

Memorandum of Understanding between the State Agency under the Individuals with Disabilities Act (IDEA) and the State Autism Developmental Disabilities Monitoring Program (State ADDM)

Parties

This Memorandum of Understanding (MOU) is made between the [State Department of Education (<SEA>), Local Educational Agency (<LEA>), OR State Lead Agency (<SLA>) (IDEA Agency)] which implements the early intervention program under [Part B or Part C] of the Individuals with Disabilities Education Act (IDEA), henceforth referred to as the "Data Provider" and the <State> Autism and Developmental Disabilities Monitoring Program (<State ADDM>). It designates <State ADDM> as an authorized representative of Data Provider for the purposes of collecting information from early intervention or education records in order to describe characteristics and estimate the prevalence of developmental disabilities in the state of <State>.

Background

In 2000, the Centers for Disease Control and Prevention (CDC) established ADDM, an ongoing population-based, multiple source surveillance system for developmental disabilities. Developmental disabilities (DDs) are defined as a group of chronic conditions attributable to a cognitive, physical (e.g., motor or sensory), speech, language, or psychological impairment manifested during the developmental period, birth to 22 years. These conditions, likely to be lifelong, may result in substantial functional limitations and problems with attaining markers of adulthood such as competitive employment or independent living. Developmental disabilities may also require specialized medical, educational and other intervention services throughout the lifespan of an individual requiring coordination by many different agencies to maximize the individual's functioning; lack of coordination may result in greater financial and societal costs.

<State ADDM> was established in <year> through funding received as part of a cooperative agreement with CDC. When <State ADDM> began, it monitored <conditions> among 8-year-old children who resided within <surveillance area> and has since evolved to also monitor early identification of DDs and transition. Currently all ADDM sites monitor 4-year children as well regarding early identification. <Describe any changes to surveillance area or conditions over time>. Currently, <State ADDM> assists public health initiatives through the following activities: <describe current activities>.

Under established agreements with relevant state authorities, <State ADDM> contributes de-identified data to the ADDM Network that is operated by CDC as part of its public health initiatives (see, <https://www.cdc.gov/ncbddd/autism/addm.html>). Through the ADDM Network, the CDC publishes estimates of the prevalence and characteristics of autism spectrum disorder (ASD) and other DDs based on information obtained from records of children living in communities across the United States (https://www.cdc.gov/mmwr/volumes/69/ss/ss6904a1.htm?s_cid=ss6904a1_w). ADDM also publishes community reports for each participating site. The <State ADDM> Community Report for X <year>, based on ADDM data, can be found here: <X>.

Purpose

<State ADDM>'s goals are to:

- Estimate the population-based prevalence of DDs (including autism, intellectual disability, and cerebral palsy), among children in communities throughout <State> over time;
- Describe characteristics of children with one or more DDs and how these characteristics may change over time;
- Assess possible relationships between birth characteristics, such as low birthweight and premature delivery, and the occurrence of DDs;
- Provide a basis of information for initiating special studies of children who have at least one of the DDs tracked by ADDM.

<State ADDM> provides the primary means of estimating the population-based prevalence of DDs (including autism, intellectual disability, and cerebral palsy) for children in <State>. <State ADDM> relies on information from both health and education records to form a complete picture of the prevalence. Medical sources provide data based on select ICD-9 and ICD-10 code criteria and educational sources contribute data on all children who receive special education services. Information from education records is an essential component of surveillance for DDs because many children receive developmental evaluations in educational settings. Without access to early intervention and education records, <State ADDM> will not be able to provide comprehensive population-based estimates of the occurrence of DDs among children in <State> or describe the entire set of services that children with DDs receive. Understanding the prevalence and characteristics of autism and other DDs allows for public health action that ensures timely access to intervention services. Additional information about ADDM can be found here: <https://www.cdc.gov/ncbddd/developmentaldisabilities/ADDM.html>.

<Data Provider>' as the IDEA Agency has the following goals:

- Serve as the <State educational agency, local educational agency OR State lead agency> responsible in the <State> for implementing the Individuals with Disabilities Act (IDEA), to make <early intervention services OR a free appropriate public education> available to <children with disabilities OR infants and toddlers with disabilities and their families>;
- Find ways to identify children eligible for IDEA services as early as possible (child find);
- Provide services under IDEA to eligible children with disabilities and their families;
- Improve outcomes for children receiving IDEA services; and
- Ensure that it meets IDEA's procedural safeguards (notice and disclosure), confidentiality requirements, and records retention and destruction requirements.

Data to be Shared

This section must identify the specific personally identifiable information (PII) under IDEA or Family Education Rights and Privacy Act (FERPA) that will be disclosed by the IDEA agency.

Once a year, <State ADDM> requests individual-level records that include a child's full name, address, date of birth, sex, race, ethnicity, guardian's name, and eligibility category (e.g. for IDEA Part B – the specific learning disability, speech language, Autism Spectrum Disorder, Developmental Delay, or for IDEA Part C, diagnosed condition and the nature of the condition if available, developmental delay, etc.). Records are requested based on October full-time education (FTE) counts and include records of children ages [birth to 3

or 3-21 years]. Data are supplied securely to <State ADDM> electronically through FileShare or via secure USB drives. Upon receipt of initial data, trained data abstractors, schedule appointments with schools or record centers to review records for additional data elements. With the proliferation of electronic information systems, <State ADDM> is also able to electronically receive data elements thereby reducing the burden of manual, in-person, review provided that such electronic transfer complies with applicable Federal and State information security requirements, including the Health Insurance Portability and Accountability Act of 1996 (HIPAA Security Rule) (see, <https://www.hhs.gov/hipaa/for-professionals/security/index.html>).

Data elements (see Appendix A) are abstracted from records by trained staff at each ADDM site. These data are entered into an online secured REDCap database. While the database is designed and updated at CDC, each <State ADDM> site maintains its own local copy of REDCap which houses PII. After data collection is completed, <State ADDM> sites submit de-identified data through a password-protected secure link to CDC for summary analyses. Data are limited to the minimum elements necessary to administer the program. The specific data elements collected are outlined in Appendix A. Any PII disclosed by the <Data Provider> as part of the data elements directly relates to the evaluation analyses identified in the Agreements section below.

Personal identifiers (i.e., name, address, date of birth, and guardian information) are collected in order for <State ADDM> staff to identify cases that were not recognized through other sources and to ensure that no child is counted twice. Identifiers are also needed in order to determine county of residence for prevalence estimates. Records are linked to birth records in order to determine if the child was born in <State> and to obtain additional birth certificate variables for descriptive and risk factor analyses. After records are linked, a Tracking ID is automatically assigned within the database, and specific personal identifiers (all names of child and guardian, addresses or other geographic identifiers, dates of birth and other dates) are removed. No personal identifiers are included in the analysis dataset that is provided by ADDM states to CDC such that it would be considered to contain personally identifiable information (PII) under IDEA or FERPA or Protected Health Information (PHI) under the HIPAA Privacy Rule.

Authorities

<State ADDM> conducts its work as a designated agent of the <State> Department of Health and <State> Department of Education through memoranda of understanding that are developed in each ADDM site. In addition, <State ADDM> may make additional memoranda or data use agreements directly with school systems.

<State ADDM> is an authorized representative of the IDEA agency under this MOU under the Individuals with Disabilities Education Act or IDEA. The IDEA contains two sets of confidentiality provisions. Part C of the IDEA contains confidentiality regulations in 34 C.F.R. Part 303 that apply to the early intervention records of children referred to Part C from birth to age three. Part B of the IDEA contains confidentiality regulations in 34 C.F.R. Part 300 that apply to the education records of children with disabilities ages three through 21. Both IDEA Parts C and B incorporate exceptions under FERPA in 34 C.F.R. Part 99. All three confidentiality regulations generally prohibit the disclosure of PII contained in early intervention or education records without the consent of the parent for children under the age of 18. Under IDEA Part C, early intervention records are defined as records required to be collected, maintained or used by the lead agency as part of its authority under 34 C.F.R. 303.403; the records accessed by <State ADDM> for purposes of this MOU are early intervention records, and subject to IDEA Part C. Under IDEA Part B in 34 C.F.R. Part 300 and FERPA in 34 C.F.R. Part 99, education records are defined as records directly related to a student and maintained by the school; the records accessed by <State ADDM> at the IDEA agency and local educational agencies and

public schools for purposes of this MOU are education records, and subject to FERPA and Part B of the IDEA.

Both IDEA and FERPA contain specific exceptions to the general rule that PII in early intervention or education records may not be disclosed without prior, written parental consent. Under FERPA regulations in 34 C.F.R. §99.35 (a)(1), PII may be disclosed under FERPA and IDEA to organizations in connection with an audit or evaluation of Federal or State supported education programs. By serving as an authorized representative under the audit/evaluation exception of the <Data Provider> and reporting data to <Data Provider>, <State ADDM> accesses the PII in early intervention or education records using this IDEA and FERPA exception for the purpose of providing evaluation information to help the IDEA program improve its child find, service delivery, and child outcomes purposes.

Confidentiality

Consistent with applicable laws including IDEA and FERPA, personnel working on <State ADDM> will treat all data collected as sensitive information that must be maintained as confidential and protected from both advertent and/or inadvertent disclosure to the fullest extent possible. As necessary and appropriate, <State ADDM> staff will undergo annual confidentiality training and may be required to sign a confidentiality nondisclosure agreements assuring that all identifying or potentially identifying information will be kept confidential and will be used only for purposes as provided in this MOU and applicable law. PII is not be disclosed to anyone other than those officials designated as the authorized representative of the IDEA agency and specifically the "authorized agents of <State ADDM>" and is protected from further redisclosure to any third party. The REDCap online database used for <State ADDM> is accessed through a secure access management portal (SAMS), which requires a multifactor authentication process.

Under IDEA, a participating agency and individuals working for a participating agency (which includes the SEA and LEA under IDEA Part B and the State Lead Agency and early intervention service (EIS) providers and programs under IDEA Part C) must comply with the confidentiality provisions of IDEA and maintain the confidentiality of PII in early intervention and education records. The participating agency must comply with the IDEA confidentiality provisions in the IDEA Part C regulations in 34 C.F.R. §§ 303.401 through 303.417 and IDEA Part B regulations in 34 C.F.R §§ 300.610 – 300.627. Under this agreement, <State ADDM > must comply with the privacy provisions of IDEA (and FERPA if applicable) as the authorized representative of the IDEA Agency.

How Data are used

Aggregated case counts are used with U.S. census data to determine prevalence estimates and track them over time. Data are used to describe characteristics of the disabilities being monitored, assess risk factors, examine short- or long-term outcomes (e.g., linkage to death certificates), and to assess attributes of the performance of the surveillance system such as reporting completeness, timeliness, accuracy, and validity. To meet the IDEA/FERPA exception and public health reporting requirements, <State ADDM> provides summary information in the form of reports, presentations, or specialized analysis to health and education sources based on established agreements and upon request to improve programing. Evaluation information can help the IDEA program improve its child find, service delivery, and child outcomes purposes. <State ADDM> is also willing to collaborate with partners to produce customized reports or analyses that address specific needs. Information might include age of identification or eligibility determination of ASD by subgroups (e.g., gender, race, county), disparities in identification of ASD or in receipt of ASD services, or disparities in classification of special education eligibility.

Agreements:

<State ADDM> agrees:

- That access to the data covered by this MOU shall be limited to the minimum amount of data and minimum number of individuals necessary to achieve its stated purpose (i.e., individual's access to the data will be on a need-to-know basis);
- That all PII gathered from the education records will be protected from further redisclosure to any third party in personally identifiable form to the extent required by applicable law;
- That PII from early intervention or education records will not be disclosed to anyone other than those officials designated as "authorized agents of <State ADDM>";
- That PII obtained by <State ADDM> from early intervention or education records be destroyed as soon as all statistical analyses have been performed as set forth in this MOU, or when the information is no longer needed for the purposes identified in this MOU and the requirement under the cooperative agreement with the CDC, whichever date comes first. <State ADDM> must also ensure compliance with the IDEA notice and data destruction requirements under 34 C.F.R. §§ 300.611 and 300.624 and 34 C.F.R. §§ 303.403 and 303.416.

<State ADDM> further agrees:

- To share aggregate data collected from early intervention or education records with <Data Provider> on a yearly basis or earlier upon request;
- To provide at least annually or semi-annually (at least six months) summary reports, presentations, or other analyses needed to fulfill the audit/evaluation requirements of the IDEA and FERPA exception to <Data Provider> at regular intervals or upon request;
 - Information may include, but is not limited to, prevalence of DDs by county for service planning and disparities in identification of children by sex, race/ethnicity, or other factors as well as any other analysis available that can help the IDEA program implements its child find, service delivery, and child outcomes for children who need IDEA services.
 - <State ADDM> could provide the <Data Provider> with the following analyses (to the extent that such data are available) on an aggregated and de-identified basis to help evaluate and improve implementation of the IDEA program:
 - Percentage of students with autism (identified in either/both health or school settings) who are receiving IDEA services and the eligibility category under which they are being served;
 - Percentage of students identified with autism but who were referred to the IDEA agency and not determined eligible for IDEA;
 - How co-occurring intellectual disability is associated with ASD eligibility and the types and frequency of use of IDEA services;
 - Characteristics (e.g., race/ethnicity, sex, socioeconomic status (SES) indicators) that are more common among kids with ASD who are receiving IDEA services under a different eligibility criteria (other than ASD);
 - Characteristics of children (e.g. race/ethnicity, sex, age at first diagnosis, SES indicators) identified with ASD who had been enrolled in early intervention services;
 - Characteristics of children (e.g. race/ethnicity, sex, age at first diagnosis, SES indicators) identified with ASD who had not been identified under either the diagnosed condition or

development delay eligibility criteria;

- For children not determined eligible under IDEA Part C by the IDEA agency, the levels of functioning in the five developmental areas under IDEA Part C and how the child was identified with ASD; and/or
- For children not determined eligible under IDEA Part B by the IDEA agency, aggregated deidentified data on how those students were diagnosed with ASD, what services were provided to those students through health care or other systems.

<Data Provider> agrees to:

- Designate <State ADDM> as an authorized representative of <Data Provider> for the purpose of accessing the data identified in this MOU for persons with DDs and performing the evaluation/analysis as specified by IDEA and FERPA;
- Provide access to specified data elements housed within any online system at the <Data Provider>;
- Provide letters of support to districts to facilitate establishment or renewal of district-level agreements for access to data elements not housed at the State level.

Modification provision

This agreement remains in effect for three years or until [X date] and may be revoked before that date by either party at any time upon [insert period of days: e.g., 30] days written notice. It has been reviewed and agreed upon by both parties.