

Foreword

The three main functions of the Erie County Public Health “System” are to conduct community health assessments, develop policy from that assessment data, and to assure our citizenry that we are meeting our mission and vision statements.

The public health system is comprised of numerous entities that are involved in providing care and support to individuals and population spectrums.

The Children with Special Needs Health Assessment Report is our first attempt to collect data from the parents/guardians of children in this specific group. This survey process has yielded results that will provide us with the data necessary to apply for grants in order to address those issues in this assessment that are deemed to be negatively impacting Quality of Life. The data collected is a representation of children ages 0-21 identified as having Special Needs in Erie County. This data, as an example, will be used to support our policies and bring our parents/guardians the necessary tools they need to eliminate, or at least reduce, the barriers they face when raising a child with Special Needs.

This assessment is special. The results are uniquely tied to Erie County. Our challenge now is to get this information out to our communities and to work on improving Quality of Life for these children and their families.

Your participation in this project is invaluable. On behalf of the Erie County Board of Health and the Erie County Board of Developmental Disabilities, thank you for caring about our current status and ways that we can work together for improvement.

Sincerely,



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Children with Special Needs: Methods

Methods

Overview

This report provides an overview of Erie County children with special needs who participated in a survey during 2011. The findings are based on self-administered surveys using a structured questionnaire. The Erie County Board of Developmental Disabilities collected the data. The Erie County Health Department and Hospital Council of Northwest Ohio helped with data collection, guided the health assessment process and integrated sources of primary and secondary data into the report.

Design

Written surveys were sent in the mail to 620 Erie County households of children with special needs as identified through programs of the Board of Developmental Disabilities, Jobs & Family Services, and the Northpoint Educational Service Center. A total of 139 households (22%) participated in the survey. Letters were sent from the agency the special needs child was enrolled in. Each family only received one survey, if they were serviced with programs from multiple agencies. If two or more children in a family had special needs, they were asked to report fill out the survey for the child whose birthday comes next in calendar year.

Instrument Development

National surveys such as the U.S. Department of Health & Human Services' *National Survey of Children with Special Needs*, the Child and Adolescent Health Measurement Initiative's *National Survey of Children's Health*, and the CDC's *Behavioral Risk Factor Surveillance System* (BRFSS) were used as a baseline for survey questions.

Limitations

The results of this survey cannot be generalized to the entire population of Erie County children with special needs, as a random sampling method was not used. Having a large sample size (n=139) allows for inferences to be made regarding the data outcomes. However, if any important difference existed between the respondents and the non-respondents regarding the questions asked, this would represent a threat to external validity of the results.

Children with Special Needs: Executive Summary

Health & Functional Status

Approximately 40% of parents reported their child had an emotional, developmental or behavioral problem which needed treatment or counseling. 54% of parents reported their child needed or used medication. 52% of parents reported their child had a developmental delay. 13% of parents reported their child was on a special diet ordered by the doctor.

Health Insurance

In 2011, 10% of Erie County parents reported there was a time in the past year their child was not covered by health insurance. 49% of parents reported their child's insurance usually covers services that meet their needs.

Access and Utilization

In 2011, 27% of Erie County parents had transportation issues when their child needed to get to school or therapy. More than half (59%) of parents reported they needed to go outside of Erie County to get health care services for their child. 96% of parents usually took their child to a doctor's office for health care.

Family Functioning

In 2011, 43% of parents reported they or other family members provide care or support related to their child's identified disability around the clock. 26% of parents reported they or a family member had to stop working because of their child's health condition(s). 55% of parents rated their mental and emotional health as excellent or very good.

Care Coordination

In 2011, 17% of parents reported they could use extra help arranging or coordinating their child's care. The majority (91%) of parents arranges or coordinates the care for their child. 31% of parents reported that the doctors usually included them in their child's care.

Children with Special Needs Sample Demographic Profile*

Variable	2011 Survey Sample*
Child's Age	
0-2 years	20.8%
3-5 years	20.1%
6-11 years	18.8%
12-18 years	27.3%
19 & over	13.0%
Child's Race / Ethnicity	
White	82.5%
Black or African American	4.4%
Mixed race/other	10.2%
Hispanic Origin (may be of any race)	2.9%
Parent Education	
Less than High School Diploma	4.5%
High School Diploma	25.4%
Some college/ College graduate	70.1%
Parent Income	
\$14,999 and less	21.1%
\$15,000 to \$24,999	8.3%
\$25,000 to \$49,999	34.5%
\$50,000 to \$74,999	15.8%
\$75,000 or more	20.3%

* The percents reported are the actual percent within each category who responded to the survey. Percents may not add to 100% due to missing data (non-responses).

Erie County Board of Developmental Disabilities: Age Groups Served

- ❖ Ages 0-2 (23%)
- ❖ Ages 3-5 (8%)
- ❖ Ages 6-11 (12%)
- ❖ Ages 12-18 (11%)
- ❖ Ages 19 and over (46%)

(Source: Erie County Board of Developmental Disabilities, Dec 2011)

Children with Special Needs: Health and Functional Status

Key Findings

Approximately 40% of parents reported their child had an emotional, developmental or behavioral problem which needed treatment or counseling. 54% of parents reported their child needed or used medication. 52% of parents reported their child had a developmental delay. 13% of parents reported their child was on a special diet ordered by the doctor.

Health and Functional Status

- ◆ Approximately 40% of parents reported their child had an emotional, developmental or behavioral problem which needed treatment or counseling.
- ◆ 54% of Erie County parents reported their child needed or used medications that were prescribed by a doctor, other than vitamins.
- ◆ About one-third (33%) of parents reported their child had one or more of the following allergies:
 - Pollen (4%)
 - Mold (4%)
 - Grasses (3%)
 - Ragweed (3%)
 - Milk (3%)
 - House dust mites (2%)
 - Soy (2%)
 - Peanuts (<1%)
 - Dogs (<1%)
 - Cats (<1%)
- ◆ 13% of Erie County parents reported their child was on a special diet as ordered by the child's doctor. An additional 5% had their child on a special diet by parent's choice.
- ◆ Erie County parents reported a doctor had told them their child had the following:
 - Developmental delay (52%)
 - Delayed speech, apraxia (speech issues) (50%)
 - Learning disability (40%)
 - Autism (31%)
 - ADD/ADHD (25%)
 - Asthma (16%)
 - Depression, anxiety, or emotional problems (15%)
 - Allergies (15%)
 - Behavioral health issue (15%)
 - Other disability or issue (12%)
 - Epilepsy or other seizure disorder (9%)
 - Down syndrome (9%)
 - Heart problems (9%)
 - Cerebral palsy (7%)
 - Arthritis or other joint problems (7%)
 - Migraine or frequent headaches (5%)
 - Cystic fibrosis (2%)
 - Hydrocephalus (2%)
 - Spina bifida (2%)
- ◆ Almost half (45%) of parents reported their child had been to the emergency room in the past year. 13% had been three or more times.
- ◆ Over one-quarter (28%) of parents reported their child had been to urgent care in the past year. 4% had been three or more times.
- ◆ Just over one-third (35%) of parents reported that their child's identified disability always affects their ability to do things other children their age do. 11% reported it never affects their child.
- ◆ About one in eleven (9%) parents reported their child's health care needs change all of the time. 26% reported they changed once in a while and 53% reported they were usually stable.

Erie County Board of Developmental Disabilities Diagnoses

- ❖ Erie County special needs population of birth through adulthood had been diagnosed with the following:
 - Developmental delay (36%)
 - Autism (9%)
 - ADD/ADHD (7%)
 - Cerebral Palsy (6%)
 - Epilepsy or other seizure disorder (5.5%)
 - Down Syndrome (4%)
 - Depression, anxiety, or emotional problems (1.5%)

(Source: Erie County Board of Developmental Disabilities, Dec 2011)

- Other (8%)

Children's Health and Functional Status

- ◆ One-third (33%) of parents reported their child wore glasses and 9% has difficulty seeing even when wearing glasses or contact lenses.
- ◆ 5% of parents reported their child used a hearing device and 4% has difficulty hearing even when using the hearing device.
- ◆ Almost one-quarter (22%) of children with special needs were obese and an additional 9% were overweight. 11% were underweight.
- ◆ Erie County parents reported their child had the following difficulties:
 - Breathing or other respiratory problems, such as wheezing, or shortness of breath (19%)
 - Swallowing, digesting food, or metabolism (18%)
 - Repeated or chronic physical pain, including headaches (11%)
 - Blood circulation (4%)
- ◆ Compared to other children their age, parents reported their child had difficulties with the following:
 - Speaking, communicating, or being understood (71%)
 - Learning, understanding, or paying attention (65%)
 - Taking care of themselves, such as eating, dressing and bathing (54%)
 - Making and keeping friends (39%)
 - Coordination or moving around, such as crawling, moving arms or legs, walking, running, (33%)
 - With behavior problems (33%)
 - With feeling anxious or depressed (26%)
 - Using their hands, such as grabbing objects, holding a cup, using a fork, etc. (19%)
- ◆ Parents reported their child missed school for the following reasons on average in the past year: illness (5.6 days/year), medical appointments (2.1 days/year), injury (1.8 days/year), and behavior (0.4 times/year).
- ◆ 38% of parents reported that because of a physical, mental or emotional problem, their child has difficulty finding a program that offers any activity, such as sports, social groups, compared to other children their age.
- ◆ Erie County parents of children ages 5 and older reported their child had difficulties with the following routine tasks:
 - Bathing or showering (40%)
 - Dressing (29%)
 - Eating (20%)
 - Using the toilet, including getting to the toilet (16%)
 - Getting in and out of bed or chairs (10%)
 - Getting around inside the home (7%)

National Survey of Children with Special Health Care Needs

- ❖ 53% of U.S. parents reported their child with special health care needs had allergies.
- ❖ 39% of U.S. parents reported their child with special health care needs had asthma.
- ❖ 30% of U.S. parents reported their child with special health care needs had ADD/ADHD.
- ❖ 21% of U.S. parents reported their child with special health care needs had depression, anxiety, or emotional problems.
- ❖ 42% of U.S. parents reported their child with special needs had an emotional, developmental, or behavioral problem that needed treatment or counseling.
- ❖ 35% of U.S. parents reported their child with special needs ability to do things that other children can do was never affected.
- ❖ 78% of U.S. parents reported their child with special needs needed or used medications that were prescribed by a doctor.

(Source: National Survey of Children with Special Health Care Needs Chartbook 2005-2006)

Children with Special Needs: Health Insurance

Key Findings

In 2011, 10% of Erie County parents reported there was a time in the past year their child was not covered by health insurance. 49% of parents reported their child's insurance usually covers services that meet their needs.

Health Insurance

- ◆ One in ten (10%) parents reported there was a time in the past year that their child was not covered by any health insurance.
- ◆ Erie County parents reported their child had the following types of health insurance: private insurance (31%), Medicaid (26%), multiple types of insurance including private insurance (15%), multiple types of governmental insurance (15%), BCMH (4%), Medicare (2%), single service plan (2%) and others (5%).

National Survey of Children with Special Health Care Needs

- ❖ 91% of U.S. parents reported their child with special needs was covered by health insurance.
- ❖ 59% of U.S. parents reported their child with special needs had private health insurance.
- ❖ 29% of U.S. parents reported their child with special needs used special education services

(Source: National Survey of Children with Special Health Care Needs
Charitbook 2005-2006)

Adequacy of Health Insurance

- ◆ Almost half (49%) of parents reported that their child's health insurance usually offers benefits or covers services that meet his/her needs.
- ◆ 25% of parents reported that their child's insurance did not allow him/her to get the health care services he/she needed. The following needed services/equipment were not always covered by insurance: physicians (13%), therapies (12%), medications (9%), adaptive equipment (7%), and medical supplies (4%).

Child's insurance covered the following:	Yes	No	Don't know
Well-child visits	86%	7%	7%
Doctor visits	95%	5%	<1%
Hospital stays	90%	4%	6%
Dental	79%	18%	3%
Vision	74%	23%	3%
Mental health	65%	12%	23%
Prescription coverage	92%	7%	1%
Immunizations	84%	10%	6%
Physical therapy	67%	7%	26%
Occupational therapy	66%	8%	26%
Speech therapy	66%	8%	26%
Specialty visits	71%	8%	22%
Home care	33%	14%	53%
Respite care	24%	16%	60%

Children with Special Needs: Access & Utilization

Key Findings

In 2011, 27% of Erie County parents had transportation issues when their child needed to get to school or therapy. More than half (59%) of parents reported they needed to go outside of Erie County to get health care services for their child. 96% of parents usually took their child to a doctor's office for health care.

Access and Utilization

- ◆ In the past year, three-fourths (75%) of Erie County parents reported that someone in the household received assistance from one of the following programs: Supplemental Security Income (SSI) (36%), Help Me Grow/Early Intervention Specialists (34%), Benefits from SNAP/food stamps (28%), free or reduced cost breakfast or lunches at school (28%), WIC program (25%), Bureau for Children with Medical Handicaps (24%), cash assistance from a welfare program (4%), subsidized childcare through Erie County Job & Family Services (4%).
- ◆ 59% of Erie County parents reported they needed to go outside of Erie County to get health care services for their child.
- ◆ 51% of parents reported they travel greater than 45 miles for health care needs for their child, decreasing to 40% of those with incomes less than \$25,000.
- ◆ Parents reported going to the following places outside of Erie County for their child's health care needs: Cleveland (54%), Norwalk (23%), Toledo (23%), Lorain (11%), Akron (8%), Westlake (6%), Bellevue (3%), and Cincinnati (2%).
- ◆ 60% of parents reported their child saw one to two different specialty doctors in the past year. 20% reported their child saw three to five specialists and 3% reported six or more.
- ◆ Parents reported their child usually goes to the following place for routine care: a doctor's office (96%), clinic or health center (7%), hospital outpatient department (4%), friend/relative (3%), internet (1%), school (1%) or some other place (1%).
- ◆ 19% of Erie County parents reported that in the past year they have delayed or gone without health care for their child.
- ◆ Erie County parents gave the following reasons for delaying or not getting care for their child: type of care needed was not available in my area (9%), did not have enough money to pay the health care provider (8%), appointment conflict with other responsibilities at home or at work (7%), type of care was not covered by my health plan (6%), transportation (5%), and could not get an appointment soon enough (5%).
- ◆ Over one-quarter (27%) of parents had transportation issues when their child needed to get to school or therapy. The following issues were reported: could not afford gas (12%), no driver's license (11%), and no car (10%).
- ◆ Two-thirds (66%) of respondents said that their child has an Individual Education Plan (IEP). Another 24% reported that their child is not in school yet.
- ◆ The following were significant problems the child had at school:
 - Paying attention in class (44%)
 - Understanding instructional materials (40%)
 - Communicating with teacher and other students (39%)
 - Following rules or controlling their behavior (30%)

National Survey of Children with Special Health Care Needs

- ❖ 23% of U.S. parents reported their child with special needs used physical, speech, or occupational therapy.
- ❖ 16% of U.S. parents reported their child with special needs had at least one health care service they needed but did not receive.

(Source: National Survey of Children with Special Health Care Needs Chartbook 2005-2006)

Children with Special Needs: Access & Utilization

Specialists	Referred but did not go	Referred and went	Did not look/not applicable
Heart doctor (cardiologist)	0%	19%	81%
Ear, nose and throat doctor	1%	41%	58%
Endocrinologist	1%	10%	89%
Mental health doctor	2%	26%	72%
Cancer doctor	0%	2%	98%
Other specialist	4%	58%	38%

Child attends the following:	Yes	No, but interested	No, but not interested
Day care	15%	14%	71%
Day camp	7%	24%	69%
Sports	19%	28%	53%
Social groups	18%	33%	48%

National Survey of Children with Special Health Care Needs

- ❖ 33% of U.S. parents reported their child with special needs needed a referral in the past year and 21% had a problem getting a referral.
- ❖ 78% of U.S. parents reported their child with special needs used a doctor's office as their usual source of health care.
- ❖ 33% of U.S. parents reported their child with special needs used eye glasses or had vision problems.
- ❖ 5% of U.S. parents reported their child with special needs used hearing aids.

(Source: National Survey of Children with Special Health Care Needs Chartbook 2005-2006)

Children with Special Needs: Access & Utilization

Services	Needed services?	Received care?	Did not receive care?	Did not need services?
Routine preventive care	3%	61%	14%	22%
Specialty care	4%	51%	15%	30%
Preventive dental care	4%	44%	25%	27%
Other dental care	1%	22%	30%	47%
Prescription medications	3%	60%	13%	25%
Physical therapy	2%	34%	24%	40%
Occupational therapy	3%	42%	22%	33%
Speech therapy	4%	55%	12%	29%
Mental health care or counseling	2%	13%	35%	50%
Substance abuse treatment or counseling	2%	<1%	38%	59%
Home health care	1%	12%	32%	55%
Eyeglasses or vision	5%	37%	19%	39%
Hearing aids or hearing care	2%	7%	36%	55%
Mobility aids or devices (adaptive equipment)	3%	10%	35%	52%
Communication aids or devices	3%	3%	37%	57%
Medical supplies	2%	16%	30%	52%
Durable medical equipment (Kaiser-Wells or O.E. Meyer)	2%	14%	31%	53%
Dietician	3%	11%	33%	53%

Children with Special Needs: Family Functioning

Key Findings

In 2011, 43% of Erie County parents reported they or other family members provide care or support related to their child's identified disability around the clock. 26% of parents reported they or a family member had to stop working because of their child's health condition(s). 55% of parents rated their mental and emotional health as excellent or very good.

Impact on the Family

- ◆ In the past year, 20% of parents indicated that the family had to pay more than \$1,000 for their child's medical care. 4% paid \$5,000 or more and 36% paid nothing for their child's medical care.
- ◆ Parents paid out-of-pocket costs for the following services for their child:
 - Co-payments (52%)
 - Dental care (24%)
 - Vision care (19%)
 - Special foods (12%)
 - Adaptive equipment (12%)
 - Home modifications (4%)
- ◆ 43% of parents reported that they or other family members provide care or support related to their child's identified disability around the clock.
- ◆ Over one-quarter (26%) of parents reported that their child's health condition(s) caused financial problems for their family.
- ◆ Over one-quarter (26%) reported that they or other family members stopped working because of their child's health condition(s). An additional 23% have cut down on the hours they work because of their child's health.

National Survey of Children with Special Health Care Needs

- ◆ 20% of U.S. parents reported they paid more than \$1,000 in out-of-pocket costs for their child with special needs health care.
- ◆ 18% of U.S. parents reported their child's health condition(s) caused financial problems for the family.
- ◆ 24% of U.S. parents with a special needs child reported they had to quit or cut back their hours at work.

(Source: National Survey of Children with Special Health Care Needs Chartbook 2005-2006)

- Occupational therapy (4%)
- Mental health services (4%)
- Behavioral health (4%)
- Physical therapy (3%)
- Speech therapy (3%)

Parental Health

- ◆ About three-fifths (60%) of parents rated their health as excellent or very good, decreasing to 49% of parents with incomes less than \$25,000. 9% of parents had rated their health as fair.
- ◆ 55% of parents rated their mental and emotional health as excellent or very good.
- ◆ Parents reported they dealt with anxiety, stress, or depression in the following ways: talking to someone (71%), eating (33%), exercising (33%), doing hobbies (24%), and using medication (21%). 12% of parents reported they did not have anxiety, stress or depression.
- ◆ Parents reported that someone in their household had missed work due to their child approximately 6.2 days in the past year.

Services Needed by Parent or Other Family Member	Needed services	Received care	Did not receive care	Did not need services
Respite care	5%	11%	52%	32%
Genetic counseling	2%	8%	55%	35%
Mental health care or counseling	4%	19%	48%	29%

Children with Special Needs: Care Coordination

Key Findings

In 2011, 17% of parents reported they could use extra help arranging or coordinating their child's care. The majority (91%) of parents arranges or coordinates the care for their child. 31% of parents reported that the doctors usually included them in their child's care.

Care Coordination

- ◆ Parents reported the following individuals arranged or coordinated care for the child: parent (91%), Help Me Grow Service Coordinator/Early Intervention Specialist (11%), other family member (7%), therapist (7%), nurse (5%), someone else (5%), case manager (4%), guardian (3%), friend (3%), social worker (1%), and hospital discharge planner (1%).
- ◆ In the past year, 17% of Erie County parents felt that they could use extra help arranging or coordinating their child's care among the different health care providers or services.
- ◆ The Erie County Board of Developmental Disabilities provides service coordination to 75% of all eligible individuals in their program. *(Source: Erie County Board of Developmental Disabilities, Dec 2011)*
- ◆ Approximately half (49%) of Erie County parents were very satisfied with the communication among their child's doctors, school and/or team. 7% were very or somewhat dissatisfied.

Family Centered Care

- ◆ 45% of Erie County parents reported that their child's doctors and other health care providers always listen carefully to them.
- ◆ When asked how often in the past year did their child's doctors and other health care providers help you feel like a partner in their care, 53% of parents reported always, decreasing to 47% of those with incomes less than \$25,000.
- ◆ About one-third (31%) of parents reported that the doctors usually included the parents in their child's care, increasing to 37% of those with incomes less than \$25,000. Only 2% of parents reported their children's doctors never include them as a partner in their child's care.

Transition Issues

- ◆ Over one third (35%) of parents reported their health care providers have talked to them or their child about health care needs as their child becomes an adult.
- ◆ One quarter (25%) of parents reported someone had talked to them about how to obtain or keep some type of health insurance coverage as their child becomes an adult.
- ◆ 22% of parents reported their health care providers encourage their child to take responsibility for their health care needs in taking medications, understand their health or following medical advice.
- ◆ Parents reported a discussion about the following would be helpful to them: guardianship (19%), health insurance (19%), your child's health care needs (17%), and doctors who treat adults (14%).

Ease of Care

- ◆ Over one-fifth (22%) of parents reported they had difficulty trying to use services for their child's care.
- ◆ They reported the following difficulties: types of services their child needed were not available in the area (13%), long waiting lists (12%), did not have enough money to pay for services (11%), child was not eligible for the types of services needed (10%), and problems in communication with service providers (9%).

National Survey of Children with Special Health Care Needs

- ◆ 15% of U.S. parents reported their child with special needs thought they could use help arranging and coordinating care for their child.
- ◆ 24% of U.S. parents with a special needs child reported they were very satisfied with communication among their child's health care providers.

(Source: National Survey of Children with Special Health Care Needs Chartbook 2005-2006)

Children with Special Needs Health Assessment Information Sources

Source	Data Used	Website
U.S. Department of Health & Human Services, Health Resources & Services Administration, Maternal and Child Health Bureau. <i>The National Survey of Children with Special Health Care Needs Chartbook 2005-2006</i> . Rockville, Maryland.	<ul style="list-style-type: none"> ◆ Health and functional status ◆ Health care coverage ◆ Access and utilization ◆ Care coordination ◆ Family-centered care ◆ Impact on family ◆ Survey questions 	http://mchb.hrsa.gov/cshcn05/
Centers for Disease Control & Prevention. <i>Behavioral Risk Factor Surveillance System</i> . Atlanta, GA	<ul style="list-style-type: none"> ◆ Survey questions 	http://www.cdc.gov/brfss/questionnaires/questionnaires.htm

2011 Erie County Developmental Disability/ Special Health Care Needs Survey

Answers Will Remain Confidential!

We need your help! We are asking you to complete this survey and return it to us within the next 7 days. We have enclosed a \$2.00 bill as a “thank you” for your time. We have also enclosed a postage-paid envelope for your convenience.

This health survey is being sponsored by Erie County Board of Developmental Disabilities and the Erie County Health Department. If you have any questions or concerns, please contact Lisa Guliano by phone at (419) 502-4120 or email her at lguliano@eriecbdd.org.

You have been selected to complete this survey on your child who has a developmental disability and who is living with you. *If you have more than one child in this group living with you, please use the child whose birthday comes next in the calendar. If you have twins, please use the oldest of the twins.*

Instructions:

- Please complete the survey now rather than later.
- Please do NOT put your name on the survey. Your responses to this survey will be kept confidential. No one will be able to link your identity to your survey.
- Please be completely honest as you answer each question.
- Answer each question by selecting the response that best describes you or your child.

Thank you for your assistance. Your responses will help to make Erie County a healthier place for all of our residents.

Turn the page to start the survey →

Erie County Developmental Disability/Special Health Care Needs Survey

Demographics

1. How many people in each age group and gender are living in your household?

Age	Male	Female
Less than 1		
1-3		
4-5		
6-8		
9-11		
12-18		
19+ Years		

2. What is your child's birth date?

____/____/____
Month Day Year

3. What gestational age was your child born?

_____ Weeks

4. What is your child's gender?

- Male
- Female

5. How much does your child weigh without shoes?

POUNDS _____

- Don't know

6. How tall is your child without shoes?

FEET _____

INCHES _____

- Don't know

7. Which one of these groups would you say best represents your child's race? **(CHECK ALL THAT APPLY)**

- White
- Black or African American
- Multiracial
- Asian
- Native Hawaiian or Other Pacific Islander
- American Indian/Alaska Native
- Other (specify): _____

8. Is your child of Hispanic or Latino origin?

- Yes
- No

9. What is the highest grade or level of education attained by anyone in your household?

- Never attended school or only attended kindergarten
- Grades 1 through 8 (Elementary)
- Grades 9 through 11 (Some high school)
- Grade 12 or GED (High school graduate)
- College 1 year to 3 years (Some college or technical school)
- College 4 years or more (College graduate)
- Post graduate education (Masters or Doctorate degree)

10. What is your relationship to your child?

- Mother (biological, step, foster, adoptive)
- Father (biological, step, foster, adoptive)
- Grandparent
- Aunt/Uncle
- Other family member
- Other non-relative

11. What is your zip code? _____

12. At any time during the past 12 months, even for one month, did anyone in this household receive the following? **(CHECK ALL THAT APPLY)**

- Cash assistance from a state or county welfare program (OWF/Welfare)
- SNAP (food stamps)
- Benefits from Women, Infants, and Children (WIC) program
- Free or reduced cost breakfasts or lunches at school
- Supplemental Security Income (SSI)
- Subsidized childcare through Erie County JFS
- Bureau for Children with Medical Handicaps (BCMH)
- Help Me Grow/Early Intervention Specialist
- None of the above

Erie County Developmental Disability/Special Health Care Needs Survey

13. Is your gross annual household income (before taxes) from all sources...
- Less than \$10,000
 - \$10,000 to \$14,999
 - \$15,000 to \$19,999
 - \$20,000 to \$24,999
 - \$25,000 to \$34,999
 - \$35,000 to \$49,999
 - \$50,000 to \$74,999
 - \$75,000 to \$99,999
 - \$100,000 or more

Child Health and Functional Status

14. During the past 12 months, about how many days did your child miss school because of any of the following?
- _____ days missed to illness
 - _____ days missed to injury
 - _____ days missed to medical appointments
 - _____ days missed to transportation
 - _____ days missed to behavior
 - None
 - Did not go to school
 - Home schooled
15. During the past 12 months, how many times did your child visit a hospital emergency room?
- _____ number of visits
 - None
 - Don't know
16. During the past 12 months, how many times did your child visit an urgent care center?
- _____ number of visits
 - None
 - Don't know
17. Does child currently need or use medicine prescribed by a doctor, other than vitamins?
- Yes
 - No
 - Don't know

18. Does child have any kind of emotional, developmental or behavioral problem for which he/she needs treatment or counseling?
- Yes
 - No
 - Don't know
19. How often does your child's identified disability affect [his/her] ability to do things other children [his/her] age do?
- Never
 - Sometimes
 - Usually
 - Always
 - Don't know
20. Do your child's health care needs change all the time, change once in awhile or are usually stable?
- Child's health care needs change all the time
 - Child's health care needs change only once in a while
 - Child's health care needs are usually stable
 - None of the above
 - Don't know
21. Does your child wear glasses or contact lenses?
- Yes
 - No
 - Don't know
22. Does your child have any difficulty seeing even when wearing glasses or contact lenses?
- Yes
 - No
 - Don't know
23. Does your child use a hearing device?
- Yes
 - No
 - Don't know
24. Does your child have any difficulty hearing even when using a hearing device?
- Yes
 - No
 - Don't know

Erie County Developmental Disability/Special Health Care Needs Survey

25. Would you say (he/she) experiences any difficulty with any of the following? **(CHECK ALL THAT APPLY)**
- Breathing or other respiratory problems, such as wheezing or shortness of breath
 - Swallowing, digesting food, or metabolism
 - Blood circulation
 - Repeated or chronic physical pain, including headaches
 - None of the above
26. Compared to other children [his/her] age, would you say he/she experiences any difficulty with any of the following? **(CHECK ALL THAT APPLY)**
- Taking care of [himself/herself], such as eating, dressing and bathing
 - Coordination or moving around, such as crawling, moving arms or legs, walking, running, etc.
 - Using [his/her] hands, such as grabbing objects, holding a cup, using a fork, etc.
 - Learning, understanding, or paying attention
 - Speaking, communicating, or being understood
 - With feeling anxious or depressed
 - With behavior problems
 - Making and keeping friends
27. Because of a physical, mental or emotional problem, does your child 5 years old or older get help from another person with any of the following? **(CHECK ALL THAT APPLY)**
- I do not have a child 5 years old or older
 - Bathing or showering
 - Dressing
 - Eating
 - Getting in and out of bed or chairs
 - Using the toilet, including getting to the toilet
 - Getting around inside the home

28. To the best of your knowledge, does your child currently have any of the following? **(CHECK ALL THAT APPLY)**
- Asthma
 - Attention Deficit Disorder (ADD) or Attention Deficit Hyperactive Disorder (ADHD)
 - Autism or Autism Spectrum Disorder (ASD)
 - Down Syndrome
 - Developmental disability
 - Depression, anxiety, an eating disorder, or other emotional problems
 - Diabetes
 - Heart problems, including congenital heart disease
 - Blood problems, such as anemia or sickle cell disease (This does not include sickle cell trait.)
 - Cystic Fibrosis
 - Cerebral Palsy
 - Muscular Dystrophy
 - Epilepsy or other seizure disorder
 - Migraine or frequent headaches
 - Arthritis or other joint problems
 - Allergies
 - Learning disability
 - Hydrocephalus
 - Spina bifida
 - Behavioral health issues
 - Delayed speech, apraxia (speech issues)
 - Other: _____
29. Because of a physical, mental, or emotional problem, does your child now have any difficulty finding a program that offers any activity, such as sports, social groups for your child, compared to other children their age?
- Yes
 - No
 - Don't know

Erie County Developmental Disability/Special Health Care Needs Survey

30. Has a health professional ever told you that your child had any of the following allergies?

(CHECK ALL THAT APPLY)

- Peanuts
- Wheat
- Soy
- Milk
- Eggs
- Bees
- Strawberries
- Kiwi
- Watermelon
- Gluten
- Red dye
- Pollen
- Grasses
- Ragweed
- Fungi
- Mold
- House dust mites
- Dogs
- Cats
- Other _____
- Yes, and my child has an Epi-pen for the allergy
- None of the above

31. Is your child following a special diet?

- Child is not on a special diet
- Yes, the diet was ordered by the child's doctor
- Yes, the diet was the parent's choice

32. What transportation issues do you have when your child needs to get to school or therapy?

(CHECK ALL THAT APPLY)

- No car
- No driver's license
- Can't afford gas
- Disabled
- Car does not work
- No car insurance
- Other car issues/expenses
- I do not have any transportation issues

Access to Care - Use of Services and Unmet Needs

33. What kind of place do you usually go to when your child needs routine care?

- My child does not have usual place
- Doctor's office
- Hospital emergency room
- Hospital outpatient department
- Clinic or health center
- School (Nurse's office, athletic trainer's office, etc.)
- Friend/relative
- Internet
- Some other place
- Does not go to one place most often
- Don't know

34. In the past 12 months, have you needed to go outside of Erie County to get health care services for your child?

- Yes
- No

35. How far do you travel for health care needs for your child?

- Less than 45 miles
- Greater than 45 miles
- Don't know

Erie County Developmental Disability/Special Health Care Needs Survey

36. Outside of Erie County, where do you go for any sort of health care needs for your child? **(CHECK ALL THAT APPLY)**

- Akron
- Cincinnati
- Cleveland
- Columbus
- Lorain
- Norwalk
- Toledo
- Other: _____

37. How many different specialty doctors did your child see during the past 12 months?

- None
- 1-2 specialty doctor(s)
- 3-5 specialty doctors
- 6 or more specialty doctors
- Don't know

38. Have you looked for any of the following specialists for your child?

Heart doctor?	<input type="checkbox"/> Referred, but did not go	<input type="checkbox"/> Referred and went	<input type="checkbox"/> Did not look/Not applicable
Ear, Nose and Throat doctor?	<input type="checkbox"/> Referred, but did not go	<input type="checkbox"/> Referred and went	<input type="checkbox"/> Did not look/Not applicable
Endocrinologist?	<input type="checkbox"/> Referred, but did not go	<input type="checkbox"/> Referred and went	<input type="checkbox"/> Did not look/Not applicable
Mental Health Doctor?	<input type="checkbox"/> Referred, but did not go	<input type="checkbox"/> Referred and went	<input type="checkbox"/> Did not look/Not applicable
Cancer Doctor?	<input type="checkbox"/> Referred, but did not go	<input type="checkbox"/> Referred and went	<input type="checkbox"/> Did not look/Not applicable
Other specialist?	<input type="checkbox"/> Referred, but did not go	<input type="checkbox"/> Referred and went	<input type="checkbox"/> Did not look/Not applicable

39. In past 12 months, have you delayed or gone without health care for your child? Health care is defined as other kinds of care like dental care, mental health services, physical, occupational, or speech therapies.

- Yes
- No
- Don't know

40. Why did you delay or not get health care for your child? **(CHECK ALL THAT APPLY)**

- My child did get all health care they needed
- Couldn't get through to health care provider's office on the telephone
- Couldn't get an appointment soon enough
- Clinic or doctor's office was not open when I could get there
- Transportation
- Didn't have enough money to pay the health care provider
- Type of care needed was not available in my area
- Health care provider did not have the skills needed
- Type of care was not covered by my health plan
- Could not get approval from my health plan or doctor
- Had to wait too long to see the health care provider
- Had no phone to call to get an appointment
- Could not get a referral from my primary care physician
- Language, communication or cultural problems with the health care provider
- Appointments conflict with other responsibilities at home or at work

41. An Individual Education Plan (IEP) is a written plan for a child with special needs, describing what that child will learn. Does your child now have an Individual Education Plan?

- My child is not in school yet
- Yes
- No

Erie County Developmental Disability/Special Health Care Needs Survey

42. Does your child have significant problems at school with any of the following? **(CHECK ALL THAT APPLY)**

- I do not have a child who goes to school
- Understanding instructional materials
- Paying attention in class
- Following rules or controlling their behavior
- Communicating with teacher and other students
- None of the above

43. Does your child with special needs attend the following?

Day care	<input type="checkbox"/> Yes	<input type="checkbox"/> No, but interested	<input type="checkbox"/> No, but not interested
Day camp	<input type="checkbox"/> Yes	<input type="checkbox"/> No, but interested	<input type="checkbox"/> No, but not interested
Sports	<input type="checkbox"/> Yes	<input type="checkbox"/> No, but interested	<input type="checkbox"/> No, but not interested
Social groups	<input type="checkbox"/> Yes	<input type="checkbox"/> No, but interested	<input type="checkbox"/> No, but not interested

44. In past 12 months, was there any time when your child needed the following services: **(CHECK ALL THAT APPLY)**

Routine preventive care:	<input type="checkbox"/> Needed services?	<input type="checkbox"/> Received care?	<input type="checkbox"/> Did not receive care?
Specialty care:	<input type="checkbox"/> Needed services?	<input type="checkbox"/> Received care?	<input type="checkbox"/> Did not receive care?
Preventive dental care:	<input type="checkbox"/> Needed services?	<input type="checkbox"/> Received care?	<input type="checkbox"/> Did not receive care?
Other dental care:	<input type="checkbox"/> Needed services?	<input type="checkbox"/> Received care?	<input type="checkbox"/> Did not receive care?
Prescription medications:	<input type="checkbox"/> Needed services?	<input type="checkbox"/> Received care?	<input type="checkbox"/> Did not receive care?
Physical Therapy:	<input type="checkbox"/> Needed services?	<input type="checkbox"/> Received care?	<input type="checkbox"/> Did not receive care?
Occupational Therapy:	<input type="checkbox"/> Needed services?	<input type="checkbox"/> Received care?	<input type="checkbox"/> Did not receive care?
Speech Therapy:	<input type="checkbox"/> Needed services?	<input type="checkbox"/> Received care?	<input type="checkbox"/> Did not receive care?
Mental health care or counseling:	<input type="checkbox"/> Needed services?	<input type="checkbox"/> Received care?	<input type="checkbox"/> Did not receive care?
Substance abuse treatment or counseling:	<input type="checkbox"/> Needed services?	<input type="checkbox"/> Received care?	<input type="checkbox"/> Did not receive care?
Home health care:	<input type="checkbox"/> Needed services?	<input type="checkbox"/> Received care?	<input type="checkbox"/> Did not receive care?
Eyeglasses or vision:	<input type="checkbox"/> Needed services?	<input type="checkbox"/> Received care?	<input type="checkbox"/> Did not receive care?
Hearing aids or hearing care:	<input type="checkbox"/> Needed services?	<input type="checkbox"/> Received care?	<input type="checkbox"/> Did not receive care?
Mobility aids or devices (adaptive equipment):	<input type="checkbox"/> Needed services?	<input type="checkbox"/> Received care?	<input type="checkbox"/> Did not receive care?
Communication aids or devices:	<input type="checkbox"/> Needed services?	<input type="checkbox"/> Received care?	<input type="checkbox"/> Did not receive care?
Medical supplies:	<input type="checkbox"/> Needed services?	<input type="checkbox"/> Received care?	<input type="checkbox"/> Did not receive care?
Durable medical equipment (Kaiser-Wells or O.E. Meyer):	<input type="checkbox"/> Needed services?	<input type="checkbox"/> Received care?	<input type="checkbox"/> Did not receive care?
Dietician:	<input type="checkbox"/> Needed services?	<input type="checkbox"/> Received care?	<input type="checkbox"/> Did not receive care?

45. Which of the following problems have you had getting adaptive equipment for your child? **(CHECK ALL THAT APPLY)**

- Child does not require any adaptive equipment
- There were no problems getting adaptive equipment
- Medicaid process is too slow
- Denial of medical coverage
- Insurance does not cover it
- Need multiple pieces of equipment but only able to get one

Erie County Developmental Disability/Special Health Care Needs Survey

Care Coordination

46. Who arranges or coordinates your child's care?
(CHECK ALL THAT APPLY)
- Parent
 - Guardian
 - Other family member
 - Friend
 - Nurse
 - Therapist
 - Social worker
 - Hospital discharge planner
 - Case manager
 - Help Me Grow Service Coordinator/Early Intervention Specialist
 - Someone else
47. During the past 12 months, have you felt that you could have used extra help arranging or coordinating your child's care among these different health care providers or services?
- Yes
 - No
 - Don't know
48. Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with the communication among your child's doctors, school and/or team?
- Very satisfied
 - Somewhat satisfied
 - Somewhat dissatisfied
 - Very dissatisfied
 - No communication needed or wanted
 - Don't know

Family Centered Care

49. In the past 12 months, how often did your child's doctors and other health care providers listen carefully to you?
- Never
 - Sometimes
 - Usually
 - Always

50. In the past 12 months, how often did your child's doctors and other health care providers help you feel like a partner in [his/her] care?
- Never
 - Sometimes
 - Usually
 - Always

Transition Issues

51. Have your child's doctors or other health care providers talked with you or your child about [his/her] health care needs as he/she becomes an adult? (*ages 12-17 only*)
- Yes
 - No
 - Don't know
52. Eligibility for health insurance often changes as children reach adulthood. Has anyone discussed with you how to obtain or keep some type of health insurance coverage as your child becomes an adult? (*ages 12-17 only*)
- Yes
 - No
 - Don't know
53. How often do your child's doctors or other health care providers encourage him/her to take responsibility for [his/her] health care needs in taking medication, understanding [his/her] health or following medical advice? (*5-17 only*)
- Never
 - Sometimes
 - Usually
 - Always
 - Don't know
54. Would a discussion about any of the following be helpful to you? **(CHECK ALL THAT APPLY)**
- Doctors who treat adults
 - Your child's health care needs
 - Health insurance
 - Guardianship
 - Other: _____
 - None of the above

Erie County Developmental Disability/Special Health Care Needs Survey

Ease of Service

55. Thinking about your child's needs and all the services that he/she needs, have you had any difficulties trying to use these services during the past 12 months?
- Yes
 - No
 - Don't know
56. Did you have any difficulties because of the following reasons? **(CHECK ALL THAT APPLY)**
- Could not get information needed
 - Too much paperwork was required
 - Didn't have enough money to pay for the services
 - Transportation
 - Couldn't get services when needed
 - Long waiting lists
 - Problems in communication between service providers
 - Language, communication or cultural problems with service providers
 - Couldn't find service providers who had the skills your child needed
 - Types of services your child needed were not available in your area
 - Types of services your child needed were available but he/she was not eligible
 - Types of services your child needed were available but he/she used up all eligible benefits
 - Didn't have time to figure it all out
 - None of the above

Health Insurance

57. During the past 12 months, was there any time when your child was not covered by any health insurance?
- Yes
 - No
 - Child was always covered by insurance

58. During the past 12 months, what kind of health coverage did your child have?
- Child did not have insurance
 - Medicaid (CareSource, Wellcare)
 - Medicare
 - SCHIP
 - Medigap
 - Military
 - Private insurance
 - Single service plan (dental, vision, prescriptions, etc.)
 - BCMH
 - Other _____

59. Does your child have insurance that covers the following:

Well child visits?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
Doctor visits?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
Hospital stays?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
Dental?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
Vision?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
Mental health?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
Prescription coverage?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
Immunizations?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
Physical therapy?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
Occupational therapy?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
Speech therapy?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
Specialty visits?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
Home care?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
Respite care?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know

Erie County Developmental Disability/Special Health Care Needs Survey

Adequacy of Health Care Coverage

- 60. Does your child's health insurance offer benefits or cover services that meet [his/her] needs?
 - Never
 - Sometimes
 - Usually
 - Always
 - Don't know
- 61. Does your child's health insurance coverage allow him/her to get the health care services he/she needs? **(CHECK ALL THAT APPLY)**
 - Yes
 - No, not all physicians that are needed are covered
 - No, not all therapies that are needed are covered
 - No, not all medications that are needed are covered
 - No, not all adaptive equipment that are needed are covered
 - No, not all medical supplies that are needed are covered

Impact on the Family

- 62. During the past 12 months, how much would you say that the family paid for your child's medical care? *Do not include health insurance premiums or costs that were or will be reimbursed by insurance or another sources. Do include out-of-pocket payments for all types of health-related needs such as co-payments, dental or vision care, medications, special foods, adaptive equipment, home modifications, and any kind of therapy.*
 - Nothing, \$0
 - Less than \$250
 - \$250 to \$500
 - More than \$500, but less than \$1,000
 - \$1,000 to \$5,000
 - More than \$5,000

- 63. During the past 12 months, what has the family paid out-of-pocket for your child's health related-needs? **(CHECK ALL THAT APPLY)**
 - Have not had to pay out-of-pocket costs
 - Co-payments
 - Dental care
 - Vision care
 - Special foods
 - Adaptive equipment
 - Home modifications
 - Physical therapy
 - Occupational therapy
 - Speech therapy
 - Mental health services
 - Behavioral health
- 64. How many hours per week do you or other family members spend providing care or support related to your child's identified disability?
_____ hours per week
 - Less than one hour
 - Around the clock
 - Don't know
- 65. Have your child's health condition(s) caused financial problems for your family?
 - Yes
 - No
 - Don't know
- 66. Have you or other family members stopped working because of your child's health condition(s)?
 - Yes
 - No
 - Don't know
- 67. Not including the family members who stopped working, have you or other family members cut down on the hours you work because of your child's health?
 - Yes
 - No
 - Don't know

Erie County Developmental Disability/Special Health Care Needs Survey

Parental Health

68. In general, your health is:
- Excellent
 - Very good
 - Good
 - Fair
 - Poor
69. In general, your mental and emotional health is:
- Excellent
 - Very good
 - Good
 - Fair
 - Poor
70. In the past 12 months, was there any time when you or other family members needed the following services? **(CHECK ALL THAT APPLY)**

Respite care	<input type="checkbox"/> Needed services?	<input type="checkbox"/> Received care?	<input type="checkbox"/> Did not receive care?
Genetic counseling	<input type="checkbox"/> Needed services?	<input type="checkbox"/> Received care?	<input type="checkbox"/> Did not receive care?
Mental health care or counseling	<input type="checkbox"/> Needed services?	<input type="checkbox"/> Received care?	<input type="checkbox"/> Did not receive care?

71. Approximately how many days in the past 12 months did you or someone in your household miss work due to your child?
- _____ days missed
- Don't work
 - Don't know

72. How do you deal with anxiety, stress, or depression? **(CIRCLE ALL THAT APPLY)**
- I do not have anxiety, stress, or depression
 - Talk to someone
 - Exercise
 - Eat
 - Drink Alcohol
 - Smoke
 - Use illegal drugs
 - Sleep
 - Use Medication
 - Hobbies
 - Journal
 - Attend Support Group
 - Gamble
 - Shop

Certain questions provided by: Child and Adolescent Health Measurement Initiative, Data Resource Center for the National Survey of Children's Health, Portland, Oregon: U.S. Department of Health and Human Services, Health Resources and Services Administration, 2003-2007. Centers for Disease Control and Prevention. Behavioral Risk Factor Surveillance System. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, 2007-2009. Other questions are © 2011 Hospital Council of NW Ohio.

Thank you for your time and opinions!
Please place your completed survey in the pre-stamped and addressed envelope provided and mail today!