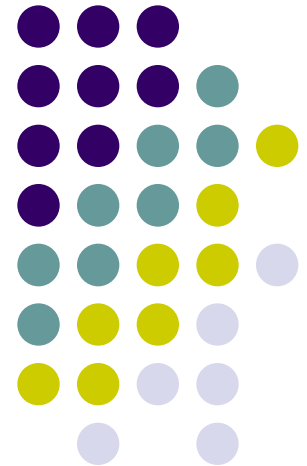


*Autism and Developmental Disabilities Plan:  
Western Maryland – Did We Get it Right?*

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**Maryland Office for Genetics and  
People with Special Health Care Needs;  
The Parents' Place of Maryland**





# WELCOME AND INTRODUCTIONS

# The Office for Genetics and People with Special Health Care Needs (OGPSHCN)



Maryland's Title V Children and Youth with Special Health Care Needs (CYSHCN) program

- Provide and ensure access to comprehensive health care, including long-term care services, for CYSHCN
- Facilitate the development of family-centered, community-based, culturally effective, and comprehensive care for CYSHCN and their families.

OGPSHCN's mission is to assure a comprehensive, coordinated, culturally effective and consumer-friendly system of care that meets the needs of Maryland's CYSHCN and their families.



# The Parents' Place of Maryland (PPMD)

Purpose is to ensure that families of children with any kind of disability or special health care need have the knowledge and assistance they need to make informed decisions that support their child's health, education, and development. We provide peer support to families, and information and education to families, professionals and the community at large.

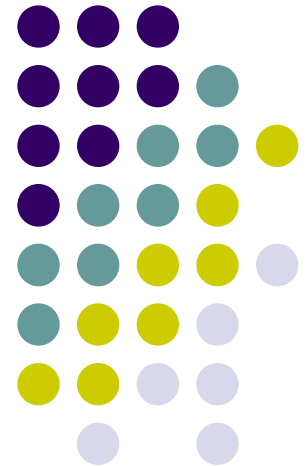
## Maryland's:

- Family-to-Family Health Information Center
- Parent Training and Information Center
- Family Voices State Affiliated Organization
- Consortium for CYSHCN (CoC)

# Participant Introductions

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- **Your name**
- **Your organization**
- **Your interest in children/youth with ASD and DD and their families**
- **Were you here last year?**





# Purpose of Today's Meeting

- Review the purpose and progress of the Autism Spectrum Disorder and other Developmental Disabilities (ASD/DD) Planning Grant
- Evaluate a draft of the statewide plan (focus on Western Maryland)
- Network among ASD/DD stakeholders



# Agenda and Materials Orientation

- Review Agenda
- Review Meeting Materials
- Questions/Concerns before we proceed?



# BACKGROUND/REVIEW





# Project Background

- Develop a Statewide Plan to Improve Systems of Health Care and Related Services for Children and Youth with Autism Spectrum Disorders and other Developmental Disabilities

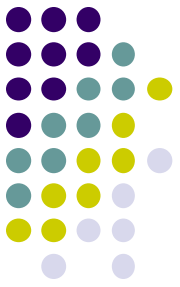


# ASD and other DD Planning Grant

*The State Planning Grant for Improving Services for CYSHCN with Autism Spectrum Disorder (ASD) and other Developmental Disabilities (DD), awarded to The Parents' Place of Maryland in partnership with OGCSHCN:*

- 2 years
- health care and related services
- part of the federal Combating Autism Initiative

# Who are Children with Special Health Care Needs?



*CYSHCN are kids; kids who also happen to need extra care*

- Have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions
- require health and related services of a type or amount beyond that required by children generally

# Core Outcomes for CYSHCN



1



2



3



4



5

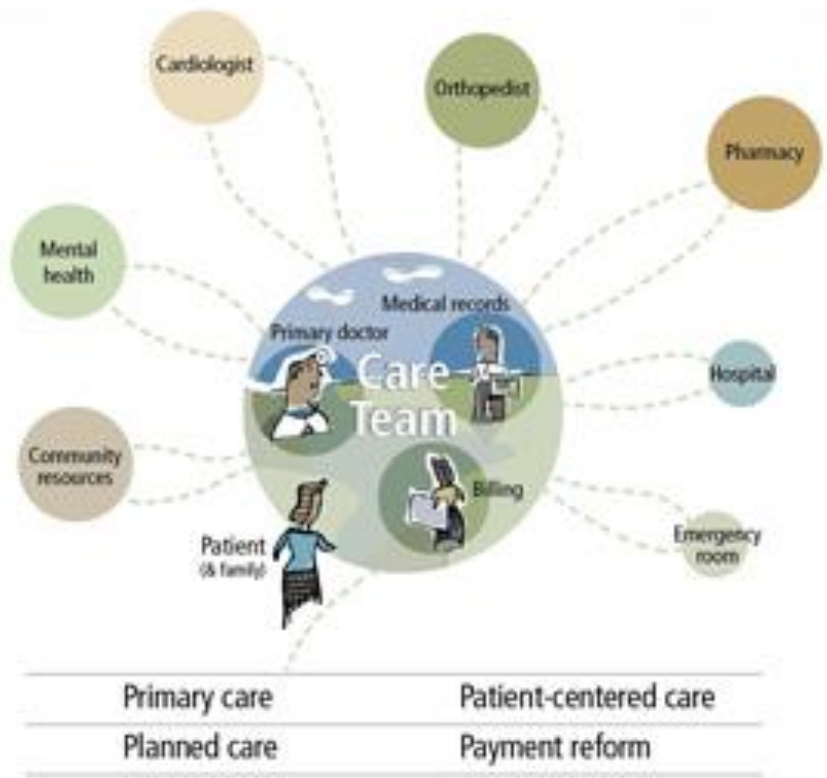
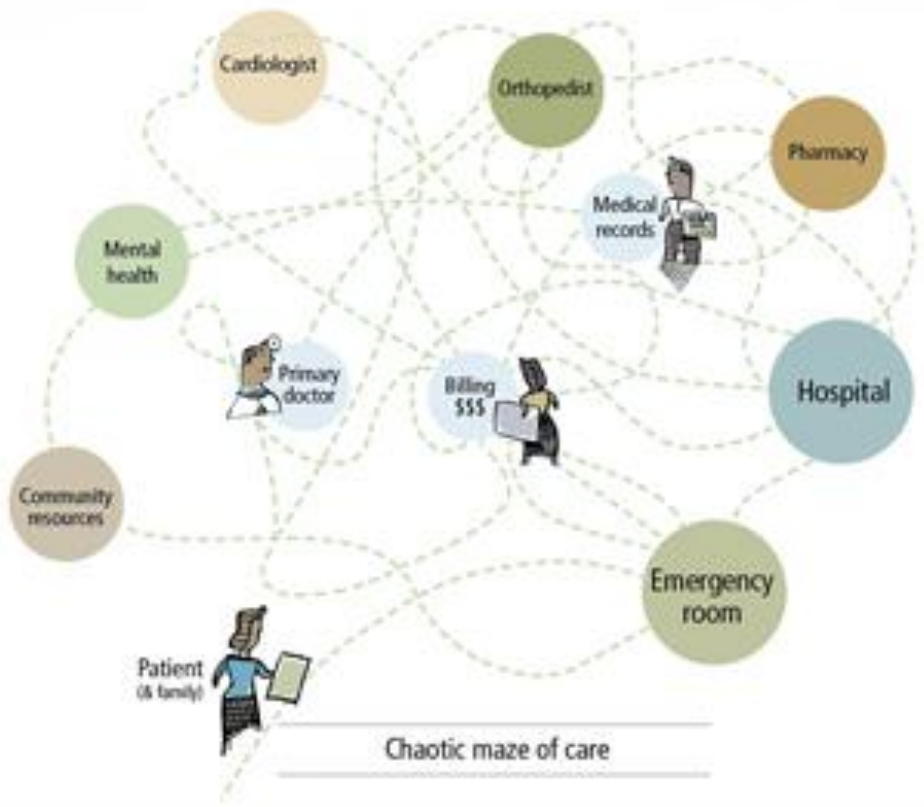


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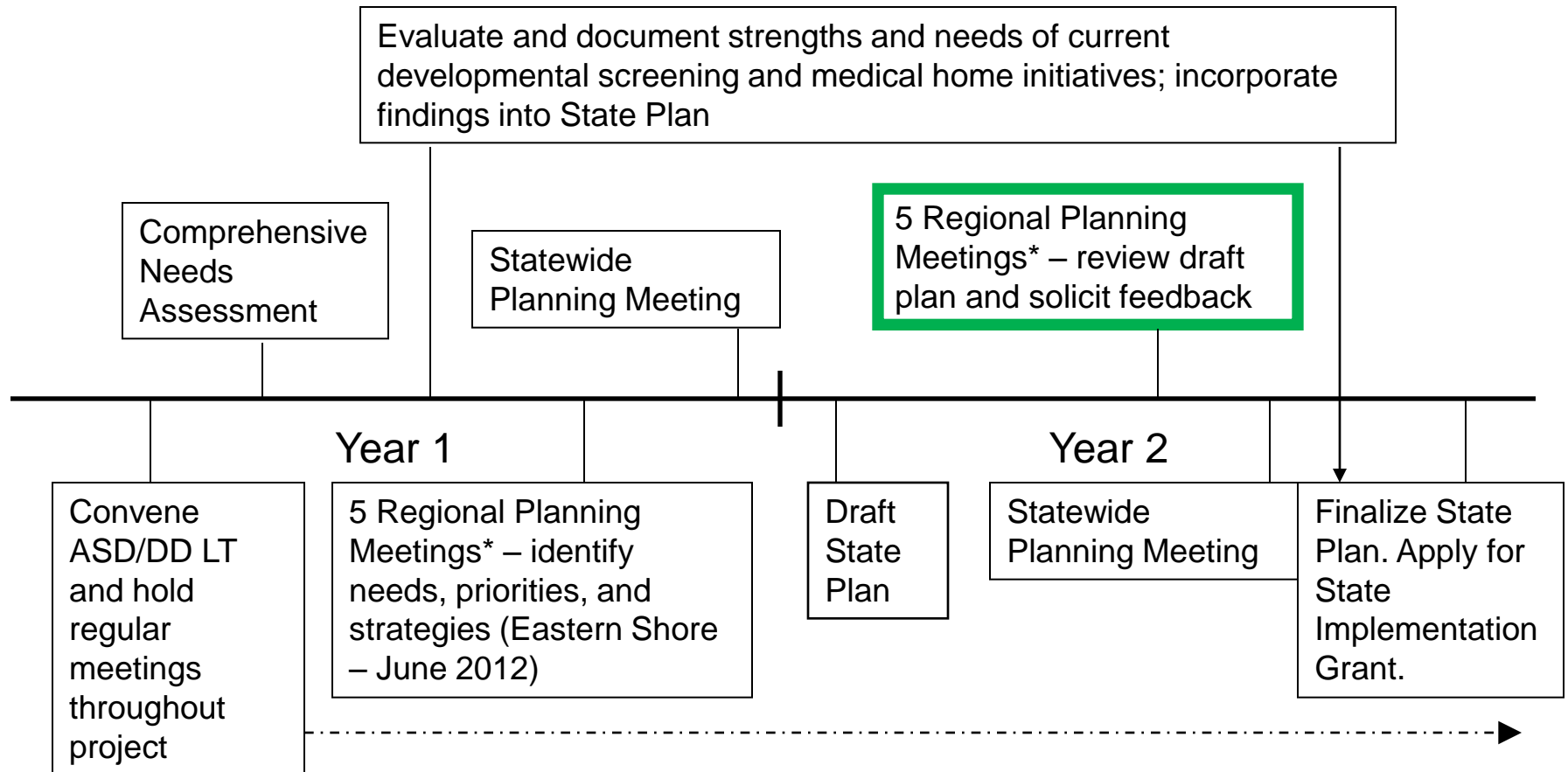


# What is a “medical home”?!

- NOT a *place*, but rather an *approach* to providing **comprehensive** primary care.
- **The American Academy of Pediatrics (AAP)** developed the medical home model for delivering primary care that is:
  - Accessible
  - Continuous
  - Comprehensive
  - Family-centered
  - Coordinated
  - Compassionate
  - Culturally effective

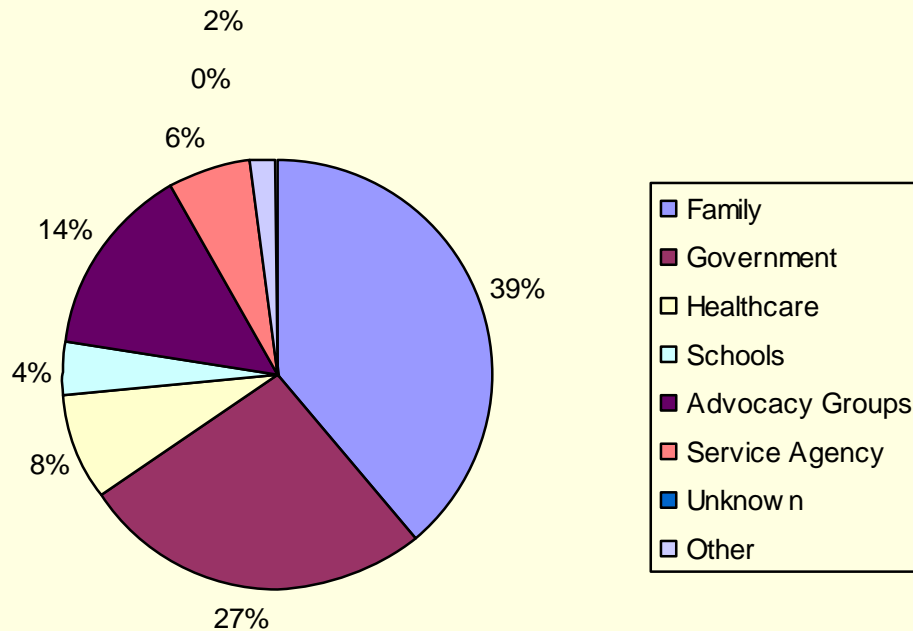


# Planning Grant Timeline



# Top 5 Identified Regional Priorities

## Western Maryland



DATE: May 24, 2012

LOCATION: Christ Lutheran Church, Lavale, MD

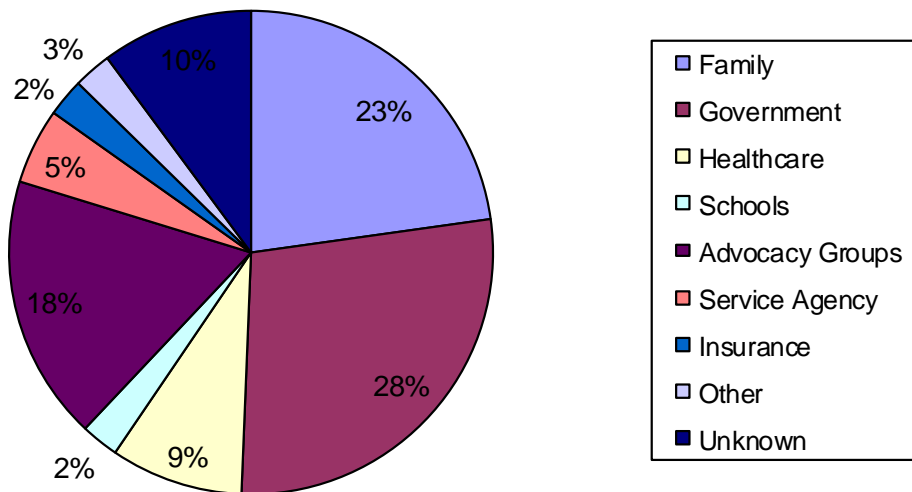
NUMBER OF ATTENDEES: 49

- **Access to needed therapies**  
(ABA/Behavioral, Speech/language, occupational, and physical)
  - Diagnosis and referral
  
- **Needed services are community-based and easy to use**
  - Child care and respite care
  - Transportation
  
- **Adequate Health Insurance and Financing**
  
- **Training for School and Child Care Personnel**
  
- **Mental Health Treatment and Services**
  - Diagnosis and referral



# Top 5 Identified Statewide Priorities

## Statewide



DATE: July 25, 2012

LOCATION: The Meeting House, Columbia, MD

NUMBER OF ATTENDEES: 79

- ***Adequate Health Insurance and Financing***
- ***Access to needed therapies***  
(ABA/Behavioral, Speech/language, occupational, and physical)
  - ***Diagnosis and referral***
- ***Youth transition to adulthood***
- ***Needed services are community-based and easy to use***
- ***Training and Education for school personnel and child care providers***

*Additionally, stakeholders with a statewide perspective identified effective **cross-sector collaboration** among government, non-profit, families and professional organizations as a top priority which, if addressed, would support work to improve identified priorities in all areas of the state.*

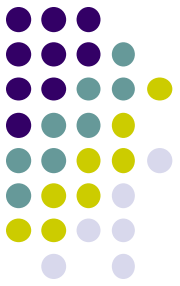
Top Priority Needs By Region:	Statewide and Central	Eastern Shore	Capital Area	Southern MD	Western MD
Adequate Health Insurance and Financing <sup>MCA 3, 4</sup>	X	X	X	X	X
Access to Needed Therapies <sup>MCA 3, 4, 5</sup>	X	X	X	X*	X
Needed Services are Community-Based and Easy-to-Use <sup>MCA 5</sup>	X	X		X	X
Training and Education for School and Child Care Personnel <sup>MCA 10, 12</sup>	X		X	X	X
Youth Transition to Adulthood <sup>MCA 4, 8</sup>	X		X		
Effective cross-sector collaboration, including families <sup>MCA 1, 2, 5, 11, 12</sup>	X*				
Mental Health Treatment and Services <sup>MCA 5, 12</sup>		X		X*	X
Access to Primary and Specialty Care <sup>MCA 5, 7</sup>		X		X*	
Access to Child/Before and After School/Respite Care <sup>MCA 5, 12</sup>			X		
Family Support and Advocacy <sup>MCA 5, 9, 10</sup>				X	

# Highlights from 2012

## Western Maryland Action Planning

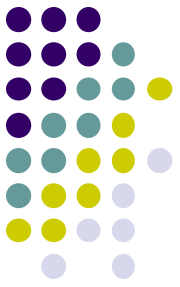


- “Develop a diagnostic team”
- “Develop a regional center to encompass all therapy, diagnosis and treatment.”
- “Create child care/ resource centers and in-/out-of-home respite care that serves CYSHCN.”
- “Provide a community center for a centralized team approach for medical and specialty care (OT, PT, SLP, medical).”
- “Train staff for direct care; identify a location; develop a relationship between specialists and local professional providers.”



# THE PLAN

# Overall Plan Strategies (synthesized from all meetings)



1. Train providers how to best meet the needs of children with ASD/DD and their families (*including medical, school and child care personnel*)
2. Initiate development of medical homes
3. Promote family/professional partnerships through education and info dissemination
4. Build a family-led policy influence infrastructure primarily around the issue of insurance and financing
5. Develop multidisciplinary clinics in rural areas
6. Create regional 'hubs' for information, resources and point-of-entry
7. Engage and partner with higher education programs and facilities
8. Focus on provider recruitment and retention

# STRATEGY I: Train providers how to best meet the needs of children with ASD/DD and their families



## WHO AND WHAT TO TRAIN ON?

### Primary care providers

- Developmental screening
- Online resources ( Bi-PED, MCHAT scoring)
- Youth Health Care Transition
- Medical and Dental Home??
- Insurance navigation, coding and proper billing ( incl. Medical Home functions)
- How best to serve CYSHCN with ASD and DD
- How to partner with families

### Allied Health/Habilitative Services Providers

- Youth Health Care transition
- Medical Home awareness
- Insurance navigation, coding and proper billing (incl. Medical Home functions)
- How best to serve CYSHCN with ASD and DD
- How to partner with families

### School teachers, staff, and administrators

- How best to serve CYSHCN with ASD and DD
- Behavior management techniques
- How to partner with families

### Child Care Providers

- Developmental Screening +
- How best to serve CYSHCN with ASD and DD
- Behavior management techniques
- How to partner with families

### Respite Providers

- How best to serve CYSHCN with ASD and DD
- Behavior management techniques
- How to partner with families



# SUB-STRATEGY I: Training and education for school and child care personnel



## **Establish a statewide, universal education and training system**

- use a tiered approach
- available to all public and private providers in Maryland serving individuals on the autism spectrum across the lifespan

## **Expand existing initiatives**

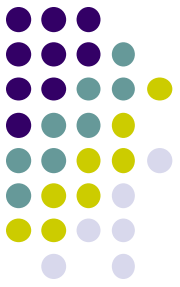
- ??

## **Evaluate the availability and effectiveness of current training opportunities for school personnel related to:**

- ASD/DD awareness
- Classroom behavioral interventions
- Family/professional partnerships

# STRATEGY 2: Initiatives to Develop Medical Homes

(corresponds to “centralized team approach for medical and specialty care”)



## ***SUB-STRATEGIES***

- **Train and provide technical assistance to Primary Care Providers**
  - Learning Collaborative?
- **Train community-based providers**
- **Train families**
- **Train youth**
- **Expand existing programs for medical home development**
- **Improve telemedicine infrastructure**
- **A parent navigator will serve as a liaison between the parent and provider**



# STRATEGY 3: Promote Family/Professional Partnerships through Education and Information Dissemination



## ***SUB-STRATEGIES***

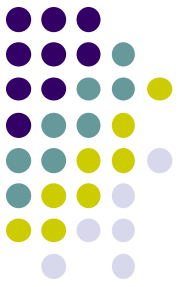
### **Train parents/ families:**

- Insurance coverage expectations in Maryland
- How to access health care financing
- How to find needed services (i.e. habilitative, respite, child care, support groups, etc.)
- How to partner with policymakers and influence policymaking
- Health Care transition
- How to partner with school and child care personnel
- IEP and 504s

### **Develop infrastructure to disseminate timely, accurate information to parents/families**

- Find out from Local Health Departments the demographic/cultural/ethnic/linguistic characteristics of the county/region.
- Facilitate a cultural competency analysis of available services and resources according to county/region demographics.
  - (i.e.) develop and disseminate to families a list of questions to ask when looking for a service
  - Disseminate information to families & community providers about insurance coverage expectations in Maryland - Compile the information & prepare consumer-friendly references

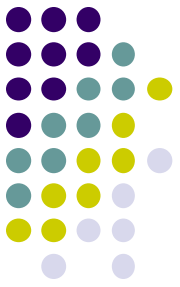
# STRATEGY 4: Build a family-led policy influence infrastructure for CYSHCN issues, primarily adequate insurance and financing



## **SUB-STRATEGIES**

- **“Health Policy Leaders” – Expand PPMD Health Leaders program; Hire a policy coordinator to build a “policy influence” infrastructure for CYSHCN issues in Maryland.**
  - Educating the legislators & regulatory agency (HSCRC) on the costs incurred by families with children with special health care needs & the effects of lower reimbursement rates on the availability of service providers (Southern MD and Eastern Shore)
  - Include families of CSHCN on decision-making bodies charged with determining levels of mandatory coverage of CSHCN
- **Explore Medicaid Buy-in option for Maryland CYSHCN**
- **Establishing a catastrophic fund for families of children with special health care needs using a sliding scale (use New Jersey's catastrophic fund as a model)**

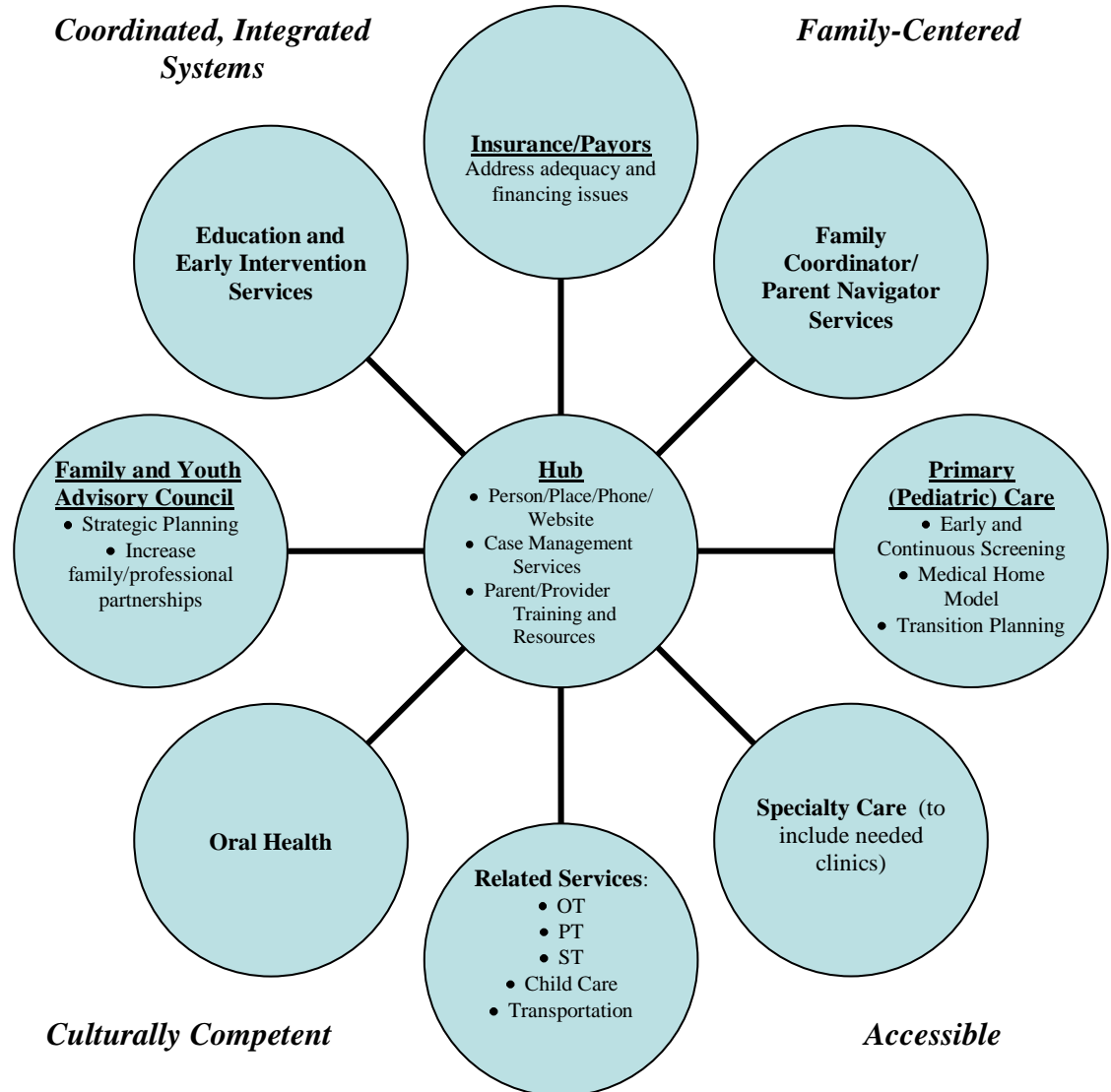
# STRATEGY 5: Develop multi-disciplinary clinics in rural regions



## ***SUB-STRATEGIES***

- Facilitate meetings and some seed money (\$20,000-\$25,000) to pilot development of a diagnostic team (physician, developmental pediatric doctor, neuro-psychologist, speech/language pathologist, LP, occupational therapist, physical therapist, audiologist, assistive technologist, vision therapist, nutritionist, social worker, behavioral specialist, educator not in a district dictated by age and disability of an individual) / regional center to encompass all therapy diagnosis and treatment in Western Maryland.
- Partner to send needed specialists to Western MD facilities to provide needed therapies and specialty care.
- Provide a community center for centralized team approach for medical and specialty care - medical, OT, PT, SLP ( multi-disciplinary team approach), and oral health??
  - Training staff for direct care; identify a location; develop a relationship between specialists and local professional providers; and
  - A resource navigator (person) to community services (Western MD)

# STRATEGY 6: Regional hubs for information, resources, services, and point of entry



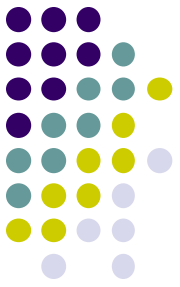
# STRATEGY 7: Engage and partner with higher education programs and facilities



## ***SUB-STRATEGIES***

- **Facilitate regional meeting(s) between universities and community and clinical providers to develop collaborative plans to educate students through partnerships with clinicians while serving the medical needs of the CYSHCN community.**
  - Connect faculty and students from relevant programs in community colleges and universities to efforts to provide multi-disciplinary clinics/ services in Western and Southern Maryland and the Eastern Shore.
- **Could expand the Prince George's Community College's Multi-Disciplinary Developmental Clinic**
- **Expand existing efforts to connect students/programs to families of CYSHCN with ASD/DD.**
- **What about engaging students from community colleges offering programs for students with ID/DD? (collaboration with self-advocates entering transition)**

# STRATEGY 8: Provider recruitment and retention



## ***SUB-STRATEGIES***

- **Establish incentive program to encourage & maintain professionals to practice in rural areas**
- **Expand existing efforts to connect students/programs to families of CYSHCN with ASD/DD**
  - PPMD Family as Faculty program
  - Maggie's Light Community Works program



**Priority By Priority**

**SMALL GROUP DISCUSSIONS  
AND WORK**

# Matching Priorities and Strategies



## *PRIORITIES*

- Adequate Health Insurance and Financing
- Access to Needed Health Care (therapies; mental health services)
- Needed services are Community Based and Easy to Use
- Training for school and child care personnel

## *STRATEGIES*

- Train Providers (medical, school and child care)
- Medical Homes
- F/P Partnerships
- Policy Influence
- Multidisciplinary Clinics
- Regional Hubs
- Recruit/Retain Providers
- Higher Ed Partnerships



# Form groups of 4 to 7 people



## ***GROUP FACILITATOR***

- Keeping the group on topic
- Keeping the discussions moving according to the timeframe
- Reporting out to the larger group

## ***GROUP RECORDER***

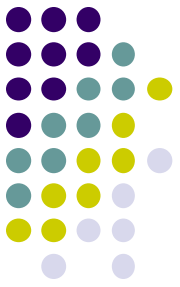
- Recording group members' names and contact information
- Capturing the main points of group discussions/ideas/feedback
- Returning group worksheet to Meeting Facilitator

# Priority: Adequate Insurance and Financing



Strategy	Time Table	CURRENT Partners	POTENTIAL Partners
Catastrophic Illness Relief Fund	2+ years out from political feasibility	None	MDLC & MD AAP Lobbyists; CoC; Families; Legislators
Medicaid Buy-In Program	Research is happening now	OGPSHCN; MIPAR; PPMD; CoC; Medicaid	To make it happen: legislators; lobbyists; families
Family-Led Policy Influence	Now; expand existing initiatives	PPMD; PFA; Autism Speaks	Arc; DD Council; Autism Society; MD Coalition of Families
Provider Training (medical billing and coding)	Now; expand existing initiatives	MD AAP; OWCA; JHU; EPSDT	
Other strategies?			

# Group Discussion



- Do the strategies seem reasonable?
- What existing initiatives do you know of in Western Maryland that correspond to the strategies?
- What groups/people/partners can help with each strategy?
- Do you know of existing resources that support the strategies?
- Are there other strategies that apply?

# Priority: Access to needed health care (therapies; mental health services)

Strategy	Time Table	CURRENT Partners	POTENTIAL Partners
Train Providers	Now – expand	B-HIPP Project	MCF; PFA; LEND
Medical Home Development	Now- partner and expand	OGPSHCN; PPMD; JHU; PATH; CARD	PCMH and other state efforts; CARD
Multi-disciplinary clinics	ASAP	?	MWPH; Local Providers/Facilities; LHDs
Regional Hubs	1+ years out from feasibility	OGPSHCN; LHDs; PPMD; MSDE/RttT	?
Provider Recruitment and Retention		Who can help connect higher ed institutions to providers? ↓	MD OPC; MHEC, local colleges and universities; local provider groups
Higher Education Partnerships	Now – expand?	PGCC Developmental Clinics	MHEC
Other strategies?			

# Group Discussion



- Do the strategies seem reasonable?
- What existing initiatives do you know of in Western Maryland that correspond to the strategies?
- What groups/people/partners can help with each strategy?
- Do you know of existing resources that support the strategies?
- Are there other strategies that apply?

# Priority\*: Training and Education for School and Child Care Personnel



Action	Time Table	CURRENT Partners	POTENTIAL Partners
Statewide, universal education and training system	Wait and see	Local Education Agencies; Maryland State Department of Education; Local Infants and Toddlers programs; Maryland Department of Health and Mental Hygiene; PACT; ??	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.
Expand existing training initiatives		PACT, Pathfinders for Autism	??

*\* This is a sub-strategy for the broader strategy of "Training providers"*

# Priority\*: Training and Education for School and Child Care Personnel Cont'd



Action	Time Table	CURRENT Partners	POTENTIAL Partners
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		Local Education Agencies; Maryland State Department of Education; Family Support Centers; The Parents' Place of Maryland (PPMD)
Other strategies?			

*\* This is a sub-strategy for the broader strategy of "Training providers"*

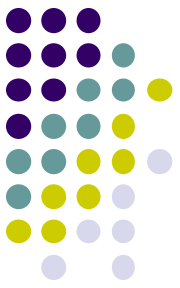
# Group Discussion



- Do the strategies seem reasonable?
- What existing initiatives do you know of in Western Maryland that correspond to the strategies?
- What groups/people/partners can help with each strategy?
- Do you know of existing resources that support the strategies?
- Are there other strategies that apply?



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



Strategy	Time Table	CURRENT Partners	POTENTIAL Partners
Medical Home Development	Now- partner and expand	OGPSHCN; PPMD; JHU; PATH; CARD	PCMH and other state efforts; CARD
Family/Professional Partnerships	Now - expand	PPMD; MD AAP; PFA; OWCA; Maggie's Light	MCDD
Multi-disciplinary clinics	ASAP	?	MWPH; Local Providers/Facilities; LHDs
Regional Hubs	1+ years out from feasibility	OGPSHCN; LHDs; PPMD; MSDE/RttT	?

# Priority: Needed Services are Community-Based and Easy to Use (con't)



Strategy	Time Table	CURRENT Partners	POTENTIAL Partners
Provider Recruitment and Retention		Who can help connect higher education institutions to providers?	LEND; MD OPC; MHEC, local colleges and universities; local provider groups
Higher Education Partnerships	Now – expand?	PG and BC Developmental Clinics	MHEC; local colleges and universities
Other strategies?			

# Group Discussion



- Do the strategies seem reasonable?
- What existing initiatives do you know of in Western Maryland that correspond to the strategies?
- What groups/people/partners can help with each strategy?
- Do you know of existing resources that support the strategies?
- Are there other strategies that apply?

# Are there any strategies (to address defined priorities) missing from the plan?

	Train Providers	Med Home	F/P Partnerships	Policy Influence	Multi-D Clinics	Regional Hubs	Higher Ed Partnerships	Provider Recruitment
Adequate Health Insurance and Financing	X	X	X	X				
Access to Needed Therapies	X	X			X	X	X	X
Needed Services are Community-Based and Easy-to-Use		X	X		X	X	X	X

# Are there any strategies (to address defined priorities) missing from the plan?

	Train Providers	Med Home	F/P Partnerships	Policy Influence	Multi-D Clinics	Regional Hubs	Higher Ed Partnerships	Provider Recruitment
Mental Health Treatment and Services	X	X			X	X	X	X
Access to Primary and Specialty Care	X	X			X	X	X	X
Training and Education to School and Child Care Personnel	X		X					

# Wrap Up



- What will it take to carry out this plan?
- Final Thoughts?
- Follow Up
- Meeting Evaluation



**THANK YOU!**