

Maryland Priorities Poll for Children and Youth with Autism and Developmental Disabilities, 2011

Results of a Poll Conducted by the Office for Genetics and Children with Special Health Care
Needs,
DEPARTMENT OF HEALTH AND MENTAL HYGIENE
and THE PARENTS' PLACE OF MARYLAND

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Introduction

Throughout the state of Maryland, Autism Spectrum Disorder (ASD) and Developmental Disabilities (DD) are two conditions that affect many children and families. The prevalence of ASD is on the rise in Maryland as well as in the United States. The Centers for Disease Control and Prevention's (CDC) [Autism and Developmental Disabilities Monitoring Network \(ADDM\)](#), which estimates national ASD prevalence based on the number of cases among 8 year-old children in 12 study sites across the nation, found that the prevalence of ASD increased nationwide by 57% from 2002 to 2006 and that the average prevalence is approaching 1% (or 9.0 per 1,000 children). The estimated prevalence in Maryland is slightly higher, at 9.2 per 1,000 children). It is difficult to estimate the prevalence of children with DD; however, the [National Survey of Children with Special Health Care Needs](#) (NS-CSHCN) provides some relevant data. According to the 2009-10 NS-CSHCN, 15.1% of all children in the United States have a special health care need. Within that population, 68.9% of children have one or more bodily function difficulties; 60.5% have one or more activities or participation difficulties; and 58.8% have one or more emotional/behavioral difficulties. Learning disabilities are one type of developmental disability. The 2010 [National Health Interview Survey](#) conducted by the CDC estimates that in 2010, almost 5 million (8%) children nationwide aged 3 -17 years had a learning disability. When compared with children with excellent or very good health, children with fair or poor health status were almost five times as likely to have a learning disability (6% and 28%, respectively) and more than twice as likely to have ADHD (7% and 18%, respectively).

Maryland is home to several well-known institutions that are excellent sources of diagnosis, intervention and research on ASD and DD. However, these resources are not systematically addressed or integrated with other services which lead to gaps in resources and information throughout the state. In addition, multiple barriers exist around finding a medical home for children with ASD or other DD, as well as to the smooth transition to adult health care for many of these youth and their families. A systematic approach to overcoming these and other barriers around core outcomes for children and youth with special health care needs must be developed at the state level to ensure that those with ASD and DD and their families have access to a system of care that is easy to use, culturally competent, comprehensive, coordinated, and family-centered.

Goal of the Poll

[The Parents' Place of Maryland](#) (PPMD), in partnership with the [Office for Genetics and Children with Special Health Care Needs](#) (OGCSHCN) in the Maryland Department of Health and Mental Hygiene (DHMH) was awarded a federal "State Planning Grant for Improving Services for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities" from the federal Maternal and Child Health Bureau. The grant was awarded on September 1, 2011 and is expected to last two years.

The purpose of this grant is to develop a comprehensive statewide plan for Maryland to improve the system of health care and related services for children and youth who have Autism Spectrum Disorder (ASD) and other Developmental Disabilities (DD). Activities for this grant are being planned and coordinated with current ASD and DD initiatives and partners in the state, including the [Maryland Commission on Autism](#) and the [Maryland Center for Developmental Disabilities](#).

As part of the needs assessment OGCSHCN and PPMD conducted an online poll of a diverse group of ASD and DD stakeholders - individuals with interest in and knowledge of Maryland's children and youth with ASD and other DD - to obtain their views about top priorities for this population in Maryland.

The report presents the results of the poll, which will help to prioritize issues affecting children and youth with ASD and DD and their families and contribute to the development of an effective statewide plan for Maryland. A copy of the poll can be found on pages 36 – 40.

Description of the Poll

The poll, entitled “2011 Maryland Priorities Poll for Children and Youth with Autism and Developmental Disabilities” was created using the website, SurveyMonkey. The survey was disseminated by email to over 200 pre-identified Maryland stakeholders in late 2011. Stakeholders could then email the survey to additional interested parties. Responses were collected from December 1, 2011 to January 10, 2012. Findings from this survey should not be considered as statistically representative, as sampling was not random.

Respondents were asked to rank the top 5 priority needs of children with autism and other developmental disabilities. There were a total of 351 initial respondents to the survey; of those, 241 respondents completed the survey according to the instructions (for a completion rate of 69%), providing usable responses for the analyses included in this report.

Table 1 (on pages 6-7) lists the priorities and their definitions from which stakeholders could make a selection. This given list of priorities was identified through a comprehensive needs assessment of Maryland’s children and youth with ASD and DD¹ conducted by OGCSHCN and PPMD. The inclusion of the “Other Needs” category gave respondents an opportunity to rank a priority or priorities that were not covered in the original list.

¹ The needs assessment report on children with Autism Spectrum Disorder and Developmental Disabilities and will be posted to various websites, including OGCSHCN’s and PPMD’s, when it is completed.

Table 1. List of priorities and definitions

Priority	Definition
Access to child care and respite care	Access to child care and respite care providers who are competent and comfortable with caring for children with ASD and other DD.
Access to needed therapies	Access to therapies such as behavioral, speech/language, occupational, and physical therapies that are necessary in treating ASD and/or DD.
Access to primary and specialty health care	Any health care service that requires medical consultation or treatment.
Access to transportation	Access to any form of transportation, public or private, that is accessible and convenient for families and children with ASD and other DD.
Adequate health insurance and financing	All families of children with ASD or other DD have adequate private and/or public insurance to pay for the services they need.
Community-based easy-to-use services	Needed services for children and youth with ASD and DD are community based and are organized so that families can use them easily.
Developmental screening and diagnostic services	Screenings allow early detection of ASD and/or DD – early identification is key to assuring the best outcomes for children and youth with ASD and DD.
Effective information dissemination	Effective dissemination of information about health, family support (i.e. child and respite care), education, and community support services and resources to families of and professionals serving children and youth with ASD and other DD.
Effective local-level cross-sector collaboration	Effective cross-sector collaboration (among government, non-profit, private, and professionals serving children and youth with ASD and DD) at the local level.
Effective state-level cross-sector collaboration	Effective cross-sector collaboration (among government, non-profit, private, and professional organizations serving children and youth with ASD and DD) at the state level.
Family/Professional Partnerships	Families of children and youth with ASD and other DD partner in decision making about their child's care at all levels and are satisfied with the services they receive.
Family Support and Advocacy	Families of children and youth with ASD and other DD receive support and advocacy from other families, community organizations, and advocacy organizations in providing the best possible care for their children.
Family training and education	Health-related training and information for families of children and youth with ASD and/or DD.
Medical Home	Children and youth with ASD and other DD receive coordinated, ongoing comprehensive care according to the American Academy of Pediatrics' recommended medical home model of care.
Mental health treatment and services	Children and youth with ASD and other DD have access to needed mental health treatment, counseling, and related services.
Other Needs	Other topics not covered by this list of priorities.
Training - medical and related services professionals	Training for medical and related service professionals

	in how to meet the needs of children and youth with ASD and other DD.
Training - school personnel	Training for school personnel in how to meet the needs of children and youth with ASD and other DD.
Training - other public servants	Training for other public servants (i.e. first responders such as emergency medical technicians and firefighters, judicial system personnel, etc.) in how to meet the needs of children and youth with ASD and other DD.
Recreation and leisure opportunities	Recreation and leisure opportunities for children and youth with ASD and other DD and their families.
Reducing disparities	Reducing disparities in access to services and supports for families based on regional, socioeconomic, language, and cultural barriers.
Youth transition to adulthood	Youth with ASD and DD receive the services necessary to make transition to all aspects of adult life, including adult health care, work, and independence.

Demographics

Number of Surveys returned by Stakeholders

Table 2. Number of Respondents by Stakeholder Category

Stakeholder	Number of respondents within each Stakeholder Category	Percentage of Respondents
State Government Agency	24	7.1%
Local Government Agency	16	4.8%
Professional Practice Organization	0	0.0%
Advocacy Organization	23	6.8%
Community-Based Agency Representative	21	6.3%
Medical Center/ Health Care Provider	15	4.5%
University	5	1.5%
School	40	11.9%
Student	5	1.5%
Insurer	4	1.2%
Parent	142	42.3%
Interested Maryland Resident	41	12.2%
Total	336	

**Respondents could choose multiple stakeholder categories.*

Table 2 shows the number of respondents by stakeholder category. Respondents of the poll were asked to indicate the stakeholder category which they represented and could choose multiple categories. A large majority of respondents indicated that they were a parent (42.3%) of a child with ASD and/or DD. The second highest number of respondents indicated that they were interested Maryland residents (12.2%) and the third highest stakeholder category represented was members of the school system (11.9%).

There were low response rates for the professional practice organization, university, student and insurer categories. These categories were subsequently dropped from the subgroup analysis by stakeholder category due to the low sample size. However, the responses from those stakeholder categories were included in the overall stakeholder category and regional rankings analyses.

Number of Surveys returned by Counties and by Regions

Map 1: Counties and Regions throughout the state of Maryland



Stakeholders were asked to indicate the jurisdiction(s) that they served as the primary focus area for their work with and/or knowledge of Maryland's children and youth with ASD and DD. Respondents could choose multiple jurisdictions and could also indicate "statewide" if their focus incorporated the entire state of Maryland.

Table 3: Number of Respondents by County

County	Number of Respondents	Percentage of Respondents
Allegany	9	2.9%
Anne Arundel	10	3.3%
Baltimore City	15	4.9%
Baltimore	34	11.1%
Calvert	24	7.8%
Caroline	6	2.0%
Carroll	5	1.6%
Cecil	7	2.3%
Charles	11	3.6%
Dorchester	4	1.3%
Frederick	7	2.3%
Garrett	1	0.3%
Harford	18	5.9%
Howard	11	3.6%
Kent	12	3.9%
Montgomery	39	12.7%
Prince George's	11	3.6%
Queen Anne's	8	2.6%
St. Mary's	33	10.8%
Somerset	1	0.3%
Talbot	4	1.3%
Washington	6	2.0%
Wicomico	2	0.7%
Worcester	1	0.3%
Statewide	27	8.8%
Total	306	

**Respondents could choose multiple counties.*

Table 3 displays the number of respondents by county. The counties that were most often represented were Montgomery County (12.7%), Baltimore County (11.1%) and St. Mary's County (10.8%). The counties that were least represented by respondents were Garrett County (0.3%) in the Western Maryland region as well as Somerset (0.3%), Worcester (0.3%) and Wicomico (0.7%) counties on the Eastern Shore.

Table 4 displays the number of respondents by Maryland region. The majority of respondents (29.6%) represented the Central Maryland region. Nearly a quarter of respondents represented the Southern Maryland region; 19.2% selected a county or counties in the Capital Region; 10% selected Eastern Shore counties; and 6.4% of represented Western Maryland. Nearly eleven percent selected the "Statewide" option.

Table 4: Number of Respondents by Region

Region	Number of Respondents	Percentage of Respondents
Western	16	6.4%
Capital	48	19.2%
Southern	60	24.0%
Central	74	29.6%
Eastern Shore	25	10.0%
Statewide	27	10.8%
Total	250	

**Respondents could indicate counties within multiple regions.*

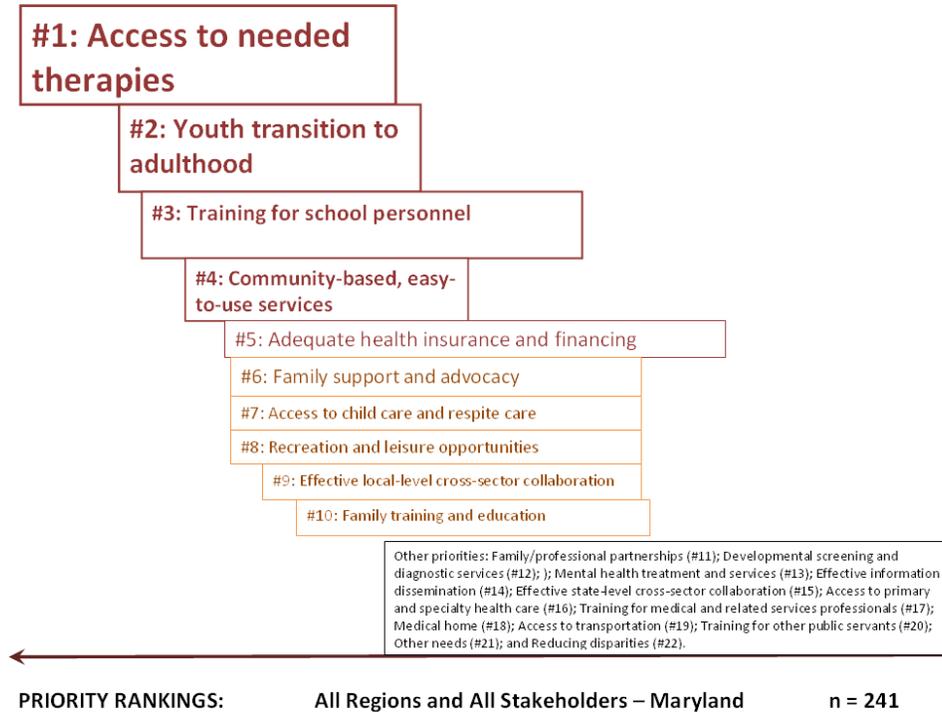
Priority Rankings

Poll respondents were asked to rank the top 5 priority needs for Maryland’s children and youth with ASD and other DD from a list of 21 priorities (respondents could mention priorities not included in the original list by indicating “Other Need” and typing in their suggestions). Table 1 on pages 6 – 7 displays the list of priorities in which respondents could make a selection. Respondents’ rankings were analyzed as a whole (designated as the “overall” category), and subgroup analyses of poll responses were done by region and by stakeholder category. The overall category rankings, as well as the regional and stakeholder subgroup rankings, were determined by the following method:

Three measures were used: (1) the percentage of respondents who ranked a priority in their top five; (2) the percentage of respondents who ranked a priority in their top two priorities; and (3) the percentage of respondents who ranked a priority as their number one priority. First, the priority most often indicated within respondents’ top five rankings (according to measure 1) was considered the number one priority for the group/subgroup; the number two priority most often indicated within respondents’ top five rankings was considered the number two priority for the group/subgroup, and so on. In many cases, priorities had the same ranking according to measure 1; in these cases, we looked at how often each priority was indicated by respondents’ as being their number one or number two priority (according to measure 2), and the priority most often ranked in the respondents’ top one or two rankings was chosen as the higher priority. In some cases, this method still produced a tie between priorities; in those cases, we gave the higher rank to the priority that was most often indicated by respondents as being their number one priority (according to measure 3.) In several cases, this still produced a tie, and these priorities were given the same ranking. See [Appendix](#) for tables listing priorities with corresponding percentages in the top five, top one and two, and number one ranking categories (by region and stakeholder category).

Priority Rankings – By Region

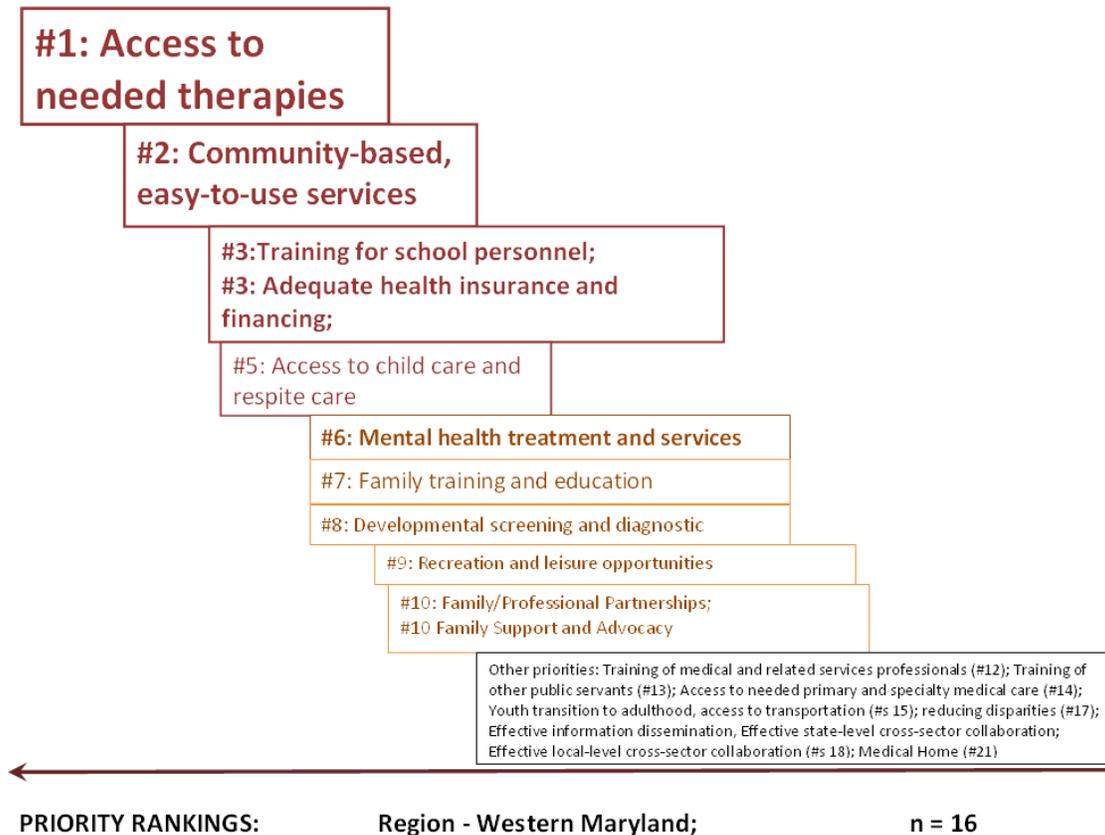
Maryland – Combined (all regions, all stakeholders)



There were two hundred forty-one respondents representing all regions and all stakeholders. When asked to rank their **top 5 needs for children and youth with ASD and other DD**, 45.2% of overall respondents ranked “**access to needed therapies**,” making it the highest ranked priority for poll takers. Over thirty-seven percent (37.3%) included “**youth transition to adulthood**,” making it the second highest priority for children and youth with ASD and DD, according to this poll. More than one-third (35.3%) of respondents chose “**training for school personnel**,” making them the region’s third highest priority. Slightly less than a third (32.4%) of respondents selected “**community-based, easy-to-use services**” which was ranked as the number four priority. Priority number five is, “**adequate health insurance and financing**” which was selected in the top 5 priorities list of nearly thirty percent (29.9%) of respondents. Nearly twenty-nine percent (28.6%) of respondents selected the number six priority, “family support and advocacy.” Over twenty-eight percent (28.2%) of respondents selected “access to child care and respite care” and “recreation and leisure opportunities” in their top five lists, making them the number seven and eight priorities. Twenty-six percent (26.1%) of the respondents chose the number nine priority, “effective local-level cross-sector collaboration.” A little over twenty-two percent (22.4%) of respondents included “family training and education” making this the number ten priority for children and youth with ASD and DD for all regions and all stakeholders.

* A percentage breakdown of priorities for all regions and all stakeholders is provided on [pg. 28](#).

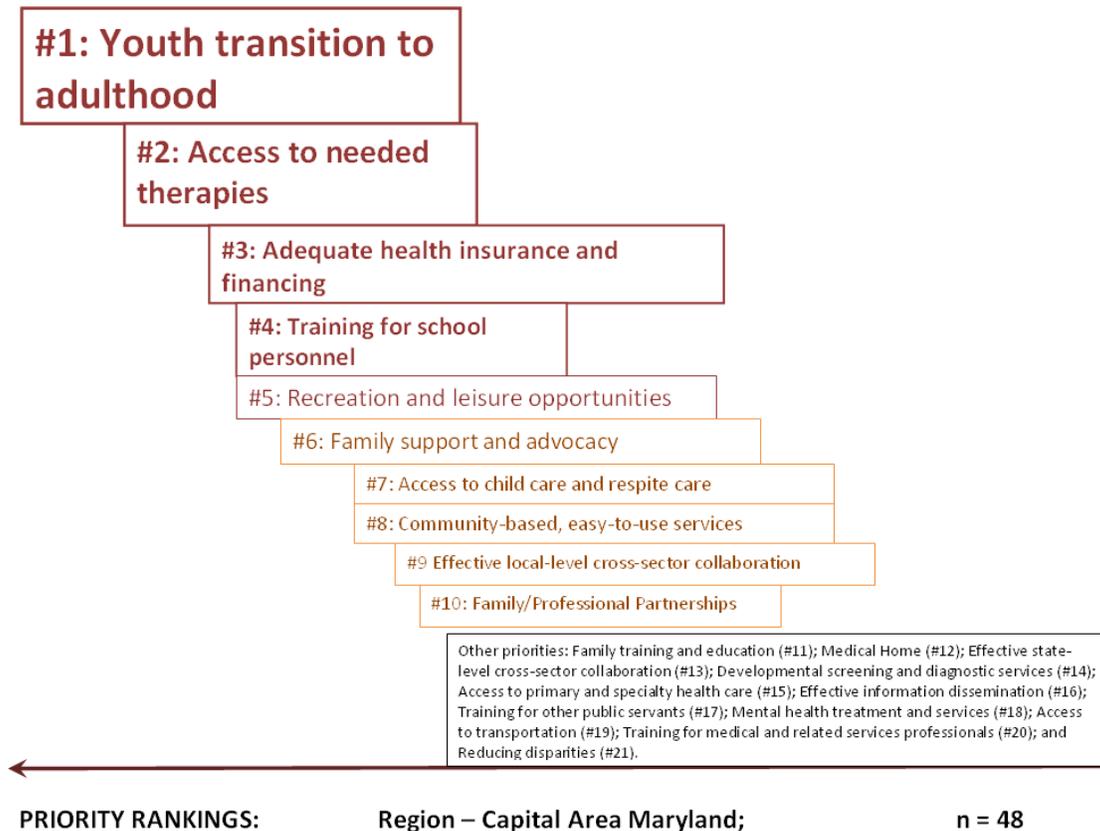
Western Region



There were sixteen respondents representing the Western Maryland region. When asked to rank their **top 5 needs for children and youth with ASD and other DD**, 50.0% of respondents from Western Maryland included “**access to needed therapies**,” making it the number one priority in the region according to the poll. Nearly forty-four percent (43.8%) included “**community-based, easy-to-use services**,” making it the second highest priority for children and youth with ASD and DD for the region according to this poll. More than one-third (37.5%) of respondents representing Western Maryland chose “**training school personnel**” and “**adequate health insurance and financing**,” making them the region’s number three priorities. Number five priority, “**access to child care and respite care**” was also selected by more than a third (37.5%) of respondents. Slightly less than a third (31.3%) of those who represented the Western Maryland respondents selected “**mental health treatment and services**,” family training and education,” and “**developmental screening and diagnostic services**,” corresponding to the number six, number seven and number eight priorities for the region. One quarter (25.0%) of respondents included “**recreation and leisure opportunities**,” “**family/professional partnerships**,” and “**family support and advocacy**,” making these the number nine and ten priorities for children and youth with ASD and DD in Western Maryland.

*A percentage breakdown of priorities for this region is provided on [pg. 29](#).

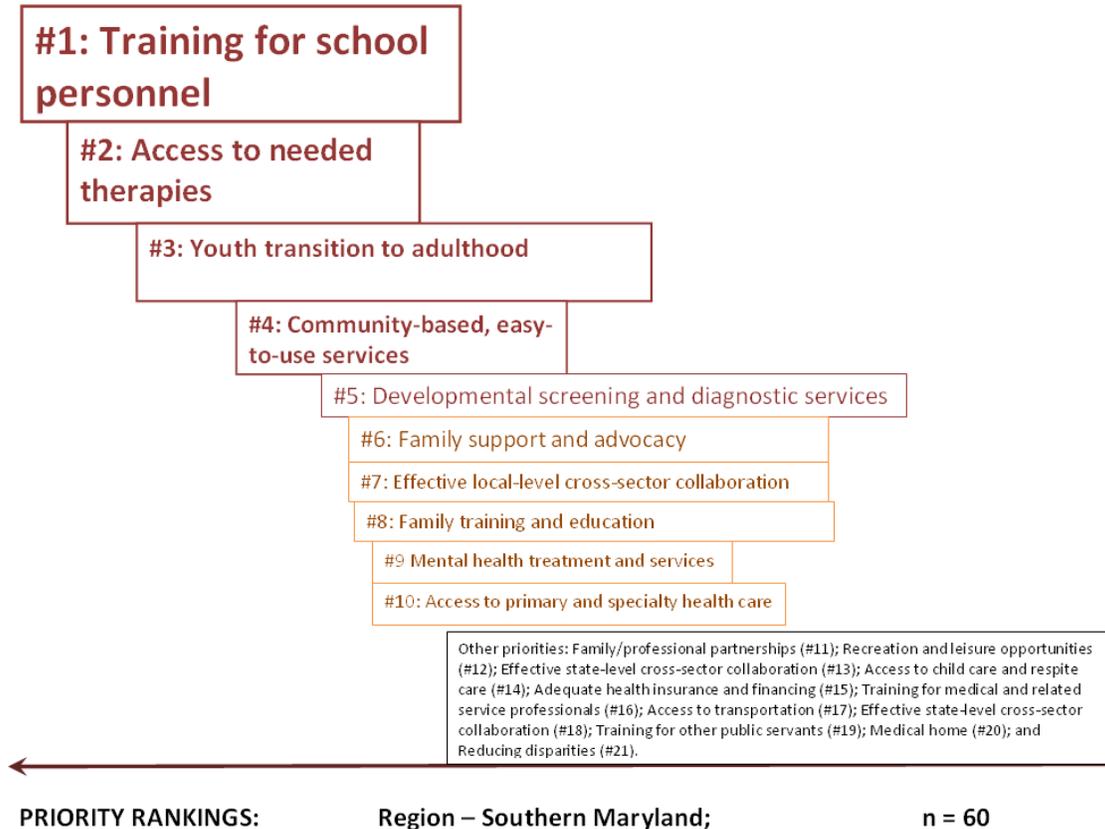
Capital Region



There were forty-eight respondents representing the Capital Area region of Maryland. When asked to rank their **top 5 needs for children and youth with ASD and other DD**, 56.3% of respondents from the Capital Region included “**youth transition to adulthood**,” making it the number one priority for children and youth with ASD and DD in the region according to the poll. Nearly forty-eight percent (47.9%) included the number two priority, “**access to needed therapies**,” in their top 5 priorities. Nearly forty percent (39.6%) of respondents chose “**adequate health insurance and financing**,” which was ranked as the number three priority. More than thirty-five percent (35.4%) chose “**training for school personnel**” and “**recreation and leisure opportunities**,” the number four and five priorities for this region. A third (33.3%) of the respondents from the region included “family support and advocacy” in their top five, making this the number six priority. Nearly thirty percent (29.2%) of the poll takers chose both “access to child care and respite care” and “community – based easy-to-use services” and they were subsequently ranked priority number seven and eight. A quarter (25.0%) of poll takers representing the Capital Area included “effective local – level cross-sector collaboration” making this the number nine priority. Almost twenty-three percent (22.9%) identified “family/professional partnerships” in their top 5 list of priorities, making this the number ten priority for Capital Maryland.

*A percentage breakdown of priorities for this region is provided on [pg. 29](#).

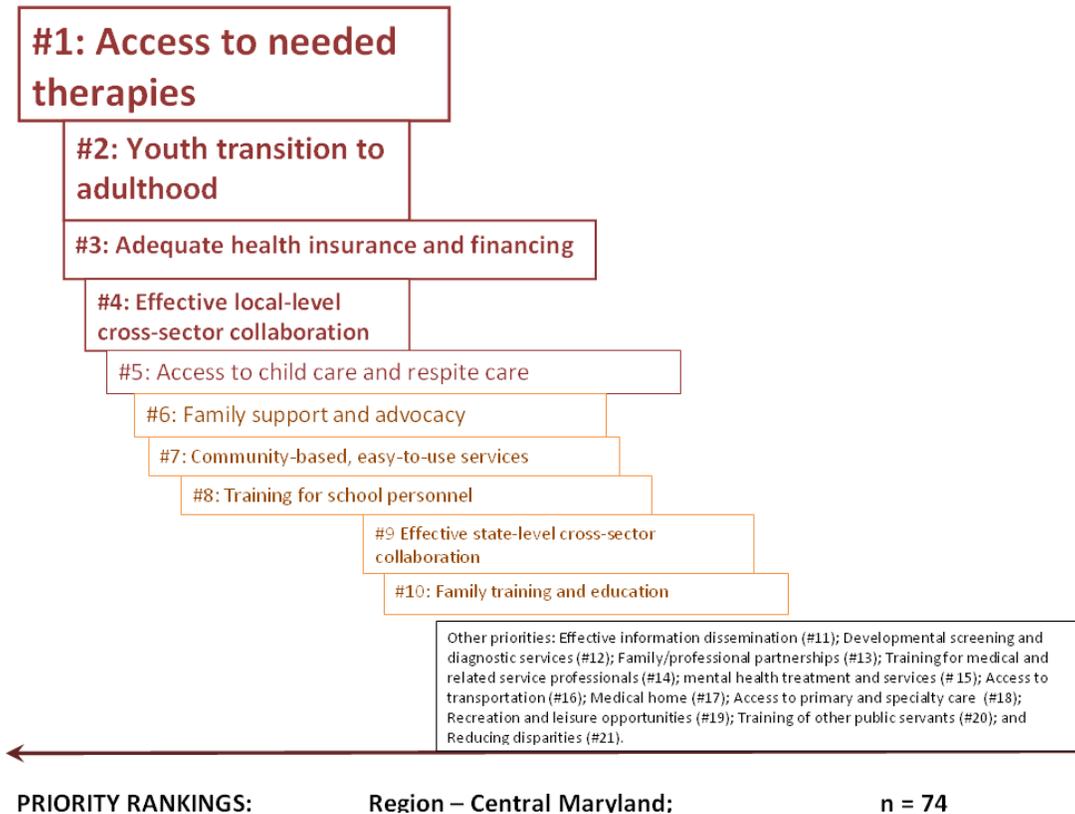
Southern Region



There were sixty respondents representing the Southern Maryland region. When asked to rank their **top 5 needs for children and youth with ASD and other DD**, 50.0% of respondents from Southern Maryland included “**training for school personnel**,” making it the number one priority for children and youth with ASD and DD in the region according to the poll. Nearly forty-seven percent (46.7%) included “**access to needed therapies**” making it the second highest priority for the region according to this poll. Forty percent (40.0%) of respondents representing Southern Maryland chose “**youth transition to adulthood**,” making it the third highest priority. A third (33.3%) of these respondents selected “**community-based easy-to-use services**” and it was ranked as priority number four. A little over twenty-eight percent (28.3%) selected the “**developmental screening and diagnostic services**,” the number five priority. “Family support and advocacy” and “effective local-level cross-sector collaboration” were both chosen by nearly twenty-seven percent (26.7%) of respondents and ranked the sixth and seventh priorities for the Southern region according to this poll. A quarter (25.0%) of respondents chose the number eight priority, “family training and education.” Over twenty-three percent (23.3%) of respondents included “mental health treatment and services” and “access to primary and specialty health care” making these the number nine and ten priorities for children and youth with ASD and DD in Western Maryland.

*A percentage breakdown of priorities for this region is provided on [pg. 30](#).

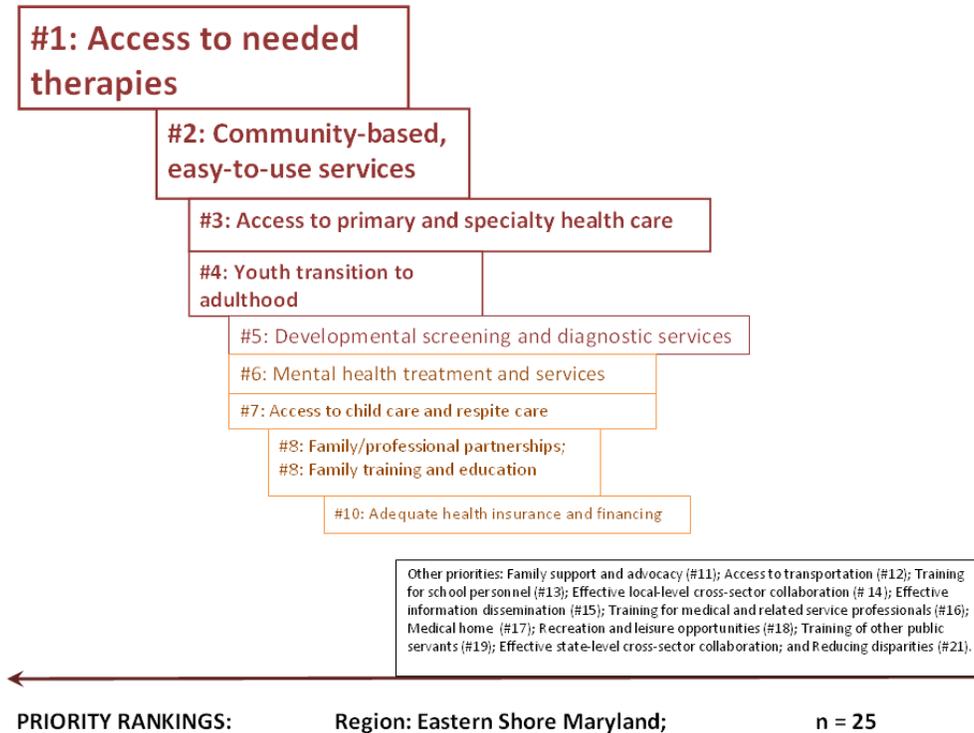
Central Region



There were seventy-four respondents representing the Central Maryland region. When asked to rank their **top 5 needs for children and youth with ASD and other DD**, 43.2% respondents included “**access to needed therapies**,” making it the number one priority for the region according to this poll. A little over thirty-seven percent (37.8%) ranked the number two and three priorities, “**youth transition to adulthood**” and “**adequate health insurance and financing**” in their top 5 priorities. Nearly thirty-seven percent (36.5%) of respondents chose “**effective local-level cross-sector collaboration**” and it was ranked the number four priority for the region, according to this poll. Over a third (35.1%) of the respondents included “**access to child care and respite care**” in their top five, making this the number five priority. The number six priority, “family support and advocacy,” was selected by over thirty-two percent (32.4%) of respondents representing the Central Maryland region. More than thirty percent (31.1%) of chose “community-based easy-to-use services” and it was ranked the number seven priority. Less than thirty percent (29.7%) selected “training – school personnel,” making it the number eight priority. The number nine priority, “effective state-level cross sector collaboration” was chosen by over twenty-one percent (21.6%) of the respondents representing Central Maryland. Around twenty percent (20.3%) identified “family training and education” in their top five, making this the number ten priority for Central Maryland.

*A percentage breakdown of priorities for this region is provided on [pg. 30](#).

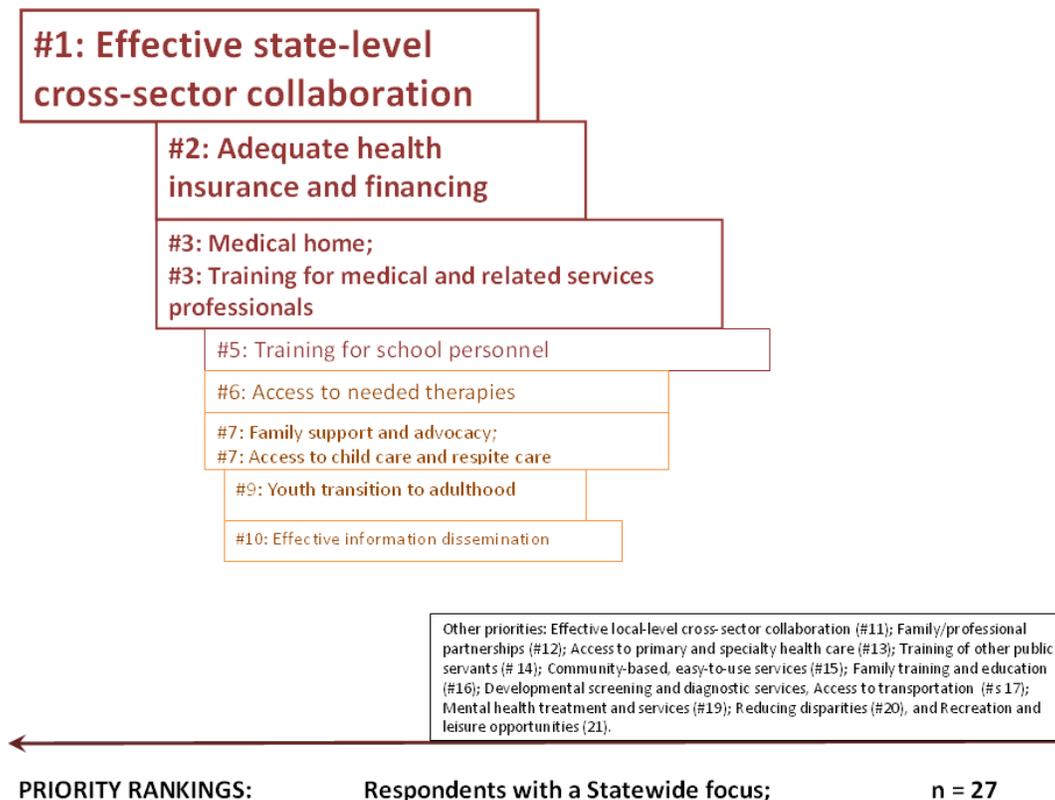
Eastern Region



There were twenty-five respondents representing the Eastern Shore region of Maryland. When asked to rank their **top 5 needs for children and youth with ASD and other DD**, 48.0% respondents from the Eastern Shore ranked “**access to needed therapies**,” making it the number one priority for the region according to the poll. Thirty-six percent (36.0%) included “**community-based easy-to-use services**” making it the second highest priority for children and youth with ASD and DD for the region according to this poll. Thirty-two percent (32.0%) of respondents representing the Eastern Shore of Maryland chose “**access to primary and specialty health care**” and “**youth transition to adulthood**” making it the region’s number three and four priorities, according to this poll. Twenty-eight percent (28.0%) of poll-takers representing the Eastern Shore, included “**developmental screening and diagnostic services**,” “**mental health treatment and services**” and “**access to child care and respite care**,” corresponding to the number five, number six and the number seven priorities. Less than twenty-five percent (24.0%) included the number eight priorities “**family/professional partnerships**” and “**family training and education**” priorities in their top 5 needs for children and youth with ASD and other DD. One fifth (20%) of respondents included “**adequate health insurance and financing**,” making it the number ten priority for children and youth with ASD and DD on the Eastern Shore.

*A percentage breakdown of priorities for this region is provided on [pg. 31](#).

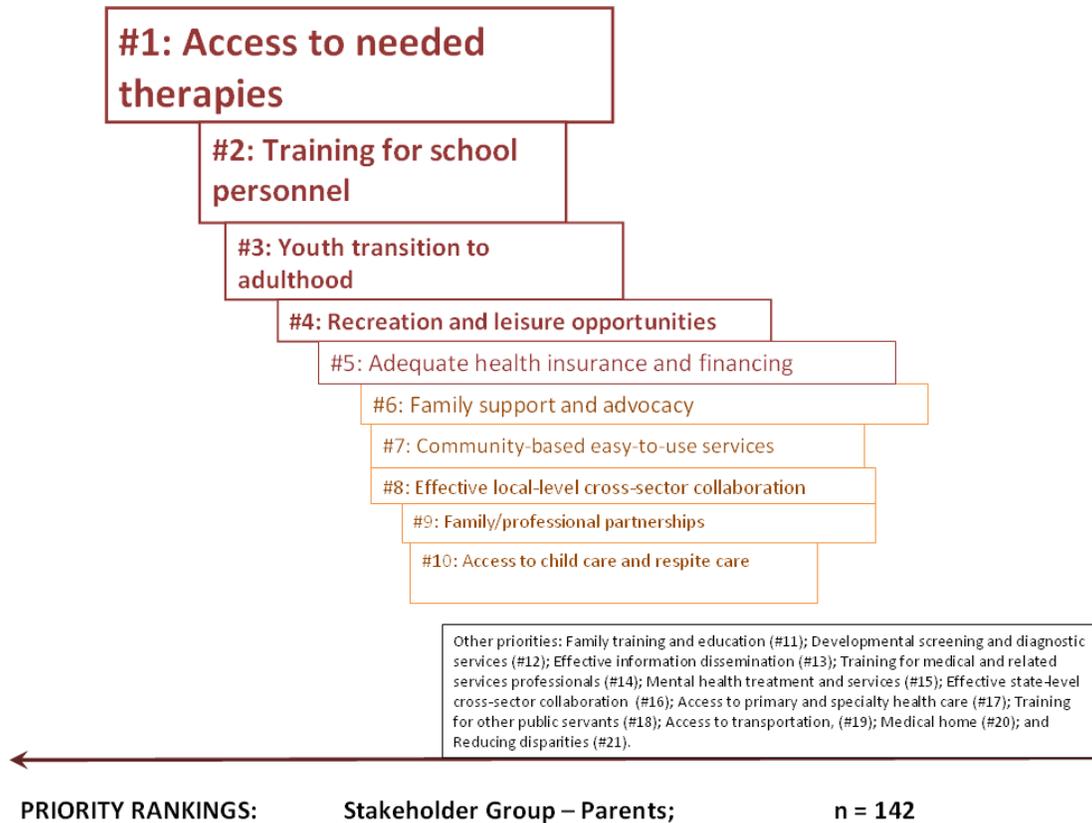
Statewide (this category is not to be confused with the Overall Maryland category, which represents all respondents in the state.)



There were 27 respondents with a statewide, as opposed to a particular regional, focus. When asked to rank their **top 5 needs for children and youth with ASD and other DD**, 44.4% of these respondents included “**effective state-level cross-sector collaboration**” in their top priorities, making it the number one priority for children and youth with ASD and DD in the region according to this poll. A third (33.3%) of the respondents from the region included “**adequate health insurance and financing**,” and it was ranked as the second highest priority for the region. The number three priorities, “**medical home**” and “**training-medical and related services professionals**,” were also included by thirty-three percent (33.3%) of respondents. The number five priority, “**training – school personnel**,” the number six priority, “**access to needed therapies**” and the number seven priorities, “**family support and advocacy**,” and “**access to child care and respite care**,” were all chosen by 29.6% of the respondents with a statewide focus. Almost twenty-six percent (25.9%) identified “**youth transition to adulthood**” and “**effective information dissemination**” in their top five, making this the number nine and number ten priority for the respondents with a Statewide focus, according to this poll.

*A listing of percentages for each priority in this focus is provided on [pg. 31](#).

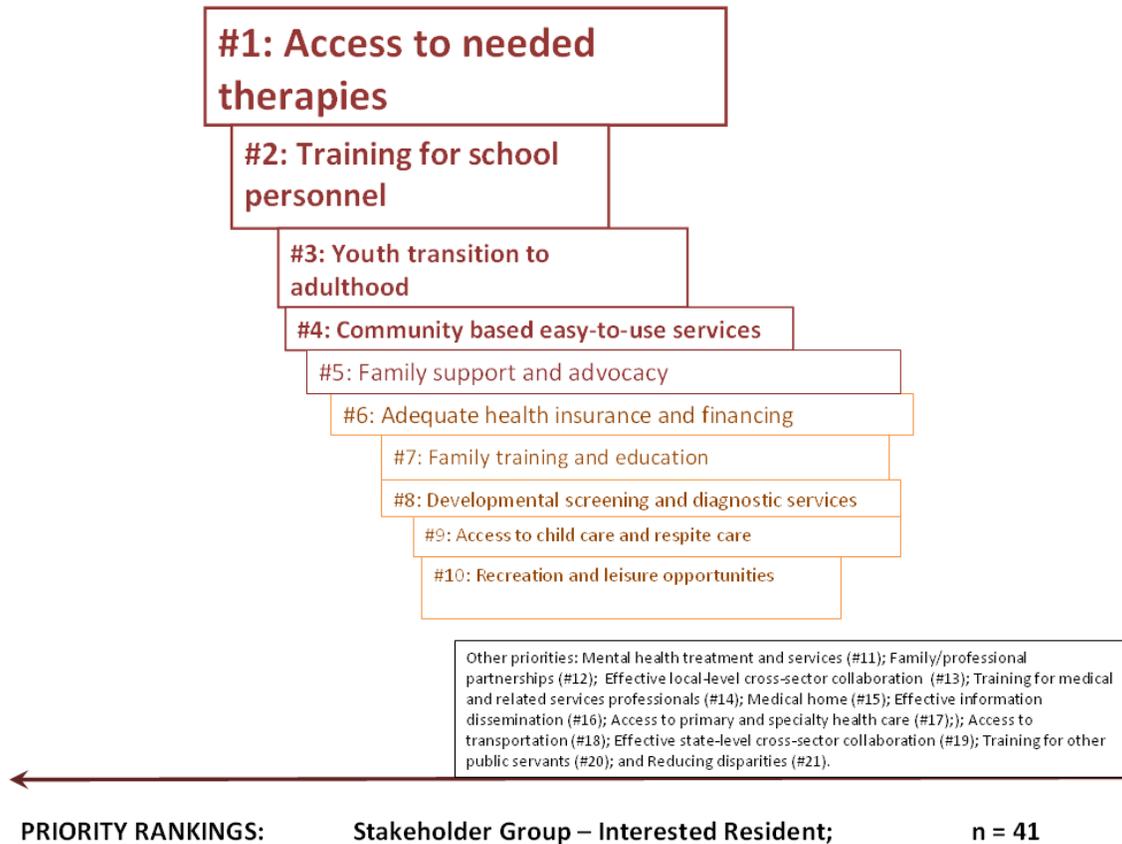
Priority Rankings – By Stakeholder Parents



There were one hundred forty-two respondents representing the stakeholder group, parents. When asked to rank their **top 5 needs for children and youth with ASD and other DD**, 50.7% of respondents from this stakeholder group, Parents, included “**access to needed therapies**,” in their top 5 rankings, making it the number one priority for children and youth with ASD and DD among the group, according to this poll. Forty-three percent (43.0%) of parents selected priority number two, “**training –school personnel**.” Over forty percent (40.8%) of these respondents included “**youth transition to adulthood**” in their top five making this the number three priority. Nearly thirty-five (34.5%) of parents included rank number four, “**recreation and leisure opportunities**” in their top 5 priorities. Over thirty percent (31.0%) of parents chose “**adequate health insurance and financing**,” making it the number five priority. Above twenty-seven percent (27.5%) of parents chose priority six, “family support and advocacy.” More than twenty-six percent (26.1%) included “community-based easy-to-use services” and “effective local-level cross-sector collaboration” and these were ranked number seven and eight priorities. Around twenty-four percent (23.9%) included the ninth priority, “family/professional partnerships.” Less than twenty-four percent (23.2%) identified “access to child care and respite care,” in their top five making this the number ten priority for children and youth with ASD and DD.

*A percentage breakdown of priorities for this stakeholder group is provided on [pg. 32](#).

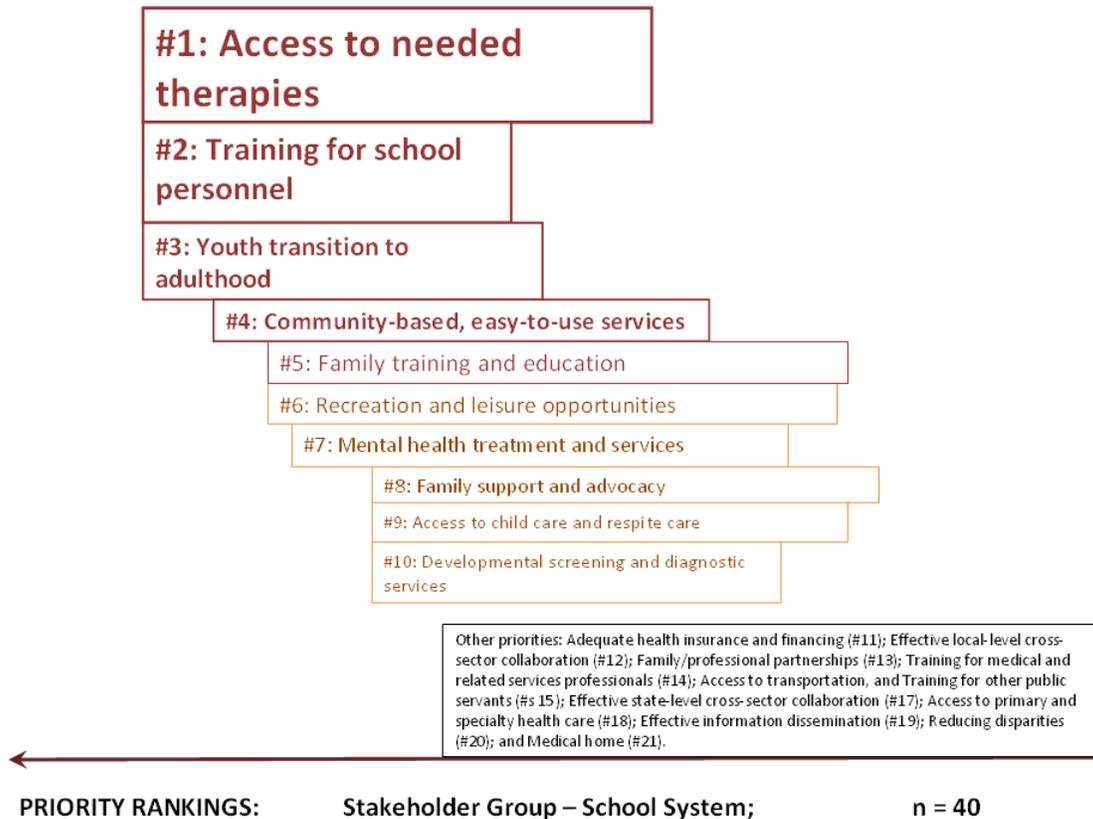
Interested Maryland Resident



There were forty-one respondents representing the stakeholder group, interested resident. When asked to rank their **top 5 needs for children and youth with ASD and other DD**, 43.9% of this group included **“access to needed therapies,”** making it the number one priority for children and youth with ASD and DD according to this poll. Forty-two percent (41.5%) of interested Maryland residents included the number two priority **“training –school personnel.”** Priority number three, **“youth transition to adulthood,”** was selected by almost forty percent (39.0%) of the interested resident stakeholder group. More than thirty-four percent (34.1%) of interested Maryland residents selected **“community-based easy-to-use services,”** which was ranked as the number four priority. Over thirty percent (31.7%) of the interested Maryland residents included the **“family support and advocacy,”** making it the number five priority. Priority number six, **“adequate health insurance and financing”** was included in the top 5 priorities by over twenty-nine percent (29.3%) of interested Maryland residents. Slightly less than twenty-seven percent (26.8%) included the number seven rank, **“family training and education”** and the number eight rank, **“developmental screening and diagnostic services”** in their top 5 priorities. Less than twenty-five percent (24.4%) included **“access to child care and respite care”** and **“recreation and leisure opportunities”** in their top five making these the number nine and the number ten priorities.

*A percentage breakdown of priorities for this stakeholder group is provided on [pg. 32](#).

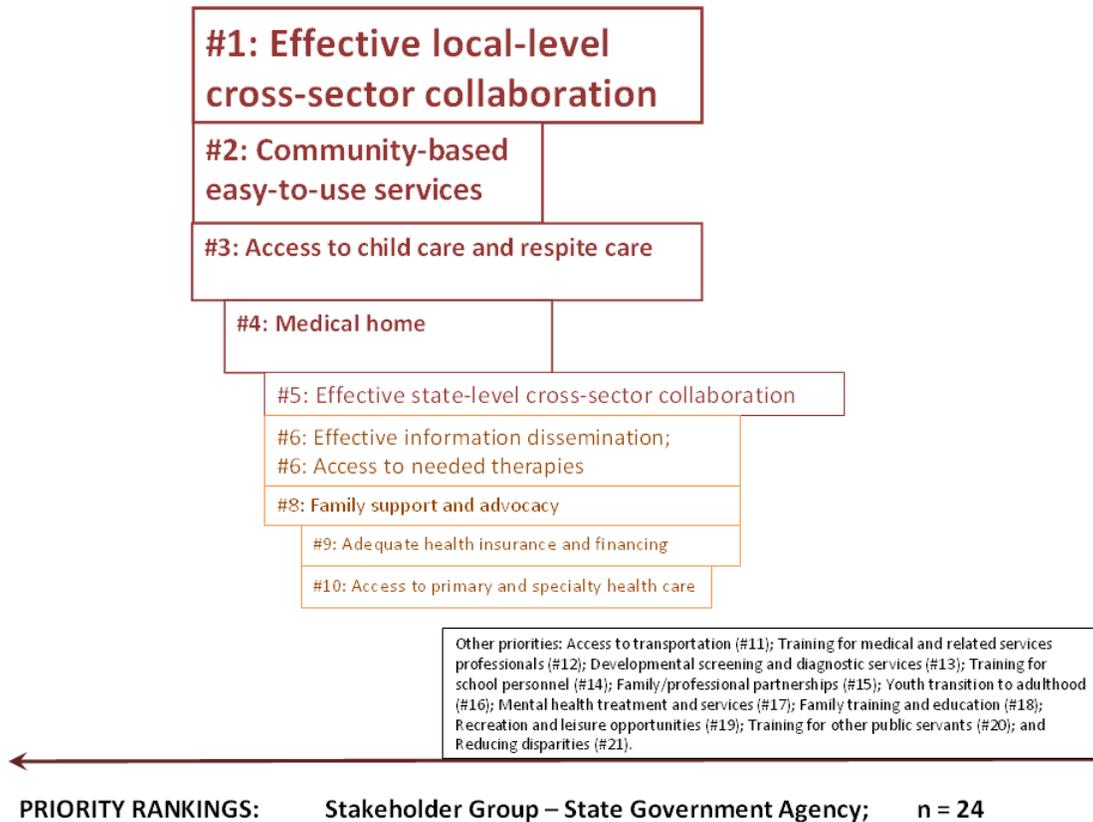
School



There were forty respondents representing the stakeholder group, school system. When asked to rank their **top 5 needs for children and youth with ASD and other DD**, 42.5% of the stakeholder group included “**access to needed therapies**,” making it the number one priority for children and youth with ASD and DD among the group according to this poll. Above forty-two percent (42.5%) of those representing the school system included the number two, “**training – school personnel**” and number three, “**youth transition to adulthood**” in their top 5 priorities. More than a third (37.5%) of the respondents from the stakeholder group included “**community-based easy-to use services**” in their top 5 priorities and it was ranked as the number four priority. Under a third (32.5%) of representatives selected the number five priority, “**family training and education**” and the number six priority, “recreation and leisure opportunities” in their top 5 priorities. Thirty percent (30.0%) of respondents included the “mental health treatment and services” in their priorities and it was ranked the number seven priority. A quarter (25.0%) identified “family support and advocacy,” “access to child care and respite care,” “developmental screening and diagnostic services,” in their top five, making them the number eight, nine and ten priorities for children and youth with ASD and DD according to the stakeholder group, school system.

*A percentage breakdown of priorities for this stakeholder group is provided on [pg. 33](#).

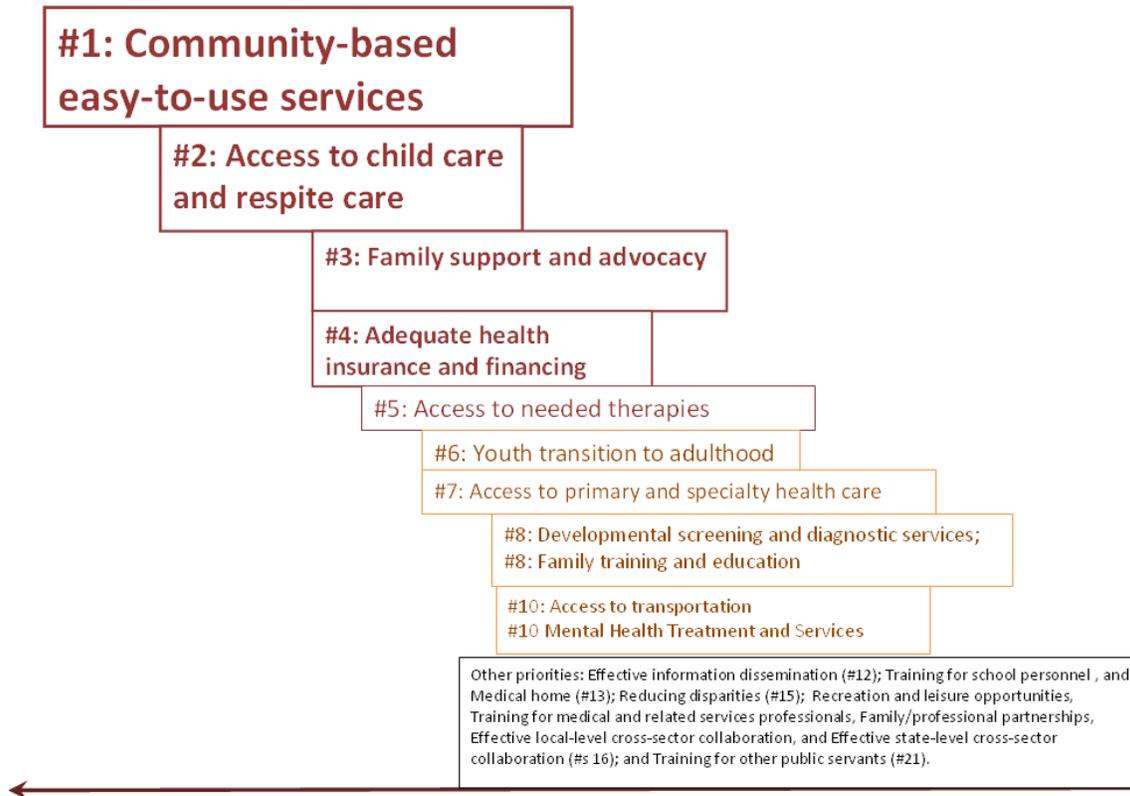
State Government Agency



There were twenty-four respondents representing the stakeholder group, state government agency. When asked to rank their **top 5 needs for children and youth with ASD and other DD**, 37.5% of respondents from this stakeholder group included “**effective local-level cross-sector collaboration**,” making it the number one priority for children and youth with ASD and DD among the group according to this poll. Nearly thirty-eight percent (37.5%) included “**community-based easy-to-use services**” and “**access to child care to and respite care**,” making them priorities number two and three. A third (33.3%) of the respondents from the state government agency included “**medical home**” in their top 5 priorities and it was ranked as the number four priority. Around thirty percent (29.2%) of state government agency workers included the number five priority, “**effective state-level cross-sector collaboration**,” the number six priorities, “effective information dissemination” and “access to needed therapies,” and the number eight priority, “family support and advocacy” in their top 5 priorities. A quarter (25.0%) of respondents included “adequate health insurance and financing” and “access to primary and specialty health care,” making these the number nine and ten priorities for children and youth with ASD and DD for the stakeholder group, state government agency.

*A percentage breakdown of priorities for this stakeholder group is provided on [pg. 33](#).

Local Government Agency

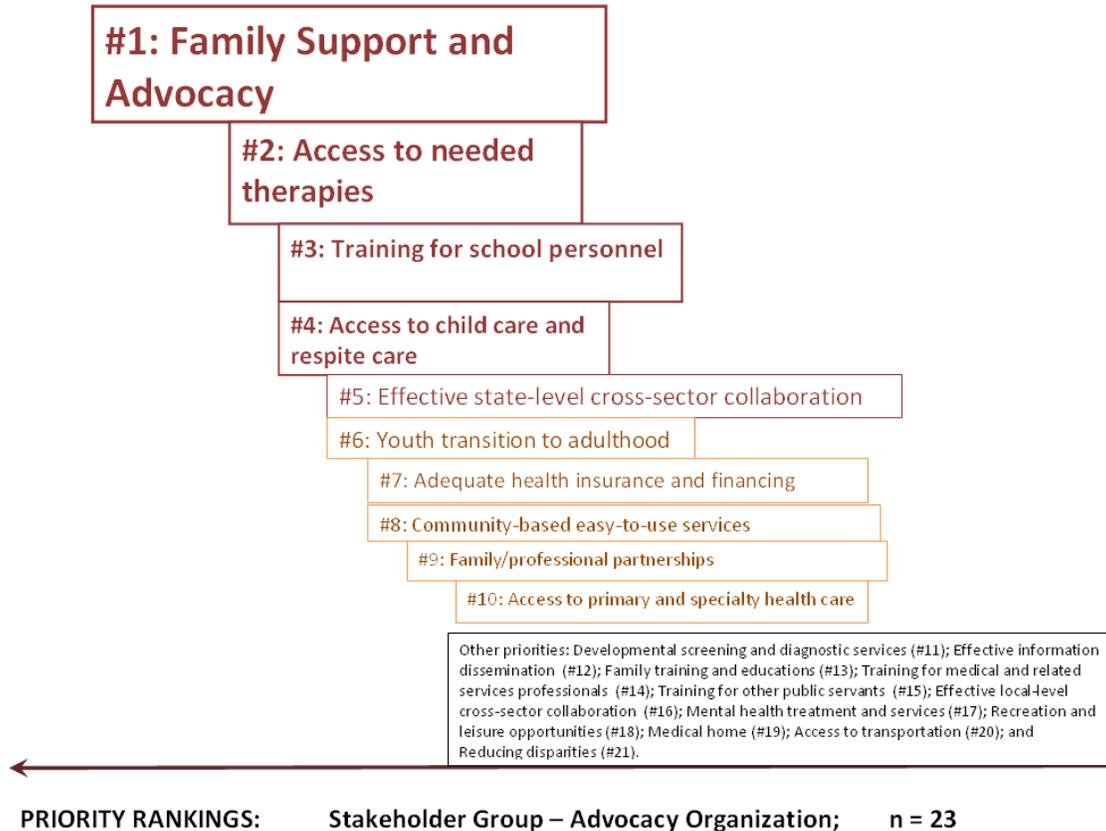


PRIORITY RANKINGS: Stakeholder Group – Local Government Agency; n = 16

There were sixteen respondents representing the stakeholder group, local government agency. When asked to rank their **top 5 needs for children and youth with ASD and other DD**, 68.8% of these respondents agency included “**community-based easy to-use services**” in their top priorities, making it the number one priority for children and youth with ASD and DD among the group according to the poll. Over fifty percent (56.3%) of respondents chose the number two priority, “**access to child care and respite care**” in their top 5 priorities. Priority three, “**family support and advocacy**” and priority four “**adequate health insurance and financing**,” were both chosen by nearly forty-four percent (43.8%) of the respondents representing the local government agency. Priority number five, “**access to needed therapies**” was selected by thirty-eight percent (37.5%) of these respondents. Less than a third (31.3%) of the respondents from local governments included “youth transition” and “access to primary and specialty health care,” making them the number six and seven priorities. A quarter (25.0%) of poll takers representing the local government agency, included “developmental screening and diagnostic services” and “family training and education” making these the number eight priorities. A quarter (25.0%) of respondents identified “access to transportation” and “mental health treatment and services” in their top five, making these the number ten priorities for children and youth with ASD and other DD according to local government agency poll takers.

*A percentage breakdown of priorities for this stakeholder group is provided on [pg. 34](#).

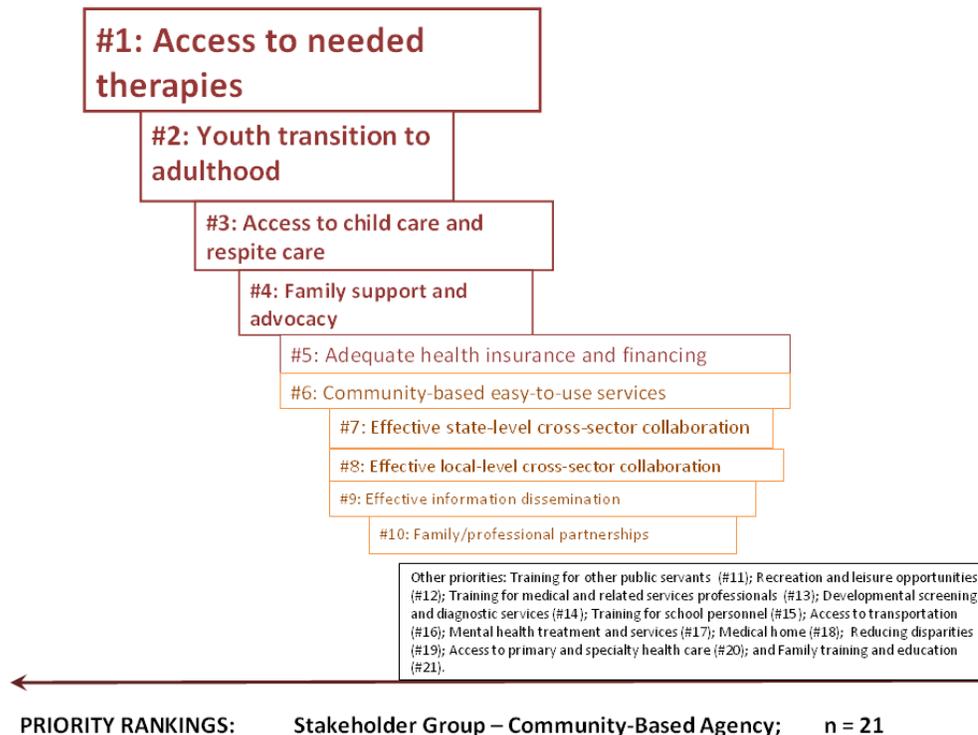
Advocacy Organization



There were twenty-three respondents representing the stakeholder group, advocacy organization. When asked to rank their **top 5 needs for children and youth with ASD and other DD**, 52.2% of respondents who represented this group included **“family support and advocacy”** in their top priorities, making it the number one priority for children and youth with ASD and DD among the group according to the poll. Over forty-three percent (43.5%) included rank number two, **“access to needed therapies”** in their priority listing. Nearly forty percent (39.1%) of these poll takers, included **“training - school personnel”** and **“access to child care and respite care,”** and therefore ranked priority number three and priority number four. Less than thirty-five percent (34.8%) of the respondents from the advocacy organizations included priority five, **“effective state-level cross-sector collaboration”** and the priority six, **“youth transition to adulthood.”** Thirty percent (30.4%) selected the priority seven, **“adequate health insurance and financing”** and priority eight, **“community-based easy-to-use-services”** in their list of top 5 priorities for children with ASD and other DD. Over a twenty-six percent (26.1%) of poll takers representing the advocacy organization, included **“family/professional partnerships.”** Over a twenty-one percent (21.7%) identified **“access to primary and specialty health care”** in their top five making this the number ten priority for those who represented the advocacy organization.

*A percentage breakdown of priorities for this stakeholder group is provided on [pg. 34](#).

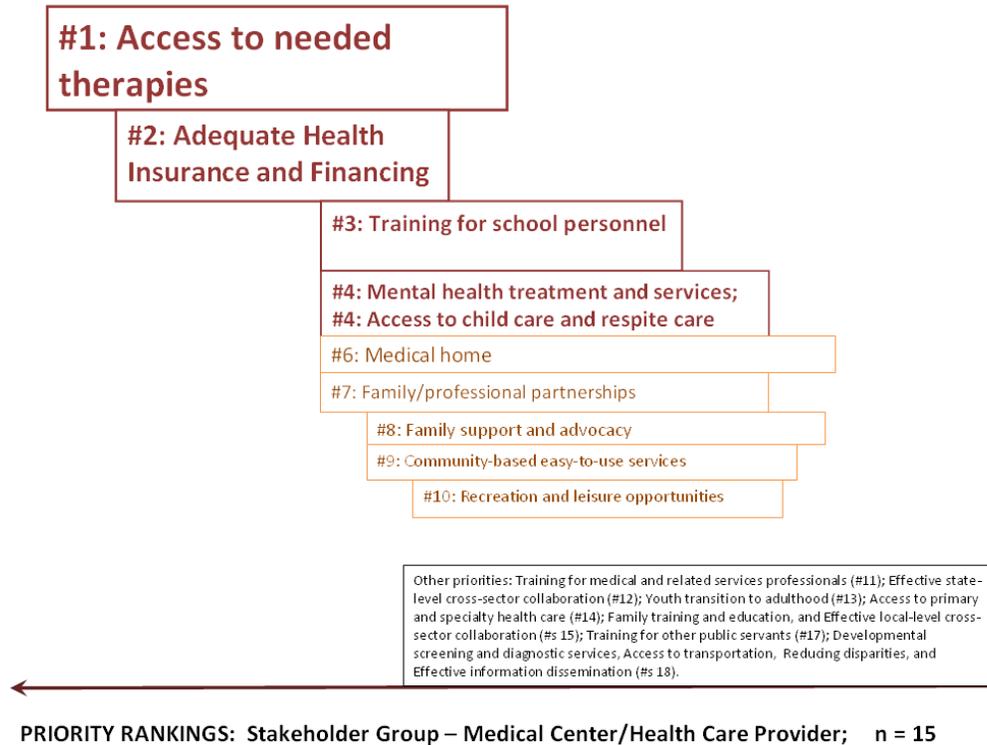
Community-Based Agency Representative



There were twenty-one respondents representing the stakeholder group, community-based agency. When asked to rank their **top 5 needs for children and youth with ASD and other DD**, 52.4% of respondents who represented the community-based agency included “**access to needed therapies**” in their top priorities, making it the number one priority for children and youth with ASD and DD among the group according to this poll. Over forty-seven percent (47.6%) of respondents representing the stakeholder group, community-based agency, included “**youth transition to adulthood**” in their list of top 5 priorities making it the number two highest priority for the stakeholder group. Nearly forty-three percent (42.9%) of respondents selected the “**access to child care and respite care**” which was then ranked as the number three priority. Thirty-eight percent (38.1%) of the respondents from this stakeholder group selected the number four priority, “**family support and advocacy**,” in their top 5 list of priorities. A third (33.3%) of those representing the community-based agency included “**adequate health insurance and financing**” and “community-based easy-to-use services” which were ranked the number five and number six priority. Over twenty-eight percent (28.6%) of poll takers from this group selected “effective state-level cross-sector collaboration,” “effective local-level cross-sector collaboration,” and “effective information dissemination” making them the number seven priority, number eight priority and the number nine priority. Less than twenty-four percent (23.8%) identified “family/professional partnerships” in their top five making this the number ten priority of the community-based agency.

*A percentage breakdown of priorities for this stakeholder group is provided on [pg. 35](#).

Medical Center/Health Care Provider



There were fifteen respondents representing the stakeholder group, medical center/health care provider. When asked to rank their **top 5 needs for children and youth with ASD and other DD**, 60.0% of respondents who represented this group included “**access to needed therapies**” in their top priorities, making it the number one priority for children and youth with ASD and DD among the group according to the poll. Over fifty percent (53.3%) of respondents included the second highest ranked priority, “**adequate health insurance and financing**” in their list of top five priorities. Over a third (33.3%) of the respondents included the number three priority, “**training –school personnel,**” the number four priorities, “**mental health treatment and services**” and “**access to child care and respite care,**” the number six priority, “**medical home,**” and the number seven priority, “**family/professional partnerships**” in their list of top 5 priorities for children and youth with ASD and other DD. Less than twenty-seven percent (26.7%) of poll takers representing the stakeholder group, medical center/health care provider, included the “**family support and advocacy,**” and “**community-based easy-to-use services**” making these the number eight and nine priority. Twenty percent (20.0%) identified “**recreation and leisure opportunities**” in their top five, making this the number ten priority for the medical center/health care provider stakeholder group.

*A percentage breakdown of priorities for this stakeholder group is provided on [pg. 35](#).

Comments

The poll provided asked respondents to share additional comments on priorities for children and youth with ASD and DD in Maryland. Below is a selection of those comments:

The provision of services for these children requires a comprehensive approach that includes family, public and private providers focused on the diverse needs of children with ASD and DD.

- State Government Agency Worker

A person's mental and physical well being are paramount to their ability to be successful in a job and as contributing members of their community. Ultimately we should all be concerned with the end target, that being an individual who is healthy, successful, contributing member of the community. Whether we serve or are focused on young children or young adults, we all hope that our efforts lead to the [person's mental and physical well being].

- School System Representative

The health needs of Children and Youth with ASD and other DD have been woefully underserved and the State of Maryland needs to start addressing these needs as a priority concern for both the disabled individuals and their families/caregivers.

- Parent

Families need better information from trusted sources on how to evaluate pseudoscientific claims about autism and "therapies". Families need accurate, unbiased information about what it means to be Autistic.

- A Person with Autism

Family training and education: I think that there is not enough support or encouragement for families to get the proper training and education for their loved ones. There are places/locations where this information is available, but families are often not updated to this information. Effective cross-sector collaboration (state/local): this is so very important because I'm personally seeing these agencies operate in a "[solo]" state of mind. I often have to call 3 agencies, explain what's going on, and never once have I been able to do this without using up much time and energy. Even after all that work I find that I still don't qualify because my child is considered "not needy" enough.

- Parent

Appendix

Priority Ranking – Maryland Combined

Priority:	Top 5 Priority:	# 1 or #2 Priority:	# 1 Priority:
1 Access to needed therapies	45.2%	24.1%	12.9%
2 Youth transition to adulthood	37.3%	19.5%	10.4%
3 Training - school personnel	35.3%	14.9%	7.1%
4 Community-based easy-to-use services	32.4%	11.6%	6.2%
5 Adequate health insurance and financing	29.9%	16.6%	9.5%
6 Family Support and Advocacy	28.6%	12.9%	6.6%
7 Access to child care and respite care	28.2%	8.7%	2.5%
8 Recreation and leisure opportunities	28.2%	6.6%	4.1%
9 Effective local-level cross-sector collaboration	26.1%	7.9%	2.5%
10 Family training and education	22.4%	7.9%	3.7%
11 Family/Professional Partnerships	21.6%	9.1%	5.4%
12 Developmental screening and diagnostic services	20.7%	8.3%	3.3%
13 Mental health treatment and services	17.8%	9.1%	5.4%
14 Effective information dissemination	17.4%	4.6%	2.9%
15 Effective state-level cross-sector collaboration	17.0%	6.6%	5.8%
16 Access to primary and specialty health care	16.6%	7.5%	2.5%
17 Training - medical and related services professionals	15.8%	4.6%	1.7%
18 Medical Home	14.1%	5.4%	2.9%
19 Access to transportation	13.3%	4.1%	1.2%
20 Training - other public servants	10.4%	3.7%	0.4%
21 Other needs	7.5%	5.0%	3.7%
22 Reducing disparities	5.8%	0.4%	0.0%

Priority Ranking by Region

Western Region

Western n = 16				
Priorities in Ranked Order:	Top 5 Priority:	# 1 or #2 Priority:	# 1 Priority:	
1 Access to needed therapies	50.0%	31.3%	18.8%	
2 Community-based easy-to-use services	43.8%	18.8%	6.3%	
3 Training - school personnel	37.5%	18.8%	12.5%	
3 Adequate health insurance and financing	37.5%	18.8%	12.5%	
5 Access to child care and respite care	37.5%	12.5%	0.0%	
6 Mental health treatment and services	31.3%	25.0%	18.8%	
7 Family training and education	31.3%	12.5%	0.0%	
8 Developmental screening and diagnostic services	31.3%	6.3%	6.3%	
9 Recreation and leisure oppourtunities	25.0%	12.5%	12.5%	
10 Family/Professional Partnerships	25.0%	6.3%	6.3%	
10 Family Support and Advocacy	25.0%	6.3%	6.3%	
12 Training - medical and related services professionals	25.0%	6.3%	0.0%	
13 Training - other public servants	18.8%	12.5%	0.0%	
14 Access to primary and specialty health care	18.8%	6.3%	0.0%	
15 Youth transition to adulthood	12.5%	0.0%	0.0%	
15 Access to transportation	12.5%	0.0%	0.0%	
17 Reducing disparities	6.3%	6.3%	0.0%	
18 Effective information dissemination	6.3%	0.0%	0.0%	
18 Effective state-level cross-sector collaboration	6.3%	0.0%	0.0%	
18 Effective local-level cross-sector collaboration	6.3%	0.0%	0.0%	
21 Medical Home	0.0%	0.0%	0.0%	

Capital Region

Capital n = 48				
Priorities in Ranked Order:	Top 5 Priority:	# 1 or #2 Priority:	# 1 Priority:	
1 Youth transition to adulthood	56.3%	22.9%	18.8%	
2 Access to needed therapies	47.9%	27.1%	14.6%	
3 Adequate health insurance and financing	39.6%	25.0%	16.7%	
4 Training - school personnel	35.4%	12.5%	8.3%	
5 Recreation and leisure oppourtunities	35.4%	10.4%	8.3%	
6 Family Support and Advocacy	33.3%	14.6%	4.2%	
7 Access to child care and respite care	29.2%	6.3%	2.1%	
8 Community-based easy-to-use services	29.2%	6.3%	0.0%	
9 Effective local-level cross-sector collaboration	25.0%	4.2%	0.0%	
10 Family/Professional Partnerships	22.9%	14.6%	8.3%	
11 Family training and education	20.8%	8.3%	0.0%	
12 Medical Home	16.7%	8.3%	2.1%	
13 Effective state-level cross-sector collaboration	16.7%	6.3%	6.3%	
14 Developmental screening and diagnostic services	14.6%	6.3%	2.1%	
15 Access to primary and specialty health care	12.5%	6.3%	4.2%	
16 Effective information dissemination	10.4%	4.2%	0.0%	
17 Training - other public servants	10.4%	2.1%	0.0%	
18 Mental health treatment and services	8.3%	4.2%	2.1%	
19 Access to transportation	8.3%	2.1%	0.0%	
20 Training - medical and related services professionals	6.3%	0.0%	0.0%	
21 Reducing disparities	4.2%	0.0%	0.0%	

Southern Region

Southern n = 60				
Priorities in Ranked Order:	Top 5 Priority:	# 1 or #2 Priority:	# 1 Priority:	
1 Training - school personnel	50.0%	21.7%	6.7%	
2 Access to needed therapies	46.7%	23.3%	10.0%	
3 Youth transition to adulthood	40.0%	20.0%	8.3%	
4 Community-based easy-to-use services	33.3%	11.7%	6.7%	
5 Developmental screening and diagnostic services	28.3%	13.3%	5.0%	
6 Family Support and Advocacy	26.7%	11.7%	5.0%	
7 Effective local-level cross-sector collaboration	26.7%	8.3%	3.3%	
8 Family training and education	25.0%	10.0%	8.3%	
9 Mental health treatment and services	23.3%	11.7%	8.3%	
10 Access to primary and specialty health care	23.3%	11.7%	3.3%	
11 Family/Professional Partnerships	23.3%	8.3%	3.3%	
12 Recreation and leisure oppourtunities	21.7%	6.7%	3.3%	
13 Access to child care and respite care	18.3%	6.7%	3.3%	
14 Effective information dissemination	18.3%	3.3%	3.3%	
15 Adequate health insurance and financing	16.7%	10.0%	6.7%	
16 Training - medical and related services professionals	15.0%	6.7%	3.3%	
17 Access to transportation	13.3%	1.7%	0.0%	
18 Effective state-level cross-sector collaboration	11.7%	3.3%	3.3%	
19 Training - other public servants	11.7%	0.0%	0.0%	
20 Medical Home	10.0%	5.0%	5.0%	
21 Reducing disparities	6.7%	0.0%	0.0%	

Central Region

Central n = 74				
Priorities in Ranked Order:	Top 5 Priority:	# 1 or #2 Priority:	# 1 Priority:	
1 Access to needed therapies	43.2%	24.3%	13.5%	
2 Youth transition to adulthood	37.8%	23.0%	9.5%	
3 Adequate health insurance and financing	37.8%	17.6%	9.5%	
4 Effective local-level cross-sector collaboration	36.5%	10.8%	5.4%	
5 Access to child care and respite care	35.1%	14.9%	4.1%	
6 Family Support and Advocacy	32.4%	17.6%	10.8%	
7 Community-based easy-to-use services	31.1%	12.2%	6.8%	
8 Training - school personnel	29.7%	12.2%	5.4%	
9 Effective state-level cross-sector collaboration	21.6%	8.1%	5.4%	
10 Family training and education	20.3%	6.8%	4.1%	
11 Effective information dissemination	18.9%	5.4%	4.1%	
12 Developmental screening and diagnostic services	16.2%	5.4%	2.7%	
13 Family/Professional Partnerships	14.9%	5.4%	5.4%	
14 Training - medical and related services professionals	14.9%	4.1%	1.4%	
15 Mental health treatment and services	13.5%	6.8%	4.1%	
16 Access to transportation	13.5%	5.4%	2.7%	
17 Medical Home	12.2%	5.4%	2.7%	
18 Access to primary and specialty health care	6.8%	1.4%	0.0%	
19 Recreation and leisure oppourtunities	4.1%	5.4%	1.4%	
20 Training - other public servants	4.1%	4.1%	0.0%	
21 Reducing disparities	4.1%	0.0%	0.0%	

Eastern Region

Eastern n = 25				
Priorities in Ranked Order:	Top 5 Priority:	# 1 or #2 Priority:	# 1 Priority:	
1 Access to needed therapies	48.0%	24.0%	16.0%	
2 Community-based easy-to-use services	36.0%	24.0%	20.0%	
3 Access to primary and specialty health care	32.0%	20.0%	8.0%	
4 Youth transition to adulthood	32.0%	16.0%	8.0%	
5 Developmental screening and diagnostic services	28.0%	12.0%	0.0%	
6 Mental health treatment and services	28.0%	12.0%	4.0%	
7 Access to child care and respite care	28.0%	4.0%	0.0%	
8 Family/Professional Partnerships	24.0%	8.0%	4.0%	
8 Family training and education	24.0%	8.0%	4.0%	
10 Adequate health insurance and financing	20.0%	16.0%	8.0%	
11 Family Support and Advocacy	20.0%	12.0%	8.0%	
12 Access to transportation	20.0%	12.0%	0.0%	
13 Training - school personnel	20.0%	8.0%	4.0%	
14 Effective local-level cross-sector collaboration	20.0%	0.0%	0.0%	
15 Effective information dissemination	16.0%	4.0%	4.0%	
15 Training - medical and related services professionals	16.0%	4.0%	4.0%	
17 Medical Home	12.0%	4.0%	4.0%	
18 Recreation and leisure oppourtunities	12.0%	0.0%	0.0%	
19 Training - other public servants	8.0%	4.0%	0.0%	
20 Effective state-level cross-sector collaboration	4.0%	0.0%	0.0%	
20 Reducing disparities	4.0%	0.0%	0.0%	

Statewide

Statewide n = 27				
Priorities in Ranked Order:	Top 5 Priority:	# 1 or #2 Priority:	# 1 Priority:	
1 Effective state-level cross-sector collaboration	44.4%	25.9%	25.9%	
2 Adequate health insurance and financing	33.3%	22.2%	14.8%	
3 Medical Home	33.3%	7.4%	0.0%	
3 Training - medical and related services professionals	33.3%	7.4%	0.0%	
5 Training - school personnel	29.6%	11.1%	7.4%	
6 Access to needed therapies	29.6%	11.1%	3.7%	
7 Family Support and Advocacy	29.6%	7.4%	0.0%	
7 Access to child care and respite care	29.6%	7.4%	0.0%	
9 Youth transition to adulthood	25.9%	22.2%	14.8%	
10 Effective information dissemination	25.9%	7.4%	3.7%	
11 Effective local-level cross-sector collaboration	22.2%	18.5%	0.0%	
12 Family/Professional Partnerships	22.2%	11.1%	3.7%	
13 Access to primary and specialty health care	18.5%	7.4%	3.7%	
14 Training - other public servants	18.5%	7.4%	3.7%	
15 Community-based easy-to-use services	18.5%	0.0%	0.0%	
16 Family training and education	14.8%	0.0%	0.0%	
17 Developmental screening and diagnostic services	11.1%	3.7%	3.7%	
17 Access to transportation	11.1%	3.7%	3.7%	
19 Mental health treatment and services	11.1%	3.7%	0.0%	
20 Reducing disparities	11.1%	0.0%	0.0%	
21 Recreation and leisure oppourtunities	7.4%	3.7%	3.7%	

Priority Ranking by Stakeholder

Parents

Parent n = 142				
Priorities in Ranked Order:	Top 5 Priority:	# 1 or #2 Priority:	# 1 Priority:	
1 Access to needed therapies	50.7%	25.4%	12.0%	
2 Training - school personnel	43.0%	16.9%	8.5%	
3 Youth transition to adulthood	40.8%	23.2%	12.7%	
4 Recreation and leisure oppourtunities	34.5%	8.5%	4.9%	
5 Adequate health insurance and financing	31.0%	16.9%	10.6%	
6 Family Support and Advocacy	27.5%	14.1%	6.3%	
7 Community-based easy-to-use services	26.1%	11.3%	5.6%	
8 Effective local-level cross-sector collaboration	26.1%	6.3%	2.8%	
9 Family/Professional Partnerships	23.9%	10.6%	7.7%	
10 Access to child care and respite care	23.2%	4.9%	0.7%	
11 Family training and education	21.8%	7.0%	2.8%	
12 Developmental screening and diagnostic services	19.0%	6.3%	2.8%	
13 Effective information dissemination	16.9%	4.2%	2.8%	
14 Training - medical and related services professionals	16.2%	5.6%	2.8%	
15 Mental health treatment and services	15.5%	9.2%	5.6%	
16 Effective state-level cross-sector collaboration	15.5%	2.1%	1.4%	
17 Access to primary and specialty health care	14.8%	7.7%	3.5%	
18 Training - other public servants	11.3%	4.2%	0.7%	
19 Access to transportation	10.6%	3.5%	0.7%	
20 Medical Home	9.2%	4.9%	2.1%	
21 Reducing disparities	4.2%	0.0%	0.0%	

Interested Maryland Resident

Interested Maryland Resident n = 41				
Priorities in Ranked Order:	Top 5 Priority:	# 1 or #2 Priority:	# 1 Priority:	
1 Access to needed therapies	43.9%	17.1%	9.8%	
2 Training - school personnel	41.5%	12.2%	7.3%	
3 Youth transition to adulthood	39.0%	17.1%	0.0%	
4 Community-based easy-to-use services	34.1%	17.1%	12.2%	
5 Family Support and Advocacy	31.7%	17.1%	7.3%	
6 Adequate health insurance and financing	29.3%	19.5%	12.2%	
7 Family training and education	26.8%	7.3%	7.3%	
8 Developmental screening and diagnostic services	26.8%	7.3%	2.4%	
9 Access to child care and respite care	24.4%	12.2%	2.4%	
10 Recreation and leisure oppourtunities	24.4%	2.4%	0.0%	
11 Mental health treatment and services	22.0%	9.8%	4.9%	
12 Family/Professional Partnerships	19.5%	12.2%	12.2%	
13 Effective local-level cross-sector collaboration	19.5%	9.8%	4.9%	
14 Training - medical and related services professionals	19.5%	4.9%	2.4%	
15 Medical Home	17.1%	7.3%	2.4%	
16 Effective information dissemination	17.1%	0.0%	0.0%	
17 Access to primary and specialty health care	14.6%	9.8%	4.9%	
18 Access to transportation	12.2%	2.4%	0.0%	
19 Effective state-level cross-sector collaboration	9.8%	4.9%	2.4%	
20 Training - other public servants	7.3%	0.0%	0.0%	
21 Reducing disparities	0.0%	0.0%	0.0%	

School

School n = 40				
Priorities in Ranked Order:	Top 5 Priority:	# 1 or #2 Priority:	# 1 Priority:	
1 Access to needed therapies	42.5%	27.5%	20.0%	
2 Training - school personnel	42.5%	17.5%	7.5%	
3 Youth transition to adulthood	42.5%	15.0%	5.0%	
4 Community-based easy-to-use services	37.5%	15.0%	7.5%	
5 Family training and education	32.5%	12.5%	10.0%	
6 Recreation and leisure oppourtunities	32.5%	7.5%	5.0%	
7 Mental health treatment and services	30.0%	17.5%	10.0%	
8 Family Support and Advocacy	25.0%	12.5%	5.0%	
9 Access to child care and respite care	25.0%	12.5%	2.5%	
10 Developmental screening and diagnostic services	25.0%	10.0%	2.5%	
11 Adequate health insurance and financing	22.5%	10.0%	5.0%	
12 Effective local-level cross-sector collaboration	22.5%	5.0%	2.5%	
13 Family/Professional Partnerships	20.0%	10.0%	5.0%	
14 Training - medical and related services professionals	17.5%	5.0%	0.0%	
15 Access to transportation	15.0%	0.0%	0.0%	
15 Training - other public servants	15.0%	0.0%	0.0%	
17 Effective state-level cross-sector collaboration	12.5%	7.5%	5.0%	
18 Access to primary and specialty health care	10.0%	7.5%	2.5%	
19 Effective information dissemination	10.0%	5.0%	2.5%	
20 Reducing disparities	7.5%	0.0%	0.0%	
21 Medical Home	5.0%	2.5%	2.5%	

State Government Agency

State Government Agency n = 24				
Priorities in Ranked Order:	Top 5 Priority:	# 1 or #2 Priority:	# 1 Priority:	
Effective local-level cross-sector				
1 collaboration	37.5%	20.8%	4.2%	
2 Community-based easy-to-use services	37.5%	12.5%	12.5%	
3 Access to child care and respite care	37.5%	12.5%	4.2%	
4 Medical Home	33.3%	12.5%	4.2%	
Effective state-level cross-sector				
5 collaboration	29.2%	16.7%	12.5%	
6 Effective information dissemination	29.2%	8.3%	4.2%	
6 Access to needed therapies	29.2%	8.3%	4.2%	
8 Family Support and Advocacy	29.2%	4.2%	0.0%	
9 Adequate health insurance and financing	25.0%	16.7%	12.5%	
10 Access to primary and specialty health care	25.0%	12.5%	4.2%	
11 Access to transportation	25.0%	8.3%	0.0%	
12 Training - medical and related services professionals	25.0%	4.2%	0.0%	
13 Developmental screening and diagnostic services	20.8%	12.5%	8.3%	
14 Training - school personnel	16.7%	8.3%	8.3%	
15 Family/Professional Partnerships	16.7%	8.3%	0.0%	
16 Youth transition to adulthood	12.5%	12.5%	12.5%	
17 Mental health treatment and services	12.5%	8.3%	0.0%	
18 Family training and education	12.5%	4.2%	4.2%	
19 Recreation and leisure oppourtunities	12.5%	0.0%	0.0%	
20 Training - other public servants	4.2%	4.2%	0.0%	
21 Reducing disparities	4.2%	0.0%	0.0%	

Local Government Agency

Local Government Agency n = 16				
Priorities in Ranked Order:	Top 5 Priority:	# 1 or #2 Priority:	# 1 Priority:	
1 Community-based easy-to-use services	68.8%	12.5%	6.3%	
2 Access to child care and respite care	56.3%	18.8%	12.5%	
3 Family Support and Advocacy	43.8%	25.0%	18.8%	
4 Adequate health insurance and financing	43.8%	18.8%	12.5%	
5 Access to needed therapies	37.5%	18.8%	6.3%	
6 Youth transition to adulthood	31.3%	12.5%	6.3%	
7 Access to primary and specialty health care	31.3%	12.5%	0.0%	
8 Developmental screening and diagnostic services	25.0%	18.8%	0.0%	
8 Family training and education	25.0%	18.8%	0.0%	
10 Access to transportation	25.0%	6.3%	6.3%	
10 Mental health treatment and services	25.0%	6.3%	6.3%	
12 Effective information dissemination	18.8%	6.3%	6.3%	
13 Training - school personnel	12.5%	6.3%	6.3%	
13 Medical Home	12.5%	6.3%	6.3%	
15 Reducing disparities	6.3%	6.3%	0.0%	
16 Recreation and leisure oppourtunities	6.3%	0.0%	0.0%	
16 Training - medical and related services professionals	6.3%	0.0%	0.0%	
16 Family/Professional Partnerships	6.3%	0.0%	0.0%	
16 Effective local-level cross-sector collaboration	6.3%	0.0%	0.0%	
16 Effective state-level cross-sector collaboration	6.3%	0.0%	0.0%	
21 Training - other public servants	0.0%	0.0%	0.0%	

Advocacy Organization

Advocacy Organization n = 23				
Priorities in Ranked Order:	Top 5 Priority:	# 1 or #2 Priority:	# 1 Priority:	
1 Family Support and Advocacy	52.2%	17.4%	8.7%	
2 Access to needed therapies	43.5%	17.4%	17.4%	
3 Training - school personnel	39.1%	17.4%	8.7%	
4 Access to child care and respite care	39.1%	17.4%	0.0%	
5 Effective state-level cross-sector collaboration	34.8%	13.0%	13.0%	
6 Youth transition to adulthood	34.8%	13.0%	4.3%	
7 Adequate health insurance and financing	30.4%	17.4%	8.7%	
8 Community-based easy-to-use services	30.4%	8.7%	8.7%	
9 Family/Professional Partnerships	26.1%	13.0%	8.7%	
10 Access to primary and specialty health care	21.7%	8.7%	0.0%	
11 Developmental screening and diagnostic services	21.7%	4.3%	4.3%	
12 Effective information dissemination	17.4%	4.3%	4.3%	
13 Family training and education	17.4%	4.3%	0.0%	
14 Training - medical and related services professionals	13.0%	13.0%	4.3%	
15 Training - other public servants	13.0%	8.7%	4.3%	
16 Effective local-level cross-sector collaboration	13.0%	4.3%	0.0%	
17 Mental health treatment and services	8.7%	4.3%	0.0%	
18 Recreation and leisure oppourtunities	8.7%	0.0%	0.0%	
19 Medical Home	4.3%	0.0%	0.0%	
20 Access to transportation	4.3%	0.0%	0.0%	
21 Reducing disparities	4.3%	0.0%	0.0%	

Community-Based Agency Representative

Community-Based Agency Representative n = 21				
Priorities in Ranked Order:	Top 5 Priority:	# 1 or #2 Priority:	# 1 Priority:	
1 Access to needed therapies	52.4%	23.8%	9.5%	
2 Youth transition to adulthood	47.6%	23.8%	9.5%	
3 Access to child care and respite care	42.9%	14.3%	0.0%	
4 Family Support and Advocacy	38.1%	19.0%	14.3%	
5 Adequate health insurance and financing	33.3%	14.3%	9.5%	
6 Community-based easy-to-use services	33.3%	9.5%	4.8%	
7 Effective state-level cross-sector collaboration	28.6%	19.0%	19.0%	
8 Effective local-level cross-sector collaboration	28.6%	19.0%	4.8%	
9 Effective information dissemination	28.6%	4.8%	4.8%	
10 Family/Professional Partnerships	23.8%	4.8%	4.8%	
11 Training - other public servants	19.0%	9.5%	4.8%	
12 Recreation and leisure oppourtunities	19.0%	4.8%	4.8%	
13 Training - medical and related services professionals	19.0%	4.8%	0.0%	
14 Developmental screening and diagnostic services	19.0%	0.0%	0.0%	
15 Training - school personnel	14.3%	9.5%	4.8%	
16 Access to transportation	14.3%	0.0%	0.0%	
17 Mental health treatment and services	9.5%	9.5%	4.8%	
18 Medical Home	9.5%	4.8%	0.0%	
19 Reducing disparities	9.5%	0.0%	0.0%	
20 Access to primary and specialty health care	4.8%	4.8%	0.0%	
21 Family training and education	4.8%	0.0%	0.0%	

Medical Center/Health Care Provider

Medical Center/Health Care Provider n = 15				
Priorities in Ranked Order:	Top 5 Priority:	# 1 or #2 Priority:	# 1 Priority:	
1 Access to needed therapies	60.0%	13.3%	6.7%	
2 Adequate health insurance and financing	53.3%	33.3%	20.0%	
3 Training - school personnel	33.3%	33.3%	20.0%	
4 Mental health treatment and services	33.3%	20.0%	6.7%	
4 Access to child care and respite care	33.3%	20.0%	6.7%	
6 Medical Home	33.3%	6.7%	6.7%	
7 Family/Professional Partnerships	33.3%	6.7%	0.0%	
8 Family Support and Advocacy	26.7%	20.0%	13.3%	
9 Community-based easy-to-use services	26.7%	13.3%	6.7%	
10 Recreation and leisure oppourtunities	20.0%	6.7%	6.7%	
11 Training - medical and related services professionals	20.0%	6.7%	0.0%	
12 Effective state-level cross-sector collaboration	20.0%	0.0%	0.0%	
13 Youth transition to adulthood	13.3%	6.7%	6.7%	
14 Access to primary and specialty health care	13.3%	0.0%	0.0%	
15 Family training and education	13.3%	0.0%	0.0%	
15 Effective local-level cross-sector collaboration	13.3%	0.0%	0.0%	
17 Training - other public servants	6.7%	6.7%	6.7%	
18 Developmental screening and diagnostic services	6.7%	0.0%	0.0%	
18 Access to transportation	6.7%	0.0%	0.0%	
18 Reducing disparities	6.7%	0.0%	0.0%	
18 Effective information dissemination	6.7%	0.0%	0.0%	

Copy of Poll

About the Survey

The Parents' Place of Maryland (PPMD), in partnership with the Office for Genetics and Children with Special Health Care Needs (OGCSHCN) in the Maryland Department of Health and Mental Hygiene (DHMH) has been awarded a federal "State Planning Grant for Improving Services for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities" from the federal Maternal and Child Health Bureau.

The purpose of this grant is to develop a comprehensive statewide plan for Maryland to improve the system of health care and related services for children and youth who have Autism Spectrum Disorder (ASD) and other Developmental Disabilities (DD). Activities for this grant are being planned and coordinated with current ASD and DD initiatives and partners in the state, including the Maryland Commission on Autism and the Maryland Center for Developmental Disabilities.

As part of the needs assessment, the OGCSHCN and PPMD are reaching out to a diverse group of individuals with interest in and knowledge of the children and youth with ASD and other DD to obtain their views about top priorities for this population in Maryland.

This survey will help the grant leadership team to prioritize issues affecting children and youth with ASD and DD and their families in Maryland in developing a statewide plan.

Your input is critical. Please help by completing the attached survey. It should only take 5 minutes. Thank you.

QUESTIONS?

If you have any questions about this survey, please contact Meredith Pyle at the Office of Genetics and Children with Special Health Care Needs at 410-767-5185 or mpyle@dhhm.state.md.us.

Taking the Survey - Steps

1. Complete Section I. You have the option of providing your contact information or remaining anonymous.
2. Complete Section II by ranking your top 5 needs for the Children with Autism and other DD population.

The survey also allows you to add "Other Needs" that are not listed and to describe these needs. If you add an "Other Need" to a list, please describe this need in the comment box provided and include it in your top 5 ranking.

3. In the comment boxes at the end of each ranking, please share additional thoughts, concerns and information regarding children and youth ASD and other DD in Maryland.

Thanks for your input!

Your Information

***1. Please indicate which stakeholder category you represent (Mark all that apply):**

- State Government Agency
- Local Government Agency
- Professional Practice Organization
- Advocacy Organization
- Community-Based Agency Representative
- Medical Center/Health Care Provider
- University
- School
- Student
- Insurer
- Interested Parent
- Interested Maryland Resident
- Other (please specify)

***2. Which Maryland jurisdiction serves as the primary focus area for your work with and/or knowledge of the target population(s)? (Please select all that apply)**

- | | |
|--|---|
| <input type="checkbox"/> Allegany County | <input type="checkbox"/> Howard County |
| <input type="checkbox"/> Anne Arundel | <input type="checkbox"/> Kent County |
| <input type="checkbox"/> Baltimore City | <input type="checkbox"/> Montgomery County |
| <input type="checkbox"/> Baltimore County | <input type="checkbox"/> Prince George's County |
| <input type="checkbox"/> Calvert County | <input type="checkbox"/> Queen Anne's County |
| <input type="checkbox"/> Caroline County | <input type="checkbox"/> St. Mary's County |
| <input type="checkbox"/> Carroll County | <input type="checkbox"/> Somerset County |
| <input type="checkbox"/> Cecil County | <input type="checkbox"/> Talbot County |
| <input type="checkbox"/> Charles County | <input type="checkbox"/> Washington County |
| <input type="checkbox"/> Dorchester County | <input type="checkbox"/> Wicomico County |
| <input type="checkbox"/> Frederick County | <input type="checkbox"/> Worcester County |
| <input type="checkbox"/> Garrett County | <input type="checkbox"/> Statewide |
| <input type="checkbox"/> Harford County | |

3. Contact information (optional):

Name

Title

Organization

Phone number

Email address

Target Population: Children and Youth with Autism and other DD

Follow these instructions to rank your top priority needs:

- Identify your top 5 priority needs (from the list below) for children and youth with ASD and DD in Maryland.
- Rank your top priorities from 1-5 (with 1 being most important) for this population.
- If you do not see a priority need on the list, record that need in "Other Need." If you add an "Other Need" it must be included in your top 5 ranking.
- Do not combine priorities already listed to create a new priority.

4. Please rank your top 5 needs for Children and Youth with ASD and other DD, with 1 being the most important. (Please note that the priorities presented in this list were identified through multiple needs assessment activities through OGCSHCN, the Maryland Commission on Autism, the Maryland State Department of Education, and the Maryland Center for Developmental Disabilities.)

	Please rank
Effective cross-sector collaboration (among government, non-profit, private, and professional organizations serving children and youth with ASD and DD) at the state level	<input type="text"/>
Effective cross-sector collaboration (among government, non-profit, private, and professional organizations serving children and youth with ASD and DD) at the local level	<input type="text"/>
Families as decision making partners in their child's health care and education	<input type="text"/>
Family support and advocacy	<input type="text"/>
Medical Home (primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally effective)	<input type="text"/>
Adequate health insurance and health care financing	<input type="text"/>
Developmental screening and diagnostic services	<input type="text"/>
Needed services are community-based and easy to use	<input type="text"/>
Youth transition to adulthood	<input type="text"/>
Access to child care and respite care	<input type="text"/>
Access to convenient and accessible transportation	<input type="text"/>
Access to primary and specialty health care	<input type="text"/>
Access to needed therapies (behavioral, speech/language, occupational and physical)	<input type="text"/>
Mental health treatment and services	<input type="text"/>
Training for medical and related services professionals (in how to meet the needs of children and youth with ASD and other DD)	<input type="text"/>
Training for school personnel (in how to meet the needs of children and youth with ASD and other DD)	<input type="text"/>
Training for other public servants (in how to meet the needs of children and youth with ASD and other DD)	<input type="text"/>
Family training and education	<input type="text"/>
Reducing regional, socioeconomic, language and cultural disparities	<input type="text"/>
Recreation and leisure opportunities for children and youth with ASD and other DD and their families	<input type="text"/>

Effective dissemination of information (health, family support, education, community support and resources)

Other Need 1

Other Need 2

Other Need 3

If you ranked an "Other Need" above, please list and identify as "Other Need 1", "Other Need 2" and "Other Need 3" in the space provided below.

5. Please use the space below to provide additional comments or concerns about the health needs of Children and Youth with ASD and other DD in Maryland.