

Autism Waiver

Study of a Large, Statewide Medicaid Home and Community-Based Services Autism Waiver Program

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Maryland's Home and Community Based Services Waiver for Children with Autism Spectrum Disorder allows eligible children with Autism Spectrum Disorder to receive specific waiver services and certain Medicaid services to support them in their homes and communities.

Findings from research conducted by Towson University show improvement in child/youth progress and increased satisfaction with Family Quality of Life

Maryland's Autism Waiver

- 1915(c)
- Focus on children at greatest risk of requiring an institutional level of care
- Nature and scope
- Partnership between Medicaid agency and education agency
- 14 year relationship
- Regulations COMAR 10.09.36

Overview of Autism Waiver

Medical and Technical Criteria

- ICF-ID.
- Medical and technical eligibility criteria.

Financial Criteria

- Child's monthly income may not exceed 300% of SSI benefits, and the countable assets may not exceed \$2,000 or \$2,500 (depending on eligibility category).

Criteria

- MOU
- Role of Maryland State Department of Education and Maryland Department of Health and Mental Hygiene
- Responsibilities
 - Joint monitoring
 - Waiver renewal
 - Provider recruitment and training
 - Regulations
 - Reportable event tracking
 - Sanctions and recovery
- Intergovernmental transfer capacity

Nature of the Partnership

- Provider community
- Local school systems
- Service coordination within school setting
- Medicaid experience/eligibility determination
- Inter-governmental transfer capacity
- Home and community based thrust
- Parent focused
- Economy/ROI

Advantages of Partnership with Education Agency

- Federal relationship
- Waiver experience
- Linkages with other service areas: developmental disabilities, mental health, EPSDT, ACA
- Coordination across programs
- Financial management of Medicaid
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Advantages of Partnership with Medicaid Agency

- Local school systems
- Community providers – for profit and non-profit
- Residential providers
- Service coordination agencies
- College and universities
- Advocates
- Parents
- Technology vendor

Other Partners

- 1000 current enrollees
- 4000 registry members
- 8 year wait
- July 2007 registrants recently enrolled
- Benefits of enrollment process / challenges
- Eligibility determination and criteria

Enrollment

- Intensive Individual Support Services
- Therapeutic Integration – Regular
- Therapeutic Integration – Intensive
- Adult Life Planning
- Respite Care
- Environmental Accessibility Adaptations
- Family Consultation
- Residential Habilitation
- Medical Services

Service Delivery – Therapeutic

- Defining risk of institutional care
- Determining when a child can no longer be cared for in the home and community
- Options for care for children requiring mental health services
- Application of technology for tracking
- Evaluating impact

Challenges - Overall

Towson University in collaboration with the Maryland State Department of Education have engaged in research related to impact of the Maryland's Autism Waiver on children/youth and families.

Since 2008, three Autism Services and Supports surveys have been conducted by Towson University to measure family quality of life (FQoL) and child progress for families who have children on the waiver or registry (a list for children interested in applying for the waiver as slots become available).

Maryland's Autism Waiver

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Survey Response Rates

Year		Total Families Surveyed	Total Responses	Response Rate
2008	Waiver	723	229	31.7%
	Registry	2298	632	27.5%
	Total	3021	869*	28.8%
2011	Waiver	783	292	37.3%
	Registry	1291	342	26.5%
	Total	2074	647 ⁺	31.2%
2014	Waiver	980	303	30.9%
	Registry	1440	451	31.3%
	Total	2420	754	31.2%

* Includes 8 disenrolled

⁺ Includes 13 unknown if waiver or registry

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Significant Findings

1. There is a positive correlation between families who receive autism waiver services and reported FQoL.
 - Waiver recipients reported significantly higher overall family quality of life satisfaction than those on the registry;
On 5 point scale, waiver mean = 3.91 vs. registry = 3.56
2. There is a positive correlation between receiving autism waiver services and improved social and independent living skills.
 - Over the 12 month period prior to completing the survey, 51.5% of waiver recipients reported improved social progress compared to 45.3% of those on the registry; 53.3% of waiver recipients reported improved independent living skills compared to 47.2% of those on the registry.
3. Waiver recipients reported significantly higher service adequacy ratings.

2008 Survey Results

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Significant Findings

1. There is a positive correlation between families who receive autism waiver services and reported FQoL.
 - Waiver recipients reported significantly higher satisfaction with overall family quality of life.
On 5 point scale, Waiver mean = 4.04 vs. Registry = 3.74
2. A longer time on the waiver is positively correlated with higher satisfaction with overall FQoL.
3. Over 80% of all respondents indicated that their child either stayed the same or showed improvement in the areas of academic performance, independent living skills, ability to communicate, relationships with peers, and behavior. The most progress was reported in academic performance and independent living skills.

2011 Survey Results

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State Medicaid directors in 49 states (Arizona was excluded) and District of Columbia were asked to complete a survey on facilitators and barriers to adoption of autism specific 1915(c) waiver. Responses received = **42**; Response rate = **84%**

Responses Received

State has an autism specific 1915(c) waiver (n=10)	State would like an autism specific 1915(c) waiver (n=7)	State reported other 1915(c) waiver as autism specific (n=4)	State reported no perceived need for an autism specific waiver (n=21)
Arkansas	Hawaii	Maine	Alaska
Colorado	Mississippi	Ohio	Alabama
Connecticut	New Mexico	Virginia	California
Kansas	Nevada	Washington	District of Columbia
Massachusetts	Oklahoma		Florida
Maryland	Tennessee		Georgia
Missouri	Texas		Iowa
Montana			Idaho
South Carolina			Indiana
Utah			Kentucky
			Louisiana
			Michigan
			Minnesota
			New Hampshire
			North Carolina
			Pennsylvania
			South Dakota
			Vermont
			Wisconsin
			West Virginia
			Wyoming

Perceived Facilitators to State Adoption of an Autism Specific 1915(c) Waiver

- States with an autism specific 1915(c) waiver:
 - ☐ Support from state legislature
 - ☐ Advocacy efforts
 - ☐ Family support
 - ☐ State agency support
- States that would like an autism specific 1915(c) waiver:
 - ☐ Support from state legislature
 - ☐ State agency support
 - ☐ Support from governor

Perceived Barriers to State Adoption of an Autism Specific 1915(c) Waiver

- States with no reported perceived need for an autism specific waiver:
 - ☐ Children and youth with ASD are served well enough under other waivers
 - ☐ Insufficient funding available
- States that would like an autism specific 1915(c) waiver:
 - ☐ Insufficient funding available
 - ☐ Lack of trained/certified providers

2014 Survey Results – State Study

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Summer 2014 conducted 49 Interviews

- 21 families with child on waiver and 28 families with child on registry
- Age range 5 -21
- Interviewers
 - Comprehensive training
 - Seven – Professionals, graduate students, and post-MS students
 - OT, Child Life, Social Work, Clinical Psychology

2014 Interviews

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Content Analysis

- Transitions Across the Life Span
- Family as Case Manager
- Problem Solving and Decision Making
- Advocacy Attitude
- Resource Identification and Utilization (including services and professional partnerships)
- Stress and Coping ...resilience, resourcefulness, passion, investigative skills, persistence
- Waiver Service Utilization and Perceived Impact
- Advice for Other Families

2014 Interview Outcomes

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- Child Progress...waiver vs. registry status was significantly associated with child progress over the reported 6 months in the area of independent living skills. Parent reported more progress in independent living skills
- Use of other services...compared to registry families, parents receiving waiver services were
 - 1.78 times more likely to use transportation services
 - 1.94 times less likely to use increased speech therapy
 - 1.22 less likely to use increased other childcare services
 - 2.28 times more likely to have higher frequency of special dieting

2014 Survey – Preliminary Results

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- Family Quality of Life...waiver families reported a significantly higher FQoL compared to registry families
 - Family Interaction Satisfaction was significantly higher for waiver families
 - Parenting Satisfaction was significantly higher for waiver families
 - Emotional Well-Being was significantly higher for waiver families
 - Disability-Related Support was significantly higher for waiver families
 - Physical/Material Wellbeing Satisfaction was not found to be higher for waiver families

2014 Survey – Preliminary Results

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- Employment

- Trend but not significant registry families were 1.5 times more likely to report...
 - “The needs of my child with autism prevent me from working as much as I would like to work”
 - This suggests that families on the registry were 1.5 times more likely to report that needs of their child with autism interfered with employment
- Waiver families only...How have waiver services affected [respondent’s] employment status or the employment of others in the household
 - Results indicated that waiver services were seen as having a positive impact on employment

2014 Survey – Preliminary Results

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- Service documentation
- Credentialing of technicians/supervisors
- Mental health services
- Parental choice for more restrictive placement
- Implications of HCBS Final Rule on center based services(residential habilitation and therapeutic integration)
- Safety of children and technicians
- Medical emergencies

Program Challenges

- Automating compliance monitoring
- On-line POC and treatment plans
- 1915(i) specific to younger children
- Parent portal for monitoring progress
- Additional waiver slots
- Screening of children on registry
- Integrated data systems across agencies

Future Plans

- Clear and defined roles
- Flexibility
- Understanding of respective state regulations, policies and culture
- Partnerships: advocates, universities/researchers, sister agencies
- Focus on target population and not a solution for all needs

Best Practices and Questions