

Getting an Autism Spectrum Disorder Diagnosis: Where Do I Go from Here?

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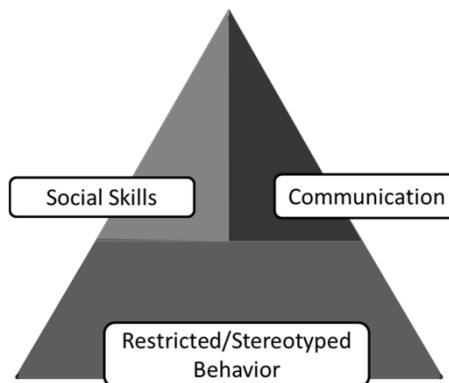
Updated 4/16/18



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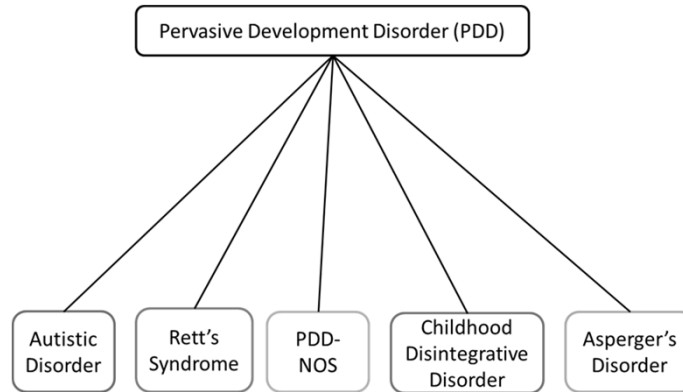
Affected Areas in Autism in DSM IV (Used before May 2013)



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DSM-IV Diagnoses (Used before May 2013)



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Affected Areas in Autism in DSM V (In Use Since May 2013)

Autism Spectrum Disorder (ASD)



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Severity Levels (Specifiers)

- Level 1: “Requiring support”
- Level 2: “Requiring substantial support”
- Level 3: “Requiring very substantial support”



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Social Communication Disorder in DSM V (In use as of May 2013)

Social Communication Disorder

Social and Communication

**Rule Out Restricted/Repetitive
Behaviors**











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Other Affected Areas to Consider with an ASD Diagnosis

-  Attention/Impulsivity/Hyperactivity
-  Speech and Language Delay
-  Motor Delay (fine and gross motor)
-  Sensory Integration Disorder
-  Emotional Disorder (Anxiety, Depression)
-  Executive Functioning
-  Autoimmune/Health Issues
-  Habits/Environmental Factors



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Autism Waiver

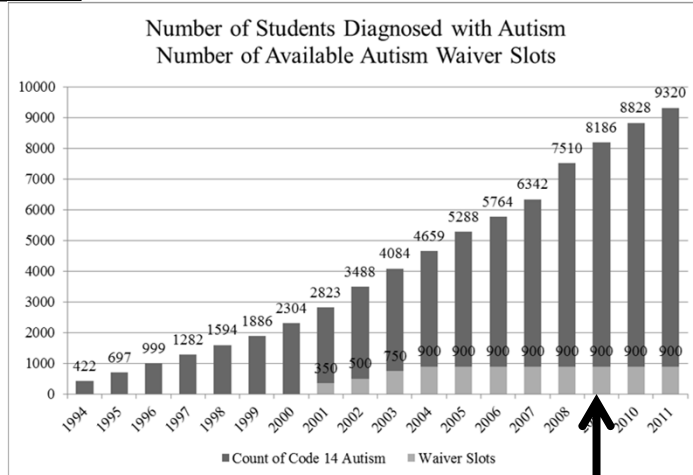
- Families must get on Registry by calling Autism Waiver Services Intake: #1-866-417-3480 to give demographic information
 - Child is then assigned a number on a wait list
 - 1100 children now have this Waiver, up from 900 children, but very long waiting list since one child gets dis-enrolled before another child is added
 - Waves family income, but children must be financially eligible, have diagnosis of autism/PDD, meet level of care criteria, and have at least 12 hours of special education and related services
 - Services--Medical Assistance, respite care, family training, in-home supports, therapeutic integration, environmental modifications, etc.



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Autism Waiver: Available Slots



Source: SSI Count of Code 14, MSDE Count of Waiver Slots



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Other Financial Options

- Federal--**Supplemental Security Income (SSI)** and State adds Medical Assistance, eligibility has income limits and disability diagnosis necessary to apply, Start Childhood Disability online
- State--**Maryland Children's Health Insurance Program (MCHIP):** Medical Assistance coverage without or with a monthly premium depending on income. # 1-800-456-8900
- State and some local health departments—**Children and Youth with Special Health Care Needs:** #1-800-638-8864
- Private Grant--**Jill Fox Memorial Fund**---application for small funds to be completed by staff at KKI CARD



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DDA: Developmental Disabilities Administration

Maryland Health Department program for developmentally disabled persons, services for some children but mostly for adult services.

- Apply any time when you get the diagnosis of ASD and eligibility will be determined and priority will be established
- How to Apply:
<http://dda.health.maryland.gov/SitePages/howtoapply.aspx>
 - Send copies of evaluations attached to application, consider attaching a personal cover letter stating seriousness of needs
 - Complete online or send back via mail
- Send Application to:
 - Central Region: 410-234-8200
 - Western Region: 310-791-4670
 - Southern Region: 301-362-5100
 - Eastern Region: 410-334-6920



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DDA Home and Community Based (HCBS) Waivers Overview

DDA has new waivers that will provide service to 800 people on the DDA's waiting list:

- DDA Capped Supports Waivers:
 - **Family Supports Waiver**—children birth to 21 have Support Services up to \$12,000 annually
 - **Community Supports Waiver**—children and adults will have Meaningful Day and Support Services up to \$25,000 annually
- DDA Comprehensive Waiver:
 - **Community Pathways Waiver**—children and adults will have Meaningful Day, Support and Residential Services



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Low Intensity Support Services (LISS)

- **LISS funds must be applied for timely**, are DDA funded
- New changes may occur but currently two rounds/fiscal year and funds are up to \$2,000 per year. First step is the Random Selection Application, then if selected the completed application.
- This year LISS Random Selection Application can be sent now. One page form is located on DDA website:
<http://dda.health.maryland.gov/SitePages/liss.aspx>
- Providers assigned in the four DDA regions:
 - Central--Penn-Mar: 1-877-282-8202
 - Southern--MD Community Connection: 301-583-8880
 - Western--Penn-Mar:1-877-282-8202
 - Eastern--United Needs and Abilities: 1-800-776-5694



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Behavioral Support Services

- DDA funds limited **Behavioral Support Services** by region:
 - WEST: ARC of Washington County
 - SOUTH: ARC of Southern Maryland;
 - CENTRAL: Humanim, Inc.
 - EAST: Somerset Community Services, Inc.
- **KKI Behavior Psychology**: 443-923-7500
 - PDD Clinic – for developmental and disruptive behaviors
 - NBU Clinic –more intensive behavioral needs in either in-patient or out-patient setting
- **Therapeutic Behavioral Support (TBS) and Psychiatric Rehabilitation Program (PRP)**: funded by Medical Assistance only, In-home services, must be clinically necessary
- **Applied Behavior Analysis (ABA)**: funded by Medical Assistance and various private insurances, must be medically necessary



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Respite Care

- Autism Waiver families have licensed respite providers and camp
- Other DDA waivers and LISS funds can be used for blocks of respite care and summer camps (funds extended until August 30 for camp)
- Private grant for respite care through the Jill Fox Fund-- see KKI CARD social worker for these funds
- Some of the ARCs has respite care funds with application

** *good way to take care of yourself and your child*



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Educational Resources

- **Parents Place of Maryland:** #410-768-9100 (free consultation by phone only)
- Autism educational consultants/advocates:
 - See Pathfinders for Autism web site, listed under Advocacy and Legal, look for Educational Advocate or Special Education Attorney
 - costs range in price per hour
 - They can observe class, write reports, assist with IEP meeting, assist with mediation/ due process
- **Project Heal** at Kennedy Krieger Institute, legal services on sliding fee scale #443-923-4416
- **Disability Rights Maryland** (DRM was formerly MDLC) offers free legal services or helps to find a pro-bono attorney
 - See their publication “*Special Education Rights and Wrongs*”
- Homeschooling networks



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Parent/Sibling Support Groups

Check Pathfinders for Autism website under Support Groups

- **Autism Society of America (ASA):1-800-3AUTISM**
- **Local ASA Chapters:** Baltimore-Chesapeake (Baltimore City & Baltimore County) , FOCAS (Carroll County), Calvert, Southern Maryland; Eastern Shore, Queen Anne's, Frederick, Northern Chesapeake SNAG (Harford County); Howard, Montgomery, Prince Georges, Washington
Anne Arundel Chapter replaced with R.I.S.E.
- **Maryland Asperger Syndrome Support Groups/ASPEN**
- **Sibshops:** groups for siblings of children who are disabled
- **Adult Autism Resource Group (AARG)**
- **BARC, Loyal Clinical Centers, other informal parent groups exist in schools and on Facebook**



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Kennedy Krieger Institute (KKI) Resources

- Therapists-KKI/CARD: Speech and Language Pathology, Assistive Technology, Occupational Therapy, Psychology, Neuropsychology, Developmental Pediatrics; Neurology, Psychiatry, Nursing, Genetic Counseling, Clinical Social Work, Social Skills Groups, Research (REACH)
- Other KKI Departments: Behavioral Psychology, Assistive Technology, Nutrition, Audiology; Sleep Clinic, Feeding Clinic, NBU, Social Skills Groups, Psychiatry, Neurology, etc.
- KKI CFSP: Home-based Speech, OT, and Clinical Social Work
- Resource Finder: (800) 390-3372
[-ResourceFinder@ kennedykrieger.org](mailto:ResourceFinder@kennedykrieger.org)



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Information and Referral Resources

Pathfinders for Autism Resource Center

Walk in appointments; phone #: 1-866-806-8400

www.pathfindersforautism.org

Developmental Disabilities Administration (DDA):

<http://dda.health.maryland.gov/SitePages/services.aspx>

Autism Speaks Resource Guide

<https://www.autismspeaks.org/family-services/resource-guide>



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Thank you!

Please review our resource listing of services in your packet and ask for help if questions. Autism is a journey you should not take alone.

Please fill out and return your survey as you leave. Your suggestions are valued.

Thank you for coming!



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