

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

Christ Lutheran Church, LaVale, MD

April 19, 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 Western Maryland (Garrett, Allegany, and Washington counties). The plan is based on feedback obtained from [another planning meeting in 2012](#) and is designed to address high priority needs in Western Maryland, including access to needed therapies; community-based services that are easy-to-use; adequate insurance and financing, training for school and child care personnel, and mental health treatment and services. 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 inadequacy of Medicaid coverage when receiving health care services in the neighboring states of West Virginia and Pennsylvania; the need to partner with higher education institutions not only across Maryland, but universities in neighboring states to attract/recruit health professionals to the Western region of Maryland and establish multidisciplinary clinics; inadequacy of transportation services through Medical Assistance (MA) program offered to families with children and youth with ASD/DD; and the need to expand transition programs for youth with special health care needs to middle school students.

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: Western 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 Western Maryland including Washington, Garrett and Allegany 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.**

| Adequate Insurance and Financing | | | | | |
|---|--|-------------------------|--|---|--|
| Strategy | Time Table | CURRENT Partners | POTENTIAL Partners | Existing Initiatives | Related Resources |
| Catastrophic Illness Relief Fund <i>(reimburse for expenses related to caring for a child)</i> | <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>Connect with 211, Network of Care</i> | <i>United Way Day of Caring – not local in Allegany</i> <i>Camp Hope</i> <i>Legal and Individual offices</i> <i>Trust, wills, etc. for developmental disabilities special needs</i> <i>Local Management Board</i> | <i>County specific community partnership</i> |

Adequate Insurance and Financing

| Strategy | Time Table | CURRENT Partners | POTENTIAL Partners | Existing Initiatives | Related Resources |
|--------------------------------|---|--|--|---|---|
| Medicaid Buy-In Program | <p><i>Research is happening now</i></p> <p><i>Know how fits with Health Care Reform/ Health Insurance Exchnages</i></p> | <p><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></p> | <p><i>To make it happen: legislators; lobbyists; families, Edwards Kelly</i></p> | <p><i>Garrett County Health Department- pick up Medicaid insurance – family pays \$50-60 because too much income, so no longer qualify for insurance coverage (SSI)</i></p> <p><i>Autism Waiver</i></p> <p><i>County specific legislators</i></p> <p><i>Employed Individuals with Disabilities (EID) program, Medicaid Buy-in, 18+ older, Social Services Health Department, New Directions, Support brokers</i></p> | <p><i>Garrett County Health Department- pick up Medicaid insurance – family pays \$50-60 because too much income, so no longer qualify for insurance coverage (SSI)</i></p> <p><i>Autism Waiver</i></p> <p><i>County specific legislators</i></p> <p><i>Social workers County specific benefits counselors</i></p> |

Adequate Insurance and Financing

| Strategy | Time Table | CURRENT Partners | POTENTIAL Partners | Existing Initiatives | Related Resources |
|---|--|---|--|--|---|
| <p>Family-Led Policy Influence Infrastructure <i>(Need child care, transportation, lodging assistance if want parents to participate in leadership training/ opportunities)</i></p> | <p><i>Now; expand existing initiatives</i></p> | <p><i>The Parents' Place of Maryland (PPMD); Pathfinders For Autism (PFA); Autism Speaks Family Support Services (Maryland State Department of Education), Coalition of Families for Children's Mental Health (MCF)</i></p> | <p><i>Arcs; Developmental Disabilities Council; Autism Society chapters; Maryland Coalition of Families for Children's Mental Health (MCF) Developmental Disabilities Administration, Autism Speaks in Allegany County – Marcia Hardinger</i></p> <p><i>University of Maryland, Hagerstown or community colleges in Western Maryland</i></p> <p><i>Jamey Tobery-</i></p> | <p><i>Yes- in Central Maryland (Montgomery County)</i></p> <p><i>Family Leadership Institute (FLI)/ Maryland Coalition of Families</i></p> <p><i>PRAY(providing relief for autistic youth) in Washington county</i></p> <p><i>Parent Training Information (PTI) Centers and Parent support centers, Maryland Coalition of Families, Abilities Network plans for training and organizing</i></p> | <p><i>Disability Advisory Committee</i></p> <p><i>Special Education Citizens Advisory Committee (SECAC)</i></p> <p><i>Low Intensity Support Services (LISS)</i></p> |

Adequate Insurance and Financing

| Strategy | Time Table | CURRENT Partners | POTENTIAL Partners | Existing Initiatives | Related Resources |
|--|---|--|---|----------------------|-------------------|
| | | | <i>Nystrom</i> | | |
| Provider Training (medical billing and coding) <i>multiple levels of training</i> | <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) Allegany county has a coding class/course – current coders to be a resource to doctors; work with Maryland office</i> | <i>Billing professionals People setting up billing systems State (Department of Health and Mental Hygiene) Train office managers</i> | | |

| Adequate Insurance and Financing | | | | | |
|---|-------------------|---------------------------------|---------------------------|-----------------------------|--------------------------|
| Strategy | Time Table | CURRENT Partners | POTENTIAL Partners | Existing Initiatives | Related Resources |
| | | <i>managers to learn coding</i> | | | |
| Other strategies? <i>Making it possible for insurance coverage to be accepted when crossing state lines.</i> | | | | | |

Other comments/ suggestions:

Modify Medical Assistance (MA) transportation based on choice of provider, not closest provider.

Possibly useful partnership in addressing the priority – community fundraisers, Rotary, 211, Cenetan????

| Access to needed health care (therapies and mental health services) | | | | | |
|--|--|--|---|--|--|
| Strategy | Time Table | CURRENT Partners | POTENTIAL Partners | Existing Initiatives | Related Resources |
| Train Providers <i>(Pediatricians, dentists,</i> | <i>Now – expand To access, to provide services</i> | <i>Maryland Behavioral Health Integration in Pediatric Primary</i> | <i>Maryland Coalition of Families for Children’s Mental Health (MCF);</i> | <i>Western Maryland Area Health Education Center (WMAHEC), existing training</i> | <i>Ideas: Strategy – train MD to be adult providers about autism/ any DD</i> |

Access to needed health care (therapies and mental health services)

| Strategy | Time Table | CURRENT Partners | POTENTIAL Partners | Existing Initiatives | Related Resources |
|--|--------------------------------|---|---|--|---|
| <i>specialist, technicians – all levels within agency)</i> | | <i>Care (B-HIPP)</i> | <i>Pathfinders for Autism (PFA); Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Apples Co-op extension agency</i> | <i>partnerships; use existing professional groups 211, Septem (Maryland Coalition of Families)</i> | <i>Current pediatricians link with adult MD to provide info/ support about ASD/DD Train parents to use medical jargon so that they can go talk to MD/ dentists (need training strategies) Intensive Behavior Management Program (IBMP) Developmental Disabilities Administration (DDA) provider agency – Kathy Balint</i> |
| Medical Home Development providers | <i>Now- partner and expand</i> | <i>Office for Genetics and People with Special Health Care Needs (OGPSHCN);</i> | <i>Patient Centered Medical Home (PCMH) and other state efforts; Center</i> | <i>Waivers, The Rare and Expensive Case Management (REM) program, Resource/</i> | <i>Medical Advocacy in Virginia (Pilot Program)</i> |

Access to needed health care (therapies and mental health services)

| Strategy | Time Table | CURRENT Partners | POTENTIAL Partners | Existing Initiatives | Related Resources |
|--|-------------|--|---|--|---|
| | | <p><i>The Parents' Place of Maryland (PPMD); JHU; Pediatric at the Harbor (PATH); Center for Autism and Related Disorders (CARD)</i></p> | <p><i>for Autism and Related Disorders (CARD), Mental Health Association (MHA), The League – a Children's Place</i></p> <p><i>Insurance companies – Evergreen, Kaiser Permanente approach</i></p> | <p><i>service coordination</i></p> | |
| <p>Multi-disciplinary clinics</p> | <p>ASAP</p> | <p><i>The League- a children's place</i></p> | <p><i>Mount Washington Pediatric Hospital (MWPH); Local Providers/Facilities; Local Health Departments (LHDs)</i></p> <p><i>Tri-state Federally Qualified Health Center (FQHC), University of Maryland, Johns Hopkins University,</i></p> | <p><i>Sheppard Pratt, the League- a Children's Place, Villa Maria, Western Maryland Health System (WMHS), satellite clinics, Local Health Departments (LHDs)</i></p> | <p><i>Bring in specialist a certain number of times a month for 'clinics'</i></p> |

Access to needed health care (therapies and mental health services)

| Strategy | Time Table | CURRENT Partners | POTENTIAL Partners | Existing Initiatives | Related Resources |
|----------------------|--------------------------------------|--|---|--|-------------------|
| | | | <p><i>Health Departments</i> <i>The League- a Children's Place,</i> <i>Towson University (has an adult peer and speech/ language clinic to work with high school age students)</i> <i>Allegany County College (has Occupational Therapy, Physical Therapy)</i></p> <p><i>Kennedy Krieger Institute (KKI),</i> <i>Johns Hopkins University (JHU)</i></p> | | |
| Regional Hubs | <i>1+ years out from feasibility</i> | <i>Office for Genetics and People with Special Health Care Needs (OGPSHCN); Local Health Departments</i> | <i>211, NOC (Network Operation Center??), MD Locator Services, 7am Navigator Services??,</i> | <i>Local Management Boards, Local Care Team?? (LCT), Early Childhood Council</i> | |

Access to needed health care (therapies and mental health services)

| Strategy | Time Table | CURRENT Partners | POTENTIAL Partners | Existing Initiatives | Related Resources |
|----------|------------|---|---|----------------------|-------------------|
| | | <p><i>(LHDs); The Parents' Place of Maryland (PPMD); Maryland State Department of Education/Race to the Top (MSDE/RttT, Pathfinders For Autism (PFA), Service Coordination- need to qualify through Developmental Disabilities Council; Health Departments have service coordinator</i></p> | <p><i>Disability Support Services, CSAS/ Developmental Disability Administration, Headstart/ Early Head Start, Human Resource Development Commission (HRDC)/ Community Action Council (CAC) Family Navigators, Maryland Coalition of Families (MCF), Hospitals, Local Health Departments (LHD), Local clinics, universities or community colleges, the League- a children's place</i></p> | | |

Access to needed health care (therapies and mental health services)

| Strategy | Time Table | CURRENT Partners | POTENTIAL Partners | Existing Initiatives | Related Resources |
|---|----------------------|--|---|--|--|
| Provider Recruitment and Retention | | <i>Who can help connect higher education institutions to providers? Help with loan forgiveness</i> | <i>Maryland Primary Care Office (MD PCO); Maryland Higher Education Commission (MHEC), local colleges and universities; local provider groups</i> | <i>Loan Repayment Program (LARP)- loan assistance incentives</i> | <i>Community therapy providers. Expand services over the age of five (5) linked to currently existing services</i> |
| Higher Education Partnerships | <i>Now – expand?</i> | <i>PGCC Developmental Clinics Monocacy Neurodevelopmental</i> | <i>Maryland Higher Education Commission (MHEC); , local colleges and universities Garrett College, Allegany College, Frostburg University</i> | <i>Western Maryland Area Health Education Center (WMAHEC)</i> | |
| Other strategies? | | | | | |

Other comments/ suggestions:

Under “Train providers” and “Medical Home development” add area aging agencies as related resources; Bring developmental pediatric providers to the region

Under 'Higher Education Partnerships' – Could Western Maryland colleges partner with colleges in neighboring states, like West Virginia University, which has Occupational Therapy (OT), Physical Therapy (PT) and Speech Therapy majors?

Under 'Higher Education Partnerships' – Partnering between specialties? There is poor retention in Mental Health agencies. Could students be linked to area families? (Similar to Parents' Place's "Family as Faculty" program)

Training and Education for School and Child Care Personnel

| Strategy (these are all sub-strategies for "Training Providers") | Time Table | CURRENT Partners | POTENTIAL Partners | Existing Initiatives | Related Resources |
|---|---|---|--|---|---|
| <p>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> | <p><i>Childcare providers need a lot of training on range of normal development</i></p> | <p><i>Kennedy Krieger Institute (KKI), Sheppard Pratt, Western Maryland Area Health Education Center (WMAHEC), colleges and universities Case management through Maryland State Department of Education (need to be increased) Johns Hopkins</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; the Parents' Place of Maryland (PPMD), Maryland</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>Autism Society, childcare administration, families, adults with autism, websites, American Academy of Pediatrics (AAP), Caring Communities, Board of Education (BOE), autism specialist, public schools in Washington county, autism resource team, assistive technologist,</i></p> |

Training and Education for School and Child Care Personnel

| Strategy (these are all sub-strategies for "Training Providers") | Time Table | CURRENT Partners | POTENTIAL Partners | Existing Initiatives | Related Resources |
|--|---|---|---|--|------------------------------|
| | | <i>University provide training to educators, Allegany College provides training for childcare providers</i> | <i>Coalition of Families (MCF), Pathfinders For Autism (PFA)</i> | | <i>behavioral specialist</i> |
| Expand existing training initiatives | <i>Increase competencies in areas</i> | | <i>PACT; PFA; community colleges, Intensive Behavior Management Program (IBMP), CHAPMS, Arc, Connect to Learn</i> | | |
| Evaluate the availability and effectiveness of current training opportunities for school personnel related to ASD/DD | Dependent upon local education agencies and/or Maryland State Department of Education willingness and | | <i>Local Education Agencies; Maryland State Department of Education; Family Support Centers; The Parents' Place</i> | <i>Online or in person training and instructional assistant needs to pass test</i> | |

Training and Education for School and Child Care Personnel

| Strategy (these are all sub-strategies for "Training Providers") | Time Table | CURRENT Partners | POTENTIAL Partners | Existing Initiatives | Related Resources |
|---|------------|------------------|--------------------|----------------------|-------------------|
| awareness; family/professional partnerships; classroom <u>behavioral interventions</u> (<i>much need in training on behavioral strategies and disability awareness</i>); and other related topics | resources | | of Maryland (PPMD) | | |
| Other strategies? <i>Parent surrogates</i> | | | | | |

Other comments/ suggestions:

Curriculum for Children and Youth with Special Health Care Needs must include transitioning into adolescence. Expand transition program (life skills) to middle school instead of age 18 (Allegany county)

Needed Services are Community-Based and Easy to Use

| Strategy | Time Table | CURRENT Partners | POTENTIAL Partners | Existing Initiatives | Related Resources |
|--|---------------------------------------|---|--|--|-------------------|
| <p>Medical Home Development Need more Managed Care Organizations/ Health Maintenance Organization serving Western Maryland; need more respite providers</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) Children's Medical Group Local Health Departments</i></p> | <p><i>Children's medical group, tri-state community health system, Smithsburg Family practice (website: http://mhcc.maryland.gov/pcmh/), Johns Hopkins physicians, the Rare and Expensive Case Management (REM), waiver</i></p> | |
| <p>Family/Professional Partnerships</p> | <p><i>Now - expand</i></p> | <p><i>The Parents' Place of Maryland (PPMD); Maryland Chapter,</i></p> | <p><i>Maryland Center for Developmental Disabilities (MCDD), Local Management Boards, family</i></p> | <p><i>Contract parent advocacy groups to identify people to serve as board members</i></p> | |

Needed Services are Community-Based and Easy to Use

| Strategy | Time Table | CURRENT Partners | POTENTIAL Partners | Existing Initiatives | Related Resources |
|-----------------------------------|----------------------------|--|--|----------------------|-------------------------|
| | | <i>American Academy of Pediatrics (MD AAP); Pathfinders for Autism (PFA); The One World Center for Autism (OWCA); Maggie's Light, Partners for Success</i> | <i>navigators, family centers,</i> | | |
| Multi-disciplinary clinics | <i>As soon as possible</i> | <i>The League- a children's place, Local Health Departments, Shriner</i> | <i>Mount Washington Pediatric Hospital (MWPH); Local Providers/Facilities; Local Health Departments (LHDs)</i> | | <i>Parent advocates</i> |

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>Pediatricians are critical doorway to services, head Start, Infants and Toddlers, Maryland Coalition of Families, 211, service coordinators through Developmental Disability Council</i> | | |
| Provider Recruitment and Retention | | <i>Who can help connect higher education institutions to providers?</i> | <i>Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND); Maryland</i> | | |

Needed Services are Community-Based and Easy to Use

| Strategy | Time Table | CURRENT Partners | POTENTIAL Partners | Existing Initiatives | Related Resources |
|--------------------------------------|----------------------|--------------------------------|--|----------------------|-------------------|
| | | | <i>Primary Care Office (MD PCO); Maryland Higher Education Commission (MHEC), local colleges and universities; local provider groups</i> | | |
| Higher Education Partnerships | <i>Now – expand?</i> | <i>PG Developmental Clinic</i> | <i>Maryland Higher Education Commission (MHEC); local colleges and universities, Frostburg State – adaptive developmental clinic</i> | | |

| Needed Services are Community-Based and Easy to Use | | | | | |
|--|-------------------|-------------------------|---------------------------|-----------------------------|--------------------------|
| Strategy | Time Table | CURRENT Partners | POTENTIAL Partners | Existing Initiatives | Related Resources |
| Other strategies? | | | | | |

Other comments/ suggestions:

“Open House” education/ public education for friends extended family, employees. People need to feel welcome.