

Priority: Youth Transition to Adulthood

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	
Time Table	Now-expand
CURRENT Partners	<p><i>Office for Genetics and People with Special Health Care Needs (OGPSHCN); The Parents’ Place of Maryland (PPMD); Johns Hopkins University (JHU); Pediatric at the Harbor (PATH); Center for Autism and Related Disorders (CARD)</i></p> <p><i>Local Health Departments</i></p>
POTENTIAL Partners	<p><i>Patient Centered Medical Home (PCMH) and other state efforts; Center for Autism and Related Disorders (CARD), Health Enterprise Zones (HEZs)</i></p> <p><i>Service Coordination, Inc.; Dine and Learn Education Support Group</i></p> <p><i>Local School System; service coordinators</i></p> <p><i>Waiver providers; local hospitals; MedChi, Arcs</i></p> <p><i>Maryland Transition.org; Maryland Chapter of Family Practice; American Academy of Pediatrics (AAP); Department of Social Services</i></p>

Please note that the content in this document 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.

Priority: Youth Transition to Adulthood

<p>Existing Initiatives</p>	<p><i>Sickle Cell at Johns Hopkins; i-Home at Johns Hopkins</i></p> <p><i>Medical/Pediatric discipline at Johns Hopkins (2 years plus 2 years in pediatric and internal medicine) This attracts medical professionals with an interest in developmental disabilities.</i></p> <p><i>Baltimore Medical Systems</i></p> <p><i>Arc – developing medical home; State of Wisconsin; Illinois Healthcare checklist; Ohio; Resource Network – Kennedy Krieger Institute (KKI) webinar resources; Centers for Autism and Related Disorders (CARD), Specialized Health Needs Interagency Collaboration (SHNIC), Maryland Center for Developmental Disabilities (MCDD) – written manuals</i></p> <p><i>School nurses (invite to IEP meetings and include healthcare transition in IEP); Interagency Transition Council: Division of Rehabilitative Services (DORS), Developmental Disability Administration (DDA), mdtransition.org</i></p> <p><i>Comment: Provide resources to coordinators themselves</i></p>
<p>Related Resources</p>	<p>??</p>
<p>Strategy: Family/Professional Partnerships</p> <p><i>Comment: Need a volunteer pro-bono attorney!</i></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 Health Departments</i></p>

Please note that the content in this document 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.

Priority: Youth Transition to Adulthood

POTENTIAL Partners	<p><i>Maryland Center for Developmental Disabilities (MCDD)</i> <i>Maryland Division of Rehabilitation Services (DORS); Service Coordination Inc., Maryland State Department of Education (MSDE); employers; parent advisory groups; Initiative on transition for those on Autism waiver; Centers for Independent Living (CIL); Developmental Disability Administration (DDA)</i></p> <p><i>Maryland Disability Law Center (MDLC) – more training on Medical Day/ Medical Home for families and how to access it is needed. Care providers need training for persons with ASD/DD</i></p> <p><i>Local school systems</i></p> <p><i>Centers for Independent Living (CILs) benefits counseling; resource coordinators, Arcs; Local Autism Societies; family navigators; Local Education Agencies (LEAs)</i></p> <p><i>“The League” and Community Colleges</i></p>
Existing Initiatives	<p><i>Annual Transition Conference; Howard County Transition Council; local transition fairs; Life Transition series held at local levels</i></p> <p><i>Local Education Agency (LEA) speaker series; Kennedy Krieger Institute (KKI) transition series; Department of Disabilities (DOD) – Maryland transition.org</i></p>
Related Resources	<p><i>Transition Services Assessment; Missouri Family Resource Center; Maryland Transition.org</i></p> <p><i>Maryland Disability Law Center (MDLC); libraries</i></p> <p><i>Comment: Need parent training!</i></p> <p><i>Comment: Home-schooling – where to get information?</i></p>
Strategy: Regional Hubs	

Please note that the content in this document 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.

Priority: Youth Transition to Adulthood

Time Table	<i>1+ years out from feasibility</i>
CURRENT Partners	<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>
POTENTIAL Partners	<i>Developmental Disability Administration (DDA); service coordinators; Division of Rehabilitation Services (DORS)</i> <i>Centers for Independent Living (CILs)</i> <i>Region 3 (through DDA??) hub for Medical providers</i>
Existing Initiatives	<i>Youth councils depending on the county</i>
Related Resources	<i>Libraries; computer availability</i>

Strategy: Train Providers

*Comment:
Medical providers need training in transition of adults with cognitive disability*

Time Table	<i>Now – expand</i>
CURRENT Partners	<i>Maryland Behavioral Health Integration in Pediatric Primary Care (B-HIPP)</i> <i>The Parents' Place of Maryland</i>
POTENTIAL Partners	<i>Maryland Coalition of Families for Children's Mental Health (MCF); Pathfinders for Autism (PFA);</i>

Please note that the content in this document 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.

Priority: Youth Transition to Adulthood

	<p><i>Leadership Education in Neurodevelopmental and Related Disabilities (LEND)</i></p> <p><i>Rare and Expensive Medicine (REM)</i> <i>Developmental Disability Administration (DDA); Rare and Expensive Medicine (REM)</i> <i>Maryland Center for Developmental Disabilities (MCDD)</i> <i>Mental Health Associate (MHA), Maryland Developmental Disabilities Council (MDDC)</i></p>
<p>Existing Initiatives</p>	<p><i>Adult services providers</i></p> <p><i>Talbot County.</i></p> <p><i>Comment: Higher reimbursements – more time spent with patients</i></p>
<p>Related Resources</p>	<p><i>Comment: Need families train families sharing success stories, creating videos and webinars</i></p>
<p>Other Strategies</p>	<p><i>Disseminate OGPSHCN information to the world!</i></p>
<p>Comments</p>	<ul style="list-style-type: none"> - <i>Need to get to families early and hear success stories</i> - <i>Use technology to improve access to trainings. What do you do about families without technology?</i> - <i>Start earlier than 13 years</i> - <i>Primary Care Physicians have trouble accessing resources so they cannot offer assistance to families</i> - <i>Need a link between school and healthcare providers</i>

Please note that the content in this document 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.

Priority: Youth Transition to Adulthood

- *Schools need to focus more on transition*
- *Provider requirement standards and training mandates. Mandated outcomes to receive funding*
- *Multidisciplinary requirement for transition medical services*
- *Benefits counseling training for both providers and consumers*
- *Need consistency in available services*

Questions

Please note that the content in this document 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.