2011 AMCHP and Family Voices National Conferences

WORKING TOGETHER TO IMPROVE MATERNAL AND CHILD HEALTH

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The Role of Family Organizations in Achieving the 6 Core Outcomes

A Tale of Two States (MD & NJ) & Two Family Organizations

State Title V CSHCN programs, family leaders, providers, and other partners are being asked to work together to implement the six core outcomes for CYSHCN.

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The Context: Barriers

- State funding and position cuts & hiring freezes have impacted health, educational, and social services
- System is complex; multiple agencies and organizations assuming responsibility for a portion of the CYSHCN population or a specific set of services
- Insufficient integration, shared planning, or sharing of resources to address needs

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50 Reasons Not To Change

Why Family organizations?

- Indispensable partners in improving the quality of and access to service systems
  - Bring multiple perspectives & diverse strengths and talents that can help achieve goals
  - Provide "reality check" with experiences & knowledge about communities, families, & services
  - Able to reach groups of families and people to provide information resources, and to gain knowledge
  - Critical for advocacy & accountability

Family Organization Roles

- Source of knowledge and support
- Provide perspective
- Build relationships
- Communicate with honesty
- Reach out and engage families, especially families from underserved communities
- Build parent leadership capacity & *sustainability*
- Encourage changes
- Monitor implementation to make sure improvements take place

Two examples

- Parents Place of Maryland
- Statewide Parent Advocacy Network of NJ

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Community of Care

Maryland Consortium for Children with Special Health Care Needs

The Parents' Place of Maryland
Maryland's Family-to-Family Health Information Center
Parent Training and Information Center
Maryland Family Voices
410-768-9100
www.ppmd.org

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Community of Care

Maryland Consortium for Children with Special Health Care Needs

The Partners

The Parents' Place of Maryland
Title V CSHCN (OGCSHCN)
Johns Hopkins School of Public Health
MD Chapter AAP
Johns Hopkins School of Medicine
Maryland Health Kids (EPSDT)

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Maryland's SIG Goals

- Implement the leadership & infrastructure to achieve & sustain an integrated, *community-based system* of services
- Improve *developmental screening* & linkage with appropriate community-based services
- Improve access to *medical homes* that are part of an integrated, community-based system of services
- Increase focus on the unique needs of YSHCN, including health care *transition*

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Maryland Consortium for CYSHCN (CoC)

Broad alliance of concerned stakeholders that engage in shared planning, implementation, and evaluation of strategies to achieve the six core outcomes for CYSHCN

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

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Maryland CoC

- Educate members, stakeholders, families, providers on needs of CYSHCN and their families
- Support & enhance ongoing efforts at the community level through mini-grants and collaborative activities
- Guide, inform, and evaluate the Title V needs assessment & statewide parent survey
- Influence policy & legislation
- Serve as an incubator for family leadership

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Maryland CoC

- Persistent focus on key systems & central issues
- Understanding specific changes needed
- Working to bring about changes

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Developmental Screening

- Collaborative regional training for pediatricians
  - MD Chapter AAP, EPSDT, pediatricians, PPMD staff, and Pathfinders for Autism
  - Over 450 pediatric practices
- Quarterly workgroup
  - Started with ABCD
  - Increased Medicaid reimbursement & added 30 mos. screening
  - Includes all partners above + early intervention

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Developmental Screening

- Intensive support for selected pediatric practices
  - provide on-site intensive support for office implementation & collect data
- Outreach and training for family practice sites
  - reaching out to family practice sites providing training and support

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Developmental Screening

- Family initiative in low income urban communities
  - Families reaching out to families to enhance understanding of developmental screening ; providing information, resources , & support

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Opportunities: Title V CSHCN 5 year priorities

- Sustain strategic partnerships
- Medical Home
- Data Systems & Sharing
- Transition

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www.marylandcoc.com
Maryland Consortium for Children with Special Health Care Needs
home page | about the project | consortium | core outcomes | resources | summit | contact us
Home Page
The Maryland Community of Care Consortium for Children with Special Health Care Needs (COCC) is dedicated to improving systems of care for children and their families in the state.
The COCC is a working group of diverse stakeholders, including families, providers, advocates, consumers, administrators, and professionals from the public and private service systems.
Funded by a grant from the federal Maternal and Child Health Bureau, the COCC offers a forum for information exchange, problem solving, consensus building, and collaborative action to address gaps and barriers in services for children with special health care needs (CSHCN) and their families.
Using the national agenda for CSHCN and core outcomes as a starting point, the COCC works to create systems of care that promote optimal health, functioning, and quality of life for Maryland CSHCN and their families.
Why the Consortium?
More than 217,000 children in Maryland have special health care needs.
Almost 1 in 4 Maryland households with children report having a child with special health care needs, greater than the national average.
Over 1/3 of Maryland families of CSHCN do not have insurance that is adequate to pay for the services they need.
Only about 55% of families of CSHCN report that they are partners in decision-making and satisfied with care; Maryland ranks 42nd among the states in successfully achieving this goal.
Data from 2005-06 National Survey of CSHCN
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Integrated Community Systems of Care for CYSHCN & Families-NJ
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NEW JERSEY DEPARTMENT OF HEALTH AND SENIOR SERVICES
DEPARTMENT OF CHILDREN AND FAMILIES
Cover our Kids Community Campaign
NJFAMILYCARE
1-800-701-0710
DHS
PCORE
American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN
New Jersey Chapter
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Core Team & Leadership Team

- Core Team
  - SPAN (FV, F2F, Family WRAP)
  - AAP-NJ/NJPCORE
  - NJDHSS, DHS, DCF
- Leadership Team/ Advisory Committee:
  - Parents
  - Professionals
  - Advocacy organizations
  - HMOs, hospitals, FQHCs
  - Others

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SPAN'S MISSION

- To empower families and inform and involve professionals and other individuals interested in the healthy development and education of children, to enable all children to become fully participating and contributing members of our communities and society.

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SPAN'S FOCUS

- SPAN's foremost commitment is to children with the greatest need due to poverty; disability & SHCN; discrimination based on race, sex, language, or immigrant status; geographic location; or family or other special circumstances
- Our motto: *Empowered Parents: Educated, Engaged, Effective!*

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Focus on Underserved

- Collaboration with
  - NJ Immigration Policy Network
  - Hispanic Directors Association
  - NAACP
  - FQHCs
  - National Center on Cultural Competence
- Resources
  - Traducelo Ahora
  - Language line
  - Diverse staff & volunteers

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"One-Stop" for Families

- Family Voices
- Federation of Families for Children's Mental Health
- Family to Family Health Information Center
- Integrated Systems
- PTI
- Parent to Parent

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SPAN & Medical home

"SPAN is not a place. It is a model of delivering family support that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective."

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Purpose: Integrated Systems

- To engage stakeholders in activities aimed at improving results on the MCHB six core outcomes for children and youth with special healthcare needs and their families (SIG), including CYSHCN-ASD/DD (SIG II)

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Core Outcomes: SIG I & II

- Families are partners at all levels & satisfied with services
- Families have adequate public & private insurance
- There is early and continuous screening to identify needs
- Community-based services are organized so families can access them easily
- Services are provided within the context of a medical home
- YWD make effective transitions to adult life

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Families are partners & satisfied with services

- Family Resource Specialists provide support at SCHS CMUs in each county (SIG I) & at Clinical Enhancement Centers (SIG II)
- Parent leadership development & training
- Parent partners in medical home visits
- Parents co-lead & participate in all workgroups

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Resource Parent Leadership Training
(All available as individual workshops)

- Medical home
- Medically Necessary Services
- Family-Health care professional collaboration with Primary Care Providers & Specialists
- Non-discrimination & cultural competence
- Individualized School Health Plan
- Community Based Waivers for Children
- Transition to Adult Health Services

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Adequate insurance

- Ensuring families and health providers are aware of existing health coverage & other resources
- Enrolling immigrant families
- Advocacy to expand and enhance coverage

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Awareness of health financing resources

- Comprehensive Health Resource Parent training:
  - The Medical Home
  - Health coverage (how to get it & services)
  - Family Care-Children's Program (SCHIP)
  - Medicaid Managed Care & Early Periodic Screening, Diagnosis & Treatment

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Focus on immigrant families

- Outreach to immigrant families
- Identify if they and/or their children are eligible for Medicaid or NJ Family Care
- Assist them with enrollment
- Connect them to other resources

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Early & continuous screening

- Assuring Better Child Development pilot with AAP
- Advocating for use of standard routine screening tools
- Informing families & providers of screening resources such as EI, EPSDT

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Easy to access community services

- Primary care providers are aware of existing community services & how to connect families
- Family Resource Specialists help directly connect families
- Mini-grants to local communities to improve accessibility of services
- Expand use of community service tools
- Partnerships with county FSO & CMOs, SCHS CMUs, REICs

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Medical home

- Over 3 years, expand Medical home pilots to 9 counties:
  - Hospital
  - FQHC
  - 4-6 other pediatric practices in each county
- Parents as partners on medical home teams
- Expand use of medical home tools

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Transition to Adult Life

- Disseminate existing transition tools
- Develop & disseminate additional transition tools for families, youth, & health providers
- Pilot approaches to making health transition more effective
- Training & TA for families, providers, youth
- Statewide Youth Council & website

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Our Integrated Systems Plan

- Develop accurate "map" of strengths & needs NJ's systems of care for CYSHCN & families
- Know how others have addressed these issues
- Facilitate representative stakeholder workgroups to identify strategies to address barriers
- Implement solutions
- Evaluate impact

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NJ Performance on Core Outcomes on CYSHCN Survey

- Outcome 1: Family participation & satisfaction: 55.4%
- Outcome 2: Medical home: 40.8%
- Outcome 3: Adequate insurance: 59.9%
- Outcome 4: Screening 71.7%
- Outcome 5: Easily accessible services: 88%
- Outcome 6: Effective transition: 37.9%

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Participation Opportunities

- Learning Collaboratives
- Quarterly Leadership/ Advisory meetings (75+ organizations!)
- Monthly Medical Home Leadership Action Group conference calls
- Periodic workgroup meetings

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Related SPAN Projects

- Family to Family Health Information Center
- Family WRAP
- CHIPRA Immigrant Outreach & Enrollment Project

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F2F Project Activities

- Provide supports to families:
  - Information/materials & website
  - Training
  - Telephone technical assistance
  - Direct peer-to-peer in person technical assistance to families with limited skills and capacity
  - Develop leadership skills to engage in advocacy and systems change

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Simple Tips

- Be present
- Build relationships
- Be flexible
- Be responsive
- Be insistent
- Follow through
- Offer a variety of opportunities
- Share the vision
- Enhance capacity
- Provide support & resources

(Not so simple to do . .)

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