter titled “The Costs of Autism.” The 2006 press release from Harvard’s School of Public Health can be found at <http://archive.sph.harvard.edu/press-releases/2006-releases/press04252006.html>.

⁴ The newest version of the Diagnostic Statistical Manual (DSM V), issued in May 2013, removes distinct diagnostic categories related to Autism and Pervasive Developmental Disorder. Instead, it adopts a continuum of mild to severe conditions known by the single diagnosis Autism Spectrum Disorder. This change includes the elimination of Asperger’s Syndrome and PDD NOS as distinct diagnostic categories. A description of these changes and their rationale can be found at the America Psychiatric Association’s website under “What’s New” See <http://www.dsm5.org/Documents/Autism%20Spectrum%20Disorder%20Fact%20Sheet.pdf>; see also, <http://www.goodtherapy.org/blog/dsm-v-5-criteria-aspergers-autism-spectrum-1203128>.

⁵ As noted in the Center’s June 2013 Q&A, services are delivered to youth with ASD under a variety of treatment modalities, most with an emphasis on highly structured, data-driven approaches to skill development and the extinguishment of problematic behaviors, such as Acquired Behavioral Analysis (ABA). Other treatment interventions include DIR Floor Time, augmentative and alternative communication, speech, occupational and physical therapies and positive behavioral supports. These services are most commonly provided in the home and in educational settings.

Department of Education under Part C of the IDEA.⁶ Other related early education and child care services may be funded by Title I for disadvantaged children, federal block grants, or Title V Maternal and Child Health, and may be covered by private insurance. Services are routinely delivered by a network of facility and home-based providers overseen by a lead agency, often the state Department of Public Health.⁷ States may secure additional Medicaid reimbursement for EI services, including certain specialty services delivered to infants and toddlers with ASD, as Massachusetts does under its 1115 Demonstration waiver.⁸

2. Approach to service delivery

Services are generally easy to access through medical professionals or self referral for children with disabilities ages 0 to 3. Eligibility criteria vary from state to state. States may, at their discretion, extend services beyond age three for students with disabilities, prior to their eligibility for kindergarten enrollment.⁹ Youth receive clinical assessments to determine service needs and set treatment goals to address any physical, cognitive, communication, social-emotional, and adaptive developmental needs. Services may include specialized instruction, speech therapy, occupational therapy, physical therapy, psychological services and family training and counseling.¹⁰ In addition, each eligible child and family must be provided service coordination.¹¹ For youth with Autism, specialized early

⁶ See, e.g., Wright's Law Q&A on Early Intervention at <http://www.wrightslaw.com/info/ei.index.htm>.

⁷ Abt Associates, *Report on State Services to Individuals with Autism Spectrum Disorders (ASDs) Services Project*; Center for Medicare and Medicaid Services (CMS) ASD Services Project (April 1, 2011) (hereafter Report on State Services).

⁸ Massachusetts's Medicaid program, MassHealth, funds therapeutic behavioral services for children with a diagnosis of Autism who are eligible for EI and in one of the following MassHealth categories: Standard, CommonHealth or Family Assistance. Youth in receipt of Autism waiver services are not eligible for MassHealth funded specialty services. See MassHealth Transmittal Letter, July, 2012 at <http://www.mass.gov/eohhs/docs/masshealth/transletters-2012/eip-20.pdf>.

⁹ See, <http://www2.ed.gov/programs/osepeip/index.html> "The Individuals with Disabilities Education Act (IDEA), as amended, allows states, at their discretion, to make available for early intervention services under Part C to children with disabilities beyond age 3 until the children enter or are eligible under state law to enter kindergarten or elementary school, if the children are eligible for services under the Preschool Grants for Children of Disabilities Program."

¹⁰ For an excellent review of comprehensive services for youth with Autism, see Abt Associates, *Meeting the Needs of Individuals with Autism Spectrum Disorders through Comprehensive Services*, Final Report to the Centers for Medicare and Medicaid Services, Center for Medicaid and State Operations, Disabled and Elderly Health Programs Group, Division of Community and Institutional Services, Final Report S-10 CMS-33 No. 2 (September 2011) (hereafter *Meeting the Needs*)

¹¹ *Id.*

intervention services have demonstrated effectiveness in increasing IQ, receptive language and overall skill development.¹²

3. Benefits and limitations

EI can include a range of services and supports needed by youth with ASD, and can deliver them at what is considered to be a critical developmental juncture. EI providers and the evaluations they produce are often critical to obtaining appropriate educational services and supports for a child transitioning into a pre-school or other Head Start setting.

Yet despite these strengths, and clinical evidence of success, EI services are increasingly threatened by financial and programmatic resource limitations. The age restrictions (0-3) mean that EI services provide the greatest benefit to families of youth with early identification of developmental concerns. Many toddlers are not diagnosed definitively with ASD until multiple, significant milestones are missed. A large scale study done in 2009 found that the median age for diagnosis of ASD is 6 years old, with more than one quarter of children not diagnosed until age 8.¹³

4. State program models

(1) Massachusetts

Massachusetts' Office of Special Services is located within the Department of Public Health's EI program. The Office "oversees policy development, standards and monitoring of specialty service providers, and provides technical assistance, training and consultation to program staff, families, community collaborators and other state agencies around specialty service issues."¹⁴ The Massachusetts Act Early program promotes education and screening for the early identification of conditions like ASD. Initial eligibility evaluations for early intervention also include behavioral indicators of Autism or pervasive developmental disorder (PDD). Since 2009, access to specialized Autism services requires not just a positive Modified Checklist for Autism in Toddlers (MCHAT) screen, but also a confirmed diagnosis, obtained through a specialized evaluation using

¹² Geraldine Dawson, Sally Rogers, Jeffrey Munson, Milani Smith, Jamie Winter, Jessica Greenon, Amy Donaldson, and Jennifer Varley. Randomized, Controlled Trial of an Intervention for Toddlers With Autism: The Early Start Denver Model, *Pediatrics*, Nov. 2009 DOI.

¹³ Shattuck, et al. (May 2009), *Timing of the Identification Among Children with Autism Spectrum Disorder: Findings from a Population-Based Surveillance Study*, Journal of the American Academy of Child and Adolescent Psychiatry.

¹⁴ <http://www.mass.gov/eohhs/gov/departments/dph/programs/family-health/early-intervention/family-info/specialty-services.html>.

standardized tools and conducted by a medical professional trained in ASD.¹⁵ A network of specialty providers, including Autism Resource Centers, is maintained to serve those found eligible. Specialty providers can perform a variety of functions -- delivering direct services, offering technical assistance to families and other EI providers, and assisting with transitional planning.¹⁶

(2) California

California is one state which employs the Early Start Denver Model in its early intervention programming. Washington State University conducted a multi-year, controlled study of toddlers with Autism using this model. The approach to treatment is considered somewhat novel, because it employs both the rigors of applied behavioral analysis and developmental relationship-based approaches, the latter of which uses play to build relationship with the child. Outcomes from this study are documented in the *Journal of Pediatrics*.¹⁷ A secondary outcome of the same study revealed more normalized brain waves for study participants compared to typically developing peers.¹⁸

Easter Seals of Central California is a provider of this comprehensive, evidenced-based treatment for infants and toddlers diagnosed with ASD. Their Early Intervention Autism Program provides intensive treatment interventions in consultation with speech and occupational therapists and special educators.

¹⁵ See Policy Changes Regarding Confirmed Diagnosis of Autism Spectrum Disorder, effective January 2009 at <http://www.mass.gov/eohhs/docs/dph/com-health/early-childhood/asd-ssp-eligibility.pdf>.

¹⁶ See, Collaboration Among Families, Early Intervention Programs and Specialty Providers at <http://www.mass.gov/eohhs/docs/dph/com-health/early-childhood/collaboration-among-families.pdf>.

¹⁷ The study was conducted with 48 children with Autism, ages 18- to 30-months. One group of children received 20 hours a week of the intervention from UW specialists as well as five hours a week of parent-delivered therapy. Children in the second group were referred to community-based programs for therapy. While there was no substantial difference between the groups at the outset of the study, at the conclusion the following changes were noted: "...the IQs of the children in the intervention group had improved by an average of approximately 18 points, compared to a little more than four points in the comparison group. The intervention group also had a nearly 18-point improvement in receptive language (listening and understanding) compared to approximately 10 points in the comparison group. Seven of the children in the intervention group had enough improvement in overall skills to warrant a change in diagnosis from autism to the milder condition known as pervasive developmental disorder not otherwise specified. Only one child in the community-based intervention group had an improved diagnosis." University of Washington (2009, November 30). Early Intervention for Toddlers with Autism Highly Effective, Study Finds. *Science Daily*.

¹⁸ Dawson, et al., Early Behavioral Intervention Is Associated With Normalized Brain Activity in Young Children With Autism; *Journal of the American Academy of Child & Adolescent Psychiatry*; Volume 51, Issue 11, pp 1150-1159, November 2012; See also, [http://www.jaacap.com/article/S0890-8567\(12\)00643-0/abstract](http://www.jaacap.com/article/S0890-8567(12)00643-0/abstract).

Activities and interactions are designed to enhance each child's communication, social interaction, learning, and active participation in everyday activities and routines. These interventions are delivered in the child's home and community and in consultation with educators and related service providers. Parent coaching and training are provided as well.¹⁹

B. Special Education (IDEA)

1. Overview

The IDEA guarantees eligible students with disabilities access to a Free and Appropriate Public Education (FAPE)²⁰ and the provision of specialized education and related services, provided that disability adversely impacts their educational performance and necessitates specialized instruction. Students whose primary disabling condition is ASD will most likely be assessed under the eligibility impairment category of Autism.²¹ As part of qualifying for special education services under this category, youth must satisfy the following regulatory definition:

i) Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.

(ii) Autism does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance, as defined in paragraph (c)(4) of this section.

(iii) A child who manifests the characteristics of autism after age three could be identified as having autism if the criteria in paragraph (c)(1)(i) of this section are satisfied.

34 CFR 300.8(c)(1).

Youth who meet the eligibility criteria above have a legal entitlement to special education services, which can be enforced through administrative and court proceedings up until they are 22 years of age.

¹⁹ The Easter Seals program description can be found at http://centralcal.easterseals.com/site/PageServer?pagename=CACN_PS_autismservices_earlyintervention.

²⁰ See, e.g., 20 U.S.C. §§ 1401(9) and 1414(d)(1)(A).

²¹ See, 20 U.S.C. §1401(3)(A)(1).

2. Approach to service delivery

Special education and related services are delivered in the context of an Individual Education Plan (IEP) and can be comprehensive in nature and involve specialized instruction, assistive technology, a variety of therapies which promote access to the curriculum, including speech, occupational and physical therapy, social skills and travel training, psychological services, vocational education, parent counseling and training, and the implementation of behavior support plans.²² However, these services must be educationally related in order to fall within the school district's responsibility.

3. Benefits and limitations

Special education services for students with ASD should be highly individualized, free, and able to be delivered in an ongoing and consistent way. Some schools or districts have the capacity to deliver specialized instruction and behavioral supports to youth with ASD in the general education setting. Many only accomplish this level of integration as a result of grouping all youth with ASD together in one, substantially separate classroom or program.

Schools can be required by the IDEA to perform functional behavior assessments, and to deliver school-based and in-home behavior therapy. However, in practice these services are hard fought, not widely available, and rarely delivered with the frequency students need to effectively generalize skills from one environment to another. Behavior therapy is sometimes delivered by school clinicians with less than optimal qualifications and who do not employ a family-centered approach. They are selected, and often directly employed, by the school. As a result, it can be more difficult for them to depart from a school district's stated position on service provision or placement. Typically, all information generated as a result of a school-funded evaluation or behavioral service is part of the student's record, potentially exposing private issues within the family home to school scrutiny.

With appropriately individualized services and specialized instruction, students with ASD should be able to make effective progress in the least restrictive educational environment.²³ But despite the potential for the IDEA and special education services to meet the educational and habilitative needs of youth with ASD in their home communities, students with serious maladaptive behaviors or

²² See, e.g., 34 CFR §§ 300.34(a) and 300.39.

²³ The Autism Speaks publication, *Educating Students with Autism*, provides a useful summary of the various types of specialized services and instructional methods from which youth with Autism can benefit. See, http://www.autismspeaks.org/sites/default/files/sctk_educating_students_with_autism.pdf.

who are in need of highly specialized interventions often are forced to accept, or to affirmatively seek, more restrictive out-of-district placements.

3. State program models

(i) Specialized schools

Among families and professionals in the Autism community there can be some ambivalence around the potential for effective integration. This view appears rooted in the belief that only highly specialized settings are likely to afford youth with ASD access to the educational supports and instruction required for them to make effective progress. As a result, one common approach to meeting the needs of students with ASD is the development of specialized private schools. Models include charter schools devoted to youth with Autism,²⁴ and therapeutic day and residential schools.²⁵ Some programs offer a continuum of educational services from pre-school through transition to adulthood.²⁶ The Southwest Autism Research and Resource Center (SARRC) Community School in Arizona is an example of educational programs which intentionally integrate children with ASD and typically developing children. SARRC offers children 18 months to 5 years of age a normative preschool experience with low teacher/student ratios.²⁷ The importance of selecting the right private school program from the myriad of

²⁴ Jamie Pagliaro is the Executive Vice President of Rethink Autism and founding Executive Director of the New York Center for Autism Charter School. The program's "Key Components of an Effective School-Based Autism Program" identifies seven important steps for the delivery of effective supports to students with Autism: 1) individualized assessment; 2) functional curriculum; 3) research-based teaching; 4) low staffing ratios; 5) family involvement; 6) data tracking; and 7) training and supervision.

²⁵ The Boston Higashi School is devoted to serving students with Autism and employs a philosophy based on the tenants of Daily Life Therapy developed by the late Dr. Kiyoo Kitahara of Japan. As the program website describes, "Dr. Kiyoo Kitahara's method provides children with systematic education through group dynamics, the intermingling of academics and technology, art, music and physical education. The goal of this educational approach is for individuals to achieve social independence and dignity, and to benefit from and contribute to society." Notably, this philosophy rejects the use of medication as a behavioral intervention for the treatment of anxiety, hyperactivity or aggression, and denies admission to students prescribed medication for this purpose. See, <http://www.bostonhigashi.org/about.php?id=9>.

²⁶ The Monarch Center for Autism in Cleveland, Ohio offers a comprehensive array of programs and services for individuals ages three through adulthood, with Autism Spectrum Disorders, including a preschool (three to six years); a day school for children and adolescents (5 to 22 years); a transitional education program (14 to 22 years); an adult autism program (18 and older); autism residential treatment for children, adolescents and adults; summer and extended school year programs; family training, support and social activities; consultation and therapy. <http://www.monarchcenterforautism.org/>.

²⁷ Abt Associates, *Report on State Services to Individuals with Autism Spectrum Disorders (ASDs) Services Project*; Center for Medicare and Medicaid Services (CMS) ASD Services Project (April 1, 2011) p. 39; see also, www.autismcenter.org/about_sarrc.aspx.

options, has spawned a cottage industry of websites and programs devoted to identifying and reviewing Autism programs across the country.²⁸

(ii) Quality standards

Some school districts have worked to identify programmatic and resource needs of students with Autism, and to improve their educational interventions, by creating quality standard guidelines. Colorado's development of Autism Program Quality Indicators is intended to help school staff and district leadership to evaluate the effectiveness of educational programs on an individual and systemic basis across six domains: 1) Individual Evaluation and Individualized Education Program; 2) Curriculum, Instruction and Methodology; 3) Review and Monitoring of Progress and Outcomes; 4) Family Involvement and Support; 5) Transition Planning; and 6) Behavior.²⁹ New Jersey's Department of Education also created Autism Program Quality Indicators, designed to assist school personnel in reviewing and improving the provision of educational services to youth on the Spectrum.³⁰

(iii) Teacher training and school-based consultation

Many educational and treatment programs specializing in ASD market their expertise to public education providers, using clinical and educational staff to provide technical assistance, direct services and consultation to schools serving students with Autism. The Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH) Autism Program is based out of the University of North Carolina, but has a national reputation for its work in support of parents and youth with Autism. TEACCH also conducts training nationally and internationally and provides consultation for teachers, residential care providers, and other professionals from a variety of disciplines. Their research activities include psychological, educational, and biomedical studies.³¹ The May Institute in Massachusetts is another example of a provider engaged in programming, education, research and consultation on issues related to ASD and developmental disabilities. May offers its consultation services to public schools, educational collaboratives, private agencies and individual youth and

²⁸ See, e.g., <http://www.thebestschools.org/blog/2012/03/10/schools-children-autism/>.

²⁹ <http://www.cde.state.co.us/cdesped/download/pdf/AutismQualityIndicators.pdf>.

³⁰ <http://www.nj.gov/education/specialed/info/autism.pdf>.

³¹ <http://www.teacch.com/>.

families while also providing training for special educators, aides and other school staff.³²

C. *Expansion of Private Insurance Benefits*

1. Overview

A total of 37 states and the District of Columbia now have laws related to Autism and insurance coverage. At least 30 states have mandated coverage for ASD within the private insurance market.³³ Most of this legislation has been enacted in the last four years.³⁴

2. Approach to service delivery

Recipients must have access to insurance coverage through their employers or on the private market, unless available through subsidized insurance system as in Massachusetts. Most state statutes cover forms of treatment determined to be medically necessary by the insured's physician or psychologist, and delivered in accordance with a treatment plan.

3. Benefits and limitations

Private insurance mandates can reach large numbers of youth and families, especially in states where the number of insured residents is high. Families access care through existing insurance channels, and are not excluded from coverage by virtue of income. However, not all insurance plans must comply with these statutory mandates. For instance, self-insured plans are often excluded from coverage requirements. Most laws only cover youth up to 21 years of age, mirroring Early Periodic Screening, Diagnosis, and Treatment (EPSDT) requirements. Many states also cap the dollar amount insurance companies can be required to spend on an individual member.³⁵

³² The May Institute also describes itself as a national leader in training and assisting schools in the implementation of Positive Behavioral Interventions and Supports (PBIS). See, <http://www.mayinstitute.org/services/consultation/about.html>.

³³ These are Alaska, Arizona, Arkansas California, Colorado, Connecticut, Florida, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Massachusetts, Michigan, Missouri, Montana, Nevada, New Hampshire, New Jersey New Mexico, New York, Pennsylvania, Rhode Island, South Carolina, Texas, Virginia, West Virginia and Wisconsin. Other states, like Alabama, provide limited coverage.

³⁴ A detailed table of states and the parameters of their legislation can be found at www.nscl.org/issues-research/health/autism-and-insurance-coverage-state-laws.aspx.

³⁵ See, e.g., Illinois requires all individual, group accident and health insurance or managed care plans to provide coverage for the diagnosis and treatment of ASD for individuals under 21 years of age up to a maximum annual benefit of \$36,000 per year.

4. States program models

(1) Vermont

In 2010, the legislature passed Act 127, mandating private insurance companies cover the evidence-based diagnosis and treatment of early childhood developmental disorders, including ABA therapy. The law defines early childhood developmental disorders to include ASD. Coverage includes behavioral health treatment, pharmacy, psychiatric, psychological and therapeutic care. A plan may not limit the number of visits with an Autism services provider. In 2012, Act 158 amended the law to allow children to receive care from birth to 21 years of age. However, as of January 2014, if these benefits exceed the essential health benefits specified under the ACA, they will not be required of qualified health plans offered through a health benefit exchange.

(2) Massachusetts

Known as ARICA,³⁶ Massachusetts' Autism insurance law went into effect in January 2011. It covers the diagnosis and treatment of ASD regardless of age and without annual or lifetime cost caps. Insurers are required to come into compliance in policies scheduled for renewal after January 2011. Self-funded plans covered by ERISA are not subject to the coverage requirements. Covered services include ABA therapy, medications and psychiatry, care from a psychologist, and services delivered by licensed, certified speech, occupational and physical therapists and social workers. ARICA will not cover services delivered in school settings.³⁷

(3) New Hampshire

In 2010 New Hampshire legislated coverage of professional services and treatment programs for PDD or Autism, including ABA. However, the policy may limit coverage to \$36,000 a year for children 0-12 and \$27,000 from age 13.³⁸

D. Expansion of Public Insurance Benefits

1. Overview

³⁶ The text of the law can be found at <http://www.mass.gov/legis/laws/seslaw10/sl100207.htm>.

³⁷ Massachusetts Parity law (2008 Mass Acts, C. 256) also required individual and group insurance policies to provide mental health benefits in a nondiscriminatory way for the diagnosis and treatment of biologically based mental disorders, including Autism.

³⁸ N.H. Rev. Stat. Ann. § 417-E:2 (2010 N.H. Laws, Chap. 363; HB 569 of 2010).

While state expansion of private insurance coverage for ABA and related services has been widespread, few if any of these legislative initiatives sought, or resulted in, a similar expansion in public insurance coverage. Although federal EPSDT litigation has succeeded in securing the provision of various medically necessary services for children and youth with emotional disabilities, only a handful of cases have secured similar relief for youth with ASD.³⁹

2. Approach to service delivery

Most state Medicaid plans provide an established set of optional and mandatory benefits to persons who are categorically needy, a demographic set to expand in many states under the Affordable Care Act (ACA).⁴⁰ Many states, like Massachusetts, use large 1115 waiver programs to expand its Medicaid population to include families with slightly higher incomes or individuals who have disabling conditions as defined by the Social Security Act.

Medicaid and state public insurance programs typically pay for the screening and diagnostic assessments necessary to identify youth with ASD, both in routine well child screenings and through specialized autism screens like the M-Chat, administered between 18 and 24 months.⁴¹ Medicaid also covers a range of medically necessary, rehabilitative services which can benefit youth with ASD, like speech, physical and occupational therapy.⁴² However, the federal government has consistently viewed some of the most promising ASD treatments, like ABA therapy, as habilitative and properly considered to be an educational intervention not covered by Medicaid.

³⁹ See, *Parent's League for Effective Autism Services v. Kelley*, 565 F.Supp.2d 905 (S.D. Ohio 2008); *K.G. v. Dudek*, 2012 WL 1438974 (S.D. Fla., March 26, 2012).

⁴⁰ Implementation of the Affordable Care Act also will have some important benefits for youth with ASD, affording free preventative screenings (including screens for autism at 18 and 24 months), protecting against denial because of pre-existing conditions, allowing coverage under a parent's insurance policy until age 26, and increased emphasis on development of community-based, long term care options. Finally, expanded access to affordable insurance exchanges and Medicaid expansion will provide coverage to more youth and families, including increased access to mental health and habilitative services. (See Section III, 4 *supra*) Children and adults with ASD may also benefit from the ACA's efforts to build upon Medicaid's current Medical Home Demonstration program, with implementing states able to access short term, enhanced FMAP rates. See, Abt, *Report on State Services* at 30.

⁴¹ For instance, Pennsylvania requires licensed developmental specialists, such as pediatrician, neurologists and psychologists, to perform standardized assessments for determine ASD diagnosis. With such a diagnosis, youth can seek ASD services in the State Medicaid HealthChoices program or under private insurance. Wisconsin has a similar insurance mandate, under which Medicaid reimburses providers for ASD screening on a fee-for-service basis. *Id.*, *Report on State Services* at 14.

⁴² For a thorough discussion of a comprehensive array of services and funding mechanisms, see *Meeting the Needs* at 37-40.

At the same time as the federal government consistently rejected the application of EPSDT requirements to evidence-based practices like ABA, CMS has become involved in research efforts related to ASD, serving as a member of the Interagency Autism Coordinating Committee (IACC) whose mission is to coordinate HHS's ASD initiatives and to promote the development and delivery of effective treatment interventions.⁴³

3. Benefits and limitations

The inclusion of evidence-based treatments for ASD as a Medicaid State Plan service has clear advantages over waiver programs, which may limit the total number of slots or waive important Medicaid provisions like state-wideness or comparability. From the point of state governments, there are administrative and financial costs to opening up this level of access -- navigation of the state plan amendment process, the rapid development of highly qualified workforce, creation of network capacity sufficient to provide medically necessary services with reasonable promptness, and the unknown costs associated with making specific services for youth with ASD available on a statewide basis.

Finally, there are legal hurdles associated with persuading federal courts and CMS that services like ABA are: (1) rehabilitative under 42 U.S.C. 1396(a)(13), that can be prescribed for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level; and (2) considered medically necessary to correct or ameliorate a child's condition under 1396(d)(a) rather than an experimental or educational service.⁴⁴ The perceived boundary between educational and medical assistance has been staunchly defended by CMS, despite emerging evidence of the effectiveness of services like ABA. As a result, states like Massachusetts have obtained CMS state plan approval for in-home behavior therapy by describing the essential functions of the service (functional behavioral assessment, individual treatment planning) rather than labeling that service as a particular evidence-based practice.⁴⁵

Given the landscape of health care reform opportunities under the Affordable Care Act (ACA), there may be additional ways to secure broader community-based, long term care services for persons with ASD, including changes to § 1915(i) of the Social Security Act, and options for funding the provision of

⁴³ The IACC was established by Congress in connection with passage of the Combating Autism Act of 2006. In 2011, the IACC published a Strategic Plan for Autism Spectrum Disorder Research which can be found at <http://iacchhs.gov/strategic-plan/2011/index.shtml>.

⁴⁴ A discussion of case law in this area can be found in *K.G. v. Dudek*, 2012 WL 1438074 *8 (S.D. Fla. March 26, 2012).

⁴⁵ See further discussion of Massachusetts In-Home Behavior Therapy service, *supra*.

targeted home and community-based services as part of the Medicaid state plan.⁴⁶

4. Medicaid Expansion and Essential Health Benefits (EHB)

Implementation of expanded public insurance coverage under the ACA is underway. Regulations concerning essential health benefits packages, applicable federal standards and mental health parity laws, and the state benchmark plan selection process all have potential implications for access to rehabilitative services and, therefore, any initiative seeking to advance this goal.⁴⁷

As of 2014, the ACA's EHB provisions require small group and individual market plans as well as marketplace (exchange) insurance plans to provide coverage in ten broad categories, including mental health/behavioral health and rehabilitative/habilitative services and devices. Large group (self-insured and ASO) and "grandfathered" plans are excluded from this requirement. States are allowed to define the contours of their respective EHB package using a base "benchmark plan" offered in their existing insurance market. Twenty-six states have made this selection. The rest will default to the largest small business plan in their state as a benchmark. States may select a benchmark plan that includes state coverage mandates, like the ABA coverage mandate in many state private insurance markets.⁴⁸

In addition to the state benchmark plan, new federal regulations also refer to a standardized EHB benchmark plan. This federally-defined benchmark plan may require states to increase available coverage if their base benefits package falls short of the federal standard. Also, broader application of the federal Mental Health Parity and Addiction Equity Act of 2008 will require individual and small market group plans offering mental health and substance abuse benefits to provide them at a level equal to available medical and surgical benefits.

Despite these considerable improvements in access to coverage, if the federal government allows states to establish their own definition of rehabilitative services

⁴⁶ Under 1915(i), states have the option to target HCBS benefits to one or more specific populations; establish separate additional needs-based criteria for individual services; establish a new Medicaid eligibility group for people who get State plan HCBS; define the HCBS included in the benefit; and allow any or all HCBS to be self-directed. See, e.g., <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Home-and-Community-Based-Services/Home-and-Community-Based-Services-1915-i.html>.

⁴⁷ A concise issue brief on the impact of ACA expansion and parity on persons with mental health needs can be found at http://aspe.hhs.gov/health/reports/2013.mental/rb_mental.cfm.

⁴⁸ Additional details on the selection process, by state, can be found at www.ncsl.org.

under the EHB package, access to Medicaid coverage for these treatments could vary considerably from state to state, given that state benchmark plans vary in their coverage for mental health, ABA and habilitative therapies generally.⁴⁹

5. State program models

(1) Washington

Pursuant to a settlement negotiated by the Northwest Justice Project, a class of children under 21 with ASD will be able to access functional assessments and ABA therapy as part of a regular benefit offered by Apple Health for Kids, a program that includes all Medicaid covered children. The settlement is predicated on CMS's approval of ABA therapy. CMS has yet to approve the ABA benefit contemplated by the Settlement agreement. In the interim, assessments and services are being provided by with state dollars.⁵⁰

(2) Ohio

Ohio was providing ABA and other support services to youth with ASD through a State-certified community mental health agency, but became concerned it could lose federal financial participation for these services – a fear that was confirmed by CMS in a March 2008 letter stating that the agency, “generally views treatment for Autism as habilitative rather than rehabilitative – as such, the CPST claims by Step by Step may not comply with Ohio’s state plan.” *Parent’s League for Effective Autism Services v. Kelley*, 565 F.Supp.2d 905, 909 (S.D. Ohio 2008). The State’s subsequent efforts to discontinue provision of this service were prevented by a temporary restraining order.

(3) Massachusetts

As part of the Judgment in *Rosie D*, the defendants designed and then sought State Plan approval for a service called In Home Behavior Therapy (IHBT). The intention behind IHBT was to design a service which could address the needs of youth with a variety of disabling conditions. Rather than restrict it to a single evidence-based practice, it was described by articulating a set of functions central to the delivery of a home-based, behavioral intervention -- performance of an FBA, development of an individualized behavior plan, and the capacity to

⁴⁹ A 2012 report by the American Academy of Pediatrics surveyed five state's potential benchmark plans and concluded that considerable variations exist in coverage for mental health and habilitative services frequently sought by youth with ASD. See, *A Comparative Review of Essential Health Benefits Pertinent to Children in Large Federal, State, and Small Group Health Insurance Plans: Implications for Selecting State Benchmark Plans*, prepared by Peggy McManus for the American Academic of Pediatrics (July 2012).

⁵⁰ Additional information on changes instituted by the Washington Health Care Authority can be found at www.hca.wa.gov/news or <http://hrsa.dshs.wa.gov/abatherapy>.

involve a behavior monitor for data collection, modeling and evaluation of interventions. Similarly, the service was staffed with clinicians who had a variety of qualifications, including clinicians and psychologists who are Board Certified Behavior Analysts (BCBA) or supervised by someone who is, in order to facilitate/support statewide delivery and access. While providers are not necessarily providing ABA therapy, they do have the capacity to deliver IHBT consistent with the principles of ABA, using a clinician who is BCBA certified, and in a highly individualized way based on the youth's needs and strengths.

E. *Medicaid Waiver Programs*

1. Overview

Section 1915(c) of the Social Security Act affords states the option of waiving certain federal Medicaid requirements and offering an array of home and community-based services not otherwise available or reimbursable under their state plans, provided the provision of those services in the community is demonstrated to be cost neutral as compared to institutional care.⁵¹ Waivers also allow states to target specific populations of persons with disabilities and to expand the pool of individuals who would otherwise be eligible for Medicaid benefits in the community.⁵²

2. Approach to service delivery

More than 44 states have received waivers to provide home and community-based services to persons with developmental disabilities.⁵³ In certain states, existing DD waiver programs or have been revised or consolidated with other existing waivers in order to include persons with ASD.⁵⁴ In the past, the GAO reported that state Autism waivers generally offered the same or similar services as their developmental disability waivers, with the exception of early intervention behavioral therapies targeted to young children.⁵⁵ Where the eligibility criteria of general I/DD waivers do not include Autism, it has become increasingly common for states to request and receive federal funding for separate waiver programs

⁵¹ A comprehensive listing of state 1915(c) waivers and waiver applications can be found at <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Home-and-Community-Based-1915-c-Waivers.html>.

⁵² For instance, Massachusetts ABI waiver is designed to serve persons with income up to 300% of the SSI federal benefit rate, well above income eligibility criteria set for MassHealth Standard in the community.

⁵³ Spigel, Saul; *Medicaid Autism Waivers and State Agencies Serving People with Autism*, OLR Research Report, April 10, 2007.

⁵⁴ See, e.g., New Mexico, Wisconsin, Indiana.

⁵⁵ See <http://www.gao.gov/new.items/d06700.pdf>.

specifically targeted to youth and adults with ASD that provide Autism-specific services.⁵⁶

3. Benefits and limitations

As noted above, use of 1915(c) waivers affords states considerable flexibility in addressing the community service needs of persons with disabilities, providing access to FFP for non-state plan services, and offering mechanisms to control costs, including the limitation of available waiver slots. Although the provision of intensive ABA therapy and other related treatment interventions involve significant costs over lengthy periods of time, waivers with cost neutrality formulas tied to the cost of ICF-I/DD institutions should be able to deliver high volume, high cost care to youth with ASD without exceeding overall cost neutrality requirements.

Despite these benefits, states have identified a consistent set of obstacles which impact the quality, availability and efficacy of service delivery. These obstacles center around the specialized nature of ASD services, and include the lack of clinical expertise for network development and program staffing, provider access issues in rural areas, a shortage of training programs to support future workforce expansion, the challenges of serving transition age youth with ASD, and the need for delivery systems capable of offering life-long services and support.⁵⁷

4. States program models

(1) Massachusetts

Since 2007, the Department of Developmental (DDS) Disabilities Autism Division has operated a modest 1915(c) Autism waiver. This waiver delivers one-to-one behavioral, social and communication-based interventions as well as ADL/skill development (including ABA and Floor Time) through a service called Expanded Habilitation, Education. The waiver also provides services to promote community integration, such as family training, home adaptation, vehicle modification and respite. The Participant Direction model allows families to design their own programs with the help of an Autism Support Broker and to select providers based on their child's assessed level of need, with a maximum budget of \$25,000 dollars. Additionally, families are connected to a targeted case manager in the DDS Autism Division. The waiver serves up to 157 youth, 8 years of age and under who meet the level of care required for service in an ICF-MR facility and

⁵⁶ States operating waiver programs specifically for youth with ASD include Colorado, Indiana (now expired), Maryland, Massachusetts, Wisconsin and Utah.

⁵⁷ Surveyed states include New Mexico, Maine, Connecticut, Missouri, Pennsylvania, and Arizona. See, *Report on State Services* at 18.

are eligible for MassHealth Standard. Waiver services are delivered via a regional network of seven Autism Support Centers.⁵⁸

(2) Indiana

In 2002, Indiana developed an Autism waiver serving youth from 0 to 22 years of age. However, youth with Aspergers or PDD NOS (as distinguished from Autism) were clinically ineligible for waiver services. The original waiver offered applied behavioral analysis, and community transition support. It employed a person-centered, individual support planning process. Participating youth were eligible for a broader range of services under the DD waiver as well.⁵⁹

This Autism waiver was allowed to expire on December 31, 2012, and subsequently combined with the Indiana Developmental Disabilities Waiver. Now renamed the Community Integration and Habilitation Waiver, the new program serves persons with developmental disability, intellectual disability and ASD, regardless of age. The consolidation of waiver programs reportedly did not result in any service reductions to either population. Case management was changed from an administrative service to a mandatory waiver service.⁶⁰

(3) Maryland

The Office of Special Education in partnership with the Department of Health and Mental Hygiene jointly applied for Maryland's Autism waiver program in 2000. Eligible children ages 1-21 with ASD receive services in their homes, communities and educational settings. These services include case management, respite, family training, environmental safety modifications, therapeutic integration, adult life planning, and regular or intensive day habilitation, including extended day services to avoid return to residential care.⁶¹ Eligibility is based on the child's income, which may not exceed 300% of the SSI benefit level. Youth also must be receiving EI services or at least 12 hours of special education services per week. In 2005, the waiver reportedly served 900 individuals. Although operating without a specific enrollment cap, the waiver was closed for some period time thereafter.⁶²

⁵⁸ A description of the waiver program can be found at <http://www.mass.gov/eohhs/docs/dmr/awp/autism-waiver-overview-2012.pdf>.

⁵⁹ See Spigel, Saul; *Medicaid Autism Waivers and State Agencies Serving People with Autism*, OLR Research Report, 2007.

⁶⁰ A copy the DD waiver amendment can be found at <http://170.107.180.99/WMS/faces/protected/35/print/PrintSelector.jsp>.

⁶¹ See, e.g., www.bcps.org/offices/special_ed/special-ed-autism-waiver.html.

⁶² See Spigel, Saul; *Medicaid Autism Waivers and State Agencies Serving People with Autism*, OLR Research Report, 2007.

(4) California

California's waiver for persons with developmental disability is one of the largest HCBS waivers in the country.⁶³ The waiver serves individuals with ASD provided they meet the Lanterman Act definition of developmental disability, are eligible for Medi-Cal, receive services through one of 21 regional service centers, and demonstrate the level of need necessary for an ICF-MR. The waiver covers a wide range of services for youth and adults including transportation, respite, habilitation, in-home services, home health aides, family training, residential care, crisis and behavioral interventions and nutritional consultation.⁶⁴ Regional centers assist applicants with diagnosis, conduct eligibility determinations and, for those found eligible, assign case managers to assist with service planning.

F. State Agency Programs

1. Overview

Many youth with ASD already receive medically necessary screenings, assessments and service delivery through a variety of locally funded government systems, including state Departments of Public Health, Education, Medicaid, Disability and even child welfare.

Over the last several decades, states have expanded their service networks – adding comprehensive, community-based systems designed to provide more integrated supports for persons with intellectual and developmental disabilities as well as those with serious and persistent mental illness. However, youth with ASD and their families are often caught in the middle of these two service systems, dependent on some aspects of both to complement their educational services, but not optimally served under either. This is particularly true for youth with more profound forms of ASD and who require highly specialized or intensive service interventions.⁶⁵ To the extent these expansions are reliant on waiver programs, youth must also be Medicaid eligible in order to access these service systems. Creating sufficient access to a continuum of community-based services for persons with ASD will be an increasingly significant challenge, as improved

⁶³ Waiver description and related materials can be found at <http://www.dds.ca.gov/DDSHomePage.cfm>.

⁶⁴ *Report on State Services* at 28.

⁶⁵ See, Montes G, Halterman JS, Magyar CI. Access to and satisfaction with school and community health services for US children with autism spectrum disorder. *Pediatrics* (2009); 124 (suppl. 4) S407-S413.

Autism surveillance leads to larger numbers of youth transitioning into adulthood with identified service needs.⁶⁶

2. Approach to service delivery

Most states include Autism in their definition of developmental disability, giving their DD agency programmatic responsibility for the population of youth and adults with ASD.⁶⁷ Commonly, access to state agency services is governed by statutory eligibility criteria and dependant upon the availability of state budgetary resources. In some jurisdictions, Autism services are provided pursuant to state law entitlements, creating an enforceable right to care.⁶⁸

Connecticut is one of five states whose DD definition appears to exclude Autism unless the individual also has a qualifying intellectual disability.⁶⁹ In such states, youth with ASD are often under-served, caught between state agencies serving youth with mental illness or intellectual disabilities. At least three states, including Massachusetts, currently operate a government bureau or division focused on youth with ASD. These entities are often affiliated with the state agency responsible for persons with developmental disabilities.⁷⁰ Even where these divisions operate discrete waiver programs for youth with Autism, the available resources are often grossly insufficient to meet the level of need. With the support of the Governor's Autism Commission, Massachusetts is one state where advocacy groups are renewing efforts to expand the roles of existing state disability agencies to include youth and adults with ASD.⁷¹

⁶⁶ Many states also offer long term services and supports to adults with Autism. The work of states like Connecticut, Arizona, New Mexico, Pennsylvania, Indiana, Maine and Missouri are highlighted in the *Report on State Services*. See also, *Meeting the Needs*.

⁶⁷ See n. 11, *infra*.

⁶⁸ See, California's Lanterman Act of 2010. The Act mandates the California Department of Developmental Services to develop new standards for diagnosis and that these standards be evaluated for effectiveness. California DDS staff collaborated with Missouri on the development of standards. *Report on State Services* at 13.

⁶⁹ Others states whose DD definition excludes Autism are Alabama, Massachusetts, Mississippi and Virginia.

⁷⁰ Among these are Massachusetts Division of Autism, Pennsylvania's Bureau of Autism Services and the Missouri Office of Autism Spectrum Disorders. Pennsylvania's Bureau of Autism Services works to align policy and program initiatives, promote innovation and evidenced based services, and fill gaps in care for individuals with ASD by offering technical assistance to other state agencies responsible for caring for persons with ASD. *Report on State Services* at 10.

⁷¹ An Act to Permit the Department of Developmental Services to Provide Services to Adults with Developmental Disabilities (HD02945)(SD00777) will expand DDS eligibility to include all people with developmental disabilities who meet certain conditions for "substantial functional limitations."

3. Benefits and limitations

State agency services are available to a broad group of youth and families who might otherwise be ineligible for Medicaid funded programs.⁷² State agencies can provide supports which would not qualify as forms of medical assistance, but are important to families caring for children with disabilities, including respite, therapeutic after school programs, and financial grants to subsidize school vacation programming or the purchase of sensory items.⁷³ However, as noted above, state agency resources are typically accompanied by strict eligibility criteria and their availability dependent on agency resources rather than individual treatment needs. Youth who are denied needed services, or whose services are subsequently reduced due to budgetary reasons, may have administrative due process rights within the relevant state agency, but in most instances there is no entitlement to state funded services.

4. States program models

(1) California

California's Department of Developmental Services delivers services and supports to individuals with a variety of developmental disabilities, including intellectual disability, cerebral palsy, epilepsy, autism and related conditions. Services are provided through state-operated developmental centers and contracts with 21 nonprofit, regional centers which assist families in accessing services and supports.⁷⁴

Because the Department serves both youth and adults, it provides a comprehensive range of services through its regional centers, including assessment and diagnosis, service coordination, residential care, behavior support, transportation, day programs, employment, family support, individual training and support, counseling, early intervention and legal advocacy. These centers also perform outreach and community education and undertake certain quality assurance and monitoring functions within the service system.⁷⁵

IV. Conclusion

⁷² However, this level of access is less critical in states where families with financial means can receive medically necessary services through their private insurance plans.

⁷³ *Meeting the Needs* at 31-34. Certain services, like respite, also can be delivered under a 1915(c) waiver program to persons who are financially and clinically eligible.

⁷⁴ See <http://www.dds.ca.gov/General/Services.cfm>.

⁷⁵ See, e.g., Tri-County Regional Center brochure at <http://www.tri-counties.org/phocadownload/rc-system-one-page-profile-final-lo.pdf>.

When assessing the adequacy of service provision to youth with ASD, advocates must look across a wide range of state and federal programs to understand who is served, and how those services are funded and delivered. They must become familiar with a corresponding range of legal frameworks, from state statutes to federal Medicaid law, in order to understand the nature of youths' entitlements to services and the mechanisms available to enforce their access to care. Finally, to conceive of and implement the breath of specialized services youth with ASD and their families require, familiarity with both private and publicly funded benefits is critical, especially as implementation of the ACA is poised to alter the landscape of insurance coverage and access to mental health and rehabilitative benefits for youth in many states.