



February 12, 2019

Marie Meszaros  
Office of Civil Rights  
U.S. Department of Health and Human Services  
Hubert H. Humphrey Building  
200 Independence Avenue, S.W.  
Washington, D.C. 20201

Re: Request for Information on Modifying HIPAA Rules To Improve Coordinated Care

Dear Ms. Meszaros,

On behalf of the American Network of Community Options and Resources (ANCOR), we thank you for consideration of our input to the request for information on modifying the Health Insurance Portability and Accountability Act (HIPAA) privacy and security regulations.

ANCOR is the national trade association representing private providers of disability community and health services across the country. We represent over 1,600 private provider agencies and also 57 state associations of disability service providers. Our members are mostly funded by the Medicaid home and community-based service waiver and ICF/IID programs for individuals with intellectual and developmental disabilities (I/DD). Thus, our members meet a high bar to comply with current HIPAA regulations.

We believe that due to the nature of our members' services we have unique input to your request for information. Our members' services are typically provided to people with I/DD not uncommonly 24/7 for their entire lifespan. Additionally, the goal of the HCBS program and the federally mandated result of providing these services is to ensure full access to the community for the individuals receiving the supports and services which includes employment, shopping, key life skills, and integrated extracurricular activities separate from health related services. We recommend that forthcoming regulations for Medicaid providers of home and community-based services waiver program should meet compliance with the HCBS Settings Final Rule (42 CFR Part 430, 431 et al.) to ensure individuals are participating in community-based activities in relation to the HIPAA regulations and guidance that often only focuses on providers that are providing care within the four walls of a facility.

With that in mind, there are 5 core areas we would like to address

- I. In question 18, you inquire whether OCR should “modify the Privacy Rule to clarify the scope of covered entities' ability to disclose PHI to social services agencies and community-based support programs where necessary to facilitate treatment and coordination of care with the provision of other services to the individual?”

Our response to this inquiry is a qualified “yes”, there can be a less burdensome authority to disclosure with other programs that can still maintain the integrity of an individuals’ protected health information (PHI). The individuals with disabilities that our members serve on a daily basis are out in the community seeking opportunities to integrate into housing, employment and general society. The facilitated ability for a direct support professional (DSP) who works directly with the person with a disability to coordinate with a multitude of community supports about the needs and qualities of the individual would make for better results in the programming. Our goal is to ensure that the time and energy of the DSP is dedicated to the quality of services and meeting the needs of the person they support, not to overly burdensome paperwork that pulls them away from the support.

An individual receiving support or their legal guardian, should have a clear understanding about the scope of the information to be released, the nature of the parties to whom that information may be released and the purpose and condition(s) under which that release of information may occur. An example: The individual receiving services wants to volunteer at the library. The individual gives informed, written consent that it is acceptable for their DSP to release that information to the staff and volunteers at the library with whom the individual may be volunteering. The information to be shared is clearly defined as only that information necessary to accomplish the individual’s goal. This might include any personal assistance the individual needs (help with toileting or eating, for example). It would not include the release of other PHI that is not necessary to accomplish the individual’s goal (unrelated medical history or unrelated social history, for example). Therefore, we suggest the consideration of a broader release of information that is inclusive of parties and information to accomplish community integration goals of the individual and with the scope of the information to be released limited as such.

Further, It would be helpful to have a Universal Authorization Form that has an expiration date longer than one year. This form should be one that all providers could use and would need to cover rules and regulations to which all the various health care providers need to adhere. Some treating providers do not recognize the validity of an Authorization Form from another provider. In those cases they may require their own Authorization Form to be completed and this can be tremendously burdensome as well as disruptive to services.

- II. In question 19 you ask, “Should OCR expressly permit disclosures of PHI to multi-disciplinary/multi-agency teams tasked with ensuring that individuals in need in a particular jurisdiction can access the full spectrum of available

health and social services? Should the permission be limited in some way to prevent unintended adverse consequences for individuals?

ANCOR does believe that a multi-disciplinary team should have better access to records so as not to prevent effective access to a full spectrum of services. However, we would encourage OCR to ensure input from a variety of disability self-advocacy organizations to understand the most important limitations that should be in place to avoid unintended consequences.

- III. In question 25(b) you ask, “(b) Should any changes be made to specifically allow parents or spouses greater access to the treatment information of their children or spouses who have reached the age of majority? If the Privacy Rule is changed to encourage parental and spousal involvement, what limitations should apply to respect the privacy interests of the individual receiving treatment?”

ANCOR would like to express our interest in being involved in further discussions on this topic. Many of the individuals with I/DD that our members serve have close relationships with their parents or other relatives, while some are estranged from family members and some have guardianship access. This is a topic that requires special consideration for people with I/DD and we would request involvement in further discussion as you consider any future changes to current law.

- IV. In addition to the above questions, ANCOR would like to request redefining the definition of “protected health information” for purposes of disability community services and specifically the Medicaid waiver programs (1915(c), 1915(i), 1915(k), etc.) under Section XIX of the Social Security Act.

ANCOR is well aware of issues across the country in securing effective, value-based outcomes due to HIPAA restrictions. For example:

- a. Cell phone program software
  - i. Direct support professionals are often in the community with the individuals with I/DD that they support and using mobile devices to coordinate destinations and schedules. As a result of HIPAA requirements, funds are allocated to pay for training and software programs that protect cell phone information. Regardless of the requirements, our workforce works tirelessly to protect the private medical information of the individuals that they support. Therefore these funds could be instead used on addressing our sector’s workforce crisis, improved wages, etc.
- b. Sharing of photos and engagement on social media
  - i. Congressional officials, state and local officials, and potential employers of the individuals we serve often inquire about what services we provide and how it impacts the person served. Because of HIPAA restrictions, our members are unable to share photos or social media of the wonderful successes of our programs

to integrate individuals successfully in the community. If just one person our members serve does not sign permissions, they are unable to post anything in regards to the group's success. Social media is also an important feature for the individual, who may not have friends outside of their support staff and can engage in the community through use of social media. Currently DSPs cannot assist with this community engagement without potentially violating HIPAA. We urge OCR, with the goal of highlighting the success of these community programs, to reevaluate the restrictions we have to show the valuable outcomes of the individuals we support throughout their lifetime.

- c. Listing of names
  - i. ANCOR believes redefining protected health information is key to relieving the intensive burdens that weigh on our members in their daily provision of supports. We have had members advised by federal officials that any reference to the individuals they support, even by name, associates them to the Medicaid program and is a violation of HIPAA. That means that our provider members cannot even list the names of the individuals they serve throughout the lifespan without risking violation. We believe that this does not serve the outcomes of people with disabilities best and instead replicates the same unseen/hidden nature of people with disabilities who lived in large state run institutions. ANCOR supports a new definition that would clearly restrict the sharing of diagnosis, documented incidents and prescribed medications, but permits the provider to highlight the individual's participation in community programs without having to meet hefty permissions of every person involved for every occurrence.
- d. Specific challenges to I/DD services and existence of legal guardianship roles
  - i. It can be burdensome for providers and a barrier to service provision when there are co-legal guardians who do not live together and do not agree. For example, the provider has to obtain divorce decree paperwork to ascertain where the consent(s) can come from and this relationship has to be determined through the lifespan of often daily provision of services.

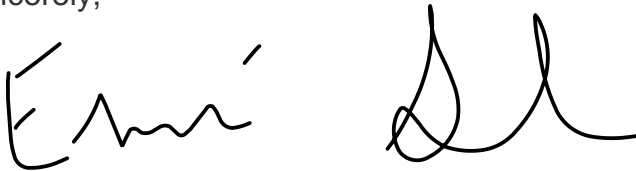
- V. In addition to the above questions ANCOR would like to request that OCR consider the elimination of the acknowledgement requirement.

ANCOR believes that this requirement is unnecessarily burdensome and could be easily replaced by accepting evidence (the date) of the notice being given to the recipient or their legal representative. We have members who have shared that individuals sometimes get very upset when asked to sign the acknowledgement

because they may feel they disagree with a component, etc. but then it can disrupt the delivery of their services.

Thank you again for your consideration of our input. We remain committed to being a resource to you as you consider future rulemaking and thank you in advance in considering the important impact that this rulemaking has on people with intellectual and developmental disabilities and the providers that support them.

Sincerely,

A handwritten signature in black ink, appearing to read "Esme Grewal". The signature is fluid and cursive, with a large initial "E" and "G".

Esme Grant Grewal, Esq.  
Vice President of Government Relations  
ANCOR  
[egrewal@ancor.org](mailto:egrewal@ancor.org)  
202-579-7789