

TITLE V DATA INTEGRATION TIP SHEET: PARENTAL CONSENT

The successful integration of Title V data into an Early Childhood Integrated Data System (ECIDS) requires supporting families' desires to have reasonable control over the sharing of child level data while also integrating data for analysis and research to improve programs and child and family outcomes. Regardless of whether parental consent to share data is required, many data sources consider it best practice to give parents the option to choose if their child's data are shared with third parties, such as the ECIDS.

- ✓ Title V programs should review federal, state, local, and internal program rules, regulations, laws, and policies regarding parental consent. Title V programs should also check the ECIDS Data Governance Manual for any ECIDS requirements regarding parental consent.
- ✓ Title V programs should have and regularly review transparency policies, even when data sharing is allowable without parental consent, to ensure parents are informed of third party data sharing. This policy should include the use, storage, security, and destruction of the child's personally identifiable information.
- ✓ Title V programs may consider adding an "opt-in" option for parents allowing for specific data element sharing with the ECIDS. Parental consent should never be considered a broad or general consent to share all data contained within the Title V system.
- ✓ Title V programs should regularly review policies and audit and evaluate the ECIDS to ensure data sharing aligns with the permissions granted in the Data Sharing Agreement and is used for authorized purposes only.
- ✓ Title V programs should regularly review verification processes and verification data, both internally and with the ECIDS, to ensure consent mechanisms have been implemented and are properly functioning.
- ✓ Title V programs should inform parents through parental consent forms that if a parent revokes consent, revocation is not retroactive and will not apply to any data which have already been shared and integrated.

Parental Consent Resources and Tools

- [U.S. Consent/HIPAA Authorization Forms and Medical Record Release for Data Collection in a Covered Entity](#)
- [The Family Educational Rights and Privacy Act Guidance for Parents](#)
- [Understanding the Confidentiality Requirements Applicable to IDEA Early Childhood Programs Frequently Asked Questions \(FAQS\)](#)
- [A Parents' Guide to Student Data Privacy](#)