

Kroh, Karen

#3160

14-540-340

From: Mochon, Julie
Sent: Tuesday, January 03, 2017 10:43 AM
To: Kroh, Karen
Subject: FW: Access to records

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RECEIVED
IRRC

From: Cheryl Dougan [mailto:cld7@lehigh.edu]
Sent: Tuesday, January 03, 2017 12:23 AM
To: Mochon, Julie
Cc: Richey, Nancy; Thaler, Nancy
Subject: Access to records

Hi Julie,

I realize that the deadline for submitting comments on regulations has passed. Due to circumstances, I was unable to formally submit the following request for amendment by December 20. My sincere apologies.

Despite my tardiness, I hope you will consider my concern that parents or other designated decision makers do not currently have ready access to records kept by provider agencies. Without such access, we cannot adequately evaluate whether our children are being appropriately served, by a particular agency. In many cases, parents are the ones most able to cross reference information, such as nutritional intake, activity level, with bowel and bladder issues.

I expressed this concern in an email exchange with Nancy Thaler that was forwarded to you and others at ODP on August 10, so perhaps this request is already being addressed.

§ 6100.54. Recordkeeping

Please include language stating that a provider must provide the individual and the persons designated by the individual free and full access to the PSP and to the individual records upon request. (Should a timeline be designated? If so, consider the need for family members to make informed decisions quickly, at times.) Ideally, decision makers would have immediate access to information through a secure web portal in the electronic record keeping system, similar to the way health networks now operate. As more providers move to electronic record keeping software, this provision should be among their foremost concerns in deciding vendors.

Perhaps language to the effect:

"The provider shall make provision for individuals, or designated decision makers (individual's parent, guardian, advocate) to have easy access to records, either through a secure web portal or as hard copy."

I also suggest that the language regarding right to access all records be included with regards to Individual Rights. In the case of ODP services, this information would be broader than the requirements of the "Individuals' Right under HIPAA to Access their Health Information," and include daily activity records and the like.

www.hhs.gov/hipaa/for-professionals/privacy/guidance/access/

I noticed language in the § 6500.43. [Family living] Life sharing specialist section (p.249), that addressed the issue of access to records. Ideally, this right to access records would apply to all individuals served through ODP.

§ 6500.185. Access.

The individual, and the individual's parent, guardian or advocate, shall have access to the records and to information in the records. If the [family living] life sharing specialist documents, in writing, that disclosure of specific information constitutes a substantial detriment to the individual or that disclosure of specific information will reveal the identity of another individual or breach the confidentiality of persons who have provided information upon an agreement to maintain their confidentiality, that specific information identified may be withheld.

Thank you for your consideration and your time dedicated to this complex undertaking. And again, my apologies for not meeting the deadline. I am not adept at reading and understanding regulatory language.

Cheryl Dougan
Parent