

Delaware Health Status Report for Children with Disabilities and Special Health Care Needs



Prepared for the Division of Developmental Disabilities Services, Delaware Health and Social Services
by the Center for Disabilities Studies, University of Delaware

April 2008



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Healthy Delawareans with Disabilities Project Advisory Panel

Many thanks to all of the members of the Advisory Panel who served the HDWD Project and the HDWD: Bridging the Gap Project. Without their support and input these initiatives would not have been possible.

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The project was managed and coordinated by the Division of Developmental Disabilities Services from Delaware Health and Social Services. If you are interested in more information about this project, contact Thomas Kelly, MD, MPH, BSN at (302) 744-9600 or thomas.kelly@state.de.us, or Alisha Raiford-Hall at (302) 369-2186 ext. 255 or alisha.raiford-hall@state.de.us.

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Executive Summary

This report presents information about the health status of children with disabilities and special health care needs in Delaware. Topics that are addressed in this report are their health, care needs, access to medical care and a medical home, and daily support variables such as schooling, friendships and safety.

Families of children with disabilities and special health care needs were solicited to participate in the survey at events such as health fairs and through partnerships with service delivery organizations. Special efforts were made to include families of children with intellectual disabilities in the survey. A total of 132 families were interviewed between January and May 2007.

Demographic Information

The large majority of the respondents of the survey were the parents (97.0%) of children with a disability or special health care need. Most respondents were female (90.9%). Most participants (84.1%) reported that they had other children living at home.

Of the families who participated in the survey 65.2% were from New Castle County, 21.2% from Sussex County, and 13.6% from Kent County. A majority of the participating families reported an annual household income over \$50,000 (56.7%).

The majority of children with a disability or special health care need of participating families were male (59.1%) and a majority of children were identified as being White/Caucasian (73.8%).

Almost 30% of children of participating families were newborn to 5 years of age, 27.7% were 6 to 11 years of age, and 43.1% were 12 to 17 years of age.

Respondents were asked to identify all disabilities or health conditions of their children. Almost 66% of children had a learning or cognitive disability, over 44% had a visual impairment, almost 11% had a hearing impairment, over 50% had a physical disability, and approximately 17% had a mental health condition. When asked which disability or health condition caused the child the most difficulties, a cognitive or learning disability was the disability most often mentioned (38.6%). Respondents were also asked when their child's condition was identified and approximately 38% reported that their child's condition had been identified at birth.

General Health Concerns

Just over two thirds (66.9%) of the participating parents or legal guardians reported that their child's health was excellent or very good. Approximately 30% reported that their child's health was good to fair and 3.1% said that their child's health was poor. Children with physical disabilities and cognitive or learning impairments had the highest percentages of reported poor health. Children with other conditions and sensory impairments had the highest percentages of reported excellent health.

Care Needs

Survey respondents were asked if and what type of special equipment their children needed. Forty percent (40.2%) of children of participants require the use of special equipment. The majority of those responding that their children needed special equipment reported the use of wheelchairs (83.8%), followed by adaptive switches (35.1%), accessible vans (35.1%), and specially-fitted beds (32.4%). A total of 56.7% of children needed help with personal care such as bathing, eating, dressing, and getting around the house. A total of 73.5% of children also needed help with everyday or school-related activities. When asked who provided care for their children the large majority of respondents indicated that a parent/guardian provided the most help (96.9%). None of the respondents indicated that a paid caregiver provided care for their child.

Weight and Exercise

Survey respondents were asked about their children's weight and physical activity. Across the age groups, excluding birth to five year olds, at least 22% had been told that their children were overweight. Many of these respondents had also been told that their children's weight was related to their health condition.

When asked about their children's dietary needs, 19-32% of the respondents indicated that their children needed a special diet because of their disability or special health care need.

Respondents were asked about the types of play and exercise in which their children were involved. Respondents reported that their children, from birth to 17, were involved in play with family members, peers, and prescribed activities and exercises. Of note are the children aged 6-11; almost 29% of these respondents reported that their children do not participate in any extra-curricular physical activities.

Insurance & Medical Care

Respondents were asked about their children's insurance coverage. A large majority (97.0%) of participants reported that they had health insurance for their children. Employer based insurance was the most common source (59.8%) followed by Medicaid/Delaware Physicians Care, Inc./Diamond State Partners (37.8%).

All but one participant (99.2%) reported that their children had at least one person they thought of as their children's primary care doctor or health care provider. Over 24% reported their children had more than one health care provider. Most participants (82.6%) indicated they were very satisfied with their children's primary care provider.

When asked about specific experiences with receiving health care services, 93.9% of participants reported a perceived partnership with a primary care provider in coordinating care for their children. Nearly all (96.2%) respondents reported that the relationships with their children's providers were based on trust and respect and that information was exchanged honestly and respectfully.

Participants were asked about access to dental care for their children. Eighty-six percent (85.6%) of respondents reported that their child was currently receiving dental/oral care.

Survey respondents were asked about specific barriers they may have encountered when seeking health care for their children. Cost and lack of transportation were reported as issues by 40.0% of those who could not see a doctor. Physical access barriers and lack of services were reported by 30.0%. Of the 14.5% who indicated that they encountered physical barriers when seeing a doctor, 58.8% reported barriers related to buildings and other issues. Barriers related to medical equipment (e.g., exam tables, dental equipment) were reported by 47.1% of survey respondents who experienced challenges, and barriers related to services were reported by 41.2%.

More than one third of participants (34.1%) indicated they experienced other types of difficulties acquiring health care for their children including finding child care for their other children (40.0%), transportation issues (26.7%), and financial difficulties related to out-of-pocket expenses (28.9%).

Parenting a Child with a Disability or Special Health Care Need

Participants of the survey were asked about parenting, and supports and obstacles associated with parenting a child with a disability or special health care need. While challenges were reported, almost 88% of those surveyed indicated that they

have a spouse or partner who has been consistently involved in the life and care of their children.

When asked to identify two areas that have created the greatest difficulty in parenting a child with a disability or special health care need, 55.7% of the participants stated stress, 32.0% indicated not having enough time to themselves, 30.3% reported financial burdens, and 18.9% reported interference with work.

When asked to identify the sources of information caregivers found most useful relative to technical support and health education, 75.0% found the information they receive from a doctor or another health care professional most useful, followed by doing their own research on the internet (56.1%), and reading specific books and going to the library (47.0%).

Other Topics

All participants were asked several questions about their children's education. A total of 97.0% of those surveyed reported that their children participate in educational activities, including playgroups (21.1%), structured therapy (37.5%) and school activities (92.2%). Survey participants were asked to anticipate whether their child would have difficulties as he/she moved to the next life stage. A variety of difficulties were expected including difficulties with peer relationships, physical health, emotional/mental health, academic progress, and sexual development.

For newborn to 5-year olds, academic progress (57.6%) and peer relationships (54.5%) were anticipated to be difficult. In addition, 27.3% of caregivers expected parental separation difficulties. In the 6 to 11-year old group, 55.9% of caregivers expected making friends to be challenging and 55.9% expected difficulties with sexual development. For the 12 to 17-year old group academic progress (48.0%), mental health (60.0%), and sexual development (36.0%) were anticipated to be challenging.

In addition to these topics, respondents also reported on their children's peer relationships, bike and car safety, and television and computer usage. The majority of children in all age groups were reported as having friends outside the family (at least 89%). Regarding their children's safety, 97.4% of caregivers of newborns to 5-year olds reported having a child-safety seat in the car, and 97.1% of 6 to 11-year olds and 94.4% of 12 to 17-year olds were reported as using seatbelts in cars. The majority of 6-11 year olds (83.3%) and 12-17 year olds (60.9%) were reported as wearing helmets when riding a bicycle.

Regarding watching television or using the computer, the majority of children newborn to 5 years (57.9%) and 6-11 years (61.1%) watch 1-2 hours of television daily. Almost 89% of 12-17 year olds use a computer/internet to look up topics of interest (75.0%), do school work (68.8%), and to play video games (62.5%).

Recommendations

Members of the Healthy Delawareans project reviewed the results of the survey and provided feedback. This report offers thirteen recommendations to improve the health and wellness of children with disabilities and special health care needs in Delaware.

The recommendations provided need to be coordinated across health care providers, human service providers, advocacy agencies, and schools that work with children with disabilities and special health care needs and their families.

All of the recommendations need to be implemented with input by and approval of children with disabilities and special health care needs, their families, and their care providers.

1. Support child mental health services and initiatives offered by state and private agencies and organizations to ensure that all initiatives and programs are provided statewide and are readily accessible to children with disabilities and special health care needs through a coalition of state, private, and not-for-profit organizations.
2. Support the effective implementation of respite care programs for families of children with disabilities and special health care needs between the ages of newborn to 21 years and educate families about their rights to receive respite services through a coalition of state government, family advocates and provider services to address the overwhelming need for respite services for families of children with disabilities and special health care needs.
3. Develop and implement health education and prevention programs that are inclusive of children with disabilities and special health care needs.
4. Support existing health education and prevention programs in becoming and being inclusive of children with special health care needs.
5. Support schools in including children with disabilities in inclusive settings for at least 80% of their instructional time.
6. Develop and provide culturally responsive healthy lifestyle education materials about topics such as healthy eating, exercise, and reduced TV time, to parents of all children, including children with disabilities and special health care needs.

7. Develop and provide culturally responsive health education materials about topics such as preventive health care, routine check-ups, and vaccines for children, to parents of all children, including children with disabilities and special health care needs.
8. Develop and implement safety education activities for children and adolescents that are inclusive of children with disabilities and special health care needs and enable existing safety education activities to become and be inclusive of children with disabilities and special health care needs.
9. Address barriers to access of medical and social services through a coalition of state, private, and not-for-profit organizations and legislation and educate providers and families on their rights, responsibilities and opportunities. Barriers that need to be addressed are: a) provider barriers, such as lack of knowledge regarding disabilities and special health care needs and inaccessible facilities and equipment, b) client and family barriers, such as lack of knowledge of the medical and service systems, and c) systems barriers, such as inadequate funding mechanisms and services.
10. Provide education to health care providers and families regarding the importance of a medical home for children with disabilities and special health care needs.
11. Develop and implement transition services for children with disabilities and special health care needs and their families that help and support school, employment, and medical transitions.
12. Provide education to health care providers and families regarding the importance of early transition preparation so that children and adolescents with disabilities and special health care needs experience a smooth transition from the pediatric to the adult health care system.
13. Provide education to school personnel, educational transition coordinators, and families regarding the importance of adequate preparation for children and adolescents with disabilities and special health care needs to enable them to experience a smooth transition from school into the workforce or higher education.

Introduction & Methodology



Introduction

The Healthy Delawareans with Disabilities (HDWD) 2010 project was a health and wellness program conducted between 2005 and 2007 that focused on promoting health and wellness of individuals with disabilities in Delaware. The project was based on the Healthy People 2010 Initiative, a national 10-year plan to help federal, state, local, private, and community agencies and organizations in their efforts to promote health and wellness. HDWD 2010 was coordinated and managed by the Division of Developmental Disabilities Services (DDDS) of the Delaware Department of Health and Social Services (DHSS) and funded by the National Center on Birth Defects and Developmental Disabilities (NCBDDD) of the Centers for Disease Control and Prevention (CDC).

HDWD 2010 had five overarching goals, which included:

- increasing statewide knowledge about factors that affect the health and wellness of people with disabilities and that contribute to illnesses and secondary health conditions,
- developing a statewide Advisory Panel to promote health and wellness for people with disabilities,
- developing the Advisory Panel into a statewide resource for technical assistance on issues of health and wellness for people with disabilities,
- producing a report on the health and wellness of people with disabilities, and
- developing and implementing several pilot health and wellness promotion programs for individuals with disabilities in Delaware.

HDWD 2010 was successful in achieving its goals. This final report of the HDWD 2010 project focuses on the findings regarding health and well-being of children with disabilities in Delaware.

Find Out More

www.hdwd2010.com

www.udel.edu/cds/health.html

www.dhss.delaware.gov/ddds/

www.dhss.delaware.gov/dhss/

www.udel.edu/cds

Methodology

Rationale for Survey

Delaware has few data sources on the health and wellbeing of children with disabilities. One source is a report published in 2000 by the Center for Applied Demography and Survey Research (CADSR) at the University of Delaware for Delaware Health and Social Services. It included information about children with special health care needs, based on the responses of 116 families of children with special health care needs. These families had been identified through Child Development Watch (CDW), Delaware's Part C of the Individuals with Disabilities Education Act early intervention program. In addition, the 2003 National Survey of Children's Health (NSCH) and the 2005/2006 National Survey of Children with Special Health Care Needs (NS-CSHCN) include data for Delaware.

The HDWD 2010 project advisory panel set the goal of collecting more detailed information from families about the specific needs of children with special health care needs. Families of children with disabilities and special health care needs were selected at health events and through partnerships with organizations and agencies serving children with disabilities and special health care needs in Delaware. Special efforts were made to include families of children with intellectual disabilities in the survey, as they are often underrepresented and little health care data exist about this population of children.

Preparation for Study

To increase knowledge about factors that affect health and wellness of children with disabilities and special health care needs, a selected group of Advisory Panel members of the HDWD 2010 project developed a survey that addressed topics such as children's health status, children's care needs, access to medical care and a medical home, and variables that influence families' daily lives in such areas as friendships and safety. The Advisory Panel approved the survey before data collection began.

Survey Participants

Families who considered themselves as having a child with a disability or special health care need and whose children were between newborn and 17 years of age participated in the survey. The sample for this survey was recruited through health fairs, summer camps, and outreach to community organizations across Delaware. Families who participated were also asked to share information about the survey

with other families. The combined efforts of advocacy groups, camp counselors, disability specific support groups, community members, and many other agencies and organizations worked to identify a total of 167 families for the survey. Of this group of 167 families, a total of 132 families (79.0%) participated in the interviews.

Data Collection

The *Childhood Survey on Health, Disabilities, and Quality of Life* was developed to collect information about children with disabilities and special health care needs in Delaware. Survey questions were developed by HDWD 2010 Advisory Panel members who had a special interest in children with special health care needs and disabilities. The survey consisted of 64 general questions asked of all families and age-specific questions for three age groups: a) newborn to 5 years of age (17 additional questions), b) 6 to 11 years of age (18 additional questions), and c) 12 to 17 years of age (32 additional questions). In addition, a Teen Risk-Behavior Survey for 14- to 17-year-old adolescents was developed and asked of adolescents of families who participated in the general survey. The risk-behavior survey addressed issues of sexual activity, drug-use, and smoking. Adolescents needed to be able and willing to complete the survey and have parental consent to participate in the risk-behavior survey. Both surveys were reviewed and approved by the HDWD 2010 Advisory Panel. The Human Subjects Review Board of Delaware Health and Social Services (DHSS) reviewed the surveys and granted permission to conduct the survey with families of children with disabilities and special health care needs in Delaware. The approval notice from the Human Subjects Review Board was received on September 12, 2006.

In September 2006, Delaware community members with an interest and experience in the human services field participated in a one-day training to conduct the childhood survey with families in in-person interviews.

Survey participants were recruited through health fairs, at summer camps and through outreach to community organizations. Interested families completed a survey sign-up sheet that was returned to the Center for Disabilities Studies (CDS). Once CDS received a completed sign-up sheet, the family's information was entered into a Microsoft Access database.

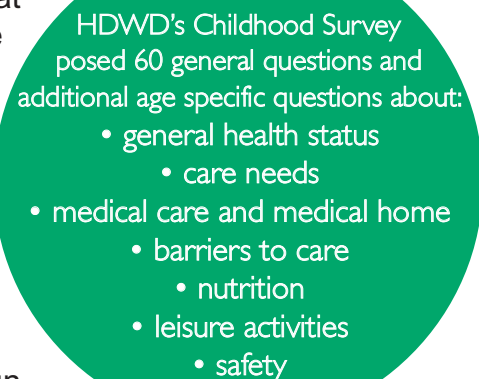
A total of 13 trained interviewers scheduled and conducted in-person surveys with participating families. Interviewers collected information between January and May 2007. Interviews lasted from 30 to 90 minutes and were held at a location chosen by the families. Families received \$15.00 for their participation after they completed the interview.

Data Analysis

The data were analyzed between July and November of 2007. CDS staff used the Statistical Package for the Social Sciences (SPSS 14.5) to analyze the data. Basic descriptive statistics were calculated.

Challenges and Strengths

Collecting information from families of children with disabilities and special health care needs for this survey brought with it some challenges. The participants of this survey were not selected randomly. Families were recruited through outreach and word-of-mouth. While this does not mean that findings are of less significance, there is a higher risk of bias to the survey results. The data reported may not be a representation of all families with children with disabilities and special health care needs in Delaware. In addition, for some of the subsamples there are a relatively small number of respondents. This is particularly true for some of the additional, age-specific questions for families of 12- to 17-year-olds and for the adolescents responding to the teen risk survey. Questions in the age-specific section of the childhood survey about violent behaviors, such as being in a fight, being threatened or being exposed to a knife or gun, and questions about smoking, yielded so few responses that the collected data could not be interpreted and was not reported. A total of 20 adolescents completed the teen risk survey; of those, less than ten responded to questions about drug use and sexual behaviors, which did not allow for interpretation of results and reporting.



HDWD's Childhood Survey posed 60 general questions and additional age specific questions about:

- general health status
 - care needs
- medical care and medical home
 - barriers to care
 - nutrition
- leisure activities
 - safety

While caution needs to be taken when interpreting the findings of this report, this is one of the first times that a comprehensive, diverse group of families of children with disabilities and special health care needs in Delaware has been asked about health, risk factors, and care needs. One of the strengths of this report is the representation of families with children who have a variety of disabilities and special health care needs. In addition, it is an account of the current experiences of families, not a retrospective analysis of previous experiences. Finally, this report addresses age-specific needs of children and families as specific questions addressed the three distinct age groups.



Health, Wellness & Lifestyle Findings

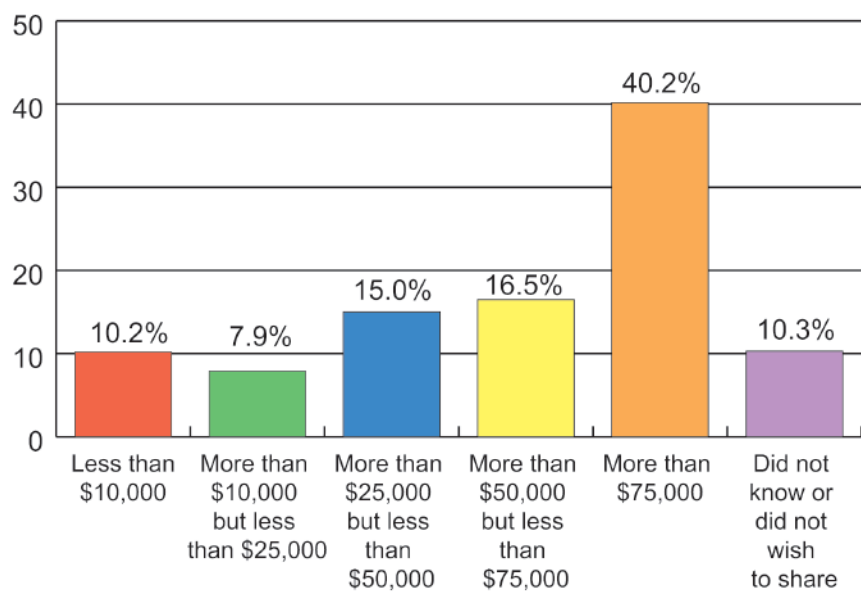


Demographic Information

Respondents, Residence, Income

Respondents were asked to identify their relationship to the child with the disability or special health care need. A large majority of survey respondents were the parent of the child (97.0%) and most of all respondents were female (90.9%). In addition, the majority of participating parents had other children (84.1%) living at home. The majority of families who participated in the survey lived in New Castle County (65.2%), with 21.2% living in Sussex County, the most southern of the counties in Delaware, and 13.6% living in Kent County. Of all participating families 10.2% earned an annual household income of less than \$10,000, 7.9% earned between \$10,000 and less than \$25,000, 15.0% earned an annual income of \$25,000 to less than \$50,000, 16.5% earned between \$50,000 and less than \$75,000, and 40.2% earned \$75,000 or more. A total of 10.3% of participants did not know what their annual household income was or did not wish to answer the question. Comparing the annual household income of survey participants to the annual household income of the general Delaware population shows that households with an income of less than \$10,000 and \$75,000 and more were slightly overrepresented, and household incomes of \$10,000 to less than \$75,000 were underrepresented in the survey population.¹ Figure 1 illustrates families' annual household incomes for survey participants.

Figure 1. Families' annual household income (n=127)



¹ U.S. Census Bureau, 2006 American Community Survey

Children's Gender, Age, Race, Ethnicity

Participating family members or legal guardians were asked about the gender, age, race, and/or ethnicity of their child with a disability or special health care need. A majority of the children were male (59.1%). Almost 30% of the children were new-born to 5 years of age, 27.7% were 6 to 11 years of age, and 43.1% of children were 12 to 17 years of age. The average age of children was 9.53 years. Survey respondents identified 73.8% of children as White/Caucasian, 19.7% as Black/African-American, and 6.5% as Other, including children who were Asian and multiracial. Approximately 9.0% of children were identified as being Hispanic/Latino. Table 1 illustrates children's gender, age, race and ethnicity by primary disability.

Table 1. Children's gender, age, race and ethnicity, by primary disability

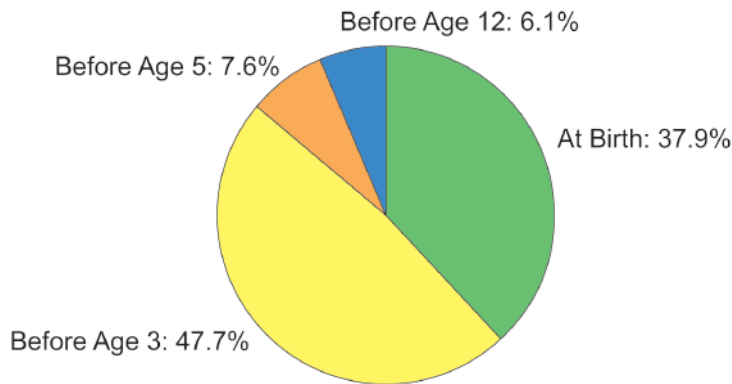
	Sensory Impairment (Hearing/vision) %	Physical Disability %	Mental Health Condition %	Cognitive or Learning Disability %	Other Impairment %	Total %
Child Gender (n=132)						
Male	38.5	51.6	55.6	71.4	65.2	59.1
Female	61.5	48.4	44.4	28.6	34.8	40.9
Race (n=117)						
White	66.7	67.7	85.7	75.0	73.9	73.8
Black/African American	33.3	29.0	14.3	13.6	17.4	19.7
Other*	-	3.2	-	11.3	8.6	6.5
Ethnicity** (n=127)						
Hispanic/Latino	21.4	9.4	11.1	10.2	-	9.4
Age (n=125-130)						
0-5 years (n=36)	11.1	33.3	5.6	30.6	19.4	29.2
6-11 years (n=36)	8.3	22.2	-	41.7	27.8	27.7
12-17 years (n=53)	11.3	20.8	13.2	43.4	11.3	43.1
Average Age (in Years)						9.53

* Includes Asian and multiracial

** Because of the way the survey was structured, most respondents who indicated that their child was Hispanic/Latino skipped the question regarding their child's race.

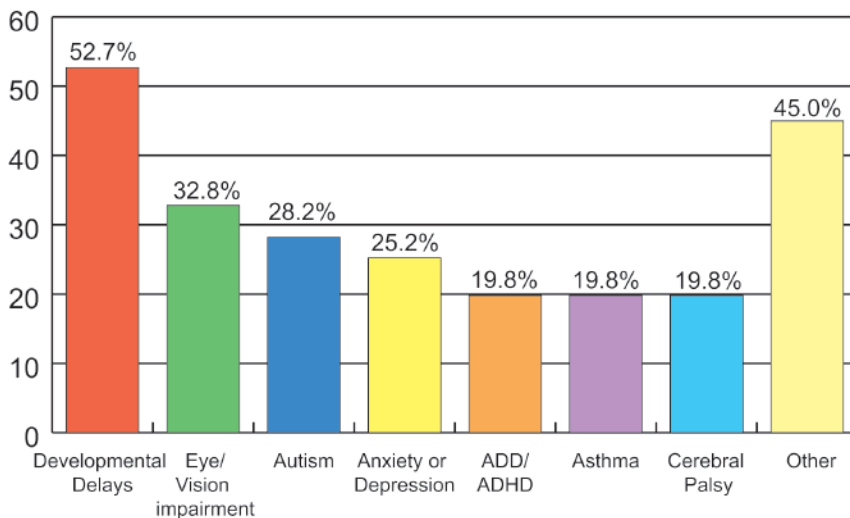
Respondents were asked at what age their child's disability or health condition had been identified. For 37.9% of children their condition had been identified at birth, 47.7% were identified before three years of age, 7.6% before five years of age, and 6.1% before twelve years of age. One child was identified after twelve years of age. Figure 4 shows the age at which children's conditions were first identified.

Figure 4. Age at which children's disability or health condition was identified, by primary disability or health condition



During the interview, participants were asked to identify their child's medical diagnosis. Respondents could provide multiple answers to this question. Figure 5 shows the more common medical diagnoses identified by survey participants (a complete list of medical diagnoses can be found in the appendix) with developmental delays (52.7%), eye/vision impairment (32.8%), and autism (28.2%) being conditions most often identified.

Figure 5. Children's more common medical diagnoses[†]



[†] Percentages total more than 100% as participants could give more than one answer.

General Health Concerns

Health Status

Participating parents or legal guardians were asked about the general health of their children. Almost 24% reported that their child's health was excellent and 43.3% reported that their child's health was very good. Approximately 30% reported that their child's health was good to fair and 3.1% said that their child's health was poor. Children with physical disabilities (6.3%) and cognitive or learning disabilities (4.1%) had the highest percentages of reported poor health while children with other conditions (26.1%) and hearing and vision impairments (35.7%) had the highest percentages of reported excellent health. Table 2 shows children's health status by primary disability or health condition.

Table 2. Children's health status, by primary disability or health condition (n=132)

	Sensory Impairment (Hearing/Vision) %	Physical Disability %	Mental Health Condition %	Cognitive or Learning Disability %	Other Condition %	Total %
Excellent	35.7	21.9	11.1	22.4	26.1	23.6
Very Good	50.0	34.3	33.3	44.9	52.2	43.3
Good/Fair	14.3	37.5	55.6	28.6	21.7	29.9
Poor	-	6.3	-	4.1	-	3.1

Physical Health

Survey participants were asked about their child's physical health and how often during the past month their child's health had not been good. Of all respondents 4.0% reported that their child's health had not been good very often, 18.3% said somewhat often, 42.9% seldom, and 34.9% stated that their child's health was never "not good" during the past month. Respondents were also asked how often in the past month they thought their child had felt very healthy and full of energy. Almost 58% indicated very often, 29.1% answered somewhat often, 11.0% said seldom, and 2.4% responded never. Those children with vision or hearing impairments were most often reported to be energetic (71.4%), second only to those children whose primary condition was listed as "other" (77.3%). Table 3 illustrates how often children's physical health had not been good and how often children felt healthy and full of energy.



Table 3. Children's physical health and energy level, by disability

	Sensory Impairment (Hearing/Vision) %	Physical Disability %	Mental Health Conditions %	Cognitive or Learning Disability %	Other Impairment %	Total %
Frequency, in past month, child's physical health was not good (n=131)						
Very Often	-	6.5	-	4.1	4.3	4.0
Somewhat Often	14.3	35.5	33.3	10.2	8.7	18.3
Seldom	42.9	38.7	22.2	51.0	39.1	42.9
Never	42.9	19.4	44.4	34.7	47.8	34.9
Frequency, in past month, child was full of energy (n=127)						
Very Often	71.4	41.9	22.2	60.9	77.3	57.4
Somewhat Often	28.6	45.2	44.4	26.1	9.1	29.1
Seldom	-	9.7	33.3	10.9	9.1	11.0
Never	-	3.2	-	2.2	4.5	2.4

Participants were asked how often during the past month their child did not get enough rest or sleep. Almost 8% (7.8%) indicated very often, 23.3% said somewhat often, 45.7% stated seldom and 23.3% responded never. Respondents of children with mental health conditions most often reported that their children were not getting enough sleep (22.2%).

Emotional Health

Participants were asked about their child's emotional health during the past month. Of all participants, 8.3% felt that their child's mental health was not good very often during the past month, 19.8% answered somewhat often, 36.4% seldom and 35.5% never. Children with mental health conditions had the highest reported rate of emotional health that was not good with 88.9% of respondents reporting that their child's emotional health was "very often" or "somewhat often" not good. Respondents with children with cognitive or learning disabilities reported that their child's emotional health was "very often" or "somewhat often" not good (29.8%).

Participants were also asked how often their child felt worried, stressed, tense, or anxious during the past 30 days. A total of 16.8% of respondents reported that their child felt worried, stressed, tense, or anxious very often; 21.8% said somewhat often, 36.1% responded seldom and 25.2% indicated that their child had never felt worried, stressed, tense or anxious during the past 30 days. Again, respondents of children with a mental health condition reported the highest percentage (88.9%) of children being worried, stressed, tense, or anxious “very often” or “somewhat often”, followed by the percentage of children with other impairments (50.0%) and cognitive or learning disabilities (42.2%). Table 4 illustrates how often children’s emotional health had not been good and how often they had been worried, stressed, tense, or anxious.

Table 4. Children’s emotional health and anxiety level, by disability

	Sensory Impairment (Hearing/vision) %	Physical Disability %	Mental Health Condition %	Cognitive or Learning Disability %	Other Impairment %	Total %
Emotional/Mental health was not good, in past month (n=126)						
Very Often	-	6.7	22.2	8.5	9.5	8.3
Somewhat Often	-	16.7	66.7	21.3	14.3	19.8
Seldom	64.3	26.7	-	40.4	38.1	36.4
Never	35.7	50.0	11.1	29.8	38.1	35.5
Frequency, in past month, child felt worried, stressed, tense, or anxious (n=122)						
Very Often	-	6.5	55.6	20.0	20.0	16.8
Somewhat Often	14.3	16.1	33.3	22.2	30.0	21.8
Seldom	57.1	32.3	-	37.8	40.0	36.1
Never	28.6	45.2	11.1	20.0	10.0	25.2

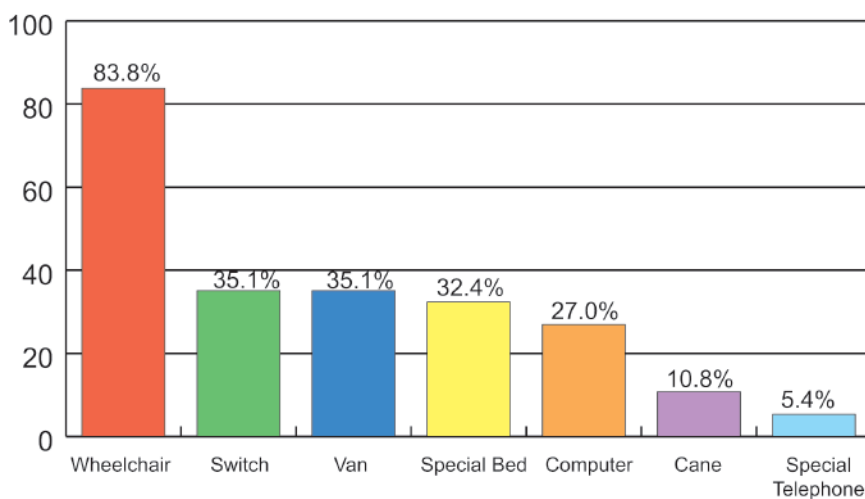
Participants were also asked if their children received any treatment or counseling for their mental health condition and if so, what type of treatment they received. Almost 29% (28.8%) of 132 respondents reported that their child received some type of treatment. Of these 63 respondents who indicated that their child received mental health treatment, 76.9% reported that their child received counseling by a mental health provider, 53.8% stated that their child received prescribed medication, 7.7% reported that their child participated in community-based peer support, and 23.1% stated that their child received some other type of help.

Care Needs

Equipment

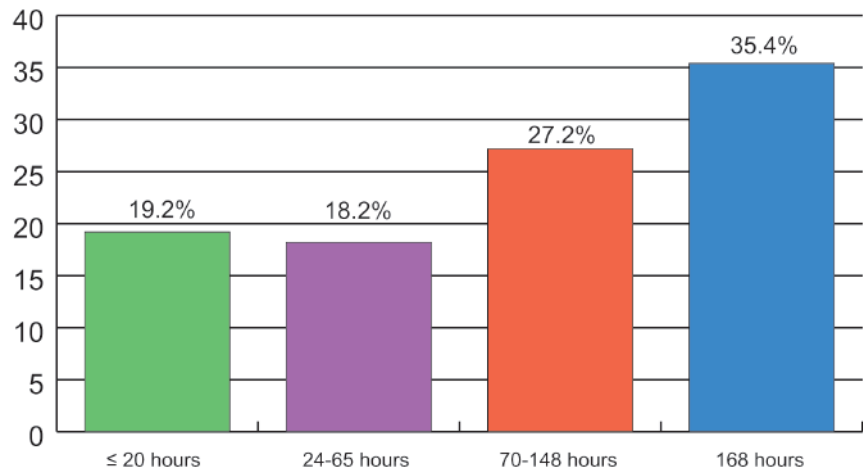
Some children with disabilities require special equipment, such as wheelchairs, walkers, hearing aids or communication devices, in order to participate in daily routines and activities. Survey respondents were asked if and what type of special equipment their child needed. Forty percent (40.2%) of children of participants required the use of special equipment. The majority of those responding that their child needed special equipment reported the use of wheelchairs (83.8%), followed by adaptive switches (35.1%), accessible vans (35.1%), and specially-fitted beds (32.4%). Figure 6 illustrates the reported equipment used by children of participants.

Figure 6. Special equipment used by children of respondents (n=137)[†]



[†] Percentages total more than 100% as participants could give more than one answer.

Figure 8. Hours of care provided to children with disabilities and special health care needs (n=99)

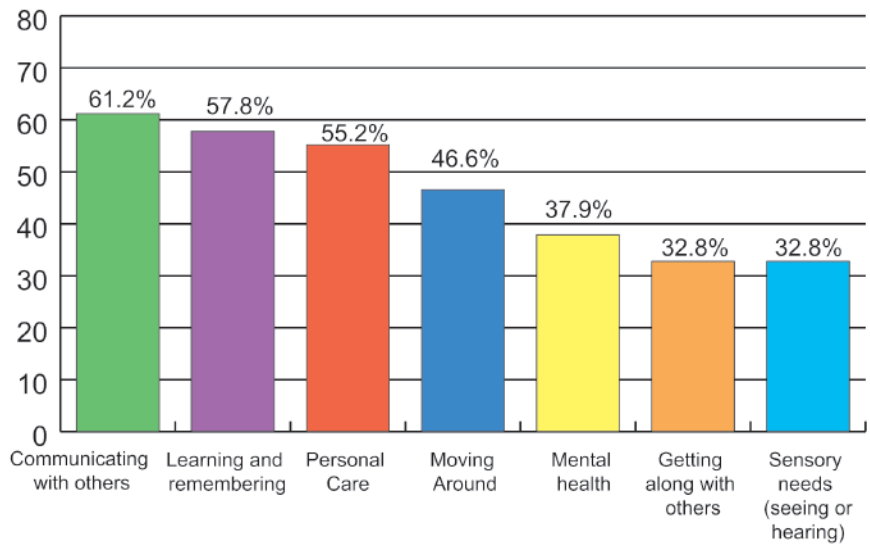


On average, caregivers provided 97 hours of care per week and 35.4% of respondents provided around the clock care.

Future Care Needs

Survey participants were asked about their children's future needs. When asked to list all the areas respondents think their child will need help with in the future due to his/her disability or special health care need, 61.2% thought that their child will need help with communicating with others, 57.8% with learning and remembering, and 55.2% with personal care. Figure 9 shows responses regarding children's future needs.

Figure 9. Anticipated future needs[†]



[†] Percentages total more than 100% as participants could give more than one answer.

Respondents were also asked about other anticipated long-term needs of their children. Almost 85% of participants had already thought about what the long-term adult needs of their child will be. Approximately 71% of participants reported that their child will need specialized occupational training, 69.9% think that their child will need specialized medical or health care supports, and 58.4% feel that their child will need specialized residential supports. A total of 12.4% of respondents were not sure what their child's future needs will be.

Weight and Exercise

Weight

Survey respondents were asked if they were ever told their children were underweight or overweight. Of all respondents of children in the newborn to 5-year-old age group, 5.7% stated that they were told that their child was overweight, 22.9% were told that their child was underweight, and 71.4% were told that their child was within the normal weight range for their age. Fifty percent (50.0%) of respondents whose child was identified as being overweight or underweight were told that their child's weight was related to his/her health condition or disability. In comparison, of respondents of children 6- to 11-year-olds, 22.9% were told that their child was overweight, 20.0% were told their child was underweight, and 70.6% of overweight or underweight children were told that their weight was related to their disability or health condition. For the 12- to 17-year-old group, 27.2% of respondents were told that their child was overweight, 6.2% were told their child was underweight, and 34.5% were told that their child being over or underweight was related to his/her disability or health condition. Table 5 shows children's weight by age.

Table 5. Children's weight, by age group

	Newborn to 5 year-old age %	6 to 11 year-olds %	12 to 17 year-olds %
Underweight	22.9	20.0	6.2
Normal weight range	71.4	57.1	66.7
Overweight	5.7	22.9	27.2
Overweight or underweight due to health condition			
Yes	50.0	70.6	34.5
No	50.0	29.4	65.5

Special Diets

Survey respondents were asked about their child's dietary needs. Respondents were asked if their child needed a special diet because of their disability or special health care need and how the need for a special diet affected their family budget. Of the children in the survey age newborn to 5-years-old, 31.6% were on a special diet because of their condition. Of those respondents, 16.7% stated that the special diet put a strain on the family budget, 33.3% indicated that it added some additional, but moderate costs, and 50.0% felt that their children's special diet did not add any additional costs. Families learned about their child's nutritional needs from a primary care provider (44.7%), a friend/family member, (18.4%) or WIC/nutritionist (13.2%).

Responses for children age 6 to 11 years showed similar information. Approximately 31% used a special diet, with one third (33.3%) indicating that the diet added some additional but moderate cost to the family budget and two-thirds (66.7%) stating that the diet did not add any additional expense. Approximately 64% of respondents said that their children's special diet was supported by their schools.

In the 12- to 17-year-old group, 19.4% of participants said their child was using a special diet due to his/her disability or special health care need. Of those on a special diet, 87.5% of respondents answered that their child's diet was supported by his/her school. Table 6 illustrates special diet needs by age group.

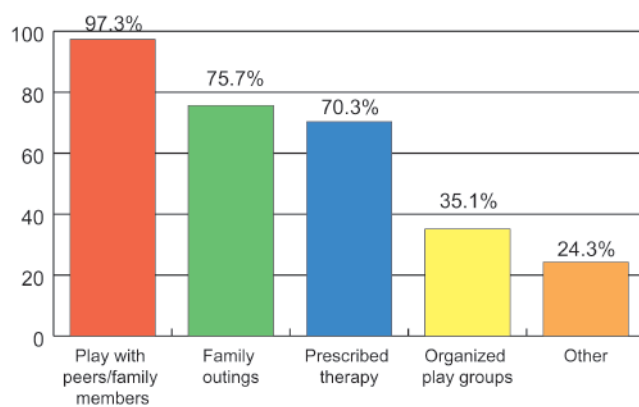
Table 6. Special diet needs, by age group

	Newborn to 5 year-old age %	6 to 11 year-olds %	12 to 17 year-olds %
Special diet due to condition	31.6	30.6	19.4
How diet affected the family financially			
Special diet puts strain on family, financially	16.7	-	n/a
Added some additional, but moderate costs	33.3	33.3	n/a
Did not add any additional cost	50.0	66.7	n/a
Where they learned about nutritional needs			
Primary care provider	44.7	n/a	n/a
Friend/family member	18.4	n/a	n/a
WIC/nutritionist	13.2	n/a	n/a
Diet supported by schools	n/a	63.6	87.5

Exercise

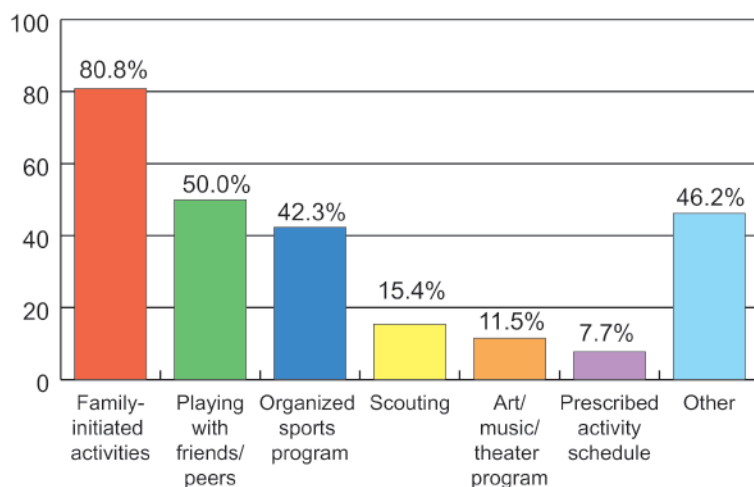
Exercise is an important component of health for children and adolescents and survey respondents were asked about the types of play and exercise in which their children were involved. When asked what type of physical activity/exercise their newborn to 5-year-old child engaged in, 97.3% of respondents stated that their child played with peers and/or family members, 75.7% responded that their child participated in family outings, and 70.3% reported that their child participated in prescribed therapy activities/exercises. Figure 10 illustrates all play and exercise activities in which children of the newborn to 5-year-old group were engaged.

Figure 10. Play and exercise activities, for children under 6 years of age (n=37)[†]



Survey respondents with children in the 6- to 11-year-old group were asked if their child participated in extra-curricular or non-school physical activity or exercise. Almost 29% reported that their child does not participate in any extra-curricular physical activities, while 71.4% stated that their child does participate in non-school physical activities. The most reported forms of involvement were family initiated activities (80.8%), playing with friends or peers (50.0%) and organized sports programs (42.3%). Figure 11 shows all extra-curricular activities in which 6-to 11-year-olds participated.

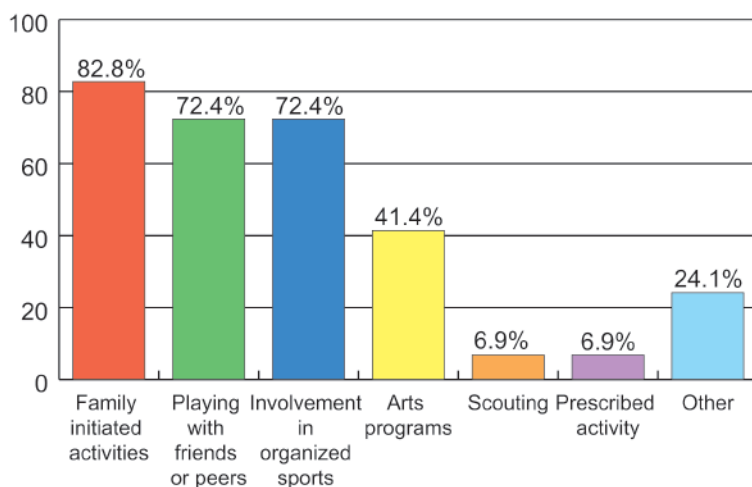
Figure 11. Play and exercise activities, for children 6 to 11 years of age (n=26)[†]



[†] Percentages total more than 100% as participants could give more than one answer.

When respondents of 12- to 17-year-olds were asked the same questions as the younger age groups regarding exercise, 19.4% stated that their child does not participate in any extra-curricular physical activity, while 80.6% responded that their child does. The types of physical activities in which 12- to 17-year-olds participated were similar to the ones of the 6- to 11-year-olds. Family-initiated activities (82.8%), playing with friends or peers (72.4%), and involvement in organized sports (72.4%) were the most reported types of activity. All exercise activities are shown in Figure 12. Respondents for this age group were also asked if their children had exercised during the last month. Of all respondents for this age group 17.1% stated that their child had not exercised during the last month while 82.9% said that their child had exercised. The most frequent reasons given for exercising were because the child enjoyed exercising (64.3%) and to be with friends (42.9%).

Figure 12. Exercise activities, for children 12 to 17 years of age (n=28)[†]



Insurance and Medical Care

Insurance Coverage

Respondents were asked about their child's insurance coverage, one of the most important factors in receiving appropriate health care (Lewit & Schuurman Baker, 1995). Ninety-seven percent (97.0%) of participants reported that they had health insurance for their children. Employer based insurance was the most common source (59.8%) followed by Medicaid/Delaware Physicians Care, Inc./Diamond State Partners (37.8%).

Access to a Medical Home

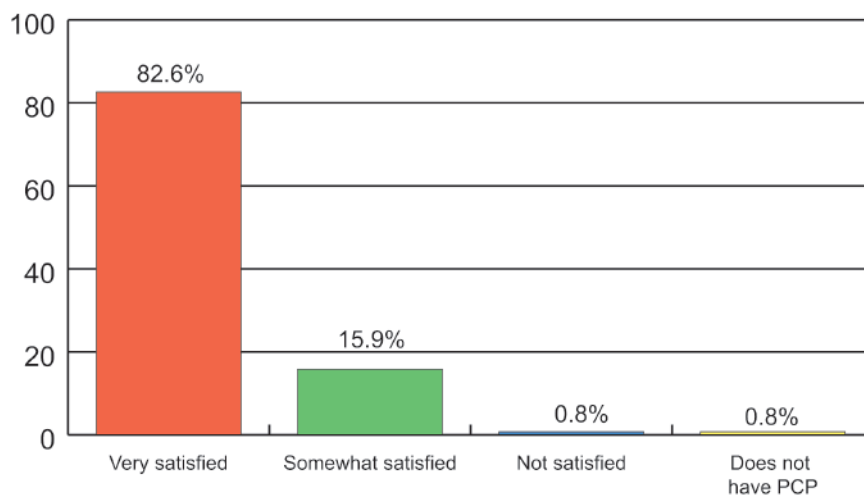
The American Academy of Pediatrics (AAP) states that, "a medical home is not a

[†] Percentages total more than 100% as participants could give more than one answer.

building, house, or hospital, but rather an approach to providing health care services in a high-quality and cost-effective manner. Children and their families who have a medical home receive the care that they need from a pediatrician or physician (pediatric health care professional) whom they trust. The pediatric health care professionals and parents act as partners in a medical home to identify and access all the medical and non-medical services needed to help children and their families achieve their maximum potential" (AAP, 2004). Survey respondents were asked a series of questions to explore if their children had an established medical home through which they received medical care as described above. All but one participant (99.2%) reported that they had at least one person they thought of as their children's primary personal doctor or health care provider and 24.2% reported more than one provider.

Most participants (82.6%) indicated they were very satisfied with their child's primary care provider; 15.9% were somewhat satisfied, and 0.8% were not satisfied with the care they received. Less than one percent of the respondents reported that their child did not have a primary care provider (see figure 13).

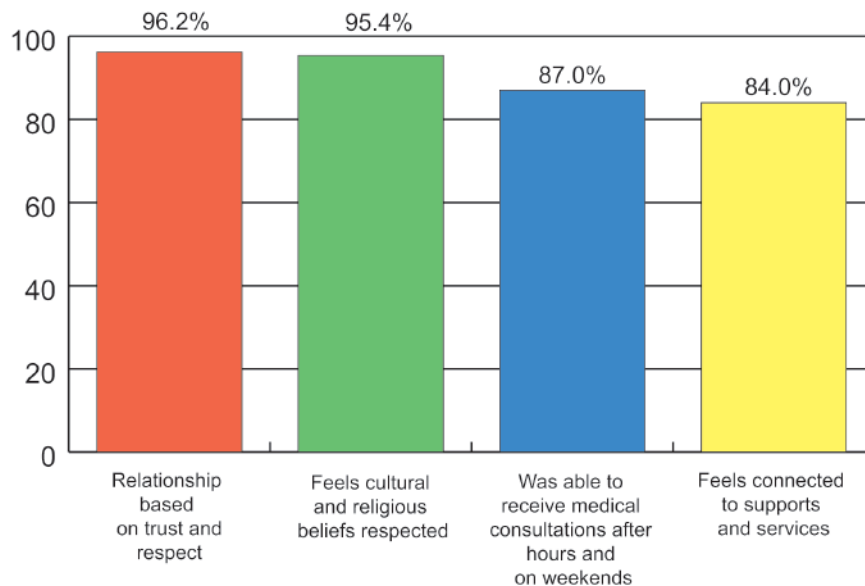
Figure 13. Satisfaction with primary care physician



When asked about the level of encouragement that caregivers received after their child was first diagnosed with his/her disability or special health care need, 33.9% reported that they received a great amount of support, 28.3% received an adequate amount of support, 23.6% received some support, and 14.2% felt they did not receive any amount of support from their doctors and other health care professionals.

When asked about more specific experiences with receiving health care services, 93.9% of participants reported a perceived partnership with a primary care provider in coordinating care for their child. Nearly all (96.2%) respondents reported that the relationships with the child's providers were based on trust and respect and that information was exchanged honestly and respectfully. Almost 96% of respondents reported that they felt their cultural and religious beliefs were respected. Eighty-four percent (84.0%) of participants reported feeling connected to supports and services required to meet the child's and family's needs and 87.0% indicated they had medical consultation available to them after hours and on weekends. Figure 14 illustrates these findings.

Figure 14. Relationship of caregivers and health care providers (n=110-126)

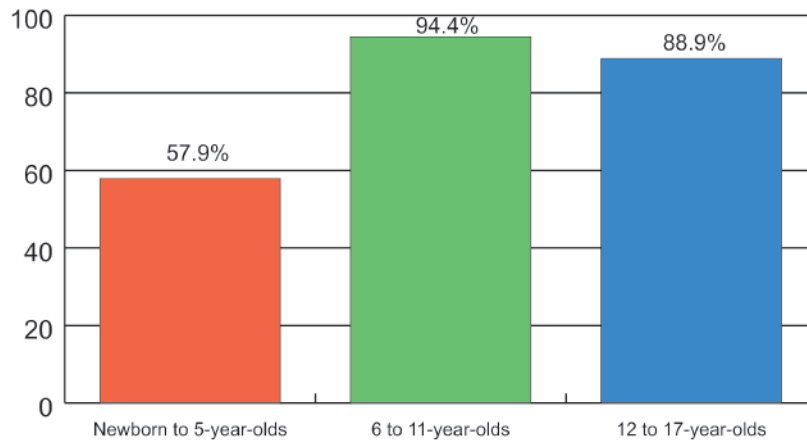


Access to Dental Care

Participants were asked about access to dental care for their children. Almost eighty-six percent (85.6%) of respondents reported that their children were currently receiving dental/oral care. The percentages of respondents reporting current dental care varied by age group with the youngest age group, newborn to five years, reporting the lowest rate of dental care (57.9%). Participants reporting on children ages 6 -11 years reported that 94.4% received dental care and those with children ages 12 -17 years reported 88.9% currently receive dental care (see figure 15).

Participants who indicated that their children received dental care were asked who recommended that they seek dental care. For the large majority of children 12- to-17-years of age the primary care provider (87.5%) recommended that they see a

Figure 15. Access to dental care, by age of child



dentist. For younger children, parents reported that either the primary care provider made the recommendation or the parents thought of it themselves. In respondents with children under age six who receive dental care, 28.6% reported that the primary care provider suggested seeking care and 71.4% reported thinking of it themselves. In respondents with children 6-11 years old, 14.7% reported that the primary care provider suggested seeking care, and 73.5% reported thinking of it themselves.

Barriers and Challenges

When seeking health care it can sometimes be challenging receiving the services one needs. Transportation, cost, and physical barriers have been stated as challenges individuals experience (Scheer, Kroll, Neri and Beatty, 2003). Survey respondents were asked about specific barriers they may have encountered when seeking health care for their children with disabilities or special health care needs.

Almost eighty-six percent (85.5%) of participants indicated that they had no problem being able to see a doctor in the past 12 months. Out of the 14.5% who could not see a doctor, 40.0% reported cost and lack of transportation as barriers and 30.0% reported physical access barriers and lack of services as reasons for not seeing a doctor.

Overall, 14.5% of participants indicated that they encountered physical barriers when seeking health care for their children in the last 12 months. Barriers related to buildings and other issues were reported by 58.8% of those who reported barriers. Barriers related to medical equipment (e.g., exam table, dental equipment) were reported by 47.1% of survey respondents who experienced challenges, and

barriers related to services were reported by 41.2%. Transportation issues were reported as a barrier by 23.5% of respondents.

More than one third of participants (34.1%) indicated they experienced other types of difficulties acquiring health care for their children. Difficulty finding child care for other children was reported by 40.0% of respondents. Transportation problems (26.7%) and financial difficulties related to out-of-pocket expenses (28.9%) were included in the difficulties reported. Other difficulties that participants reported were the lack of convenient office hours (33.3%), excessive paperwork (8.9%), and language barriers (6.7%). Table 7 shows all barriers and difficulties encountered by survey respondents when seeking health care for their children.

Table 7. Barriers in seeking and receiving health care

Not able to see a doctor in the last 12 months due to barriers (n=19)	14.5%
Reasons for not being able to see a doctor[†]	
Barriers related to building and other issues	58.8%
Barriers related to medical equipment	47.1%
Barriers related to services	41.2%
Transportation	23.5%
Experienced difficulties in acquiring health care[†] (n=45)	34.1%
Difficulties finding childcare for other children	40.0%
Transportation problems	26.7%
Financial difficulties	28.9%
Lack of convenient office hours	33.3%
Excessive paperwork	8.9%
Language barriers	6.7%

[†] Percentages total more than 100% as participants could give more than one answer.

Parenting a Child with a Disability or Special Health Care Need

Parent Involvement

Participants of the survey were asked about parenting, and supports and obstacles associated with parenting a child with a disability or special health care need. While challenges in parenting a child with a disability or special health care need were reported, almost 88% of those surveyed indicated that they have a spouse or partner who has been consistently involved in the life and care of their children.

Parenting Challenges

Respondents of the survey were asked about a variety of challenges they may experience in parenting a child with a disability or special health care need. Questions addressed emotional responses to their child's diagnosis, variables negatively influencing their parenting, and impact on parenting other children. Parents were also asked if they thought their emotions were an obstacle in trying to understand their child's condition(s) when first diagnosed. Forty-six percent (45.7%) did not think their emotions were an obstacle, whereas 31.5% strongly agreed that their emotions were an obstacle, and 22.0% thought their emotions were somewhat of an obstacle in trying to understand their child's condition.

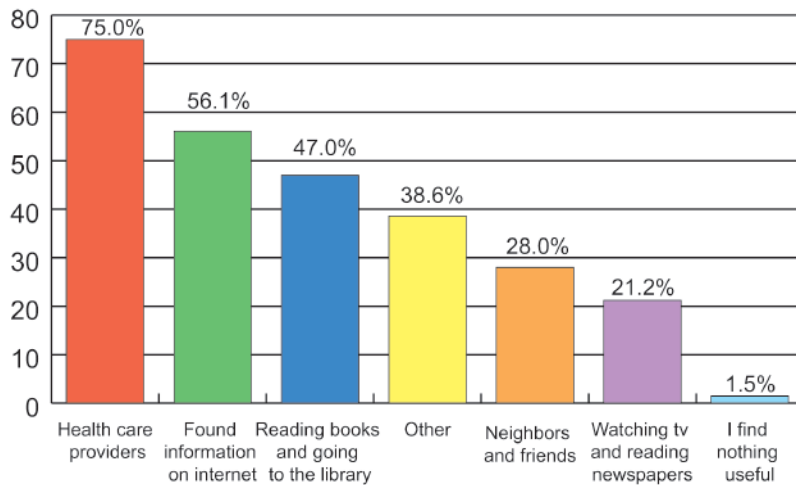
When asked to identify two areas that have created the greatest difficulty in parenting/caregiving a child with a disability or special health care need, 55.7% of the participants stated stress, 32.0% indicated not having enough time to themselves, and 30.3% reported financial burden. In addition, 23.0% reported that taking care of a child with a disability or special health care need impacts family relationships and 18.9% reported that it interferes with work.

Of the 110 respondents who indicated having other children, 44.3% did not think that parenting a child with a special health care need had caused difficulties in their ability to care for/parent their other children, whereas 25.5% thought strongly that it did cause difficulties, and 27.4% thought that it somewhat caused difficulties.

Parenting Supports

Respondents were asked about sources of support that helped them in caring for their child with a disability or special health care need, including information and emotional support from friends.

When asked to identify the sources of information caregivers found most useful relative to technical support and health education, 75.0% found the information they received from a doctor or another health care professional most useful, followed by doing their own research on the internet (56.1%), and reading specific books and going to the library (47.0%). Figure 16 illustrates all sources of information and their usefulness.

Figure 16. Source of health information and usefulness[†]

Participants were also asked whether they had received help, encouragement, and/or assistance from friends. Of all the respondents, 45.0% agreed that their friends were a great source of help, encouragement, and/or assistance, 32.8% indicated that their friends somewhat offered support, and 22.1% stated that their friends were not a great source of help.

Common challenges in supporting a child with a disability included:

- Stress
- Financial burden
- Interference with work
- Not enough time for self or family

Other Topics

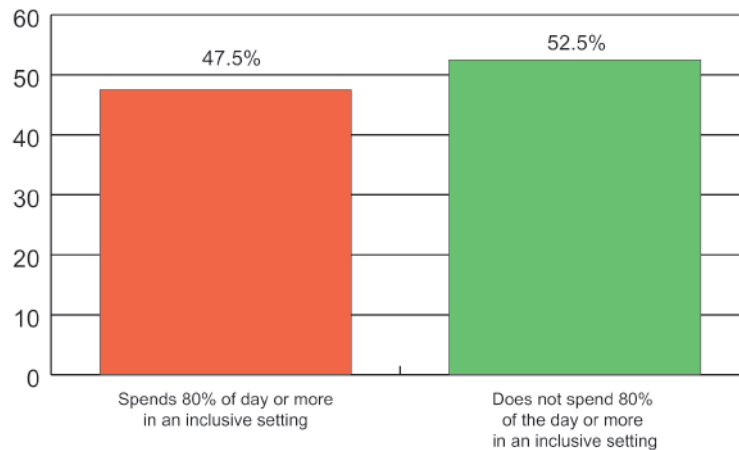
Inclusion

All participants were asked several questions about their children's education, particularly regarding inclusion and their children's Individualized Education Plan (IEP), if applicable. A total of 97.0% of those surveyed reported that their child participates in educational activities, including playgroups (21.1%), structured therapy (37.5%) and school activities (92.2%).

Of those in a school setting, approximately 24% were in preschool, 5.8% in kindergarten, 19.8% in grades 1 to 4, 11.6% in grades 5 to 6, 23.1% in grades 7 to 9, and 13.2% in grades 10 to 12. Of all children attending school, 2.5% were in a non-graded setting. Out of 122 responses for children 6 or older, 52.5% of respondents indicated that their child does not spend at least 80% of his/her school day in an inclusive settings (i.e. settings with same aged peers without special health care needs) and 47.5% indicated that their child does (see Figure 17).

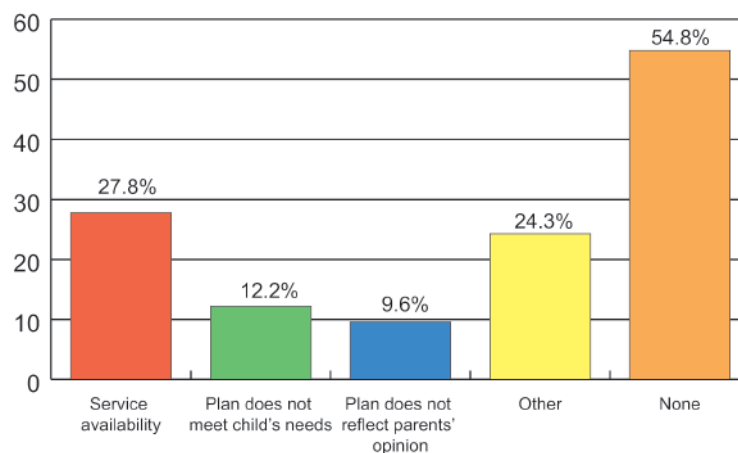
[†] Percentages total more than 100% as participants could give more than one answer.

Figure 17. Children attending inclusive school settings at least 80% of their day



When asked about educational or IEP development for their child, 88.6% of 123 respondents said that they participated in the development of their child's educational plan. Of those who did, 98.1% thought that their participation was helpful and important to the development of the plan. Respondents were asked what kinds of difficulties they have had during the planning process for their child's IEP. Out of 148 responses, 27.8% reported difficulties with service availability, 12.2% did not think that the plan met their child's needs, and 9.6% thought that the plan did not reflect their opinions. Approximately 24% indicated other types of difficulties and 54.8% reported no difficulties (see Figure 18).

Figure 18. Difficulties experienced by caregivers in the IEP process†

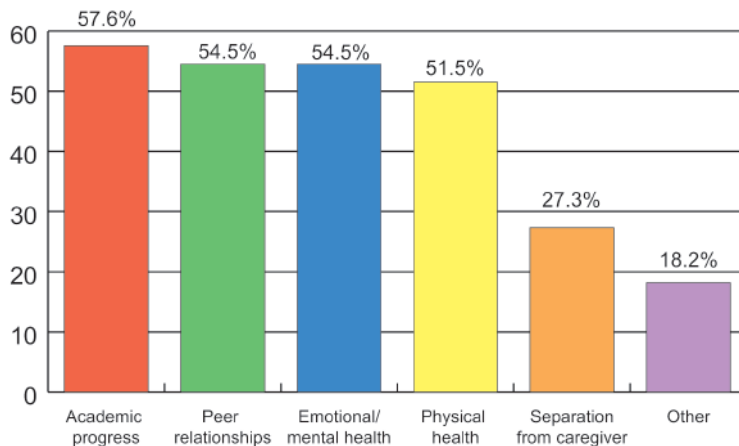


[†] Percentages total more than 100% as participants could give more than one answer.

Transition

Transitions for all children can be difficult, but sometimes it can be especially so for children with disabilities (Committee on Children with Disabilities 2000; Folsom-Meek, Nearing, and Bock, 2007). With varying issues raised, depending on age, survey participants were asked to anticipate whether their child would have difficulties as he/she moved to the next life stage. For those with children under the age of 6, respondents were asked if they thought their child would experience difficulties as he/she transitioned to school. Fifty-five percent (54.5%) of respondents anticipated that their child would have difficulties with peer relationships. Fifty-two percent (51.5%) of respondents felt that their child would have difficulties related to his/her continued physical health and 54.5% anticipated difficulties related to continued emotional/mental health challenges. Fifty-eight percent (57.6%) reported that academic progress may present difficulties. Parental separation issues were anticipated by 27.3% of participants with a child in this age group. A small group of respondents with children under 6 years anticipated other, non-specified difficulties (18.2%). Figure 19 shows the anticipated challenges in the transition process into school.

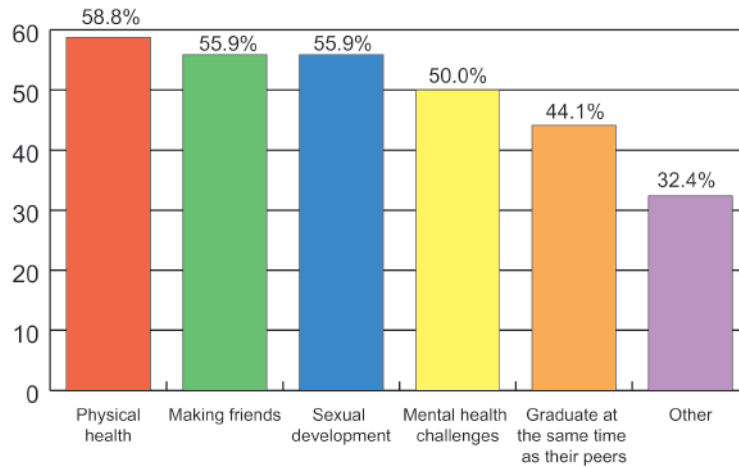
Figure 19. Anticipated challenges in the transition process into school, for children under 6 years of age[†]



For those with children ages 6 to 11 years, anticipating the potential challenges of the teenage years was the focus of the questions. Fifty-six percent (55.9%) of respondents anticipated that making friends would be a significant challenge for their child as he/she moved into the teenage years. Fifty-nine percent (58.8%) of respondents felt that their child would have difficulties related to physical health and 50.0% anticipated difficulties related to continued mental health challenges. Fifty-six percent (55.9%) felt that their child would encounter challenges related to sexual development as he/she transitioned into the teenage years. Forty-four percent (44.1%) reported that being able to graduate at the same time as peers would be a great challenge for their child. Thirty-two percent (32.4%) of respondents also anticipated other, non-specified difficulties. Figure 20 shows the anticipated challenges for 6- to 11-year-olds.

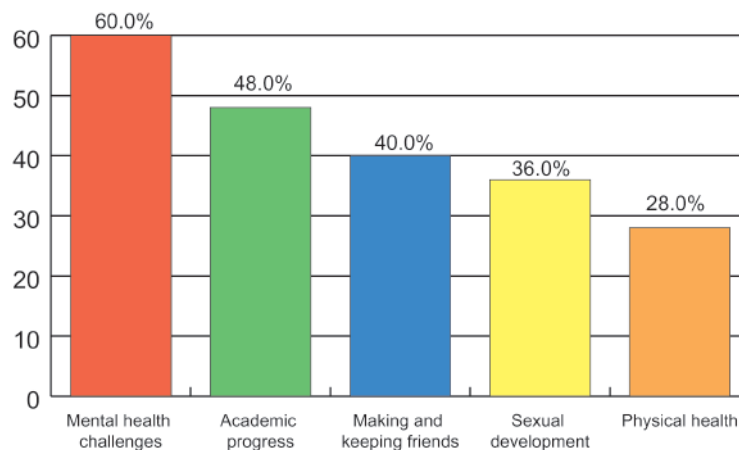
[†] Percentages total more than 100% as participants could give more than one answer.

Figure 20. Anticipated challenges in the transition process into adolescence, for children 6 to 11 years of age†



Children between 12 and 17 years of age are poised to enter adolescence, and then adulthood. Transitions during this time period may pose various challenges for all children but may hold additional challenges for children with disabilities and special health care needs. Forty percent (40.0%) of respondents anticipated that their child would have trouble making and keeping friends as he/she got older. Twenty-eight percent (28.0%) believed that their child would have continued physical health issues and sixty percent (60.0%) thought that continued mental health challenges would present problems for their child. Difficulty with normal academic progress was something 48.0% of participants with children in this age group saw in their child's future. Thirty-six percent (36.0%) of respondents with children in this age group anticipated challenges with sexual development and dating as their child grew older. Figure 21 illustrates the anticipated challenges for children 12 to 17 years of age.

Figure 21. Anticipated challenges in the transition process into adulthood, for children 12 to 17 years of age[†]



[†] Percentages total more than 100% as participants could give more than one answer.

Friendships

The childhood survey also explored children's friendships, as they are an important part of the development of all children. A question of interest was if children had friends outside their families, and if so in which settings. In the youngest age group (newborns to 5-year-olds), 89.5% of 39 participants indicated that their child does have friends outside the immediate family, which includes friends from child care (78.1%), family members outside of the immediate family (53.1%), friends from church or other community-organized activities (46.9%), and neighborhood children (43.8%). Almost 89% of respondents of the 6- to 11-year-old group reported having friends outside the immediately family. When respondents in the 12- to 17-year-old group were asked if they thought their child's special health care need causes problems when making friends, nearly one-third of the respondents felt that it causes problems (31.4%). Forty percent (40.0%) of 35 respondents of children in the oldest age group indicated that their child had a friend that they would consider a "boyfriend" or "girlfriend".

Safety

Respondents were asked age group specific questions about safety that included questions about car and bike safety. Participants with children between newborn and 5 years of age were asked whether their child had a child-safety or booster seat for use in the respondent's vehicle, to which 97.4% said that they did. Ninety-two percent (91.7%) of those who used a booster or car seat for their child reported that the seat fit their child well. Three respondents (8.3%) said they did have a car or booster seat but the child had outgrown it. When asked if their child wore a seat belt when riding in a vehicle, 97.1% of respondents of 6- to 11-year-olds reported that their child did. Ninety-four percent (94.4%) of respondents of 12- to 17-year-olds stated that their child always wore a seat belt when riding in someone else's car and no one responded that their child "rarely" or "never" wore a seatbelt.

Respondents of children in the older age groups were asked if their child rode a bicycle and if so, whether their child wore a helmet. Fifty-one percent (51.4%) of respondents of the 6- to 11-year-old group reported that their child rode a bicycle and 83.3% indicated that their child was wearing a helmet when riding. For the 12- to 17-year-olds, respondents reported that 63.9% rode a bicycle. For that age group, the rate for wearing a helmet was 60.9% (all or most of the time), while 39.1% of the respondents reported that their child rarely or never wore a helmet when riding a bike.

Television and Computer Use

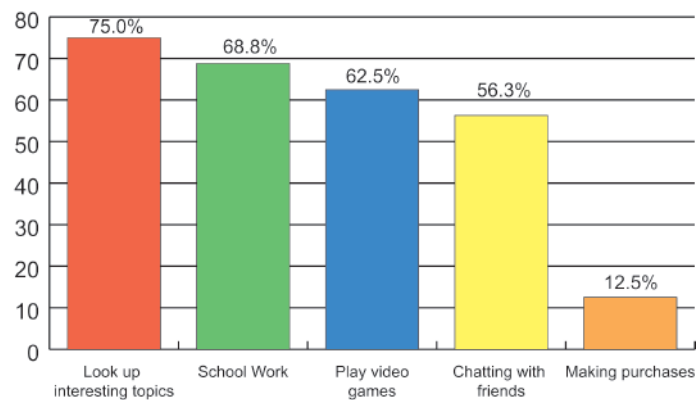
Survey participants were asked about their children’s television and computer use as this information may have implication on health lifestyle variables, such as exercising and playing with peers (Subrahmanvam, Kraut, Greenfield, and Gross, 2000). Of the respondents of the newborn to 5-year-old age group, 10.5% reported that their child did not watch any television on an average day; 7.9% reported that their child watches 30 to 45 minutes a day; 57.9% watch between one and two hours per day, and 23.7% were reported as watching two and a half to six hours of television on an average day. For the 6- to 11- year-old age group, 8.3% of respondents reported their child watching 30 to 45 minutes on average, 61.1% watch between one and two hours per day, and 30.6% were reported to watch between two and a half and six hours of television on an average day. Table 8 outlines hours of television watched a day by each age group.

Table 8. Anticipated challenges in the transition process into adolescence, for children under 11 years of age

	Newborn to 5 year-olds %	6 to 11 year-olds %
Did not watch any television	10.5	-
30 to 45 minutes daily	7.9	8.3
1 to 2 hours daily	57.9	61.1
Two and a half to six hours daily	23.7	30.6

Respondents of children between 12 and 17 years of age were asked about their children’s internet use. Almost 89% (88.6%) stated that their child uses the computer/internet. When asked about the purpose of using the computer/internet, 75.0% reported that their child uses the computer to look up interesting topics, 68.8% use it for school work, and 62.5% play video games on the computer. Other activities were chatting with friends (56.3%) and making purchases (12.5%). Figure 22 outlines computer activities of 12- to 17-year-olds.

Figure 22. Computer/Internet use, for children 12 to 17 years of age†



† Percentages total more than 100% as participants could give more than one answer.



Recommendations



Recommendations

The findings of this survey illustrate the health status and needs of children with disabilities and special health care needs and their families. Of particular interest are the needs regarding emotional health of children, their transition from pediatric care to community-based adult health care, barriers to receiving health care, and family supports. The following recommendations are based on the information collected for this HDWD childhood survey. Despite the fact that the data is not population-based, this report illustrates that children with disabilities and special health care needs and their families have a variety of needs that are currently unsatisfactorily addressed or not at all addressed by the health care and social services systems. This report is one of the first of its kind in Delaware and should, therefore, be widely distributed and studied by public and private agencies and health care providers who are involved in providing care and services to this specific group and the population as a whole.

The recommendations provided offer guidance and insight into helping children with disabilities and special health care needs and their families lead healthier lives.

Many of the following recommendations can be accomplished within services and programs already available to the public. Recommendations provided need to be coordinated across health care providers, human service providers, advocacy agencies, and schools that work with children with disabilities and special health care needs and their families. All of the recommendations need to be implemented with input by and approval of children with disabilities and special health care needs and/or their care providers/families.

1. Support child mental health services and initiatives offered by state and private agencies and organizations to ensure that all initiatives and programs are provided statewide and are readily accessible to children with disabilities and special health care needs through a coalition of state, private, and not-for-profit organizations.
2. Support the effective implementation of respite care programs for families of children with disabilities and special health care needs between the ages of newborn to 21 years and educate families about their rights to receive respite services through a coalition of state government, family advocates and provider services to address the overwhelming need for respite services for families of children with disabilities and special health care needs.
3. Develop and implement health education and prevention programs that are inclusive of children with disabilities and special health care needs.
4. Support existing health education and prevention programs in becoming and being inclusive of children with special health care needs.

5. Support schools in including children with disabilities in inclusive settings for at least 80% of their instructional time.
6. Develop and provide culturally responsive healthy lifestyle education materials about topics such as healthy eating, exercise, and reduced TV time, to parents of all children, including children with disabilities and special health care needs.
7. Develop and provide culturally responsive health education materials about topics such as preventive health care, routine check-ups, and vaccines for children, to parents of all children, including children with disabilities and special health care needs.
8. Develop and implement safety education activities for children and adolescents that are inclusive of children with disabilities and special health care needs and enable existing safety education activities to become and be inclusive of children with disabilities and special health care needs.
9. Address barriers to access of medical and social services through a coalition of state, private, and not-for-profit organizations and legislation and educate providers and families on their rights, responsibilities and opportunities. Barriers that need to be addressed are: a) provider barriers, such as lack of knowledge regarding disabilities and special health care needs and inaccessible facilities and equipment, b) client and family barriers, such as lack of knowledge of the medical and service systems, and c) systems barriers, such as inadequate funding mechanisms and services.
10. Provide education to health care providers and families regarding the importance of a medical home for children with disabilities and special health care needs.
11. Develop and implement transition services for children with disabilities and special health care needs and their families that help and support school, employment, and medical transitions.
12. Provide education to health care providers and families regarding the importance of early transition preparation so that children and adolescents with disabilities and special health care needs experience a smooth transition from the pediatric to the adult health care system.
13. Provide education to school personnel, educational transition coordinators, and families regarding the importance of adequate preparation for children and adolescents with disabilities and special health care needs to enable them to experience a smooth transition from school into the workforce or higher education.



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Appendix

Medical Diagnoses*

	Responses	
	N	Percent
Attention Deficit Disorder/ Attention Deficit Hyperactivity Disorder	26	6.8%
AIDS/HIV	1	0.3%
Autism	37	9.7%
Asthma	26	6.8%
Childhood Cancer	1	0.3%
Cerebral Palsy	26	6.8%
Chromosomal anomaly	12	3.2%
Depression	9	2.4%
Down Syndrome	10	2.6%
Anxiety/and or other emotional problems	24	6.3%
Developmental Delays	69	18.2%
Diabetes	5	1.3%
Eye/Vision impairment (blindness)	43	11.3%
Hearing impairment (deafness)	11	2.9%
Heart disease	6	1.6%
Hypertension/High blood pressure	1	0.3%
Lung disease/Emphysema	6	1.6%
Muscular Dystrophy	2	0.5%
Osteoporosis	1	0.3%
Stroke	1	0.3%
Traumatic Brain Injury	4	1.1%
Other	59	15.5%
Total	380	100.0%

* Respondents could identify more than one medical diagnosis.



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