



# Pennsylvania Autism Surveillance Project (PASP)



## What is PASP?

**The Pennsylvania Autism Surveillance Project (PASP)**, a cross-agency collaboration between the Pennsylvania Departments of Human Services (DHS), Education (PDE) and Health (DOH), is conducting public health surveillance as part of the Autism Developmental Disabilities Monitoring (ADDM) Network, under funding provided by the Centers for Disease Control and Prevention (CDC).



## What are the goals of PASP?

- **Improve early detection** of autism
- **Improve service delivery** for autism across the lifespan
- **Increase coordination of care** for children with disabilities across their schools and health care
- **Provide resources** to families



## What allows PASP to access educational records?

- Student records are accessed by trained PASP staff. Consent for record review is not required for PASP. As stated by the Privacy Technical Assistance Center, in accordance with **Family Educational Rights and Privacy Act (FERPA)**:  
Both IDEA and FERPA contain specific exceptions to the general rule that personally identifiable information (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. PASP 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.
- PASP is partnered with the Pennsylvania Department of Education to conduct public health surveillance.
- Data collection for ADDM surveillance is based on record review and does not require direct contact with students or families.





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## What safeguards will PASP incorporate to ensure confidentiality?

- PASP complies with all confidentiality policies, practices, and guidance as outlined in Family Educational Rights and Privacy Act (FERPA), Individuals with Disabilities Education Act (IDEA), and Health Insurance Portability and Accountability Act (HIPAA).
- PASP is able to electronically receive data elements thereby reducing the burden of manual, in-person, review and potential disruption in the school setting.
- Only minimal data necessary will be collected to meet the needs of our project.
- All data are de-identified prior to transmission to CDC.
- No student information or record review tracking will be identifiable or recognizable outside the scope of the project.
- Under no circumstance will identifiable data be shared with anyone outside of the PASP team
- PASP will destroy all identifying information when it is no longer needed and when PASP is complete.



## What can school districts expect of PASP staff?

- There will be no evaluative impact on your school or school district resulting from your engagement with PASP.
- School districts will contact PASP as soon as possible to determine how electronic records (including all assessments, evaluations, Evaluation Reports and IEPs) will be accessed or schedule dates and times to conduct record review. Please contact us at [RA-PWPASP@pa.gov](mailto:RA-PWPASP@pa.gov)
- School staff will provide access to records for requested children. If electronic records are not available and it is necessary to review records on site, school staff will provide a quiet and confidential location for PASP staff to conduct review.
- Trained staff will review and conduct abstraction of records using the provided list of children to identify suspected or confirmed diagnoses of Autism and/or Developmental Disability.
- De-identified data from surveillance at all school districts in Berks, Chester and Delaware counties will be included in national data as published by the CDC. [Click here for an example of a recent report from the CDC ADDM Network.](#)



## What can PASP offer to school districts?

- A snapshot of autism prevalence in your district
- Linkage to information about DHS supports and services
- Become part of the PASP network with access to helpful information, resources and training opportunities

