

# **A Discussion of the System Designed to Help Children with Severe Autism Spectrum Disorder (ASD) in Massachusetts**

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*The author is the parent of an adult son diagnosed with autism.*

## ***A message from the author to primary care clinicians***

The system for receiving care and intervention for children with severe ASD (autism spectrum disorder) is complex, confusing, and chaotic. Families must learn to navigate this system in order to receive help and intervention for their affected children. There are a few steps that primary care clinicians can take to help. As you will read in my article below, early intervention in this population has been found to be very beneficial for ASDs. Therefore, screening for ASD and appropriate referral will make a huge difference in the lives of these families. If you require help in finding a resource for a specialist who can make a definitive diagnosis of autism, please contact your local [Massachusetts Child Psychiatry Access Project \(MCPAP\) team](#). To learn more about identifying, diagnosing, and managing autism spectrum disorders, visit the AAP-endorsed Centers for Disease Control and Prevention's *Autism Case Training - A Developmental-Behavioral Pediatrics Curriculum (ACT)* at [www.cdc.gov/AutismCaseTraining](http://www.cdc.gov/AutismCaseTraining). To learn more about autism spectrum disorders from the AAP, visit [www.medicalhomeinfo.org/about/cocwd/autism.aspx](http://www.medicalhomeinfo.org/about/cocwd/autism.aspx).

If your patient's family has difficulty understanding how to navigate the new insurance laws pertaining to autism, please have them contact a specialist at the Autism Insurance Resource Center via e-mail at [info@disabilityinfo.org](mailto:info@disabilityinfo.org) or by calling (781) 642-0248 or (800) 642-0249. Another great resource for understanding financing of special healthcare needs including autism is [Mass Family Voices](#). Families may e-mail them at [massfv@fcsn.org](mailto:massfv@fcsn.org) or call them at (800) 331-0688, ext. 301.

You will find a brief article about navigating the special education system by clicking the link below: <http://www.mcpap.com/pdf/NavigatingTheSpecialEducationSystemInMassachusetts.pdf>.

Until the component parts of this system learn to work together towards transparency and a common goal of helping those they serve, we will continue to see skyrocketing costs and a disjointed suboptimal system. It is my hope that you will take any opportunity that you can to advocate for change in this system. This might include responding to articles in the media, participating in local AAP chapter pediatric counsels, and any other creative ways you can think of to facilitate change.

## **Introduction to the system**

There are a multitude of ways that children and youth with severe ASD receive help in the system which provides care and treatment in Massachusetts. It is reasonable to believe that the adult Developmental Disabilities Services (DDS) system, health insurance provisions, and early intervention all may affect the cost of special education and healthcare for children and youth with severe ASD. However, we have no data to determine how the component parts of the system affect each other. Special education programs may not be offering all the tools available to help these children and youth despite very high costs to educate. This article discusses the Massachusetts system for children and youth diagnosed with severe ASD.

## **Lack of access to various approaches**

There are a multitude of therapies and approaches that have been used to help people diagnosed with ASD. However, this discussion is limited to selected approaches specifically focused on increasing attention span, receptiveness to learning, and reducing severe maladaptive behavior such as aggression and self-injury. The severe autism population often lacks attention span and is actually resistant to receiving any type of instruction. Neuroimaging research has shown that children with autism have impaired circuits in the caudate nucleus, a critical part of circuits that link the prefrontal cortex of the brain. This part of the brain plays a critical role in maintaining and focusing attention.<sup>1</sup> Strategies that schools, parents, programs, and agencies have used to promote a more willing learner include but are not limited to:

1. Behavior modification techniques
2. Use of routines and schedules
3. Vigorous exercise
4. Medication

Many of our educational programs for the ASD population in Massachusetts use one or more of the first three strategies mentioned above to promote learning receptiveness.

Some public and private school programs in Massachusetts consider themselves ABA (applied behavioral analysis) based and are modeled after experiments performed by the late O. Ivar Lovaas, PhD.<sup>2</sup> ABA was derived from operant conditioning techniques pioneered in the works of behaviorist, BF Skinner, PhD. Skinner built his research on the conditioned theories of Ivan Pavlov.<sup>3</sup> Effectiveness of ABA for maladaptive behavior reduction and skill acquisition in the ASD population has been well documented.<sup>4, 5, 6, 7, 8</sup> While some behavior modification techniques have included aversive therapies, many behavior modification programs in Massachusetts concentrate on shaping and rewarding positive target behavior rather than punishing undesirable behavior. Systematic reviews have not found definite evidence to support claims that the Lovaas method is superior to other interventions.<sup>9</sup>

In the past several years, behaviorists such as James D. Partington, PhD, and Marc Sundberg, PhD, have further refined behavior modification techniques to include using a comprehensive system to develop language and communication in those with developmental disabilities.<sup>10</sup> This idea is also based on the works of BF Skinner, and the source for this type of intervention

comes from Skinner's book titled *Verbal Behavior*. Behavioral Psychologist Vincent J. Carbone, PhD, and others have promoted the idea of using the Verbal Behavior techniques with the ASD population for the past several years. Dr. Carbone has endorsed this idea to parents, families, and school systems across the globe at various lectures, forums, and symposia.<sup>11</sup>

Ideas involving routines to reach children with ASD have been used in many programs across the globe, including the famous statewide TEACCH (Treatment and education of autistic and related communication handicapped children) program in North Carolina which was created and pioneered by Eric Shopler, PhD.<sup>12</sup> This approach uses strategies based around physical and visual structure, schedules, work systems and task organization.<sup>13</sup> The TEACCH approach was based on a pilot study that showed that children made good progress with this method.<sup>14</sup> In North Carolina's statewide autism program, all children with ASD may receive education based on the TEACCH approach. Programming based on the TEACCH method is largely unavailable in Massachusetts.

Kiyo Kitahara, PhD, founder of the Higashi School, pioneered Daily Life Therapy which provides children with systemic education through group dynamics, modeling, and vigorous physical activity.<sup>15</sup> While the effectiveness of Daily Life Therapy requires further study, vigorous physical activity has been shown to provide benefits to the general population.<sup>16,17,18</sup>

Medications have not been proven to correct the core deficits of ASDs and are not the primary treatment. Use of medication, especially the use of risperidone, an atypical antipsychotic, to treat aggression and self-injurious behavior in this population, has been successful.<sup>19,20</sup> In 2006, risperidone became the first drug approved by the FDA for use in the autistic population over age 5. Atypical antipsychotic medications have a wide range of side effects associated with them, including tardive dyskinesia and weight gain.<sup>21</sup> AAP guidelines indicate that medication may be considered for target symptom complexes in ASD when treatable medical causes are ruled out and behavioral interventions produce suboptimal results.<sup>22</sup>

American Academy of Pediatrics guidelines indicate that intensive programming is the first line of treatment for children and youth with ASD. These guidelines do not select a preferred technique or philosophy.

Parents have reported that individual programs and schools for children and youth diagnosed with ASD in Massachusetts tend to rely on the program's favored methodology. This is true even when the child or youth with ASD fails to respond to the program's favored approach. Parents have even reported that some ABA programs in Massachusetts totally reject the idea of using Verbal Behavior techniques, which is based on the same science that ABA programs embrace.<sup>23</sup> Some other programs such as the Boston Higashi School refuse to allow their students' access to psychiatric medication regardless of the particular mental state of the child or youth.<sup>24</sup>

## **Who pays for special education?**

Students with severe autism may receive special education services at a public school program, at a collaborative program which combines the resources of more than one school district, in a home-based program, or in a private specialty school. The money for these programs usually comes from a combination of school district, state, and federal funding. Taxpayers pay for these programs.<sup>25</sup>

## **Early intervention may affect special education and healthcare costs**

It is logical to believe that the connecting systems of early intervention (serving ages under 3) and adult services (serving age 22 and older) might have an impact on the consumption of special education services and other costs such as healthcare. Currently there are no definitive studies to prove this impact. Healthcare utilization and costs are substantially higher for children and adolescents with ASDs compared with children without ASDs.<sup>26,27,28</sup> The O. Ivar Lovaas studies provide evidence that appropriate early intervention in young children with ASD can have a profound effect on progress.<sup>29</sup>

As a result of an EPSDT (Early and Periodic Screening, Diagnosis, and Treatment) lawsuit, otherwise known as the %Rosie D. lawsuit,+MassHealth requires that primary care providers offer behavioral health screenings using MassHealth-approved, standardized screening tools. Two of these standardized screening tools do screen for Autism Spectrum Disorder. These tools are the M-CHAT (Modified Checklist for Autism in Toddlers) and the PEDS (Pediatric Evaluation of Developmental Status). In Massachusetts, if a patient screens positive on these tools, they must be referred to a specialist for a definitive diagnosis before early intervention specialty services (i.e., services that are appropriate for this population) may be started. Wait lists for a specialist to make a definitive diagnosis can take months. In Massachusetts, even the most severe and obvious cases of ASD must go through the process of obtaining a definitive diagnosis from a specialist. A provisional diagnosis by a primary care doctor and a positive screen is not considered acceptable by our present early intervention system.<sup>30</sup> At age 3, local education authorities (i.e., school systems) and the Department of Elementary and Secondary Education are financially responsible for the education of the child. We may be detecting ASD in some children and youth earlier, but we are delaying the treatment that they so desperately need, and we have no studies looking at how this delay affects the costs of other services to be consumed later on. Early intervention services are administered through the Department of Public Health.

## **Residential placements and special education costs**

Parents of children and youth with severe ASD commonly report that specialists have recommended 24/7 education, care, and intervention. Some families receive evaluation recommendations that stipulate that their children require extended school days and year-round programming.<sup>31</sup> Residential placements are one way children and youth with severe ASD receive more intensive education and care. In Massachusetts, residential placements for the severe autism population are granted to fulfill educational needs and are funded by a combination of school district, state, and federal funding. These placements are usually in a group home setting and are extremely costly.

Private residential programs average about \$105,000 per year per child and can cost as high as \$292,000 per year per child.<sup>32</sup> School-age residential services are delivered via private organizations and are funded by public money. While it is certainly possible that serving such high-needs individuals is indeed expensive, very little information about the individual expenditures of these programs is released to the public.

While free and appropriate education entitlements are specifically mandated by both state and federal law for school-age special education students, adults with severe disabilities do not enjoy the same protections. If parents opt to place their children in a residential placement before the age of 22, they are protected by the strong regulations of the Individuals with Disabilities Act (IDEA). If they wait until after age 22, they do not have those same protections. This may prompt some families to place children in residential placements earlier than they may have under different circumstances.

Private schools that offer residential placements to school-age children and youth do so at their own discretion. Despite an exhaustive internet search, this author could find no data that would show age trends of children with ASD placed in residential settings. If children are being served in residential placements at younger ages, this results in higher special education costs over the school-age years for that particular individual.

## **The maze of services for autism treatment and care**

There are several other programs and services that families may seek for their children diagnosed with ASD.

### *An Act Relative to Insurance Coverage for Autism (ARICA)*

In January 2011, An Act Relative to Insurance for Autism went into effect. This law requires health insurers to provide coverage for the treatment of ASD. Self-funded or ERISA (Employee Retirement Income Security Act) plans are exempt from ARICA. ERISA plans are regulated by federal rather than state law. According to Amy Weinstock, executive director of the Autism Insurance Resource Center, there are a few companies with self-funded plans that have opted to voluntarily abide by ARICA even though they are not required by law. MassHealth is exempt from ARICA as well.<sup>33</sup> However, MassHealth covers in-home behavioral treatment through Children's Behavioral Health Initiative (CBHI) as explained below. ARICA covers treatment for

habilitative or rehabilitative care including ABA (applied behavior analysis), pharmacy care, psychiatric care, psychological care, and therapeutic care. A licensed physician or a licensed psychologist must determine that the care for the individual is medically necessary. There is no age limit for care mandated under ARICA.

#### *In-home services funded through the school system*

School systems are obligated to pay for free and appropriate education (FAPE) for special needs students. They are also obligated to provide accommodations so that the individual can gain access to the general curriculum (603 CMR 28.00). For example, if a student has behaviors that interfere with the learning process, it may be determined that the school system must pay for behavior modification programming to reduce or extinguish these behaviors. Treatment of these behavior may need to be consistent and beyond the regular school day. On August 22, 2011, the Department of Elementary and Secondary Education issued an advisory which clarifies that obligations for free and appropriate education under the IDEA are not affected by care and services obtained under ARICA.<sup>34</sup>

#### *DDS/DESE Residential Prevention Programming*

The DDS/DESE residential prevention programming is specifically designed to avoid or delay residential placements. This program, administered through the Department of Developmental Services, is targeted to special education students who require an intensive level of supports. Funding from this program may be used for ABA therapy among a host of other items to fulfill the needs of individuals with severe difficulties. Because of recent cuts in services, this service is not readily available to new applicants.<sup>35</sup>

#### *Autism Waiver Program*

The Office of Medicaid and the Department of Developmental Services Autism Division offers an Autism Waiver Program for children age birth through the age of 8. The Waiver allows children to receive expanded habilitation and education (in-home Services and supports, such as Applied Behavioral Analysis (ABA) for a total of three years. At the conclusion of the three years of the intensive in-home services, a child may access ongoing supplemental services (for example respite and goods and services, etc.) that meet the child's needs and help with the transition out of the intensive Autism Waiver Program, until the child's 9<sup>th</sup> birthday. Waiver Services are supplemental to the special education services provided under IDEA (Individuals with Disabilities Education Act). There are several eligibility criteria for this program. Among other requirements, the child must be found by the MassHealth agency to be eligible for MassHealth Standard coverage based on family income. The Autism Division announces application periods in which they accept new applications for the Autism Waiver Program. Families may apply for this program through autism support centers throughout the Commonwealth. (For a list of Autism Support Centers in the Commonwealth, download <http://www.mc pap.com/pdf/PCCScreeningToolkitUpdate04292010.pdf> and see page 73). Recipients of this program are determined through a lottery. One hundred thirty children may participate in this program at any given time.<sup>36</sup>

### *In-Home Behavioral Services through the Children's Behavioral Health Initiative (CBHI)*

For children and youth on MassHealth, in-home behavioral services offer valuable support to a child or youth who has challenging behaviors that interfere with everyday life. A clinician and a trained paraprofessional work closely with the child and family to create and implement treatment plans that diminish, extinguish, or improve specific behaviors.<sup>37</sup>

MassHealth in-home behavioral health services may be accessed through a clinical hub provider. These clinical hubs are outpatient therapy, in-home therapy, or ICC (Intensive Care Coordination).

Children and youth with severe ASD who are not already on MassHealth may apply for MassHealth via CommonHealth, the Medicaid buy-in program for children and adults with disabilities. There is no income limit for CommonHealth, though there is a sliding scale premium based on family income.

### **Another message to primary care clinicians**

There has been much discussion in the media about the rise in special education costs for special needs populations. However, there is much that we don't know about the present system for treating and caring for people diagnosed with severe autism. The system that serves this population is confusing and difficult to navigate.

We thank you for reading this article and for caring for children and youth with severe ASD in your practices. We hope that this article has given you an idea of the complexity of the system that families with children with severe ASD face.

Please feel free to call your [regional MCPAP hub](#) for help with resources for your pediatric patients diagnosed with autism.

## Resources

Links to the American Academy of Pediatrics Guidelines:

[Identification and Evaluation of Children with Autism Spectrum Disorder](#)  
[Management of Children with Autism Spectrum Disorders](#)

To learn more about identifying, diagnosing, and managing autism spectrum disorders, visit the AAP- endorsed Centers for Disease Control and *Prevention's Autism Case Training-A Developmental-Behavioral Pediatrics Curriculum (ACT)* at [www.cdc.gov/AutismCaseTraining](http://www.cdc.gov/AutismCaseTraining).

To learn more about autism spectrum disorders from the AAP, visit [www.medicalhomeinfo.org/about/cocwd/autism.aspx](http://www.medicalhomeinfo.org/about/cocwd/autism.aspx)

Information on side effects of atypical antipsychotic medication:

<http://mcpap.com/pdf/MCPAPAntipsychoticGuidelinesFinal.pdf>

Information about navigating the special education system in Massachusetts:

<http://www.mcpap.com/pdf/NavigatingTheSpecialEducationSystemInMassachusetts.pdf>

Information about Early Intervention may be found at the Mass Family Ties website at:

<http://massfamilyties.org/index.php>

More information about Early Intervention may be found on the MA Health and Human Services website at:

[http://www.mass.gov/?pageID=eohhs2subtopic&L=6&L0=Home&L1=Consumer&L2=Community+Health+and+Safety&L3=Family+and+Community+Health&L4=Early+Childhood&L5=Early+Intervention+\(EI\)&sid=Eeohhs2](http://www.mass.gov/?pageID=eohhs2subtopic&L=6&L0=Home&L1=Consumer&L2=Community+Health+and+Safety&L3=Family+and+Community+Health&L4=Early+Childhood&L5=Early+Intervention+(EI)&sid=Eeohhs2)

Diagnostic criteria for eligibility for early intervention specialty services can be downloaded at

[http://www.mass.gov/Eeohhs2/docs/dph/com\\_health/early\\_childhood/asd\\_ssp\\_eligibility.pdf](http://www.mass.gov/Eeohhs2/docs/dph/com_health/early_childhood/asd_ssp_eligibility.pdf)

Information about ARICA from the Autism Insurance Resource Center can be found at

<http://www.disabilityinfo.org/arica/>. Families may contact an autism insurance information specialist at the Autism Insurance Resource Center via e-mail at [info@disabilityinfo.org](mailto:info@disabilityinfo.org) or by calling (781) 642-0248 or (800) 642-0249.

Information about Autism Waiver Services may be found at:

[http://www.mass.gov/?pageID=eohhs2terminal&L=7&L0=Home&L1=Consumer&L2=Disability+Services&L3=Services+by+Type+of+Disability&L4=Intellectual+Disability&L5=Intellectual+Disability+Support&L6=Autism+Spectrum+Services&sid=Eeohhs2&b=terminalcontent&f=dmr\\_c\\_autism\\_waiver&csid=Eeohhs2](http://www.mass.gov/?pageID=eohhs2terminal&L=7&L0=Home&L1=Consumer&L2=Disability+Services&L3=Services+by+Type+of+Disability&L4=Intellectual+Disability&L5=Intellectual+Disability+Support&L6=Autism+Spectrum+Services&sid=Eeohhs2&b=terminalcontent&f=dmr_c_autism_waiver&csid=Eeohhs2)

Information about financing healthcare for children with special healthcare needs including ASD

can be found at the Mass Family Voices website at <http://www.massfamilyvoices.org/> Mass Family Voices or the Autism Insurance Resource Center will help families with navigating CBHI services, and with applying for CommonHealth insurance.

For a list of Autism Support Centers in the Commonwealth, download <http://www.mcpap.com/pdf/PCCScreeningToolkitUpdate04292010.pdf> and see page 73

For a question regarding your patient diagnosed with ASD or your patient with any mental health issue, please feel free to call your [regional MCPAP hub](#).

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