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Options for Autism Spectrum Disorder Surveillance in Maine

Report prepared by the Maine Center for Disease Control and Prevention
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Introduction

Background

An April 10, 2006 memorandum from the Health and Human Services Committee of the Maine State Legislature directed the Maine Center for Disease Control and Prevention (Maine CDC) to "work with stakeholders and provide a report to the Committee in January 2007 on options for developing and implementing a system for determining the incidence rates and prevalence of autism spectrum disorders in Maine."

Maine CDC staff met with stakeholders in May 2006 to discuss plans for the project. Staff then researched possible surveillance options, which were presented and discussed at another stakeholders meeting in October 2006. (Stakeholders group members are listed in the Appendix.)

This report begins with a brief overview of autism spectrum disorders (ASD) and general surveillance concepts. Each surveillance option is then described, including general characteristics, resources needed, strengths, limitations and barriers, and the recommendations of stakeholders and Maine CDC staff. The report concludes with a summary of recommendations for next steps toward building an ASD surveillance system in Maine. (Note: The term "autism spectrum disorders" is used in this report rather than "pervasive developmental disorders", which is the diagnostic category heading under which the various autism spectrum disorders fall.)[1]

Autism spectrum disorders

ASD refers to a continuum of cognitive and neurobehavioral disorders that include three core features: (1) impairments in socialization; (2) impairments in verbal and nonverbal communication, and (3) restricted and repetitive patterns of behavior.[2] The impairment associated with ASD is lifelong.[3] ASD includes autistic disorder, Asperger disorder, and pervasive developmental disorder – not otherwise specified (PDD-NOS).[4] Distinctions between these specific diagnoses are based on the number and severity of behaviors. Clinicians must make subjective decisions about the quality of behaviors when applying diagnostic criteria. As such, there can be inconsistencies in the use of diagnostic labels.[5]

There is no single medical or genetic screening test, diagnostic laboratory test, or standardized psychological measure available to diagnose ASD; the diagnosis is based on developmental and medical history and the presence of unusual patterns of behavior.[5, 6] ASD can manifest differently at different ages and developmental levels,[7] which makes it more difficult to identify children with the condition.[8]

It is possible to reliably detect ASD by 3 years of age, and in some cases as young as 18 months. Eventually, it may be possible to accurately diagnose ASD by 1 year of age or even earlier.[9] Early diagnosis is important, because intensive early intervention (i.e., 2+ years during the preschool years) has been shown to lead to improved outcomes for most young children with ASD.[2] However, diagnosis is often delayed until school age;[10] only about half of children with ASD are diagnosed before kindergarten.[9]

Surveillance

Public health surveillance is defined as the "ongoing, systematic collection, analysis, interpretation, and dissemination of data on health-related events for use in public health action to reduce morbidity and mortality and to improve health."[11]

Prevalence and incidence are two measures frequently reported by surveillance systems. Prevalence refers to the number of people in a population who have the condition at a specified time. Prevalence is particularly important for estimating services needed.[12] Information on the prevalence of ASD and characteristics of individuals with ASD could help the state better develop or tailor services for people with the condition.[13]

Incidence, on the other hand, refers to the number of people in whom the condition first begins during a specified period of time. Incidence rates are more sensitive indicators than prevalence rates of possible changes in etiologic factors. Determining the incidence of ASD is difficult because age of onset is hard to define and to ascertain. Most epidemiologic studies of ASD have therefore looked at prevalence. The few studies that have reported incidence have done so based on year of diagnosis rather than year of onset. Since ASDs are long-lasting, prevalence will be larger than incidence.[12]

Recent prevalence rates for ASD are consistently higher than those reported in the 1970s and 1980s. The question remains as to precisely how much of the increase is due to an actual increase in the occurrence of the condition. It is "widely accepted, however, that at least a significant part of the dramatic increase is due to a combination of other factors,"[4] including: (a) broadening of diagnostic criteria and concepts; (b) recognition that ASDs sometimes co-occur with other conditions and can occur within a wide range of cognitive abilities; (c) increased awareness of how autism presents in children with IQ < 50 or IQ > 70; (d) increased awareness on the part of professionals and the public leading to more (and earlier) referrals for assessment; (e) increased and improved services and better access to those services; (f) decreasing age at diagnosis; (g) differences in case definition and case-finding methods; (h) differences in the size of the population being studied, and (i) migration.[12, 14-19] Rutter concludes that while a large proportion of the increase in the rate of ASD is explained by factors such as those noted here, we cannot rule out the possibility that there has been a true rise in the incidence of ASD.[20] Fombonne adds that prevalence data demonstrate the magnitude of the problem, which has "clearly been underestimated in the past."[17]

It is important to take the factors mentioned in the previous paragraph into account when designing an ASD surveillance system. For example, it is crucial that the case definition and case finding procedures remain constant over time, that the system control for population changes, and focus on an age by which one would expect most children to have been diagnosed, etc. Addressing these issues will maximize the likelihood that the surveillance system can accurately estimate how common ASDs are in Maine and whether there are changes in prevalence over time. The selected surveillance option(s) must be sustainable, with the expectation that needed resources will continue to be available for many years.

All surveillance systems should be evaluated periodically, and modified as needed, so that the data they yield can be accurately interpreted.[21] Quality control procedures also are needed.[22]

The federal Center for Disease Control and Prevention's *Updated Guidelines for Evaluating Public Health Surveillance Systems*[23] would provide a useful framework for evaluating ASD surveillance efforts in Maine.

Autism Spectrum Disorder Surveillance Options

Maine CDC staff worked to develop a comprehensive listing of ASD surveillance options, ranging from simple ones that would require few resources to highly complex ones that would be resource intensive. Some of the options utilize existing data (e.g., education administrative data, clinical administrative data, survey data); others would require the collection of new data.

Eleven ASD surveillance options were identified:

- Centers for Disease Control and Prevention model
- Department of Education December 1 count
- Maine Education Data Management System
- Clinical administrative datasets
- Linkages between multiple datasets
- National Survey of Children's Health
- National Survey of Children with Special Health Care Needs
- Maine Child Health Survey
- Registry
- Reportable condition
- Population-based screening

Each identified option is presented below, including general characteristics, resources needed, strengths, limitations and barriers, and stakeholder group recommendations.

Centers for Disease Control and Prevention Model

Description

- Model used by the federal Center for Disease Control and Prevention's (CDC) Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP), an active, population-based program that monitors the occurrence of five developmental disabilities (ASD, mental retardation, cerebral palsy, hearing loss, and vision impairment) in 8-year-old children.[6]
- ASD defined as including autistic disorder, PDD-NOS, and Asperger syndrome; does not include childhood disintegrative disorder (due to its rarity) or Rett disorder (due to the debate over whether it is an ASD).[6]
- Uses both school and clinical (e.g., hospitals and associated clinics, developmental disabilities diagnostic/evaluation centers, private physicians/clinicians) data sources.[6]
- Two-phase process:

    - Phase 1: Abstractors screen records looking for ASD diagnoses, indications that child might have an ASD, or descriptions of behaviors associated with ASD diagnostic criteria; if any of these are present, the record is abstracted, including demographic information, test results (e.g., intelligence, developmental, adaptive behavior, autism), verbatim descriptions of behaviors associated with ASD, and other important information.[6]
        - At school sources, screen special education records of children with select eligibilities (e.g., autism, intellectual disability).
        - At clinical sources, screen records of children with select diagnoses (including, but not limited to, ASD).
    - Phase 2: Clinician reviewers with training/experience in diagnosis/assessment of ASDs review and code abstracted information and determine whether child meets ASD case definition.
- Based completely on record review; no physical examinations of the children are done.
- Access to records is through institutional permission rather than parental consent.[6]
- Used in Atlanta and by several states that CDC funds to conduct ASD surveillance.

Resources Needed

- Recommended staffing for state ASD surveillance projects funded by CDC:[24]
    - Principal investigator (part-time);
    - Project coordinator (full-time);
    - 2+ abstractors (full-time);
    - 2+ clinician reviewers (part-time);
    - Epidemiologist (minimum of .30 FTE);
    - Programmer / data manager (minimum of .20 FTE).
- Average annual funding from CDC to states doing ASD surveillance: approximately $350,000 per state per year; most project staff are supported by this funding.[24]

Strengths

- Multiple data sources, so less likely to miss children who have an ASD; for example, children who are home-schooled and therefore not picked up through schools might be picked up through a clinical source.
- Probably the most complete case ascertainment of any of the surveillance options being considered in this report.
- Does not rely on child having been diagnosed with an ASD or receiving special education services in an autism program; 18% of the children who met the ASD case definition in 1996 did not have a prior ASD diagnosis or indications of suspected ASD.[6]
- Would be able to compare prevalence rates in Maine to those found in CDC-funded states using similar methodology.

Limitations / Barriers

- Challenges in gaining access to data sources:
    - Education records are a critical component of the CDC model; in 1996 study year, 40% of children with ASD in MADDSP were identified only at school sources.[6] However, there are challenges accessing school records. The Family Educational Rights and Privacy Act of 1974 (FERPA) requires parental consent to access

education records, except in limited circumstances. In 2000, the U.S. Department of Education (US DOE) entered into a memorandum of agreement with CDC, designating CDC as an authorized representative of US DOE and allowing access to education records without parental consent. Several states funded by CDC for ASD surveillance entered into similar agreements with their state DOEs. However, a 2003 change in US DOE's interpretation of FERPA stated that written parental consent is needed to access personally-identifiable education records and that only individuals under the direct control of a state education agency can be designated as authorized representatives. US DOE did not renew the memorandum of agreement with CDC when it expired in 2005. As of May 2006, 9 of the 16 autism surveillance sites funded by CDC had state-level memorandums of agreement giving them access to education records.[13]

  - Discussions would have to be held with the Maine DOE to determine if a memorandum of agreement could be developed that would allow access to education records without parental consent.
  - If parental consent is required, low response rates are expected, which would result in incomplete data.[13] Not only would the ASD prevalence rate likely be underestimated, but also the descriptive picture of children with ASDs might be biased, because children of parents who provide consent might well be different from children of parents who do not consent.
  - A 2003 law required the U.S. Department of Health and Human Services and the U.S. DOE to submit a report to Congress by June 2005 describing ways to overcome the challenges CDC faces in accessing education records. As of June 2006, US DOE and CDC had not agreed on options and could not estimate when the report would be submitted.[13]
- While provisions of HIPAA allow clinical sources ("covered entities") to "provide protected health information to public health authorities … without the consent or authorization of the individual,"[25] it does not requires that they do so. Any surveillance project likely would still need to obtain institutional review board approval or exemption at many, if not all, clinical sources.

- Resource intensive in terms of staff, funding, and time; challenging to produce timely prevalence estimates.
  - Likely need to limit to a single year of age in order to be able to produce timely estimates.
- CDC provides extensive training and support to states receiving funding for ASD surveillance. It would be quite difficult to use their methodology without such training and support.
- Prevalence rates reflect administrative prevalence; child must have come to the attention of service providers in order to be picked up by the surveillance program; will miss children with ASD who are not served by any of the data sources.
- Validation study needed to determine what percentage of children who meet the surveillance case definition would also meet clinical diagnostic criteria; such a study is underway at CDC.
- Prior CDC funding opportunities for states to conduct ASD surveillance have required that the proposed surveillance be conducted in an area that has at least 30,000 births per year.[26-28] If CDC offers future funding opportunities with similar restrictions, Maine would have to

partner with at least one other state to meet this requirement, thereby increasing the complexity of the surveillance system and the resources needed to implement and maintain it.

Stakeholder Group Recommendation

- Consider pursuing this option only if CDC funding becomes available in the future.

Follow-Up Note

- CDC is currently funding three sites to develop methodology to determine the population-based prevalence of ASD in early childhood (i.e., under 4 years of age). These three sites are now eligible to apply for additional funding to implement the methodologies they develop.[29, 30] These methodologies might (after they have been implemented and revised as needed) provide ideas for additional surveillance options in Maine.

Department of Education December 1 Count

Description

- Aggregate administrative data maintained by the Office of Special Education Programs, U.S. Department of Education on children served under the Individuals with Disabilities Education Act (IDEA), the federal law designed to ensure a free appropriate public education for students with disabilities.[3]
- Includes students receiving "special education services that are provided by or paid for by the state, whether in private or public school."[31]
- Part C serves children ages birth through 2 years; Part B serves children ages 3 through 21 years.
- Available data for children served under Part B includes primary disability classification as of December 1st of each school year.
- Autism added as an optional primary disability category in the 1991-1992 school year and became a required category beginning with the 1992-1993 school year.[32]
- US DOE provides a definition of autism.[33] States, and districts within a state, operationalize the federal definition as they see fit.[34]
    - Maine Administrators of Services for Children with Disabilities defines autism as one of the pervasive developmental disorders, including Pervasive Developmental Disorder (PDD), PDD-NOS, Asperger syndrome, autistic disorder, Rett syndrome, and childhood disintegrative disorder.[35]

Resources Needed

- Epidemiologist (part-time).

Strengths

- Covers a wide age range.
- Uses existing data already collected by Maine Department of Education, so fewer resources are needed.
- Data are available in a timely manner.
- Easy to access data on federal and Maine Web sites.

Limitations / Barriers

- Will likely underestimate the true prevalence of ASD because will not include children with ASDs who:
    - Are home-schooled (approximately 2% of Maine students were home-schooled in the 2004-2005 school year[36-38]; no disability information is available on these children);
    - Attend private school at family's expense (approximately 7% of Maine students attended private schools in the 2004-2005 school year[36-38]; we do not know what proportion of these were at family's expense; if home school district paid the tuition, then child would be included in the December 1 count data);
    - Are classified under a different disability category (e.g., other health impairment) – CDC MADDSP 1996 data showed that 91% of children who met the ASD case definition received special education services, but of these children, only 41% of the 3-10 year olds[6] and 48% of the 6-10 year olds[3] had autism as their primary eligibility category;
    - Have multiple disabilities and are counted in the "multiple disabilities" category or in the category for one of their other disabilities;
    - Are not receiving any special education services (i.e., are served completely through regular education services).
- These are administrative data and were not intended to be used for tracking autism prevalence[39]; the IDEA disability classification is "an administrative tool rather than a standardized clinical diagnosis."[31]
- Not all children with an autism primary disability would meet clinical criteria for ASD diagnosis.
- Preschoolers are usually (though not always) placed in developmental delay category, rather than a more specific disability category[31] such as autism.
- Would likely need to restrict analyses to 6-17 year olds. Data are available for birth to 21-year-olds, but autism category only available for 3-21 year olds. Also, not all 3-5 and 18-21 year olds are in school, so it would be hard to identify an appropriate denominator for prevalence rates for 3-5 and 18-21 year olds.
- States now have the option of using the "developmental delay category" beyond age 5 years. If Maine starts using developmental delay as a category for 6-9 year olds, that will make it harder to use DOE data because younger children with autism might be classified in the developmental delay category.
- Concerns have been raised about anomalies in the data that would make it unreliable (e.g., significant increases in numbers even at age 17 years; unexpected drop in prevalence between 11 and 12 years followed by increases at older ages).[39]
- Need to be careful when comparing school-data-based rates across states or across districts within a state; differences may be due, at least in part, to differences in states'/districts' abilities to identify/serve children with ASDs.
    - Different states have different eligibility criteria for autism, which in turn influence the autism rate obtained using school data. Oregon, which has the highest autism prevalence using December 1 count data, has broad criteria for autism eligibility.[39]
    - Study in Texas (using school data, but not December 1 count data) found that rates of diagnosed autistic disorder (a subset of ASD) were associated with school district revenue, the proportion of children in the district who were economically disadvantaged, and school population size.[40]

  - National study found that administrative prevalence of autism in DOE data was positively associated with “education-related spending, the number of pediatricians in the state, and the number of school-based health centers in the state.”[41]
- Rates may fluctuate due to changing eligibility criteria over time.
- Rates within a state may vary based on how eligibility criteria are operationalized across districts.
- Need to consider whether changes in prevalence could be due in part to people choosing to move to or from Maine because they have a child with an ASD.
- Efforts by the education community to identify and serve children with ASD may have changed over time,[31] resulting in changes in prevalence rates calculated using DOE data.
- Need to also monitor prevalence of other conditions (e.g., specific learning disabilities) to see if increase in autism prevalence is accompanied by decrease in prevalence of other condition(s) and might therefore be due to diagnostic substitution.[34]
- Cannot simply use the raw data as provided by DOE; need to calculate rates in order to take changes in population size into account.[17]
- Aggregate data, so cannot be linked with other data sources to obtain de-duplicated count of children with ASD.

Stakeholder Group Recommendation

- Based on limitations listed above, do not use this option.

Maine Education Data Management System (MEDMS)

Description

- Administrative database of Maine students, including primary disability for students in special education.

Resources Needed

- Epidemiologist (part-time).

Strengths

- Same as for December 1 count option.
- Individual-level records, so might be usable for linkages.

Limitations / Barriers

- Same as for December 1 count option.
- Maine CDC does not currently have access to this database.
- FERPA issues would have to be addressed, unless all identifiers were removed from dataset.

Stakeholder Group Recommendation

- Would be valuable to link this dataset with one or more clinical administrative datasets; see “Linkages between Multiple Datasets” option below.

- Maine CDC could provide epidemiologic technical support to Maine DOE on the structure, content, and use of the MEDMS dataset.

Clinical Administrative Datasets

Description

- Administrative datasets are available containing records of certain health care encounters; records include International Classification of Diseases (ICD) codes relevant for each encounter.
    - ICD codes for ASD include 299.0 for infantile autism and 299.8 for PDD-NOS and Asperger disorder.
- Possible datasets include:
    - All-payer (paid medical, dental, and pharmacy claims from most insurers in the state, including MaineCare and Medicare; available from the Maine Health Data Organization);
    - MaineCare (Medicaid);
    - Hospital outpatient (hospital outpatient clinic visits, including emergency room; available from the Maine Health Data Organization).

Resources Needed

- Epidemiologist (part-time).

Strengths

- Covers a wide age range.
- Uses existing data already collected by other agencies, so fewer resources are needed.
- All-payer database includes a unique identifier that allows analyst to identify encounters for a single person across multiple providers; same should be true of the MaineCare dataset.

Limitations/Barriers

- Only identifies individuals who have been diagnosed with ASD and for whom encounter data includes an ASD ICD code.
- ASD ICD codes (e.g., 299.0, 299.8) may not be reimbursable under certain circumstances, so providers may bill using a different code, such as the one for static encephalopathy.
- No way to validate diagnoses (i.e., ICD codes).
- At present, Maine CDC does not have access to the MaineCare dataset.
- Not all individuals with ASD are enrolled in MaineCare.
- Outpatient dataset does not include a unique identifier that would allow analyst to identify encounters for a single person across multiple providers, so end up counting number of outpatient visits, rather than number of people making those visits.
- All-payer database is only available beginning in 2003.[42]

Stakeholder Group Recommendation

- Would be valuable to link all-payer and/or MaineCare datasets with the Maine Education Data Management System data; see "Linkages between Multiple Datasets" option below.
- Explore whether the MaineCare dataset contains more in-depth information than could be found by looking at MaineCare records in the all-payer dataset.

Linkages between Multiple Datasets

Description

- Obtain individual-level data from multiple data sources (preferably school and clinical sources) and then link them to get a deduplicated count of individuals with ASD.

Resources Needed

- Epidemiologist (part-time);
- Data manager / programmer (part-time).

Strengths

- Has some of the strengths of the CDC model without requiring as many resources.
- Could cover a wide age range.
- Multiple sources, so less likely to miss children with ASD.
- Uses existing data already collected by other agencies, so fewer resources are required.

Limitations / Barriers

- Would need to include individual level school records in order to maximize case ascertainment
    - Requires at least some identifiers, so would need to address FERPA issues.
- Datasets would have to have identifiers in common that could be used for linkage.
- No way to validate diagnoses.
- Different data sources may use different ASD case definitions (e.g., clinical diagnosis at a doctor's office vs. primary disability classification at a school).
- Can only identify children who have already been diagnosed with ASD by a clinical provider or been given an autism primary disability classification at school.

Stakeholders Group Recommendation

- Continue exploring this option for Maine.
- Consider linking Maine Education Data Management System (MEDMS) dataset with all-payer and/or MaineCare datasets. Next steps would include, but are not necessarily limited to:
    - Maine CDC and DOE staff should meet to discuss FERPA issues since identified individual-level data would be needed.
    - Obtain data dictionary (i.e., list of data items) for all datasets under consideration

        - Determine if MaineCare database has greater depth of information on individuals with ASDs; decide whether to whether to include MaineCare, all-payer, or both datasets in linkage.
        - Determine if variables are present that could be used to link the datasets.
    - Obtain necessary permissions to use datasets.
    - Obtain institutional review board approval (or exemption) for the project.

National Survey of Children's Health

Description[43]

- Survey of the physical and emotional health of children from birth through 17 years of age.
- Designed to provide both national and state-level estimates.
- Sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration.
- 2003-2004 survey included question: "Has a doctor or health professional ever told you that [CHILD] has autism?"[44]
- Next survey cycle has not yet been announced, but could be 2007-2008.

Resources Needed

- Epidemiologist (part-time).

Strengths

- State-level estimates are theoretically possible.
- Uses existing data already collected by another agency, so fewer resources are required.
- Dataset can be downloaded at no charge from the National Center for Health Statistic's Web site.
- Covers a wide age range.

Limitations / Barriers

- Unable to obtain reliable or precise estimate for autism in Maine using the 2003-2004 survey data; the estimate does not meet the National Center for Health Statistics' standards for reliability or precision (i.e., the relative standard error was >30%).
    - Might be possible to pay for extra surveys to be administered during next round to increase likelihood that Maine would have large enough sample size to obtain reliable/precise autism prevalence estimates.
- Survey question asks only about "autism"; it is not clear how parents of children who have PDD-NOS or Asperger disorder would have answered the question.[45]
- Parent-reported data; no means of validating parental responses.
- Parental report depends on family having access to appropriate health / educational services for diagnosis and on providers communicating an autism diagnosis to the parent.[45]
- May be missing children who meet autism eligibility requirements at school but have not been diagnosed with ASD by a health care professional.

- Will miss children with ASD who have not yet been diagnosed and who are not receiving any special education services for autism.
  - Higher percentage of parents reported concerns about learning and emotional problems than reported professional diagnoses (6-17 year olds; 2003 survey); may reflect children whose developmental problems have not yet been recognized by health care providers.[15]
- Question of whether children of survey nonrespondents are more likely to have an ASD.
  - No consistent evidence that this is the case (based on screening studies), but may miss some children with ASD due to nonrespondents.[18]

Stakeholders Group Recommendation

- Not a good option at present due to difficulty getting reliable/precise state-level estimates and too narrow wording of survey question.
- Reconsider using this option if question wording is broader in next cycle and state-level estimates are possible.

National Survey of Children with Special Health Care Needs

Description[46]

- Survey of the prevalence and impact of special health care needs among children from birth through 17 years of age.
- Designed to provide both national and state-level estimates.
- Sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration.
- 2005-2006 survey included question: "To the best of your knowledge, does (S.C.) [subject child] currently have Autism or Autism Spectrum Disorder, that is, ASD?"[47]
- Next survey cycle has not yet been announced, but could be 2009-2010.

Resources Needed

- Epidemiologist (part-time).

Strengths

- State-level estimates are theoretically possible.
- Uses existing data already collected by another agency, so fewer resources are required.
- Will be able to download dataset at no charge from the National Center for Health Statistic's Web site.
- Covers a wide age range.

Limitations / Barriers

- We probably will not know until Fall 2007 whether we will be able to obtain a reliable/precise estimate for autism / ASD in Maine from the 2005-2006 survey.

    - Might be possible to pay for extra surveys to be administered during next round to increase likelihood that Maine would have large enough sample size to obtain reliable/precise autism / ASD prevalence estimates.
- Survey question asks only about “autism” or “autism spectrum disorder (ASD)”; it is not clear how parents of children who have PDD-NOS or Asperger disorder would have answered the question – they may or may not understand that the latter two conditions are considered ASDs.
- Parent-reported data; no means of validating parental responses.
- Parental report depends on family having access to appropriate health / educational services for diagnosis and on providers communicating a diagnosis to the parent.[45]
- Will miss children with ASD who have not yet been diagnosed and who are not receiving special education services for autism.
- Question of whether children of survey nonrespondents are more likely to have an ASD.
    - No consistent evidence that this is the case (based on screening studies), but may miss some children with ASD due to nonrespondents.[18]

Stakeholders Group Recommendation

- Check to see if state-level estimates are possible when data from the 2005-2006 survey are released in 2007.
- Probably not a good option at present due to likely difficulty getting reliable/precise state-level estimates and too narrow wording of survey question.
- Reconsider using this option if question wording is broader in next cycle and state-level estimates are possible.

Maine Child Health Survey

Description[48]

- Survey of health and well-being of Maine kindergarten and 3rd grade students.
- Developed and run by Maine CDC.
- Completed by parents.
- Done every 2-3 years.
- Two ASD questions will be added to the survey, beginning with the 2006-2007 cycle:
    - To the best of your knowledge, does your child currently have Autism, PDD-NOS, or Asperger's Disorder?
    - Does your child receive special education services for Autism, PDD-NOS, or Asperger's Disorder at school?

Resources Needed

- Epidemiologist (part-time).

Strengths

- Could generate state-level prevalence estimates (given high enough response rate).

- Could provide estimate of percentage of children with ASD that are receiving special education services through schools (again, given high enough response rate).
- Tacking on to an existing survey, so fewer resources are required.
- Local control over wording of questions (unlike national surveys).

Limitations/Barriers
- Response rate on previous kindergarten/3rd grade Maine Child Health Survey was quite low; as such, results were not considered to be representative of all kindergarten/3rd grade children in the state.
- Parental report depends on family having access to appropriate health / educational services for diagnosis and on providers communicating an autism diagnosis to the parent.[45]
- Parent-reported data; no means of validating parental responses.
- Will miss children with ASD who have not yet been diagnosed and who are not receiving any special education services for autism.
- Question of whether children of survey nonrespondents are more likely to have an ASD.
    - No consistent evidence that this is the case (based on screening studies), but may miss some children with ASD due to nonrespondents.[18]

Stakeholders Group Recommendation
- Proceed with this option, provided response rate for 2006-2007 survey is sufficiently high. (General guideline is that response rate should be 60% or higher in order for results from survey respondents to be considered representative of all kindergarten and 3rd grade students in the state.)

Follow-Up Note
- In January 2007, it was announced that the 2006-2007 kindergarten-3rd grade survey cycle would be cancelled, due to low school participation. The next administration of the survey might, instead, take place in the 2007-2008 school year.[49]

Registry

Description
- Listing of all individuals with ASD in a given area.
- ASD registries exist in several states, with varied purposes (e.g., determine prevalence, recruit research subjects) and characteristics (e.g., mandatory vs. voluntary). Examples include:
    - Utah Registry of Autism and Developmental Disabilities[50]
        - Purpose: Collect and share information about prevalence of ASD and other disabilities; measure change in prevalence over time; provide information about ASD to families, providers, and the public; training.
        - Self-registration; voluntary; all ages; information collected includes demographic, family (parents, siblings, other), diagnostic, school, and employment.

- Autism Center of Virginia Registry[51]
    - Purpose: Listing of individuals and families who want to know when people are being recruited for research projects.
    - Voluntary enrollment by families with a child or other family member who has been diagnosed with ASD; provide basic information (name, contact information, date of birth, general family information, educational services received); complete autism screening questionnaires (with summary score information included in registry); all ages.
- Delaware Autism Surveillance and Registration Program[52]
    - Purpose: Provide accurate and ongoing source of data for public health officials to use for prevalence estimation, cluster investigation, identification of risk factors, and assessment of outcomes.
    - Birth through 17 years, with confirmed autism; Department of Health and Human Services will have access to medical records of children with confirmed autism; religious exemption; information collected includes contact, demographic, age symptoms first noted, diagnostic information, current medications, co-morbid conditions.
    - Mandated reporting sources (physicians, surgeons, dentists, podiatrists other health care providers [including, but not limited to: psychiatrists, school and clinical psychologists, speech and language pathologists, licensed clinical social workers, nurses (including school nurses)], hospitals, clinical labs); must report within 30 days of diagnosis; follow-up information submitted at least once each year.
    - Registry law went into effect in January 2006.[53]
- Illinois – Autism Spectrum Disorders Registry[54]
    - Purpose: Monitor incidence; better target intervention resources; inform health professionals and the public about risks, early detection and treatment; promote high quality research; "promote Illinois as a national leader in research into the causes, effects, and treatment of autism spectrum disorders."
    - Mandated reporters include physicians and clinical psychologists; also voluntary self-reporting.
    - Report within 30 days of diagnosis.
    - Law went into effect on 8/19/2005.
    - Registry has not yet been funded.[55]
- New Hampshire Autism Registry[56]
    - Purpose: Conduct epidemiologic surveys of ASD and facilitate services planning for children and families.
    - Mandated reporters include physicians, psychologists, and other licensed/certified health care providers who diagnose children with ASD; information to be reported will include diagnostician, demographics, and specific diagnosis.
    - Effective date was 8/7/2006; provision that the "department of health and human services shall seek grant money from the Centers for Disease Control and Prevention and any other appropriate entity and may accept grants, gifts, and donations from any source for the registry … The department of health and human services shall not expend any state appropriations for any purpose

    - related to the establishment of the registry. The autism registry shall not become operational until the grant or other appropriate grants or moneys are secured."
  - Missouri Autism Project Registry[57]
    - Purpose: Serve as comprehensive information resource to direct state policies and service decisions; provide autism information to families and health care providers; facilitate research to improve outcomes of individuals with ASD.
    - 1 year planning grant awarded in June 2004.
  - West Virginia Autism Spectrum Disorders Registry[58, 59]
    - Primary purpose: Track the number of West Virginia residents diagnosed with ASD each year.
    - Began 1/1/2004.
    - ASD is a reportable condition; mandated reporters include "neurologists, pediatricians, family physicians, psychiatrists, clinical psychologists. *School psychologists are not required to report at this time*"; must report within 1 month of diagnosis; report demographic, diagnostic, medication, and diagnostician information.
    - Does not collect name, address or phone number; does collect first letter of last name, last 4 digits of social security number, and date of birth.
    - Legislatively mandated.
- Could be done in tandem with making ASD a reportable condition; see next surveillance option.

Resources Needed
- Epidemiologist (part-time);
- Data manager / programmer (part-time);
- Project coordinator (part-time).

Strengths
- Could cover a wide age range.
- Self-reporting could lead to inclusion of individuals who would be missed using other options for ASD surveillance.
- Might be able to calculate both incidence and prevalence rates (but see limitations section below).
- Could be used to provide the Maine DOE and other service providers with a list of children and families who will need services (assuming participants agree to the release of their names).

Limitations / Barriers
- Questionable completeness.
- Could be difficult to calculate either incidence or prevalence. Incidence might be problematic unless registry tied to mandated reporting at time of initial diagnosis. Prevalence might be problematic unless develop method for tracking people over time in order to know if they are still living in Maine in future years.
- No validation of diagnoses; likely no way of knowing if a diagnosis is changed.
- Would miss children who have ASD but have not been diagnosed.

- May need enabling legislation.
- May not become operational if established through legislation, but no funding provided.

Stakeholder Group Recommendation

- Not a good option at this time; consider implementing in the future only if evidence becomes available from other states showing that accurate incidence and/or prevalence estimates can be obtained using registry data. Would need to come to consensus regarding purpose of registry.

Reportable Condition

Description

- Add ASD to list of notifiable conditions in Maine.
- Mandated reporters could include physicians and psychologists, as well as any other professionals who diagnose children with ASD.
- Examples of states in which ASD is a notifiable condition: Colorado,[60] West Virginia,[61] Washington.[62]
- Could be done in tandem with establishing an ASD registry; see previous surveillance option.

Resources Needed

- Epidemiologist (part-time);
- Data manager / programmer (part-time);
- Project coordinator (part-time).

Strengths

- Would allow us to calculate ASD incidence rates.
- Could cover a wide age range.
- Could tie in well with practice parameter on screening and diagnosis of autism that was published in 1999/2000 and endorsed by multiple professional organizations, including American Academy of Pediatrics and American Psychological Association;[2, 63] two-stage approach:
    - Stage 1: “Routine Developmental Surveillance and Screening Specifically for Autism” – performed by all providers on all children at every well-child visit to identify children at risk for any form of atypical development.
    - Stage 2: “Diagnosis and Evaluation of Autism” – more in-depth evaluation of already-identified children to differentiate autism from other developmental disorders.

Limitations / Barriers

- Probable incomplete reporting by providers.
    - Review of notifiable infectious disease reporting found completeness varied by condition: average of 79% completeness for tuberculosis, sexually-transmitted diseases and AIDS vs. average of 49% for other reportable infectious diseases.[21]

- Would miss children diagnosed in other states, leading to underestimate of incidence and possibly invalid conclusions about the geographic distribution[64] of ASDs in Maine.
    - Particular issue for children living in border communities who travel to out-of-state facilities for services and children who are diagnosed before moving to Maine.
- Can school psychologists be mandated reporters? Atlanta-based study found that 24% of children with ASD diagnoses were first diagnosed at a school.[65]
- Would need mechanism for updating registry if diagnosis is changed and individual who was originally diagnosed with ASD is no longer thought to have the condition.
- No validation of diagnoses; would not know if reporter was qualified to diagnose ASDs; possibility of misclassification if rely on provider's diagnosis without knowing qualifications, testing done, etc.
- Would be incidence based on when child was diagnosed.
    - Study in metropolitan Atlanta found that mean age at initial evaluation was 48 months, but mean age at first ASD diagnosis was 61 months;[65] many parents of children with ASD have serious concerns about their child's development long before child's initial evaluation.[66]
    - Trend toward more and earlier diagnosis would make it appear that incidence was increasing.[12]
- Could not be used to calculate prevalence because would not know if person was still living in Maine during subsequent years.
- Limitations on time and reimbursement are barriers to routine screening for ASD.[4]
- Would need periodic training for health care providers and mandated reporters:
    - Address issues that have been identified as contributing to failure to report (e.g., lack of awareness of legal requirement to report and which conditions are reportable; lack of awareness of how and to whom to report; belief that someone else will report the case; intentional failure to report in order to protect patient privacy).[21]
    - Provide training on practice parameters for screening and diagnosis of autism.[2, 63]

Stakeholder Group Recommendation

- Not a good option at this time; consider implementing in the future only if evidence becomes available from other states showing that accurate incidence estimates can be obtained using reportable condition data.

Population-based Screening

Description

- Developmental screening is a brief assessment designed to identify children for whom a more intensive diagnosis or assessment is needed;[67] involves the use of specific tests to identify unrecognized disorder.[68]
- ASD meets criteria for screening: "autism has long-term negative effects, it is reasonably common and a cause of parental concern, screening is non-invasive, and early intervention can be effective in reducing negative symptoms."[69]

- Screening should be as universal as possible; need assessment tools that can be used by non-medical staff (e.g., childcare workers), administered quickly and efficiently, and scored quickly.[70]
- Examples of screening tests include: Modified Checklist for Autism in Toddlers (M-CHAT); Social Communication Questionnaire (SCQ)[70]; Autism Spectrum Screening Questionnaire (ASSQ; for high-functioning autism, including Asperger syndrome, in school-age children)[71, 72]
- Screening instruments address domains thought to be important for diagnosis (e.g., language/communication, reciprocal social interaction, stereotyped behavior patterns); cutoff scores identify children who have high probability of having ASD and should receive further assessment.[70]
- Measures must have adequate sensitivity and specificity; may be more important to minimize false negatives than false positives, but there are costs associated with false positives.[70, 71]

Resources Needed

- Project coordinator (full-time);
- Epidemiologist (part-time);
- Data manager / programmer (part-time).

Strengths

- Could identify children with ASD at an earlier age than they might otherwise have come to attention of providers; the earlier a child is diagnosed, the earlier they can begin receiving intervention services.
    - Intensive early intervention (i.e., 2+ years during the preschool years) leads to improved outcomes for most young children with ASD.[2]
    - Early diagnosis is important to ensure that parents can receive genetic counseling before conceiving additional children.[73]
- Does not rely on children being referred to specialty clinics.[20]
- Does not rely on children having been diagnosed already or having come to the attention of providers, leading to more complete case ascertainment.
- Screening instruments (e.g., CHAT, M-CHAT) are available that do not require significant resources or training.[69]
- Could calculate incidence rates.
- Could be part of a broader screening effort that aims to identify children with various developmental disorders.

Limitations / Barriers

- Need to ensure that appropriate diagnostic and treatment services are in place before implementing screening program.
- Need to identify screening tool that works well in general population; screening tool would have to be appropriate for people with low reading levels or for whom English is a second language.
- Sensitivity and specificity of screening tools have varied quite a bit across studies.[70]
    - Checklist for Autism in Toddlers (CHAT): a general population screen study found high positive predictive value and specificity, but low sensitivity (missed 82% of the children ultimately identified as having autism).[68]

    - Modified Checklist for Autism in Toddlers (M-CHAT) is another possibility; one study found good specificity and predictive value positive; high sensitivity, but need more follow-up data; not yet enough evidence to recommend using routinely in primary care.[69]
- Consequences of screening "errors":[70]
    - Resources needed to assess false positives may take away from services for true positives.
    - Stress on family if child screens positive[70]; that stress is unnecessary stress if it turns out to be a false positive result.
    - False negative screens can lead to delays in diagnosis and treatment.
- Would have to be sensitive to possibility that parents of some children who screen positive may not yet have had concerns about their child's development and screening results might be totally unexpected.[68]
- Higher functioning children with milder symptoms might be less likely to be identified through screening process.[70]
- Would need to consider gathering screening information from both family and other (e.g., school, daycare) informants since autistic behavior may differ across settings[71] and parental reports may be unreliable.[70]
- Would not want providers to rely entirely on screening tools; primary care providers should have a general understanding of characteristics of ASD in young children.[70]
- Would require massive reporting system.
- Could not be used to calculate prevalence because would not know if identified children were still living in Maine during subsequent years.
- Participation rate might be low (both at initial screening stage and at later diagnostic stage).
    - Could result in selection bias due to non-participation: Norwegian study found that "reports on the prevalence of autism in a responder group underestimate true prevalence."[71]

Stakeholder Group Recommendation

- Not a feasible option.

Estimated Financial Costs for Staff in the Various Models

The following is an estimate of the costs for staff positions needed in the various models presented. Historically it has been a challenge to find well trained and qualified epidemiologists to work in Maine. Our best success has been hiring epidemiologists via a cooperative agreement with the University of Southern Maine, School of Applied Medical Sciences. A full time epidemiologist with salary, fringe and operational costs (rent, phone, information technology) costs about $100,000 per year. Annual salaries for other staff used in the various models include: full time project coordinator approximately $54,848 to $62,760 (Comprehensive Health Planner I at step 4, Comprehensive Health Planner II at step 4, respectively); full time programmer/data manager approximately $54,848; full time abstractor approximately $25 per hour via contract ($52,000 per year); and a part time clinician reviewer would cost about $75 to

$100 per hour times roughly 20 hours per week. In addition to the salary for the positions outlined above, one needs to plan for an additional $8,000 to $10,000 per year per each position for operating expenses (includes rent, phone, information technology, photocopying, printing and distribution of annual reports).

Summary

Eleven possible approaches to ASD surveillance in Maine were described, including key characteristics, resources needed, strengths, and limitations and barriers. All options were discussed at a stakeholder group meeting. Members of the stakeholder group also were given the opportunity to provide feedback on a draft of this report.

The stakeholder group and Maine CDC staff recommend a two-pronged approach to ASD surveillance in Maine at this time:

1. Use the Maine Child Health Survey to identify the prevalence of parent-reported ASD among kindergarteners and 3rd graders.
2. Explore the possibility of linking the Maine Education Data Management System database with one or more administrative clinical databases such as MaineCare or the all-payer dataset. Initial steps in this process would include contacting the dataset "owners" to request access to the data, finding out what variables are included in each dataset (including those that could be used to link datasets), addressing FERPA issues, and obtaining any needed institutional review board approvals or exemptions.

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Appendix: Stakeholders Group

Stakeholders group members received invitations to the two meetings, meeting minutes, and related emails, and had the opportunity to review and comment on a draft of this report.

Name	Organization
Julia Bell	Maine Developmental Disabilities Council
Mike Belliveau	Environmental Health Strategy Center
Laurie Bertulli [*]	Children’s Developmental Services, Maine Department of Education
Don Burgess [‡]	Maine Chapter, American Academy of Pediatrics
Linda Butler [‡]	Spurwink Institute
Andy Cook [‡]	Children’s Behavioral Health Services, Maine DHHS
Grace Crawford [‡]	Private practice physician
Victoria Dalzell	Maine Medical Center
Cathy Dionne [*]	Autism Society of Maine
Aubrie Entwood	Maine Chapter, American Academy of Pediatrics
Becky Grant-Widen [*]	Parent
Bill Hughes [‡]	Office of Adults with Cognitive & Physical Disabilities Services, Maine DHHS
Nancy Intrieri-Cronin [*‡]	Autism Society of Maine
Arthur Lerman	Maine House of Representatives
Andy Maclean	Maine Medical Association
Craig Mason	University of Maine, Orono
Cindy Mervis [*‡]	University of Southern Maine; Maine Center for Disease Control and Prevention, Maine DHHS
Dora Anne Mills [*‡]	Maine Center for Disease Control and Prevention, Maine DHHS
Douglas Patrick	Children’s Behavioral Services, Maine DHHS
John Pelletier [‡]	University of New England College of Osteopathic Medicine
Barbara Poirier [*]	University of Southern Maine
Valerie Ricker [*‡]	Maine Center for Disease Control and Prevention, Maine DHHS
Tim Rogers	Eastern Maine Counseling and Testing
Charyl Smith [*]	Maine Medical Association
Gordon Smith	Maine Medical Association
Joan Smyrski	Children’s Behavioral Health Services, Maine DHHS
David Stockford [‡]	Maine Department of Education
Lindsey Tweed [*‡]	Children’s Behavioral Health Services, Maine DHHS
Toni Wall [*]	Maine Center for Disease Control and Prevention, Maine DHHS

Maine DHHS: Maine Department of Health and Human Services

[*] Attended May 31, 2006 stakeholders group meeting
[‡] Attended October 4, 2006 stakeholders group meeting