

# Priority: Needed Services are Community-Based and Easy-to-Use

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 Central Maryland including Anne Arundel, Baltimore, Baltimore City, Carroll, Harford, and Howard Counties as well as across the entire state. Groups’ comments and feedback are in red type. Areas highlighted in yellow indicate that there was not enough information on written group feedback forms to be sure of the meaning.

## Strategy: Medical Home Development

### Comments:

- *The strategy should be problem/diagnose specific*
- *The model could work, but not sure how it is going to be implemented under the new Affordable Care Act*
- *Insurance companies are reluctant to buy-in*
- *Baltimore has a program called “Mental Health Home Base”- can this be available in more areas?*
- *Need to incorporate dental homes for CYSHCN*

Time Table	<i>Now- partner and expand</i>
CURRENT Partners	<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>Infants and Toddlers; Local Mental Health providers</i>
POTENTIAL Partners	<i>Patient Centered Medical Home Pilot (PCMH) and other state efforts; Center for Autism and Related Disorders (CARD), Health Enterprise Zones (HEZs)</i> <i>Maryland Healthcare Commission funded a program (enriched primary care and a certification program) to do a medical in-home pilot</i>  <i>Insurance companies (due to the chance for increased reimbursement being an incentive for practices to be doing more work)</i>

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	<p><i>Local health departments; Foster Care Parent Association; community hospitals; American Medical Association (AMA); American Academy of Pediatrics (AAP)</i></p> <p><i>Medical schools; Advanced Placement for Nurse Practitioners; all Health and Allied Health training programs; Mental Health providers</i></p> <p><i>Federally Qualified Health Centers (FQHC); Dental Coalition</i></p> <p><i>Comment: One specific location and access all services.</i></p> <p><i>Healthy Start; Maternal Child Health Programs; Social Services; Infants and Toddlers, Local Mental Health providers; Pediatrics at home program; Pediatrics at the Harbor.</i></p>
<p><b>Existing Initiatives</b></p>	<p><i>Comment: The practices currently involved in the medical home initiative are more motivated and knowledgeable</i></p> <p><i>Maryland Behavioral Health Integration in Pediatric Primary Care (B-HIPP)</i></p> <p><i>American Academy of Pediatrics (AAP); Rare and Expensive Case Management (REM) Connecticut State Model (211); East Baltimore Medical (Federal program)</i></p>
<p><b>Related Resources</b></p>	<p><i>Comment: Primary Care Physicians bring resources in to the practice for success and their cost money where ??? comes from</i></p> <p><i>Medical home brochure – Prince George’s county; Physician Outreach Program – Prince George’s County</i></p> <p><i>Consider Arc- state/ grant/ insurance funds for navigators in pediatric practices/hubs</i></p> <p><i>City/ county-specific resource guide; county/city resources ( specific to jurisdiction); Maryland Behavioral Health Integration in Pediatric Primary Care (B-HIPP)</i></p>

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	<p><i>National Center for Medical Home Initiative</i></p> <p><i>Comments:</i></p> <ul style="list-style-type: none"> <li><i>-Issues with turnover rates in Rare and Expensive Case Management (REM) staff</i></li> <li><i>-No universal distribution of resources, providers, and infrastructure in rural areas</i></li> <li><i>-Points of resistance in successfully implementing Medical Homes: lack of incentive, loss in freedom to practice as clinicians wish</i></li> <li><i>-There is a need for greater care coordination</i></li> </ul>
<p><b>Strategy: Family/Professional Partnerships</b></p>	
<p>Time Table</p>	<p><i>Now – expand</i></p>
<p>CURRENT Partners</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 (OWCA); Maggie’s Light</i></p>
<p>POTENTIAL Partners</p>	<p><i>Maryland Center for Developmental Disabilities (MCDD)</i>  <i>Service coordinators, local school systems</i>  <i>Local Arcs; local Autism Societies; family navigators, Centers for Independent Living (CILs); local hospitals</i>  <i>Maryland Disability Law Center (MDLC)</i></p> <p><i>Developmental Disabilities Administration (DDA; National Institute of Mental Health – parent training and workshops. Research contact person – Kayleen Duhalt; colleges’ Speakers Bureau; Partners for Success</i></p>
<p>Existing Initiatives</p>	

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<p>Related Resources</p>	<p><i>Partners for success – Maryland State Department of Education (MSDE), Family Support Network</i></p> <p><i>Comments:</i></p> <ul style="list-style-type: none"> <li>- <i>Need more knowledge on community and in-home resources</i></li> <li>- <i>Families need to know what resources are available in local communities. How can we get this info to primary care providers so that they can better serve families?</i></li> <li>- <i>Early intervention – walk through step-by-step navigation before transition period – awareness</i></li> </ul> <p><i>Autism Society; Disease-specific Advocacy and Care Groups; Maryland Behavioral Health Integration in Pediatric Primary Care (B-HIPP); Child Locate</i></p>
<p><b>Strategy: Multi-disciplinary clinics</b></p> <p><i>Comments:</i></p> <ul style="list-style-type: none"> <li>- <i>The clinics should be condition-specific</i></li> <li>- <i>Have interpreters whenever needed</i></li> </ul>	
<p>Time Table</p>	<p><i>As soon as possible</i></p>
<p>CURRENT Partners</p>	<p><i>??</i></p>
<p>POTENTIAL Partners</p>	<p><i>Mount Washington Pediatric Hospital (MWPH); Local Providers/Facilities; Local Health Departments (LHDs)</i></p> <p><i>Federal or State coordination needed from Health Departments; Major Pediatric Hospitals; Doctors Without Borders but State-based; small group cross disciplinary approach and therapies</i></p> <p><i>Kennedy Krieger Institute/ Center for Autism and Related Disorders (CARD); DC Children’s Hospital; Al Dupont Hospital; Children’s National Medical Center</i></p>

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	<p><i>Office for Genetics and People with Special Health Care Needs (OGPSHCN)</i></p> <p><i>University of Maryland; Johns Hopkins University; local hospitals; school-based Health Alliance</i></p> <p><i>Insurance companies</i></p>
Existing Initiatives	<p><i>Johns Hopkins Hemophilia Clinic (Federally funded)</i></p> <p><i>Comments:</i></p> <ul style="list-style-type: none"> <li>- <i>Need is lower in urban centers</i></li> <li>- <i>May need to fund them on the state level; what are the infrastructural costs/funding sources</i></li> <li>- <i>Design sustainability</i></li> <li>- <i>Transportation? Mobile clinics</i></li> </ul> <p><i>Regional clinics – Mid Shore Consortium</i></p> <p><i>School health centers, faith based centers, Head Start centers, Judy Centers</i></p>
Related Resources	<p><i>One World Center for Autism; insurance companies</i></p>
<p><b>Strategy: Regional Hubs</b></p>	
Time Table	<p><i>1+ years out from feasibility</i></p>
CURRENT Partners	<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>Department of Health and Mental Hygiene (DHMH)</i></p>
POTENTIAL Partners	<p><i>Comment: Need is lower in central region</i></p>

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	<p><i>The Parents' Place of Maryland (PPMD)</i></p> <p><i>Kennedy Krieger Institute/ Center for Autism and Related Disorders (CARD); Maryland Behavioral Health Integration in Pediatric Primary Care (B-HIPP); Dental Coalition</i></p> <p><i>Local Departments of Social Services (DSS); local community agency; Pathfinders for Autism</i></p>
Existing Initiatives	<p><i>Comment: Tody's idea for a mobile unit should become an existing initiative</i></p> <p><i>Navigators; service coordinators</i></p> <p><i>Intra-agency website; Transitioning Maryland link; Autism Portal (Maryland State Department of Education); Maryland Center for Disabilities; Network of Care</i></p>
Related Resources	<p><i>United Way; 211-call for help for the state of Maryland for resources on everything – must “own and be current” with their information</i></p> <p><i>American Red Cross, Arc, Autism Society of America, Developmental Disability Administration (DDA), Service Coordination; Maryland Learning Links; internet databases for resources - each organization/ county has one, but there is no consistency across the board</i></p> <p><i>Comments:</i></p> <ul style="list-style-type: none"> <li><i>- you want a regional hub, but you do not want a wrong door</i></li> <li><i>- Is there access to support services for caregivers in crises- referrals to family support, mental health? Most services seem to focus on kids</i></li> <li><i>- Where do interpreter services fit in?</i></li> <li><i>- Consider adding wellness/ adaptive recreation to the list of resources in the hub ( once established)</i></li> <li><i>- Consider regional care coordinators</i></li> </ul>

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Strategy: Provider Recruitment and Retention	
Time Table	??
CURRENT Partners	<p><i>Who can help connect higher education institutions to providers?</i></p> <p><i>Comment: Professional organizations for all disciplines need to recruit</i></p> <p><i>The Parents' Place of Maryland; Maggie's Light</i></p>
POTENTIAL Partners	<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, Health Enterprise Zones (HEZs)</i></p> <p><i>Hospitals; schools of Social Work; Employee Assistance</i></p> <p><i>American Academy of Pediatrics, Maryland Chapter</i></p> <p><i>Infants and Toddlers; Higher Education Commission</i></p> <p><i>Division of Rehabilitative Services (DORS)</i></p> <p><i>More exposure through programs such as Rise Up; McDaniel College – place students in disabilities service settings</i></p>
Existing Initiatives	<p><i>Health Enterprise Zones (HEZs)</i></p> <p><i>Higher Education Commission; Loan Assistance Repayment Program (LARP)</i></p> <p><i>Allied health programs – include into curriculum; Best Buddies; family perspective programs such as Maggie's Light</i></p> <p><i>Comment: Expose all students to disparities, developmental disabilities in high schools, colleges/ higher ed. institutions</i></p>
Related Resources	<p><i>Comment: CEU's being offered</i></p>

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### Strategy: Higher Education Partnerships

*Comment: Huge struggle is the turnover rate of qualified staff working with CYSHCN*

Page | 8

Time Table	<i>Now – expand?</i>
CURRENT Partners	<i>PG Developmental Clinic</i>
POTENTIAL Partners	<p><i>Maryland Higher Education Commission (MHEC); local colleges and universities</i></p> <p><i>Replication of Prince George’s Developmental Clinic</i></p> <p><i>Essex Developmental Clinic; Towson University/ Hussman Center</i></p>
Existing Initiatives	<p><i>Center for Adults with Autism at Towson University; Dr. Kean program??, Carroll County Summer program</i></p> <p><i>Interns; Institute for Wellbeing</i></p> <p><i>Teach for America- rural communities; Best Buddies – internships</i></p> <p><i>LARP, Maryland State, J-1 Visa (exchange visa) programs; Maryland Higher Education, National Health Service Corps</i></p> <p><i>Higher reimbursement given to health professionals</i></p>
Related Resources	<p><i>Money!</i></p> <p><i>Incentivized programming – LARP; Healthcare Payment reform; co-location incentives- collaboration and communication</i></p>

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	<p><i>Comment:</i>  <i>Placement in existing clinics in the community: inability to negotiate with individual providers due to contractual relationships with larger corporations; establish relationships with large corporations and schools- send their students and faculty to areas with disabilities</i></p>
<p><b>Other Strategies</b></p>	
<p><b>Comments</b></p>	<ul style="list-style-type: none"> <li>- <i>It is critical to have interpreters on-site in clinics/hubs that serve non-English speaking families</i></li> <li>- <i>Eliminate policies that are in the way of collaboration across sectors (HIPAA, FERPA). Educators need to open their doors to healthcare and social services, etc.</i></li> <li>- <i>Families need early childhood mental health line (similar to B-HIPP's line available to providers)</i></li> <li>- <i>Provide an efficient way to stay current on resources</i></li> <li>- <i>Relationship building between physicians and individuals who are stakeholders for CYSHCN</i></li> <li>- <i>One place to get all information is needed!</i></li> <li>- <i>Need constant and current dissemination of information and training for regional hubs to be successful</i></li> <li>- <i>Regions DO think they are working together, but there is something missing</i></li> </ul>

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- *Training is key because of rapid turnover*
- *Universal form/application to make requests to various agencies (ex., services, food stamps, etc.)*
- *211 is helpful participant for parents because you can connect with a person. Maybe this is what a regional hub can do.*
- *Consider accessibility- physical access for people in wheel chairs/ mobility issues, language, and other barriers to access*
- *Consider school based health-clinics- able to bill insurers in Maryland*
- *Frequently, existing materials are not useful for non-English speaking population. Full-time interpreters are much needed!*

### Questions

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