



**Massachusetts Family-to-Family Health Care Information & Education Center**

*A project of Mass Family Voices @ Federation for Children with Special Needs, funded by a 2004 Real Choice Systems Change Grant from the Centers for Medicare and Medicaid Services*

**Topical Conference Call: Tuesday, December 13, 2005**

**Topic:** The Medicaid Autism Waiver Project

**Goal:** To review the legislation about the Massachusetts application for a Medicaid Autism Waiver, learn about Autism Waivers in other states, and hear what's being proposed for Massachusetts.

**Conference Call Summary:**

**Welcome** – Beth Dworetzky, *Mass Family Voices @ Federation for Children with Special Needs*

Mass Family Voices is a state chapter of Family Voices, a national, grassroots organization of families, friends and professional partners who speak on behalf of children and youth with special health care needs. Mass Family Voices is also home of the Massachusetts Family-to-Family Health Care Information and Education Center. The Family-to-Family Center is one of 31 federally funded, parent-run centers throughout the country. Funding is provided through a 2004 Real Choice Systems Change grant from the Centers for Medicare and Medicaid Services. One Family-to-Family Center activity is to offer topical conference calls on subjects of interest to families of children and youth with special health care needs.

Thank you very much for taking the time to participate in today's call about the **Medicaid Autism Waiver Project**. Our presenter is Ann Guay. I'll let her introduce herself and begin the call.

My name is Ann Guay and I am a Volunteer Advocate for Mass Advocates for Children (<http://www.massadvocates.org>). I am the Chair of Government Affairs of Advocates for Autism of Massachusetts (<http://www.arcmass.org/AFAM/>) and serve on the Parent Board of the Autism Support Center, as I am also the parent of a child with autism.

On October 5, 2005, Governor Romney signed the Children's Autism Medicaid Waiver Bill. This bill requires the Executive Office of Health and Human Services (EOHHS) to apply for a Medicaid Home and Community Based Services Waiver for eligible children with autism to receive services.

## What is a Medicaid Waiver? An Overview of the Federal Medicaid Waiver

### Requirements:

Home and Community-Based Services (HCBS) Waivers were established by section 1915 (c) of the Social Security Act. HCBS waivers began in 1981 to encourage alternatives to institutionalization by waiving certain federal Medicaid Requirements to provide community support services to beneficiaries who would otherwise require institutional care. The state receives a 50% reimbursement for the costs of all services under the waiver. States can waive financial eligibility requirements.

HCBS waivers are granted for an initial period of three years and can be renewed at five year intervals. They must be:

1. Provided to individuals who would otherwise require the level of care provided by an institution;
2. Cost neutral (meaning that it cannot cost more for someone to be under the waiver than in an institutional setting).

## Overview of Current Autism Spectrum Disorder (ASD) Waiver Programs

### Wisconsin:

**Administering Agency:** Department of Health and Family Services

**Age Range:** 0-22 years

Ages 0-8:

The children are eligible for intensive face-to-face services for a maximum of 35 hours a week for three years.

Ages 8-22

Child is allocated approximately \$10,000 annually to acquire a variety of services available under the waiver. Services include OT (Occupational Therapy), speech, case management, education supports and respite care.

**Number of Slots Available:** Approximately 1000

**Eligibility:** Children on the Autism Spectrum

**Financial:** Must qualify for Medicaid services or the child can be admitted through the Katie Beckett eligibility determination (the family's income is not used to determine Medicaid eligibility for children with long-term disabilities or complex medical needs that are living with their families).

**Coordination with Education:** Intensive Services must be coordinated with relevant educational services through the public schools.

(2)

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[www.massfamilyvoices.org](http://www.massfamilyvoices.org)

**Provider Qualifications:** The state has established provider qualifications for lead therapists, senior therapists and line staff.

## **Indiana**

**Administering Agency:** Center for Medicare and Medicaid Services and the Bureau of Developmental Disabilities

**Age Range:** 0-22 years

**Number of Slots Available:** Approximately 400

**Eligibility:** Children must have an autism diagnosis. The waiver does not cover children with PDD/NOS (Pervasive Developmental Disorder/Not Otherwise Specified) or Asperger's Syndrome.

**Financial:** The child must be Medicaid eligible. Parents' income is taken into account when determining eligibility.

**Services Provided:** Applied Behavior Analysis, behavior management, community education, respite care, occupational therapy, speech therapy and nutritional counseling

**Provider Qualifications:** The state has established provider qualifications for lead therapists, senior therapists and line staff.

## **Colorado**

**Administering Agency:** Health Care Policy and Finance/Medicaid

**Age Range:** 0-6 years

**Number of Slots Available:** Approximately 75 beginning 1/1/06

**Eligibility:** Children must have an autism diagnosis. The waiver does not cover children with PDD/NOS or Asperger's Syndrome.

**Financial:** The child must be Medicaid eligible. Parents' income is taken into account when determining eligibility.

**Services Provided:** Behavior therapy, occupational therapy, speech therapy and psychological services.

**Caps:** Children are limited to waiver services in the amount of \$25,000 or less each year.

**Provider Qualifications:** The state has established provider qualifications for lead therapists, senior therapists and line staff.

## Maryland

**Administering Agency:** Maryland Department of Education

**Age Range:** 0-21 years

**Number of Slots Available:** Approximately 900

**Eligibility:** Children with an autism spectrum disorder. The waiver does cover children with PDD/NOS and Asperger's Syndrome.

**Financial:** Financial eligibility is based on a child's income. Parental income is not considered.

**Services Provided:** Intensive individual support services including Applied Behavior Analysis, after school and extended day services, service coordination, respite care and family training.

**Caps:** Intensive individual support services are limited to 30 hours a week. Respite care is limited to 168 hours a year. Therapeutic integration is limited to 2-4 hours a day, five days a week

**Provider Qualifications:** All waiver service providers must be approved Medicaid providers and appropriately licensed or certified. The state has established provider qualifications for lead therapists, senior therapists and line staff.

### Initial Issues to be Decided in Massachusetts

Age Range

Financial Eligibility

Services to be covered by the waiver

Service caps

Qualification of Service Providers

**Proposed Next Steps:** A group of interested parties, including providers, advocates, parents and support centers, has met throughout the last year to consider recommendations regarding eligibility, provider qualifications and the range of services to be covered by the new Massachusetts Medicaid Waiver. The group has examined children's autism Medicaid waiver programs in other states and will make recommendations to EOHHS in January 2006. EEOHS must submit its final children's autism Medicaid waiver application to the federal government by April 2006. The waiver application will describe the number of slots and range of services the Commonwealth will offer. Once submitted, the federal government will review the application and determine whether or not to approve the Massachusetts children's autism Medicaid waiver application. The application process can be lengthy, and it is anticipated that it will be some time before children with ASD in Massachusetts will receive services through the autism waiver.

Parents interested in advocacy efforts in support of the new children's autism Medicaid Waiver can contact Attorney Guay at:

Mass Advocates  
(617) 357-8431, ext. 301  
Mguay70046@aol.com

### **Conference Call Questions & Answers**

**1. Who [what agency] will determine a child's eligibility for the Medicaid Autism Waiver?**

The Department of Mental Retardation and its new Division of Autism is taking the lead in developing the waiver application.

**2. For a child to be eligible for the waiver, s/he must be "at risk" for institutionalization. Does that mean right now, or in the foreseeable future?**

It means the child may be at risk for institutionalization right now or down the road.

**3. Has Massachusetts considered having the Department of Education (DOE) the lead agency for waiver determination [as in Maryland]?**

It does not appear as if Massachusetts will adopt the same model as in Maryland.

**4. How and where can families get involved in advocacy around the Medicaid Autism Waiver?**

We need families from throughout the state to be involved in advocacy efforts. Parents interesting in assisting in advocacy efforts in support of the new children's autism Medicaid waiver can contact Ann Guay at Mass Advocates at (617) 357-8431, ext. 301 or [Mguay70046@aol.com](mailto:Mguay70046@aol.com). Another way to get involved is to become a member of Advocates for Autism in Massachusetts (<http://www.arcmass.org/AFAM/>) and be part of advocacy efforts at the Massachusetts State House. It's very important to go to Beacon Hill and meet with your elected officials. It's empowering as well. The Commonwealth has applied for the waiver, but there's no funding for it yet. Remember, your advocacy efforts are not limited to your family. Reach out to friends and extended family members as well and ask them to speak to their Massachusetts state legislators about budget support for the waiver.

**5. How can families stay updated about what's happening with the waiver?**

There's a listserv that provides updates. Send your contact information to [massfv@fcsn.org](mailto:massfv@fcsn.org) and it will be forwarded to me (Ann Guay), and I'll get you connected or contact me directly at the e-mail listed above.

**6. Is Massachusetts proposing a cap on services offered through the waiver, and if so, what will it be?**

This has not yet been determined, although we certainly expect that a cap will be proposed.

**7. How many slots will there be?**

(5)

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[www.massfamilyvoices.org](http://www.massfamilyvoices.org)

This has not yet been determined.

**8. How does this fit with the Autism Division within DMR (the Department of Mental Retardation)?**

The recommendations are being given to the Autism Division.

**9. How long before the waiver is in place?**

This is a many-step process. In April the application will be submitted to Washington D.C. for approval. Massachusetts must also allocate money in the budget. We're hoping it won't be longer than 12 months.

April 11, 2006 is Autism Awareness Day. For more information, visit the AFAM web site at [www.arcmass.org/AFAM](http://www.arcmass.org/AFAM).

**Additional Resources and Supports**

Federation for Children with Special Needs – provides technical assistance with special education issues. <http://www.fcsn.org> or 1-800-331-0688

**Autism Resource Centers**

Asperger's Association of New England  
Phone: 617- 393-3824  
Website: <http://aane.autistics.org>

Autism Alliance of MetroWest  
Serving: MetroWest  
Phone: 508-652-9900  
Website: [www.autismalliance.org](http://www.autismalliance.org)

Autism Resource Center  
Serving: Central Massachusetts  
Phone: 508-595-9101  
Website: [www.arccm.org](http://www.arccm.org)

The Autism Support Center  
Serving: Northeast  
Phone: 978-777-9135  
Website: [www2.shore.net/~nsarc/Home.htm](http://www2.shore.net/~nsarc/Home.htm)

Boston Families for Autism  
Serving: Boston  
Phone: 617-327-9486

Community Autism Resources  
Serving: Southeast  
Phone: 508-379-0371  
Website: [www.community-autism-resources.org](http://www.community-autism-resources.org)

Community Resources for People with Autism  
Serving: Western Massachusetts

(6)

Phone: 413-529-2428  
Website: [www.theassn.org/crautismindex.htm](http://www.theassn.org/crautismindex.htm)

TILL: Autism Support Center  
Serving: Greater Boston  
Phone: 781-302-4600  
Website: [www.tillinc.org/index.htm](http://www.tillinc.org/index.htm)

The Family Autism Center  
Serving: Norfolk County/South West  
Phone: 781-762-4001 x 329  
Website: <http://www.sncarc.org/autism.html>

Advocates for Autism in Massachusetts  
AFAM  
c/o The Arc of Massachusetts  
217 South Street  
Waltham, MA 02453  
<http://www.arcmass.org/AFAM/>

Family TIES (Together In Enhancing Support) a statewide information and support network for families of children with disabilities, special health care needs, or chronic illnesses. 1-800-905-8347 or [www.massfamilyties.org](http://www.massfamilyties.org)

The Concord Special Education Parent Advisory Council at <http://www.concordspedpac.org/>

**YOUR FEEDBACK IS IMPORTANT TO US!**

**If you participated on this call and have not yet returned your conference call evaluation, please do so.**

**If you were unable to participate on this call, but would like to participate in future calls, have ideas for topics you'd like to hear about, or a "speaker" to suggest, please e-mail: [massfv@fcsn.org](mailto:massfv@fcsn.org). Your suggestions are always welcome.**