

**Southern 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 Health Department, Infants and Toddlers Program and school staff; and community and family service, support and advocacy groups and agencies for a day-long learning and strategic planning session. Group learning and activities led participant to agree on what the top priorities for children and youth with autism and other developmental disabilities in Southern 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 Southern Maryland are:

- Access to Care –
 - Needed therapies
 - Primary and specialty care
 - Mental health
 - Developmental screening and diagnostic services
- Training for school and child care personnel
- Easy-to-use community-based services/central care coordination through a regional center (“assisted point of entry”)
- Adequate insurance coverage, reimbursement, and financing
- Family support and advocacy

The next page provides 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: Access to Care – Needed Therapies, Primary and Specialty Care, Mental Health, Developmental Screening and Diagnostic Services

Goal 1: To provide access of trained professionals in all above areas within each county of Southern Maryland (Calvert, Charles, and St. Mary's)

Action 1: Establish incentive program to encourage & maintain professionals to practice in Southern Maryland.

Strengths	1 - space available 2 - client availability 3 - established & continually growing luxuries
Weaknesses	1 - lower salaries & reimbursement rates 2 - enough trained professionals to fill all areas
Opportunities	1 - some existing services to expand 2 - education & continued education offered in these fields in Southern Maryland.
Threats	1 - insurance & reimbursement acceptance 2 - funding & incentives to maintain staff 3 - collaboration vs. competition

Action 2: Locate existing programs that can expand into tricounty program

Strengths	1 - have some exiting programs
Weaknesses	1 - public awareness
Opportunities	1 - equate services in each county
Threats	1 - territorial 2 - staff each area appropriately

Encourage collaboration between educational institutions in Southern Maryland to offer a broader range of academic degrees &

Action 3: further education

Strengths	1 - partnerships 2 - educational Insitutions exist
Weaknesses	1 - having the educational staff & professors available to teach
Opportunities	1 - get degree in local area
Threats	1 - money 2 - competition

Priority: Training for school personnel and childcare personnel

Goal 1: For teachers and childcare personnel to have an increased understanding, skills base, and tools to meet the unique needs of CYSHCN

Action 1: **Reach out to school systems and childcare facilities to form partnerships for staff development**

Strengths	
Weaknesses	1 - resistance of school systems to outside "interference"
Opportunities	1 - broaden and expand pool of knowledge, resources, participants
Threats	1 - "don't tell us how to do our jobs" 2 - legal liability issues or concerns

Action 2: **Organize and coordinate efforts to encourage widespread participation in training**

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Action 3: **Provide or obtain appropriate curriculum and trainers to conduct training**

Strengths	1 - ensure appropriate content
Weaknesses	
Opportunities	1 - explore current training models
Threats	1 - "don't tell us how to do our jobs"

Goal 2: To train educators and childcare providers to recognize individuals with ASD & DD and to be able to respond appropriately to the individual needs and modifications

Collaborate with existing Md (Maryland?) credential (or conditional?) to utilize the existing training model (and modifying if necessary) to train & sustain childcare providers

Action 1:

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Collaborate with MSDE to modify curriculum changes to educate all teachers in ASD and DD in accordance with the changing trends & inclusive education

Action 2:

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Priority: Easy-to-Use Community-Based Services / Central Care Coordination through a regional center (“assisted point of entry”)

Goal 1: Enhance the knowledge and skills of practicing professionals

Action 1: Identify stakeholders/professionals who are providing community based services and provide service marketing

Strengths	1 - system of care with community-based services available (already in place)
Weaknesses	1 - no educated marketing in place 2 - communication
Opportunities	1 - family/systems navigation providers 2 - wraparound services
Threats	1 - budget cuts 2 - limited staffing

Action 2: Enhance services already in place

Strengths	1 - parent groups 2 - LAM 3 - Networking
Weaknesses	1 - getting the buy-in from the professional community (doctors, therapists, care providers)
Opportunities	1 - education piece 2 - building on case management already in place
Threats	1 - budget cuts 2 - limited staffing

Goal 2: Attracting new services to the community

Action 1: Identify available resources to fill service gaps.

Strengths	1 - Large talent pool. (a lot of agencies doing the same things)
Weaknesses	1 - not knowing the agencies that provide the service 2 - not working together
Opportunities	1 - building new community partners 2 - networking
Threats	1 - budget issues 2 - transportation

Action 2: Provide the data to support the need within community

Strengths	1 - strengthen the cause. Providing critical info
Weaknesses	1 - time management to gather information 2 - finding individuals knowledgeable to present information
Opportunities	1 - building new partnerships 2 - developing a valuable database
Threats	1 - budget 2 - transportation 3 - getting results back

Priority: Adequate Insurance, Coverage, and Financing

Goal 1: Decrease the financial burden on families of children with special needs

Action 1: Establish a catastrophic fund for families of children with special health care needs using a sliding scale (use New Jersey's catastrophic fund as a model)

Strengths	1 - there are working models 2 - help families
Weaknesses	1 - legislative push back because it would be an increase in taxes
Opportunities	1 - grow fund to help reduce the financial burden on families
Threats	1 - tax

Action 2: Disseminate information to families & community providers about insurance coverage expectations in Maryland.

Strengths	1 - empowering people 2 - informed constituents
Weaknesses	1 - variability in requirements of coverage
Opportunities	1 - decrease burden on the state
Threats	1 - insurance company lobbyists

Action 3: Compile the information & prepare consumer-friendly references

Strengths	1 - empowering people 2 - informed constituents
Weaknesses	1 - variability in requirements of coverage
Opportunities	1 - decrease burden in the state 2 - improve services to children
Threats	1 - having correct & accessible data

Goal 2: Improve reimbursement rates for healthcare providers practicing in Southern Maryland and rural communities

Action 1: Educating the legislators & regulatory agency (HSCRC) on the costs incurred by families with children with special health care needs & the effects of lower reimbursement rates on the availability of service providers

Strengths	1 - data is already collected
Weaknesses	1 - we are not considered a stakeholder right now 2 - information must be presented in an interesting way
	1 - create a partnership between legislators & regulatory community

Opportunities	
Threats	1 - since we are not already there they can say "no"

Action 2: Include families of CSHCN on decision-making bodies charged with determining levels of mandatory coverage of CSHCN

Strengths	1 - families give first hand knowledge to people who make decisions
Weaknesses	1 - traditionally no stakeholder input
Opportunities	1 - have an impact on the level of services
Threats	1 - since it is a closed community. They can say "no."

Priority: Family Support & Advocacy

Goal 1: Elevate the visibility of the single point of information in each county, i.e. every family should know where to go and who they can talk to for information and support regarding their child's condition(s).

Infant & Toddlers, 504, and IEP chairpersons will include pamphlet with information from single point of access in their county &

Action 1: explain to parents

Strengths	1 - entity exists 2 - pamphlets exist 3 - families need it 4 - long term benefit for schools
Weaknesses	1 - different names & funding sources 2 - changing entity 3 - info not up to date 4 - personnel turnover 5 - short staff 6 - funding cuts 7 - lack of program awareness
Opportunities	1 - creating advocacy channel for parents 2 - improve child wellness 3 - reduce parent frustration
Threats	1 - buy - in from school personnel & won't promote 2 - fear from school personnel of information

Action 2 : Provide orientation & updated information at beginning of school year to ALL school staff (Include testimonial from parent/child who benefited.) Special education director would coordinate this and disseminate. Administrators, guidance counselors, IEP and 504 chairpersons should receive this information, especially.

Strengths	1 - gives info to many more people 2 - updated information including changes
Weaknesses	1 - info given only annually 2 - getting everyone together 3 - lack of funds/changing funds
Opportunities	1 - fewer frustrated parents & staff
Threats	1 - school staff not paying attention

Action 3 Provide information to handout at doctor's offices

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Southern Maryland Higher Education Center
March 29, 2012 8:30 am – 3:00 pm