



Statewide Parent
Advocacy Network

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Health Information Technology Can Help Families of Children with Special Health Care Needs

Health Information Technology (HIT) can help parents manage care for their child with a disability or special health care need. This factsheet will explain what it is, how it works, and the need for parental consent for its use.

What is Health Information Technology? Health Information Technology is using health information electronically. This can be done by e-prescribing, setting appointments, accessing test results, etc. An important piece of HIT is the Electronic Health Record (EHR.) EHRs are medical records that can be available online by providers, used on flash drives, or through patient portals that families can access, too.

How is Health Information Technology used? Health Information Technology can be used to share information between health care providers, as well between providers and families. This is particularly important for children with complex needs as one condition or medication could affect others. HIT can also help avoid duplicative tests and procedures. It is important that parents make sure that the information being shared is accurate and current, and ask for corrections if needed. There are protections in place to prevent unauthorized access to the private health information of individuals under the Health Insurance Portability and Accountability Act (HIPAA).

What are the pros/cons of parental consent? Families must agree whether or not to share health information. It is important that all medical providers have access to needed information. Sometimes only part of a record is needed or by certain professionals, such as in the case of a school nurse. Families can give permission to share with an individual or a health system like a hospital or health center, especially if they don't see the same doctor for each appointment. In addition, parents can withdraw consent at a later time. Families need to know that there is also the choice to "opt out" from sharing information initially. However, if something happens and a patient can't communicate, complete electronic health records will help.

Families need to know that having all of their child's health information in one place can help coordinate care. This results in less medication mistakes, reducing preventable medical errors, timely services for emergencies, and most importantly better health outcomes for their child with special needs.

Resources:

The Health Insurance Portability and Accountability Act (HIPAA) – how information is protected
www.dlc-ma.org/Resources/Health/HEA%2013%20HIPAA_healthrecords_HHS.pdf

The Office of Civil Rights "Your Health Information Privacy

Rights" www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/consumer_rights.pdf

Spanish www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/privacy-rights-20130204-spn.pdf

Health Information Technology Tools & Resources: www.healthit.gov/patients-families/tools-resources

Healthcare.gov - tips on preventing fraud

www.healthcare.gov/how-can-i-protect-myself-from-fraud-in-the-health-insurance-marketplace/

Spanish www.cuidadodesalud.gov/es/how-can-i-protect-myself-from-fraud-in-the-health-insurance-marketplace/

To empower families and inform and involve professionals and others interested in the healthy development and education of children, to enable all children to become fully participating and contributing members of our communities and society.