Assistive Technology Needs for Children with Autism Spectrum Disorder in the United States

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INTRODUCTION

Autism spectrum disorders (ASDs) are a group of developmental disabilities (DDs) that include autistic disorder; Asperger's syndrome, and pervasive developmental disorder, not otherwise specified. Children with ASDs may have problems with socialization and communication, as well as delays in gross and fine motor skills. Specifically, children with ASD may have low muscle tone, coordination challenges, sensory integration and/or emotional issues that impact their motor skills. Assistive technologies are important tools to aid the children in enhancing communication with family members and their peers and to enhance their ability in daily activities.

In 2009, the public health surveillance conducted by the Centers for Disease Control and Prevention (CDC) reported prevalence estimates of 1 in 110 children, which increased from 1 in 150 children in 2007. ⁱ As this public health problem continue to grow, it is important to identify current needs for assistive technology for children with ASD and challenges in activities of daily living and social participation as reported by parents.

Methods

The data came from the 2005-2006 National Survey on Children with Special Health Care Needs (NS-CSHCN), conducted by the CDC's National Center for Health Statistics (NCHS), with funding and direction from MCHB, HRSA. The primary purpose of the 2005-2006 NS-CSHCN is to assess the prevalence and impact of special health care needs among children in the US. Furthermore, the survey explores the extent to which children with special health care needs (CSHCN) have medical homes, adequate health insurance, access to needed services, adequate care coordination, functional difficulties and parental perception of care at both the national and State levels.

The 2005-2006 NS-CSHCN was a telephone survey conducted between April 2005 - February 2007, with a total sample size of 40,840 CSHCN from birth through 17 years of age. A random-digit-dial sample of households

with children <18 years of age was selected from each of the 50 states and DC. All children living in a household are screened for special health care needs. If more than one CSHCN is living in a household, one is randomly selected to complete the interview. The respondent was the parent or guardian who knew most about the child's health status and health care. Methodological details of the survey are described elsewhere.ⁱⁱ

Children with ASD and selected DD were defined as children whose parent responded positively to questions related to the following conditions: "Were you ever told by a doctor or other health care provider that [CHILD's NAME] had autism, Asperger's disorder, pervasive developmental disorder, or other autism spectrum disorder?"

Variables

The measures for need in the area of assistive technology included parental report of need for communication aids or devices and mobility devices in the past 12 months. The measures for difficulty in activities of daily living and social participation included the following: 1) taking care of self; 2) coordination; 3) using hands; 4) learning, understanding and paying attention; 5) difficulty speaking, communicating or being understood; 6) speaking, communicating or being understood; 7) feeling anxious or depressed; 8) behavior problems; and 9) making and keeping friends.

Results

Table 1 describes the socioeconomic and demographic characteristics of children with ASD captured in the survey. Over 70 % of children with ASD were non-Hispanic White. More than 80% of the children with ASD are over the age of six years old. 96.5% of these children have health insurance at the time of survey. Almost 68% of the children live in two-parent household.

Table 2 delineates the assistive technology needs of children with ASD and the difficulties in daily activities and social participation. Parental report on the need for communication device was slightly over 15%. The need for durable medical equipment was lower just above 7%. However, parents reported many difficulties in activities and especially in social participation. Over 70% of the parents reported specific difficulties in making and keeping friends and speaking, communicating or being understood. About 90% of the parents reported their child had difficulty learning, understanding or paying attention. Slightly over 50% of the parents reported difficulty with behavior problems and taking care of self.

Special Health Care	10000	
	N=2123	
Characteristics (weighted percents)	%	SE
Weighted percents in children with ASD		
Child race/ethnicity		
Hispanic	10.04	0.65
Non-Hispanic White	73.19	0.96
Non-Hispanic Black	9.81	0.65
Non-Hispanic Multirace/Other,	6.96	0.55
Household poverty level		
<100%	14.60	0.77
100-199%	21.53	0.89
200-399%	29.58	0.99
400+%	25.81	0.95
Unreported	8.48	0.60
Childa age		
3-5 years	16.30	0.80
6-11 years	43.15	1.08
12-17 years	40.56	1.07
Insurance		
Yes, Insured at the time of survey	96.5	0.40
No, Uninsured at the time of survey	3.54	0.40
Family Structure		
Two parent	67.92	1.03
Single mother, no father present	26.11	0.97
Other	5.97	0.52

Table 1. Descriptive socioeconomic and demographic characteristics of children with Autism

Table 2 Observed assistive technology needs and difficulties with activities and social participation: The 2005-2006 National Survey of Children with Special Health Care Needs

	N=2123	
Characteristics (weighted percents)	%	SE
Needed durable medical equipment		
No	92.65	0.57
Yes	7.35	0.57
Needed communication aids or devices		
No	84.48	0.79
Yes	15.13	0.78
Don't know	0.38	0.14
Difficulty with taking care of self		
No	47.13	1.09
Yes	52.78	1.09
Don't know	0.09	0.07
Difficulty with accordination		
Difficulty with coordination No	57.98	1.07
Yes	41.88	1.07
Don't know	0.14	0.08
Difficulty using hands		
No	51.06	1.08
Yes	48.85	1.08
Don't know	0.09	0.07
Difficulty learning, understanding, or paying attention		
No	8.86	0.62
Yes	90.71	0.63
Don't know	0.38	0.13
Difficulty speaking, communicating or being understood		
No	22.87	0.91
Yes	76.90	0.91
Don't know	0.19	0.09
Difficulty with feeling anxious or depressed		
No	33.76	1.03
Yes	62.94	1.05
Don't know	3.21	0.38
Difficulty with behavior problems	44.33	1.08
Yes	44.33 55.24	1.08
Pes Don't know	0.38	0.13
	0.00	0.13
Difficulty making and keeping friends		
No	28.26	0.99
Yes	70.55	0.99
Don't know	1.10	0.23

Discussion

Based upon the analysis in Table 2, there is a gap between the parental perceived need for assistive technology and the reported difficulties in daily activities and social participation. Assistive technology can play an important role in helping the child learn and understand materials at school. Moreover, alternative and augmentative

communication devices can enhance communication between children with ASD and their peers. The results suggest that parents may not be familiar with assistive technology and the benefits of incorporating "low" tech to "high" tech assistive technology into aspects of daily living that can improve the functional capabilities of children with ASD. Future public awareness and outreach efforts could target parents with children with ASD to enhance their understanding in applying assistive technology solutions that can improve their child's ability in performing daily activities and social participation.

ⁱ Rice C. Prevalence of autism spectrum disorders --autism and developmental disabilities monitoring network, six sites, United States, 2006. Morbidity and Mortality Weekly (MMWR) Rep. 2009;58(SS01):1-20

ⁱⁱ Blumberg SJ, Welch EM, Chowdhury SR, Upchurch HL, Parker EK, Skalland BJ. Design and operation of the National Survey of Children with Special Health Care Needs, 2005–2006. National Center for Health Statistics. Vital Health Stat 1(45). 2008.