



Report and Recommendations  
for  
Implementation of 409.906(26), Florida Statutes

*Authorization to seek Federal approval for a  
Medicaid State Plan Amendment or a Medicaid Waiver  
for children ages birth through five diagnosed with  
Autism, Autism Spectrum Disorder, or Down Syndrome*



## Table of Contents

<b>I.</b>	<b>INTRODUCTION.....</b>	<b>3</b>
<b>II.</b>	<b>BACKGROUND AND CURRENT PROGRAMS.....</b>	<b>3</b>
	Autism and Autism Spectrum Disorder (together, ASD)	
	Down Syndrome	
	Importance of Obtaining an Accurate Diagnosis	
	Early Intervention in Down Syndrome and Autism Spectrum Disorders	
	Applied Behavior Analysis	
	Applied Behavior Analysis Provider Qualifications	
	Medicaid Services for Children Diagnosed with ASD and/or Down Syndrome	
<b>III.</b>	<b>RECENT DEVELOPMENTS.....</b>	<b>9</b>
	Garrido v Dudek	
	Policy Development for Coverage of Applied Behavior Analysis	
<b>IV.</b>	<b>ISSUES, CONCERNS and CONSIDERATIONS.....</b>	<b>9</b>
	Staffing Resources	
	Medicaid Managed Care	
<b>V.</b>	<b>COST ANALYSIS.....</b>	<b>10</b>
	Cost to the State	
<b>VI.</b>	<b>CONCLUSIONS.....</b>	<b>11</b>
	Timeframe to develop and implement a waiver or state plan amendment, based on information detailed in this report	
<b>VII.</b>	<b>REFERENCES.....</b>	<b>11</b>
	<b>APPENDIX A: CURRENT PROGRAMS SERVING CHILDREN AND SERVICE ISSUES.....</b>	<b>14</b>
	Medicaid Early and Periodic Screening, Diagnosis and Treatment (EPSDT)	
	Medicaid Developmental Disabilities Waivers	
	Medicaid Prepaid Mental Health Plan (PMHP)	
	State Children’s Health Insurance Program (SCHIP)	
	Commercial Insurance Mandate	
	Coverage Gaps between Existing Programs Serving Children with ASD	

## I. INTRODUCTION

Section 409.906(26), Florida Statutes, provides the Agency for Health Care Administration (Agency) with authority to seek federal approval for a Medicaid State Plan amendment or a Medicaid waiver to provide therapeutic services for children who are five years of age and under diagnosed with Autism or Autism Spectrum Disorder (together, ASD) or Down syndrome:

*The agency is authorized to seek federal approval through a Medicaid waiver or a State Plan amendment for the provision of occupational therapy, speech therapy, physical therapy, behavior analysis, and behavior assistant services to individuals who are 5 years of age and under and have a diagnosed developmental disability as defined in s. [393.063](#), an autism spectrum disorder as defined in s. [627.6686](#), or Down syndrome, a genetic disorder caused by the presence of extra chromosomal material on chromosome 21. Causes of the syndrome may include Trisomy 21, Mosaicism, Robertsonian Translocation, and other duplications of a portion of chromosome 21. Coverage for such services shall be limited to \$36,000 annually and may not exceed \$108,000 in total lifetime benefits. The agency shall submit an annual report beginning on January 1, 2009, to the President of the Senate, the Speaker of the House of Representatives, and the relevant committees of the Senate and the House of Representatives regarding progress on obtaining federal approval and recommendations for the implementation of these home and community-based services. The agency may not implement this subsection without prior legislative approval.*

This report provides information regarding ASD and Down syndrome, and includes information regarding current service options for children and recent developments that may impact the intent of the legislation.

## II. BACKGROUND AND CURRENT PROGRAMS

### **Autism and Autism Spectrum Disorder:**

Autism is a pervasive brain developmental disorder that affects communication, behavior, social skills and play, causes restricted and repetitive behavior, and is generally diagnosed in the early childhood years. This set of symptoms distinguishes Autism from milder Autism Spectrum Disorders such as Asperger Syndrome (World Health Organization, 2006). For the purposes of this report, the term Autism Spectrum Disorder (ASD) will include Autism and all other levels within the Autism Spectrum, including Asperger Syndrome.

National prevalence data reveals that one in 88 children have ASD, increasing to one in every 54 for boys (Centers for Disease Control and Prevention, 2008). Applying these prevalence rates to the numbers of children through 20 years of age in Florida in state fiscal year 2011 yields the following estimates of children who might need treatment:

**Table #1****Estimated Numbers of Children with Autism Spectrum Disorder in Florida in SFY 11-12:**

	<b>Total Estimated Number of Children in Florida</b>	<b>Estimated<sup>1</sup> Number of Children in Florida with ASD Based on Prevalence 1:88<sup>2</sup></b>	<b>Estimated<sup>3</sup> Number of Children in Florida with Down Syndrome Based on Prevalence<sup>4</sup> 1:691</b>	<b>Total with ASD or DS</b>
<b>All Children<sup>5</sup> Age 17 or Younger CY 2010</b>	3,990,247	45,344	5,775	51,119
<b>Children Enrolled in Medicaid<sup>6</sup> through 20 Years of Age (Average monthly caseload, SFY 2011-2012*)</b>	2,133,600	24,245	3,088	27,333

*\*Note: Data for this number comes from Florida Medicaid, FMMIS/DSS and is based on SFY 11/12 enrollment data. This does not correlate one-for-one with 2010 data from the U.S. Census Bureau.*

**Down Syndrome**

Down syndrome occurs when a body develops three, rather than two, copies of the 21st chromosome. This additional genetic material alters the course of development and causes the characteristics associated with Down syndrome. Down syndrome is the most common of all genetic disorders. One in every 691 live births is a child with Down syndrome, representing approximately 6,000 births per year in the United States. Today, more than 400,000 people in the United States have Down syndrome (The National Down Syndrome Society, 2010).

**Importance of Obtaining an Accurate Diagnosis**

Making a diagnosis of Down syndrome simply requires visual identification, confirmed with a genetic blood test. Autism spectrum disorders, however, cannot be diagnosed by a physical test, but rather a specified number of characteristics listed in the Diagnostic and Statistical Manual of

<sup>1</sup> Estimated ASD = total divided by 88

<sup>2</sup> Centers for Disease Control and Prevention, Autism Spectrum Disorders (ASD), "Data and Statistics". Accessed from <http://www.cdc.gov/ncbddd/autism/data.html> on 7/3/2012.

<sup>3</sup> Estimated Down Syndrome = total divided by 691

<sup>4</sup> Centers for Disease Control and Prevention, Birth Defects, "Facts About Down Syndrome". Accessed from <http://www.cdc.gov/ncbddd/birthdefects/DownSyndrome.html> on 7/3/2012.

<sup>5</sup> U.S. Census Bureau, Data Set: B27001 2010 American Community Survey 1-Year Estimates, "HEALTH INSURANCE COVERAGE STATUS BY SEX BY AGE Universe: Civilian non-institutionalized population", Accessed from [http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS\\_10\\_1YR\\_B27001&prodType=table](http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_10_1YR_B27001&prodType=table) on 10/24/12. Census data was not available for ages 18 through 20.

<sup>6</sup> SFY2010-2011 Medicaid Recipient Enrollment Data, data obtained from FMMIS/DSS.

Mental Disorders (DSM-IV-TR) must be present, in ranges inappropriate for the child's age. ASD can be especially difficult to diagnose in young children where speech and reasoning skills are still developing. It is even more difficult to reach an accurate diagnosis on the less severe end of the spectrum. Diagnosis is based on a combination of parent interviews, non-medical tests, observation, and professional judgment. Some specialists in ASD recommend a multi-disciplinary evaluation that can involve a day or more of observation of a child interacting and functioning in multiple situations.

There are few medical professionals specifically trained to diagnose ASD. The people best qualified are those professionals who have had the most experience in making this diagnosis. Professionals may include developmental pediatricians, pediatric neurologists, child psychologists, or physical, speech, or occupational therapists who frequently work with children with ASD.

There are various methods for diagnosing ASD, and there is no consistent diagnostic process across the state. ASD specific screening tools used in Florida are:

- The Checklist for ASD in Toddlers (CHAT) (Baron-Cohen, 1992)
- Pervasive Developmental Disorder Screening Test (PDDST) (Siegel, 1998)
- Modified Checklist for ASD in Toddlers (M-CHAT) (Robins, Fein, & Barton, 1999)

M-CHAT is considered to be the best screening tool for ASD, but it has not been utilized universally as a screening tool (Governor's Task Force on ASD Spectrum Disorders, July 2008). However, the American Academy of Pediatrics now recommends administering the M-CHAT screen at two visits: First at 18 months and again at 24 months (Massachusetts Department of Health and Human Services, Mass.org).

There are also general screening tools for diagnosing developmental delays that are used in Florida:

- Ages & Stages Questionnaires
- Child Development Inventories
- Parents' Evaluations of Developmental Status
- Infant/Toddler Checklist for Communication and Language Development
- Communication and Symbolic Behavior Developmental Profile

It is important to limit over-diagnosis by assuring independent verification by qualified professionals. Otherwise, state and federal programs may become overwhelmed by large numbers of children with questionable diagnoses. Therefore, a verifiable diagnosis by a qualified professional would help to limit children in a new program to those who are most in need of services. Medicaid currently covers screenings as part of a physician office visit or a therapy evaluation. However, to ensure accurate diagnosis, it may be necessary to add diagnostic testing as a distinct and separately billable Medicaid service.

### **Early Intervention in Down Syndrome and Autism Spectrum Disorders**

Newborns with Down syndrome resemble all infants in their initial learning and memory abilities (Fiddler & Nadel, 2007), but without early intervention, often fall significantly behind in what they can achieve (Brighter Tomorrows Down Syndrome Education, Copyright 2008-2009 Interdisciplinary Human Development Institute, University of Kentucky).

Early intervention may be a key component in minimizing some disabilities in children with ASD and/or Down syndrome. There is no known cure for ASD and Down syndrome, but some studies suggest that early intervention can enhance brain development and help children obtain skills in self-care, social situations, and communication. All are critical components in achieving developmental milestones. These skills pave the way for individuals with developmental disabilities to participate in, and meaningfully contribute to their communities as adults. Researchers do not uniformly agree that these skills can be permanently gained through behavior therapies, but some studies suggest that physical, speech and developmental therapies, such as behavioral analysis, are effective early intervention services for children diagnosed with Down syndrome (Nemours Foundation, Kids Health 2008). Recommended intervention models for ASD involve instruction requiring active engagement with the child on a weekly basis (Lord & McGee, 2001). Researchers have reached varying conclusions as to whether behavior therapy is efficacious in long-term behavior modification.

Some studies suggest intensive early intervention in children with disabilities before age three result in a greater impact after age five (A. Wetherby, 2004), and indicate these advantages of early intervention:

- Presence of neurologic plasticity at younger ages;
- Better school placement outcomes, for example, participation in general education versus special education (Harris & Handelman, 2000);
- Better chance of graduating from high school;
- Greater developmental gains;
- Higher likelihood to live independently; and,
- Positive economic impact over a life-time.

Although there is evidence supporting the effectiveness of early intervention for some recipient populations, no single treatment approach has gained acceptance as the best-practice model for all children, or all ages of children, with ASD (Canadian Pediatric Society, 2004; Dawson & Osterling, 1997; Feinberg & Vacca, 2000; Lord & McGee, 2001; Steuernagel, 2005). The core elements of intervention models, described below, have been defined in some studies to include behavior analysis (Dawson & Osterling, 1997; Lord & McGee, 2001):

- Intervention begins early;
- Families are active participants in their child's intervention;
- Staff persons are well-trained and knowledgeable about the disability;
- There is objective evaluation of the child's progress;
- The curricula is highly structured resulting in a predictable daily routine and is focused on developing communication skills as well as other developmental skill areas;
- Teaching procedures emphasize generalization and maintenance of skills; and,
- Transitions to school are carefully planned and well supported.

### **Applied Behavior Analysis**

Applied Behavior Analysis (also called "behavior analysis" or ABA) provides assistance to a person to learn new behavior directly related to existing challenging behaviors or functionally equivalent replacement behaviors for challenging behaviors. Services may also be provided to increase existing behavior, to reduce existing behavior, and to emit behavior under precise environmental conditions. It is a highly specialized treatment service that uses data collection

and prescriptive methods to bring about behavior change. Behavioral services include training for parents, caregivers, and staff because these caregivers are integral to the implementation or monitoring of a behavior analysis services plan. Caregivers are trained to implement the procedures outside of formal treatment sessions, in a variety of settings (e.g., home, school, daycare, community).

After conducting a behavioral assessment and creating an individualized behavioral plan, a Behavior Analyst typically meets with the individual and/or primary caregivers weekly. Then Behavior Analyst Assistants meet with the individual and/or primary caregivers to implement treatment recommendations under the supervision of the Behavior Analyst. The number of weekly intervention hours varies broadly, based on the treatment approach.

Services are designed to be provided for a limited time and decrease as the caregivers gain skills and abilities to assist the recipient to function in more independent and less challenging ways. As the individual develops the skill set required for future learning and the caregivers develop the skills to provide daily intervention and respond to future behavioral needs as they arise, it is believed that the need for service provided by the behavior analyst and assistant decreases.

Recent behavior analysis outcome studies suggest additional longitudinal studies are needed in order to accurately assess long-term accumulated benefit of behavior therapy.

### **Applied Behavior Analysis Provider Qualifications**

Medicaid service providers have defined standards and qualifications for the delivery of each service. For Applied Behavior Analysis services, there are existing state and national standards that govern credentialing, provider practice, and continuing education of ABA providers. The current Florida qualifications for Applied Behavior Analysis services are:

- **Behavior Analysis Level 1:** Professionals providing Behavior Analysis services must meet the minimum requirements for a Board Certified Behavior Analyst or Florida Certified Behavior Analyst with expanded privileges under Chapter 393, F.S., or be licensed under Chapter 490 or 491, F.S. (Licensed Mental Health Counselor, Licensed Clinical Social Worker, Licensed Marriage and Family Therapist, or Licensed Clinical Psychologist, with more than three years of experience in behavior analysis post certification or licensure).
- **Behavior Analysis Level 2:** Professionals meet those same licensure or certification requirements, with less than three years of experience in behavior analysis post certification or licensure. A Florida Certified Behavior Analyst with Masters or Doctorate degrees, regardless of experience, meets Level 2 qualifications.
- **Behavior Analysis Level 3:** Providers are those who are Board or Florida Certified Associate Behavior Analysts or a Florida Certified Behavior Analyst with a Bachelor's degree or high school diploma, regardless of experience.
- **Behavior Analyst Assistant:** Providers must possess a high school diploma, plus specified training and experience. The Behavior Analyst Assistant must provide services under the supervision and direction of a Level 1, Level 2, or Level 3 behavior analysis provider.

### **Medicaid Services for Children Diagnosed with ASD and/or Down Syndrome**

The Agency for Health Care Administration oversees Florida Medicaid services provided to an average monthly caseload of approximately 2,045 children five years of age and under diagnosed with Down syndrome, ASD or both. Of the children served, 1,013 are diagnosed with ASD only,

while 892 are diagnosed with Down syndrome only and 140 are dually diagnosed with both ASD and Down syndrome (Medicaid claims data SFY-2010-2011). Medicaid pays approximately \$19.5 million per year for Medicaid State Plan occupational, physical and speech therapies for an average monthly caseload of 5,118 children (2,045 children ages 0-5 and 3,073 children ages 6-20), 20 years of age and under diagnosed with ASD or Down syndrome or both.

The chart below outlines the average annual cost of Medicaid State Plan Occupational Therapy (OT), Physical Therapy (PT) and Speech Therapy (ST) for children through 20 years of age with a diagnosis of ASD, Down syndrome, or a combination of both diagnoses:

**Table # 2**  
**Average Annual Cost of OT, PT and ST for Children Through 20 Years of Age with a Diagnosis of ASD, Down Syndrome or Both**

DIAGNOSIS	Average Monthly Caseload Medicaid State Plan PT, OT, and ST (children ages 0-5)	Average Annual Cost of Medicaid State Plan PT, OT, and ST (children ages 0-5)	Average Monthly Caseload Medicaid State Plan PT, OT, and ST (children ages 6-20)	Average Annual Cost of Medicaid State Plan PT, OT, and ST (children ages 6-20)	Average Monthly DD Waiver Caseload (children ages 0-20)
ASD	1,013	\$3,695	2,287	\$4,039	1,757
Down Syndrome	892	\$3,297	569	\$3,718	228
ASD and Down Syndrome	140	\$3,394	217	\$4,461	3
Totals	2,045	\$10,386	3,073	\$22,604	1,988

Source: FL FMMIS/DSS, SFY2010-2011 Medicaid Claims Data. ASD/down syndrome comorbidity rates approx. 7% to 10%.

The Agency also maintains five developmental disabilities home and community based services Medicaid waivers (DD waiver) which are operated by the Agency for Persons with Disabilities. Prior to recent federal court litigation in the case of Garrido v Dudek, Case No. 1:11-cv-20684 (S.D. Fla. 2011), these developmental disabilities waivers were the only Medicaid programs in Florida that provided behavioral analysis services to children with ASD or Down syndrome. These waivers serve an average monthly caseload of approximately 5,919 children 20 years of age and under (SFY09-10). As of August 1, 2012, the waiting list for DD waiver services is approximately 21,719 individuals, of which an estimated 1,988 individuals have a diagnosis of autism spectrum disorder, Down syndrome, or both.

Florida families typically receive early intervention services via one of these avenues:

- DOH Early Steps Program and the Medicaid Early Intervention Program up to age three (Medicaid Early Intervention Services do not include behavior services);
- School district services from ages 3-21;
- Developmental Disabilities home and community-based services Medicaid waivers starting at age 3;
- Private therapists and/or paraprofessionals; or

- Children’s Medical Services, where therapies are arranged to benefit the child, and all applicable Medicaid State Plan services are covered.

### **III. RECENT DEVELOPMENTS**

The state conducted a thorough analysis of options, and the results are noted in Appendix B.

#### **Garrido v. Dudek**

In February 2011, three plaintiffs brought a lawsuit against the Agency, arguing that Applied Behavior Analysis services should be covered under the State Plan. See Garrido v Dudek, Case No. 1:11-cv-20684 (S.D. Fla. 2011). On March 26, 2012, the federal judge presiding over the Garrido case entered a permanent injunction requiring the Agency to authorize and provide ABA services for the treatment of Autism Spectrum Disorders to all Medicaid-eligible children under the age of 21, effective April 2, 2012. The Agency immediately complied with the injunction. However, the Agency has filed an appeal with the U.S. Court of Appeals for the 11th Circuit seeking reversal of the trial court’s order on the basis that the scope of the injunction is overly broad and that portions of the relief provided therein must be limited to the three plaintiffs who brought the underlying suit. The Agency’s appeal is currently pending.

Recent developments in the case of Garrido have resulted in policy development and implementation of a State Plan applied behavior analysis service. Continuation of the applied behavior analysis service will require the completion and approval of a Medicaid State Plan amendment. The Centers for Medicare and Medicaid Services (CMS) require the submission of a State Plan, which contains all information necessary for Centers for Medicare and Medicaid Services to determine whether the plan can be approved to serve as a basis for Federal financial participation (FFP) in the State program (42 Code of Federal Regulations 430.10), and submittal of amendments to the State Plan are required so that CMS can determine whether the plan continues to meet the requirements for approval and ensure the availability of FFP (§ 430.12).

#### **Policy Development for Coverage of Applied Behavior Analysis**

The Agency is in the process of developing specific coverage and limitations policies that will ultimately go through the public rulemaking process prior to implementation. Federal regulations prohibit Medicaid from arbitrarily limiting a service solely based on diagnosis, including autism. The Agency is in the process of developing a State Plan amendment for federal review and approval.

Four services are mandated in s. 409.906(26), F.S.: occupational, physical, and speech therapies, and behavior analysis (including behavior assistant services). With the federal court’s decision in Garrido, Florida Medicaid is currently authorizing all four of the therapies to children through 20 years of age under the Medicaid State Plan for children with ASD. For that reason, applied behavior analysis is currently being provided to recipients under age 21 with an autism spectrum disorder and would not need to be added as a new service under s. 409.906(26), F.S.

### **IV. ISSUES, CONCERNS, AND CONSIDERATIONS**

The following issues must be taken into account when developing the requirements to cover a new Medicaid service.

## Staffing Resources

As the federally recognized State Medicaid Agency, the Agency for Health Care Administration must administer all Medicaid programs and bears the ultimate responsibility to the federal government for compliance with Medicaid laws and regulations. The Agency applies to the federal Department of Health and Human Services' Centers for Medicare and Medicaid Services for program approval, promulgates program rules, and maintains oversight. As the implementing agency of this service, the Agency will likely need at least one additional staff resource to handle the workload of implementing and managing this service.

## Medicaid Managed Care

Medicaid managed care plans are not currently capitated to provide applied behavior analysis. Children who are enrolled in a Medicaid managed care plan can receive ABA services fee-for-service. Moving forward, if ABA continues to be a mandatory covered service for children, the Agency will need to incorporate expenditures for this service into the rate setting process for health plans.

## V. COST ANALYSIS

### Cost to the State

**Table #3**

**Estimated Cost per Child for Program Services Based on Estimated Numbers of Children in Florida with Autism Spectrum Disorder in SFY 11/12 and the Developmental Disabilities Home and Community-Based Services Waiver Provider Rate Table, Approved July 2008**

	<b>Behavior Assessment</b>	<b>Certified Behavior Analyst Services</b>	<b>Behavior Assistant Services</b>		<b>Physical, Occupational, Speech Therapies</b>
<b>Units of Service<sup>2</sup></b>	1 per year	2 hours per week	Option 1: 9 hours per week (36 quarter hour units)	Option 2: 20hours per week (80 quarter hour units)	Based on current utilization for children in Medicaid with ASD and/or Down syndrome
<b>Cost per Unit</b>	\$549 max per assessment \$275 usual and customary rate	Average rate of \$17 per quarter hour for three levels of Certified Behavior Analyst	\$5 per quarter hour	\$5 per quarter hour	\$50 per evaluation \$17 per session
<b>Average Annual Cost Per Child*</b>	\$549	\$7,039	\$8,592	\$19,094	\$3,462

<b>Total Average Annual Cost** Range per Child</b>	<b>\$19,643 to \$30,145</b>
--	-----------------------------

*\*Based on averaging the DD waiver reimbursement rates for levels 1-3 of CBA. Sources: 1. FL FMMIS/DSS, SFY 2010-2011 Medicaid Claims Data, 2. Proposed iBudget DD waiver fee schedule, provided 12/2010 in rulemaking process on 7/2011. Reflects 4% reduction in rates. 3. From Therapies fee schedule effective 7/1/2008, accessed from <http://mymedicaid-florida.com/>. When possible, fees from existing DD tier waiver fee schedule and proposed iBudget fee schedule have been averaged to account for a 2 year transition period from DD tiers to iBudget.*

*\*\*New costs for children currently enrolled in Medicaid may be lower than this range because they are likely already receiving occupational therapy, physical therapy, and speech therapy and may be receiving behavior analysis if enrolled in a Developmental Disabilities Waiver.*

- CBA: (8units/week x 52 weeks/year) x \$17/unit=\$7038
- BA (9 hours per week): (36 units/week x 52 weeks) x \$5/unit=\$8,592
- BA (20 hours per week): (80 units/week x 52 weeks) x \$5/unit=\$19,094

**Table #4**

**Total Annual Range of Cost for New Program.**

<b>Population of Children with ASD or Down Syndrome</b>	<b>Number of Children Enrolled in Medicaid through 20 Years of Age (Average Monthly Caseload, SFY 2011-2012)<sup>7</sup></b>	<b>Range of Costs</b>
Children Currently Enrolled in Medicaid*	27,333	\$536.9 million to \$823.9 million

*\*New costs for children currently enrolled in Medicaid may be lower than this range because they are likely already receiving occupational therapy, physical therapy, and speech therapy and may be receiving behavior analysis if enrolled in a Developmental Disabilities Waiver.*

**VI. SUMMARY**

Four services are mandated in s. 409.906(26), F.S.: occupational, physical, and speech therapies, and behavior analysis (including behavior assistant services). With the federal court’s decision in Garrido, Florida Medicaid is currently authorizing all four of the therapies to children through 20 years of age under the Medicaid State Plan for children with ASD. For that reason, applied behavior analysis would not need to be added as a new service under s. 409.906(26), F.S.

Based on the findings delineated in this report, the Agency presents this summary to the Florida Legislature to review for consideration, in order to meet the legislative intent to serve children age five and under diagnosed with Autism, Autism Spectrum Disorder, and Down syndrome. The Agency stands ready to receive further direction from the Legislature and to implement the course of action as directed.

<sup>7</sup> SFY2010-2011 Medicaid Recipient Enrollment Data, data obtained from FMMIS/DSS.

## VII. REFERENCES

**ARCH - National Resource Center for Respite and Crisis Care Services(2008).**

<http://www.archrespite.org/archFS9.htm>

**Baron-Cohen (1992).** PEDIATRICS Vol. 114 No. 2 August 2004, pp. e166-e176

**Brighter Tomorrows Down Syndrome Education (2008).** Copyright 2008-2009

Interdisciplinary Human Development Institute, University of Kentucky.

<http://www.brightertomorrows.org/learning.html?course=2&module=13>

**Canadian Pediatric Society (2004).** Canadian Pediatric Society (CPS),*Pediatrics & Child Health* 2004; 9(4): 267-270 Reference No. PP 2004-02

**Centers for Disease Control and Prevention (2007).** CDC. Prevalence of Autism Spectrum Disorder, Autism and Developmental Disabilities Monitoring Network; Surveillance Summaries February 9,2007 MMWR 2007;56 (No.SS-1);1-11

**Dawson & Osterling (1997)** Werner, E., Dawson, G., Munson, J., & Osterling, J. (2006). Variation in early developmental course in autism and its relation with behavioral outcome at 3-4 years of age. *J. AUTISM & DEVELOPMENTAL DISORDERS* 35(3), 337-350.

**Feinberg & Vacca (2000).** Feinberg, E. & Vacca, J. (2000). The Drama and Trauma of Creating Policies on Autism: Critical Issues to Consider in the New Millennium. *Focus on Autism and Other Developmental Disabilities*, 15(3), 130-138

**Fidler, J.J, & Nadel, L. (2007).** Education and children with Down syndrome: Neuroscience, development, and intervention. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 262-271.

**Governor's Task Force on ASD Spectrum Disorders (2008).** Summary of Minutes Governor's Taskforce on Autism Spectrum Disorders Window of Opportunity Committee August 19,2008 11:00 a.m. – 12:30 p.m. Conference Call

**Harris, S., & Handle man, J. (2000).** Age and IQ at intake as predictors of placement for young children with autism: A four-to six-year follow up. *Journal of Autism and Developmental Disorders*, 30, 137-142

**Lord and McGee (2001).** Lord, C., & McGee, J. (Eds.). (2001). Educating children with autism. Washington, D.C.: National Academy Press.

**Lounds Taylor J, Dove D, Veenstra-VanderWeele J, Sathe NA, McPheeters ML, Jerome RN, Warren Z. (2012).** Interventions for Adolescents and Young Adults With Autism Spectrum Disorders. Comparative Effectiveness Review No. 65. (Prepared by the Vanderbilt Evidence-based Practice Center under Contract No. 290-2007-10065-I.) AHRQ Publication No. 12-EHC063-EF. Rockville, MD: Agency for Healthcare Research and Quality. August 2012. [www.effectivehealthcare.ahrq.gov/reports/final.cfm](http://www.effectivehealthcare.ahrq.gov/reports/final.cfm).

**Massachusetts Department of Health and Human Services (2008).**

[http://www.mass.gov/?pageID=eohhs2terminal&L=6&L0=Home&L1=Government&L2=Special+Commissions+and+Initiatives&L3=Children's+Behavioral+Health+Initiative&L4=Training+for+Providers&L5=The+MassHealth-approved+Screening+Tools&sid=Eeohhs2&b=terminalcontent&f=masshealth\\_provider\\_cbhi\\_bh-screening\\_mchat&csid=Eeohhs2](http://www.mass.gov/?pageID=eohhs2terminal&L=6&L0=Home&L1=Government&L2=Special+Commissions+and+Initiatives&L3=Children's+Behavioral+Health+Initiative&L4=Training+for+Providers&L5=The+MassHealth-approved+Screening+Tools&sid=Eeohhs2&b=terminalcontent&f=masshealth_provider_cbhi_bh-screening_mchat&csid=Eeohhs2)

**The National Down Syndrome Society (2008).**

[http://www.ndss.org/index.php?option=com\\_content&view=article&id=59&Itemid=76](http://www.ndss.org/index.php?option=com_content&view=article&id=59&Itemid=76)

**Nemours Foundation, Kids Health (2008).**

[http://kidshealth.org/parent/positive/learning/pervasive\\_develop\\_disorders.html](http://kidshealth.org/parent/positive/learning/pervasive_develop_disorders.html)

**Robins, Fein, & Barton (1999).** <http://www2.gsu.edu/~wwwpsy/faculty/robins.htm>

**Siegel (1998).** Pervasive Developmental Disorder Screening Tool - Journal of Psychoeducational Assessment, Vol. 25, No. 3, 299-306 (2007)DOI: 10.1177/0734282906298469

**Stearnagel T. (2005).** Increases in identified cases of autism spectrum disorders: policy implications. Journal of Disability Policy Studies, 16(3), 138-146.

**Dr. Amy Wetherby (2004).** <http://www.fsu.edu/news/2006/05/03/autism.study/>

**Warren Z, Veenstra-VanderWeele J, Stone W, Bruzek JL, Nahmias AS, Foss-Feig JH, Jerome RN, Krishnaswami S, Sathe NA, Glasser AM, Surawicz T, McPheeters ML. (2011).** Therapies for Children With Autism Spectrum Disorders. Comparative Effectiveness Review No. 26. (Prepared by the Vanderbilt Evidence-based Practice Center under Contract No. 290-02-HHSA-290-2007-10065-I.) AHRQ Publication No. 11-EHC029-EF. Rockville, MD: Agency for Healthcare Research and Quality. April 2011.

**World Health Organization (2006).** F84, "Pervasive Developmental Disorders International Statistical Classification of Diseases and Health Related Problems" (10<sup>th</sup> Edition ,ICD-10)

## VII. Appendix A: CURRENT PROGRAMS SERVING CHILDREN AND SERVICE ISSUES

The following sections describe the eligibility for current programs that serve children with disabilities and the services provided. This section shows that, although these programs provide many services to eligible children, some gaps still exist in service coverage for children with developmental disabilities.

### **Current Applied Behavior Analysis Services**

Effective April 2, 2012, Florida Medicaid began providing coverage of applied behavior analysis services under the Medicaid State Plan for children through 20 years of age with Autism Spectrum Disorders. To comply with the federal district court's ruling in Garrido, the Agency issued a series of provider alerts that notified qualified providers, children's case management providers, managed care plans, and physicians of the coverage and limitations for the ABA service.

ABA services begin once a physician has determined that a Medicaid-eligible child diagnosed with an Autism Spectrum Disorder is in need of applied behavior analysis. To request authorization, the recipient's physician or a behavior analysis provider must submit a request and medical records that document the recipient's diagnosis of autism spectrum disorder to the Medicaid area office. Requests undergo a brief review to confirm the recipient's Medicaid eligibility, autism spectrum disorder diagnosis, and referring physician's credentials before issuing an approval letter to the recipient and the requesting provider.

Once approved, recipients select from a list of qualified, Medicaid-enrolled ABA providers. Medicaid area offices maintain a current listing of ABA service providers and provide recipients assistance with accessing ABA services. The three existing Medicaid provider types determined qualified to render community-based ABA services are:

- Behavior analysis providers who are contracted with the Agency for Persons with Disabilities to provide behavior analysis services and who are enrolled in Florida Medicaid as developmental disabilities waiver providers.
- Certified behavior analysts who are enrolled as early intervention service providers with the Early Steps program.
- Certified behavior analysts who are employed or under contract with a community behavioral health provider to provide the Therapeutic Behavioral On-Site Services-Behavior Management service.

The providers render services, utilizing existing codes from their respective handbooks. All ABA services are billed Medicaid fee-for-service, whether or not the recipient is in a managed care plan.

Behavior analysis providers conduct a behavioral assessment, which determines the frequency and level of ABA services to be provided to the recipient and is used in the development of a behavior plan. Services may be provided up to 40 hours per week, utilizing a combination of certified behavior analyst and behavioral assistant services, as determined by the recipient's behavior plan. ABA providers conduct regular reviews of recipient progress to determine ongoing need for the services. Documentation is maintained in accordance with the provider's handbook requirements. Due to the federal court's order, utilization management and medical necessity reviews are not currently utilized for the ABA service. However, utilization

management and medical necessity reviews would be utilized with the implementation of a federally-approved State Plan amendment for ABA services.

### **Medicaid Early and Periodic Screening, Diagnosis and Treatment (EPSDT)**

Medicaid's Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program is a comprehensive and preventive child health service that implements sections 1902(a)(43) , 1905(a)(4)(B) and 1905(r) of the Social Security Act. EPSDT prescribes State Plan requirements for providing early and periodic screening and diagnosis and treatment of eligible Medicaid recipients through 20 years of age to ascertain physical and mental illnesses and conditions and to provide treatment designed to correct or ameliorate defects and chronic conditions found.

EPSDT is intentionally broad and states that Medicaid "requires that any medically necessary health care service listed at Section 1905(a) of the Act be provided to an EPSDT recipient even if the service is not available under the State's Medicaid plan to the rest of the Medicaid population." It also enables them to "assess the child's health needs through initial and periodic examinations and evaluations, and also to assure that the health problems found are diagnosed and treated early, before they become more complex and their treatment more costly" (Centers for Medicare and Medicaid Services).

EPSDT in Florida is known as the Child Health Check-Up (CHCUP) program. Medicaid reimburses for Child Health Check-Ups for eligible Medicaid recipients through 20 years of age, and children from age 1 through 4 who are enrolled in the MediKids program.

The EPSDT benefit includes screening services, as well as diagnostic and treatment services. Other EPSDT services include vision services, including diagnosis, treatment, and eyeglasses; dental services, including relief of pain and infections, restoration of teeth, and maintenance of dental health; and hearing services, including diagnosis, treatment, and hearing aids. While states are required to cover screening services, they are granted flexibility in establishing how frequently these services must be provided. As a result of this flexibility, the frequency and timing of required screening services vary considerably. Florida's CHCUP is recommended at birth, two to four days for newborns discharged in less than 48 hours after delivery, at one month, two months, four months, six months, nine months, 12 months, 15 months, 18 months, 24 months, 30 months, and once every year for ages 3-20. The CHCUP may also be requested at other times, if it is needed.

While the EPSDT benefit is important to all children, it has been especially beneficial to the children with disabilities enrolled in Medicaid. For these children, Medicaid, through EPSDT, provides more comprehensive coverage than the typical commercial insurance plan and increases access to needed services that improve the quality of daily life. Special needs children are more likely to need physical, occupational and speech therapy, respiratory care, personal care services, mental health and substance abuse services, and durable medical equipment--services available through Medicaid that are often limited or excluded under commercial health plans and even under many separate Children's Health Insurance Programs (CHIP).

### **Medicaid Developmental Disabilities Waivers**

In addition to the services provided under Garrido, Florida Medicaid covers behavior analysis and behavior assistant services for recipients with a diagnosis of a developmental disability as defined in section 393.063, F.S. through the developmental disabilities waiver programs.

Florida Medicaid recognizes three levels of behavior analysis professionals for reimbursement under the developmental disabilities waivers, as well as a paraprofessional level called Behavior Analyst Assistant. The developmental disabilities waivers limit recipients to four or less hours of behavior services per day.

Utilizing the Developmental Disabilities Home and Community-Based Services Waiver Provider Rate Table, approved July 2008, the average rate of reimbursement per quarter-hour unit of service for Behavior Analysis Level I is \$17.79, for Behavior Analysis Level 2 is \$15.54, for Behavior Analysis level 3 is \$9.67, and for Behavior Assistant Services is \$4.10. Currently the total cost of Behavior Analysis is \$7.3 million for the DD Waivers (tiers 1-3) and \$2.4 million for the Family and Supported Living Waiver (tier 4). The average annual cost per recipient for Behavior Analysis for the DD waivers is \$4,721. The average annual cost per recipient for behavior analysis services on the Family and Supported Living waiver is \$2,464.

### **Children's Health Insurance Program (CHIP)**

Children without health insurance and under the age of 19 are eligible for Florida's CHIP program, called KidCare. The family income of children wishing to enroll in the KidCare program must fall within guidelines that are based on family size. They must be a resident of Florida, a U.S. citizen or a qualified non-citizen. Children residing in a public institution are not eligible for KidCare. Florida KidCare provides basic medical care services along with speech and hearing therapy. However, it does not provide behavior analysis services and ongoing behavior intervention.

Children enrolled in Florida KidCare's Title XXI programs: Healthy Kids, MediKids and Children's Medical Services Network, have family incomes exceeding the Medicaid income limits and are under 200% FPL (Federal Poverty Level - Federal Poverty Income Guidelines). The children in families with income exceeding 200% FPL can be enrolled in the MediKids and Healthy Kids full pay programs. Florida's CHIP covered benefits and services include physician visits, hospitalizations, mental health, nursing, home health and personal care, pharmacy, dental, hearing, eye exams and glasses, and prosthetic appliances. However, children enrolled in the Title XXI or full pay programs are not eligible for Medicaid home and community-based waiver services and thus do not receive behavior analysis services.

### **Commercial Insurance Mandate**

The 2008 Florida Legislature required health insurance plans to cover the Autism Spectrum Disorder and protected those with autism from denial of insurance coverage. The bill authorizes AHCA to seek provisions for establishment of a compact with all insurers, health maintenance organizations and self-insurers to provide therapy services to patients with Autism Spectrum Disorders. Insurers that did not agree to comply with the compact are subject to an insurance mandate. The law also allows \$36,000 per year and a lifetime cap of \$200,000 in insurance coverage for habilitative therapies for children identified as autistic by age eight.

## Coverage Gaps between Existing Programs Serving Children with ASD

	<u>Medicaid State Plan</u>	<u>Title XXI - CMS Network</u>	<u>Title XXI – MediKids (ages 1 through 4) and Healthy Kids (ages 5 through 18)</u>	<u>Commercial Insurance</u>
<b><u>Age of Child</u></b>				
<b>Age 1-4</b>	Therapies & ABA*	Therapies & ABA	Therapies	Therapies & ABA
<b>Age 5-8</b>	Therapies & ABA*	Therapies & ABA	Therapies	Therapies & ABA
<b>Age 9-18</b>	Therapies & ABA*	Therapies & ABA	Therapies	Therapies**
<b>Age 19-20</b>	Therapies & ABA*			Therapies**

\*State Plan ABA covered as a result of Garrido.

\*\* If identified as autistic by age eight.

### VIII. Appendix B: OPTIONS FOR WAIVER OR STATE PLAN AMENDMENT

The law authorizes AHCA to seek a Medicaid State Plan amendment or a waiver. The chart below compares whether each program component specified in the authorizing legislation can be achieved through a State Plan amendment or waiver:

<b>Component Specified in Statute</b>	<b>State Plan Amendment</b>	<b>1915(c) Waiver</b>
<b>Diagnosis:</b> Autism, ASD, Down Syndrome	<b>Cannot</b> limit eligibility by diagnosis.	<b>Can</b> limit eligibility by diagnosis.
<b>Age:</b> Five and under	<b>Cannot</b> limit by age (could narrow to a needs based criteria; e.g., “trouble developing normally” to target developmental age or could include state defined risk factors).	<b>Can</b> limit by age.
<b>Services:</b> Behavioral Therapy, Physical Therapy, Occupational Therapy, and Speech Therapy	<b>PT, OT, and ST</b> available through state plan Medicaid for children through 20 years of age. <b>Behavioral Therapy</b> available through state plan Medicaid for children through 20 years of age as a result of <u>Garrido</u> .	<b>PT, OT, and ST</b> available through state plan Medicaid for children through 20 years of age. <b>Behavioral Therapy</b> available through state plan Medicaid for children through 20 years of age as a result of <u>Garrido</u> .

<b>Funding:</b> \$36,000 per year, per child \$108,000 per lifetime of the recipient	<b>Cannot</b> impose a dollar limit on services provided	<b>Can</b> impose a dollar limit on services provided. Services <b>must be cost effective</b> (average annual expenses must be less than or equal to the cost of care in an intermediate care facility for the developmentally disabled)
<b>Other Considerations</b>	<b>1915(i) State Plan Amendment</b>	<b>1915(c) Waiver</b>
<b>Level of Care</b>	<b>Not</b> required to meet Intermediate Care Facility for the Developmentally Disabled (ICF/DD), Hospital, or Nursing Home level of care.	<b>Must</b> meet Intermediate Care Facility for the Developmentally Disabled (ICF/DD), Hospital, or Nursing Home level of care.
<b>Income Eligibility Standard</b>	<b>Current Medicaid eligibility standards apply.</b>	<b>Limited to 300% Federal Benefit Rate OR through “Katie Beckett” eligibility criteria</b> (family income not considered for children with long term care or complex medical needs). See table below for numbers of children who would become eligible under “Katie Beckett” eligibility criteria.

**Estimated Numbers of Children with Autism Spectrum Disorder in Florida, Who Would Be Eligible if Implementing a 1915(c) Waiver:**

	Total Estimated Number of Children in Florida	Estimated Number of Children in Florida with ASD Based on Prevalence 1:88 <sup>2</sup>	Estimated <sup>3</sup> Number of Children in Florida with Down Syndrome Based on Prevalence <sup>4</sup> 1:691	Total with ASD or DS
<b>Uninsured Children CY2010<sup>8</sup></b>	127,757	1,452	185	1,637

<sup>8</sup> [http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS\\_10\\_1YR\\_B27001&prodType=table](http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_10_1YR_B27001&prodType=table) on 10/24/12.