

Using Epic SmartPhrases for Smart Planning: A Tool for DBP Clinicians to Discuss Guardianship and Supported Decision-Making

Background

- Due to their frequent contact, trust, and expertise, developmental and behavioral pediatric (DBP) clinicians are well-positioned to assist families with questions related to decision-making support needs as youth with developmental disabilities approach their 18th birthdays.
- Unfortunately, many clinicians do not feel adequately trained to engage in these types of discussions at the appropriate chronological age or developmental stage, leading to gaps in care, which can result in negative impacts felt by patients and families.¹

Guardianship

*"A guardian is defined as 'a person or agency appointed by a court to act on behalf of an individual'. Guardianship can be general or limited to certain types of decisions, such as those related to residential, educational, medical, legal, vocational, or financial issues. In all cases, guardianship should be viewed as a solution of last resort, because it removes an individual's fundamental right of self-determination. Once a guardian or co-guardians have been appointed by the Superior Court, only the court can modify or change the guardianship order."*²

Supported Decision-Making (SDM)

SDM is a patient-centered approach which helps individuals make their own decisions with the support of trusted people without court involvement. It emphasizes the idea that people with disabilities have the right to make decisions about their own lives with input from trusted supports to better understand options, consider consequences, and communicate their choices. This alternative form of autonomous decision-making allows a person to achieve a maximal level of independence while still receiving support from those who care about them.³

Problem Analysis

Integration in Real-World Practice

Guardianship is addressed differently by different DBP clinicians. There are many important issues related to conversations about guardianship and SDM. Even when clinicians discuss guardianship with families, it is not always documented in the medical record.

Oral and written communication about guardianship and SDM should be consistent and clear as well as include resources where youth and families can learn more about guardianship and SDM from when children turn 14 until they are past the age of 18.

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Objective

The purpose of this project is to create a resource for DBP clinicians, to enhance how they communicate about guardianship and SDM so that they can better support youth with developmental disabilities who are approaching adulthood and their families.

SmartPhrase Formulation

BEFORE

Age 15

Planning for future decision-making: Before your child turns 18, take some time to learn about your child making decisions as an adult. Some 18-year-olds need more help making their own choices than others. We encourage you, your child, and your family to think about how much support your child will need throughout adulthood. Some options include guardianship and supported decision-making.

Guardianship is when a family asks the court to appoint a legal guardian to make decisions for their child when they become an adult. The guardian is usually a family member who will make decisions about things like money, where to live, and medical care instead of the child.

There are less restrictive options like supported decision-making that allow your child to make more choices. If you have any questions or want to talk more, please reach out to one of our social workers.

Resources to learn more:

1. The Arc Toolkit: <https://www.thearcfamilyinstitute.org/resources/guardianship-go-bag.html>
2. NJ Guardianship Self-Help: <https://www.njcourts.gov/self-help/guardianship>

Age 16

Planning for future decision-making: As your child nears the legal age of 18, this is a good time to think about and plan for decision making in adulthood. Results of updated cognitive and adaptive testing by the Child Study Team in the IEP will be used to assess your child's current skills and help us figure out the best options for your child. We also recommend that you reach out to an attorney to guide you with planning after your child turns 17 and to protect your child's best interests. As always, you can also contact one of our social workers for more information (and to provide legal alternatives that are available for families who have a financial need).

Resources to learn more:

1. RWJ CSH Obtaining an Attorney: <https://www.rwjbh.org/documents/csh/patient%20and%20family%20resources/PC12-E-Questions-when-Obtaining-an-Attorney-for-Guardianship.pdf>
2. The Boggs Center Transition of Care Timeline: <https://boggscenter.rwms.rutgers.edu/resources/publications/transition-to-adulthood-timeline-for-parents>

AFTER



Process & Methods

1. *Literature Review* of reliable health articles by searching database(s) including: PubMed, Google Scholar. Examined relevant medical literature regarding decision-making within the transitioning period from adolescence to adulthood with focus on clinician-patient education on autonomy and decision-making. ^{4,5}
2. *Interview of Stakeholder(s)*: Identified factors that influence patient education on decision-making support within the DBP community by means of conducting informal interviews.
 - Parent(s): LEND Family Discipline [lived experience]
 - Clinician(s): Physicians and Advanced Clinicians within the DBP Specialty
 - The Boggs Center Administrator(s): LEND Director
3. *Resource Collection*: compiled current printable handouts and hyperlinks being used in real time by CSH clinicians pertaining to guardianship and SDM. ^{6,7}
4. *Resource development*: synthesized data and created drafts of concise instructions that could be included in electronic medical record documentation (i.e., Epic SmartPhrases).
5. *Personal Intelligence System/Epic Integration*: Apple Intelligence used to enhance readability of content which was then integrated into the EHR, Epic.

Next Steps

We are seeking feedback on SmartPhrase text and resources in order to maximize the utility for patients, families and clinicians

Once the SmartPhrases are finalized we will conduct a qualitative improvement (QI) project.

References

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