

**Capital Area 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, primarily from Prince George's County, including parents; a local pediatrician, local special education school staff; community and family service group representatives, and support and advocacy group 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 the Capital Area 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 in the Capital Area of Maryland are:

- Access to needed therapies (ABA/Behavioral, Speech/language, occupational, and physical)
  - Diagnosis and referral
- Youth transition to adulthood
- Access to child care, before and after school care, and respite care
- \*Training and Education for:
  - Families
  - School personnel
  - Healthcare professionals

*\*Training for school personnel was identified as one of the five areas of greatest need. The meeting participants suggested and agreed as a group that this should be expanded to include training for families and healthcare professionals as well.*
- 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: Establish local integrated therapy centers.**

Action 1: Identify current providers.

<b>Strengths</b>	<b>1</b> – urban area with better access to some therapies <b>2</b> - existing provider lists
<b>Weaknesses</b>	<b>1</b> – lack of experience working with children with ASD/DD <b>2</b> –providers need specialized training <b>3</b> - shortages of therapists in public schools
<b>Opportunities</b>	<b>1</b> – establish partnerships like through Consortium of Care <b>2</b> - partner with established specialized facilities
<b>Threats</b>	<b>1</b> – lack of knowledge of providers <b>2</b> – long wait time for appointments <b>3</b> -some providers not accepting insurance <b>4</b> - lack of providers for specific social needs

Action 2: Build a network between providers.

<b>Strengths</b>	<b>1</b> – current established working relationships
<b>Weaknesses</b>	<b>1</b> – territorial nature of some institutions <b>2</b> – difference in philosophical agendas
<b>Opportunities</b>	<b>1</b> – more business for providers <b>2</b> - increased knowledge of children with ASD/DD <b>3</b> -reduce redundancy <b>4</b> - reduce mixed messages
<b>Threats</b>	<b>1</b> – personality conflicts <b>2</b> - preconceived ideas of ASD/DD

Action 3: Develop vehicle for families and providers to communicate and interact.

<b>Strengths</b>	<b>1</b> – access to technology <b>2</b> - reduced wait time for families <b>3</b> - reduce redundancy
<b>Weaknesses</b>	<b>1</b> – some are uncomfortable with technology <b>2</b> - lack of access to translators
<b>Opportunities</b>	<b>1</b> – greater dialogue between providers and families <b>2</b> - better access to records
<b>Threats</b>	<b>1</b> – lack of access to technology <b>2</b> - fear of change <b>3</b> - families uncomfortable with providers <b>4</b> - cultural competence

**Goal 2: Identify family needs and provide needed services.**

Action 1: Identify the hardest therapy to obtain.

<b>Strengths</b>	<b>1</b> – improved community health and services <b>2</b> - better education for children and families
<b>Weaknesses</b>	<b>1</b> – very expensive area <b>2</b> –difficulty communicating needs
<b>Opportunities</b>	<b>1</b> – families feeling listened to <b>2</b> - needs have been identified in surveys
<b>Threats</b>	<b>1</b> – different opinions of parents <b>2</b> – preferences for specific therapies and approaches

Action 2: Attract providers in the identified areas of need.

<b>Strengths</b>	<b>1</b> – great number of medical schools and providers <b>2</b> - existing agencies
<b>Weaknesses</b>	<b>1</b> – lack of training in working with children with ASD/DD
<b>Opportunities</b>	<b>1</b> – develop new practices <b>2</b> - moving into new areas
<b>Threats</b>	<b>1</b> – lack of communication to providers

Action 3: Help families pay for services.

<b>Strengths</b>	<b>1</b> – limited DDA and LISS funding <b>2</b> - Family-to-Family <b>3</b> - ARC of Prince George’s County and community connections
<b>Weaknesses</b>	<b>1</b> – limits to funding <b>2</b> - paperwork processing <b>3</b> - complicated systems for families
<b>Opportunities</b>	<b>1</b> – learning the appropriate coding for processing insurance
<b>Threats</b>	<b>1</b> – long waiting list and approval process <b>2</b> - difficulty with insurance

**Priority 2: Youth Transition Into Adulthood**

**Goal 1: Enhance the knowledge of families on medical transitioning to the adult health care system.**

Action 1 Provide a template of a medical binder in multiple formats for families.

<b>Strengths</b>	<b>1</b> – available templates exist (DHMH) <b>2</b> – Oregon and Washington UCEDD’s
<b>Weaknesses</b>	<b>1</b> – dissemination of info to parents <b>2</b> – too much information at one time; need on going workshops <b>3</b> - marketed to parents early
<b>Opportunities</b>	<b>1</b> – incorporate in MSDE transition guide <b>2</b> – community based groups <b>3</b> - school system (teachers, transition specialists)
<b>Threats</b>	<b>1</b> – lack of technology <b>2</b> – budget cuts <b>3</b> - support agencies will not talk to parents early to allow for planning

Action 2 Provided updated information to families on changing requirements for medical insurance and eligibility for waivers.

<b>Strengths</b>	<b>1</b> – available training through DDA, Kennedy Krieger resource finder, Parents’ Place, Resource Connection
<b>Weaknesses</b>	<b>1</b> –no fact sheet or flowchart for parents to deal with medical insurance eligibility
<b>Opportunities</b>	<b>1</b> - community based groups <b>2</b> – school system personnel to present information to families
<b>Threats</b>	<b>1</b> – changing information doctor

Action 3 Provide a medical directory of providers for adults with disabilities with a list of questions to ask new providers.

<b>Strengths</b>	<b>1</b> – provided now by Children’s Hospital <b>2</b> - list of questions provided by Kennedy Krieger <b>3</b> - Focus on Challenging Behaviors publication
<b>Weaknesses</b>	<b>1</b> – parents waiting too long to look for new providers
<b>Opportunities</b>	<b>1</b> – community based groups
<b>Threats</b>	<b>1</b> – provider availability <b>2</b> - insurance information

**Priority 3: Access to Child Care, including before and after school care, and Respite Care**

**Goal 1** Create educational programs for child care providers to increase the capacity and number of providers who can give medical child care and quality inclusive child care services.

Action 1

Give child care providers training on light medical skills like those for certified nursing assistants.

<b>Strengths</b>	<b>1</b> – child care training systems already in place <b>2-</b> medical training programs available through community colleges
<b>Weaknesses</b>	<b>1</b> – time commitment from providers <b>2</b> – training needs may be too broad
<b>Opportunities</b>	<b>1</b> –use existing community resources and create something new <b>2</b> – improved quality of life for families
<b>Threats</b>	<b>1</b> – funding <b>2-</b> stakeholder buy-in

Action 2 Create a technical assistance resource kit that provides an overview of therapies used with children with ASD/DD.

<b>Strengths</b>	<b>1</b> – specific resources to use in inclusive child care settings exists
<b>Weaknesses</b>	<b>1</b> – funding <b>2-</b> monitoring for good use of the tools
<b>Opportunities</b>	<b>1</b> – increase experiential learning of providers <b>2-</b> increased market for providers
<b>Threats</b>	<b>1-</b> funding to get kits to all who need it

**Goal 2** Expand before and after school care opportunities for children with ASD/DD.

Action 1 Identify available space for before and after school care programs

<b>Strengths</b>	<b>1</b> – expanding on existing model <b>2-</b> some schools will accept having a program onsite
<b>Weaknesses</b>	<b>1</b> – staffing <b>2-</b> funding for start up
<b>Opportunities</b>	<b>1</b> – extra income for school system staff <b>2-</b> collaboration with community partners
<b>Threats</b>	<b>1</b> – red tape <b>2-</b> what to do with typically developing peers

**Priority 4: Training for family, school, health and community providers**

**Goal 1 Ongoing intensive family support training covering birth through age 21.**

Action 1 Ensuring adequate training of service providers on ASD/DD and cultural competence.

<b>Strengths</b>	<b>1</b> – looks at child globally and plans for outcomes from the beginning <b>2</b> - continuity of care/education
<b>Weaknesses</b>	<b>1</b> – varied family situations <b>2</b> - not enough supports
<b>Opportunities</b>	<b>1</b> – integrated trainings will improve family to professional relationships and understanding <b>2</b> - increased empathy/sensitivity across all environments
<b>Threats</b>	<b>1</b> – funding <b>2</b> - qualified trainers <b>3</b> - accountability <b>4</b> - resistance from families of typically developing children

Action 2 Integrate service providers and family trainings through workshops, home visits and encourage families to observe school settings.

<b>Strengths</b>	<b>(none listed)</b>
<b>Weaknesses</b>	
<b>Opportunities</b>	
<b>Threats</b>	

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

**Goal 1 Increase access to health insurance.**

Action 1 Change eligibility for medical assistance from income based to diagnostic needs/demands.

<b>Strengths</b>	<b>1</b> – MD Children’s Health Insurance Plan (MCHIP/MA) <b>2</b> - existing autism waiver <b>3</b> - pre-existing condition exclusion removed
<b>Weaknesses</b>	<b>1</b> – limited number of children served by autism waiver <b>2</b> – DDA does not offer health/medical insurance <b>3</b> – dental limitation/discrimination <b>4</b> - non-participating providers
<b>Opportunities</b>	<b>1</b> – MD Health Benefit Exchange Advisory Committee <b>2</b> – new Federal recommendation on ABA therapy
<b>Threats</b>	<b>1</b> - funding <b>2</b> - non-participating providers <b>3</b> - increase in premiums

**Goal 2 Increase provider participation.**

Action 1 A parent navigator will serve as a liaison between the parent and provider.

<b>Strengths</b>	<b>1</b> – some providers have personnel who are interested in medical home care <b>2</b> - partnership; community based
<b>Weaknesses</b>	<b>1</b> – some providers only see \$; they don’t have time <b>2</b> - need to have an approach to find the resources
<b>Opportunities</b>	<b>1</b> – creating/fostering programs that will help providers/families become knowledgeable about resources
<b>Threats</b>	<b>1</b> – funding <b>2</b> - providers not interested <b>3</b> - need an incentive

Action 2 Support providers in billing and reimbursements and how to build more quality medical home methods.

<b>Strengths</b>	<b>1</b> - Families as Faculty <b>2</b> - Prince George’s County Special Needs Identification & Physician Support Program <b>3</b> - creating partnerships
<b>Weaknesses</b>	<b>1</b> - funding
<b>Opportunities</b>	<b>1</b> - data supports the need <b>2</b> - collaboration with/between providers and community/families

*Capital Area Maryland- John Carroll Elementary School, Hyattsville, MD*

*June 18, 2012 8:30 am – 3:00 pm*

| Threats      1- funding

|