Maryland Planning Grant for Autism
and other Developmental Disabilities

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Genetics and Children with Special Health Care Needs
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Maryland Commission on Autism
The Office for Genetics and Children with Special Health Care Needs (OGCSHHCN)

- Maryland’s Title V Children with Special Health Care Needs (CSHCN) program -
  - Provide and ensure access to comprehensive health care, including long-term care services, for CYSHCN
  - Facilitate the development of family-centered, community-based, and culturally competent comprehensive care for CSHCN and their families.

- OGCSHHCN’s mission is to assure a comprehensive, coordinated, culturally competent and consumer-friendly system of care that meets the needs of Maryland’s CYSHCN and their families.
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)
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:

- is a two-year grant that will fund development of a comprehensive statewide plan to improve the system of health care and related services for children and youth with special health care needs with ASD and other DD.
- These funds are part of the federal Combating Autism Initiative and are designed to lead to future implementation grants to enact the state plan
Emphasis is placed on the MCHB Core Outcomes for CSHCN:

- **Families** of children and youth with special health care needs partner in decision making at all levels and are satisfied with the services they receive;

- Children and youth with special health care needs receive coordinated ongoing comprehensive care within a medical home;

- Families of CSHCN have adequate private and/or public insurance to pay for the services they need;

- Children are screened early and continuously for special health care needs;

- Community-based services for children and youth with special health care needs are organized so families can use them easily;

- **Youth** with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.
**Planning Grant Timeline**

**Year 1**
- Convene AHC LT and hold regular meetings throughout project
- 5 Strategic Planning Meetings (regional)* – review needs; prioritize; and strategize

**Year 2**
- Draft State Plan
- Statewide Planning Meeting*
- 5 Strategic Planning Meetings (regional)* – review draft plan and solicit feedback
- Finalize State Plan. Apply for State Implementation Grant.

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Evaluate and document strengths and needs of current developmental screening and medical home initiatives; incorporate findings into State Plan.

*these will be markedly different (in structure and in roles of invited stakeholders) than the MCA regional meetings and listening sessions. Findings from MCA meetings and listening sessions will be incorporated into these activities.
Similarities and Differences with MCA

Maryland Planning Grant for ASD and other DD – Differences and Similarities with MCA

**Maryland Commission on Autism**

**Purpose:** "Advise and make recommendations to the Governor, General Assembly, and relevant state agencies regarding matters concerning services for individuals with Autism Spectrum Disorders at all state levels including: health care, education, and other adult and adolescent services."

- Under-funding or lack of funding to any part of the system of care could lead to system failure.

- Emerging framework of change is: 5 systems components derived from the Commission’s activities thus far – (1) diagnosis and referral; (2) interventions; (3) supports; (4) communities of care; and (5) research and education. Five cross-cutting themes were identified, including access, quality, communication, training, and funding.

- Incorporated stakeholder input into information-gathering activities through a series of regional listening panels. Stakeholder input is also gained through workgroup participation.

**Maryland Planning Grant for Improving Services for CYSHCN with ASD and other DD**

**Purpose:** "Development of a comprehensive statewide plan to improve access to comprehensive, coordinated health care and related services for children and youth with special health care needs with ASD and other DD."

- Designed to lead to a future implementation grant of up to $300,000/year to enact the state plan.

- Framework of change is: MCHB 6 key components of a system of care for CYSHCN (1) family-professional partnerships; (2) medical home; (3) adequate health insurance and financing; (4) early and continuous screening; (5) services are community-based and organized for ease-of-use; and (6) transition to adult health care.

- Project is designed to incorporate stakeholder input into all phases of plan development, at the state and regional level, through fully collaborative activities to include data analysis, priority setting, strategy development, and final plan approval.
Framework – Core Outcomes for CYSHCN

- **Partnerships** between professionals and families of CYSHCN with ASD and DD
- **Transition** to adult health care
- **Community** services organized for easy use by families
- **Early and continuous screening** for ASD and other DD
- **Access to** a medical home which coordinates care with subspecialists and community-based services
- **Access to** adequate health insurance and financing of services
- **System of Health Care and Related Services for CYSHCN with ASD and DD**
Figure 1: Conceptual Model Linking Systems of Care and Communities of Care Through Identification, Intervention, Supports, and Research

System Components

- **Diagnosis and Referral**
  - Physicians, early interventionists, clinicians and others applying state of the art techniques to identify and refer children and youth for services.

- **Research and Education**
  - Research and education personnel collaborate with families and clinicians to understand what works, improve systems, and disseminate information.

- **Interventions**
  - Clinicians, schools, providers and homes collaborate to implement effective and state of the art interventions.

- **Communities of Care**
  - Communities understand and support families in their efforts to integrate their children, including child care, schools, churches, stores, and other public settings.

- **Supports**
  - Community and other professional and natural supports are implemented to ensure the success of interventions, including cross-agency planning and communication.
Links between CSHCN Framework and MCA Framework

Research and Education
(personnel collaborate with families and clinicians)

Medical Services
Workgroup

Interventions
(Clinicians, schools, providers and homes collaborate to implement effective and state of the art interventions)

Communities of Care
(Communities understand and support families in their efforts to integrate their children)

Supports
(Community/professional/natural supports implemented to ensure success of interventions, including cross-agency planning and communication)

Funding and Resources
Workgroup

Youth Transition to Adulthood

Medical Home

Easy to Use Community Based Systems

Adequate Insurance and Financing

Early and Continuous Screening

Workforce Dev. Workgroup

System of Health Care and Related Services for CYSHCN with ASD and DD

Diagnosis and Referral
(physics, EIs, clinicians and others applying state of the art techniques to identify and refer children and youth for services)
OGCSHCN Vision for Regional Centers for Maryland CYSHCN and Their Families

Education and Early Intervention Services

Family and Youth Advisory Council
- Strategic Planning
- Increase family/professional partnerships

Related Services:
- OT
- PT
- ST
- DME/Assistive Technology

Coordinated, Integrated Systems

Insurance/Payers
Address adequacy and financing issues

Hub
- Person/Place/Phone/Website
- Case Management Services
- Parent/Provider Training and Resources

Primary (Pediatric) Care
- Early and Continuous Screening
- Medical Home Model
- Transition Planning

Specialties Care
- All Needed Specialties (i.e. Oral, Mental Health)
- Workforce Dev.
- Local Universities

Family Support
- Family Navigator/Parent Coordinator
- Parent Mentoring
- Child Care
- Transportation
- Respite

Family-Centered

Culturally Competent

Accessible

Maryland Regions
Western
Capital
Central
Southern
Eastern Shore

Hub
Alliance and Partnership
Insurance and Finance
Primary Care
Family Support
Related Services
Specialty Care
Advisory Council
Early and Intervention
Respite
Hub

Address adequacy and financing issues

Insurance/Payers
Hub
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**Family-Centered**
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  - Address adequacy and financing issues
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  - Family Navigator/Parent Coordinator
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  - Transportation
  - Respite
- **Primary (Pediatric) Care**
  - Early and Continuous Screening
  - Medical Home Model
  - Transition Planning

**Culturally Competent**

**Accessible**
Questions?

Thank you!

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