

Planning to Improve Services for CSHCN with ASD and other DD

Southern Maryland – Population
Overview and Data

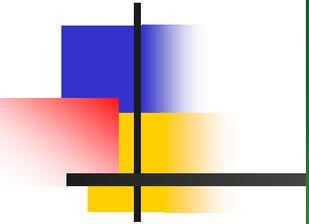
We'll talk about:

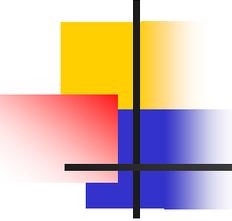
- Prevalence
- Demographic and other characteristics
- Data around each of the top 10 needs for Southern Maryland id'd through stakeholder poll

***Note: various data sources:*

- National Surveys (2009-10/2007)
- 2010 Maryland Parent Survey
- MSDE/Autism Waiver Survey
- MCDD Focus Groups (2011)
- MCA Listening Session (2010)
- PPMD/OGCSHCN Parent Focus Group (2011)







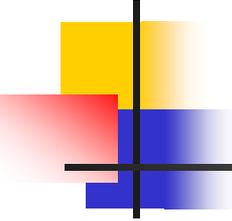
Prevalence among all children



The prevalence of ASD increased nationwide by 57% from 2002 to 2006

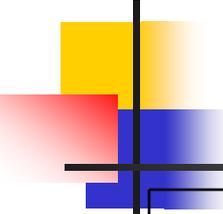
- the average prevalence is approaching 1% (or 9.0 per 1,000 children);
 - estimated prevalence in Maryland is slightly higher, at 9.2 per 1,000 children (*Source – CDC Autism and Developmental Disabilities Monitoring Network*)
-
- The 2007 NSCH estimated that almost 28% of Maryland children aged 4 months to 5 years are at moderate or high risk for developmental delay, higher than the nation as a whole (26.4%).

Prevalence within CSHCN Population



- Prevalence of CSHCN aged 0-17 years in Maryland is 15.7% (~211,000 children ages 0-17 or 244,000 aged 0-21). Within this population,
 - 31.4%: currently have ADD or ADHD
 - 13.1% currently have developmental delay
 - 1.2%* have Cerebral Palsy
 - 0.7%* have Down Syndrome
 - 7.3%: currently have ASD

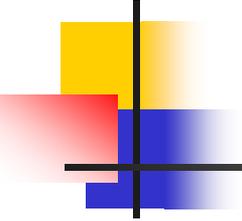
Source: 2009-10 NS-CSHCN



2010 Maryland Parent Survey

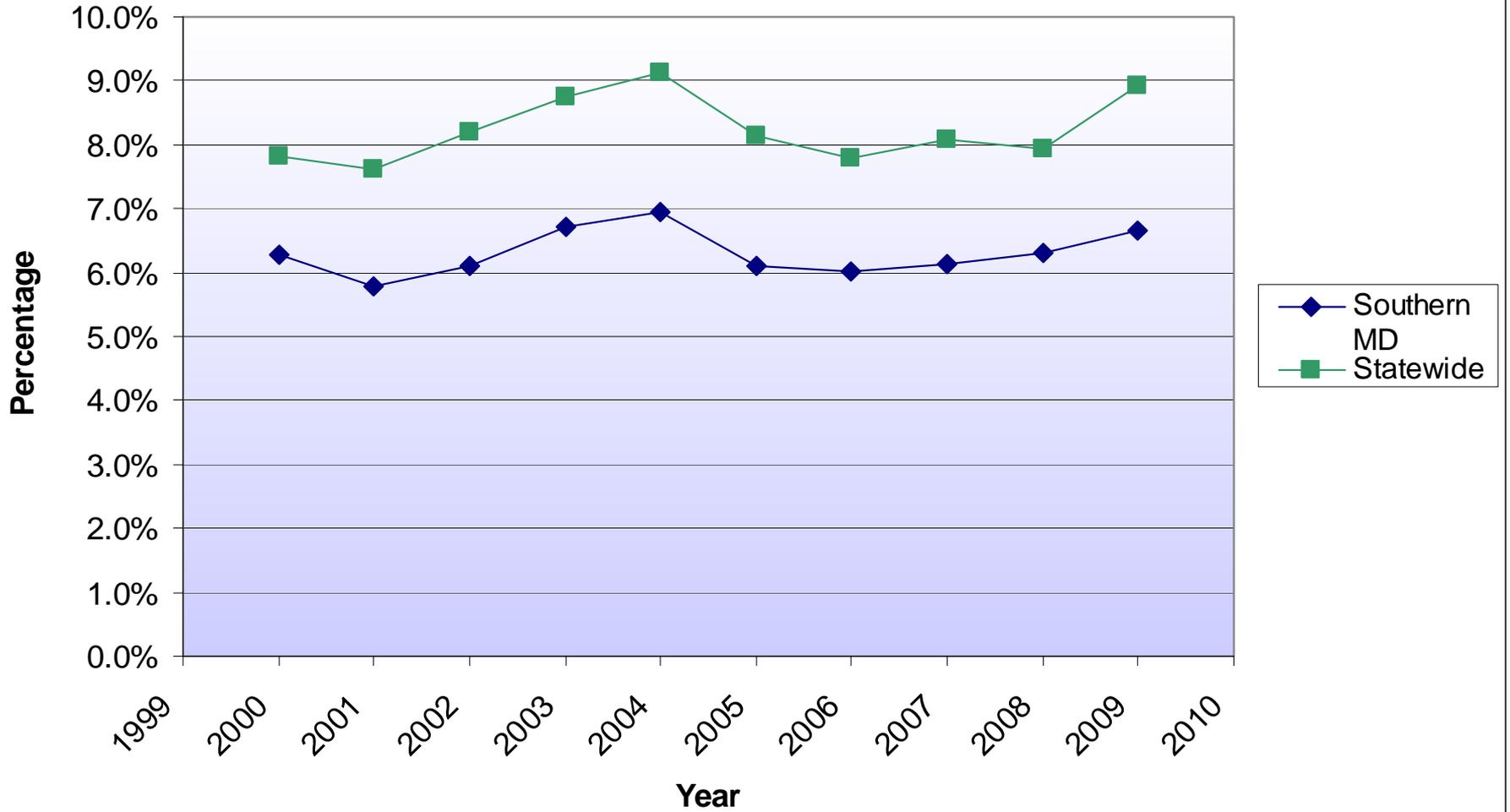
Region	Number of Survey responses- at least one child w/ASD	Number of Survey responses- at least one child w/SHCN
Statewide	293	773
Capital	85	176
Central	116	396
Eastern Shore	33	79
Southern	50	76
Western	7	42
Unknown	2	4

It is important to note that this data source cannot be considered to be representative of the target population because the sampling method used for the survey was not randomized.

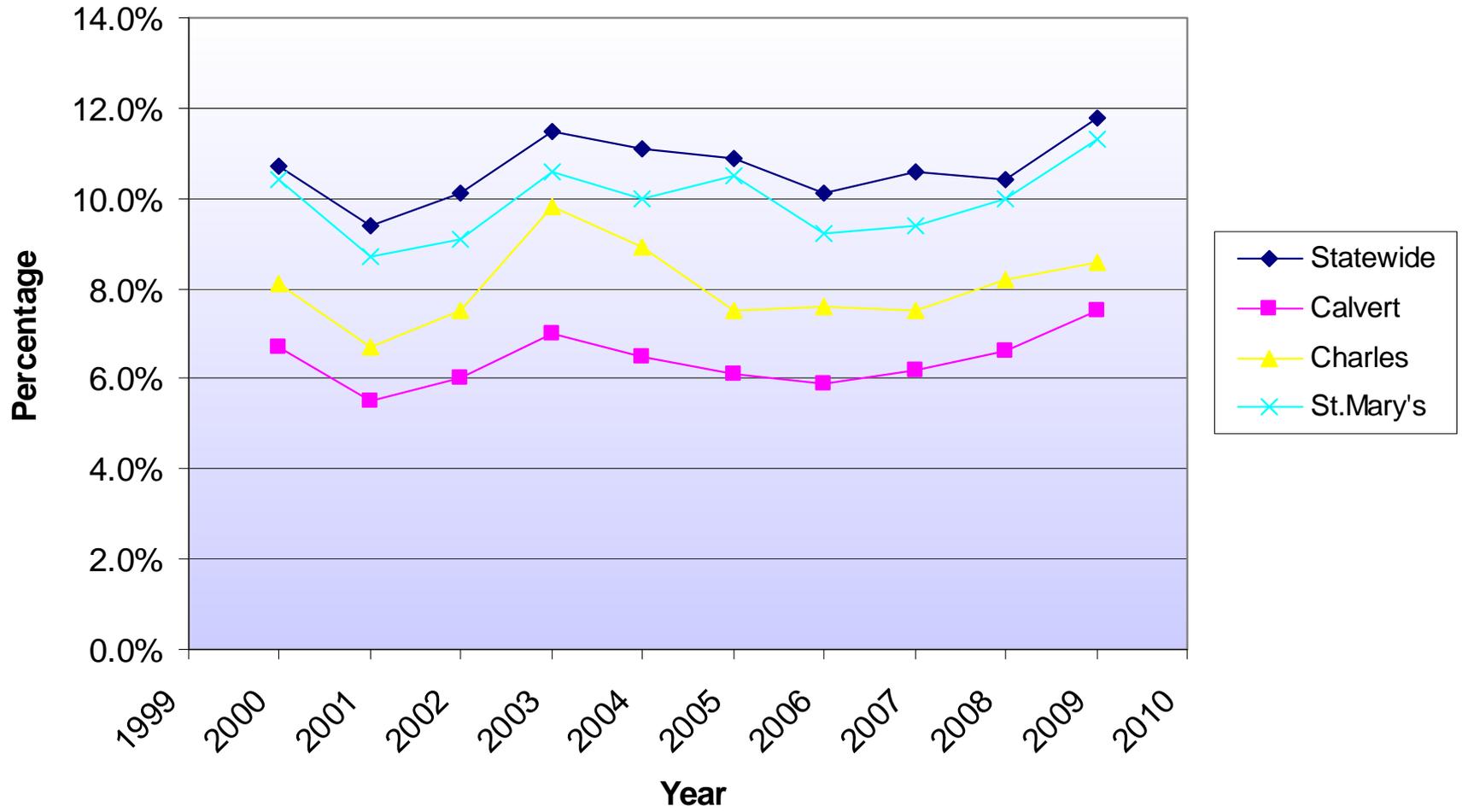


Demographic, Socioeconomic and other Characteristics

General Poverty Rates - Southern Maryland Region

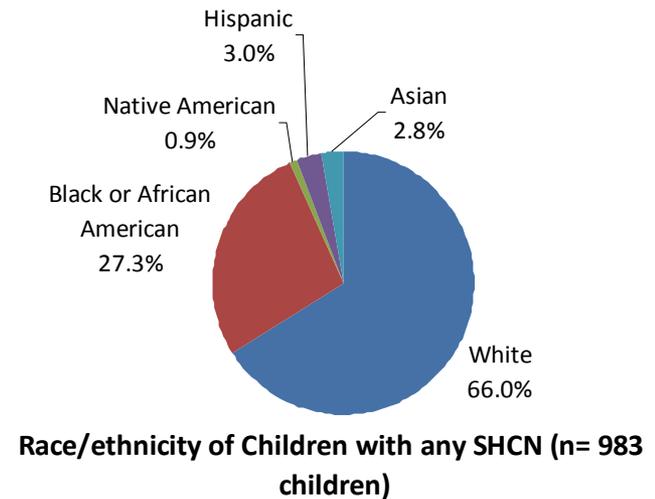
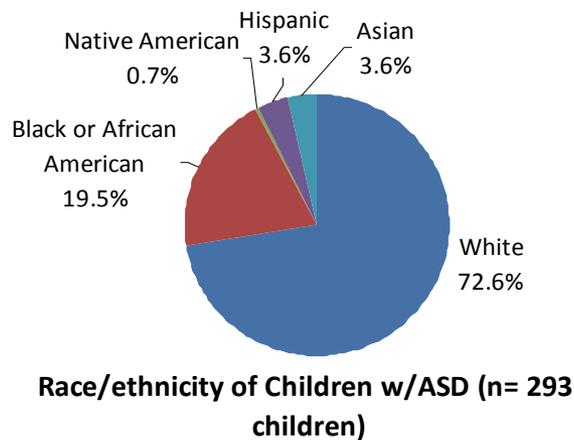


Child Poverty Rates - Southern Maryland Region



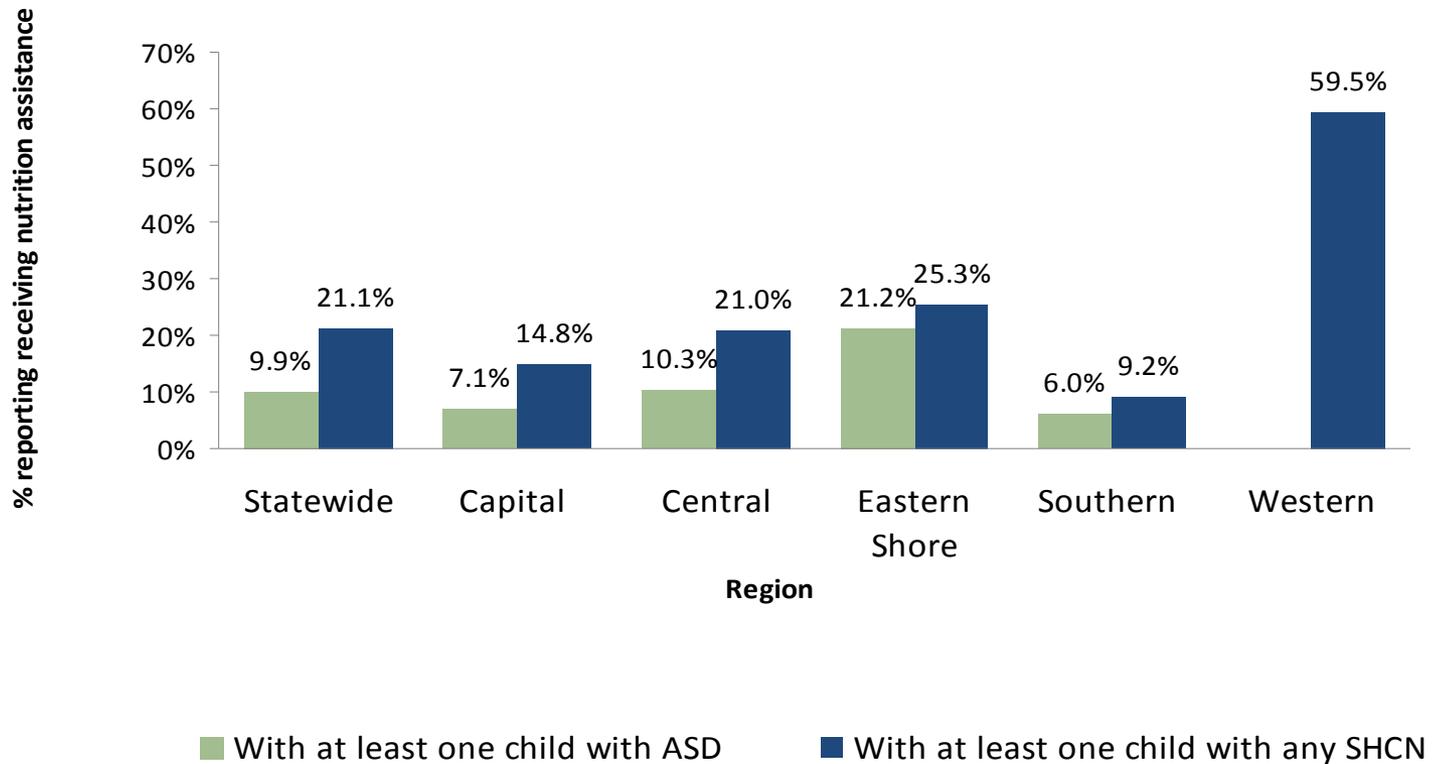
Source: U.S. Census 2010 Small Area Income and Poverty Estimates

Race/Ethnicity of Maryland CYSHCN



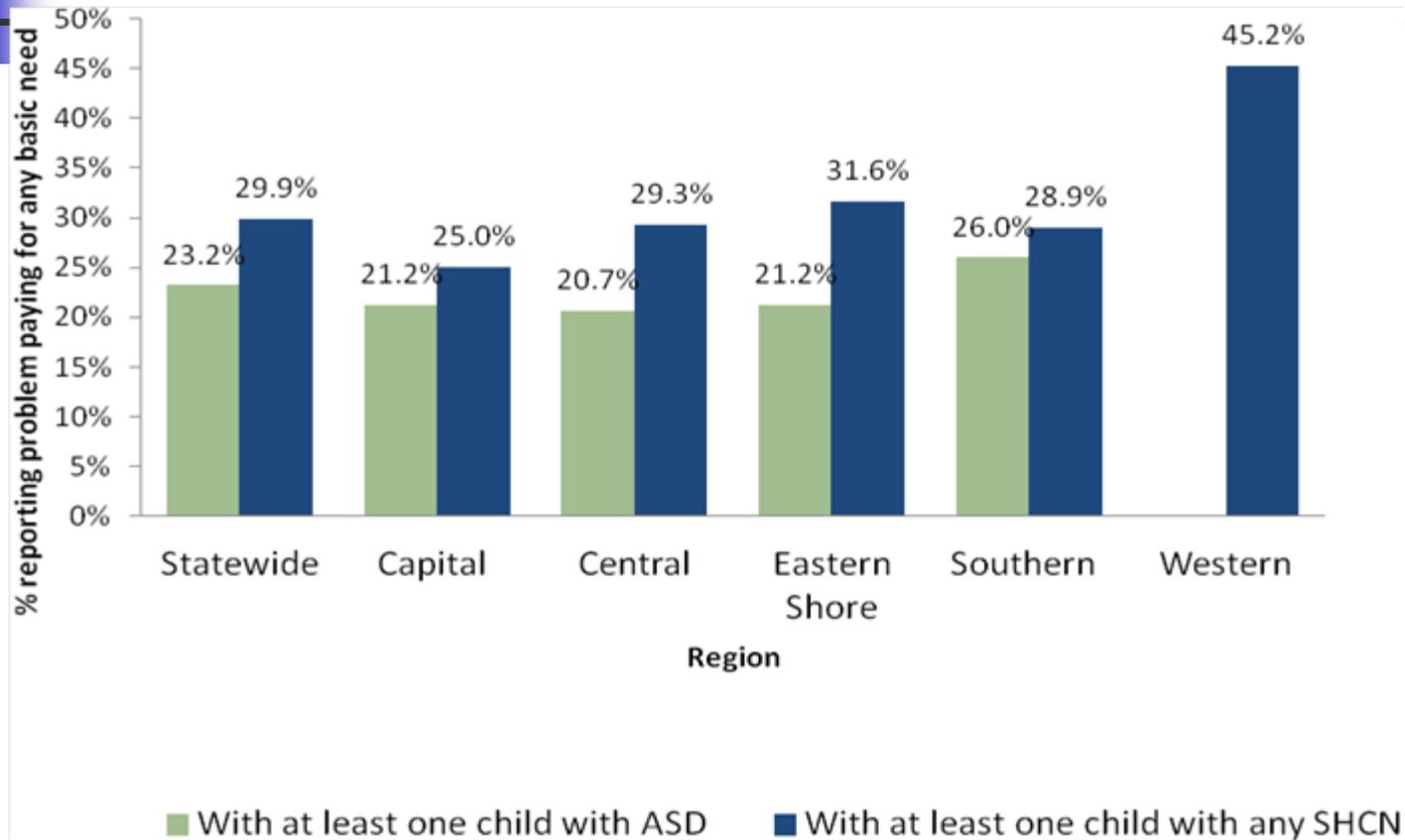
- Majority are white non-Hispanic

Maryland children with ASD receiving government-sponsored nutritional assistance - 2010

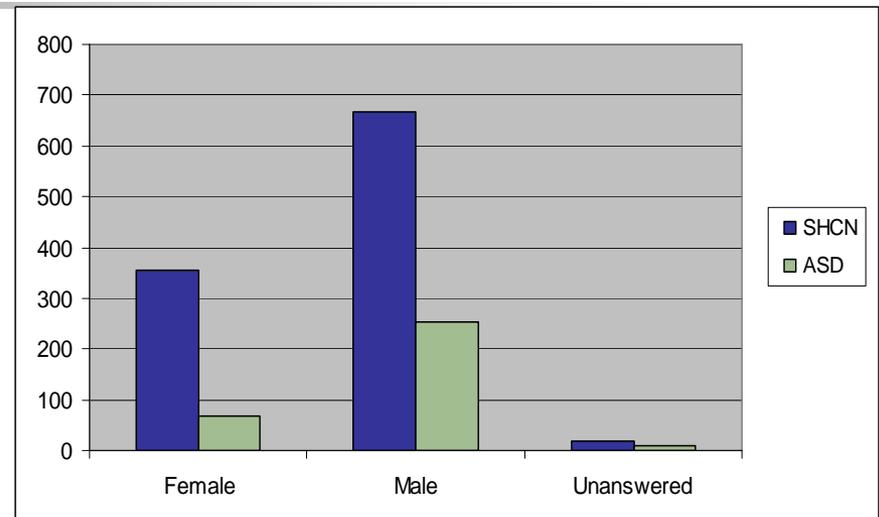
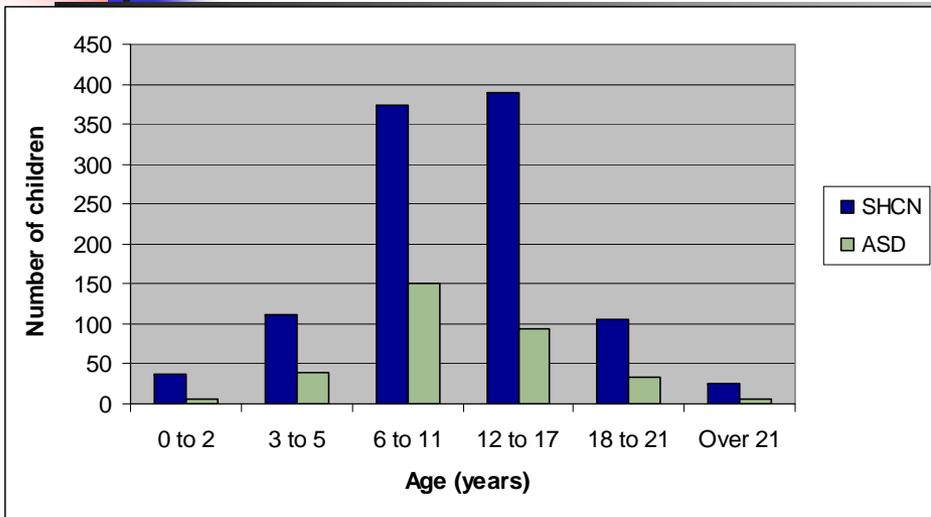


Source: 2010 Maryland Parent Survey

Difficulty Paying for Basic Needs among Families of Children with ASD and Families of Children with any SHCN



ASD: Age and Gender

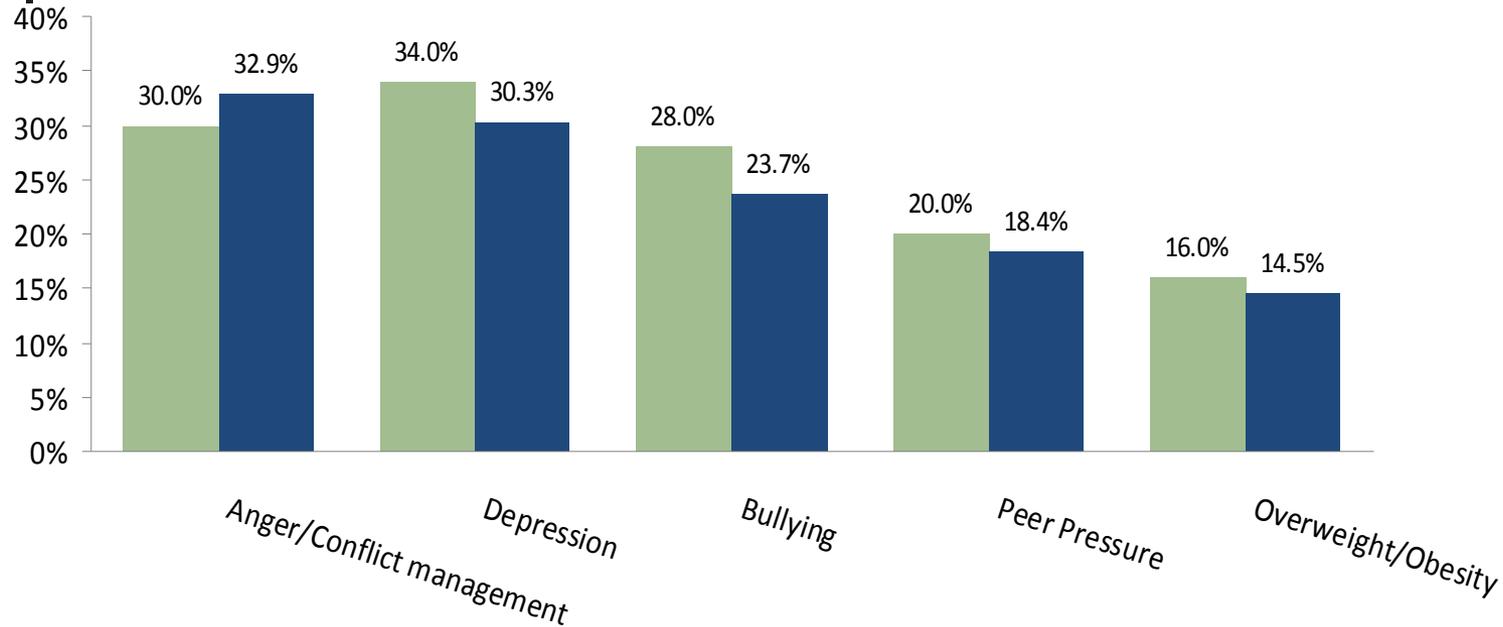


Majority of children with ASD in survey were:

- between ages 6 to 17;
- male

Source: 2010 Maryland Parent Survey

Experience with Challenging Behaviors among CYSHCN with ASD in Southern Maryland



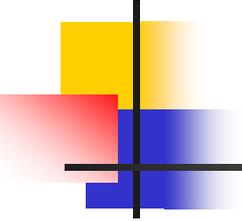
Type of Challenging Behavior or Experience

■ With at least one child with ASD

■ With at least one child with any SHCN

Source: 2010 Maryland Parent Survey

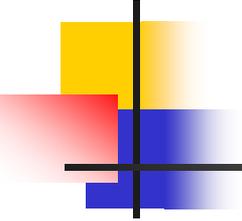


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- Get up
 - Stretch
 - Go find someone and tell them one new thing you've learned so far





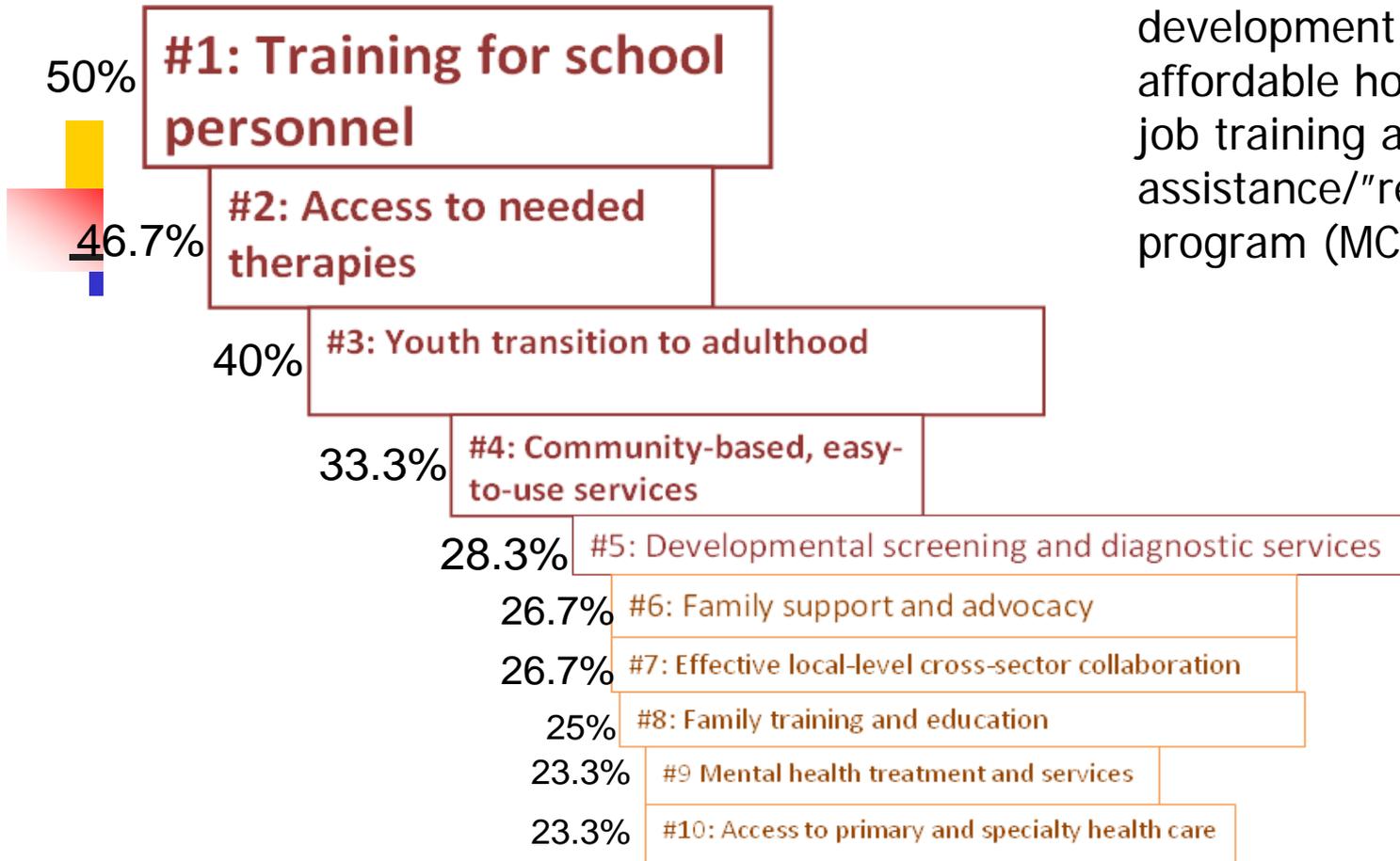
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Priority Needs and Data



Other needs: Social skills development; accessible & affordable housing; effective job training and assistance/"ready to work" program (MCDD)

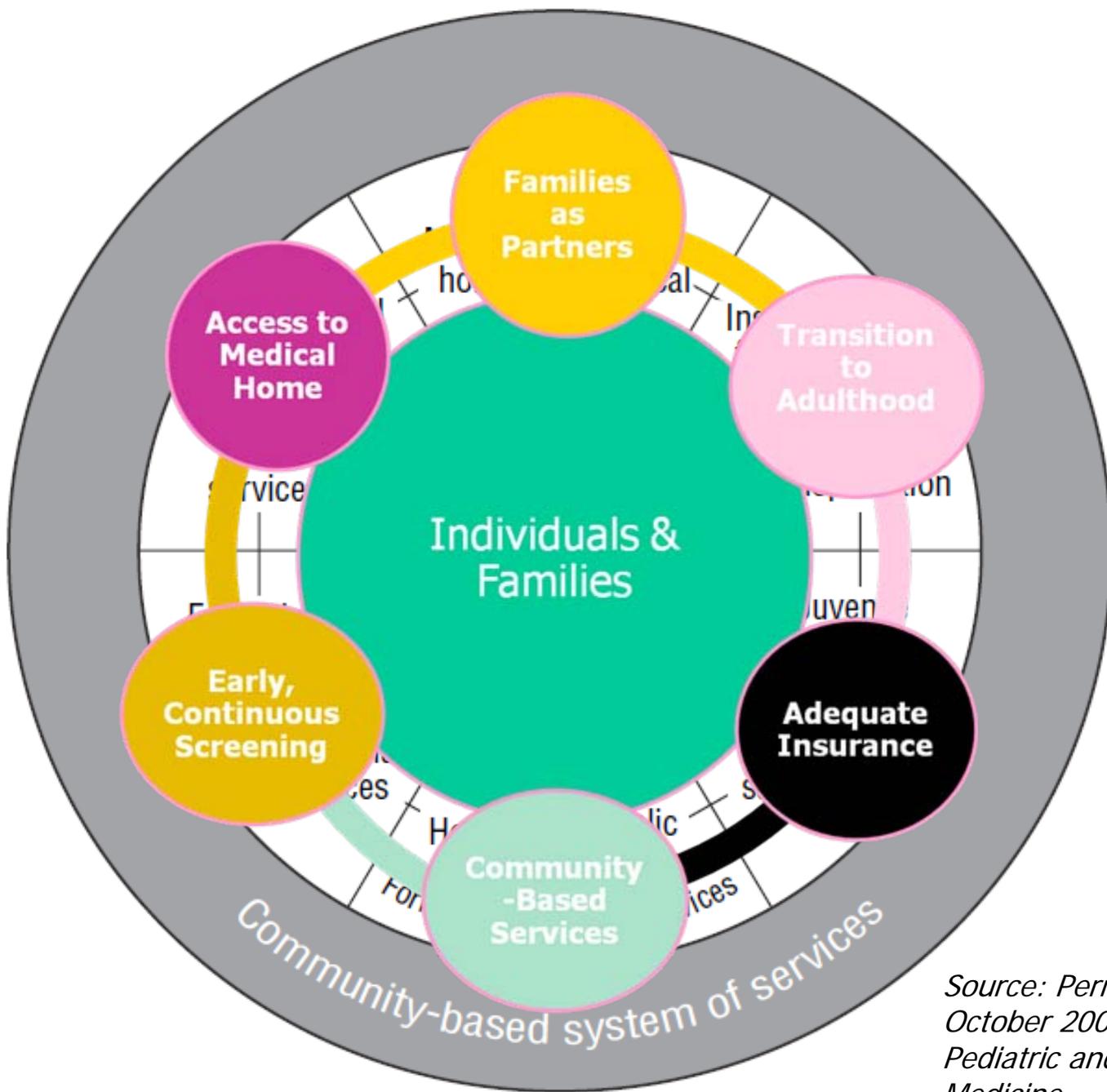


Other priorities: Family/professional partnerships (#11); Recreation and leisure opportunities (#12); Effective state-level cross-sector collaboration (#13); Access to child care and respite care (#14); Adequate health insurance and financing (#15); Training for medical and related service professionals (#16); Access to transportation (#17); Effective state-level cross-sector collaboration (#18); Training for other public servants (#19); Medical home (#20); and Reducing disparities (#21).

PRIORITY RANKINGS:

Region – Southern Maryland;

n = 60

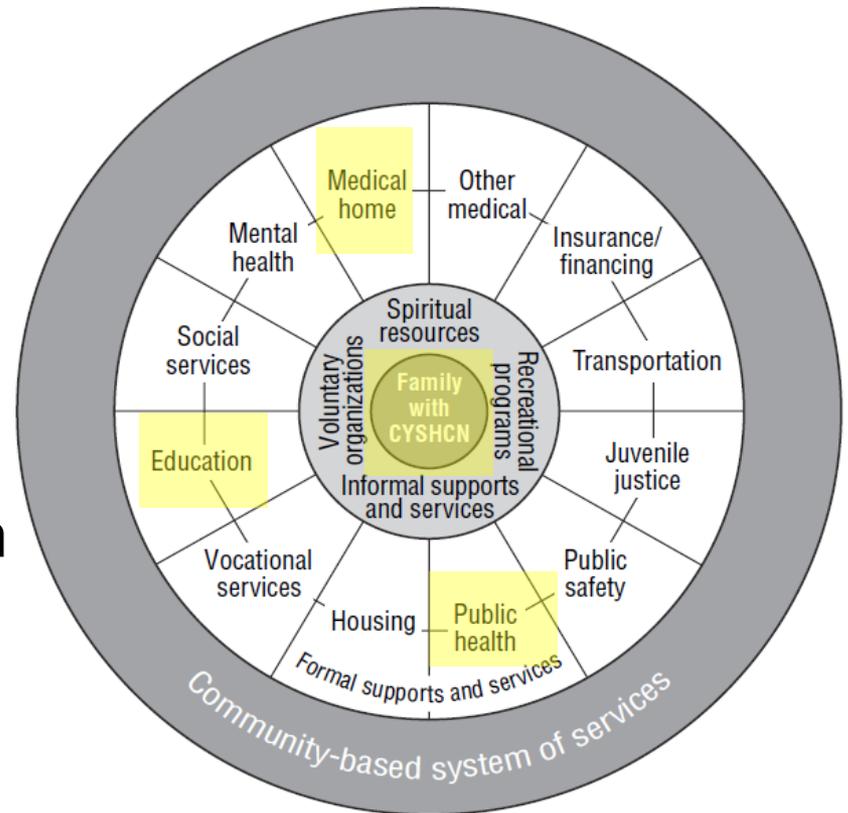


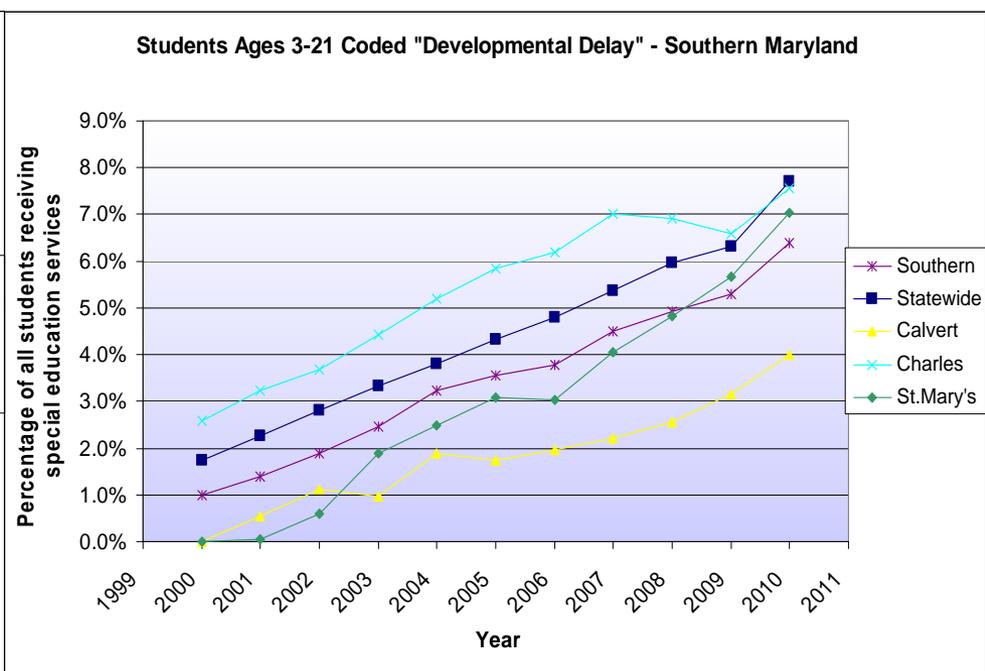
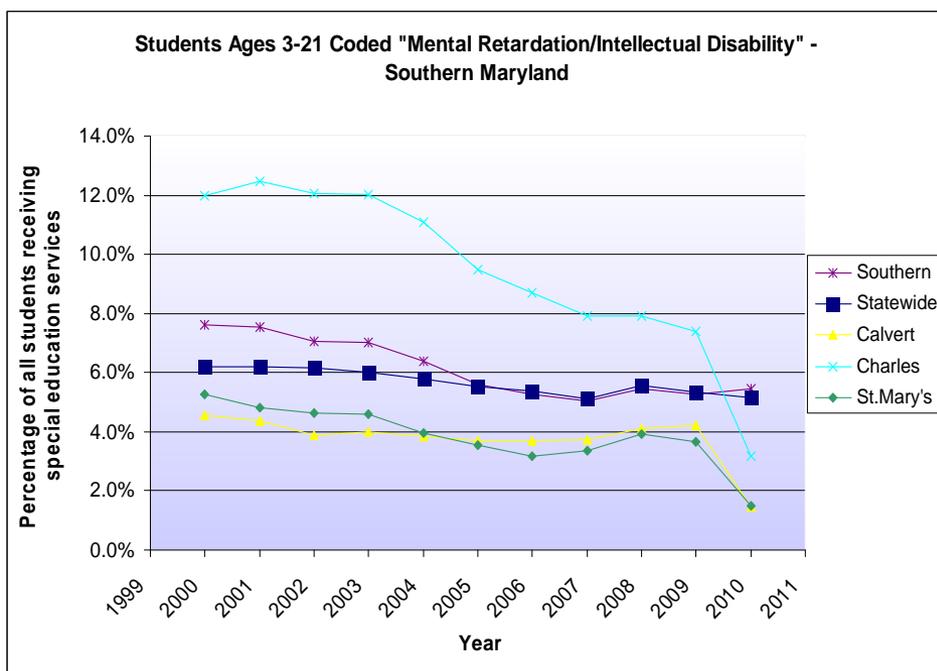
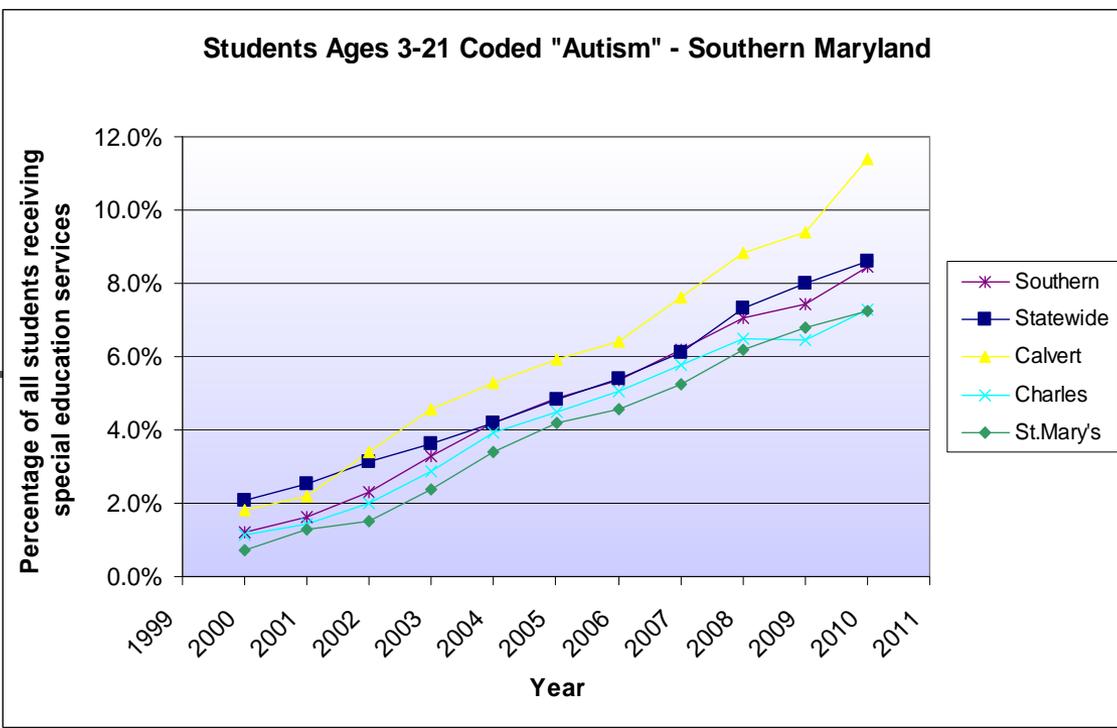
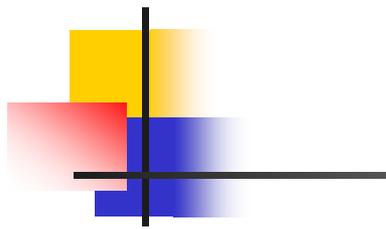
Source: Perrin, JM et al;
October 2007 Archives of
Pediatric and Adolescent
Medicine

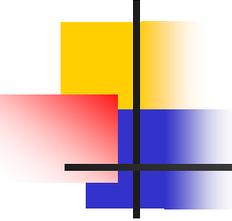
Priority: Training for School Personnel

- 50% of ASD/DD Poll respondents representing Southern Maryland ranked "Training for school personnel in how to meet the needs of children and youth with ASD and DD" in their top 5 priorities

#1





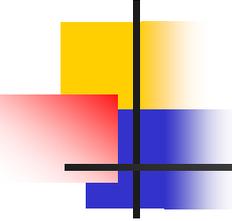


MCDD and MCA Findings



- NOT JUST School Personnel:
 - MCDD community focus groups identified “**inadequate training among professionals** working with individuals with DD” as a need in Southern Maryland; “Knowledge/Education/Information/Training” was the most common theme mentioned during these focus groups
- Kids need more social and adaptive skills:
 - Maryland Commission on Autism held a listening session in Southern Maryland in October 2010; an adult services provider spoke and said she felt that the education system “is **too focused on academic achievement** and that young people [with ASD] are **graduating without essential social and adaptive skills**”

Priority: Training for School Personnel



OGCSHCN/PPMD Parent Focus Group in Southern Maryland, October 2011

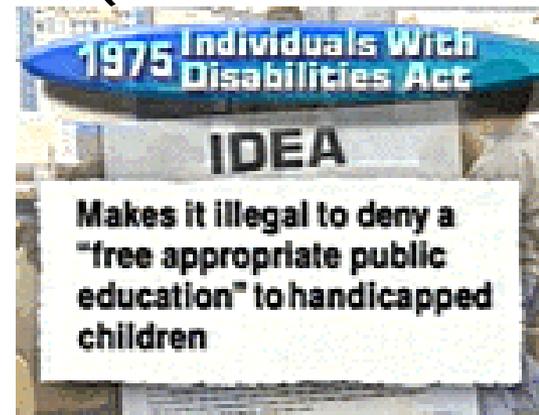
- (1) school system personnel need more training in dealing with oppositional behavior in the classroom:
 - *“There are so many kids with prefrontal lobe issues now—diagnosed or undiagnosed ADHD—that’s it’s just this epidemic in the schools where the conflicts in the classroom are just exponentially increasing because the teachers are not handling it. Even the young teachers are, ‘These are my rules. Do it my way.’”*
- (2) it takes longer to get needed special education services when schools will not accept a physician’s/medical diagnosis of autism:
 - *“The barriers that we’ve run into have been in the educational area. Those are our barriers. We’ve been told, ‘We would like to reevaluate your child.’ No! I’ve had a neurologist who is supposed to be the leading neurologist on autism on this side of the Mississippi tell me that [my child] has autism. I am going to take the diagnosis from somebody from [the school system] instead? I don’t think so.”*

Priority: Training for School Personnel

Family Satisfaction with Special Education Services in Southern Maryland

- Among families whose child has an IEP or IFSP, **51.9%** (ASD) and **59.7%** (any SHCN) are satisfied with services received.
- Among families whose child needed an evaluation from his/her school, approximately **38%** were satisfied with the service (ASD and any SHCN).

Source: 2010 Maryland Parent Survey



Core Outcome

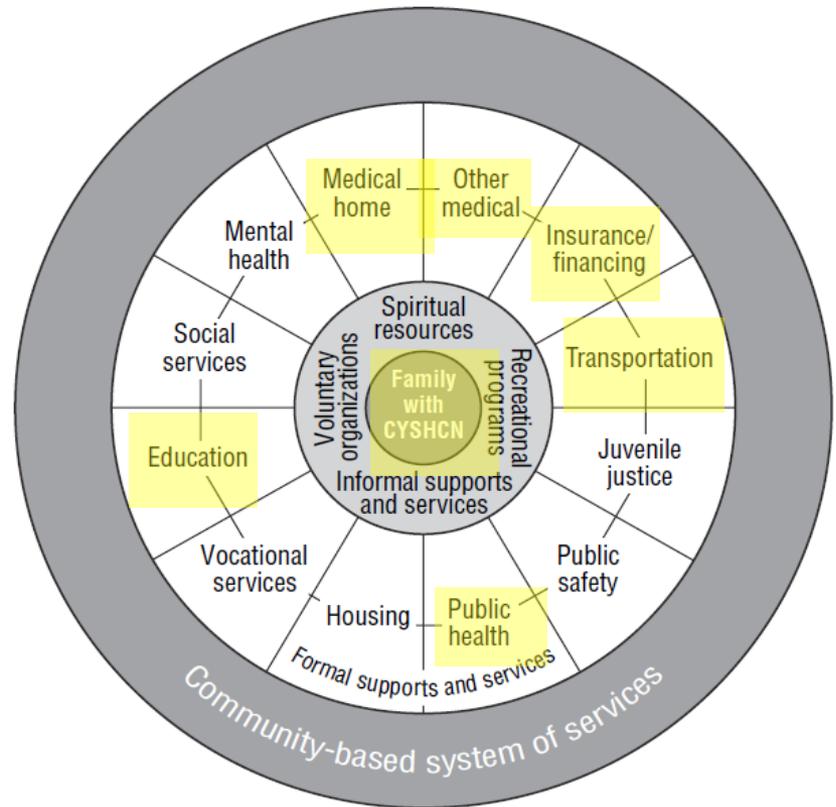


- A key component of an effective system of care for CYSHCN with ASD or other DD is **strong, effective partnerships between families and the professionals who serve them.**
- Among CYSHCN in general Maryland fares somewhat poorly (69.3%) on this outcome compared to other states, ranking 37th in the nation; among those with E/B/D issues, 61.5% in Maryland are successfully achieving this outcome.

Priority: Access to needed therapies

- 46.7% of ASD/DD Poll respondents representing Southern Maryland ranked "Access to needed therapies (behavioral, speech/language, occupational and physical) " in their top 5 priorities

#2



Priority: Access to needed therapies

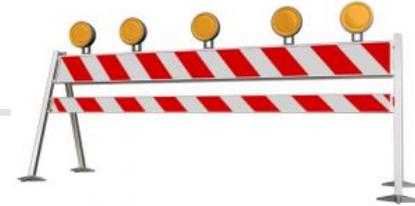
MCDD, MCA, OGCSHCN/PPMD findings...

- All found that there are **not enough** OT, speech/language, PT and behavioral therapy **providers in Southern Maryland**.
 - Waiver service coordinator from Calvert County: **most significant barrier** faced by families is the **'ruralness'** of the Southern Maryland region, and there are **very few options for** medical care, **related services**, respite care, and recreation for children with ASD – distance is prohibitive, no incentives in place to encourage providers to extend their services to the region (MCA)

Priority: Access to needed therapies

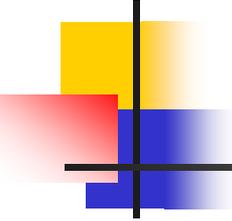


MCDD, MCA, OGCSHCN/PPMD findings...



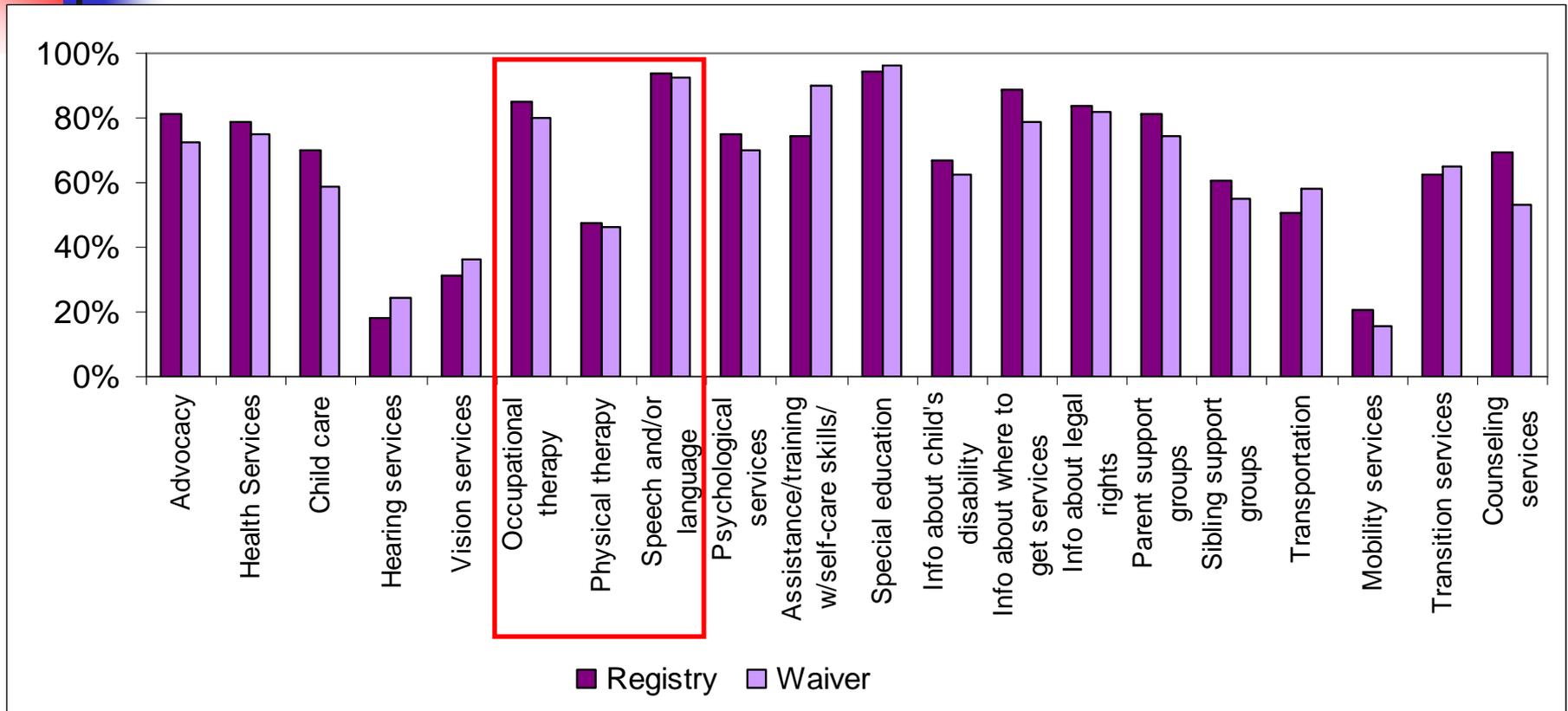
- All found that **inadequate insurance coverage is a major barrier.**
 - services not covered or inadequately covered by insurance noted most frequently were: therapies (such as speech therapy and behavioral therapies (2010 Maryland Parent Survey))
 - Health insurance companies
 - disputed whether the service or care was necessary or covered
 - the only providers available to perform the service did not accept their children's health insurance
 - something was only partially covered by insurance. (OGCSHCN/PPMD Focus Groups)

MCDD, MCA, OGCSHCN/PPMD findings...



- Pediatrician from Calvert County: needs to be insurance coverage for evidence-based behavioral therapies; diagnosis of ASD by a pediatrician should be sufficient to obtain insurance coverage for related services including speech/language, OT, and PT (MCA)

Need for Services among Families on the Autism Registry and Families Receiving Autism Waiver Services

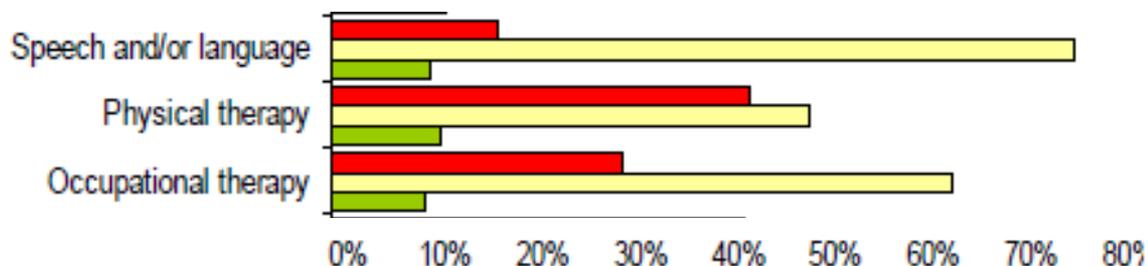


Priority: Access to needed therapies

(Source: MSDE 2009 Maryland Autism Services Survey)

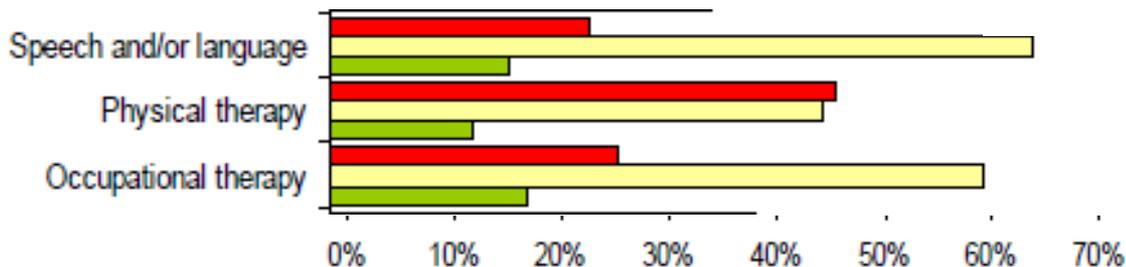
Adequacy of Services among Maryland Families on the Autism Registry and Families Receiving Autism Waiver Services

Registry Families (not on Waiver)



■ Received none of the needed service
□ Received some but not enough of needed service
■ Received enough of needed service

Waiver Families



(Source: MSDE 2009 Maryland Autism Services Survey)

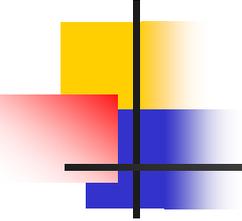
Priority: Access to needed therapies

Core Outcomes

- **Adequate Insurance:** 54.4% with E/B/D issues had adequate insurance and financing (compared to **65%** without E/B/D issues)

- **ETUCBS:** 51.3% with E/B/D issues had community-based, easy-to-use services (compared to **71.9%** without E/B/D issues)



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- Get up
 - Stretch
 - Go find someone and tell them one data point about “training school personnel” or “access to needed therapies” that surprised you.



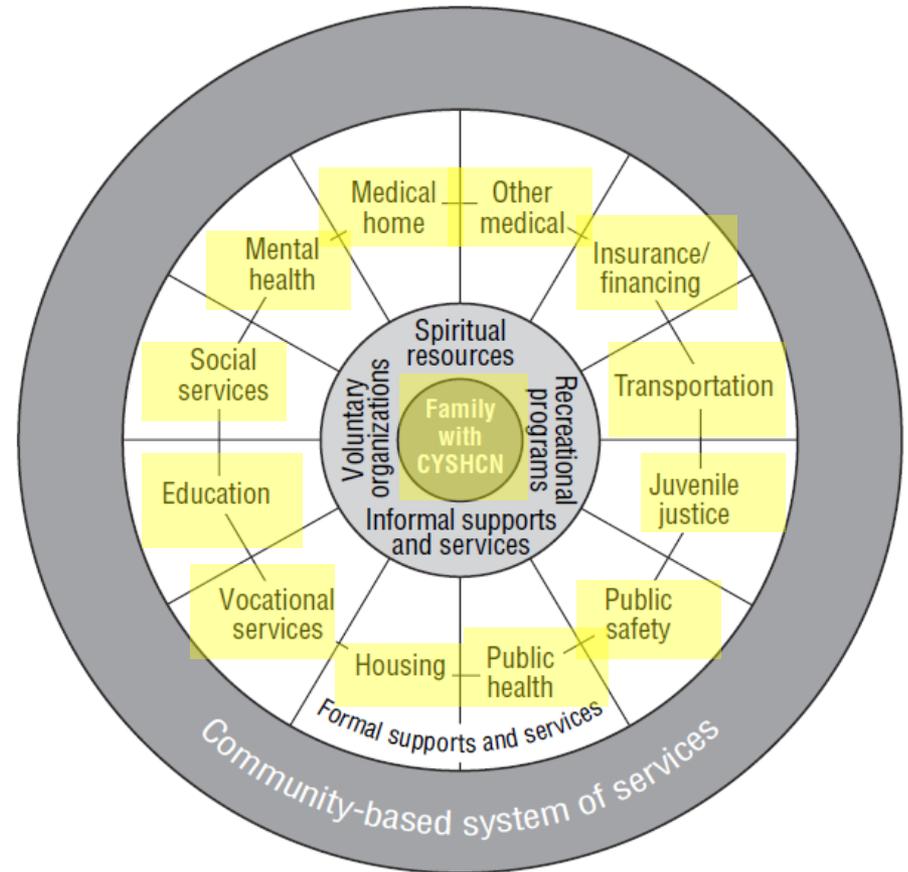


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Priority: Youth Transition to Adulthood

- 40% of ASD/DD Poll respondents representing Southern Maryland ranked "Youth Transition to Adulthood" in their top 5 priorities

#3



Priority: Youth transition to adulthood

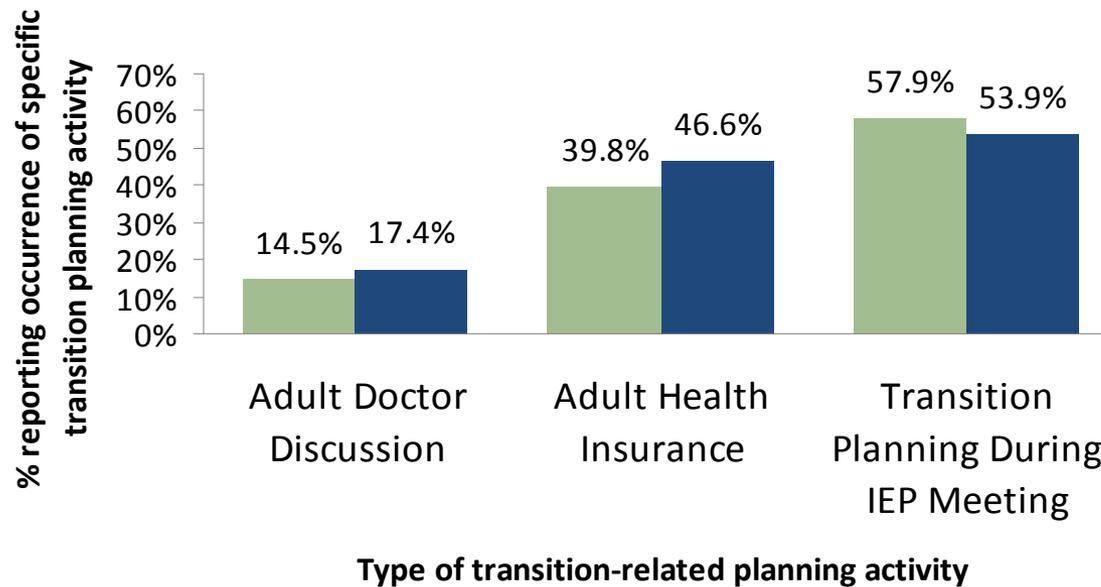
MCA Southern Maryland Listening Session



- Participants felt that youth transition services aren't working in the region:
 - need to **eliminate the divide** between child and adult service systems and to create a **seamless lifespan service delivery system**
 - **lack of service options** for transition aged youth with ASD
 - **difficulty in finding providers** willing to treat youth and young adults with severely challenging behavioral and medical needs

Priority: Youth transition to adulthood

Transition Indicators - Maryland



■ With at least one child with ASD ■ With at least one child with any SHCN

Priority: Youth transition to adulthood

Source: 2010 Maryland Parent Survey

Core Outcome

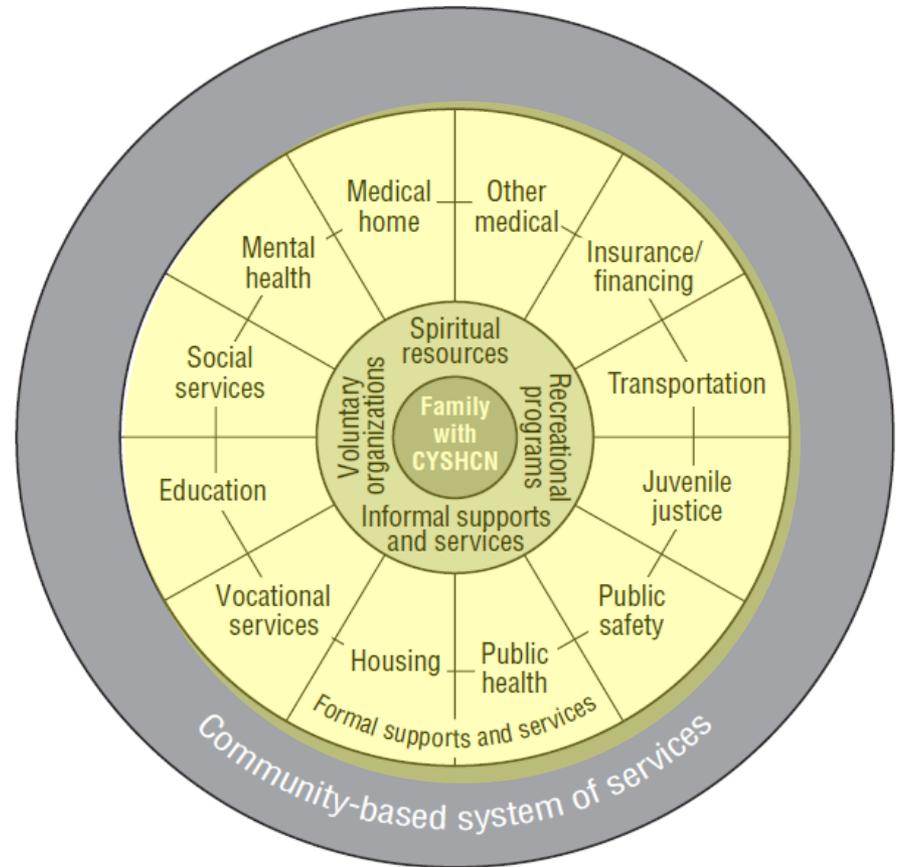


- Youth transition to adulthood is a key component of an effective system of care for CYSHCN with ASD or other DD
- Only **36.8%** of CYSHCN in Maryland are receiving all necessary services for successful transition; just **28%** among those with E/B/D issues

Priority: Easy to use Community-Based Services

- 33.3% of ASD/DD Poll respondents representing Southern Maryland ranked “Needed services are community-based and easy to use” in their top 5 priorities

#4



Priority: Easy to use Community-Based Services

- Uneven distribution of providers (more on this later)
- Insurance access barriers (remember barriers from “access to needed therapies?”)
- Transportation barriers
- System navigation barriers



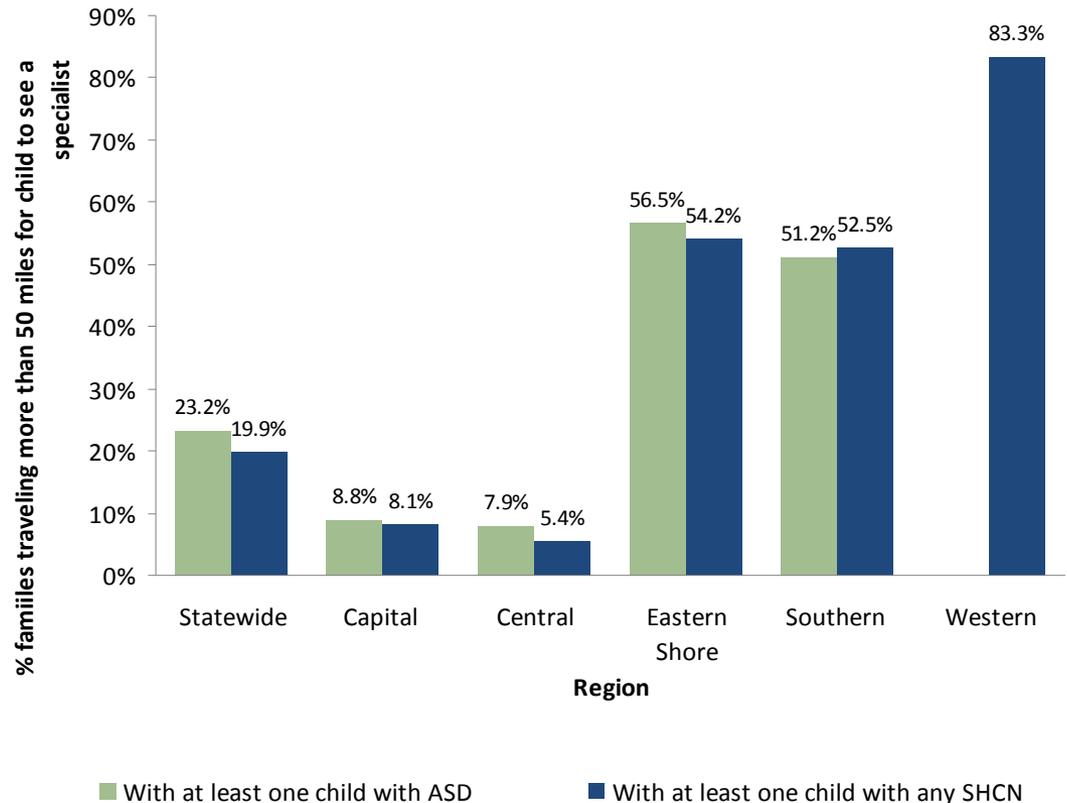


Transportation



- Southern Maryland families are far more likely to have to travel 50+ miles than are families in Central or Capital regions;

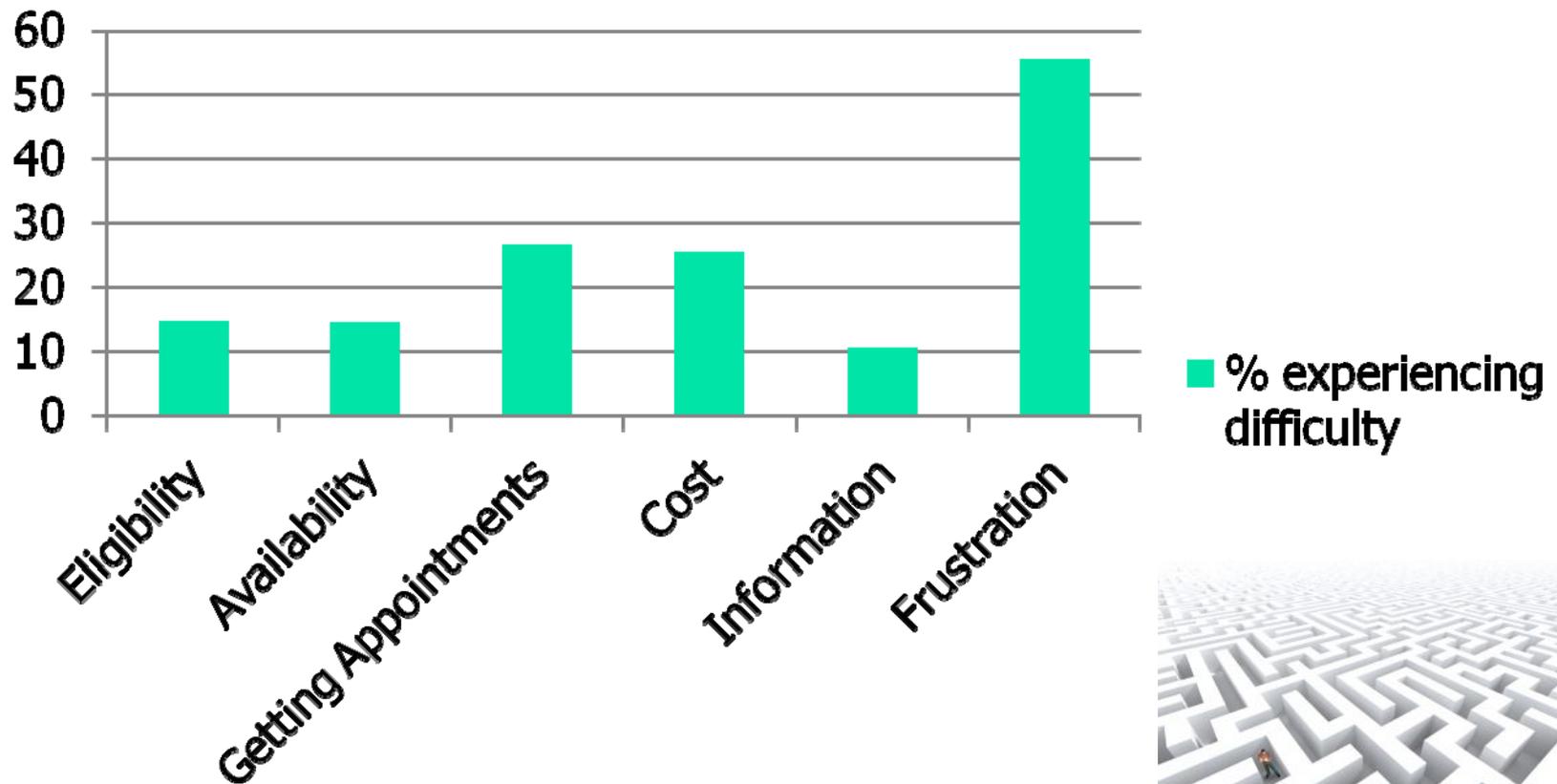
- In every data source consulted for this needs assessment, **transportation and travel to medical appointments** for families in Southern Maryland were repeatedly and consistently identified as a **major barrier** to accessing needed medical, specialty, and therapeutic care for children with ASD and other DD



Source: 2010 Maryland Parent Survey

Navigating the System- when

Maryland families try to get care for their children with E/B/D issues, they face difficulties with:



Core Outcome

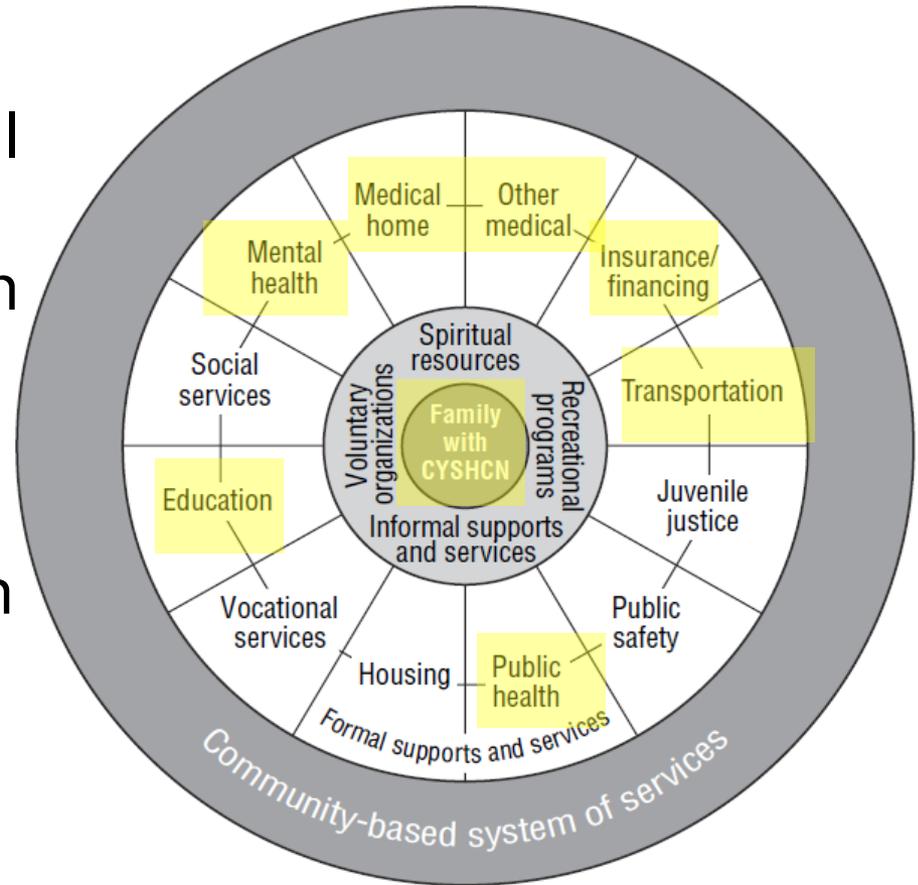


- Easy-to-use community-based services are a key component of an effective system of care for CYSHCN with ASD or other DD
- **65.1%** of CYSHCN in Maryland have community-based services that are easy to use; just **51.3%** among those with E/B/D issues

Priority: Developmental Screening and Diagnostic Services

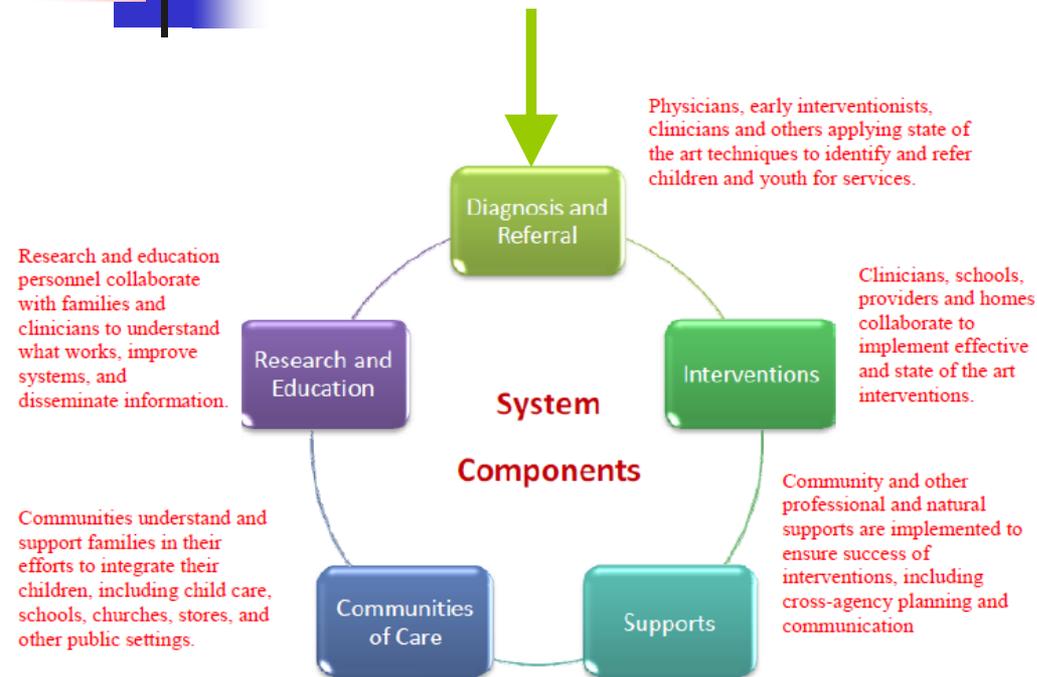
- 28.3% of ASD/DD Poll respondents representing Southern Maryland ranked “developmental screening and diagnostic services” in their top 5 priorities

#5



Maryland Commission on Autism's Conceptual Model

Linking Systems of Care and Communities of Care



- There are **not enough developmental pediatricians** available to meet demand; families must often wait 4+ months* on a waiting list before their child can be evaluated - *Southern MD pediatrician*; supported by public comments by parents

**parents in PPMD focus groups reported waiting 18+ months*

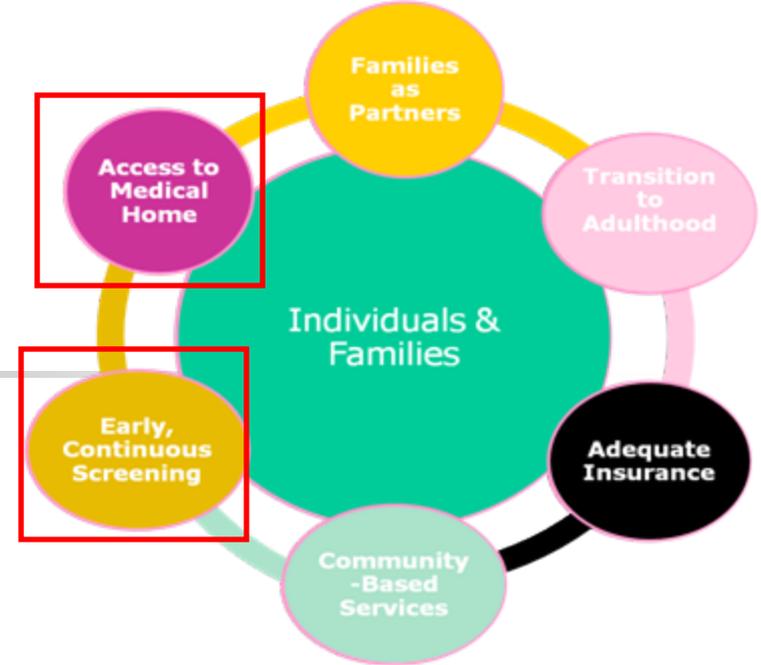
Developmental screening and diagnosis data:

- Almost 28% of Maryland children aged 4 mths - 5 yrs are at moderate or high risk for developmental delay BUT only 22% of families report that their child aged 10 mths - 5 yrs received a standardized screening for developmental or behavior problems; 46% report that they were not asked by their providers if they had concerns about their child's learning, development, or behavior in the past year (National Survey of Children's Health 2007)
- 81.2% of CYSHCN in Maryland are screened early and continuously (2009-10 NS-CSHCN)

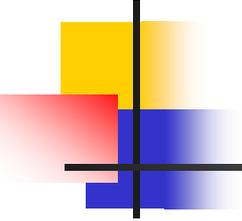
Table 13. ADDM Diagnostic Indicators (Source: ADDM 2006)

ADDM Indicator	National Average/Range	Maryland
Average age of earliest ASD diagnosis	4 years 6 months (range: 3 years 5 months-5years)	4 years 10 months
Percentage of children with a documented developmental concern before the age of 3 years	70% - 95%	70%
Percentage of children with a reported developmental regression by 24 months of age	13% - 30%	23%

Core Outcomes



- **Early, continuous screening** and **access to medical home** are key components of an effective system of care for CYSHCN with ASD or other DD
- **81.2%** of CYSHCN in Maryland are screened early and continuously
- **44.2%** of CYSHCN in Maryland receive care in a medical home model; just **25.7%** among those with E/B/D issues

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- Get up
 - Stretch
 - Go find someone and tell them one data point about one of the priority areas that you can do something to change.



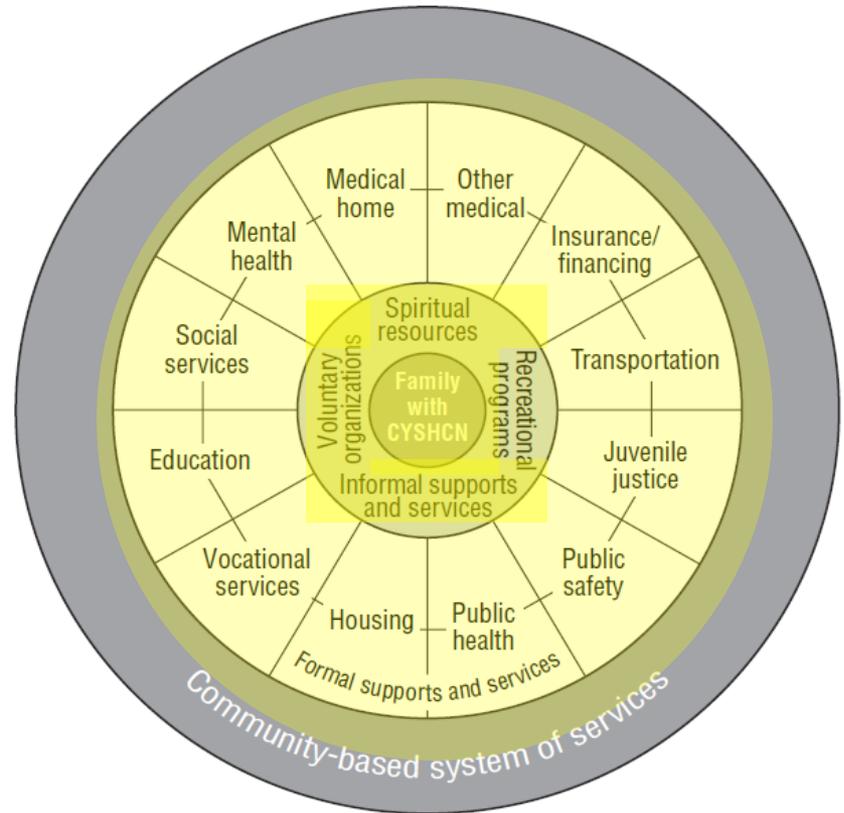


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Priority: Family Support and Advocacy

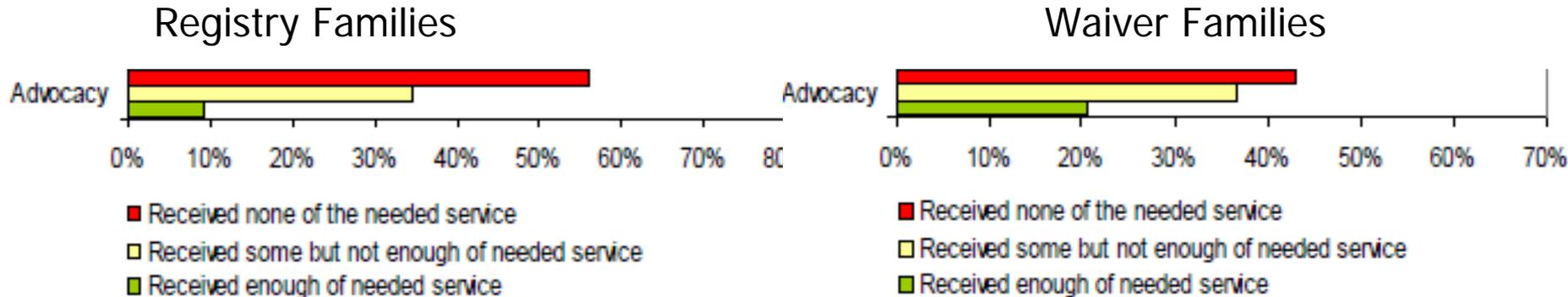
- 26.7% of ASD/DD Poll respondents representing Southern Maryland ranked “family support and advocacy” in their top 5 priorities

#6



Advocacy among families of children with ASD

- High Need for advocacy services among families on the autism registry (81.4%) and families receiving autism waiver services (72.3%) in Maryland
- Among those who needed advocacy services:



Findings from MCA and MCDD activities in Southern Maryland

- Need to teach families advocacy skills when their children are young
- parents need advocacy assistance during the IEP meetings
- Need to promote self advocacy/social/adaptive skills among youth with ASD and DD
- Southern MD has several vocal and award winning advocacy groups such as People on the Go and other self-advocates



Core Outcome



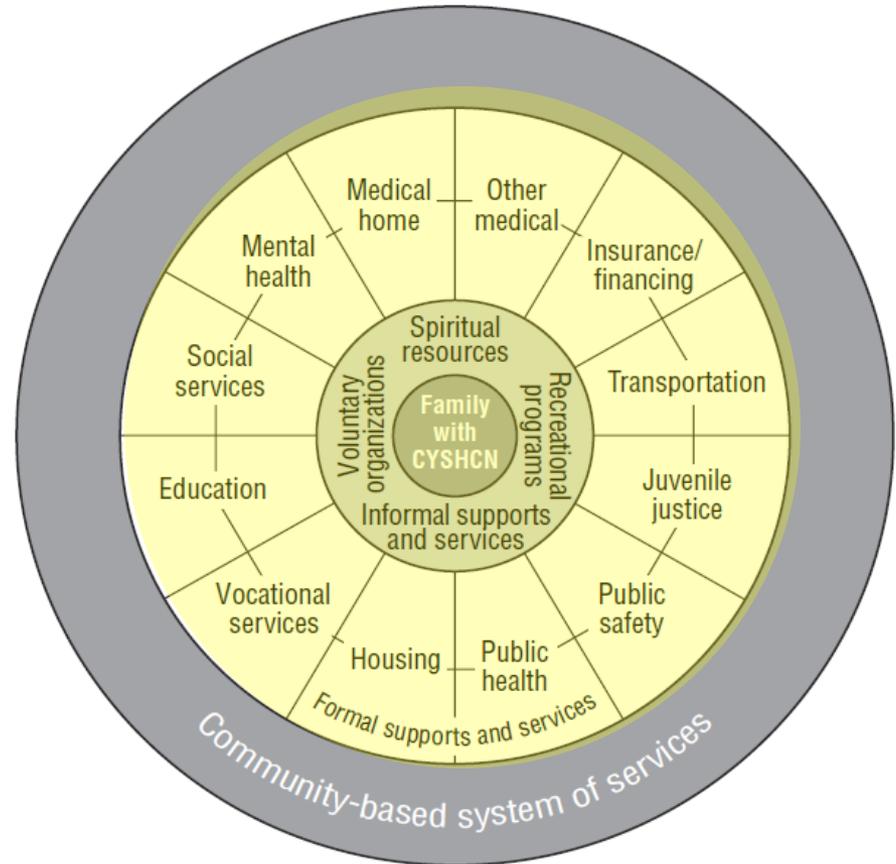
- A key component of an effective system of care for CYSHCN with ASD or other DD is **strong, effective partnerships between families and the professionals who serve them.**
- Among CYSHCN in general Maryland fares somewhat poorly (**69.3%**) on this outcome compared to other states, ranking 37th in the nation; among those with E/B/D issues, **61.5%** (compared to 59.3% nationally) are successfully achieving this outcome.

Priority: Effective local-level cross-sector collaboration

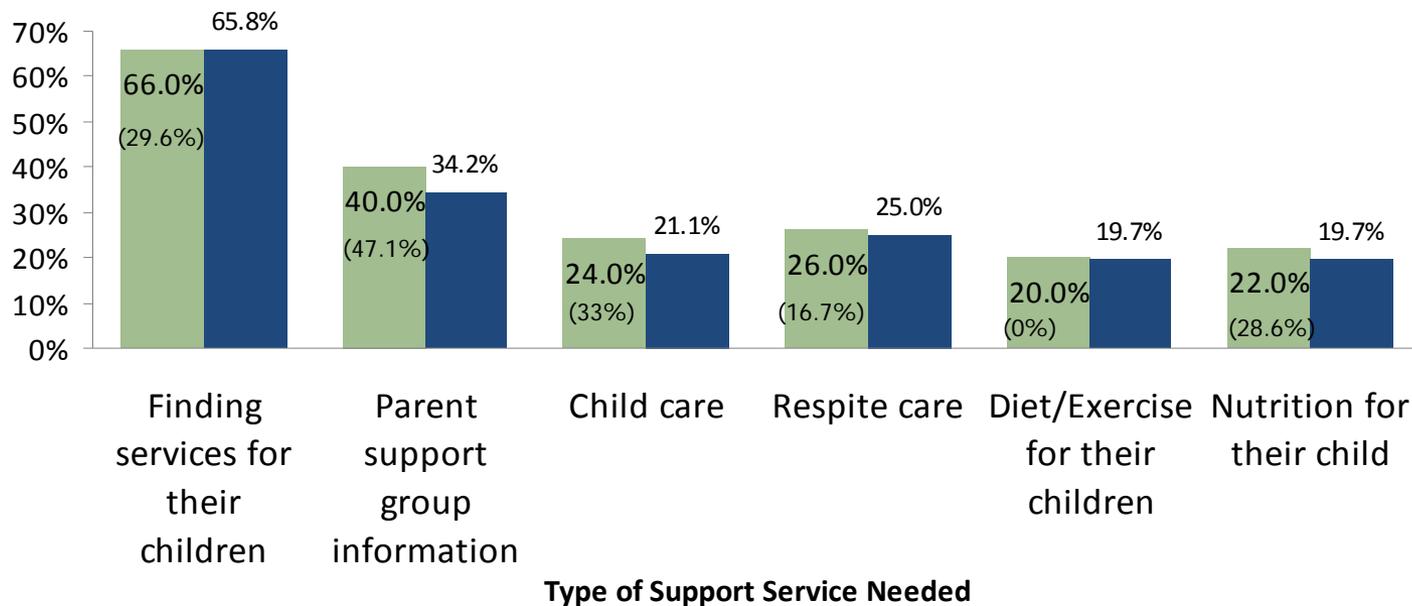


- 26.7% of ASD/DD Poll respondents representing Southern Maryland ranked “Effective cross-sector collaboration (among government, non-profit, private and professional organizations serving children and youth with ASD and DD) at the local level” in their top 5 priorities

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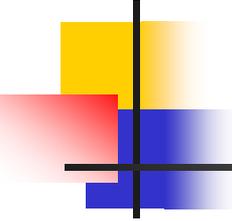


Need for Family Support Services – Southern MD



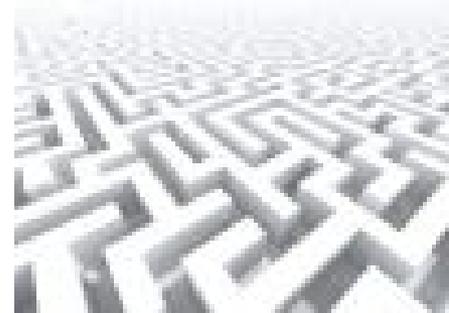
■ With at least one child with ASD

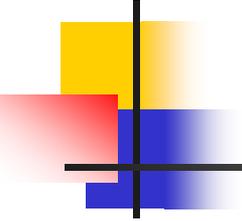
■ With at least one child with any SHCN



“Everything is so scattered that I feel like I am having to try to figure out what resources might be available for my daughter. Everyone I talk to tells me I have to talk to someone else. Why isn't there one place where I can call and find out what my daughter might be eligible for and help for me to try to get that assistance for her?”

Parent Respondent, 2010 Maryland Parent Survey





“There needs to be a better way to obtain health records from the major hospitals and other specialists so that we can coordinate the care to these children and youth. This is especially true when the pediatricians do not want to be the medical home and this responsibility falls on the local health department CSHCN nurse.” Southern MD Local Government Agency Rep

Core Outcomes



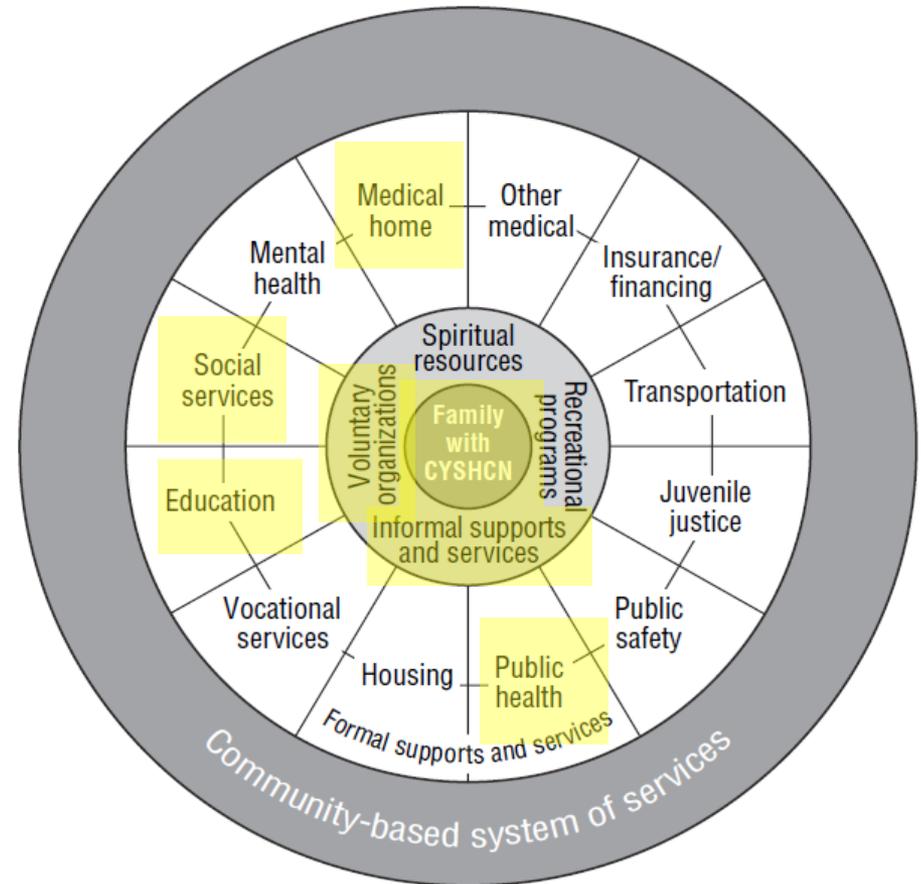
- Family-professional partnerships,
 - easy-to-use community-based services,
 - and access to medical home
- are key components of an effective system of care for CYSHCN with ASD or other DD

Priority: Family Training and Education

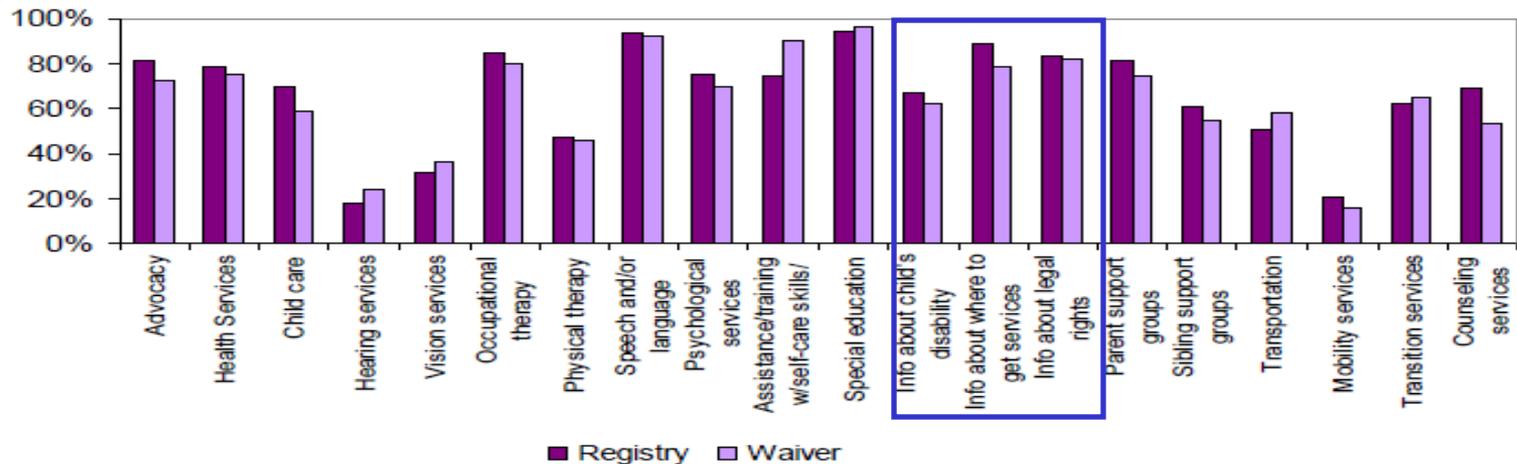


- 25% of ASD/DD Poll respondents representing Southern Maryland ranked “family training and education” in their top 5 priorities

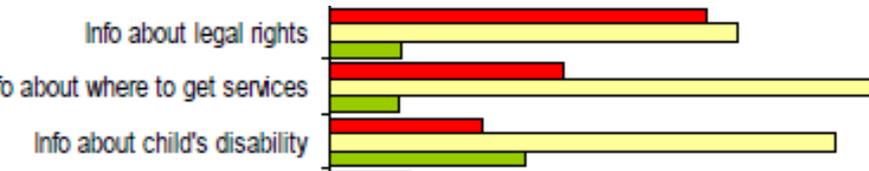
#8



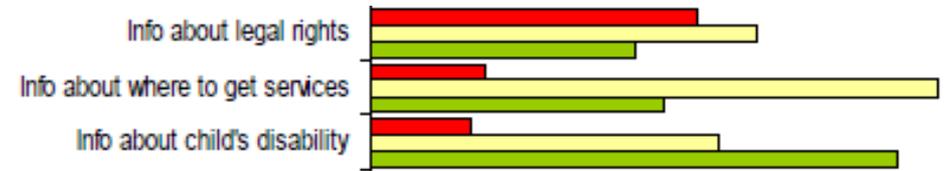
Education and training needs among families of children with ASD



Registry Families



Waiver Families



- Received none of the needed service
- Received some but not enough of needed service
- Received enough of needed service

Priority: Family training and education

(Source: 2009 Maryland Autism Services Survey)

Important topics for training include

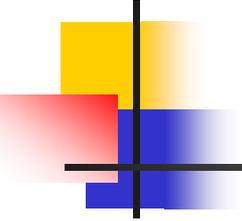


- How to navigate the special education system
- How to navigate the health care system
 - How to navigate insurance claims appeal process
- How to access needed services
- Condition specific information

Core Outcomes



- Family-professional partnerships,
 - And easy-to-use community-based services,
- are key components of an effective system of care for CYSHCN with ASD or other DD

- 
-
- Get up
 - Stretch
 - Go find someone and tell them one question you had in the last 10 minutes.



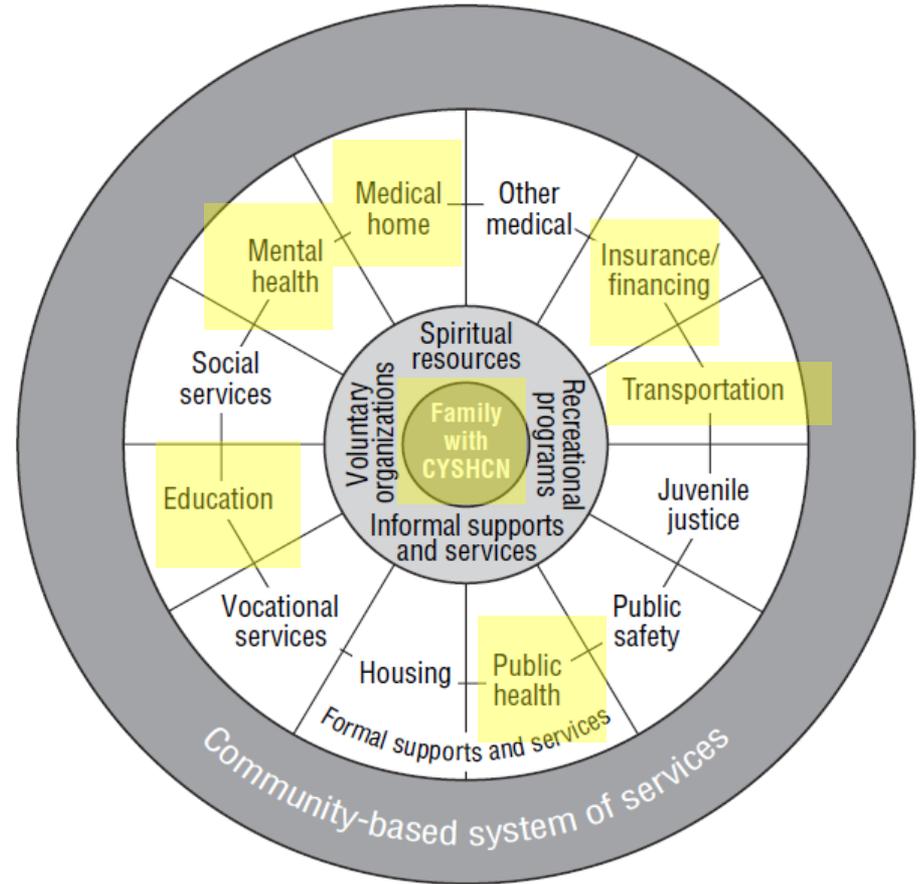


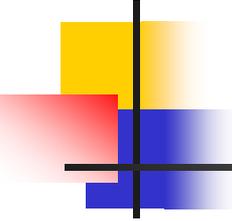
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Priority: Mental Health Treatment and Services

- 23.3% of ASD/DD Poll respondents representing Southern Maryland ranked “Mental health treatment and services” in their top 5 priorities

#9

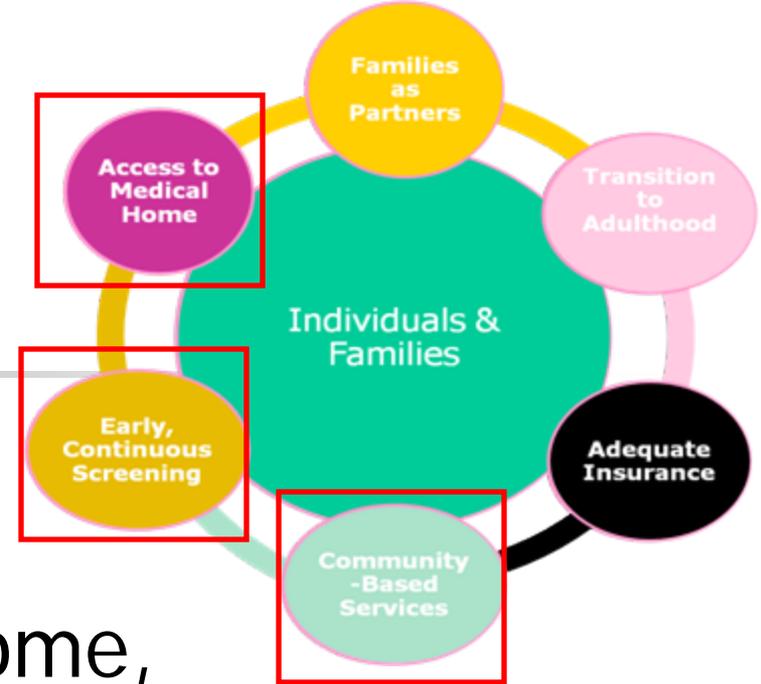




Southern MD Findings from MCDD and OGCSHCN/PPMD...

- lack of existing services, particularly for people with DD with mental health needs (MCDD)
- Some insurance companies say ASD is a mental health diagnosis rather than a neurological condition; children are then denied services or given minimal services because they say it's mental health vs. a medical condition

Core Outcomes



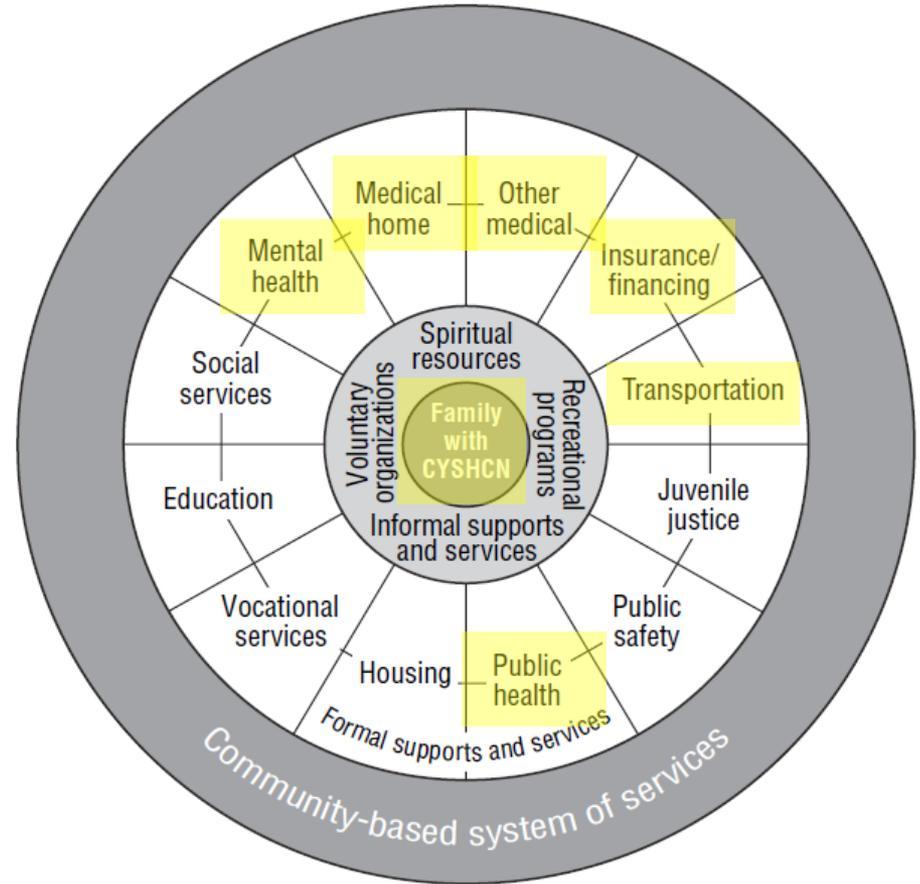
- Access to medical home,
- Early and continuous screening,
- And easy-to-use community-based services

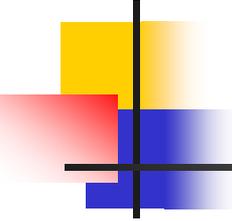
are key components of an effective system of care for CYSHCN with ASD or other DD

Priority: Access to primary and specialty health care

- 23.3% of ASD/DD Poll respondents representing Southern Maryland ranked “access to primary and specialty health care” in their top 5 priorities

#10





Issues:

- Uneven distribution of providers

- Many parents said that satellite clinics of needed specialties as well as local offices for certain providers used to be available in their areas of the state but now are not (OGCSHCN/PPMD)



Insurance/eligibility barriers

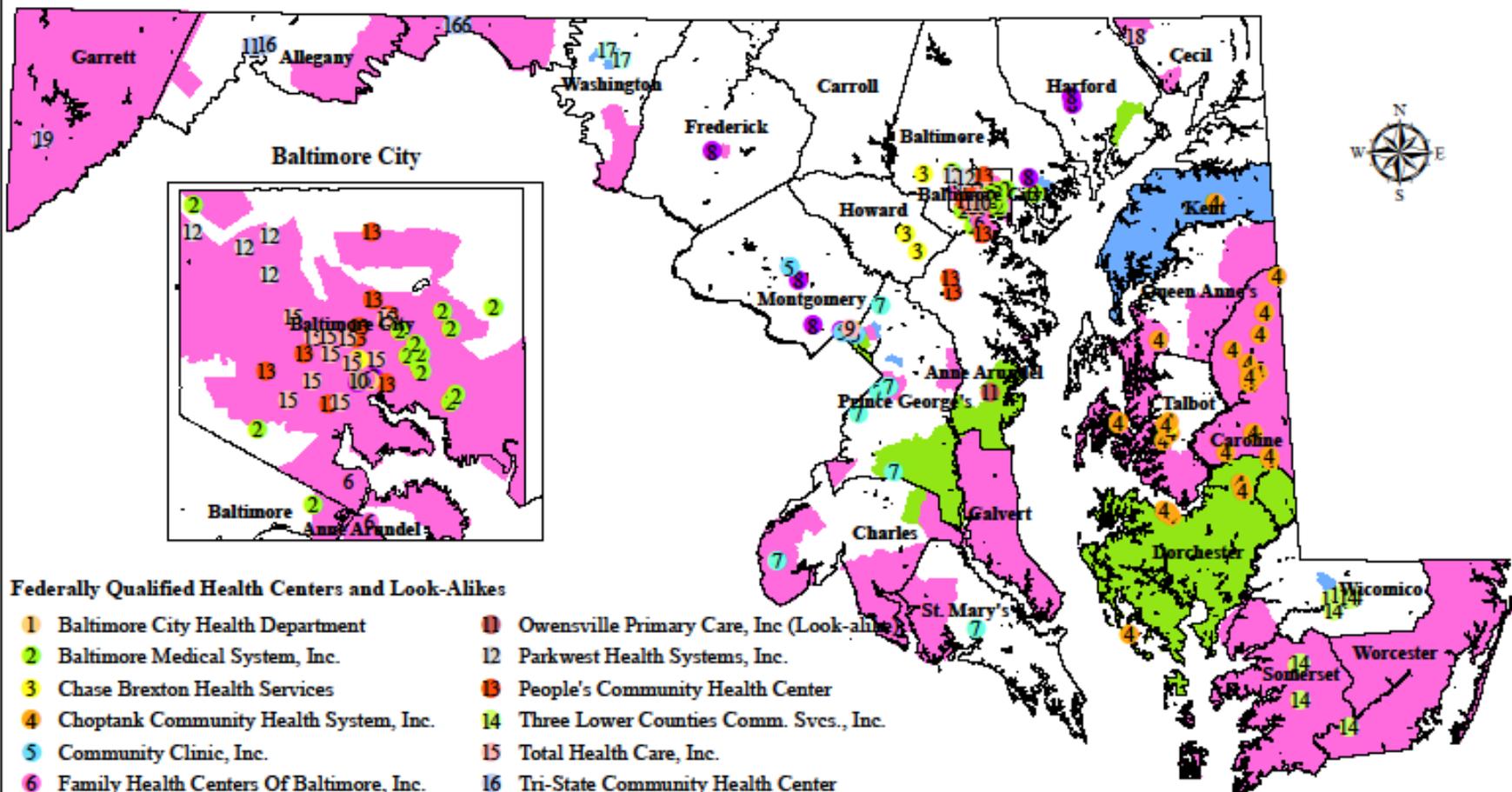
- Denied claims/inadequate coverage
- Providers don't accept MA or other types of insurance
- 14.6% of CYSCHN with E/B/D issues have delayed/unmet health care needs due to eligibility problems (*2009-10 NS-CSHCN*)



Transportation barriers

- 51.2% of Southern Maryland families of children w/ASD travel 50+ miles to see needed specialists (*2010 Maryland Parent Survey*)

Maryland Medically Underserved Area/Population Designations (MUA/Ps), Federally Qualified Health Centers (FQHCs) and Look-Alike Sites as of 1/23/2012



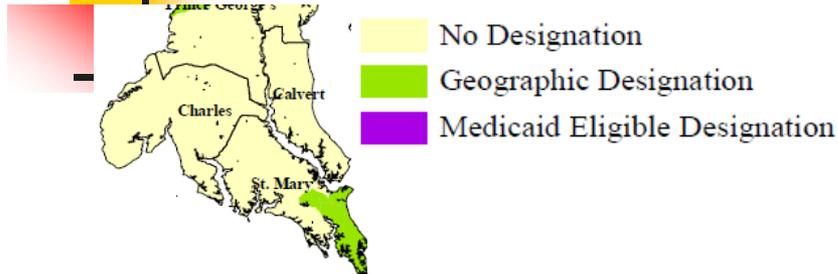
Federally Qualified Health Centers and Look-Alikes

- | | |
|---|--|
| 1 Baltimore City Health Department | 11 Owensville Primary Care, Inc (Look-alike) |
| 2 Baltimore Medical System, Inc. | 12 Parkwest Health Systems, Inc. |
| 3 Chase Brexton Health Services | 13 People's Community Health Center |
| 4 Choptank Community Health System, Inc. | 14 Three Lower Counties Comm. Svcs., Inc. |
| 5 Community Clinic, Inc. | 15 Total Health Care, Inc. |
| 6 Family Health Centers Of Baltimore, Inc. | 16 Tri-State Community Health Center |
| 7 Greater Baden Medical Services | 17 Walnut Street Community Health Center |
| 8 Health Care For The Homeless | 18 West Cecil Health Center, Inc. |
| 9 Mary's Center For Maternal & Child Care Inc | 19 Western Maryland Health Care Corporation |
| 10 Native American Lifelines Foundation, Inc. | |

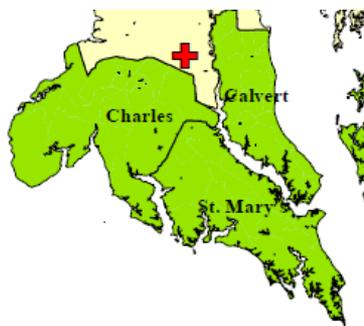
- Medically Underserved Area (MUA)
- Medically Underserved Population (MUP)
- Governor Exceptional MUP

Southern Maryland

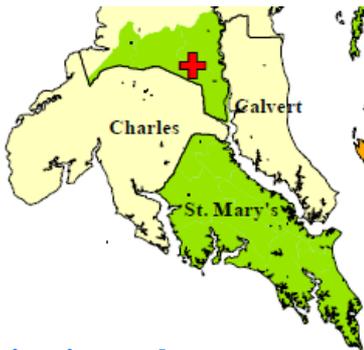
HPSA Designations for Primary Care



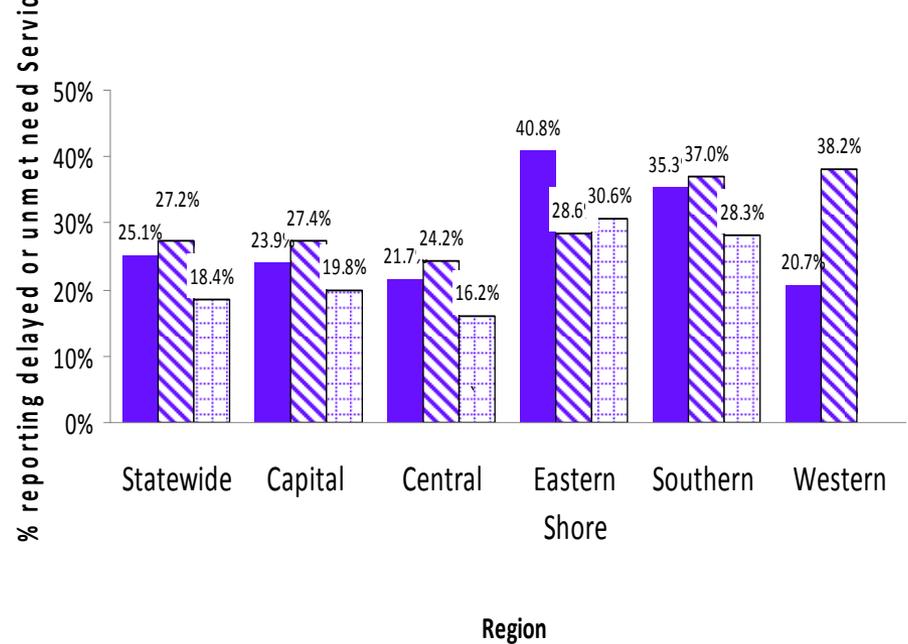
HPSA Designations for Mental Health Care



HPSA Designations for Dental Care

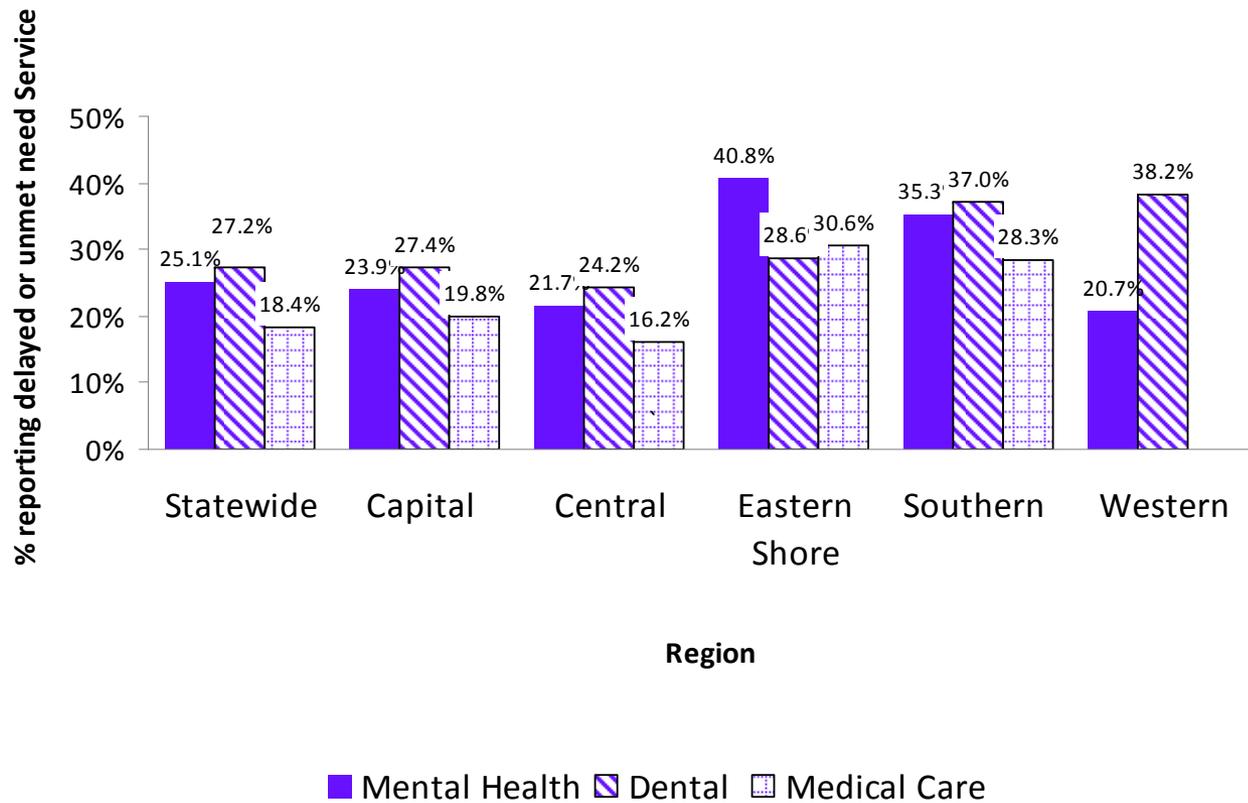


Unmet Needs for Medical Services among CYSHCN with ASD in Maryland

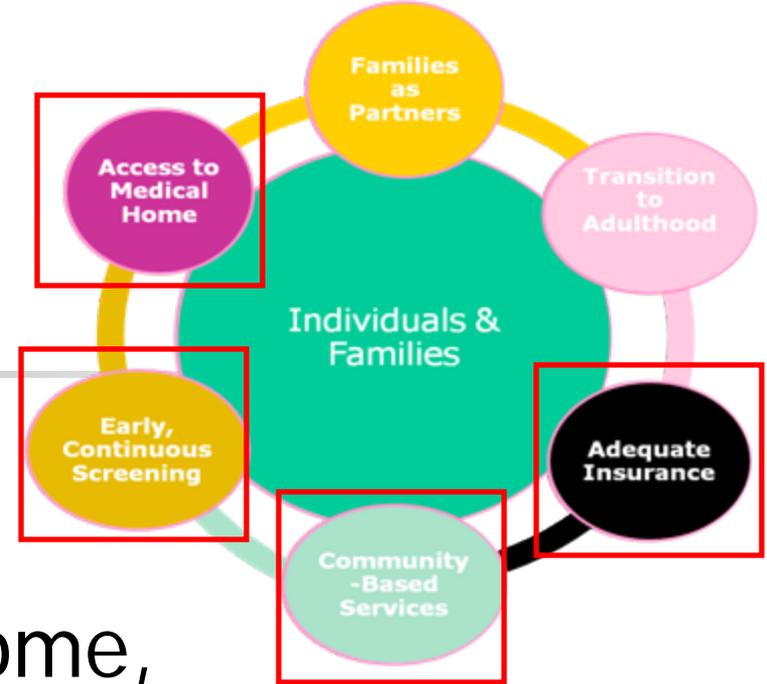


Priority: Access to primary and specialty health care

Need for Medical Services among Maryland Children and Youth with ASD



Core Outcomes



- Access to medical home,
 - early and continuous screening,
 - easy-to-use community-based services,
 - and adequate insurance and financing
- are key components of an effective system of care for CYSHCN with ASD or other DD

Phew! Done with the data...

