Affordable Care Act (ACA):
New Guidance Makes It Easier for Families of Children with Special Needs to get Medical Records

The Department of Health and Human Services (HHS) has issued new guidance on HIPAA (the Health Insurance Portability and Accountability Act.) This guidance will facilitate families of children with disabilities being able to obtain medical records, including waiving fees and sharing with third parties if requested.

What Has Changed

Families of children with special needs have had difficulties accessing and sharing their child's medical records due to costs or being unable to easily communicate with other providers. The National Partnership for Women and Families press release (see Resources) indicated that highlights of the guidance include:

- encouraging providers to give free copies of medical records to families
- posting charges for commonly asked medical records requests if applicable (e.g., for other providers)
- electronic copies of records available to families if requested
- "consumers can ask that their data be sent to 'third parties,' including consumer eHealth applications, researchers and family members"
- "Distinguishing an 'individual right of access request' from a 'HIPAA authorization'"

What is the GetMyHealthData Campaign?

The GetMyHealthData campaign is led by the National Partnership and includes other consumer groups and health care experts including technology groups and former policymakers. There is a website (see Resources) that helps families navigate the process for requesting medical records. Various issues are addressed with resources (see endnotes for links) on what to do if consumers are told:

1. HIPAA prevents the provider from sharing the information with the patient[i]

> "Seamless access to electronic health information is critical to making patients and family caregivers true and equal partners in improving health," said Debra L. Ness, president of the National Partnership.

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Only the patient (or their authorized representative) has the right to access the records. Thus, HIPAA does not prevent the provider from sharing information with the patient!

2. Only paper copies are available[ii]
   If electronic copies are kept, patients have a right to access these as well. See also #4 below.
3. There are charges for consumer's own records[iii]
   A provider can charge "reasonable costs" but there is no fee for searching or retrieving records.
4. Records aren't available electronically[iv]
   Even if the provider only keeps paper copies, providers are required to provide an electronic copy if it is "readily producible electronically" such as scanning.
5. The patient portal, or the information they need, isn't available on the portal[v]
   Providers may not require patients to use portals as not all families have Internet access. Even if the portal is utilized, there may be information not kept on the portal and patients have a right to these records as well.
6. They can't get information for someone for whom they're caring[vi]
   Parents can get records on minor children (in cases of divorce in accordance with custody.) Once children are adults, families may use other mechanisms of supported decision-making[vii] *such as power of attorney, healthcare proxy, etc. The only exceptions for children and adults are in cases of suspected abuse, neglect, or domestic violence*.

Resources

national partnership for women & families

→ National Partnership press release on new guidance: http://www.nationalpartnership.org/news-room/press-releases/leading-patient-advocates-commend-new-hhs-guidance-on-hipaa-for-encouraging-providers-to-waive-record-request-fees-and-support-consumers-in-sending-data-to-third-parties.html

GetMyHealthData

GetMyHealthData-Troubleshooting Your Request: https://getmyhealthdata.org/home/troubleshooting/

There are additional tips on the website on what consumers can do if they're told they need to pick up records in person, if they've sent a written request but received no response, or if there is missing or incorrect information in records.

This new HHS guidance will help clarify some of the confusion around HIPAA which creates unnecessary obstacles in getting health care records. By being proactive, families of children with special health care needs can eliminate these barriers and more easily access medical records needed to provide the best care for their child.

This tip sheet is based on an ACA blog authored by Lauren Agoratus, M.A. Lauren is the parent of a child with multiple disabilities who serves as the Coordinator for Family Voices-NJ and *as the southern coordinator in her the New Jersey Family-to-Family Health Information Center, both housed at the Statewide Parent Advocacy Network (SPAN) at* *www.spanadvocacy.org. More of Lauren's tips about the ACA can be found on the website of the Family Voices National Center for Family/Professional Partnerships: http://www.fv-ncfpp.org/.*

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[i] http://www.hhs.gov/sites/default/files/righttoaccessmemo.pdf
[ii] http://www.hhs.gov/sites/default/files/righttoaccessmemo.pdf
[iii] http://www.hhs.gov/hipaa/for-professionals/privacy/guidance/access/index.html
[iv] http://nate-trust.org/wp-content/uploads/2015/04/NATE-Letter-for-Patients-to-Providers-FINAL.pdf
[v] https://getmyhealthdata.org/home/how-to-request/
[vi] http://www.hhs.gov/sites/default/files/righttoaccessmemo.pdf; see also http://www.hhs.gov/hipaa/for-individuals/personal-representatives/index.html
[vii] http://www.supporteddecisionmaking.org/

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