



HHS Public Access

Author manuscript

Autism. Author manuscript; available in PMC 2015 September 08.

Published in final edited form as:

Autism. 2013 September ; 17(5): 623–629. doi:10.1177/1362361312452161.

Short report: Improving record–review surveillance of young children with an autism spectrum disorder

Lisa D. Wiggins,

Centers for Disease Control and Prevention, USA

Diana L. Robins, and

Georgia State University, USA

Marshalyn Yeargin-Allsopp

Centers for Disease Control and Prevention, USA

Abstract

Introduction—Records-based autism spectrum disorder surveillance developed at the Centers for Disease Control and Prevention has been extended to younger cohorts, although the utility of additional record sources has not been examined. We therefore conducted a pilot project to describe whether Centers for Disease Control and Prevention surveillance could identify younger children with an autism spectrum disorder evaluated as part of an ongoing screening study at Georgia State University.

Methods—In all, 31 families of children who screened positive for autism spectrum disorder and received a clinical evaluation at Georgia State University agreed to participate in the project. Of these, 10 children lived inside the surveillance area and had records abstracted and reviewed for this project. Centers for Disease Control and Prevention surveillance results (i.e. autism spectrum disorder or non-autism spectrum disorder) were compared with Georgia State University evaluation results (i.e. autism spectrum disorder or non-autism spectrum disorder).

Results—In all, 4 of the 10 children were diagnosed with an autism spectrum disorder after the Georgia State University evaluation. None of the 4 children with an autism spectrum disorder were identified by current Centers for Disease Control and Prevention surveillance methods but all 4 children were identified by Centers for Disease Control and Prevention surveillance methods when additional record sources were included (i.e. records from the statewide early intervention program and Georgia State University evaluation).

Conclusion—These findings suggest that partnering with early intervention programs and encouraging early autism spectrum disorder screening might improve autism spectrum disorder surveillance among young children.

Reprints and permissions: sagepub.co.uk/journalsPermissions.nav

Corresponding author: Lisa D Wiggins, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, 1600 Clifton Road, MS E-86, Atlanta, GA 30333, USA. lwiggins@cdc.gov.

Conflict of interest

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the CDC. Diana Robins is the co-owner of M-CHAT, LLC, for electronic versions of the M-CHAT (paper versions are available free of charge). Lisa Wiggins and Marshalyn Yeargin-Allsopp do not have any financial disclosures or conflict of interests to report.

Keywords

autism spectrum disorder; early identification; surveillance

Introduction

Autism spectrum disorders (ASDs) are developmental disabilities that affect social, communication, and behavioral development and include the diagnoses of autistic disorder, pervasive developmental disorder—not otherwise specified (PDD-NOS), and Asperger disorder (American Psychiatric Association, 1994). The Centers for Disease Control and Prevention (CDC) has estimated that about 1 in 88 children currently have an ASD, which is higher than prevalence estimates previously reported (Autism and Developmental Disabilities Monitoring Network Surveillance Year 2008 Principal Investigators, 2012). CDC's ASD prevalence estimates are used to describe the population of children with an ASD, identify changes in ASD prevalence over time, and provide suggestions about possible causes or risk factors for ASDs. CDC derives ASD prevalence estimates via a record–review methodology that involves the abstraction and review of education and health records of 8-year-old children at select screening, evaluation, and diagnostic clinics and schools during a given surveillance year. This record–review methodology is not likely to overestimate the prevalence of ASDs, but is likely to miss some children with an ASD in the general population (Nonkin-Avchen et al., 2011).

The CDC's ASD record–review surveillance methodology has recently been extended to younger cohorts at some surveillance sites. Initial analyses have suggested the estimated prevalence of ASDs among 4-year-olds to be about 8.0 per 1000 children, which is comparable with the estimated prevalence of ASDs among 8-year-olds (Nicholas et al., 2009). However, this methodology has not been tested with direct access to records from statewide early intervention programs (rather than indirect access through other education and health records utilized for 8-year-old surveillance). Direct access to early intervention records might be an invaluable tool for early ASD surveillance because states are required to provide free intervention services for children 0–36 months of age, who meet eligibility criteria. Furthermore, this methodology has not been compared with that of a direct-screening approach used to identify younger children with ASDs. Thus, the goal of this pilot project was to describe whether the CDC record–review methodology could identify children younger than 4 years with an ASD, among a small sample of children evaluated as part of an ongoing screening study at Georgia State University (GSU). A second goal was to describe how well the CDC record–review approach compared with the GSU direct-screening approach before and after the screening result was made available in surveillance records.

Methods

Children were identified from an ongoing prospective screening study at GSU. Families of children enrolled in the GSU study completed the Modified Checklist for Autism in Toddlers (M-CHAT; Robins et al. 1999b, 2001) during a routine 18-month or 24-month

well-child visit. The M-CHAT is a short parent-report checklist designed to detect risk of ASDs among children 16–30 months of age when administered during general pediatric visits. Families of children who screened positive for an ASD on the M-CHAT were administered the M-CHAT Follow-Up Interview (Robins et al., 1999a), which is a structured interview designed to clarify parents' responses and elicit examples of at-risk behaviors. Children who continued to screen positive after the Follow-Up Interview were invited for a free diagnostic evaluation.

Diagnostic evaluations were completed at the GSU clinic. The Mullen Scales of Early Learning (Mullen, 1995) was administered to assess intellectual functioning and the *Vineland Adaptive Behavior Scales*, Second Edition (Sparrow et al., 2005) was administered to assess daily living skills. The Autism Diagnostic Interview–Revised (ADI-R; Lord et al., 1994), Autism Diagnostic Observation Schedule (ADOS; Lord et al., 1999), and Childhood Autism Rating Scale (Schopler et al., 1988) were administered to assess autism-specific symptoms and behaviors. Final diagnosis was made by a licensed clinical psychologist, using clinical judgment and integrating all data obtained during the evaluation.

Contact and enrollment

There were three ways to enroll families in this project:

1. Families who previously completed a diagnostic evaluation as part of the GSU screening study were contacted by letter or telephone call, or both, within 12 months of the GSU evaluation. The current project was introduced and families were asked whether they would like to participate.
2. Newly enrolled families were introduced to this project at GSU during their initial diagnostic evaluation.
3. Newly enrolled families were introduced to this project at GSU during one of a number of follow-up sessions in the GSU clinic.

In all, 58 families were invited to be in the project. Of these 58 families, 31 agreed to participate; 17 expressed interest, but never completed the consent and release forms that enrolled them in the study; and 10 declined participation. Only families who lived inside the CDC surveillance catchment area (i.e. the five central counties of metropolitan Atlanta) and had records that could be located at existing partner data sources or the statewide early intervention program were enrolled in this project. We chose to focus on existing partner sources and the statewide early intervention program because these data sources are more feasible to access for population-based surveillance than other data sources, such as individual pediatric or therapy offices. Existing partner data sources were sources that, at the time, were partnering with the CDC ASD surveillance program (i.e. facilities that commonly evaluate and diagnose children with an ASD, such as local hospitals and autism diagnostic centers).

The 31 families who agreed to participate were placed in one of the following three categories after enrollment: (a) the family lived outside the surveillance catchment area, so records were not abstracted or reviewed ($n = 5$); (b) the family lived inside the surveillance catchment area, but did not have records that could be located at any partner data sources or

with the statewide early intervention program, so records were not abstracted or reviewed ($n = 16$); and (c) the family lived inside the surveillance catchment area and had records located at partner data sources or with the statewide early intervention program, so records were abstracted and reviewed ($n = 10$).

Procedures

CDC staff began record abstraction for children who lived inside the surveillance catchment area and had records located at partner data sources or with the statewide early intervention program ($n = 10$) after the GSU diagnostic evaluation was completed and consent for this project was obtained. Abstraction involved screening health and school records for specific ASD behaviors that relate to social criteria outlined in the *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition, Text Revision (DSM-IV-TR) (American Psychiatric Association, 2000; such as limited interest in other children) and collecting verbatim behavioral descriptions, diagnostic summaries, and developmental assessment results from records that contained an ASD behavioral trigger. Information collected from records was then sent to a CDC clinician who applied a standardized coding scheme based on the DSM-IV-TR to determine surveillance case status, grouped into ASD or non-ASD.

CDC clinician reviewers were professionals with advanced degrees and specialized training and experience in ASD assessment and diagnosis (e.g. developmental psychologists). These reviewers applied a standardized coding scheme based on the DSM-IV-TR to determine surveillance case status but did not evaluate or diagnose any child. All clinician reviewers had achieved and maintained acceptable reliability standards for coding ASD surveillance records. It is important to note that to meet ASD surveillance criteria, a child must have sufficient behavioral descriptors noted in surveillance records or a preexisting ASD clinical diagnosis or autism eligibility at a public school devoid of conflicting information contained in surveillance records. Therefore, if a documented clinical ASD diagnosis is present, it will be considered when determining surveillance case status, but it is not necessary to have this clinical diagnosis to meet ASD surveillance criteria. Further details of the surveillance methods are outlined elsewhere (Nonkin-Avchen et al., 2011; Van Naarden Braun et al., 2002; Yeargin-Allsopp et al., 2003).

Results

The focus of this project was to describe children who were and were not identified by CDC ASD surveillance rather than report sensitivity and specificity due to the small sample size (Table 1). Of the 10 children who received a diagnostic evaluation at GSU and had educational and health records reviewed by CDC, all 10 children were males and 8 children were White (the other 2 children were Asian). The mean age at the time of GSU evaluation was 26.3 months ($SD = 6.33$ months; range = 20–42 months); education and health records were abstracted and reviewed from the earliest date available to 12 months after the GSU evaluation. On the basis of the GSU evaluation, 4 children were diagnosed with an ASD and 6 children were diagnosed with not having an ASD. When only current surveillance partner records were reviewed, none of the children with an ASD were identified by record–review surveillance. When the statewide early intervention records were added to current

surveillance partner records, and only records prior to the GSU evaluation were reviewed, 2 of the 4 children with ASDs were classified correctly as having an ASD based on record–review surveillance. When record–review was extended to include the time period following the GSU evaluation, all 4 children with an ASD were classified correctly as having an ASD based on record–review surveillance. All the 6 children who did not have an ASD were classified correctly as not having an ASD based on record–review surveillance in each of the aforementioned scenarios. See Table 1 for a summary of results.

Of the 16 children who did not have records at partner sources or with the statewide early intervention program (and, therefore, did not have records abstracted and reviewed), 5 were diagnosed with an ASD by GSU. The health-care providers who evaluated these children were developmental psychologists, developmental pediatricians, and occupational therapists who commonly evaluate and treat young children with an ASD in Atlanta, Georgia (but who at the time of this study were not included as partners with CDC ASD surveillance for 8-year-old children).

Discussion

Our results found that none of the 4 children diagnosed with an ASD who were screened at 16–30 months of age by GSU were identified by CDC record–review methodology until records from the statewide early intervention program and GSU evaluation were added (at which time all 4 children were identified by CDC record–review surveillance). These results suggested at least three important considerations for surveillance protocols for younger children. First, ASD surveillance for children 30 months of age or older might be more feasible than ASD surveillance for younger children because many younger children might not have early intervention or other clinical evaluation records available for abstraction and review. The source of most toddler health information is the pediatrician, which limits the feasibility of surveillance for younger cohorts because pediatric screening and evaluation results are not recorded in a centralized database and it would be impossible to visit every pediatric office for surveillance of 4-year-olds to 8-year-olds. Entering developmental screening and evaluation results into a centralized database, such as that used to record neonatal metabolic and genetic screening, would be useful for ASD surveillance and might encourage referrals for additional developmental testing and intervention.

Second, the addition of the statewide early intervention records improved surveillance classification among those in our sample. Therefore, early ASD surveillance programs should consider partnering with statewide early intervention programs, so that more accurate prevalence estimates can be derived among younger cohorts. Early ASD surveillance programs should also consider partnering with additional health-care providers who commonly evaluate *younger* children at risk of an ASD, in addition to 8-year-old children at risk of an ASD, such as developmental psychologists, developmental pediatricians, and occupational therapists who work with children younger than 4 years of age. Particular attention should be given to methods that navigate access to these health records for public health surveillance.

Third, because record–review classification was low before the GSU evaluation, but improved after results of the diagnostic evaluation were added to surveillance records, early ASD screening and follow-up evaluation should be encouraged to maximize the number of children with an ASD identified for both clinical and surveillance purposes.

The primary limitation of our pilot project was the small sample recruited and described. Yet, we believe that the implications and lessons gleaned from our findings are valuable considerations for ASD surveillance protocols that apply to younger children. The importance of developing accurate yet feasible surveillance protocols cannot be underestimated. ASD surveillance results are often used to make policy decisions and determine research priorities. Results from this pilot project suggested that record–review surveillance with appropriate record sources may be a feasible way of determining ASD prevalence among younger cohorts. However, results also indicated that surveillance in the absence of screening and follow-up evaluation or other early detection methods might have underestimated the prevalence of ASDs among toddlers (and that use of early ASD surveillance to determine peak ASD prevalence is still premature). Additional analyses on larger, population-based samples are needed to verify and expand upon these preliminary findings.

Acknowledgments

The authors acknowledge the Modified Checklist for Autism in Toddlers study team at Georgia State University (GSU) and the Metropolitan Atlanta Developmental Disabilities Surveillance Program at the Centers for Disease Control and Prevention (CDC) for working on this project. We also thank Catherine Rice for comments on previous versions of the manuscript and the children and families who agreed to participate in this research.

Funding

This research was supported by the Centers for Disease Control and Prevention and Georgia State University Seed Grant Program.

References

- American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 4. Washington, DC: American Psychiatric Association; 1994.
- American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 4. Washington, DC: American Psychiatric Association; 2000. (text revision)
- Autism and Developmental Disabilities Monitoring Network Surveillance Year. Principal Investigators (2012) Prevalence of autism spectrum disorders—Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008. *MMWR Surveillance Summaries*. 2008; 61:1–19.
- Lord C, Rutter M, Le Couteur A. Autism Diagnostic Interview–Revised: a revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders*. 1994; 24:659–685. [PubMed: 7814313]
- Lord, C.; Rutter, M.; DiLavore, P., et al. Autism Diagnostic Observation Schedule. Los Angeles, CA: Western Psychological Services; 1999. WPS edition
- Mullen, E. Mullen Scales of Early Learning. Circle Pines, MN: American Guidance Service; 1995.
- Nicholas J, Carpenter L, King L, et al. Autism spectrum disorders in preschool aged children: prevalence and comparison to a school-aged population. *Annals of Epidemiology*. 2009; 19:808–814. [PubMed: 19541501]

- Nonkin-Avchen R, Wiggins LD, Devine O, et al. Evaluation of a records-review surveillance system used to determine the prevalence of autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2011; 41:227–236. [PubMed: 20568003]
- Robins, DL.; Fein, D.; Barton, M. Follow-up Interview for the Modified Checklist for Autism in Toddlers (M-CHAT FUI). 1999a. Self-published
- Robins, DL.; Fein, D.; Barton, M. The Modified Checklist for Autism in Toddlers (M-CHAT). Authors; 1999b.
- Robins DL, Fein D, Barton M, et al. Checklist for Autism in Toddlers: an initial study investigating the early detection of autism and pervasive developmental disorders. *Journal of Autism and Developmental Disorders*. 2001; 31:131–144. [PubMed: 11450812]
- Schopler, E.; Reichler, RJ.; Renner, BR. The Childhood Autism Rating Scale. Los Angeles, CA: Western Psychological Services; 1988.
- Sparrow, S.; Balla, D.; Cicchetti, DV. Vineland Adaptive Behavior Scales. 2. Circle Pines, MN: American Guidance Services; 2005.
- Van Naarden Braun K, Pettygrove S, Daniels J, et al. Evaluation of a methodology for a collaborative multi-source surveillance network for autism spectrum disorders—Autism and Developmental Disabilities monitoring Network, 14 Sites, 2002. *MMWR Surveillance Summaries*. 2002; 56(SS-1):29–40.
- Yeargin-Allsopp M, Rice C, Karapurkar T, et al. Prevalence of autism in a US Metropolitan area. *JAMA*. 2003; 289:49–55. [PubMed: 12503976]

Table 1

Record–review surveillance identification of children with an ASD.

ASD status based on diagnostic evaluation at Georgia State University		
	ASD (n = 4)	Non-ASD (n = 6)
<i>Record–review excluding early intervention records</i>		
ASD	0	0
Non-ASD	4	6
Total	4	6
<i>Record–review including early intervention records before diagnostic evaluation</i>		
ASD	2	0
Non-ASD	2	6
Total	4	6
<i>Record–review including early intervention records after diagnostic evaluation</i>		
ASD	4	0
Non-ASD	0	6
Total	4	6

ASD: autism spectrum disorder.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript