

Eastern Shore – Setting Priorities for Children and Youth with Autism (ASD) and other Developmental Disabilities (DD)

St. Mark's United Methodist Church, Easton, MD

March 26, 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; local child care providers; 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) on the Eastern Shore (Caroline, Cecil, Dorchester, Kent, Queen Anne's, Somerset, Talbot, Wicomico, and Worcester counties) of Maryland. The plan is based on feedback obtained from [another planning meeting in 2012](#) and is designed to address high priority needs on the Eastern Shore, including adequate health insurance and financing; access to needed health care; and community-based services that are easy-to-use. 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 oral health services as part of the medical home model, and the need to train emergency medical personnel, particularly in emergency rooms, on how best to meet the needs of individuals with ASD and DD.

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: Eastern Shore 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) on the Eastern Shore (Caroline, Cecil, Dorchester, Kent, Queen Anne’s, Somerset, Talbot, Wicomico, and Worcester counties) of Maryland. Groups comments and feedback are in **red type**.

Priority Need To Address: 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>Mid Shore Community of Care Consortium (MS CoC), Managed Care Organizations, Priority Partners, Health Officers</i>	<i>Similar to Geriatric population Nursing Homes guideline – protection for family members of SNC?? (bankruptcy, foreclosure?) when catastrophic illness happens</i> <i>Problem with Supplemental Security Income (SSI) – solely based on income – federal law must change</i>	

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			<i>round table, secretary of health – Sharfstein Legislators, Rare and Expensive Case Management (REM) program Waiver - age restrictions – (need to change autism criteria)</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); Maryland Community of Care Consortium for CYSHCN (CoC); Maryland Medicaid</i>	<i>To make it happen: legislators; lobbyists; families, Addie Eckhart, Sen. Rich Colburn, local providers, Local Health Department- Health Officer Rounds, Core Service Agencies, Mid Shore Mental Health Systems (MSMHS), Wicomico, Somerset, Worcester, Kent, Cecil counties</i>	<i>PAC (Primary Adult Care program??) –becomes part of Medical Assistance (MA) on– 1/1/14) - will cover hospitalization??; age 19 and over have to reapply after age out of Medical Assistance Program Legislative Dinner MidShore Mental Health Systems??</i>	<i>Health Department Social Services</i>

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				<p><i>(MSMHS)</i></p> <p><i>Maryland's Coalition of Families for Children's Mental Health (MCF)</i></p> <p><i>Mental Health Association in Talbot County?? (MHATC)</i></p>	
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>	<p><i>Arcs; Developmental Disabilities Council; Autism Society chapters; Maryland Coalition of Families for Children's Mental Health (MCF)</i></p> <p><i>Special Education Citizens' Advisory Committee (SECAC) (Family Support Services)</i></p> <p><i>Respite care is important (different family dynamics)</i></p>	<p><i>Parents need training on political process, i.e. how to advocate – empower families – more funding is needed for this</i></p> <p><i>"Days in Annapolis" Legislative Dinner</i></p> <p><i>Respite Care through Department of Social Services</i></p>	<p><i>Information on legislative bills – e-mail lists regarding topics of interest</i></p> <p><i>Local legislators</i></p>

Priority Need To Address: Adequate Insurance and Financing

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			<i>have different needs) Transportation needs; grandparents, single family needs</i>		
Provider Training (medical billing and coding)	<i>Now; expand existing initiatives</i>	<i>Maryland Chapter of the American Academy of Pediatrics (MD AAP); One World Center for Autism (OWCA) ; Johns Hopkins University; Early Periodic Screening, Diagnosis, and Treatment (EPSDT)</i>	<i>Oral Health providers, Managed Care Organizations – need to be trained Staff in medical offices, American Medical Association?? (AMA), Value Options, Parent Navigator in doctors’ offices, Local pediatricians and family practice</i>	Training for so many involved! Continuing Education credits or course at a community college	<i>Medical Coding book 5/20/2013 – will this help? Priority Partners Special needs coordinators for each Managed Care Organization Local Health Department, Special Needs coordinators Application for i-phone (search for ICD-9 codes)*</i>

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Other strategies? <i>Family Education</i>					

Other comments/suggestions:

- *Often families tell doctors what codes to use for proper billing. Maybe train more families?*
- *Idea: Legislative Advocacy Day (similar to Developmental Disabilities Day, Maryland Coalition of Families day, etc.)*
- *Idea: Legislative Dinners – invite local legislators to dinner; invite Maryland Coalition of Families, core services agencies, Mental Health Association in Talbot county; have each invited organization do a presentation*

Priority Need To Address: Access to needed health care (therapies; primary and specialty care; mental health services)

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Train Providers	<i>Now – expand</i>	<i>Maryland Behavioral Health Integration in Pediatric Primary Care (B-HIPP- need to get the word out!</i>	<i>Maryland Coalition of Families for Children’s Mental Health (MCF); Pathfinders for Autism (PFA); Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Managed Care Organizations need to be involved, know who their providers are!</i> <i>Department of Health and Mental Hygiene- Early and Periodic Screening, Diagnosis and Treatment- no providers on shore?</i> <i>Child care providers, Mid Shore Mental</i>	<i>Strong need for specialty providers who understand the disability and its characteristics</i> <i>Community education committee – Rural Cares</i> <i>Maryland State Department of Education (MSDE)</i> <i>Maryland Behavioral Health Integration in Pediatric Primary Care (B-HIPP) via Mid Shore Consortium of Care for Children with Special Health Care Needs (MS CoC)</i>	<i>No referrals for Special Needs children from pediatricians, many come from schools – Can Infants & Toddlers train pediatricians?</i> <i>Health Departments Colleges/ Training</i> <i>Identify training topics (annual survey)</i> <i>Four (4) pediatricians currently signed up- mid shore and lower shore (for B-HIPP?)</i> <i>Jeff Moran, Benedictine, is coordinating a parent support training for police departments/ Emergency Rooms (ER)</i>

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			<p><i>Health Systems (MSMHS), Rural Cares, School of Nursing, Chesapeake College</i></p>		<p><i>Pathfinders training – Emergency Medical Services in (Ocean City, state police)</i></p>
<p>Medical Home Development <i>Family Advisory Committee</i></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); JHU; Pediatric at the Harbor (PATH); Center for Autism and Related Disorders (CARD)</i></p>	<p><i>Patient Centered Medical Home (PCMH) and other state efforts; Center for Autism and Related Disorders (CARD)</i> <i>Local Health Departments – Children's Medical Services (CMS) program links people to services – performance Measures?? services include: endocrine, cardiology, sleep studies</i></p> <p><i>Interpreter services and transportation.</i></p>	<p><i>Electronic database effective 2014</i></p> <p><i>Accuracy issues and could affect second opinions and security issues</i></p> <p><i>Local Infants & Toddlers program</i></p> <p><i>OGPSHCN county staff</i></p>	<p><i>Concept: all players in the game</i></p> <p><i>Need for training of providers on disability (example – Emergency Room staff)</i></p> <p><i>American Academy of Pediatrics Maryland Chapter (MD-AAP)</i></p>

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Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
			<i>American Academy of Pediatrics (AAP) – regional representative</i>		
Multi-disciplinary clinics	ASAP	<i>Mid Shore Community of Care for Children with Special Health Care Needs (MS CoC), Mount Washington Pediatric Hospital (MWPH), Shore Health, Local Health Departments (LHD), Parents, Mid Shore Educational Consortium, Office for Genetics and People with Special Health Care Needs (OGPSHCN)</i>	<i>Mount Washington Pediatric Hospital (MWPH); Local Providers/Facilities; Local Health Departments (LHDs) Christiana – using residents Kennedy Krieger Institute?? Al DuPont – does not accept Priority Partners. Shore Health System/ University of Maryland (SHS/ UM)</i>	<i>Anne Arundel Medical Center has vacant space at Queenstown Emergency Facility Mid Shore Consortium of Care for Children with Special Health Care Needs (MS CoC) Specialty Clinic project Salisbury University (SU) is placing social work interns into pediatric offices Maryland Behavioral Health Integration in Pediatric Primary Care (B-HIPP)- call line</i>	<i>In past Wicomico County Health Department had funds for specialty care Dr. Blake – Mount Washington Pediatric Hospital (MWPH)</i>

Priority Need To Address: Access to needed health care (therapies; primary and specialty care; mental health services)

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>Mid Shore Mental Health referral service – Chesapeake Helps DSS Judy Center ELIAC (Early Learning Inter Agency Committee) Family Support partner- every county Resource Directory – MSDE Learning Links- resources Kennedy Krieger – community resource mapping MS CoC Specialty Clinics PFA</i>	<i>Pediatrician can link to mental health /psychologist (ex. Meds, diagnosis, referrals)</i>	<i>Chesapeake Helps</i>
Provider Recruitment and Retention		<i>Who can help connect higher education institutions to providers?</i>	<i>Maryland Primary Care Office (MD PCO); Maryland Higher Education Commission (MHEC), local colleges</i>	<i>Loan repayment program (LARP) housing assistance (especially tough in this</i>	

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			<p><i>and universities; local provider groups Hospitals Local Maryland Health Education Centers (AHECs)</i></p>	<p><i>economy) Provider malpractice insurance, Vacations, RFP (Requests for proposals??) – practices to bring psychiatrists to shore, loan repayment program (LARP)</i></p>	
<p>Higher Education Partnerships</p>	<p><i>Now – expand?</i></p>	<p><i>PGCC Developmental Clinics</i></p>	<p><i>Maryland Higher Education Commission (MHEC); , local colleges and universities Local schools – help families with conferences</i></p>	<p><i>Recruitment of providers (students) with the above incentives Local universities, colleges Worcester, Wicomico, Salisbury University Higher Education Center at Chesapeake College, Washington College and Salisbury University onsite</i></p>	<p><i>Chesapeake college, Salisbury University (SU), Rural Care trainings</i></p>

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Other strategies? <i>Coordinate loan forgiveness program so that all eligible professionals are sent to the areas when they are most needed</i>					

Other comments/suggestions:

- *Under ‘Training of Providers’ and ‘Multidisciplinary clinics’ strategies add oral health care as part of medical home.*
- *Training needs include: how to best care for individuals with behavioral challenges, behavior management techniques, how to partner with families, planning for those who need sedation, financial methods for covering non-insured care*
- *Eastern Shore oral health partners: Developmental Disabilities Association, Office of Oral Health (check their strategic plan), Mid Shore Community of Care for Children with Special Health Care Needs(MS Coc), Office for Genetics and People with Special Health Care needs (OGPSHCN), Eastern Shore Dental Society.*

Priority Need To Address: Needed Services are Community-Based and Easy to Use

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Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
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); Johns Hopkins University; Pediatrics at the Harbor (PATH); Center for Autism and Related Disorders (CARD)</i>	<i>Patient Centered Medical Home Pilot (PCMH) and other state efforts; Center for Autism and Related Disorders (CARD) Pediatricians, Shore Health – new building</i>	<i>Educate/ partner/expand Survey – Talbot is gathering data to see what families perspectives on Medical Home are (possibly expand the survey to other counties) Models- Cecil Colorectal Screening or Breast and Cervical Cancer Screening Program?? (BCCP) going into providers' offices (effective 2013)</i>	<i>It is only community-based and easy-to-use if its services are there; if they are not, then provider training to set up office as medical home model starts with primary pediatrician's office – designated person in the office relies on parent compliance. Ideally, coordinator goes into home to link, educate, etc. the family – get them plugged in to services</i>
Family/Professional Partnerships	<i>Now - expand</i>	<i>The Parents' Place of Maryland (PPMD); Maryland Chapter, American Academy of Pediatrics (MD</i>	<i>Maryland Center for Developmental Disabilities (MCDD) Chesapeake College, Maryland's Coalition</i>		<i>Chesapeake College Professional/ Parent day: speakers, workshops, respite care</i>

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		<p><i>AAP); Pathfinders for Autism (PFA); The One World Center for Autism (OWCA); Maggie’s Light Local Health Departments (LHDs)</i></p>	<p><i>of Families for Children’s Mental Health (MCF), MD Coalition of Families, Shore Health</i></p> <p><i>Involve faith-based organizations – will help with respite</i></p>		
<p>Multi-disciplinary clinics</p>	<p><i>As soon as possible</i></p>	<p><i>Mid Shore Consortium of Care for Children with Special Health Care Needs (MS CoC), Shore Health Mount Washington Pediatric Hospital (MWPH), Local Health Departments (LHDs), Parents, Talbot County Department of Social Services (TC DSS)</i></p>	<p><i>Mount Washington Pediatric Hospital (MWPH); Local Providers/Facilities; Local Health Departments (LHDs) Shore Health</i></p>		

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<p>Regional Hubs</p>	<p><i>1+ years out from feasibility</i></p>	<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>Shore Health</i></p>		<p><i>It's all about training the right people to do the coordination</i></p>

Priority Need To Address: Needed Services are Community-Based and Easy to Use

Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
<p>Provider Recruitment and Retention</p>		<p><i>Who can help connect higher ed institutions to providers?</i></p>	<p><i>Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND); Maryland Primary Care Office (MD PCO); Maryland Higher Education Commission (MHEC), local colleges and universities; local provider groups Shore Health</i></p>	<p><i>Mid shore Consortium of Care for Children with Special Health Care Needs (MS CoC) Specialty Clinic project as a measure to counteract long term inability to recruit new providers</i></p>	
<p>Higher Education Partnerships</p>	<p><i>Now – expand?</i></p>	<p><i>PG Developmental Clinic</i></p>	<p><i>Maryland Higher Education Commission (MHEC); local colleges and universities University of Maryland at Salisbury (Salisbury University)</i></p>	<p><i>Talbot County EHS program (does EHS stand for Early Head Start or Easton High School??)</i></p>	<p><i>Higher Education: University of Maryland (UM), Salisbury University (SU), Washington College</i></p>

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Strategy	Time Table	CURRENT Partners	POTENTIAL Partners	Existing Initiatives	Related Resources
<p>Other strategies?</p> <p><i>Find a way to ask/barter specialist care for weekends away in Ocean City – try to get people who own vacation properties on the Eastern Shore to donate a weekend or other time as an incentive for specialty providers who will visit the Eastern Shore to provide specialty services.</i></p>					

Other comments/suggestions:

- *Parents often experience problems with receiving prescriptions, sick notes, etc. in a timely manner. Is there a way for electronic records systems to allow parents to access the most recent testing results and/or other needs, prescriptions, sick notes, etc?*
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- *Under “Partnering with Higher Education Institutions” – Eastern Shore Area Higher Education Health Centers (AHEC) brings University of Maryland (UMD) medical students, dental students, nursing and pharmacology students to Eastern Shore. Provide mentoring **(Need more info here!!)***
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- *Under “Provider Recruitment” – use local associations and societies to encourage recruitment.*