

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

Southern Maryland Higher Education Center, California, MD

May 2, 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 school system personnel; other government representatives; 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 Southern Maryland (Charles, Calvert, and St. Mary's Counties). The plan is based on feedback obtained from [another planning meeting in 2012](#) and is designed to address high priority needs in Southern Maryland, including access to care (needed therapies, primary and specialty care, mental health, developmental screening and diagnosis services); training for school and child care personnel; community-based services that are easy-to-use; adequate insurance and financing, and family support and advocacy. 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 4 to 7 people to discuss and evaluate the plan strategies.

Major themes in participant feedback included addressing the issue of families having to travel long distance to receive services for their children with special health care needs and costs associated with the travel; absence of family-friendly language in information resources currently available to families; and a need to better market information about the already available resources to families in Southern Maryland. Additional strategies suggested by the stakeholders included creation of a reimbursement system for families of CYSHCN for travel and missed work due to the medical appointments; working out arrangements with hospitals for parking vouchers for CYSHCN (similar to Children's National Medical Center); or possibly creating a system for free public transportation for families when proof of a medical appointment is presented.

The next pages provide a summary of the draft plan strategies (organized by priority need) and the feedback that meeting participants provided regarding key partners, existing initiatives, and related resources to address the strategies outlined in the draft plan. 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.

PARTICIPANT FEEDBACK: Southern Maryland ASD/DD Regional Planning Meeting Draft Plan

This is a typed summary of all small groups' comments and feedback on the 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 Southern Maryland including Charles, Calvert and St. Mary's Counties. Groups' comments and feedback are in red type. Question marks (???) indicate that there was not enough information on written group feedback forms to be sure of the meaning.

Family Support and Advocacy					
Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
Family-Led Policy Influence	Now; expand existing initiatives	<i>The Parents' Place of Maryland (PPMD); Pathfinders For Autism (PFA); Autism Speaks</i> <i>Autism Support Group fro Southern Maryland, Charles County Autism Support Group.</i> <i>4 groups (Centers for Life Millwood??) I. Jerry</i>	<i>Arcs; Developmental Disabilities Council; Autism Society chapters; Maryland Coalition of Families for Children's Mental Health (MCF) National Alliance on Mental Illness (NAMI), Parent Centers in Schools – Partners for Success, United Cerebral Palsy</i>	<i>Family-to-Family, Autism-Aspergers Association of Calvert county (AAACC)-training support; Citizens' Advisory Committee for Special Education – outreach, support, training; Autism Support Group for Southern Maryland – training, support; National Alliance for Mental Illness – peer to peer support, family support, training,</i>	<i>Home Instruction for Parents of Preschool Youngsters (HIPPY), Promise Resource Center, Infants and Toddlers Program, Family Resource Center/ ACCESS Center, Barstow Acres. Children Center in Calvert County, the Autism Project, Navy Medicine Access.</i> <i>Partners are resources for</i>

Family Support and Advocacy

Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
		<p>2. Sue R</p> <p>3. Autism-Aspergers Association of Calvert county (AAACC)</p> <p>4. Alyssa</p>	<p>(UCP), March of Dimes, Judy Center, Family Navigator, Parent Connection, Autism-Aspergers Association of Calvert county (AAACC), Citizens' Advisory Community for Special Education, Autism Support Group for Southern Maryland, People on the Go, Maryland State Department of Education (MSDE) – Specialized Health Needs Interagency Collaboration (SHNIC)program – Barbary Opts,</p>	<p>advocacy; Partners for Success – outreach, training, referrals; People on the Go – self advocacy training; Specialized Health Needs Interagency Collaboration – student specific training on those with Developmental Disabilities/ Autism; Children's National Medical Center – training on the new Diagnostic and Statistical Manual of Mental Disorders (DSM5)</p> <p>Crystal's Carnival, State lobbyists.</p> <p>Autism Technology</p>	<p>reaching out to families.</p>

Family Support and Advocacy

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			<p><i>Children’s National Medical Center (CHMC); Maggie’s Light Foundation. Health Departments, Local Citizens’ Advisory Council, Angels Forever, Crystal’s Carnival, Personalized Therapy.</i></p> <p><i>Abilities Network, Bay Community Support Services, Center for Life Millwood, Special Education Citizens’ Advisory Committee (SECAC), Developmental Disabilities</i></p>	<p><i>Program, Autism Waiver, Developmental Disability Waiver, Arc – Legislation, Autism Technical Advisory Group</i></p>	

Family Support and Advocacy

Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
			<p><i>Administration Resource Coordinator, State Representatives, Federal Representatives, Kennedy Krieger Institute, Children's National Medical Center, Local related service providers, primary care providers, Local foundations who offer grants to Children with Special Health care Needs, Special Olympics. Survey support groups and community service providers</i></p>		

Family Support and Advocacy

Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
Regional Hubs	1+ years out from feasibility	<p><i>Office for Genetics and People with Special Health Care Needs (OGPSHCN); Local Health Departments (LHDs); The Parents' Place of Maryland (PPMD); Maryland State Department of Education Race to the Top (MSDE/RttT)</i></p> <p><i>Exceptional Family Member Program (EFMP), Judy Center, Local Management Boards, Family Navigators, Family Support Network,</i></p>	<p><i>The Promise Resource Center, Medical Staff, Macaroni Kids, Local School System, Medical Home, Mass Media.</i></p> <p><i>Arc, Developmental Disability Administration, Local Education Agencies (LEA, Local Mental Health Providers)</i></p> <p><i>Governor's Office for Children (GOC)/ Local Management Boards (LMB), Maryland Access Point (MAP), Local</i></p>	<p><i>Maryland State Department of Education – Support Networks.</i></p> <p><i>Seamless initiative for transfers (care coordination)</i></p> <p><i>Resource packet for families newly diagnosed, relocating, etc.</i></p> <p><i>Local Access Mechanism (LAM) in each county, Resource locator</i></p> <p><i>Local Management Board -Local Access Mechanism; Maryland Access Point – through department on Aging;</i></p>	<p><i>Packet of resources for families newly diagnosed, relocating, etc.</i></p> <p><i>Family System Navigator; Infants and Toddlers, schools, military medicine, Judy Center.</i></p>

Family Support and Advocacy					
Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
		<i>Local School Systems.</i>	<i>Care Team, Multi-disciplinary?? Teams Governor Office of Children; MedStar</i>	<i>Local Care Team – referral, case reviews, technical assistance; Multi-disciplinary teams – case reviews and navigation LAM- Local Access Mechanism; Care management entity, systems of care, local school systems; Health Enterprise Zone- MedStar</i>	
<p>Other strategies:</p> <ol style="list-style-type: none"> <i>1. Marketing/ branding; more reliable information available via web, print, etc.</i> <i>2. Need a website that has to be maintained so it is current with the phone support</i> <i>3. Identify language that is a multi-system approach/ parent-friendly.</i> 					

Other comments/ suggestions:

Access to needed health care (therapies, primary and specialty care, mental health services, screening and diagnosis)

Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
<p>Train Providers <i>(include ancillary services providers and first responders)</i></p>	<p><i>Now – expand</i></p>	<p><i>Maryland Behavioral Health Integration in Pediatric Primary Care (B-HIPP)</i></p>	<p><i>Maryland Coalition of Families for Children’s Mental Health (MCF); Pathfinders for Autism (PFA); Leadership Education in Neurodevelopmental and Related Disabilities (LEND)</i></p> <p><i>Doctors/ nurses, medical schools, College of Southern Maryland</i></p> <p><i>Arc of Southern Maryland – Bay Shore Community Services; Kennedy Krieger Institute, Children’s National Medical Center</i></p>	<p><i>Screening tools across the state for all doctors, not just pediatricians.</i></p> <p><i>Maryland Association of Pediatrics – Medical Home Division; local vocational-technical centers; Best Buddies programs, Continuing Education Units (CEU) for related service providers – have local colleges develop this; Maryland State police training</i></p>	<p><i>Public Health</i></p>

Access to needed health care (therapies, primary and specialty care, mental health services, screening and diagnosis)

Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
			(CNMC)		
Medical Home Development	<i>Now- partner and expand</i>	<i>Office for Genetics and People with Special Health Care Needs (OGPSHCN); The Parents' Place of Maryland (PPMD); JHU; Pediatric at the Harbor (PATH); Center for Autism and Related Disorders (CARD)</i>	<i>Patient Centered Medical Home (PCMH) and other state efforts; Center for Autism and Related Disorders (CARD), Health Enterprise Zone (HEZ) in St. Mary's County. Insurance companies, Kennedy Krieger Institute, Children's National Medical Center</i>	<i>Children's National Outreach, Kennedy Krieger Institute – Outreach American Academy of Pediatrics – Maryland Chapter</i>	<i>Public Health</i>
Multi-disciplinary clinics <i>(include</i>	<i>ASAP</i>	<i>?</i>	<i>Mount Washington Pediatric Hospital (MWPH); Local</i>		

Access to needed health care (therapies, primary and specialty care, mental health services, screening and diagnosis)

Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
<i>feeding clinics)</i>			<i>Providers/Facilities; Local Health Departments (LHDs) Children’s Hospital Local related service providers; community health round table (to help establish)</i>		
Regional Hubs	<i>1+ years out from feasibility</i>	<i>Office for Genetics and People with Special Health Care Needs (OGPSHCN); Local Health Departments (LHDs); The Parents’ Place of Maryland (PPMD); Maryland State Department of Education/Race to</i>	<i>Insurance companies, hospitals Arc, Developmental Disabilities Administration, Local Education Agencies (LEA), Local Mental Health providers, Local Primary Care Physicians (website that is kept current and has a telephone</i>	<i>Exceptional Family Member Program (EFMP), Children’s National Medical Center – case management Scattered/fractured</i>	

Access to needed health care (therapies, primary and specialty care, mental health services, screening and diagnosis)

Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
		<i>the Top (MSDE/RttT)</i>	<i>number), Health Departments, Hospitals, Local Interagency Committees</i>		
Provider Recruitment and Retention		<i>Who can help connect higher ed institutions to providers?</i>	<i>Maryland Primary Care Office (MD PCO); Maryland Higher Education Commission (MHEC), local colleges and universities; local provider groups, Health Enterprise Zone (HEZ) in St. Mary's County <i>Pre-med track through school systems</i></i>	<i>Proposed: payment for education in return for services</i>	

Access to needed health care (therapies, primary and specialty care, mental health services, screening and diagnosis)					
Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
Higher Education Partnerships <i>(not just higher education)</i>	<i>Now – expand?</i>	<i>PGCC Developmental Clinics</i>	<i>Maryland Higher Education Commission (MHEC); , local colleges and universities College of Southern Maryland (CSM), Pre-med track through school systems</i>	<i>Proposed: Payment for education in return for services Best Buddies, Vocational-technical programs for allied health; community college child care and early childhood</i>	
Other strategies? <i>Parental reimbursement for families who have to travel for services</i>					

Other comments/ suggestions:

- *Under “Train Providers” – Each county hospital has meetings (similar to ground rounds) which present opportunity to train providers*
- *There is a need for feeding clinics*
- *Recruitment/ retention is not reasonable financially!*

Needed Services are Community-Based and Easy to Use

Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
<p>Medical Home Development</p>	<p><i>Now- partner and expand</i></p>	<p><i>Office for Genetics and People with Special Health Care Needs (OGPSHCN); The Parents' Place of Maryland (PPMD); Johns Hopkins University; Pediatrics at the Harbor (PATH); Center for Autism and Related Disorders (CARD)</i></p>	<p><i>Patient Centered Medical Home Pilot (PCMH) and other state efforts; Center for Autism and Related Disorders (CARD), Health Enterprise Zone (HEZ) in St. Mary's County</i></p> <p><i>National Institute of Health (NIH), National Rehabilitation Hospital (NRH), Children's National Medical Center (CNMC), MedStar,</i></p>	<p><i>MedStar- case management (the Rare and Expensive Case Management (REM), military, Infants and Toddlers)</i></p> <p><i>Family Medical Consortium – curriculum for adults and individuals with developmental disabilities that is given to medical providers (local physicians and schools of medicine)</i></p> <p><i>Department of</i></p>	<p><i>Neutra Choice Partners</i></p>

Needed Services are Community-Based and Easy to Use

Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
			<p><i>Calvert, Civista Medical Center</i></p> <p><i>Family Medical Consortium (closest to Southern Maryland is George Washington University (GWU); Medical Homes through Department of Mental Hygiene</i></p>	<p><i>Mental Hygiene – initiatives on medical homes run through Psychiatric Rehabilitation Programs (PRPs) for individuals already involved in mental health services (public)</i></p>	
<p>Family/Professional Partnerships</p>	<p><i>Now - expand</i></p>	<p><i>The Parents’ Place of Maryland (PPMD); Maryland Chapter, American Academy of Pediatrics (MD AAP); Pathfinders for Autism (PFA); The One World Center for Autism</i></p>	<p><i>Maryland Center for Developmental Disabilities (MCDD)</i></p> <p><i>Johns Hopkins, Calvert ??, Civista Medical Center, Children’s National Medical Center, home-visiting agencies</i></p>	<p><i>MedStar – case management; advocacy agencies</i></p>	<p><i>ER- Hospitalist training</i></p>

Needed Services are Community-Based and Easy to Use

Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
		<p>(OWCA); Maggie's Light</p> <p>Infants and Toddlers Program, Child Find Program</p>	<p>Family Faculty Program (Prince George's County), Citizens' Advisory Council, Partners for Success, National Alliance on mental illness, Autism- Asperger Association of Calvert County (AAACC), Head Start Programs/ Judy Centers</p>		
<p>Multi-disciplinary clinics</p>	<p>As soon as possible</p>		<p>Mount Washington Pediatric Hospital (MWPH); Local Providers/Facilities; Local Health Departments (LHDs)</p> <p>Sheppard Pratt</p>	<p>Telemedicine, Atlantic General Hospital on Eastern Shore</p> <p>Infant and Toddlers groups, Promise Resource Center</p>	<p>Coordinated movements, personalized therapy, Calvert and St. Mary Rehab Services</p>

Needed Services are Community-Based and Easy to Use

Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
Regional Hubs	<i>1+ years out from feasibility</i>	<i>Office for Genetics and People with Special Health Care Needs (OGPSHCN); Local Health Departments (LHDs); The Parents' Place of Maryland (PPMD); Maryland State Department of Education Race to the Top (MSDE/RttT)</i>	<i>Tri-county youth services (local access mechanism), Infants and Toddlers, Child Find/ Maryland State Department of Education, Judy Centers, Head Start, Managed Care Organizations, College of Southern Maryland</i>		
Provider Recruitment and Retention		<i>Who can help connect higher education institutions to providers?</i> <i>Health and Education</i>	<i>Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND); Maryland Primary Care Office (MD PCO); Maryland Higher</i>	<i>Comment - Needed mental health, GI, genetics, neuro developmental pediatrics, pulmonary specialists</i>	

Needed Services are Community-Based and Easy to Use

Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
		<i>Johns Hopkins Hospital Staff</i>	<p><i>Education Commission (MHEC), local colleges and universities; local provider groups, Health Enterprise Zone (HEZ) in St. Mary's County</i></p> <p><i>College of Southern Maryland (CSM), Southern Maryland Higher Education Center</i></p>		
Higher Education Partnerships	<i>Now – expand?</i>	<i>PG Developmental Clinic</i>	<p><i>Maryland Higher Education Commission (MHEC); local colleges and universities</i></p> <p><i>College of Southern Maryland, Maryland Higher</i></p>	<p><i>Comment – training for the above mentioned specialists to bring them to the area</i></p> <p><i>B-HIPP</i></p>	

Needed Services are Community-Based and Easy to Use

Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
			<i>Education Commission (MHEC), Autism Project</i>		

Other strategies:

- Under "Medical Homes" – state level funding and technology?? to develop
- Under "Regional Hubs" – marketing this for each individual county where people are inclined to look for it.
- Under "Higher Education Partnerships" – Public schools do all of their own training – could invite other partners/ providers to the trainings

Other comments/ suggestions:

- Information about resources already available need to be marketed better in the Southern Maryland region
- Need more web-based and internet training available for providers

Adequate Insurance and Financing

Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
Catastrophic Illness Relief Fund	<i>2+ years out from political feasibility</i>		<i>Maryland Disability Law Center (MDLC) & Maryland Chapter-American Academy of Pediatrics (MD AAP) Lobbyists; Maryland Community of Care Consortium for CYSHCN (CoC); Families; Legislators</i>	<i>Planning and Implementation grants, Grants, taxes.</i>	
Medicaid Buy-In Program	<i>Research is happening now</i>	<i>Office for Genetics and People with Special Health Care Needs (OGPSHCN); Maryland Institute for Policy Analysis and Research; The Parents' Place of Maryland (PPMD);</i>	<i>To make it happen: legislators; lobbyists; families Department of Health and Mental Hygiene (Coordinating centers) Question – Who determines buy-in</i>	<i>Question- how long can the nation tap into this system? Where is the funding to support it? Private Insurance alternative</i>	

Adequate Insurance and Financing

Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
		<i>Maryland Community of Care Consortium for CYSHCN (CoC); Maryland Medicaid</i>	<i>criteria?</i>		
Family-Led Policy Influence Infrastructure	<i>Now; expand existing initiatives</i>	<i>The Parents' Place of Maryland (PPMD); Pathfinders For Autism (PFA); Autism Speaks</i>	<i>Arcs; Developmental Disabilities Council; Autism Society chapters; Maryland Coalition of Families for Children's Mental Health (MCF)</i>	<i>Assistive technology, Autism waiver, Developmental Disability waiver, Arc- legislation, Autism Technical Advisory Group</i>	<i>Comment - Need for training and education</i>
Provider Training (medical billing and coding)	<i>Now; expand existing initiatives</i> <i>Mental Health and Medical, other Allied professional organizations</i>	<i>Maryland Chapter of the American Academy of Pediatrics (MD AAP); One World Center for Autism (OWCA) ; Johns Hopkins</i>	<i>Mental Health Maryland Insurance Committee, Department of Health and Mental Hygiene Maryland Medical</i>		<i>DSM-V and ICD-10, billing and coding specialists, Acute Care coordinator</i>

Adequate Insurance and Financing					
Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
		<i>University; Early Periodic Screening, Diagnosis, and Treatment (EPSDT)</i>	<i>Assistance, College of Southern Maryland – coding and billing, American Academy of Family Practice Any higher education training, insurance companies, mass media; system of accountability</i>		
Other strategies?					

Other comments/ suggestions:

Training and education for school and child care personnel

Strategy <i>(these are all sub-strategies for "Training Providers")</i>	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
Establish a statewide, universal education and training system using a tiered approach that is available to all public and private providers in Maryland serving individuals on the autism spectrum across the lifespan.	??	<p><i>Specialized Health Needs Interagency Collaboration Program (SHNIC)/ Public Schools offers training to staff and parents on applied behavior analysis, but is open to all. Modeling for teachers.</i></p> <p><i>Response To Intervention (RTI); New teacher education – one night is dedicated to special education</i></p>	<p><i>Local Education Agencies; Maryland State Department of Education; Local Infants and Toddlers programs; Maryland Department of Health and Mental Hygiene; PACT; ??</i></p> <p><i>Families; Towson University, the Promise resource center; Maryland Center for Developmental Disabilities - early childhood education training</i></p>	<p><i>This was a recommendation in the Maryland Commission on Autism's final report in Fall 2012. We don't know if it will be acted on.</i></p>	<p><i>Ideas:</i></p> <ul style="list-style-type: none"> <i>- Locate # (the number??) for special needs day care providers</i> <i>- Establish: list of providers that can work directly with special needs children</i> <i>- Offer state stipend for special needs kids</i>

Training and education for school and child care personnel

Strategy (<i>these are all sub-strategies for "Training Providers"</i>)	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
Expand existing training initiatives	<i>Partners for Success program in public schools</i>	<i>Maryland State Department of Education, Johns Hopkins University</i>	<i>PACT; Pathfinders For Autism (PFA); families</i>	<i>Expand the race to the Top program; Quality Rating and Improvement System (QRIS)</i>	<i>Comment – take advantage of existing entities</i>
Evaluate the availability and effectiveness of current training opportunities for school personnel related to ASD/DD awareness; family/professional partnerships, classroom behavioral interventions; and other related topics	Dependent upon local education agencies and/or Maryland State Department of Education willingness and resources		<i>Local Education Agencies; Maryland State Department of Education, Family Support Centers; The Parents' Place of Maryland (PPMD) Autism-Aspergers Association in Calvert County (AAACC) – program evaluation dissemination for feedback</i>		

Training and education for school and child care personnel					
Strategy <i>(these are all sub-strategies for "Training Providers")</i>	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
			<i>Citizens advisory council – parent-run council through school system</i>		
Other strategies?					

Other comments/ suggestions:

- *Collaborate with public schools and the Promise Resource Center on the trainings that the public schools offer (ABA)*
- *There is a need to have a parent centered training and capacity to be competent in other skills and about their child's disability, or just the resources available to them; or how the school system operates and what they have to offer). The school system is not always the enemy – we need to work together and negotiate what you believe your child needs. Maybe parents and teachers can be trained together?*