

Statewide Maryland – Setting Priorities for Children and Youth with Autism Spectrum Disorders (ASD) and other Developmental Disabilities (DD)

MEETING SUMMARY

[The Maryland Office for Genetics and People with Special Health Care Needs](#) and [The Parents' Place of Maryland](#) convened a group of over 80 stakeholders including parents, local pediatricians, local and state Health Department representatives, local and state special education representatives, community and family service group representatives, support and advocacy group and agency representatives for a day-long learning and strategic planning session. Group learning and activities led participants to identify the top priorities statewide for children and youth with Autism Spectrum Disorders (ASD) and other Developmental Disabilities and to develop goals and action 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 Spectrum Disorders and other Developmental Disabilities and their families statewide in Maryland are:

- Adequate Health Insurance and Financing
- Access to needed therapies (ABA/Behavioral, Speech/language, occupational, and physical)
 - Diagnosis and referral
- Youth transition to adulthood
- Needed services are community-based and easy to use
- Training and Education for school personnel and child care providers

Additionally, stakeholders with a statewide perspective identified effective cross-sector collaboration among government, non-profit, families and professional organizations as a top priority which, if addressed, would support work to improve identified priorities in all areas of the state.

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: Adequate health insurance and financing

Goal 1 Essential health benefits will be available to all.

Action 1

Identify specific health services to be included in all health plans.

Strengths	1 – have essential health benefits in place 2 - health exchange advisory boards
Weaknesses	1 – funding: affordability of insurance plans
Opportunities	1 – educate legislators 2 – establish higher income levels
Threats	1 - funding 2 - needed resources 3 - limited providers

Action 2

Prioritize essential benefits and bring to the attention of state legislators.

Strengths	1 – health benefit exchange 2 - advocates in the state legislature
Weaknesses	1 – funding 2 - push back from insurers
Opportunities	1 – increase financial eligibility 1 – number of healthy people in the exchange 2 - effect on health benefit exchange by increasing financial
Threats	eligibility

Priority 2: Access to Care – Needed Therapies, Developmental Screening and Diagnostic Services

Goal 1: All jurisdictions will have qualified providers accessible to screen, diagnose and refer children at the earliest age possible (by age 2)

Action 1: Primary care training for developmental and autism screening.

Strengths	1 – web casts and other technologies
Weaknesses	1 – reimbursement
Opportunities	1 – Technology currently being modeled in MD; e.g. PPOD, CHADIS, PGSNIPS, physician coaching
Threats	

Action 2: Adequate availability of clinicians with diagnostic capabilities.

Strengths	1 – ongoing specialty facilities in MD; e.g. Kennedy Krieger Institute
Weaknesses	1 – early intervention program 2 – lack of satellite developmental clinics
Opportunities	
Threats	

Goal 2: Increase and ensure the availability of qualified therapeutic providers in every jurisdiction.

Action 1: Support the collaboration of existing providers to increase training opportunities.

Strengths	1 – existing state training
Weaknesses	
Opportunities	
Threats	

Action 2: Expansion and/or creation of satellite multi-disciplinary facilities throughout the State of MD.

Strengths	1 – Kennedy Krieger Institute CARD program 2 - The One World Center for Autism
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Weaknesses	
Opportunities	1 – *also above strengths
Threats	

Action 3: Effectively monitor the implementation of treatment recommendations and parent education.

Strengths	1 – Rethinkautism.com 2 - TEACCH (University of North Carolina)
Weaknesses	
Opportunities	1 – Rethink Autism.com which is inexpensive and available by web cast
Threats	

Priority 3: Youth Transition Into Adulthood

Goal 1: Seamless and integrated transition from school to the adult world.

Action 1 Annual documentation beginning in second grade that parents, families, and students have been explained diploma v. certificate track.

Strengths	1 – annual IEP allows this action to take place
Weaknesses	1 – overwhelming 2 – adds to bureaucratic process
Opportunities	1 – knowledgeable and empowered parents and students make informed decisions
Threats	1 – more work 2 – 2 nd grade may be too early for some students and parents to think about graduation choices

Action 2 At age 14 a transition meeting is held with all partners in attendance to develop a comprehensive transition plan.

Strengths	1 – protocol for meeting already exists
Weaknesses	1 – coordination may be difficult 2 - potentially inadequate resources
Opportunities	1 - better knowledge 2 – empowered parents and students
Threats	1 – turnover of agency partners 2 - funding

Goal 2: Students will have the skills to advocate for their health care needs.

Action 1 IEP should include healthcare component using existing curriculum.

Strengths	1 – existing resources: DORS curriculum; “My Health Decision” resource
Weaknesses	1 – lack of knowledge of school personnel and healthcare providers 2 – youth not aware of their rights
Opportunities	1 – provide training to families, youth, and providers
Threats	1 – parents not knowing how to let go

Action 2 Actively review and revise Healthcare Transition Handbook

Strengths	1 –
Weaknesses	1 –lack of medical transition information 2 - funding
Opportunities	1 - obtain input from medical and transition agencies
Threats	1 – parents unaware what to do 2 - providers don't know how to direct

Action 3 Hold a statewide symposium on youth and healthcare transition.

Strengths	1 –DHMH already holds a youth transition conference
Weaknesses	1 – need more health focus 2 – no funding
Opportunities	1 – develop partnerships with providers, parents and youth
Threats	1 – lack of capacity to implement

Goal 3: Create a seamless transition process for coordination of care.

Action 1 Get involved in medical home.

Strengths	1 – medical home model exists
Weaknesses	1 – insufficient funding 2 – legality of consent and right to records
Opportunities	1 – having an easier transition 2 – working with a special education attorney
Threats	1 – lack of planning 2 – letter of intent; medical power of attorney

Action 2 Develop statewide transition outline and guideline.

Strengths	1 – counties, parents and providers desire coordination
Weaknesses	1 –counties differ in needs, resources and providers
Opportunities	1 - working together with other counties and stakeholders
Threats	1 – lack of coordination on state level guide to counties

Action 3 Work with American Medical Association to create a webinar CME training on legal and transition issues

Strengths	1 –legal tools developed
Weaknesses	1 – not an existing program 2 – clients and parents don't know laws are changing

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Opportunities **1** – outlining and documenting plan and stakeholders **2** – have a one location resource site

Threats **1** – limited perspective **2** – availability of different stakeholders

Priority 4: Easy to use community based resources.

Goal 1 Within the defined community, providers will be aware of identified resources.

Action 1 Create a consortium model of providers and families (similar to COC) to exchange information; discuss providers/needs on a regular basis.

Strengths	1 – willing participants who want to learn 2 - participants will have updated resources
Weaknesses	1 – information changes 2 – agency buy-in 3 - agencies are territorial 4 – not everyone has access to services
Opportunities	1 –collaboration 2 – build and maintain partnerships
Threats	1 – funding 2 - territoriality

Action 2 Universal referral and release of information forms.

Strengths	1 – agency buy-in
Weaknesses	1 – some regions won't accept another regions forms
Opportunities	1 –
Threats	1 - privacy issue

Action 3

Reach out to other communities and cultures. Information dissemination to parents and providers should be multimedia.

Strengths	1 – pamphlets can be obtained almost anywhere
Weaknesses	1 – websites must be kept up-to-date 2 - not everyone has internet access
Opportunities	1 – good communication of information
Threats	

Priority 5: Training for school and childcare providers

Goal 1 Increase knowledge base of school personnel and childcare providers.

Action 1 At university level, change teacher education requirements for special education. Should be required to complete coursework beyond passing the Praxis test.

Strengths	1 – number of universities in the area 2 - number of cohorts 3 – developmental disabilities within school systems
Weaknesses	1 – not required 2 - teachers may feel personally threatened 3 – lack of communication
Opportunities	1 – know your community 2 - utilize community partners 3 - online modules 4 - new partnerships
Threats	1 – funding 2 - teacher master contracts 3 - higher education buy-in 4 - confidentiality

Action 2 Provide access to hands on training at university level.

Strengths	(none listed)
Weaknesses	
Opportunities	
Threats	

Action 3 Utilize train the trainer model and mentoring within schools.

Strengths	(none listed)
Weaknesses	
Opportunities	
Threats	

Action 4 Stipends for summer days to provide professional development for new teachers.

Strengths	(none listed)
Weaknesses	
Opportunities	

| Threats |

Action 5

Combine county professional development so we utilize resources and share professional development.

Strengths	(none listed)
Weaknesses	
Opportunities	
Threats	

Statewide Collaboration – Effective cross-sector collaboration

Goal 1 Issue- based collaboration that is client focused.

Action 1

Reach out to organizations that are stakeholders that are not at the table.

Strengths	1 – have opportunity to share information about organizations’ activities.
Weaknesses	
Opportunities	
Threats	1 – staff turnover 2 - lack of interest 3 - new leadership with every new governor

Action 2

Meet to educate and share information.

Strengths	1 – improved conversation 2 - passionate caring staff
Weaknesses	1 – possible lack of buy-in
Opportunities	1 – focus on needs of clients rather than who will serve them
Threats	1 – inaccurate information 2 – need strong leader to direct conversations and have people keep on task

Action 3

Formalize collaborations through memorandum of understanding.

Strengths	1 – identify accomplishments 2 – formalize mechanism for communication
Weaknesses	
Opportunities	
Threats	1 – MOU’s subject to change in administrations

Goal 2 Reduce duplicative efforts by different organizations.

Action 1

Share information about activities and identify areas for collaboration.

Strengths	1 – improved relationship
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Action 2

Weaknesses	1 – possible loss of momentum
Opportunities	
Threats	1 – staff turnover 2 - new administration

Identify territorialism and consider opportunities for sharing funding.

Strengths	
Weaknesses	1 –lack of buy-in
Opportunities	
Threats	1 – lack of braided funding

Action 3

Have other organizations review an organization’s report before dissemination.

Strengths	1 – accuracy of information
Weaknesses	1 – may not have mechanism for review in place
Opportunities	1 – formalized relationships
Threats	1 – may be time consuming 2 - different organizations use different vocabulary

Goal 3 Create a mechanism for ongoing information sharing and communication across state agencies and (hopefully) other organizations serving CYSHCN with ASD and DD.

Action 1 Using the State Interagency Coordinating Council and local Infants and Toddlers programs, create a pilot project around data sharing

Strengths	1 – ITP is low hanging fruit 2 – state and local existing committees 3 - people know one another
Weaknesses	1 – getting people to understand the benefit of sharing information 2 – privacy issues 3 - trust issues
Opportunities	
Threats	1 – privacy issues

Action 2 Identify other programs and collaborative groups that may benefit from techniques identified and lessons learned from Action Step 1 above.

Goal 4 Establish statewide single point of entry into Infants and Toddlers Program.

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Action 1

Set up websites, kiosks, phone system like “Help Me Grow” model

- Strengths** **1** – some data sharing agreements in place
- Weaknesses** **1** – no one knows about MDSAIL **2**- need better public relations plan
- Opportunities**
- Threats**