



2013 MARYLAND PARENT SURVEY --- DEVELOPMENT

Maryland CoC Meeting October 23, 2013

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2010 Survey Background

- Developed by
 - PPMD, OGPSHCN, CMCH
 - with assistance from JHSPH, MCDD, MSDE and Maryland CoC
- Asked parents **what works** and **what doesn't work** for families in Maryland, what services families are getting and what **gaps in services** exist
- Multiple methods of delivery – online, paper, face-to-face; **781** families of CYSHCN responded, representing all regions in Maryland
- Data was analyzed and used in Needs Assessments, and ongoing analyses are shared and disseminated across the state and are being used to inform Title V CSHCN strategic planning in Maryland.

Parent Survey

Dear Parents:

The Parents' Place of Maryland is working with Maryland's Department of Health and Mental Hygiene (DHMH) to conduct this survey to find out about your and your children's health care needs.

About this survey

Each year, states are required to conduct a statewide needs assessment. The purpose of the needs assessment is to identify and establish Maryland's priorities for the work to be carried out over the next 5 years under the federal Title V Block Grant. The Block Grant provides funds for the state to provide services to:

- **Pregnant women, mothers and infants** birth to age 1
- **Children and adolescents** age 1 to 21
- **Children and youth with special health care needs** (CYSHCN are those who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally).

As part of this assessment, we want to know about services for children and youth with special needs in your community and about key issues that affect their health. This needs assessment will help DHMH identify priorities for the next 5 years.

What You as a Parent Can Contribute to the 5-Yr Needs Assessment

- Ideas about what works and doesn't work for your children and family
- Information about services you receive and gaps in those services your family might need
- Insights about what services are like for families who use those services

Your input is critical to improving health and services for children and youth with special needs in Maryland!

If you have any questions or concerns about this survey, PLEASE call Josie Thomas at the Parents' Place of Maryland at 410-768-9100 or email josie@ppmd.org.

Thank you for your help!

Please start the survey here:

Please tell us about where you live

1. What is the zip code and county in which you live? _____ Zip code _____ County _____

About Your Children

2. Please answer the following questions for each of your children ages birth through 21.

Child	Age (years)	Sex of Child	Race/Ethnicity (check all that apply)	Special Needs of Child	Type of special Need	Child's Health Insurance (check all that apply)
1	_____	<input type="checkbox"/> Male <input type="checkbox"/> Female	<input type="checkbox"/> White (Non- Hispanic) <input type="checkbox"/> Black/African American <input type="checkbox"/> American Indian/Alaskan Native <input type="checkbox"/> Latino/Hispanic <input type="checkbox"/> Asian/Pacific Islander Other: _____	Does this child have a special need? <input type="checkbox"/> Yes <input type="checkbox"/> No	If yes, what type of special need?	<input type="checkbox"/> Private (for example: through a parent's employer or self pay) <input type="checkbox"/> Medical Assistance/Medicaid <input type="checkbox"/> Maryland Children's Health Program (MCHP) <input type="checkbox"/> Medicare <input type="checkbox"/> Military <input type="checkbox"/> No Insurance Other: _____
2	_____	<input type="checkbox"/> Male <input type="checkbox"/> Female	<input type="checkbox"/> White (Non- Hispanic) <input type="checkbox"/> Black/African American <input type="checkbox"/> American	Does this child have a special need? <input type="checkbox"/> Yes	If yes, what type of special need?	<input type="checkbox"/> Private (for example: through a parent's employer or self pay) <input type="checkbox"/> Medical Assistance/Medicaid <input type="checkbox"/> Maryland Children's Health

About Your Family's Needs

3. Do any of your children receive any of the following? Please check all that apply.

- Free Lunch
- Reduced lunch
- WIC
- Food Stamps
- None of the above

4. At the present time, are you having difficulty paying for any of the following for you and your family?

	Yes	No
Clothing		
Food		
Housing		

About Support for Your Family

5. In the past 12 months, have you needed assistance with any of the following? CHECK ALL THAT APPLY.

	If YES, check below	If YES: Did you seek help for this?	If you were satisfied with the help you received for this, check below
a. Nutrition for your children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Diet/Exercise for your children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Information about parent support groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Finding services for your children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Child care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

About Your Child's Behavior

6. In the past 12 months have any of your children engaged in or experienced the following? CHECK ALL THAT APPLY.

	If YES, check below	If YES, did you/your child seek help for this?	If you were satisfied with the help you received for this, check below
a. Gangs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Bullying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

About Your Child's Education

7. In the past 12 months, did any of your children need any of the following? CHECK ALL THAT APPLY.

	If YES, check below	Did you seek this service?	If YES, are you satisfied with the services you received?
An evaluation from his/her school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tutoring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Speech/OT/PT	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

About Your Child's Transition to Adulthood

Please answer questions 11 through 15 ONLY if you have a child age 13 or older with special needs. If you don't have a child age 13 or older with special needs, skip to question 16

11. Have any of your child's health care providers discussed having your child see a doctor who treats adults?

(Circle your answer) Yes No Don't Know

About Your Health Care Costs and Financing

17. During the past 12 months, how much would you say your family has paid for your child/children with special health care needs' medical care? Please **do not include** health insurance premiums or costs that were or will be reimbursed by insurance or another source. Please **do include** out-of-pocket payments for all types of health-related needs such as co-payments, dental or vision care, medications, special foods, adaptive clothing, durable equipment, home modifications, any kind of therapy, or other care or supplies needed.

Check ONE

- \$0 (Nothing)
- Less than \$250
- \$250 - \$499
- \$500 - \$999
- \$1000 - \$5000

About Your Family's Health Care

22. What kind of place do you and your children go when you are sick? Please check the place where you go MOST OFTEN. Check only ONE for *You* and one for *Your Children*.

	YOU	Your Children
Doctor's Office		
Hospital Emergency Room (ER)		

How did we use the data?

- Data was analyzed and used in the 2010 Title V Needs Assessment and 2012 ASD/DD Needs Assessment
- Ongoing analyses are shared and disseminated across the state and are being **used to inform Title V CSHCN and PPMD strategic planning in Maryland.**
- Data has been used by OGPSHCN, PPMD and other partners to strengthen grant proposals
- Data has been shared with partners upon request and cleaned data set is available from OGPSHCN

Unmet Needs Among **CENTRAL** Maryland CYSHCN and their Families 2010 MARYLAND PARENT SURVEY

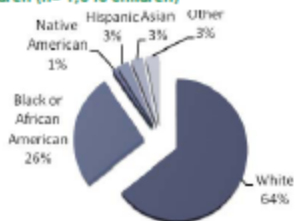
Unmet Needs Among **CAPITAL AREA** Maryland CYSHCN and their Families 2010 MARYLAND PARENT SURVEY

Unmet Needs Among Maryland CYSHCN and their Families by Region 2010 MARYLAND PARENT SURVEY

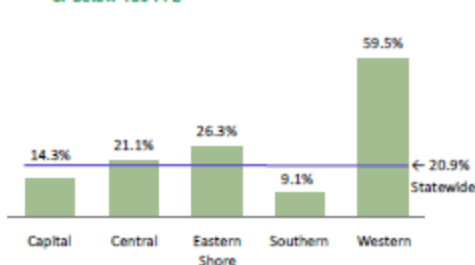
Characteristics of Responding Families and their CYSHCN¹

772 families with at least one CYSHCN (representing 1040 children) responded to the survey.

Race/ethnicity of responding families' children (n= 1,040 children)



Percent of Families with at Least One CYSHCN at or Below 185 FPL



Impact on the Family

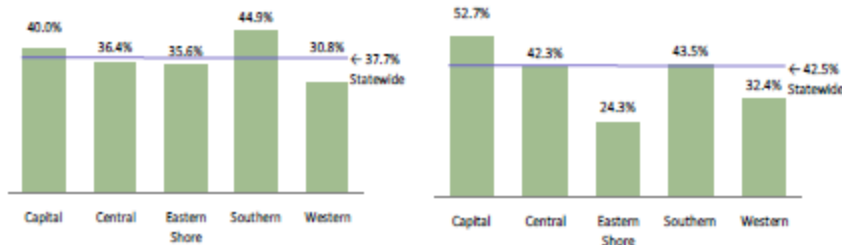
Impact on the Family	% of CYSHCN
CYSHCN whose families pay \$1,000 or more out of pocket in medical expenses per year per child	42.5
Families who report that their child's insurance does not pay for all health services needed	54.5
CYSHCN who were uninsured at some point in the last 12 months	12.7
CYSHCN whose conditions cause family members to cut back or stop working	37.7

Impact on the Family:

Families whose CYSHCN conditions cause family to cut back or stop working

Impact on the Family:

Families who paid \$1000 or more out of pocket in medical expenses per year per child



Unmet Needs Among **SOUTHERN** Maryland CYSHCN and their Families 2010 MARYLAND PARENT SURVEY

Unmet Needs Among **WESTERN** Maryland CYSHCN and their Families 2010 MARYLAND PARENT SURVEY

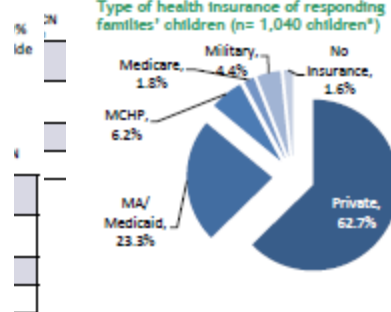
Unmet Needs Among **EASTERN SHORE** Maryland CYSHCN and their Families 2010 MARYLAND PARENT SURVEY

What Isn't Covered Adequately Under Private Insurance for Maryland CYSHCN? 2010 MARYLAND PARENT SURVEY

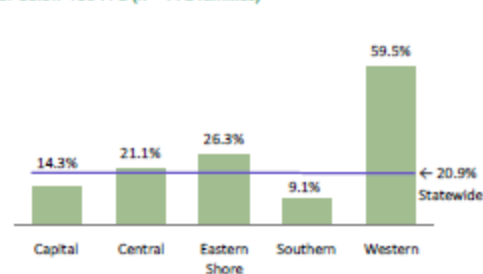
Statewide Characteristics of Responding Families and their Children and Youth with Special Health Care Needs (CYSHCN)¹

772 families with at least one CYSHCN (representing 1040 children) responded to the survey statewide.

Type of health insurance of responding families' children (n= 1,040 children^a)



Percent of Families with at Least One CYSHCN at or Below 185 FPL (n = 772 families)



^asome children have more than one type of health insurance

Some health services are not adequately covered for Maryland CYSHCN under private health insurance:

Of the 772 responding families with at least one CYSHCN, 44.3% (342 families) reported that, among CYSHCN with private health insurance, insurance did not pay for all needed health care services.

Health Services not adequately covered by private insurance for Maryland CYSHCN (n =342):



■ % reporting inadequate coverage of type of service

Let's Do it Again for 2013!





Needed Content

For What...	How Data will be used...
2015 Title V Needs Assessment	Data will help us to prioritize CYSHCN and families' needs and target resources
Systems Change grants (ASD/DD, CYE);	To evaluate grant activities impacting CYSHCN w/ASD/DD and E/SD
Habilitative Services Workgroup	To inform/bolster legislative action/interventions

What needs to be in the 2013 Survey? - 2015 Title V Needs Assessment

- Similar content to 2010 Maryland Parent Survey
 - Basic demographic, SES, condition, and type of special needs info
 - ID needs/unmet needs of child and family
 - ID impact of unmet needs
 - Measure family satisfaction with services received
 - **TAKING OUT** transition questions since we do an annual transition survey



What needs to be in the 2013 Survey? Systems Change Grants (ASD/DD & CYE)

- Question(s) that measure the percent of families reporting “that the organization and capacity of community-based services systems in MD are easy to use”
- Question(s) that measure the percent of families reporting “level of satisfaction with their role as partners with providers in shared decision-making”
- Question that indicates if a child has been diagnosed with epilepsy and/or has had seizure(s)

What needs to be in the 2013 Survey? Habilitative Services

- Do parents understand the difference between...
 - habilitative and rehabilitative services
 - a self-funded and fully insured insurance plan
- Need for hab. svcs. and where received (school, outside of school); distance traveled to get services; level of satisfaction with services received
- Satisfaction with PCP ability to ID child's need for and to refer for services

2013 Maryland Parent Survey Development

**TOO MUCH
STUFF...**



...NOT ENOUGH SPACE!

We need your help... (as usual!)

1. **15 min:** Individually... take the survey; then...
2. **10 min:** At your tables, discuss:
 - a) ***Which questions or sections were too cumbersome? (Troubleshoot to fix these!)
 - b) Was there any confusion at your table as to what certain survey questions were asking?
 - c) Are there questions you think could be cut out, and if so, why?
 - d) Would data from this survey be useful to you/your organization? How might you use it?

FOCUS ON CONTENT, NOT FORMATTING!!!

Big Group Discussion (15 minutes)

1. **15 min:** All together, discuss:
 - a) ***Which questions or sections were too cumbersome? (Troubleshoot to fix these!)
 - b) Was there any confusion at your table as to what certain survey questions were asking?
 - c) Are there questions you think could be cut out, and if so, why?
 - d) Would data from this survey be useful to you/your organization? How might you use it?

**GIVE MEREDITH YOUR SURVEY FORMS IF YOU
WROTE HELPFUL COMMENTS/IDEAS**

Timeline

- November 2013 – seek IRB approval
- December 2013-March 2014 – disseminate survey; collect responses
- April 2014 – survey closes, data entry for paper surveys
- May 2014 – data cleaning
- June 2014 and ongoing - analyses

Dissemination

- Online thru listservs
 - PPMD
 - CoC
 - Pathfinders (PFA)
 - Abilities Network (AN/EFCR)
 - Local Health Depts (LHD CYSHCN contacts)
 - MSDE Partners for Success?
 - Maryland Center for Developmental Disabilities (MCDD?)
 - Who else?

Dissemination

- At in-person family trainings/
workshops/events
 - PPMD
 - PFA
 - AN/EFCR
 - Who else?



Thanks, everyone!