

Legal Options, Challenges, and Insights in Supporting Young Adults with Disabilities

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For some young adults with special health care needs (YASHCN), turning 18 and becoming responsible for their own health management is not a difficult or stressful event because the young adult is competent to make decisions with support, guidance, and insight from his/her parents. These patients are able to make choices and understand the consequences of their actions; however, they may be delayed in their maturity to make informed decisions when compared to their healthy peers.

Other YASHCN, particularly those with intellectual disabilities, have significant hurdles in transitioning to autonomous medical decision making. For many of them, it is difficult—if not impossible—for them to make informed decisions on their own. Formal guardianship offers parents/caregivers the promise of legal protection against financial predators, ill-meaning family members, and adverse outcomes related to failure of adequate self-care. Yet guardianship is also fraught with its own threats to patient autonomy and self-determination. Described by Flynn¹ as the conflict between “best interests” and empowerment, guardianship creates tension between respect for patient autonomy and concern for patient competency, which may be in question depending on the disability. This article discusses some of the challenges impacting the parent-patient-provider relationship as it relates to guardianship, patient advocacy, and medical decision making in YASHCN.

Parents of YASHCN may be fearful of losing inclusion in the medical

decision-making process for their adult children due to concerns about HIPAA (Health Insurance Portability and Accountability Act) privacy laws. After transferring their child's care to an adult provider, parents may want to discuss guardianship options. General internists and family physicians are frequently asked to complete medical evaluations as part of the guardianship process yet are often unaware of the types of guardianship that exist or should be recommended. Additionally, physicians meeting a young adult patient for the first time may be apprehensive about assessing capacity and need for a guardian. Physicians providing care for these patients should understand the guardianship process as well as alternatives to guardianship, including power of attorney, health care power of attorney (HCPOA), representative payee, or conservatorship.

Although each state is different, most offer several levels of guardianship. Full legal guardianship means that the person is incapable of making legally binding decisions and needs another person(s) to make decisions for him/her in all aspects of life. Limited guardianship is more specific and only concerns a particular area in which a person is deemed incompetent; examples include guardianship of the person (where the guardian makes all day-to-day decisions for the person); guardianship of property (where the guardian makes all financial decisions for the person); emergency, temporary, or provisional guardianship; 90-day health care guardians; or conservators. A parent

may obtain guardianship over finances for an adult child with high functioning autism while still preserving the autonomy of the adult to make his/her own decisions regarding health care and housing. Limited guardianships may be adjusted based on changes in the level of function and can be expanded to cover additional areas as further deficits arise. A combination of different less restrictive options may be required in order to provide the best assistance.²

The legal guardianship process involves filing paperwork in the court system (Orphans Court, Court of Chancery, or Family Court, depending on the state), having the alleged disabled person's capacity and competence assessed by an attorney, and completing a hearing before a judge or magistrate. The process may take several months, and out-of-pocket expenses can range from several hundred to several thousand dollars for families in states requiring a private attorney to file for guardianship. Support in understanding guardianship options can be obtained from several sources, including a local chapter of “The Arc” (www.thearc.org), local and state agencies for developmental disabilities, or from the National Health Care Transition Center (gotransition.org).

A HCPOA is an appointed agent(s) directed by the adult patient to make medical decisions on his/her behalf if he/she becomes incapacitated. Many states also allow the patient to authorize his/her agent(s) to access medical records and speak with physicians di-

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rectly and independently via the HCPOA without needing a separate release of information for each encounter. The HCPOA preserves patient autonomy and decision-making capacity and is a revocable document, so as the young adult patient matures, he/she can revoke his/her parents as the agent or create a new HCPOA, assigning a spouse or partner the role. A HCPOA template is available online for no cost (<http://www.caringinfo.org/l4a/pages/index.cfm?pageid=3289>). Although attorneys may draft documents for a fee, attorney involvement is not required for a valid HCPOA.

Young adults with intellectual disabilities are likely to have legal guardianship in place at the time of transfer. Family caregivers of these young adults may opt for more restrictive guardianship options, despite evidence noted by Gooding showing that many have the cognitive capacity to exercise choice, particularly when given assistance from advocates.³ The concept of shared decision making as noted by Gooding allows patients with intellectual disability to have support for making health care decisions as warranted by the nature of the issue but allows the decision to ultimately rest with the patient if

appropriate. Supported decision making is similar to shared decision making in that both place the patient in the center of the decision-making process. In shared decision making, physicians and patients use decision support models and other tools to work together to decide between alternatives. With supported decision making, as described by the United Nations Committee on the Rights of Persons with Disability, the “individual is the decision maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preference of the individual.”⁴ Thus, supported decision making is a form of shared decision making utilizing the guardian as an additional support tool. In addition, physicians can help guardians recognize the best times to assist with a decision and when the patient should exercise decision making. Utilizing a guardian in supported decision making can help the young adult with intellectual disability develop medical management skills within his/her cognitive level.

Physicians can support YASHCN to be self-advocates and medical decision makers as their cognition allows. In situations where this is not possible, physicians can guide families and caregivers to choose op-

tions and navigate the formal legal processes involved in guardianship.

References

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