

Empowering Neurodivergent Adolescents and Those with I/Dd in Health Care: A Collaborative Approach to Access and Understanding of Medical Records

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Abstract

As adolescents, particularly those with intellectual and developmental disabilities (I/DD) or neurodivergent diagnoses, transition into their teenage years, the complexities of managing medical records become increasingly pronounced. This article explores the implications of granting medical record access to these youths in light of the U.S. Health Insurance Portability and Accountability Act (HIPAA) regulations and state laws allow access at age 13. It examines how cognitive and executive functioning challenges can hinder comprehension of medical information, leading to feelings of anxiety and isolation. Additionally, the article highlights the critical role of parents and caregivers in supporting youth during this transition while navigating issues of guardianship and autonomy. By analyzing the disconnect between adolescents' rights to access their records and their capacity to interpret complex medical language, the article advocates for novel care models. Recommendations include providing simplified medical information, interactive health education programs, and cooperative privacy practices to support open communication and trust. This discussion emphasizes the importance of collaboration among adolescents, families, and healthcare providers to empower youth in their healthcare journeys while respecting their unique needs and autonomy.

Introduction

As youth, particularly those with intellectual and developmental disabilities (I/DD) or neurodivergent diagnoses, transition into adolescence, the management of medical records takes on a new dimension of complexity. The U.S. Health Insurance Portability and Accountability Act (HIPAA) and various state laws mandate that patients can access their medical records at a certain age, commonly set at 13 (Sharko et al. 2022; "Informed Consent in Child Medical Care" 2024). This brings to the forefront a critical discussion regarding the implications of granting medical record access to adolescents, particularly those who may not fully comprehend the information within those records.

This article examines complex issues that arise when adolescents with I/DD or neurodivergent diagnoses are granted access to their medical records, focusing on how mental capacity affects their ability to engage with this information. It highlights the intricacies of navigating health decisions during this period of growth and recognizes challenges that may present in areas of care such as sexual health or substance use. The article continues by emphasizing considerations

contemplated by parents and guardians and the importance of their support in nurturing independence. Finally, it offers novel and practical recommendations for healthcare providers to enhance accessibility and understanding, suggesting approaches that respect adolescent autonomy while providing guidance for effective healthcare engagement.

It is important that healthcare systems navigate medical record access regulations carefully. For adolescents with I/DD or neurodivergent diagnoses, the implications of having direct access to medical records extend beyond privacy concerns. The very nature of their disabilities can hinder their ability to process complex medical information. Many youth may not fully understand what it means to access their medical records or the potential ramifications of that access.

The expectation that a 13-year-old can independently access and interpret their medical records does not consider variations in cognitive and executive functioning challenges commonly faced by neurodivergent youth or youth with I/DD. Medical records are often written in clinical language that may be confusing or alienating for these adolescents. This disconnect may lead to feelings of anxiety, frustration, or helplessness as they encounter terms and concepts they have difficulty grasping.

Executive functioning challenges are common among neurodivergent people, affecting their ability to plan, organize, and process information (Jack 2021). These challenges can manifest as difficulties in understanding the implications of their treatment plans and the importance of follow-up care. The pressure to engage with this information independently can be overwhelming, leaving many youth feeling unsupported and isolated.

For some youth, their medical history may seem abstract and intimidating. Although they have the right to access these records, they may lack sufficient support needed to interpret the information or feel uncomfortable discussing it with their healthcare providers or family members. This lack of understanding can lead to disengagement from their healthcare journey, as the overwhelming nature of accessing medical records creates barriers rather than pathways to autonomy. Issues surrounding privacy and comfort also come into play. Many adolescents may feel uncomfortable knowing sensitive information, such as sexual health history, substance use, body image, eating disorders, and mental health, is included in their medical records, which their parents or guardians can access (The American College of Obstetricians and Gynecologists 2021). This situation can inhibit open communication with healthcare providers, ultimately impacting the quality of care and support received. Adolescents may feel uncomfortable discussing such sensitive topics with their parents, particularly when they know their parents have access to their medical records. This discomfort can lead to a breakdown in communication and trust between youth and their healthcare providers.

As youth with I/DD or a neurodivergent diagnosis turn 13, the issue of guardianship may be considered by parents and caregivers (FindLaw n.d.). Guardianship laws vary by state and can take various forms. It is crucial to acknowledge the significant impact that guardianship can have on a person's rights and abilities. This type of legal relationship can reinforce stigmas around dependency and incompetence. Neurodivergent people and those with I/DD may not be incompetent. Rather, they might require support as they process and manage their healthcare information (Administration for Community Living n.d.).

Parents and caregivers remain a vital part of the healthcare journey, particularly in rehabilitation settings where family involvement often correlates with successful outcomes (American Academy of Pediatrics 2021). When youth gain direct access to their medical records, many parents may find themselves navigating the complexities of how to ensure healthcare decisions are made with a clear understanding of the adolescent's health needs, particularly as some youth may not fully comprehend many aspects of their care (American Academy of Pediatrics Clinical Report 2018).

Fortunately, under the HIPAA Privacy Rule, parents typically retain the right to access their child's medical records as personal representatives unless state laws provide otherwise or the minor has specific rights to consent for certain types of care independently (U.S. Department of Health and Human Services 2023; Guttman Institute 2004). Adolescents have the option to grant proxy access to their medical records without the need for legal guardianship. If a youth is unable to grant consent for proxy access to their medical records due to intellectual or developmental disabilities, HIPAA allows parents or guardians to access these records without explicit consent if determined to be appropriate by the health care provider (U.S. Department of Health and Human Services 2023). In these cases, the provider evaluates the youth's capacity to understand their health care information. This collaborative approach helps to cultivate better health outcomes as youth, families, and healthcare providers navigate sensitive medical issues together.

Healthcare systems can consider innovative approaches to support neurodivergent youth and those with I/DD by developing adaptive care models that respect autonomy and offer individualized support. Providers can improve comprehension by offering supplemental, simplified, and accessible summaries of medical information using plain language, visual aids, or digital tools (Farrell et al. 2014). These resources do not necessarily modify existing access to medical records but rather serve as additional support to promote understanding within current frameworks.

Additionally, interactive health education programs that teach adolescents about their medical information and the importance of privacy and autonomy could prepare them to engage with their health care in meaningful ways. Healthcare systems should also consider a family-centered approach, allowing parents and caregivers to support without limiting youth independence (American Academy of Pediatrics 2021; Learning to Listen 2014). Privacy protocols can be adapted to let adolescents decide what information their caregivers can access, helping to build trust and encouraging open communication with providers. By integrating personalized tools and resources, healthcare systems can establish a foundation that empowers youth, respects their unique needs, and promotes their ability to take part in their own healthcare decisions. These young patients can collaborate with trusted supporters to act on medical information with guidance that respects their individual needs and choices.

Access to and understanding of medical records can be a challenging process for youth with I/DD and those with neurodivergent diagnoses. With supportive tools and resources, youth can meaningfully partner with their healthcare team. Through collaboration between adolescents, their parents or guardians, and healthcare providers, a responsive approach to accessing and interpreting medical information is made possible. By utilizing plain language, visual aids, and

other tools, this shared effort supports these young individuals in participating in their healthcare journey with confidence and comprehension.

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