

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

Sheraton Columbia Town Center Hotel/ Columbia, MD

July 24, 2013

8:30 am – 3:30 pm

MEETING SUMMARY

[The Maryland Office for Genetics and People with Special Health Care Needs](#) and [The Parents' Place of Maryland](#) convened a group of stakeholders including parents and family members; local Health Department representatives; local and statewide school system personnel; other government representatives; physicians, an insurance company representative, community and family service group representatives, and support and advocacy group and agency representatives for a day-long draft plan evaluation. Attendees were evaluating a draft plan to improve systems of health care and related services for children and youth with Autism Spectrum Disorders (ASD) and other developmental disabilities (DD)* in Central Maryland (Anne Arundel, Baltimore, Baltimore City, Carroll, Harford and Howard Counties) as well as across the entire state. The plan is based on feedback obtained from [another planning meeting in 2012](#) and is designed to address high priority needs in Central Maryland as well as across the state, including **access to needed therapies, diagnosis and referral; youth transition to adulthood; needed services are community-based and easy-to-use; training and education for school and child care personnel; and adequate health insurance and financing**. Additionally, **effective cross-sector collaboration** was included in the plan as a priority that would support work to improve identified priorities in all areas of the state. Participants evaluated strategies developed to address these needs and identified key partners and resources needed to implement the strategies. Before evaluating the plan, participants briefly reviewed the background of the project and discussed an outline of the draft plan ([see presentation here.](#)) Participants then worked in small groups of 6 to 10 people to discuss and evaluate the plan strategies. The strategies are:

- Train providers how to best meet the needs of children with ASD/DD and their families
- Initiate development of medical homes
- Promote family/professional partnerships through education and information dissemination
- Build a family-led policy influence infrastructure primarily around the issue of adequate insurance and financing
- Develop multidisciplinary clinics in rural areas
- Create regional hubs for information, resources and point-of-entry
- Engage and partner with higher education programs and facilities
- Focus on provider recruitment and retention

Major themes in participant feedback included: engaging insurance companies in the process of implementing plan strategies; updating and/or adding to existing training curricula for all providers (childcare, medical, dental, respite, etc.) so that they can better serve the needs of children with ASD/DD; an issue of high turnover rates among case managers and the importance of rapid training for case managers; incentivizing providers to complete training by offering Continuing Education Units (CEUs); addressing the needs of children with ASD/DD from undocumented families and families whose first language is not English; improving collaboration between local school systems and non-profit organizations that serve children with ASD/DD; and linking case managers to primary care providers.

The participants provided feedback regarding key partners, existing initiatives, and related resources to address the strategies outlined in the draft plan on the following priorities (please click

on each priority for more details on strategies to address the priority and detailed feedback from meeting participants):

- [Access to needed therapies; diagnosis and referral](#)
- [Youth transition to adulthood](#)
- [Needed services are community based and easy to use](#)
- [Training and education for school and child care personnel](#)
- [Adequate insurance and financing](#)
- [Effective cross-sector collaboration](#)

The stated goals of the plan were shared and evaluated. The goals are as follows:

1. Ensure that Maryland **children and youth with ASD/DD** have access to:
 - Needed primary and specialty health care, including mental health and OT, PT,S/L and behavioral therapies:
 - Adequate Health Insurance and Financing
 - Services to support a successful transition to adult health care systems
2. Ensure that Maryland **families** with children and youth with ASD/DD have access to:
 - Services that are Community-based and Easy to Use
 - child care, out of school time care, and respite care services
 - Family Support and Advocacy Services
3. Ensure that Maryland **service providers** are trained in how best to meet the needs of children and youth with ASD/DD and their families. Providers include:
 - Medical Providers and Support Staff (primary care, specialty care, and emergency dept. providers)
 - Child Care and Out of School Time care providers
 - School Personnel
 - Service Coordinators (i.e. through Developmental Disabilities Administration)
 - First Responders
 - Juvenile Justice System and Court Personnel

Eighty four percent of meeting attendees agreed that these goals are clear and that they capture the priorities and strategies developed by stakeholders across the state.

**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. Please note that the content in these documents is not necessarily representative of the views of The Parents' Place of Maryland or the Office for Genetics and People with Special Health Care Needs; this content is representative of the experiences and views of diverse stakeholders across the state.*