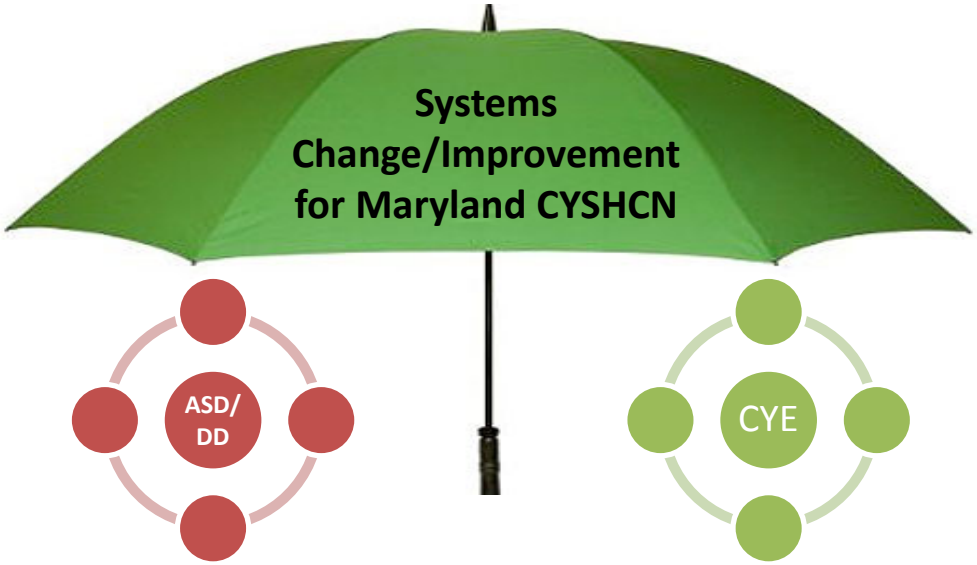
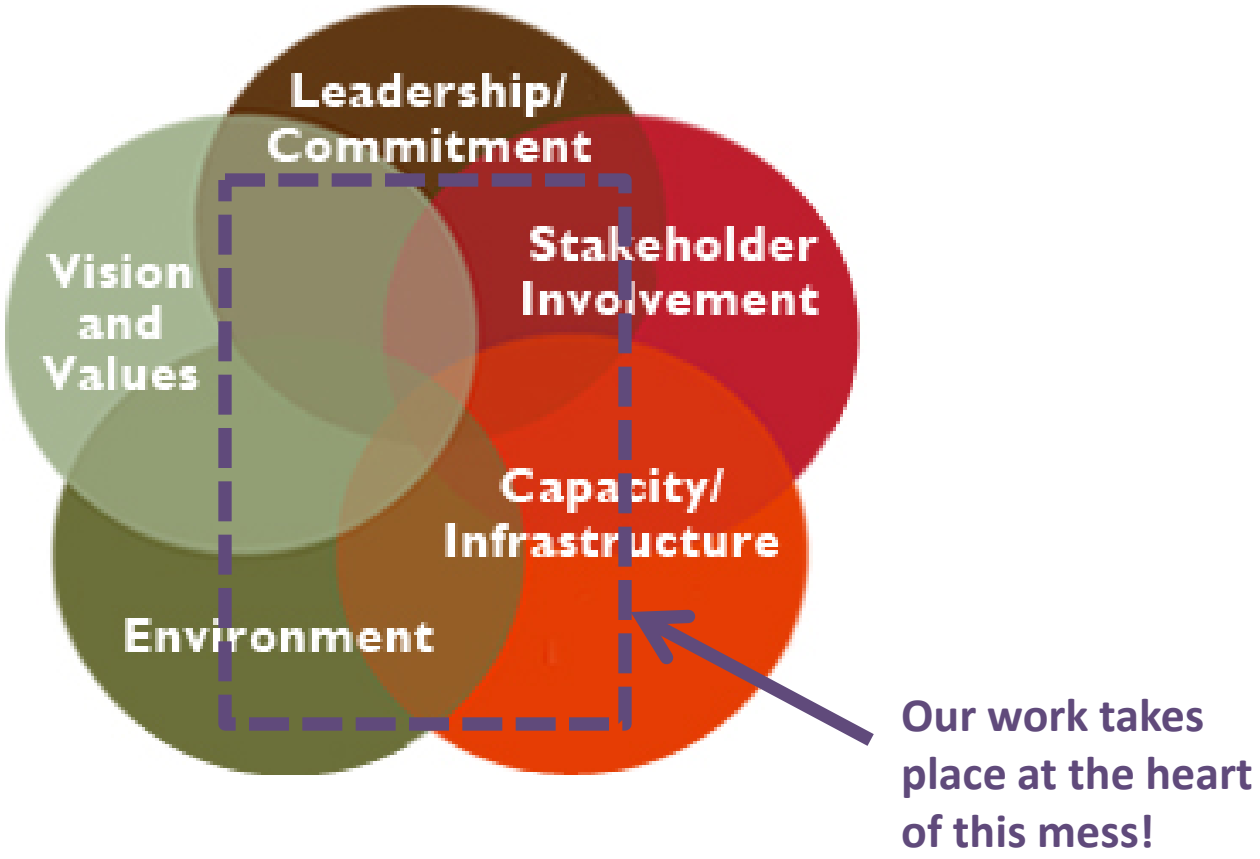


Community of Care
Maryland Consortium for Children with Special Health Care Needs

Systems Change Grants for CYSHCN; 2013-2016

CoC Meeting

10.23.13



SYSTEMS CHANGE IN MARYLAND

D70 (COC!), ASD/DD, AND CYE GRANTS

What is a Health System?

"consists of all organizations, people and actions whose primary intent is to promote, restore or maintain health." Its goals are "improving health and health equity in ways that are responsive, financially fair, and make the best, or most efficient, use of available resources"

World Health Organization. Health Policy and Systems Research: A Methodology Reader. 2002

Source: Federal D70 Grants Evaluation Findings Webinar; JSI; 07/11/12

What does it mean to build an integrated system?

"building blocks do not alone constitute a system, any more than a pile of bricks constitutes a functioning building. It is the multiple relationships and interactions among the blocks—how one affects and influences the others, and is in turn affected by them—that convert these blocks into a system."

Don de Savigny and Taghreed Adam (Eds). Systems thinking for health systems strengthening. Alliance for Health Policy and Systems Research, WHO, 2009.

Source: Federal D70 Grants Evaluation Findings Webinar; JSI; 07/11/12

Strategies for Systems Integration

1. **Build, enhance, and maximize partnerships**
2. Engage family and youth as partners, leaders, and agents of change
3. Use Continuous Quality Improvement (CQI)
4. Use Data to Build Capacity and Measure Impact
5. Provide technical assistance, resources, and support
6. Promote policy and legislative changes

Source: Federal D70 Grants Evaluation Findings Webinar; JSI; 07/11/12

A recent study shows…

While participation in a medical home collaborative was a catalyst for medical home changes in pediatric practices, real transformation requires several attributes:

- a culture of **quality improvement**
- a focus on **family-centered care with parents as improvement partners**
- **teamwork**/team-based care
- **care coordination**.

McAllister, J.W., Cooley, W.C., Van Cleave, J., Arauz Boudreau, A., & Kuhlthau, K. (2013). Medical home transformation in pediatric primary care – what drives change? *Annals of Family Medicine (11)* Supplement, pp. S90-S98.

Autism and Developmental Disabilities (ASD/DD) and Epilepsy (CYE) Grants

SYSTEMS CHANGE GRANTS

What are we trying to do?

- Strengthen, maximize, and maintain **partnerships**
- **Increase** public and provider **awareness** of signs, symptoms, etc.
- Make services **easier to use** and better organized for families
- Increase **family involvement** and family-professional partnerships
- Improve **screening** and access to **medical homes**
- Improve **youth health care transition**

Intended Outcomes of the Grants

- Improved organization and capacity of **community-based service systems** so that they are easy to use for families of Maryland CYSHCN-ASD/DD and CYE
- Increased public and provider awareness of the signs and symptoms of ASD and other related DDs and CYE
- Reduced barriers to **screening**, referral and diagnostic services for CYSHCN-ASD/DD
- Increased access to culturally competent **medical homes** that coordinate care with pediatric subspecialties
- Improved **family-professional partnerships** between families of CYSHCN-ASD/DD and CYE, primary care providers, and other stakeholders
- Increase in families and providers who encourage YSHCN-E/SD and ASD/DD to take responsibility for his/her health care needs (youth **transition**)

Logic Model Language

Remember our July meeting on the ASD/DD Plan? - Overall Plan Strategies

1. **Train providers how to best meet the needs of children with ASD/DD and their families (including medical, school and child care personnel) AND**
2. **Initiate development of medical homes**

WHO AND WHAT TO TRAIN ON?

Primary care providers

- Developmental screening; Online resources (Bi-PED, MCHAT scoring); Youth Health Care Transition; *Medical Home (see below);* How best to serve CYSHCN with ASD and DD; How to partner with families

3. **Promote family/professional partnerships through education and info dissemination**

CoC Role in Systems Change Grants

Participate in awareness and outreach activities – we will be sharing information and resources with you and we need your help to disseminate these in your day-to-day work!

- Promote use of enhanced websites (PFA; OGPSHCN Resource Locator; PPMD; MDAAP)

Continue to coordinate and collaborate with fellow CoC members and other stakeholders and LET US KNOW ABOUT IT!!!

- Use and spread what you've learned about family-professional partnerships

Maryland Consortium for Children with Special Health Care Needs

Systems Change Grants

The Parents Place of Maryland (PPMD), in partnership with the Office for Genetics and People with Special Health Care Needs (OGPSHCN) from the Maryland State Department of Health and Mental Hygiene is excited to announce that it has been awarded federal grants to improve access to care for children with Autism Spectrum Disorder and other Developmental Disabilities and children and youth with Epilepsy.

SYSTEMS CHANGE

Although each of the grants addresses the needs of children with specific conditions, the ultimate goal of the project partners is to promote development of integrated health systems for all CYSHCN in Maryland.

Rather than having a number of isolated components that rarely communicate with each other, **an integrated health system** consists of

ABOUT THE PROJECTS

"State Implementation Grant for Improving Services for Maryland Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities" project aims to strengthen the leadership and infrastructure needed to identify Maryland CYSHCN-ASD/DD by 24 months and ensure access to a family-centered medical home and comprehensive, coordinated care; reduce barriers to screening, referral and diagnostic services and increase access to medical homes that coordinate care with pediatric subspecialties; and support the development of family-professional partnerships among CYSHCN-ASD/DD and the system of care.

Project partners include the Maryland Chapter of the American Academy of Pediatrics, Pathfinders for Autism, and Johns Hopkins School of Public Health.

To view the project's logic model, click here.

"Access Improvement Grant for Maryland Children and Youth with

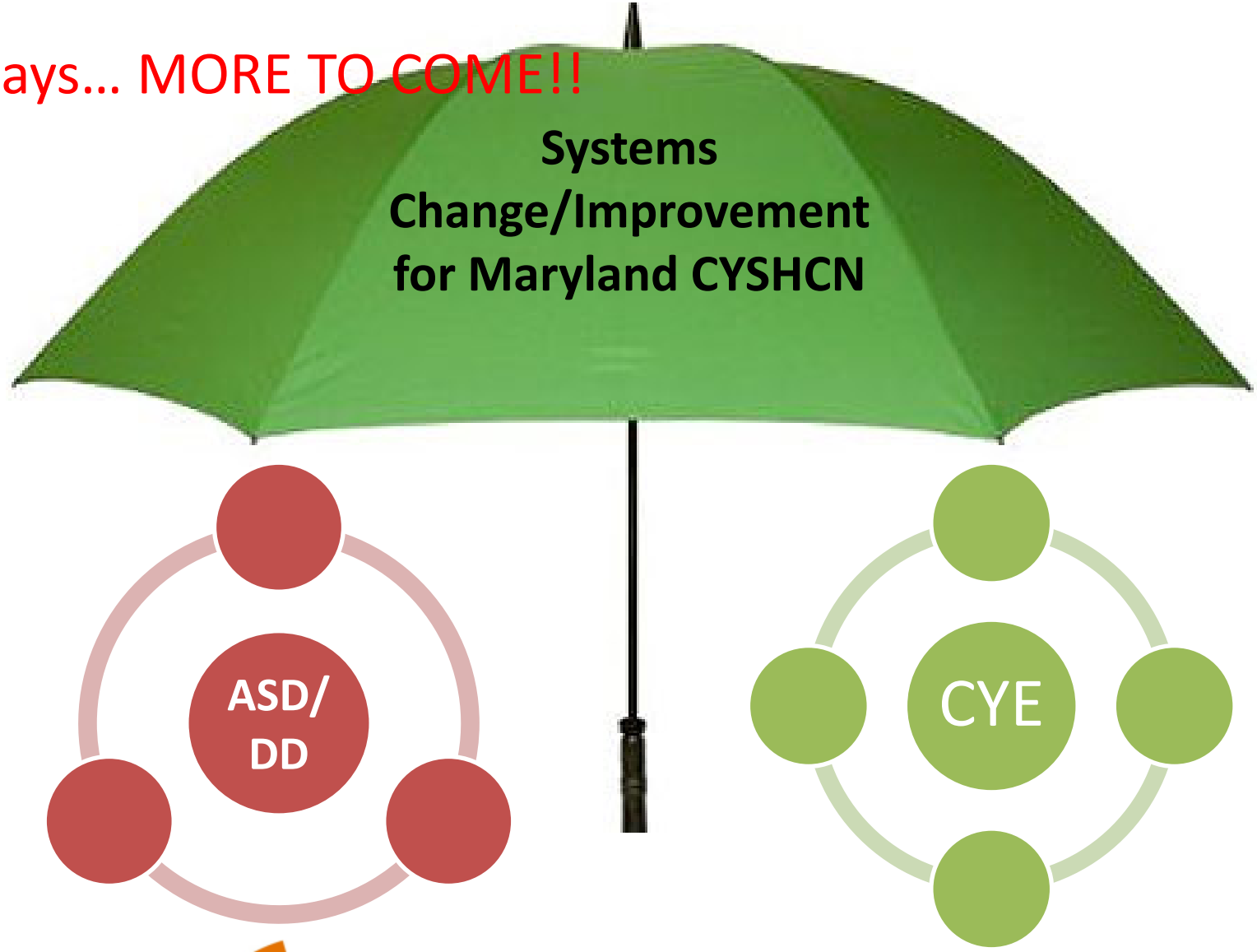
ASD/DD Project Logic Model

Target Population and Needs	Inputs	Activities	Outputs	Outcomes
• Maryland children and youth with special health care needs with autism spectrum disorders and other developmental disabilities (CYSHCN-ASD/DD) and their families • Many CYSHCN-ASD/DD do not receive timely diagnostic and intervention services, especially low-income and minority children. • Inadequate access to medical homes • Lack of family-professional partnerships • Needed services are difficult for families to access	• PPMD and OGPSHCN Project Directors, Project Manager, Family Partnerships Coordinator, Parent Medical Homes Partners, Medical Homes Coordinator, Latino Resource Coordinator Administrative Coordinator, JHSPH Evaluators • Statewide and regional Advisory Panels, to include families and youth • Key Partners' expertise and staff time including MD AAP, PFA, JHU Medical Homes Project, CNMC • Primary care practices serving CYSHCN-ASD/DD • Various developmental and ASD screening tools and curricula; medical homes training curricula, PFA Providers Toolkit including Learn the Signs Act Early • MD AAP, PFA, PPMD, and OGPSHCN resource websites	• Regularly engage state and local stakeholders to increase coordination and collaboration • Conduct awareness and outreach activities for families and providers, including low-income and minority families and providers who serve them • Enhance and promote use of MDAAP website to include resource pages for medical home, ASD, and developmental screening • Enhance, expand and promote use of statewide resource repository and information websites • "Screening and Beyond" QI Learning Collaborative with primary care practices across the state • Parent medical home partners in primary care practices	• Number of meetings and participating stakeholders, including families • Number of families, providers and other stakeholders who receive information, services, resources and/or training • 3 new MDAAP website resource pages and number of members who use them for practice enhancement • Percent of CYSHCN-ASD/DD that are identified by 24 months of age, receive first evaluation by 36 months of age, and are enrolled in interventions services by 48 months of age • A minimum of 10 practices (at least 2 from each region of the state) show increased rates of developmental/ASD screenings, timely referrals, and entry into intervention services for CYSHCN-ASD/DD • A minimum of 5 practices (at least one from each region of the state) show growth in self- and family-scoring on cultural competency, family-centeredness, and care coordination domains of the Medical	• Improved organization and capacity of community-based service systems so that they are easy to use for families of Maryland CYSHCN-ASD/DD • Increased public and provider awareness of the signs and symptoms of ASD and other related DDs • Reduced barriers to screening, referral and diagnostic services for CYSHCN-ASD/DD • Increased access to culturally competent medical homes that coordinate care with pediatric subspecialties • Improved family-professional partnerships between families of CYSHCN-ASD/DD, primary care providers, and other stakeholders

CYE Project Logic Model

Target Population and Needs	Inputs	Activities	Outputs	Outcomes
• Maryland children and youth with special health care needs with epilepsy and other seizure disorders (CYSHCN-E/SD) and their families • Many CYSHCN-E/SD do not receive timely diagnostic and treatment services, especially those in rural areas and low-income and minority children. • Inadequate access to medical homes • Lack of family-professional partnerships • Needed services are difficult for families to access	• PPMD and OGPSHCN Project Directors, Project Manager, Project Coordinator, Family Partnerships Coordinator, Parent Medical Homes Partners, Medical Homes Coordinator and Assistant, Latino Resource Coordinator, JHSPH Evaluators • Statewide CoC, EPAB and regional Advisory Panels, to include families and youth • Key Partners' expertise and staff time including MD AAP, AN/EFCR, JHU Medical Homes Project, CNMC/Maryland Pediatric Improvement Partnership • Primary care practices serving CYSHCN-E/SD • Various developmental and ASD screening tools and curricula; medical homes training curricula, PFA Providers Toolkit including Learn the Signs Act Early • MD AAP, PFA, PPMD, and OGPSHCN resource websites	• Regularly engage state and local stakeholders to increase coordination and collaboration • Conduct awareness and outreach activities for families and providers, including low-income and minority families and providers who serve them • Enhance and promote use of MDAAP website to include resource pages for medical home and E/SD treatment • Enhance, expand and promote use of statewide resource repository and information websites • "Collaborative Care" and medical home QI Learning Collaboratives with primary care practices across the state; stipends • Parent medical home partners in primary care practices ▪ Provide phone consultations for PCPs statewide to connect with pediatric neurologists	• Number of meetings and participating stakeholders, including families • Number of families, providers and other stakeholders who receive information, services, resources and/or training • 2 new MDAAP website resource pages and number of members who use them for practice enhancement • A minimum of 10 practices (at least 2 from each region of the state) show increased rates of care collaboration for CYSHCN-E/SD • A minimum of 5 practices (at least one from each region of the state) show growth in self- and family-scoring on cultural competency, family-centeredness, and care coordination domains of the Medical Home Index • Number of youth participants in TEEN program who take responsibility for their own health care	• Improved organization and capacity of community-based service systems so that they are easy to use for families of Maryland CYSHCN-E/SD • Increased public and provider of E/SD signs and symptoms and co-occurring conditions and community resources • Increased access to culturally competent medical homes that coordinate care with pediatric subspecialties • Improved family-professional partnerships between families of CYSHCN-E/SD, primary care providers, and other stakeholders • Increase in families and providers who encourage YSHCN-E/SD to take responsibility for his/her health care needs

As always… MORE TO COME!!



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