

**Eastern Shore 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 and family members; local pediatricians, local Health Department representatives, local special education school staff; other government representatives; 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 on the Eastern Shore of 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 on the Eastern Shore of Maryland are:

- Access to needed therapies (ABA/Behavioral, Speech/language, occupational, and physical)
  - Diagnosis and referral
- Access to primary and specialty care (including developmental screening and diagnostic services)
- Needed services are community-based and easy to use
  - Child care and respite care
  - Transportation
- Mental Health Treatment and Services
  - Diagnosis and Referral
- Adequate Health Insurance and Financing

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](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: Bring more therapists to the Eastern Shore.**

Action 1: Find a local provider who would provide space for a therapist to use weekly.

<b>Strengths</b>	<b>1</b> – committed individuals <b>2</b> – advocates who will refer to them <b>3</b> -large client base <b>4</b> - vacant spaces available
<b>Weaknesses</b>	<b>1</b> - insurance <b>2</b> –overhead cost for space
<b>Opportunities</b>	<b>1</b> – use residents from hospitals or volunteer doctors <b>2</b> - cohorts from colleges to provide education
<b>Threats</b>	<b>1</b> – no show rate of MA clients <b>2</b> – provider burnout <b>3</b> -personnel to locate providers <b>4</b> - lack of funding

Action 2: Provide education on insurance types and how to sign up for the different providers.

<b>Strengths</b>	<b>1</b> – ombudsman for insurance will provide education <b>2</b> - private insurance that pays more
<b>Weaknesses</b>	<b>1</b> – paperwork/payment return <b>2</b> – inaccurate information regarding insurance <b>3</b> - no show clients
<b>Opportunities</b>	<b>1</b> – Start own business <b>2</b> - MCO will provide education to the offices
<b>Threats</b>	<b>1</b> – no providers to work with

Action 3: Partner with universities and colleges to enrich program availability.

<b>Strengths</b>	<b>1</b> – many large universities within the state and neighboring states
<b>Weaknesses</b>	<b>1</b> – takes time to develop program <b>1</b> – show how Eastern Shore can benefit providers <b>2</b> - find out how other health providers market to their recruits
<b>Opportunities</b>	<b>3</b> -make a plan for marketing
<b>Threats</b>	<b>1</b> – salary capability <b>2</b> - cost of living

**Priority 2: Access to primary and specialty care (including developmental screening and diagnostic services)**

**Goal 1: Services are available to those who need them in close proximity to their homes.**

Action 1 Recruit additional primary care physicians and specialty providers to the Eastern Shore.

<b>Strengths</b>	<b>1</b> – AHEC has loan repayment program for providers <b>2</b> – laid back lifestyle <b>3</b> – opportunities to build practices quickly
<b>Weaknesses</b>	<b>1</b> – more demanding; on call more often <b>2</b> – overloaded practices <b>3</b> - lack of resources to refer families to <b>4</b> - lower salary
<b>Opportunities</b>	<b>1</b> – build residency program on Eastern Shore <b>2</b> – AHEC is attracting providers originally from the Shore to practice on the Shore <b>3</b> - talk to kids about healthcare shortages
<b>Threats</b>	<b>1</b> – inadequate insurance reimbursements <b>2</b> – concierge care pays high amounts to providers for contracted healthcare

Action 2 Use telemedicine.

<b>Strengths</b>	<b>1</b> – helps improve access to care <b>2</b> – local health department can be a site and help with transportation <b>3</b> – quicker access to appointments
<b>Weaknesses</b>	<b>1</b> –no interpersonal relationships/continuity of care is interrupted <b>2</b> – hinders physical exams <b>3</b> - need highly skilled nurses
<b>Opportunities</b>	<b>1</b> connect with specialty care <b>2</b> – bridges gap while waiting for new providers to establish on E. Shore <b>3</b> - allows providers to increase patient capacity
<b>Threats</b>	<b>1</b> – insurance would rather pay nurse practitioner than doctor <b>2</b> – cross training other providers to use it <b>3</b> – grant funded and will need money to continue

Action 3 Make navigating the insurance process easier.

<b>Strengths</b>	<b>1</b> – some people are getting services <b>2</b> - healthcare reform
<b>Weaknesses</b>	<b>1</b> – dictate the care <b>2</b> – children denied specialty services <b>3</b> – families don't know how to advocate for the care their

*Eastern Shore Maryland- St. Mark's United Methodist Church, Easton, MD*  
*June 12, 2012 8:30 am – 3:00 pm*

	children need
<b>Opportunities</b>	<b>1</b> – family navigators to support families <b>2</b> expose on flaws of the system <b>3</b> - outreach opportunities for advocacy, center team, provider of services
<b>Threats</b>	<b>1</b> – the economy

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**Priority 3: Community-based, easy-to-use services**

**Goal 1 Use technology to increase service availability in the region.**

Action 1

Educate families on ways to find resources and support groups on the internet.

<b>Strengths</b>	<b>1</b> – technology is available and easy to use
<b>Weaknesses</b>	<b>1</b> – money/funds <b>2</b> – some families are not comfortable with technology
<b>Opportunities</b>	<b>1</b> – open up public facilities like libraries and schools for families to use internet <b>2</b> – encourage providers to interact through email and texting <b>3</b> – make apps and other resources available to the general population
<b>Threats</b>	<b>1</b> – discomfort with internet <b>2</b> - trying to be flexible and safe with technology

Action 2 Educate providers about treating children with ASD and DD.

<b>Strengths</b>	<b>1</b> – cultural competence <b>2</b> - more aware of the children they treat
<b>Weaknesses</b>	<b>1</b> – doctors don't stay longer than two years
<b>Opportunities</b>	<b>1</b> – encourage providers to be open to learning
<b>Threats</b>	<b>(none listed)</b>

**Goal 2 Improve transportation services.**

Action 1

Find and use health department vehicle to transport individuals to services.

<b>Strengths</b>	<b>1</b> – vehicles already exist and are not being used
<b>Weaknesses</b>	<b>1</b> – funding <b>2</b> - identifying drivers <b>3</b> - indentifying someone to organize its use
<b>Opportunities</b>	<b>1</b> – more streamlined use of services/resources
<b>Threats</b>	<b>1</b> – liability <b>2</b> - organization of the program <b>3</b> - different counties have different rules and procedures

Action 2

Find an approach to reimburse families for traveling to services out of town.

<b>Strengths</b>	<b>1</b> – relieve stress on families
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<b>Weaknesses</b>	<b>1</b> – funding <b>2</b> - limited place for families to stay <b>3</b> - expenses
<b>Opportunities</b>	<b>1</b> – look for grants
<b>Threats</b>	<b>1</b> – finding funds

Action 3

Have families schedule appointments on the same day and travel together.

<b>Strengths</b>	<b>1</b> – increase access for families <b>2</b> - strengthen ties between counties
<b>Weaknesses</b>	<b>1</b> – funding <b>2</b> - working across jurisdictions <b>3</b> - locating an access point
<b>Opportunities</b>	<b>1</b> – opening venues for Eastern Shore families to work together
<b>Threats</b>	<b>(none listed)</b>

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**Priority 4: Mental health treatment and services**

**Goal 1** Increase the number of mental health providers on the Eastern Shore.

Action 1

Offer telemental health and telepsychiatry in all of the counties on the Eastern Shore.

<b>Strengths</b>	<b>1</b> – already offered in a few counties that can be used as models <b>2</b> - many Health Departments already have the necessary equipment
<b>Weaknesses</b>	<b>1</b> – not as personable as face-to-face <b>2</b> - may not meet all mental health needs
<b>Opportunities</b>	<b>3</b> - no one available for emergencies
<b>Threats</b>	<b>1</b> – partnerships between larger hospitals and professional schools <b>2</b> - youth may embrace the technology
	<b>1</b> – funding <b>2</b> - insurance coverage <b>3</b> - family/patient buy-in

Action 2

Bring back behavioral clinics.

<b>Strengths</b>	<b>1</b> – allowed more mental health services for families <b>2</b> - families benefitted from it
<b>Weaknesses</b>	<b>1</b> – it was tried before and closed
<b>Opportunities</b>	<b>1</b> – partnerships between larger hospitals
<b>Threats</b>	<b>1</b> – funding <b>2</b> - resistance from larger hospitals

Action 3

Increase the number of mental health providers.

<b>Strengths</b>	<b>1</b> – focus on local students who will practice in the community <b>2</b> – AHEC is located in Cambridge and can help to educate local students <b>3</b> - students receive educational opportunity
<b>Weaknesses</b>	<b>1</b> – will take a long time to produce mental health providers
<b>Opportunities</b>	<b>1</b> – scholarships, tuition assistance, loan forgiveness <b>2</b> – greater awareness about mental illness and greater acceptance <b>3</b> - scope of practice and expanded role <b>4</b> - high school technology programs to offer mental health seminar programs
<b>Threats</b>	<b>1</b> - funding <b>2</b> - younger population may change minds <b>3</b> - licensure

**Priority 5: Adequate health insurance and financing**

**Goal 1**

**Every child will have a comprehensive health insurance plan.**

Action 1

Attend public forums for health exchange committee meetings.

<b>Strengths</b>	<b>1</b> – MCHP & MA <b>2</b> - employee based health insurance <b>3</b> - waivers <b>4</b> - DDA in counties <b>5</b> - guidelines(simple)
<b>Weaknesses</b>	<b>1</b> - funding <b>2</b> – state budget practices <b>3</b> – caseloads for coordination of care <b>4</b> - geography <b>5</b> - DDA funding limited
<b>Opportunities</b>	<b>1</b> – health exchange committees accepting public input <b>2</b> – change budgeting practices
<b>Threats</b>	<b>1</b> - funding

Action 1

Educate legislatures on importance of coverage overall.

<b>Strengths</b>	<b>1</b> – representative attended this meeting <b>2</b> - have several interested legislators in MD
<b>Weaknesses</b>	<b>1</b> – limited amount of time and availability of legislators
<b>Opportunities</b>	<b>1</b> – Delegate Sossi has become involved on behalf of Representative Harris
<b>Threats</b>	<b>1</b> - issue will be piggybacked on other legislation

Goal 2 Educating providers, insurance companies and special needs case managers on the connections that need to be in place for proper care and coverage.

<b>SWOT:</b>	Incomplete
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