

The Impact of Surveillance Method and Record Source on Autism Prevalence: Collaboration with Utah Maternal and Child Health Programs

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Abstract With the increasing number of Utah children identified with autism spectrum disorders (ASDs), information on the prevalence and characteristics of these children could help Maternal Child Health (MCH) programs develop population building activities focused on prevention, screening, and education. The purpose of this study is to describe Utah's autism registry developed in collaboration with state MCH programs and assess the impact of different record-based surveillance methods on state ASD prevalence rates. The study was conducted using 212 ASD cases identified from a population of 26,217 eight year olds living in one of the three most populous counties in Utah (Davis, Salt Lake, and Utah) in 2002. ASD prevalence was determined using two records based approaches (administrative diagnoses versus abstraction and clinician review) by source of record ascertainment (education, health, and combined). ASD prevalence ranged from 7.5 per 1000 (95% CI 6.4–8.5) to 3.2 per 1000 (95% CI 2.5–3.9) varying significantly ($P < .05$) based on method and record source. The ratio of male-to-female ranged from 4.7:1 to 6.4:1. No significant differences were found between the two case ascertainment methods on 18 of the 23 case characteristics including median household income, parental education, and mean age of diagnosis. Broad support is needed from both education and health sources as well as collaboration with MCH programs to address the growing health concerns, monitoring, and

treatment needs of children and their families impacted by autism spectrum disorders.

Keywords Autism spectrum disorders · Surveillance · Prevalence · Maternal child health · Epidemiology

Introduction

Consistent with national trends, the prevalence of autism spectrum disorders (ASD) in Utah is increasing at an alarming rate [1–4]. While there are many reasons cited for the rapid growth of diagnosis [5, 6], none has demonstrated a clear cause and effect relationship [7] and many unanswered questions still remain. The increasing number of individuals identified with ASD necessitates ongoing epidemiological surveillance to establish the magnitude of the ASD prevalence and inform the state's general fiscal and public policy needs.

A February 2007 report by the Centers for Disease Control and Prevention (CDC) indicates that for the reporting year 2002, ASD prevalence among 8 year old Utah males was the second highest of 14 sites studied (12.7 per 1000) and Utah ranked third highest for overall prevalence (7.5 per 1000 eight year old children or 1 in 133 births) [1]. While the national ratio of males to females is 4:1, the Utah ratio is 6.8:1. Recent special education data in Utah indicates that school enrollment of children ages 3–21 years with ASD has increased 900% over the last ten years [8]. Clearly ASD is a child health, education, and family concern of major consequence.

Although there are numerous potential explanations for the rise in ASD prevalence rates, it is important to consider the factors behind each explanation when designing an ASD surveillance infrastructure. Effective surveillance provides state administrators with the data evidence

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necessary to ensure that the comprehensive physical, psychological, and social needs of the targeted population are met. As the number of individuals diagnosed with ASD rises, so are the demands on state health departments to provide information and support. Families frequently express disappointment in their efforts to access this support and to arrange seamless care coordination for affected family members [9]. Increasingly Medicaid and other insurance carriers are receiving requests for coverage of a variety of diagnostic services and treatment approaches [10]. In the absence of state specific data, the true number of individuals with ASDs within Utah would be unknown, leading to gaps in services, programs, and funding.

Key to the development of a Utah ASD surveillance program has been collaboration among the state Maternal and Child Health Bureau (MCHB), Children with Special Health Care Needs Bureau, the University of Utah Department of Psychiatry, the Utah Department of Health's Center for Health Data, and a new state funded program, the Utah Registry of Autism and Developmental Disabilities (URADD) [11]. URADD's mission as defined by the legislature is to determine the prevalence of ASDs and other developmental disabilities among Utah children and describe the characteristics of these children.

The Federal Title V Maternal and Child Health (MCH) Block Grant statute authorizes all MCHBs to improve the health of all mothers and children in the United States (US) [12]. With federal funding, each state strives to provide and assure access to quality maternal and child health services. To allocate funding appropriately across different population groups and needs, the federal MCHB developed a framework for Title V agencies known as "MCH Pyramid" [12]. This framework is consistent with the essential public health services and is organized under four service delivery systems (Infrastructure Building Services, Population Based Services, Enabling Services, and Direct Health Care Services). Federal Title V performance measures (e.g. medical home, community-based care coordination, family partnering, and transition) are also tied to this framework.

Within the framework of the MCH Pyramid, infrastructure building services such as a surveillance system are to be the foundation upon which population based services may be built. Information on the prevalence of ASD and the characteristics of the children with the disorder could help MCH programs undertake the development of population building activities focused on prevention, screening, and education. Such a surveillance mechanism would enable public health leaders to access descriptive information on children with ASDs, to follow trends in ASD prevalence over time, to inform service delivery and intervention strategies, and to facilitate ASD research.

Surveillance methodologies vary among states and range from simple-source to complex multi-source data

collection. Most record-based ASD studies in the United States have utilized state-developed centralized disability tracking systems [13, 14], administrative data from the United States Department of Education (USDE) [6, 15], or screening followed by comprehensive reviews of education and health records followed by chart abstraction and clinician review for case identification. The most well-known record abstraction and clinician review model was developed by the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) and is currently used for federally funded surveillance studies by the Centers for Disease Control and Prevention [16–18]. Prevalence rates have been found to be significantly lower in studies relying solely on health records compared to those using both health and education records [1]. Similarly, researchers have expressed concerns about the reliability and completeness of ASD prevalence findings using education source only data from the United States Department of Education [19].

Eight states (Colorado, Delaware, Illinois, New Hampshire, New Jersey, Utah, Washington and West Virginia) rely on public health reporting requirements for ASDs to conduct surveillance but many lack state funding for implementation. Utah's authority to conduct surveillance relies on the consequences of the Utah's health code [20] which mandates the reporting of ASD cases and related disabilities upon request to the Utah Department of Health (UDOH) by qualified professionals. Included in the health code is a provision that persons or entities reporting information covered by the rule would not be held liable for reporting the information to UDOH. All qualified health providers can be asked to report children to the registry who have an ASD or related health condition.

The following study assesses the impact of different record-based surveillance methods on ASD prevalence rates using an in-depth analysis of our 2002 study year data. It compares the ASD prevalence rates by surveillance method (administrative versus abstraction followed by clinician review) by record source (education, health, and combined). A secondary analysis investigates potential differences in case characteristics using the two surveillance methods.

Methods

Study Design

This study was conducted using 212 ASD cases identified from a population of 26,217 eight year olds living in one of the three most populous counties in Utah (Davis, Salt Lake, and Utah) in 2002. Cases were identified from administrative and child records reviewed from all major public

and private providers in the targeted ascertainment area. Source administrative records were screened using approximately 200 International Classification of Diseases, Ninth Revision (ICD-9) billing codes [21] for autism and related developmental disabilities and all administrative special education disability categories used by the USDE [22]. Trained abstractors reviewed source records of the children identified through the screening process. The MADDSP methodological approach was followed for record abstraction and has been described in detail elsewhere [16–18]. Consistent with this approach, abstracted information was collected from all source records and included descriptions of the child's development and behavior, diagnostic or classification conclusions, and source of information. Clinician reviewers scored abstracted information to determine whether the ASD case definition was met when using all records, health records only, and education records only. ASD cases were linked to vital record birth and death certificates to verify demographic and missing information on ASD cases and to identify deceased children. Data linkage between ASD cases and vital records were conducted utilizing a hybrid merging method of deterministic and probabilistic methodologies.

Surveillance Method and Case Definition

ASD cases were assigned to one or more of the following six groups by ascertainment surveillance method and record source: (1) an education administrative classification of autism (a special education disability classification of autism as defined by the Individuals with Disabilities Act), (2) health administrative diagnosis of ASD (a previously documented ICD-9 ASD diagnosis by a qualified provider), (3) an education and/or health administrative classification/diagnosis of autism and/or ASD, (4) abstraction and clinician review of education source records to determine case status (5) abstraction and clinician review of health source records to determine case status (6) abstraction and clinician record review of education and/or health records to determine case status.

Variables

The primary outcome variable of interest was ASD prevalence rates by ascertainment surveillance method (administrative versus abstraction and clinician review) and source of ascertainment (education, health, combined). Three race/ethnicity categories were used: White, non-Hispanic; Hispanic; and other non-Hispanic. Because of the small sample size associated with some groups (i.e. Black; American Indian or Alaska Native; Native Hawaiian or Pacific Islander), these groups were collapsed into the other race non-Hispanic category. Race/ethnicity and

gender of each case was determined from information contained in source records and if missing, obtained from available birth certificates.

Developmental and cognitive variables obtained from a compilation of information across all source records were compiled for each case. Variables included the presence of previous clinical diagnosis of ASD or educational classification of ASD, ASD with mental retardation (IQ < 70), history of regression and/or plateau, and age and type of developmental delays.

Since socioeconomic information was not available from health or education records, socioeconomic variables were obtained from US Census 2000 data by linking the census tract and block group of each child's 2002 residence with the corresponding demographic information for that census tract and block group. Variables obtained included: median household income in 1999, the proportion of population age 25+ with at least a bachelor's degree, and the proportion of the population living in the same county from 1995 to 2000.

Analyses

Period prevalence estimates were calculated using the denominator of the number of children aged 8 years residing in the three county surveillance area according to the Governor's Office of Planning and Budget, Utah Population Estimates Committee [23]. Percentages or means and standard deviations were calculated as appropriate for all case characteristic variables of interest as a function of each of group definition. A *t*-test was used to examine statistical differences in the distribution of each categorical variable between cases identified through administrative diagnosis/classifications obtained from education and/or health sources (Group 3) and those identified from abstraction and clinician review at education and/or health sources (Group 6).

Results

As shown in Table 1, the overall ASD prevalence rate significantly differed when groups 1–5 were each compared to group 6 ($P < .05$). The rate varied from 3.2 per 1000 (95% CI 2.5–3.9) when using a special education autism classification alone to identify cases (Group 1) to 7.5 per 1000 (95% CI 6.4–8.5) when using abstraction and clinician review to identify cases from education and/or health sources (Group 6). Abstraction and clinician review of education source records only (Group 4) and health source records only (Group 5) yielded prevalence rates of 3.9 (95% CI 3.2–4.7) and 6.1 per 1000 (95% CI 5.1–7.0) respectively. The ASD prevalence rate of group 5 (6.1 per

Table 1 Estimated prevalence of autism spectrum disorders per 1000 children aged 8 years by surveillance method, source, and race/ethnicity

Method of ASD case identification by source	Total no. of ASD cases	Overall ASD prevalence		White Non-Hispanic		Hispanic		Other Non-Hispanic	
		Rate	(95% CI)	No.	Rate (95% CI)	No.	Rate (95% CI)	No.	Rate (95% CI)
<i>Administrative diagnosis alone</i>									
Group 1 (autism educational classification only)	84	3.2**	(2.5–3.9)	75	3.5** (2.7–4.3)	6	1.7* (0.3–3.1)	3	2.3* (0.0–5.0)
Group 2 (ICD-9 ASD diagnosis only)	139	5.3**	(4.4–6.2)	122	5.7** (4.7–6.7)	13	3.7 (1.7–5.7)	4	3.1* (.06–6.2)
Group 3 (combining education and health data)	158	6.0*	(5.1–7.0)	137	6.4* (5.3–7.5)	14	4.0 (1.9–6.1)	7	5.4 (1.4–9.5)
<i>Abstraction and expert clinician review</i>									
Group 4 (education records only)	103	3.9**	(3.2–4.7)	91	4.3** (3.4–5.1)	8	2.3 (0.7–3.9)	4	3.1* (.06–6.2)
Group 5 (health records only)	159	6.1*	(5.1–7.0)	136	6.4* (5.3–7.4)	14	4.0 (1.9–6.1)	9	7.0 (2.4–11.5)
Group 6 (combining education and health records)	196	7.5	(6.4– 8.5)	170	7.9 (6.8–9.1)	15	4.3 (2.1–6.4)	11	8.6 (3.5–13.6)

Groups 1–5 are compared to group 6

** $P < .001$, * $P < .05$

Table 2 Estimated prevalence of autism spectrum disorders per 1000 children aged 8 years by surveillance method, source, and gender

Method of ASD surveillance approach by source of ascertainment	Male prevalence		Female prevalence		Male-to female ratio
	Rate	(95% CI)	Rate	(95% CI)	
<i>Administrative diagnosis alone</i>					
Group 1 (autism educational classification only)	5.3**	(4.1–6.6)	1.0*	(0.4–1.5)	5.9:1
Group 2 (ICD-9 ASD diagnosis only)	8.6**	(7.0–10.1)	1.8	(1.1–2.6)	4.8:1
Group 3 (Combining education and health data)	9.8*	(8.1–11.4)	2.1	(1.3–2.8)	4.7:1
<i>Screening, abstraction, plus expert clinician review</i>					
Group 4 (education records only)	6.5**	(5.2–7.9)	1.3	(0.6–1.9)	5.0:1
Group 5 (health records only)	10.2*	(8.5–11.9)	1.7	(1.0–2.4)	6.0:1
Group 6 (combining education and health records)	12.7	(10.8–14.5)	2.0	(1.2–2.7)	6.4:1

Groups 1–5 are compared to group 6

** $P < .001$, * $P < .05$

1000) resulted in a prevalence rate comparable to the Group 3 administrative prevalence (6.0 per 1000).

Regardless of the surveillance approach and source of record ascertainment, the ASD prevalence within each group was lower in Hispanics compared with the White-Non-Hispanic group. The rate of ASD in the Hispanic population was significantly different between group 1 and group 6 ($P < .05$). Groups 1, 2, and 4 were significantly different than group 6 in the rate of ASD in the category “other-non-Hispanics”. As shown in Table 2, the male to female ratio ranged from 4.7:1 (Group 3) to 6.4:1 (Group 6).

Significant differences were found between Group 3 and Group 6 on five of the 23 variables examined (Table 3). Differences were found between the two groups on the proportion of cases with a previous special education classification ($P = .000$), a previous ASD diagnosis ($P = .000$), autism versus ASD ($P = .000$), a general delay at 12 months ($P = .000$) and a social delay at 12 months ($P = .000$).

Discussion

Our state’s ASD prevalence significantly varied by the surveillance method and type of source records utilized. Prevalence was significantly higher using the record abstraction and clinician review method from health and/or education sources to identify cases. Differences were not surprising as this approach allowed case status determination without a prior established ASD diagnosis in the source record. Utah’s ASD prevalence rate derived from abstraction and clinician review of health source records only (Group 5) was higher than many other US communities using the same methodological approach [1]. The exclusion of education records reduced our ASD administrative prevalence rate by 12% and the abstraction and clinician review prevalence rate by 19%. Use of education records only for surveillance reduced our ASD prevalence by 47% using either method.

Table 3 ASD case characteristics by surveillance method

Method Case characteristics	Group 3			Group 6			P-value*
	Administrative diagnosis and/or classification			Abstraction and clinician review			
	n	Mean	S.D.	n	Mean	S.D.	
Child's age at earliest autism evaluation abstracted (months)	156	45.0	20.0	196	46.9	20.6	0.38
Child's age at earliest known ASD diagnosis (months)	128	51.1	18.8	145	54.1	20.5	0.21
Child's age at earliest evaluation confirming an ASD diagnosis (months)	123	52.1	18.2	136	55.1	19.8	0.20
Median household income in 1999	148	51,459	15,582	185	51,762	15,611	0.86
The Proportion of population living in the same county from 1995 to 2000	132	52.1	27.5	185	53.1	27.0	0.74
The proportion of population age 25+ with at least a bachelor's degree	132	51.5	26.7	185	49.0	27.4	0.42
Earliest age regression noted on any evaluation (months)	48	21.2	11.4	59	22.5	12.2	0.57
Earliest age plateau noted on any evaluation (months)	19	20.6	9.1	25	21.9	12.4	0.70
		Group 3		Group 6			P-value*
		n	%	n	%		
<i>Sex</i>							
Female		26	7.6	25	12.8		0.12
Male		132	83.5	171	87.2		
<i>Previous diagnosis or special education class of ASD</i>							
No		0	0.0	53	27.1		0.00
Yes		154	100	143	72.9		
<i>Comorbid intellectual disability</i>							
No		93	58.9	123	67.6		0.34
Yes		32	20.3	34	17.4		
<i>Previous ASD in records</i>							
ASD diagnosis or eligibility on record		154	97.5	161	82.1		0.00
Suspicion of ASD noted		2	1.3	21	10.7		
No mention of ASD on record		0	0.0	14	7.1		
<i>Autism versus ASD</i>							
ASD-NOS		10	6.3	33	16.8		0.00
AUTISM		19	12.0	48	24.5		
STREAMLINED ASD		112	70.9	115	58.7		
<i>General delay noted before age 3</i>							
No		14	8.9	22	11.2		0.22
Yes		141	89.2	174	88.8		
<i>Age general delay noted</i>							
≤12 months		71	44.9	75	38.3		0.00
≤24 months		55	34.8	68	34.7		
≤36 months		16	10.1	31	15.8		
<i>Social delay noted before age 3</i>							
No		68	43.0	95	48.5		0.00
Yes		88	55.7	101	51.5		

Table 3 continued

	Group 3		Group 6		P-value*
	n	%	n	%	
<i>Age social delay noted</i>					
≤12 months	30	19.0	31	15.8	0.23
≤24 months	24	15.2	28	14.3	
≤36 months	34	21.5	41	20.9	
<i>Language delay noted before age 3</i>					
No	29	18.4	45	23.0	0.09
Yes	127	80.4	151	77.0	
<i>Age language delay noted</i>					
≤12 months	13	8.2	15	7.7	0.26
≤24 months	86	54.4	99	50.5	
≤36 months	28	17.7	37	18.9	
<i>Play delay noted before age 3</i>					
No	117	74.1	153	78.1	0.17
Yes	39	24.7	43	21.9	
<i>Age play delay noted</i>					
≤12 months	5	3.2	5	2.6	0.42
≤24 months	10	6.3	12	6.1	
≤36 months	24	15.2	26	13.3	
<i>Regression noted</i>					
No	105	66.5	134	68.4	0.36
Yes	51	32.3	62	31.6	
<i>Plateau noted</i>					
No	137	86.7	171	87.3	0.43
Yes	19	12.0	25	12.7	

* Group 3 compared to group 6

Consistent differences in prevalence between the White-Non-Hispanic and Hispanic group were apparent regardless of the surveillance approach. Rather than a true difference in prevalence, this may reflect barriers to accessing care and services as an underserved population. Across groups, the ratio of males to females ranged from 4.7 to 1 to 6.4 to 1 and is consistent with reports from other studies [1, 3].

The abstraction and clinician review process allowed the collection of developmental case characteristics and cognitive profiles not afforded through queries of administrative data in isolation. Since study group assignments were based on the receipt of a previous administration diagnoses or special education disability classification of autism, it was expected that significant differences would exist between Group 3 and 6 on diagnostic indicators (previous special education diagnosis, previous ASD diagnosis, and autism versus ASD diagnosis). The proportion of cases with a general delay prior to 12 months was significantly higher in cases with administrative diagnoses whereas the proportion of cases with a social delay was significantly lower. No significant differences were found between these

two groups on the remaining variables including indicators of parental income, education, and county residential changes.

Record abstraction and clinician review were costly and time consuming but added 20% more ASD cases and important phenotypic case profiles not captured from administrative data in isolation. Since none of the cases were directly contacted or assessed it is still unknown how many of the cases were “true” ASD cases using either methodological approach. This is a significant limitation of this and other studies that rely either on record review or administrative data to population-based prevalence estimates of ASD. However, administrative health diagnoses and/or educational classifications requires at least one qualified provider to have determined ASD case status through a direct assessment process. In Utah, the ASD administrative prevalence using education and health records (6.0 per 1000) was comparable to the prevalence derived from the abstraction and review of health records (6.1 per 1000) without the added time and costs of record abstraction. Administrative diagnoses and/or educational

classifications may also be used to track the prevalence of other childhood disabilities [24].

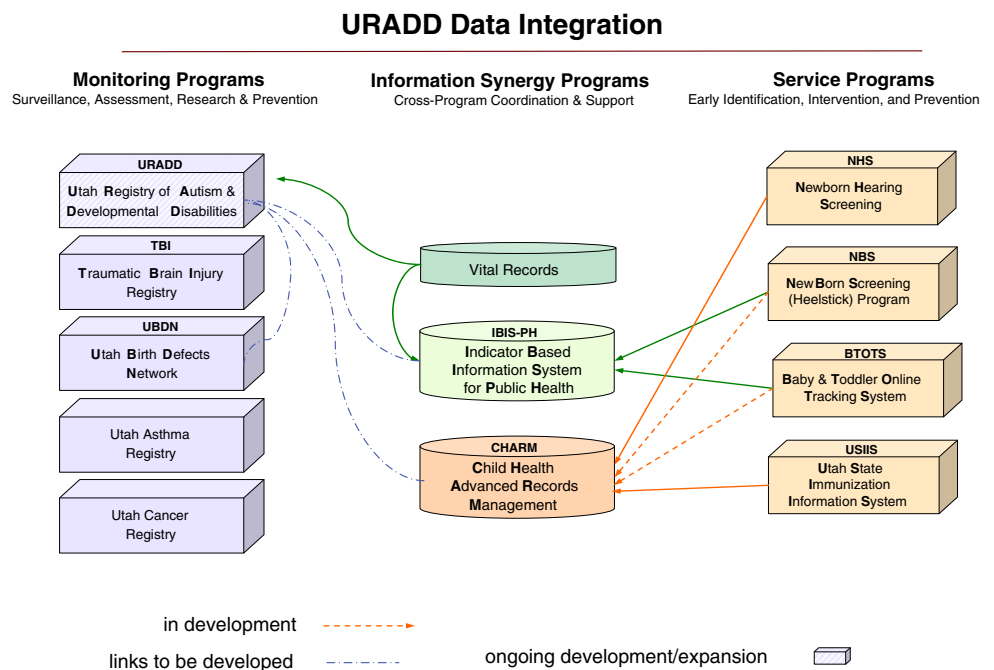
Efforts to improve public ASD awareness and implement early screening, and diagnosis may further reduce the gap between our state’s administrative ASD prevalence and rates obtained from record abstraction and clinician review. It should be noted, however, that there may be regional differences in the proportion of individuals receiving education only and health only ASD related services and regional variations in the quality of records. Thus inferences from our ASD prevalence rates to other communities should be approached with caution.

Regardless of what surveillance approach was utilized, Utah’s ASD health reporting rule expedited obtaining the necessary approval to access health information from data sources. Reporting of identifiable information to the health department such as the person’s name and birth date associated with a health condition is necessary when conducting population-based ASD surveillance. Access to this information prevents duplicated cases across reporting sources and provides the potential to conduct linkages within department health data systems such as vital records, MCHB programs, and Children with Special Health Care Needs programs. Individually identifiable information is held strictly confidential by the UDOH in a manner consistent with regulatory statutes and laws governing the collection and release of such data. In addition, the registry was required to meet all data source’s Institutional Review Board requirements.

Future Directions

ASD administrative surveillance infrastructure provides a useful mechanism for integration with other Utah monitoring programs, information synergy systems, and treatment programs as shown in Fig. 1, [25–28]. Data linkages with health and MCHB data systems will facilitate our states future efforts in gathering important phenotypic case information, identifying ASD risk factors, and conducting comparative studies with matched birth cohorts [29]. Establishing and maintaining a comprehensive integrated surveillance system is crucial not only to track cases over time but also to assist in program assessment and to improve service delivery. Children and youth with special health care needs is a major component of Title V programs. These programs focused on bringing quality specialty medical care to children with specific diagnoses. An important objective of the federal MCHB is “to support the development and implementation of comprehensive, culturally competent, coordinated systems of care for children who have or are at risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally” [30]. Increased specialization of medical care has created a challenging need for care coordination and management. An important role of Title V programs is to enhance infrastructure such as surveillance, develop population-based services that meet the needs of the MCH population, and coordinate care in partnership with providers and families.

Fig. 1 URADD ASD data integration linkage model with other Utah Department of Health databases



Summary

As the number of individuals identified with ASD is rising nationwide, conducting ASD surveillance is an important process for maintaining and disseminating information on the health status and needs of this population. It is generally expected that any surveillance system will be evaluated and modified periodically in order to ensure that it yields accurate prevalence data. This places ASD surveillance programs solidly within the scope of MCH goals and objectives. The development of new state laws and statutes allowing the reporting of ASDs and other developmental disabilities is a powerful mechanism for state surveillance systems. Broad support is needed from both education and health sources as well as collaboration with MCH programs to address the growing health concerns and treatment needs of children, youth, and families impacted by autism spectrum disorders.

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