



Considerations for Alternative Decision-Making When Transitioning to Adulthood for Youth With Intellectual and Developmental Disabilities: Policy Statement

Renee M. Turchi, MD, MPH, FAAP,^a Dennis Z. Kuo, MD, MHS, FAAP,^b John W. Rusher, MD, JD, FAAP,^c Rebecca R. Seltzer, MD, MHS, FAAP,^d Christoph U. Lehmann, MD, FAAP,^e Randall W. Grout, MD, MS, FAAP,^f
COUNCIL ON CHILDREN WITH DISABILITIES, COMMITTEE ON MEDICAL LIABILITY AND RISK MANAGEMENT

With advances in medical care, more youth with intellectual and/or developmental disabilities (IDD) are transitioning into adulthood. Patient- and family-centered, integrated care is warranted around this time of transition. Support teams (including the youth, caregivers, teachers, and pediatricians) should engage in transition planning, ideally starting between 12 and 14 years of age, to identify and develop resources to support the maturing youth's capacity for independent decision-making. Care teams should consider the varied levels of alternative decision-making support, which may include supported decision-making, medical proxy decision-making, power of attorney, and/or establishment of legal guardianship arrangements, to support the youth's health and well-being optimally. Ultimately, if independent decision-making is not appropriate, the goal for youth with IDD should be the least restrictive alternative, while preserving human rights and human dignity and promoting their autonomy. These considerations review alternative decision-making support, concepts, and legal requirements available for youth with IDD and their care teams. Pediatricians can support youth with IDD and their families in the transition process and decision-making autonomy by actively engaging the youth in care decisions, supporting needs for augmentative communication, fostering their expression of preferences and understanding of care decisions, and linking them to resources such as the medical-legal partnership model.

abstract

^aDepartment of Pediatrics, Drexel University College of Medicine & St. Christopher's Hospital for Children, Philadelphia, Pennsylvania;

^bDepartment of Pediatrics, University of Rochester, Rochester, New York; ^cDepartment of Pediatrics, University of North Carolina School of Medicine in Chapel Hill, Chapel Hill, North Carolina; ^dDivision of General Pediatrics, Department of Pediatrics, Johns Hopkins University School of Medicine, Baltimore, Maryland; ^eClinical Informatics Center, UT Southwestern Medical Center, Dallas, Texas; and ^fDivision of Children's Health Services Research, Department of Pediatrics, Indiana University School of Medicine, Regenstrief Institute, and Eskenazi Health, Indianapolis, Indiana

Drs Turchi, Kuo, Rusher, Seltzer, Lehmann, and Grout participated in conception, design, drafting, and critical revision of the clinical report, approved the final manuscript as submitted, and agree to be accountable for all aspects of the work.

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INTRODUCTION

An estimated 750 000 youth in the United States transition into adulthood each year.¹ Typically, on their 18th birthday, a youth reaches the age of majority and assumes the rights and responsibilities of adulthood, including the legal right to make medical (including family planning/reproductive),² mental health, educational, and financial decisions independently.³ For youth with intellectual and/or developmental disabilities (IDD), the absence of a formal transition plan from pediatric to adult health care is associated with delayed care and poor health outcomes,^{1,4} especially for youth with chronic health conditions.^{5–7} Health care guidance recommends the initiation of structured transition planning for youth with IDD well before the age of majority (eg, initiate transition planning at 12–14 years of age).^{8–11}

Typical health care transition guidance often assumes that the youth has the mental and intellectual capacity to make decisions that achieve health and wellness.^{12–14} However, 1 in 6 children (17%) between the ages of 3 and 17 years have a developmental disability, which may affect their decision-making ability.¹⁵ Youth with IDD may be more likely to need decision-making support, especially if they are not encouraged to gain independence, transition to adult services, and assume responsibility for their own care when appropriate.¹⁶ For youth with IDD, transition planning should include discussions about alternative decision-making arrangements when parents, caregivers, or pediatricians may be concerned that the youth will not have the capacity for independent medical decision-making at the age of majority.^{17–21}

Pediatricians are encouraged to uphold human rights and human dignity for all youth.²² Therefore, for patients with limited decision-making capacity, pediatricians should understand the various levels of autonomy and guardianship available to support patient-centered health and wellness (Table 1). Pediatricians should be familiar with local resources supporting disability and autonomy that may vary substantially by state.²³ Pediatricians may be called upon to assist in finding the best solutions for their patients (Fig 1). Federal laws (eg, the Americans with Disabilities Act) affirmed by Supreme Court decisions such as *Olmstead v. L.C.* (1999) uphold the rights of US citizens with IDD to reside in least restrictive appropriate environments and to receive resources enabling inclusion into society.^{24–26} Therefore, fostering autonomy of patients and supporting the least restrictive alternative for decision-making are essential when independent decision-making is not appropriate. With some patients, the pediatrician may be asked to participate in discussions and/or provide documentation about decision-making ability and necessary resources, including evaluation of the potential for independent medical decision-making.^{27–29} Historically, pediatricians have rarely discussed the legal aspects of transition

to adult-oriented services with the youth with IDD and subsequently, their families.¹¹

To that effect, this policy statement seeks to educate the pediatrician on:

1. the need for basic human rights and dignity for youth with IDD;
2. important terms and concepts in decision-making autonomy, including the least restrictive alternative for decision-making, supported decision-making, and legal requirements in transition experiences for youth with IDD; and
3. alternative decision-making processes, including supported decision-making, power of attorney, and guardianship, and their effects.

SUPPORT FOR BASIC HUMAN RIGHTS AND DIGNITY

Youth with IDD have the right to be recognized as persons before the law and to enjoy legal capacity in all aspects of life on an equal basis with individuals without disabilities.³⁰ Autonomy in rights, freedom, and dignity should be respected, supported, encouraged, and upheld as youth are presumed to have the capacity to make decisions until proven otherwise. Promoting equity and a positive culture of disability negates ableism, which promotes social prejudice and discrimination against people with disabilities and is informed by a belief that individuals with neurotypical abilities are superior to those with disabilities.³¹ Furthermore, youth with IDD deserve the resources, preparation, and decision-making support required to evolve appropriately in their role as a decision-maker over the course of their lifetime.³²

There is a continuum of decision-making for youth with IDD from fully autonomous decision-making to fully substituted decision-making (guardianship) in which the youth has no decision-making rights (Fig 1). The goal should always be the least restrictive decision-making environment that balances autonomy with safety and supports (Box 1).

BOX 1

CASE VIGNETTE: YOUTH WITH NEED FOR LEAST RESTRICTIVE DECISION-MAKING

A 16-year-old patient (pronouns she/her) has a history of birth at 24 weeks' gestational age, spastic quadriplegia, asthma, and intellectual disability. She lives at home with her parents and siblings and attends local public school in a special education classroom setting. The primary care pediatrician has known the patient since birth and has been collaborating with the adolescent and her family on planning pediatric to adult health care transition over the past several years. At a recent well-child visit, the parents asked about a recommendation from the orthopedic surgeons for bilateral hip osteotomies and inquired about the consent process. They asked the pediatrician about the timing of the surgery and obtaining guardianship when the adolescent turns 18.

CASE VIGNETTE ACTION:

During the latest visit, the pediatrician meets with the adolescent alone to get a sense of her understanding of her medical needs and her ideas and desires about her medical care. The patient clearly expresses that she values the support her parents provide in navigating the medical system and helping her make medical decisions. The adolescent and pediatrician discuss her hobbies, her transition plan from high school, potential day programs, and how much she likes her new job at the local library. As part of this visit, the pediatrician and patient discuss typical daily living activities and explore how much assistance she requires with decision-making. The pediatrician asks if the patient:

- o Has goals for her health?
- o Can communicate her medical problems effectively?
- o Thinks she will need her parents to continue to help make decisions for her when she is grown and how she feels about this?
- o Knows the dose, purpose, and how to administer her various medications?
- o Is left alone when her parents leave the house?
- o Knows what to do if she gets hurt or sick when her parents are not present?
- o Would like life skills training and/or job skills training as they plan her goals?
- o Signed her own employment contract with the library?

Separately, the pediatrician also obtains input from the adolescent's parents. Combined, the responses suggest to the pediatrician that the patient can take care of herself and manage day-to-day decisions with some parental support. For example, although the adolescent does not know the purpose of some of her medications, she demonstrates understanding when they are explained to her. To promote the adolescent's autonomy as much as possible, the pediatrician describes the options for decision-making, including the possibility of a supported decision-making agreement that outlines the types of supports she would prefer related to her medical care. The pediatrician mentions requesting electronic health record proxy access for her parents, allowing medical staff and clinicians to speak with her parents about her medical care, and providing the patient with clear, written recommendations to be shared with her parents after each health care visit.

The pediatrician explains to the parents that this least-restrictive approach for decision-making may be more appropriate than guardianship for the adolescent and her family based on her ability to make some decisions related to her life, financial, and health care decisions. The pediatrician also provides the patient and her parents with information about medical decision-making and gives them resources for several local agencies, including information on a medical legal partnership group. Although the patient will be encouraged to make decisions that she has the capacity to make, the power of attorney will legally allow her parents to support her by making decisions that she needs assistance with. The pediatrician also points out that the specifics of the power of attorney vary by state if the family should move in the future. The pediatrician allows the family time to ask questions and assesses everyone's understanding and comfort with the next steps in this process.

TERMS, CONCEPTS, AND LEGAL REQUIREMENTS IN DECISION-MAKING

Table 1 describes terms, concepts, and legal requirements that may be helpful for the pediatrician during discussions with families and youth.

The ability to make decisions concerning one's health care forms a continuum ranging from fully autonomous to fully substituted decision-making, punctuated by levels of supported decision-making in between these two extremes (Fig 1).³³ Balancing autonomy with appropriate supports is an important consideration.³⁴

Supported Decision-Making

Supported decision-making may be considered as an alternative to guardianship for individuals who need assistance to make some decisions as they are not fully incompetent.³⁵ The United Nations Convention on the Rights of Persons with Disabilities recognizes the right to autonomy for individuals with disabilities and stresses the importance of supported decision-making over substituted decision-making.³⁰ In recent years, numerous states have enacted laws adopting supported decision-making, and many organizations supporting youth with IDD advocate for this approach^{36,37} (see <http://www.supporteddecisionmaking.org/>) and pediatricians can familiarize themselves with the legislation/laws in their respective states. Individuals with a range of disabilities can make appropriate decisions if supports are in place (Box 1).³³

Peterson et al proposed that implementation of supported decision-making involves the individual with disabilities (1) choosing the trusted support person(s), and (2) creating an agreement with the support person(s) that identifies the decision-making domains where assistance is needed or desired and the supports that are desired.³⁷ Examples of support may include attending medical appointments, explaining what the physician said during a visit, talking through treatment options, etc. A written document outlining this agreement can be shared with health professionals and other members of the care team³⁷ leveraging health information technology, which supports this process.^{38,39} Douglas and Bigby propose an evidence-based framework to guide decision-making support, which includes 7 steps in the supported decision-making process (Fig 2).⁴⁰

Individuals with IDD who use supported decision-making report increased confidence in themselves and their decision-making, improved decision-making skills, increased engagement with their community, and perceived more control of their lives.^{33,40,41} Barriers to implementation of supported decision-making include the required time, effort, payment, training of practice team members, and resources in practice settings, as well as the need to educate

TABLE 1 Terms, Concepts, and Legal Requirements in Decision-Making	
Term	Definition
Capacity	Capacity is a term used to define an individual's ability to perform a specific task, such as signing a contract or making a medical decision. An individual's capacity to make an informed decision (eg, medical, financial) is based on 4 abilities: Appreciation of the nature of one's situation, understanding of relevant information provided, reasoning about risks and benefits of options, and expressing a choice. ^{26,51} Capacity is relatively task-specific and a health care designation that is not an "all-or-none phenomenon"; for example, a youth may have the capacity to participate in certain areas of medical decision-making, but not more complex ones (eg, end of life). ⁵²
Competence	Competence is a legal determination made by a judge and refers to the mental condition a person must have to be responsible for his or her decisions or actions. The judicial decision about competency is often informed by a multidisciplinary evaluation, which may include input from behavioral health specialists (psychiatrists and psychologists) or other physicians. ^{52,53} Note that this legal term varies from state to state, and a person who is determined by a court not to be able to make such decisions may be referred to as "incompetent," "incapacitated," "a person in need of guardianship," or "disabled," depending on the state where the legal proceeding is taking place. ⁵⁴
Autonomy	Autonomy involves an individual's right to make and put into effect decisions as guided by their own reasons. ^{34,52} When considering decision-making for youth with disabilities, respect for autonomy should be a valued principle in the same way it is for youth without disabilities.
Supported decision-making	Supported decision-making is a process that enables individuals to make their own decisions whenever possible through support. ³³ The individual identifies one or more trusted supporters (eg, friends, family, professionals) to assist in understanding, making, and communicating decisions, with the individual empowered to make the final decision. ^{35,45}
Substituted decision-making	Substituted decision-making refers to the legal appointment of a delegate or agent to make decisions on behalf of and based on the values of a person deemed not to be competent to make a decision. Examples include guardianship or power of attorney. The substitute decision-maker may be appointed by the individual with disabilities or by someone else (eg, judge). ^{50,53}
Guardian	A person or entity (such as a social services agency) appointed by a court to manage an individual's personal, health-related, or financial matters. In some states, a different term is used, such as "conservator." ²⁴ States have their own laws, procedures, and forms for guardianship. ⁵⁵

individuals with IDD, siblings, parents, and the medical community about alternatives to full guardianship^{33,41–45} and the barriers of not recognizing the potential benefit of supported decision-making.^{36,46,47} In some cases, the time spent may be a compensable service when billed appropriately, and payer policies should recognize and pay for the time and resources required for pediatricians to accomplish this important work.

Additional Less Restrictive Alternatives on the Continuum of Decision-Making

Even if a formal supported decision-making option is not available, individuals with IDD who are 18 years or older and do not need a substitute decision-maker may allow a parent/caregiver to have access to their medical record or to have independent conversations with their physicians. This scenario is comparable to adult children of the elderly who assist with caregiving and to those who allow others access to their electronic health record.⁴⁸ Additional, less restrictive alternatives can allow assistance and protection in some aspects of decision-making (often involving financial assets) while maintaining as much autonomy as possible. Table 2 describes a noncomprehensive list of alternatives that may provide the right balance of protection and autonomy while supporting least restrictive environments.

Most Restrictive Decision-Making – Guardianship

Guardianship and the appointment of a legal guardian (or conservator in some states) are the most restrictive options for decision-making and, therefore, require clear and convincing evidence that the youth is not competent to make decisions. States use different nomenclature, but the types of guardianship generally focus on either the person (duties relating to care, custody, and control of the individual) or property (management of property, estate, and business affairs), or both, which represents fully substituted decision-making.

In the guardianship process, a person who is seeking to have a guardian appointed (the "petitioner") files a petition for guardianship of a person the petitioner believes needs a guardian (the "respondent"; sometimes referred to as the "alleged incapacitated person" or "AIP") with the appropriate court official. In many jurisdictions, the court will appoint a guardian ad litem, a person appointed by the court solely for the purpose of protecting the interests of the respondent in the competency hearing. Respondents may also be assigned their own attorney.

The court may order a comprehensive evaluation of the respondent, which typically includes medical, psychological, and social work evaluations as directed by the court, as well as evaluations by other professionals, including the pediatrician, to ascertain the respondent's needs in the areas of education, mental and physical



FIGURE 1
Continuum of decision-making for youth with IDD to guide alternative decision-making options.

health, and need for various services such as occupational, vocational, or speech therapy, etc.

The guardianship proceeding is the legal process, including evaluation of evidence and a hearing, which determines the need for and details of the guardianship arrangement. If a respondent is adjudicated not to be competent, the court must select and appoint a guardian, who can be any competent adult, such as a spouse, family member, friend who may or may not be related to the

youth, or even an agency or corporate entity. In most states, guardian(s) are periodically reviewed to ensure they are acting in the best interest of the individual under guardianship.⁴⁹

SUMMARY AND CONCLUSIONS

Youth with IDD may need support to ensure personal health care, legal, and financial decision-making at the

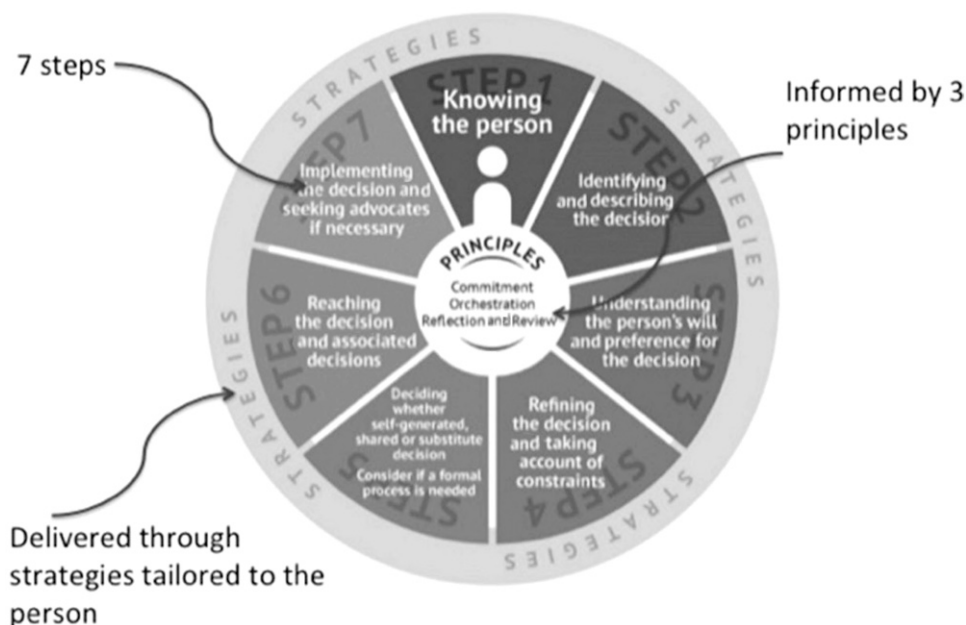


FIGURE 2
Support for decision-making practice framework: Steps, strategies, and principles. This figure elucidates the decision-making process as being composed of 7 steps grounded in 3 key principles while acknowledging that the process is iterative, fluid, and person-centered, which may require flexibility and some adaptation based on the individual's needs. *Reprinted by permission of Taylor & Francis Ltd, <https://www.tandfonline.com>. Douglas J, Bigby C. Development of an evidence-based practice framework to guide decision making support for people with cognitive impairment due to acquired brain injury or intellectual disability. *Disabi Rehabil*. 2020;42(3):434–441.*

TABLE 2 Additional Less Restrictive Alternatives on the Continuum of Decision-Making

Dimension	Concepts
Medical decision-making	<ol style="list-style-type: none"> 1. Health care power of attorney: A legal document giving 1 person the right to make health care decisions on behalf of someone else under specified circumstances 2. Advance instruction for mental health treatment: A legal document in which an individual indicates what treatment and care for mental health conditions they want in specific circumstances if they are unable to communicate their wishes
Financial decision-making	<ol style="list-style-type: none"> 1. Joint bank account: Establishing a joint bank account for an individual with another responsible person so that that person can help pay bills and manage money 2. Living trust: Putting in place a legal arrangement for an individual who is having difficulty managing property or assets alone that protects the assets for the individual 3. Special needs trust: Creating a legal trust that allows an individual with a disability to reserve assets while maintaining eligibility for government benefits 4. Power of attorney (durable/general): A legal document giving 1 person the right to conduct financial business on behalf of another without a court order
Holistic care	<ol style="list-style-type: none"> 1. Foster care 18–21: Providing continued supportive and financial services for youth aging out of foster care at age 18 y.⁴⁹

age of majority (Box 1). The continuum of supported decision-making, power of attorney (health care proxy), other decision-making options, and guardianship may be considered to support the youth at levels that promote autonomy and self-determination in decision-making. Physicians, including pediatricians, play a significant role in supporting youth with IDD in this process. The goal should always be the least restrictive alternative for decision-making for youth with IDD based on evaluation and assessment of their abilities. Planning for the process of alternative decision-making and other supports and building capacity for decision-making should be considered during the standard timeline and practice guidelines of health care transition planning.

RECOMMENDATIONS

1. Preservation of human rights and human dignity for all youth is essential while promoting autonomy of patients.
2. Pediatricians should advocate for the least restrictive decision-making environment for their patients.
3. Pediatricians can promote and support the developing autonomy of all patients by actively engaging them in conversations about care decisions while accounting for the youth's intellectual or developmental ability to express preferences and understand decisions about different aspects of their care.
4. Discussions about decision-making should be a part of the structured transition planning for youth with IDD and start between the ages of 12 and 14 years.

TABLE 3 Resources for Practitioners

Agency	Link	Description
National Center for Medical Legal Partnership	https://medical-legalpartnership.org/	Supports integration of lawyers into health systems
The Arc	https://thearc.org/	Promotes respect for the human rights of people with IDD (state and local chapters available)
National Resource Center for Supported Decision-Making	https://supporteddecisionmaking.org/	Provides pro bono legal services from state chapters to support decision-making
Centers for Independent Living	http://www.acl.gov	Advances independent living and integration for people with IDD
Disability Rights Legal Center	https://thedrlc.org/	Nonprofit that champions the civil rights of people with disabilities
Got Transition	https://www.gottransition.org/	Provides national resources on health care transition
National Disabilities Rights Network	https://www.ndrn.org/	Provides legal advocacy services for people with disabilities (largest provider in the United States)
Charting the Life Course	https://www.lifecoursetools.com/lifecourse-library/foundational-tools/	Offers tools for charting life course
Speak Up	https://speakupcolorado.com/curriculum	Offers a curriculum to help youth with IDD to become self-advocates
State Councils on Developmental Disabilities	https://acl.gov/programs/aging-and-disability-networks/state-councils-developmental-disabilities	Provides information about councils on developmental disabilities in every state

- Pediatricians can be aware of different levels of decision-making support for youth and partner with care teams, legal advocates, families, and youth in determining the right types of support needed. They can also be familiar with their local and state resources supporting disability and autonomy for youth with IDD and refer when appropriate (Table 3).
- Pediatricians can account for the relational aspect of care coordination (this includes interprofessional communication and incorporates shared knowledge, shared goals, mutual respect)⁵⁰ and benefits and barriers to supported decision-making when addressing independence for youth with IDD.
- Pediatricians can reevaluate the decision-making arrangement as part of the annual physical/mental examinations to align with the youth's desires, needs, and decision-making abilities over time.

LEAD AUTHORS

Renee Turchi, MD, MPH, FAAP
 Dennis Z. Kuo, MD, MHS, FAAP
 John W. Rusher, MD, FAAP
 Rebecca R. Seltzer, MD, MHS, FAAP
 Christoph U. Lehmann, MD, FAAP
 Randall W. Grout, MD, MS, FAAP

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STAFF

Alexandra Kuznetsov

PARTNERSHIP FOR POLICY IMPLEMENTATION LIASONS

Christoph U. Lehmann, MD, FAAP
 Randall W. Grout, MD, MS, FAAP

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 Richard L. Oken, MD, FAAP

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ABBREVIATION

IDD: intellectual and/or developmental disabilities

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Address correspondence to Renee Turchi, MD, MPH, FAAP. E-mail: Renee.Turchi@towerhealth.org

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