Sharing Information About Early Intervention

Health Insurance Portability and Accountability Act (HIPAA)

The Health Insurance Portability and Accountability Act is the law that ensures health insurance coverage for workers and their families if they should change or lose jobs. HIPAA is administered by the U.S. Department of Health and Human Services. Title II of HIPAA includes the "Privacy Rule" and is designed to protect the privacy of individually identifiable health information-referred to in the law as "protected health information (PHI)."

HIPAA requirements do not apply to how Early Intervention information is shared with health providers. HIPAA pertains to the sharing of information by health providers who are not Early Intervention providers or part of a program that receives funding from the U.S. Department of Education. Such providers are allowed under HIPAA to share information for facilitating the provision of health care with other health care providers without signed consent. Although signed consent is not needed to share treatment information, records must be kept to document what information was shared.

Family Educational Rights and Privacy Act (FERPA)

The Family Education Rights and Privacy Act (FERPA) of 1974, also known as the Buckley Amendment, is a federal law that protects the privacy of student education records.

Signed consent must be obtained for any education program that receives any funding from the U.S. Department of Education (this includes Early Intervention) to share information from an individual child's educational record, including health information. However, educational programs are able under FERPA to share general contact information, enrollment status, and dates of attendance as long as parents are notified at least annually about the program's intent to share such information and a parent has an opportunity to object with respect to his or her child. IDEA Part C (Early Intervention) privacy regulations incorporate and go beyond the provisions of FERPA. Directory information is only allowed to be released to the State Educational Agency and local school districts to identify children potentially eligible for Part B (special education) services when children are transitioning from Part C to Part B. In Rhode Island parents have an option to "opt out" of this notification.

IDEA Part C (Early Intervention)Privacy Regulations

Under Part C of the Individuals with Disabilities Education Act (IDEA), the U.S. Department of Education provides funds to the lead agency in each State to establish a statewide system of early intervention services for children ages birth to 3 years with disabilities (including developmental delays as defined by the individual state). The Part C regulations specify the rules about how Part C of IDEA is to be followed. The Part C regulations in 303.401 through 303.417 now explicitly include the confidentiality requirements that apply to Part C of the IDEA, and expressly reference the protections in the Family Educational Rights and Privacy Act (FERPA). Section 303.403(c) and now includes a definition of "participating agency," as that term applies to the Part C program. That provision also explains that participating agencies include the lead agency and Early Intervention providers, and any individual or entity that provides any Part C services, but does not include primary referral sources, public agencies, or private entities that act solely as funding sources for Part C services. Sections 303.414 and 303.414(b) Prohibit disclosure of personally identifiable information without parental consent.

Signed consent is required for a Part C (Early Intervention) program to share any personal information about children enrolled in the Part C (Early Intervention) program with anyone who is not a Part C (Early Intervention) participating provider*; not even names of children enrolled in Part C can be shared without signed consent. The Part C privacy regulations are more restrictive than FERPA with regard to sharing information about enrollment status with nonparticipating providers. Part C (Early Intervention) can share enrollment information if there is a signed consent by the parent specifying that Part C (Early Intervention) may report specific information to the identified entities. Even if there is not signed consent for individual children, Part C (Early Intervention) may report aggregate information to a public agency, such as the number of children that are being served.

*Within the Part C regulations (Section 303.403(c)), communication among Part C providers or Part C service agencies is allowed without signed consent for the sake of serving the target child. However, such an agency or provider must comply with all Part C regulations in order to be considered a "participating agency."

This document was adapted from Impact of privacy regulations How EHDI, Part C, & Health Providers can ensure that children & families get needed services; National Center for Hearing Assessment and Management, May 2008 and Changes In Early Intervention: A Summary Of Major Regulatory Changes For Parents, Early Intervention Service Providers, and State Lead Agencies Non-Regulatory Guidance; Office of Special Education Programs, Office of Special Education and Rehabilitative Services U.S. Department of Education November 2011