Southern Maryland – Setting Priorities for Children and Youth with ASD and DD
Data Handout

This document is intended to accompany the Population Overview and Data presentation in the morning.

We'll talk about:
- Prevalence
- Demographic and other characteristics
- Data around each of the top 10 needs for Southern Maryland identified through stakeholder poll

**Note: various data sources:
- National Surveys (2009-10/2007) – National Survey of Children with Special Health Care Needs (NS-CSHCN); National Survey of Children's Health (NSCH)
- 2010 Maryland Parent Survey
- Maryland State Department of Education (MSDE) Special Education Census/2009 Maryland Autism Services Survey
- Maryland Center for Developmental Disabilities (MCDD) Focus Groups (2011)
- Maryland Commission on Autism (MCA) Listening Session (2010)
- The Parents' Place of Maryland (PPMD)/Office for Genetics and Children with Special Health Care Needs (OGCSHCN) Parent Focus Group (2011)

PREVALENCE

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%).
- In 2010, almost 5 million (8%) children nationwide aged 3 -17 years had a learning disability. Children with fair or poor health status were almost five times as likely (than those with excellent or very good health) to have a learning disability (28% and 6%, respectively) and more than twice as likely to have ADHD (18% and 7%, respectively) (*Source - 2010 National Health Interview Survey*)

Prevalence within CYSHCN population in Maryland:
- 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)*

■ From 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. For example, this data set is more representative of white families of children with ASD and higher-income families of children with ASD than of lower-income families.

DEMOGRAPHIC, SOCIOECONOMIC (SES) AND OTHER CHARACTERISTICS

Some general SES data on the region:
Poverty Rates

**Child Poverty Rates - Southern Maryland Region**
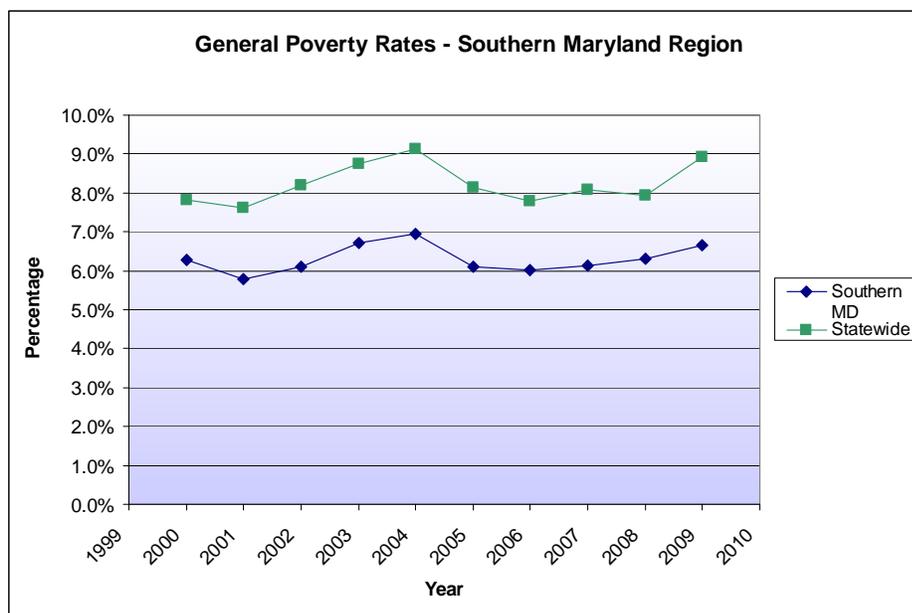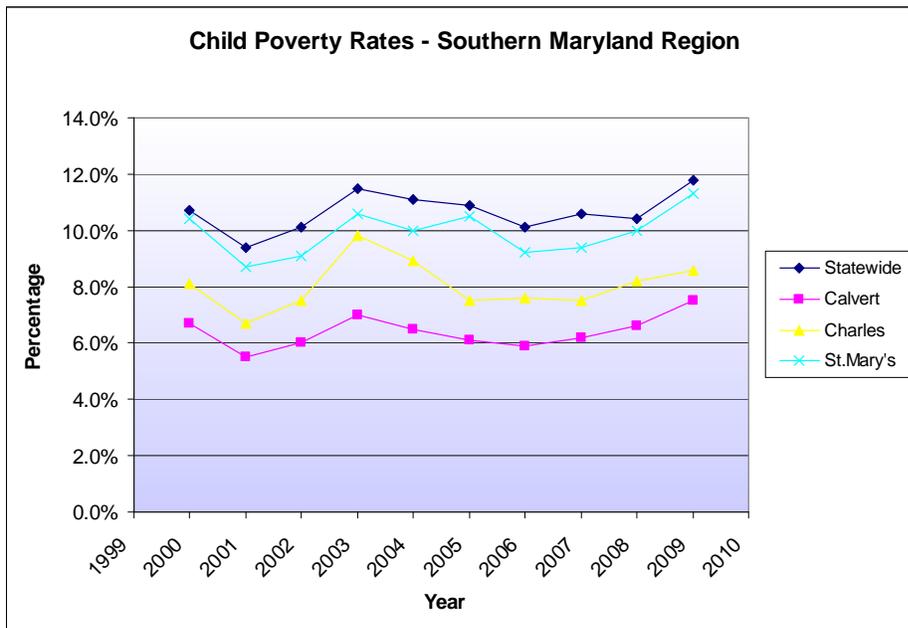
*Source: U.S. Census 2010 Small Area Income and Poverty Estimates*

Demographic Characteristics of a subsample of Maryland children and youth with special health care needs (CYSHCN):
Race/ethnicity of Maryland children and youth with ASD and with any special health care need:

Race/ethnicity of Children w/ASD (n= 293 children)

Race/ethnicity of Children with any SHCN (n= 983 children)
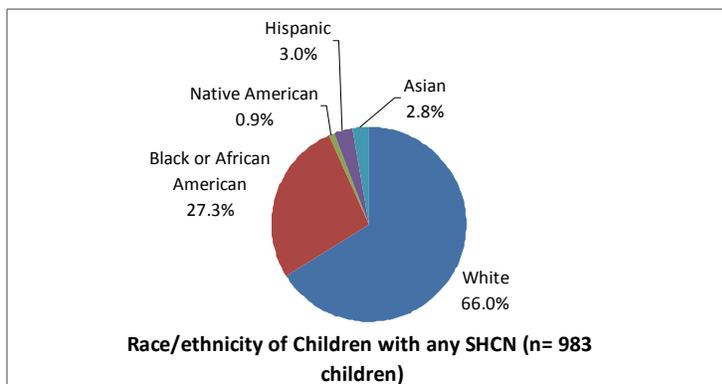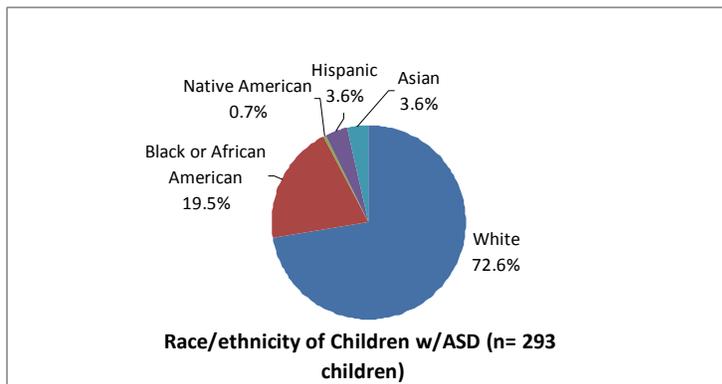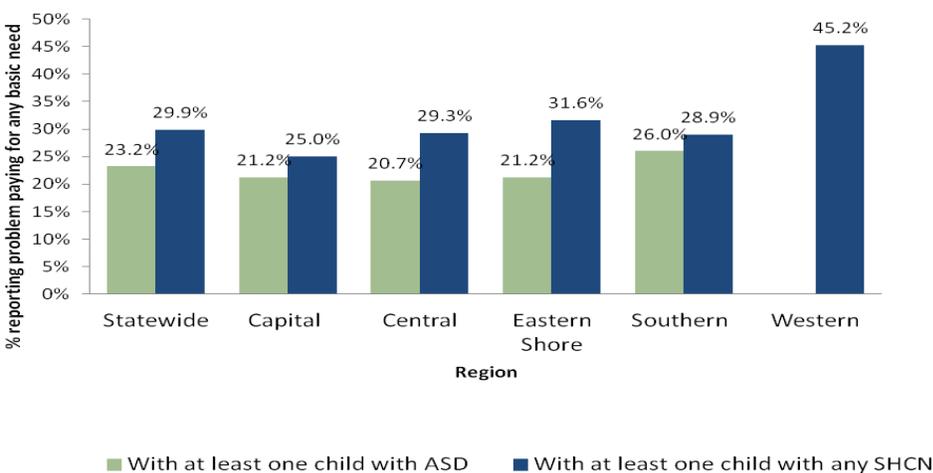
Source: 2010 Maryland Parent Survey

Maryland CYSHCN receiving government-sponsored nutritional assistance (i.e. WIC, Free or Reduced Meals, SNAP):
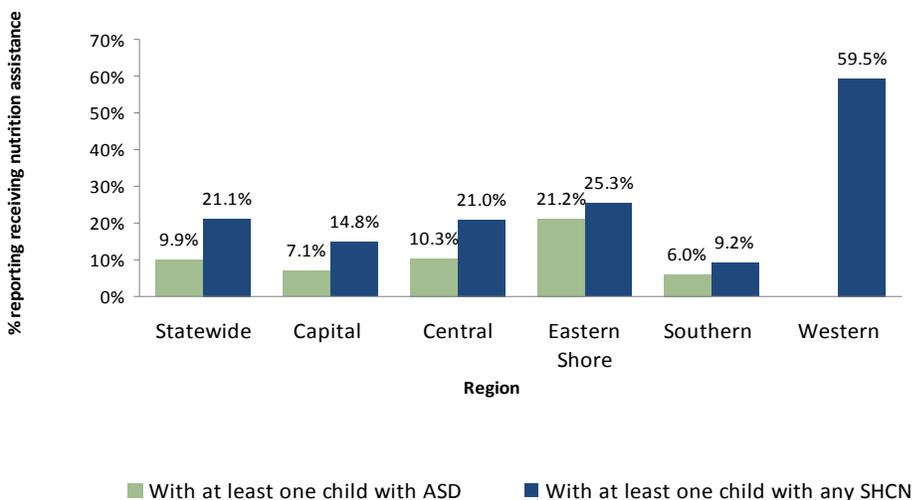
Source: 2010 Maryland Parent Survey

As a proxy for socioeconomic status, respondents were asked whether each of the children in their family received any type of government-sponsored nutritional assistance. Within this data set, statewide and across regions within the state families of children reported to have ASD are less likely than the families of children with any SHCN to receive family income-related nutrition assistance.

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

Source: 2010 Maryland Parent Survey

4

Age and Gender of Maryland children with ASD:
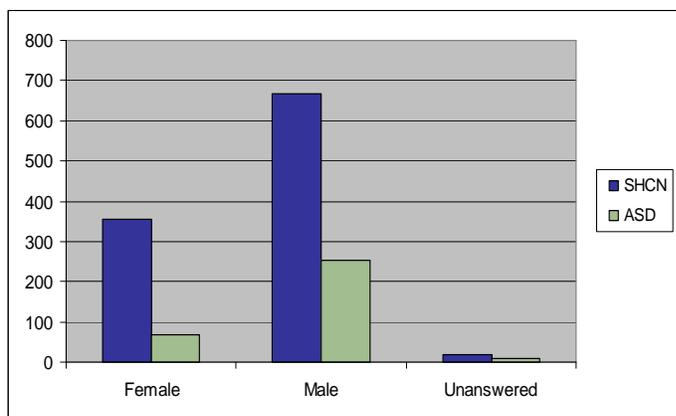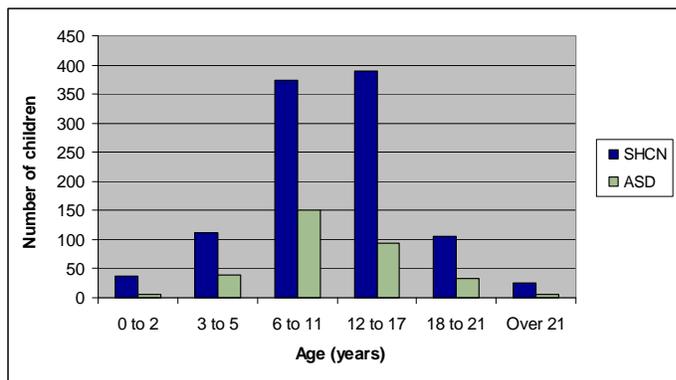
Majority of children with ASD in survey were:
- between ages 6 to 17;
- male

The majority of children with ASD represented in the survey were between the ages of 6 to 17 years (74.3%); 13.7% were between the ages of birth to 5 years, and 11.9% were ages 18 to 26 years. There were significantly more male children (76.7%) than female children (20.2%) with ASD in the survey sample.
Source: 2010 Maryland Parent Survey

Experience with Challenging Behaviors among CYSHCN with ASD in Southern Maryland:
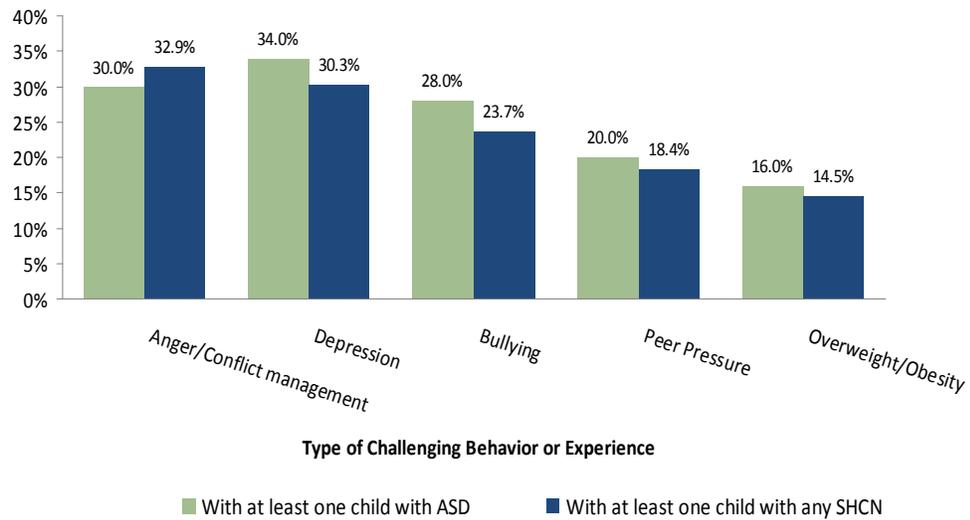
Source: 2010 Maryland Parent Survey

When examined regionally, some variation was seen within families of children with ASD, with Southern Maryland and the Eastern Shore regions reporting higher incidences of challenging behaviors than other areas of the state. For example, Southern Maryland (30.0%) and Eastern Shore (33.3%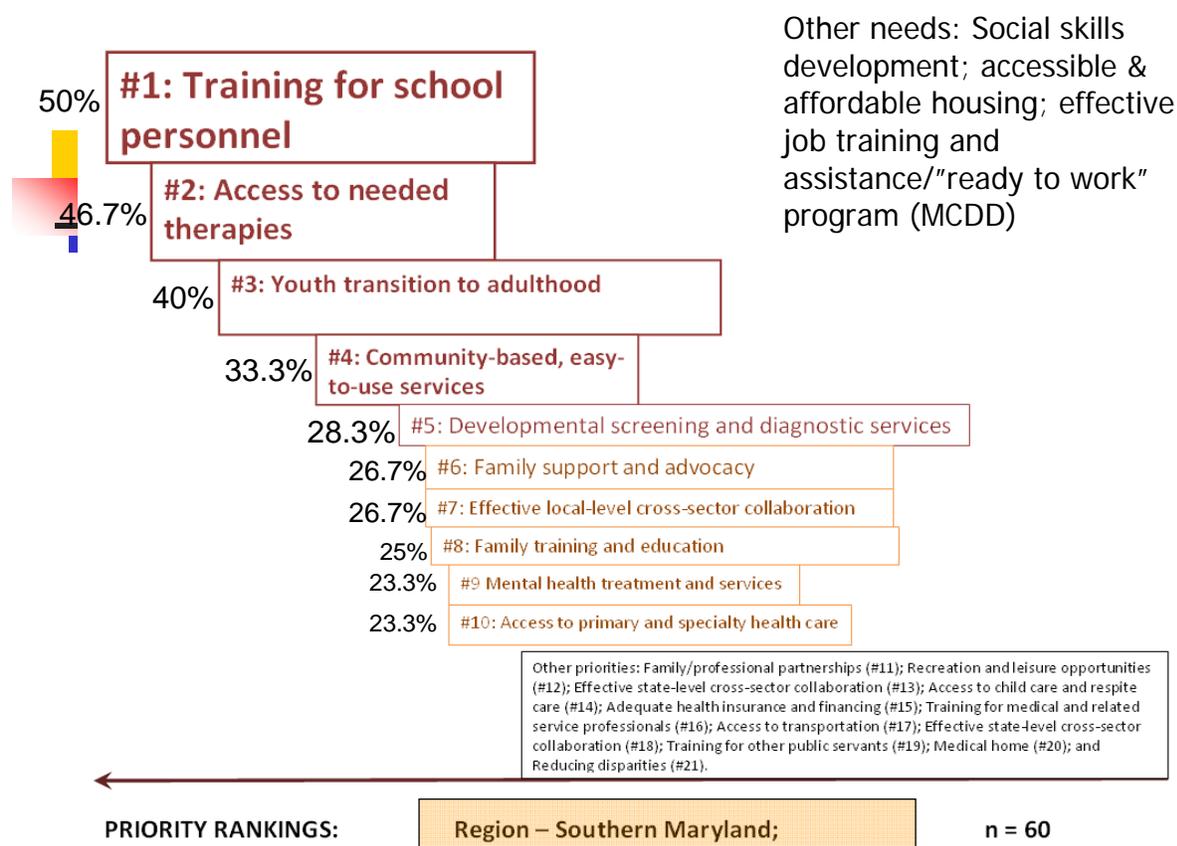) families were more likely to report issues with anger/conflict management than other regions, while Central Maryland (19.0%) families were far less likely to report issues with that behavior. Southern Maryland families were also far more likely to report issues with depression (34.0%) than the rest of the state, while the Capital Area (17.6%) was less likely to. Southern Maryland (28.0%) and Eastern Shore (24.2%) families also reported higher rates of experience with bullying than the statewide rate.
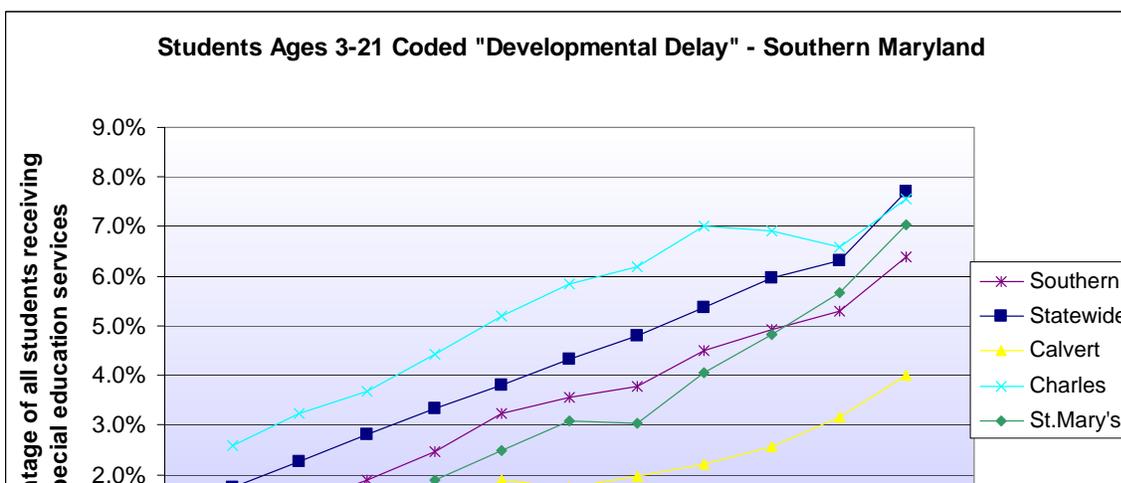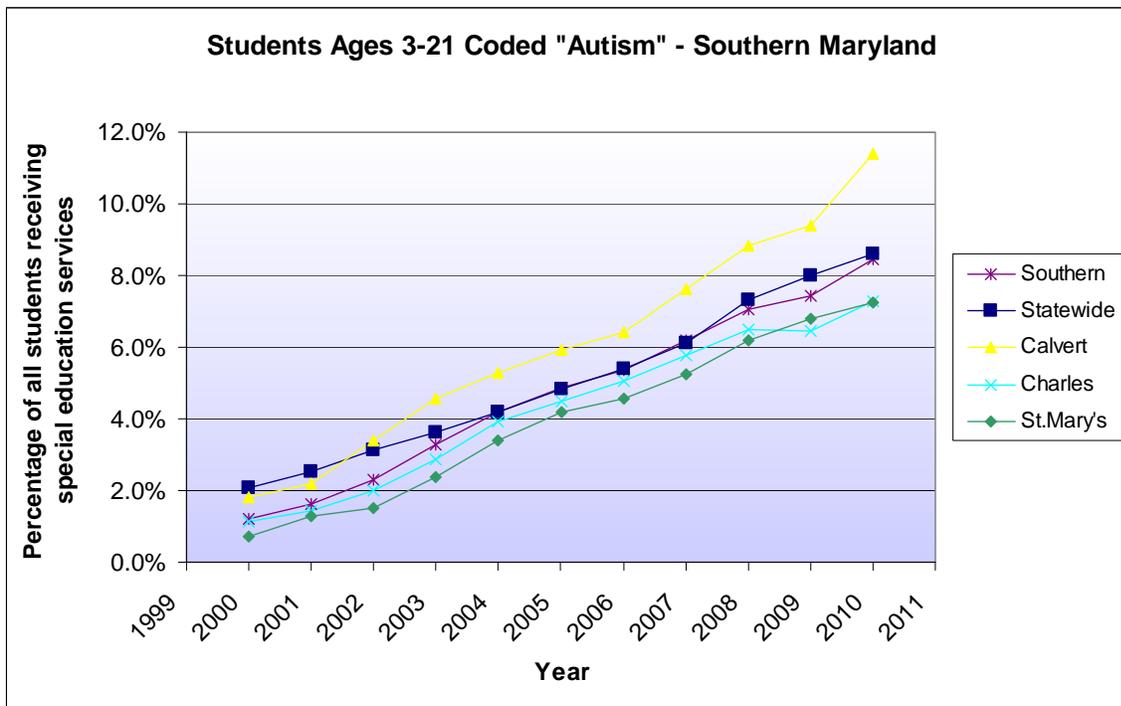
PRIORITY NEEDS AND DATA

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

50% **#1: Training for school personnel**

46.7% **#2: Access to needed therapies**

40% **#3: Youth transition to adulthood**

33.3% **#4: Community-based, easy-to-use services**

28.3% #5: Developmental screening and diagnostic services

26.7% #6: Family support and advocacy

26.7% #7: Effective local-level cross-sector collaboration

25% #8: Family training and education

23.3% #9 Mental health treatment and services

23.3% #10: Access to primary and specialty health care

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

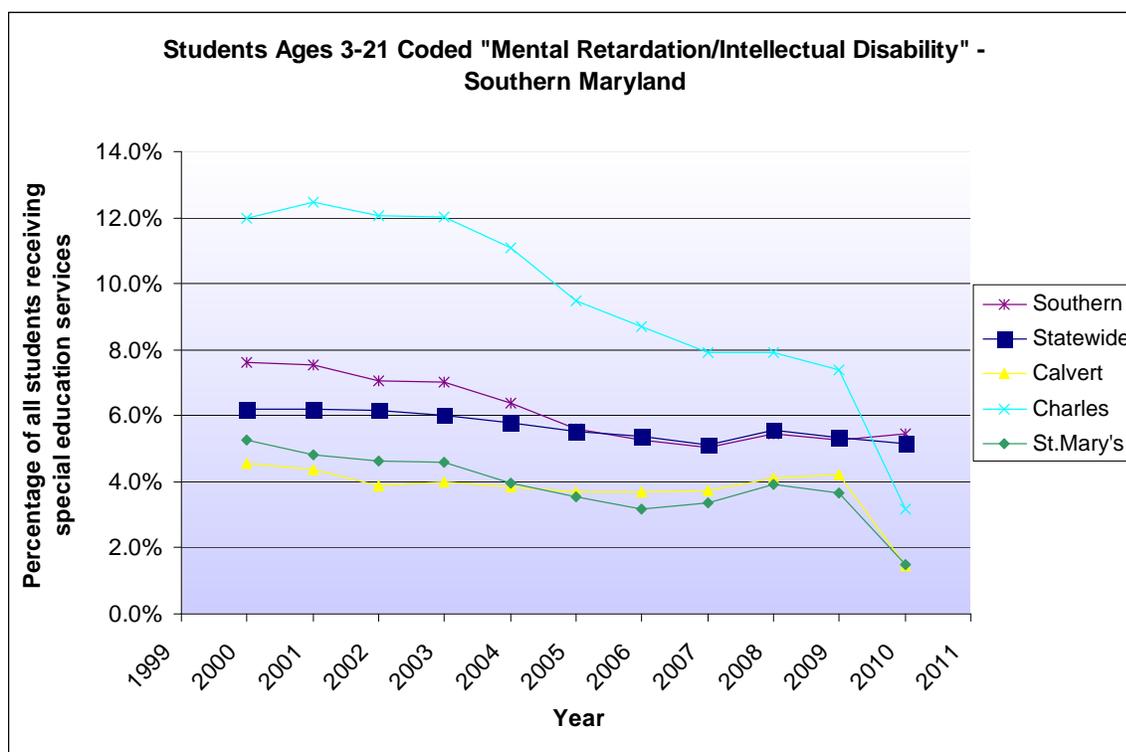## PRIORITY 1: TRAINING FOR SCHOOL PERSONNEL:

- 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 priority for the region in this poll); Community System Components: education, public health, and medical home
- 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
- 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
- OGCSHCN/PPMD Parent Focus Group in Southern Maryland, October 2011found that (1) school system personnel need more training in dealing with oppositional behavior in the classroom; and (2) it takes longer to get needed special education services when schools will not accept a physician's/medical diagnosis of autism
- Family-Professional Partnerships: 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 CYSHCN with E/B/D issues, 61.5% (compared to 59.3% nationally) are successfully achieving this outcome. *(2009-10 NS-CSHCN)*

MSDE Special Education Enrollment by Disability Type/Codes – Autism, Developmental Delay, Mental Retardation/Intellectual Disability:

Students Ages 3-21 Coded "Autism" - Southern Maryland

Students Ages 3-21 Coded "Developmental Delay" - Southern Maryland

7

Students Ages 3-21 Coded "Mental Retardation/Intellectual Disability" - Southern Maryland

Source: MSDE Special Education Census Data

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. *(2010 Maryland Parent Survey)*

Core Outcome:
- Family-Professional Partnerships: 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 CYSHCN with E/B/D issues, 61.5% (compared to 59.3% nationally) are successfully achieving this outcome. *(2009-10 NS-CSHCN)*

PRIORITY 2: 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 for the region in this poll); Community System Components: medical home, other medical, insurance/financing, transportation, public health education

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)
  - 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)
  - 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)
  - Almost every participating parent had multiple stories of delayed (by as much as 2 years) or unmet care needs for behavioral therapy, medical equipment, assistive technology, etc. because 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)

Need for Services among Families on the Autism Registry and Families Receiving Autism Waiver Services:
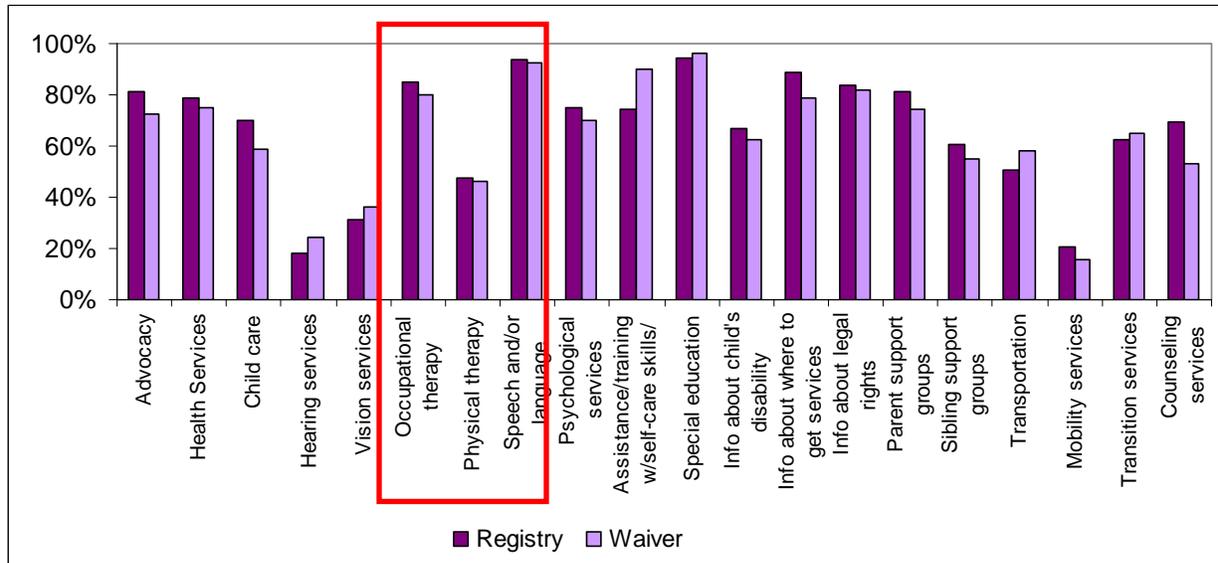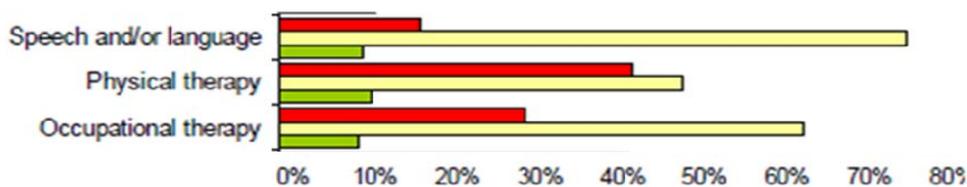
Source: MSDE 2009 Maryland Autism Services Survey

The 2009 Maryland Autism Services Survey (MASS) compared outcomes for families receiving services through the Autism Waiver to outcomes for families waiting for services on the Autism Waiver Registry and found that Waiver recipients generally reported lower rates of needs for services and reported much higher rates of service adequacy than did the families waiting on the Registry (not receiving services through the Waiver.) Both groups reported very high rates of need for special education, speech and language services, and occupational therapy.

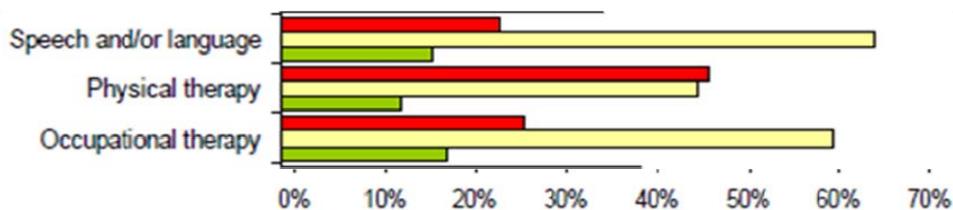Adequacy of Services among Families on the Autism Registry and Families Receiving Autism Waiver Services:

Registry Families

Source: 2009 MSDE Maryland Autism Services Survey

Core Outcomes: Adequate Insurance and Financing; Easy-to-Use Community-Based Services:

- 54.4% CYSHCN with E/B/D issues had adequate insurance and financing (compared to 65% without E/B/D issues)
- 51.3% CYSNCH with E/B/D issues had community-based, easy-to-use services (compared to 71.9% without E/B/D issues) *(2009-10 NS-CSHCN)*

PRIORITY 3: YOUTH TRANSITION TO ADULTHOOD

- 40% of ASD/DD Poll respondents representing Southern Maryland ranked "Youth Transition to Adulthood (#3 priority for the region in this poll); Community Systems Components: all

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

Transition Indicators from the 2010 Maryland Parent Survey:
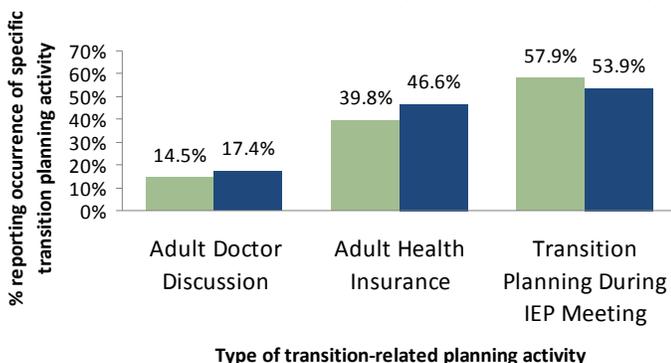
Among respondents who have a YSHCN ages 13 years or older with ASD in Maryland, 14.5% report that any of their child's health care providers have discussed having their child see a doctor who treats adults; 39.8% have considered how to obtain or keep health insurance coverage for their child as they become an adult; and 57.9% report having participated in transition planning as part of their child's IEP process. Of those families who did participate in the development of a transition plan for their child, families of children with ASD are slightly more likely to report that the transition plan was specific to their child's needs and preferences (42.2%) than are families of children with any SHCN (39.1%), and are slightly less likely to

report that they are satisfied with the transition services provided (26.3%) than are families of children with any SHCN (28.0%).

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 (*Source: 2009-10 NS-CSHCN)*

PRIORITY 4: COMMUNITY-BASED, EASY TO USE SYSTEMS
- 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 for the region in this poll); Community Systems Components: all

Main issues:
- 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 (*Source: 2010 Maryland Parent Survey*);
- 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

Navigating the System- when Maryland families try to get care for their children with E/B/D issues, they face difficulties with:
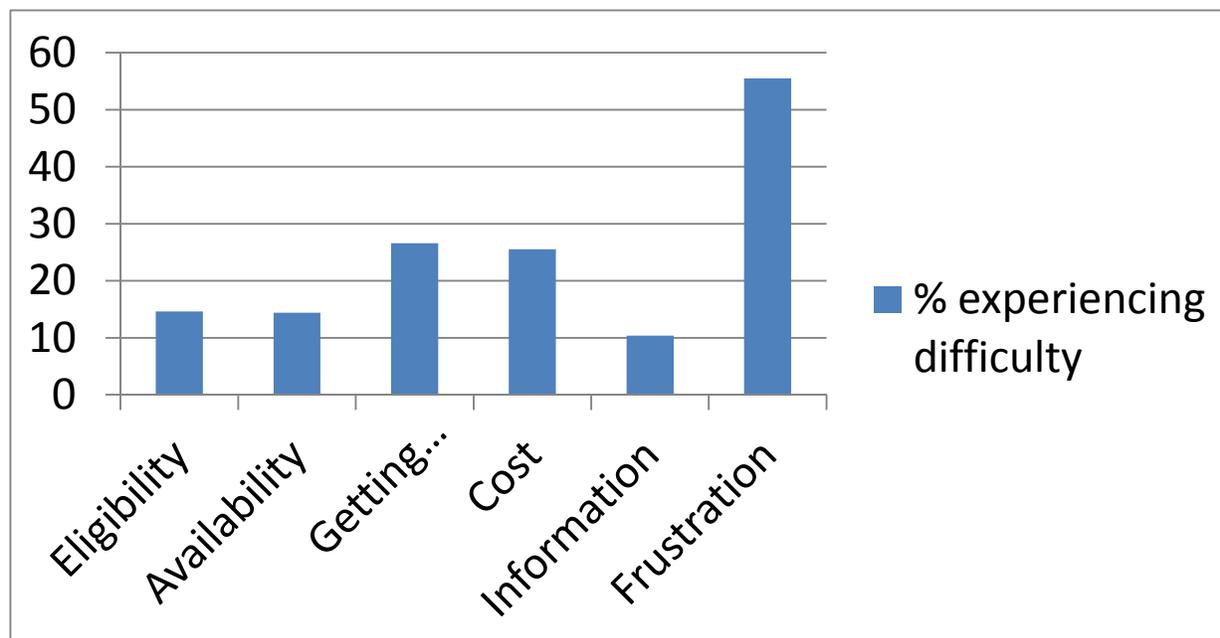
Source: 2009-10 NS-CSHCN

Core Outcome: Easy to use community-based services are a key component of an effective system of care for CYSHCN with ASD and 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 *(2009-10 NS-CSHCN)*

PRIORITY 5: 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 priority for the region in this poll); Community Systems Components: medical home, mental health, other medical, insurance/financing, transportation, public health, education

- 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 (MCA) *(*parents in PPMD focus groups reported waiting 18+ month)s*

Maryland Commission on Autism's Conceptual Model Linking Systems of Care and Communities of Care:
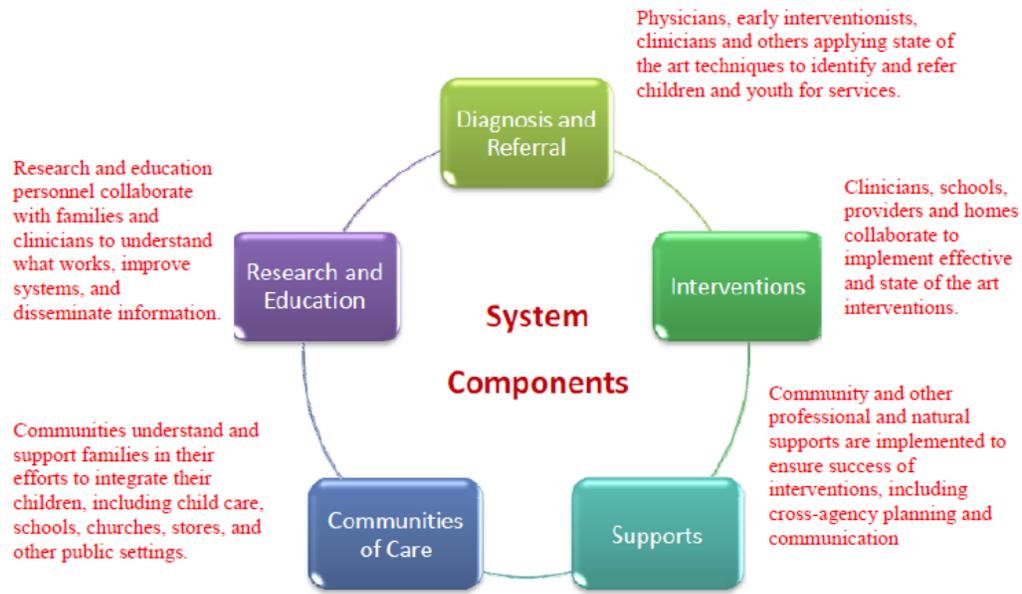
Developmental screening and diagnosis data:

- 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%

- According to the Autism and Developmental Disabilities Monitoring Network (ADDM), Maryland does not do as well as other states on diagnostic indicators.

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:

14

- 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 *(2009-10 NS-CSHCN)*

## PRIORITY 6: 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 priority for the region in this poll); Community Systems Components: all.

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:

Registry Families   Waiver Families
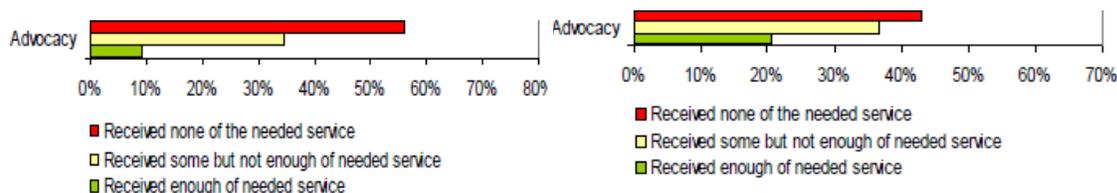
Source: 2009 Maryland Autism Services Survey

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. *(2009-10 NS-CSHCN)*

PRIORITY 7: 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 (#7 priority for the region in this poll); Community Systems Components: all.

Need for Family Support Services – Southern MD:
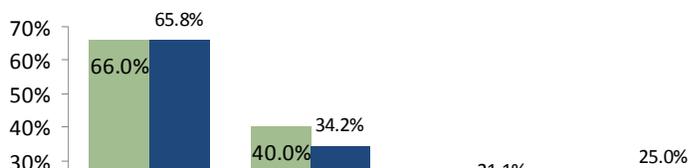
Source: 2010 Maryland Parent Survey

"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? Please make it easier for us to make sure we are accessing the proper resources and services to help our adult children with special needs (autism) know all possible options, whether Federal, state, or local to help them succeed as best they can in the adult world."
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 8: FAMILY TRAINING AND EDUCATION
- 25% of ASD/DD Poll respondents representing Southern Maryland ranked "family training and education" in their top 5 priorities; (#8 priority for the region in this poll); Community Systems Components: informal supports and services, voluntary organizations, social services, public health, social services, education, medical home.

Education and training needs among families of children with ASD:

Registry Families   Waiver Families

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
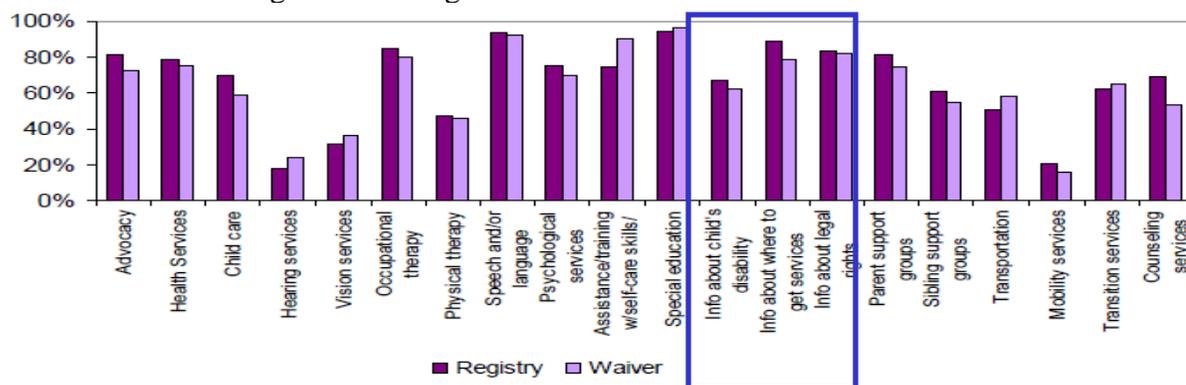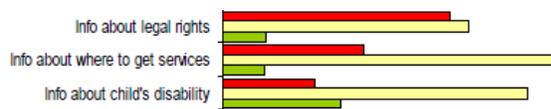- How to access needed services
- Condition specific information

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

PRIORITY 9: 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 priority for the region in this poll); Community Systems Components: mental health, medical home, insurance/financing, transportation, public health, education.

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:
- 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 10: 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 priority for the region in this poll); Community Systems Components: mental health, medical home, other medical, insurance/financing, transportation, public health.

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)*

Uneven distribution of providers:

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
2. Baltimore Medical System, Inc.
3. Chase Brexton Health Services
4. Choptank Community Health System, Inc.
5. Community Clinic, Inc.
6. Family Health Centers Of Baltimore, Inc.
7. Greater Baden Medical Services
8. Health Care For The Homeless
9. Mary's Center For Maternal & Child Care Inc
10. Native American Lifelines Foundation, Inc.

11. Owensville Primary Care, Inc (Look-alike)
12. Parkwest Health Systems, Inc.
13. People's Community Health Center
14. Three Lower Counties Comm. Svcs., Inc.
15. Total Health Care, Inc.
16. Tri-State Community Health Center
17. Walnut Street Community Health Center
18. West Cecil Health Center, Inc.
19. Western Maryland Health Care Corporation

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

Created by Office of Health Policy and Planning, Family Health Administration, DHMH. Last reviewed 2/24/2012 (no data changed)
Source: HRSA Geospatial Data Warehouse. For more information on MUA/Ps, visit http://muafind.hrsa.gov

Southern Maryland

HPSA Designations for Primary Care

No Designation	
Geographic Designation	
Medicaid Eligible Designation	

HPSA Designations for Mental Health Care

HPSA Designations for Dental Care

Unmet Needs for Medical Services among CYSHCN with ASD in Maryland
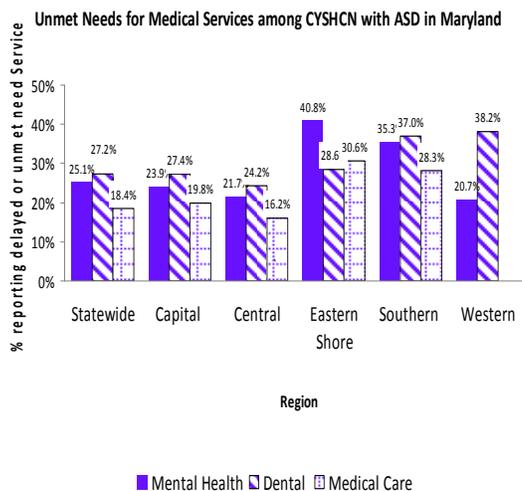
Priority: Access to primary and specialty health care

About HPSAs: A HPSA is a geographic area, population group, or health care facility (either Federal and/or State correctional institutions or public and/or non-profit medical facilities) that has been designated by the Federal government as having a shortage of health professionals. There are three categories of HPSAs: primary care (shortage of primary care clinicians), dental (shortage of oral health professionals), and mental health (shortage of mental health professionals).HPSAs are designated using several criteria, including population-to-clinician ratios. This ratio is usually 3,500 to 1 for primary care, 5,000 to 1 for dental health care, and 30,000 to 1 for mental health care. HPSA designations make places eligible for certain federal programs, including J1 Visa Waiver, National Health Services Corps, LARP, and Enhanced Medicare and Medicaid reimbursement.

- Southern Maryland has HPSAs for primary care (southern St. Mary's County), mental health care (Charles, Calvert and St. Mary's counties), and dental care (St. Mary's County.)

- Southern Maryland has higher rates of unmet needs among CYSHCN with ASD for primary and specialty medical care than the state average. (*Source: 2010 Maryland Parent Survey)*

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.