

**Western Maryland – Setting Priorities for Children and Youth with Autism (ASD)
and other Developmental Disabilities (DD)**

MEETING SUMMARY

[The Maryland Office for Genetics and Children with Special Health Care Needs](#) and [The Parents' Place of Maryland](#) convened a group of stakeholders including parents; local pediatricians, local Health Department representatives, local special education school staff; community and family service group representatives, and support and advocacy group and agency representatives for a day-long learning and strategic planning session. Group learning and activities led participants to agree on what the top priorities for children and youth with autism and other developmental disabilities in Western Maryland are and to develop goals and actions steps to address those priorities. Participants used a [data presentation](#) and [handout](#) which synthesized regional and state data from various sources to inform the prioritization process.

The top priorities that must be addressed to improve the system of care for children and youth with autism and other developmental disabilities and their families in Western Maryland are:

- Access to needed therapies (ABA/Behavioral, Speech/language, occupational, and physical)
 - Diagnosis and referral
- Needed services are community-based and easy to use
 - Child care and respite care
 - Transportation
- Adequate Insurance and Financing
- Training for School and Child Care Personnel

- Mental Health Treatment and Services
 - Diagnosis and Referral

The next pages provide a summary of goals and action steps that participants, working in small groups, developed to address each priority. These priorities, goals, and action steps will be incorporated into a state plan to improve the system of services for Maryland children and youth with special health care needs. These planning activities are funded through a federal grant. More information about the project and the grant can be found at http://www.marylandcoc.com/ASD_DD_Planning_Grant.html.

Priority 1: Access to Care – Needed Therapies, Primary and Specialty Care, Mental Health, Developmental Screening and Diagnostic Services

Goal 1: More “informed” therapy providers (“informed” meaning knowledge for age appropriate activities, disability specific strategies to provide a diagnosis)

Action 1: Development of a diagnostic team (physician, developmental pediatric doctor, neuro-psychologist, speech/language pathologist, LP, occupational therapist, physical therapist, audiologist, assistive technologist, vision therapist, nutritionist, social worker, behavioral specialist, educator not in a district dictated by age and disability of an individual).

Strengths	1 – the league 2 – children’s med. group
Weaknesses	1 – limited number of specialized providers with background in ASD and DD 2 - insurance
Opportunities	1 – partnering with colleges to develop resources, training
Threats	1 - funding 2 – qualified staff and keeping staff

Goal 2: More “informed” therapy providers to provide an ongoing therapy/ treatment.

Action 1: Develop a regional center to encompass all therapy diagnosis and treatment.

Strengths	1 – one stop
Weaknesses	1 – funding 2 - recruiting
Opportunities	1 – lots of new partnerships
Threats	1 - coordination

Priority 2: Community-based and easy-to-access services (to include child care and transportation.)

Goal 1: “One stop shop”; one application that determines eligibilities; web-based; (mimic Hagerstown Commission on Aging)

Action 1 Create an inclusive intake form; know your resources

Strengths	1 - accessibility 2 - less frustration 3 - more efficient 4 - cost effective 5 - less transportation issues
Weaknesses	1 - funding to support new people coming into the system 2 - people may not want information spread to several different agencies
Opportunities	1 - people would be able to find out what they are actually eligible for 2 - receive services they really need
Threats	1 - agencies not able to meet needs 2 - regulations 3 - agencies not willing 4 - funding carve-outs

Goal2 Create (childcare? Resource?) centers and in-home/out-of-home respite care that serve children/youth with special needs

Action 2 Hire trainers and additional staff; expand upon what already exists; train all care providers

Strengths	1 - families get support they need 2 - receiving skilled care 3 - safe/ protected from neglect
Weaknesses	1 -funding 2 - reluctance from providers
Opportunities	1 - more time for life 2 - exposed to other learning environment
Threats	1 - quality of caregiver/ employee 2 - reluctance to having people in home

Goal 3 Provide a community center for centralized team approach for medical and specialty care - medical, OT, PT, SLP (multidisciplinary team approach)

Action 3 Training staff for direct care; identify a location; develop a relationship between specialists and local professional providers

Strengths	1 - possible location 2 - access to students/ medical residents, Western MD AHEC (area health education center), RN, PTA, COTA (?) , mental health
Weaknesses	1 - funding 2 - lack of trained providers 3 - lack of transportation 4 - lack of knowledge of local services available by parents, healthcare providers and educators
Opportunities	1 - training sites available 2 - collaboration between agencies - schools, health departments, community

Western Maryland- Christ Lutheran Church, Lavale, MD

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	center team, provider of services
Threats	1 - retaining providers for the long term 2 - insurance 3 - possible inability to services

Action4

A resource navigator (person) to community services (INCOMPLETE)

Strengths
Weaknesses
Opportunities
Threats 1 - budget 2 - transportation 3 - getting results back

Priority 3: Adequate Insurance and Financing

Goal 1 Engage insurance companies to understand the need and importance of mental health services

Action 1 Recruiting; letter writing campaigns; family stories that show the need. Target insurance companies that already encompass mental health. What are the insurance providers in this area identify and target?

Strengths	1 - strong community 2 - a lot of families willing 3 - good data to show the need
Weaknesses	1 - less visibility and knowledge of issue 2 - How to get the willing families to participate 3 - economy
Opportunities	1 -social media 2 - Parents Place (Debbie) 3 - Web access to share parent stories
	4 - get local radio and media to donate time
Threats	1 - getting people to participate 2 - funding

Action 2 To educate providers and professionals about how to navigate decoding and proper billing to maximize reimbursements

Strengths	1 - less error in billing
Weaknesses	1 - coding and billing is confusing and frustrating
Opportunities	1 - forum or conference 2 - Frostburg State and AC could educate on these issues
Threats	1 - insurance companies may not want to share or educate the community on billing practices
	2 - concern about anti-trust issues may make providers unwilling to participate

Priority 4: Training for school and child care personnel

Goal 1 Resource Team comprised of Speech Therapist, Occupational Therapist, Behavioral Therapist (ABA?) and other trained teachers (current on Autism Strategies)

Action 1 Team available for consultation and follow-up; Team needs access to Experts for Consultation; Staff development of all staff on disability issues

Strengths	1 - Garrett county has a team that is currently working
Weaknesses	1 - Allegany county has one individual
Opportunities	1 - Jefferson school experts
Threats	1 - budget/ money

Goal 2 Childcare - awareness of children with disability needs; incentive to become trained and access support team

Action 2 Team available for consultation and follow-up; Team needs access to Experts for Consultation; Staff development of all staff on disability issues

Strengths	1 - Childcare Provider Association 2 - Programs that fund lunch programs could be used to provided stipend (?)
Weaknesses	1 - Willingness to participate
Opportunities	1 - Apples 2 - Headstart
Threats	1 - Funding to provide incentives

Priority 5: Mental Health Treatment and Services (including Diagnosis and Referral)

Goal 1 **Child Psychiatrists; private and public insurance for all counties; correct diagnoses; family therapy, behavior modification, psychodynamic - must be experienced; Teach parent advocacy.**

Action 1 Awareness of program/ resources - all counties. Through Primary care PA, school - all counties - Garrett needs school nurse and child psychiatrist to work hand in hand; Respite care to mental health of child and family

Strengths	1 - health department. All infants and toddlers - for Allegany and Washington. Not Garrett
Weaknesses	1 - transportation 2 - money 3 - no child psychiatrist (Garrett - must have over 90 min.) dependable services for infants and toddlers
Opportunities	1 - Link video conference to access child psychiatrist in other counties 2 - Garrett county needs child psychiatrists, all therapy or close access
Threats	1 - Lack of parent compliance - all counties 2 - lack of school to cooperate developing IEP - all counties 3 - lack of funding - all counties 4 - Garrett, Allegany are travelling to Washington for service - overloading 5 - long waiting lists - children waiting too long

Action 2 Respite Care. Funding. Web training, volunteers, support groups

SWOT:	Incomplete
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