

# **Medical Decision-Making Rights Should be Part of IEP and ISP Transition Planning**

## **Efforts Should be Coordinated with Pediatricians and Nurses**

by Thomas F. Coleman

The Missouri Medical Rights Workgroup is exploring ways to better protect the medical rights of patients with developmental disabilities. Although the primary focus is on patients who are adults, the workgroup is also investigating how youth with developmental disabilities are being prepared to assume the role of a medical decision-maker as they are transitioning to adulthood.

Many of these teenagers are involved in three systems that could, and should, assist them in preparing for their role as adults who will receive medical, dental, and other health care services. One is the school system. Another is the disability services system. The third is the health care system.

Some young adults who have serious disabilities that prevent medical decision-making capabilities may need a guardianship when they become adults. But most will not. Most young adults with such disabilities will make their own health care decisions, with or without the help of people in their circle of support.

Many teens with developmental disabilities are involved in person-centered planning in the school system through what is called an Individualized Education Program (IEP). Those who receive disability services through the state or local agencies are involved in planning through an Individual Support Plan (ISP). Both of these planning processes should be assisting young people to assume medical decision-making rights and responsibilities when they become adults. Coordinating the IEP and ISP processes would be the best approach to health care transition planning.

### **Health Care Transition Deficiencies**

A recent report by the National Alliance to Advance Adolescent Health and a nonprofit known as Got Transition noted significant deficiencies in health care transition (HCT) planning for teenagers with developmental disabilities. The report, titled “Health Care Transition Barriers, Gaps, and Interventions for Youth and Young Adults with Intellectual and Developmental Disabilities: A Landscape Analysis,” observed:

Clinical recommendations on HCT call for all Y/YA, ages 12-26, and families to receive guidance and support from their health care providers on the key elements of HCT. However, most youth, especially youth with ID/DD, do not receive recommended HCT support. According to the 2019/2020 National Survey of Children’s Health, only 20% receive HCT preparation from their

health care providers.

Many Y/YA with ID/DD and their families feel as if they have “fallen off a cliff” when it comes to their transition from pediatric to adult health care. Y/YA and families note that most of the work is left to them – building self-care skills, helping navigate health services, figuring out options for shared decision-making, finding a new adult doctor, and coordinating care plans.

## **Federal Youth Transition Plan**

The federal government recognizes the need for coordinated transition planning for youth with special needs that includes the topic of health care. This concern was addressed in a report published in 2015 titled “The 2020 Federal Youth Transition Plan: A Federal Interagency Strategy” which was prepared by the Federal Partners in Transition (FPT) Workgroup. The Workgroup included the Department of Education, Department of Health and Human Services, Department of Labor, and Social Security Administration.

The report defines “transition” as “the period of time when adolescents are moving into adulthood and are often concerned with planning for postsecondary education, careers, health care, financial benefits, housing, and more.” The report lists health care among the equal opportunity goals for students with disabilities who are transitioning to adulthood:

- Access **health care services** and integrated work-based experiences in high school to better understand how to manage their physical, mental, and emotional well-being, to enhance their job-readiness skills and career planning, and to make a successful transition from school to work and greater independence;
- Develop self-determination and engage in self-directed individualized planning to prepare them for postsecondary education, **health care management**, vocational training, and/or employment;
- Be connected to programs, services, activities, information, and supports for which they are eligible that prepare them to **self-manage their health and wellness**, pursue meaningful careers, become financially literate and capable, and make informed choices about their lives;
- Develop leadership and advocacy skills needed to exercise **informed decision-making** and personal and community leadership; and
  - Have involvement from families and other caring adults with high expectations to support them in achieving their goals.

## **IEP Transition Planning**

It has been 20 years since Congress reauthorized what was then called the Individuals with

Disabilities Education Act (IDEA). The new law is called the Individuals with Disabilities Education Improvement Act (IDEIA).

The purpose of IDEIA is to ensure that all children with disabilities get the “special education and related services” that they need in order to receive a free and appropriate public education that helps to prepare them for further education, employment and independent living.

Under the IDEIA, children with disabilities are entitled to a “free and appropriate public education.” This includes special education services which include “specially designed instruction, at no cost to parents, that meets the unique needs of a child with a disability.”

The way that a child gets special education services is through an Individualized Education Program – also called an IEP. An IEP is a written plan for how a child will receive all the services he or she needs. The school district is obligated to have an IEP in place for each child with a disability by the beginning of each school year. An IEP is developed by a specific group of people, called an IEP team.

Beginning at the age of 16, an IEP must start to include a “transition” component that identifies what transition services are needed to help the child prepare for leaving school. By the age of 17, the IEP transition component must include a statement that the student has been told of any rights that will transfer to him or her at the age of majority. Medical decision-making is one of those rights.

Under the Code of Federal Regulations (34 CFR 300.43), “*Transition services* means a coordinated set of activities for a child with a disability that—(1) Is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation.” Medical decision-making logically would fall under “adult services” and “independent living.”

In a position paper titled “Transition to Adulthood,” the Missouri Developmental Disabilities Council (MODDC) emphasizes that among various goals for an IEP transition plan, “learning about services they can use as adults” and “living on their own” should be included.

The position statement noted that “schools don’t always do a good job with transition services,” adding: “Many parents said schools told them to put their kids in guardianships. They said they weren’t told about any other options, or about how guardianships can hurt people.”

The MODDC position statement also focuses on the importance of reducing the number of unnecessary guardianships, stating: “Schools should not tell parents to get guardianship of their children with disabilities. They should help parents find the right ways to support their child. Schools should help students with disabilities learn the skills they need for adulthood.”

Concerns about a student's ability to make medical decisions once they turn 18 are one of the major reasons that guardianship comes up on an IEP transition conversation. It is important that alternatives to guardianship be seriously considered, indeed encouraged, during the IEP transition planning process.

Among these alternatives would be having several important documents in place when the student turns 18 and legally assumes the right to make their own medical decisions. Such documents would include: a medical power of attorney, designation of a patient representative, waiver of HIPAA confidentiality for a support person, designation of a support person as an ADA accommodation, and a supported decision-making agreement that identifies a health care supporter.

A project at the University of Florida emphasizes the link between educational transition and health care transition. In a presentation titled "The Role of Schools in Health Care Transition," the project refers to EdHCT as "the collaboration between the education and healthcare systems in transitioning to adulthood."

Healthcare transition is defined as "the process of transitioning from child-centered (pediatric) to adult oriented health care. Education transition is defined as a "change in status from behaving primarily as a student to assuming emerging adult roles in the community."

The project asks: "There is only one teen, why should there be two separate processes." The same could be asked of transition planning in an IEP by the school system and transition planning in an ISP by a disability service system.

According to Crystal Amini-Rad, Executive Director of Adair County SB 40 Board, the transition planning in the IEP process at most schools is vocation focused. Education about medical rights is generally not addressed in IEPs for transitioning youth.

The National Association of School Nurses has recognized that school nurses can play an important role in transition planning for students with special health care needs. A position statement explains:

[A]ll students with healthcare needs should receive coordinated and deliberate transition planning to maximize health and well-being. As an essential member of the multidisciplinary school-based team, the [school nurse] is ideally placed to provide care coordination and lead the planning team in addressing transitions for students with healthcare needs.

The position statement explains that in order to effectively support transitions for students with healthcare needs, school nurses should be knowledgeable about applicable local, state, and federal laws that impact the development and implementation of transition plans. To this end, school nurses associated with special education programs in Missouri should receive training on the medical rights of adult with developmental disabilities and incorporate that knowledge into transition planning.

## **ISP Transition Planning**

In January of 2014, the Centers for Medicare and Medicaid Services (CMS) published a final rule 42 CFR 441.301(c)(1) regarding changes to Home and Community-Based Waiver Services (HCBS). The rule requires service planning for individuals to be developed through a person-centered planning process that addresses health and other long-term services and support needs and be done in a manner that reflects an individual's preferences and goals.

The rule describes the requirements for Individual Support Plans (ISPs) that are developed through this process, including that the process must result in an ISP with individually identified personal outcomes, goals and preferences, including those related to health care and wellness.

In January 2018, the Developmental Disabilities Division of the Missouri Department of Mental Health published an "Individual Support Plan Guide." The guide focuses on the components that are required in an Individual Support Plan (ISP).

The guide explains: "The development of the ISP (the ISP is the document) reflects a person-centered planning process. It involves as many people or organizations as needed to achieve the personal outcomes for each individual. The Person-Centered Planning process helps people achieve his/her personal life goals and evolves as the individual's life evolves. The planning team consists of an individual and his/her support team."

An ISP must include the following information related to health care if such information exists: health care resources currently being utilized; supported decision-making representative; and power of attorney health care agent.

The guide describes information that must be included in an ISP for transitioning youth:

Although schools may not require transition planning until age 16 (or younger if determined by the Individualized Education Program planning team), the Division of Developmental Disabilities Individualized Support Plan must reflect supports and actions that will be taken to improve employment and post-secondary outcomes for school age children under the age of 16.

School age under 16: It is important for the team to discuss: Self-determination skills; social and other "soft skills" that are critical to success; Explore interests, aptitude, abilities and understanding adult roles; Assist the individual to learn about available work and career opportunities; Expand and build social capital (community connections/business leaders); Participate in monitored early work experiences such as volunteerism, job shadowing and community service; Develop, improve and practice independent living skills.

Age 16 and above: The ISP should consider adding the following in addition to the above: Identify community support programs (Vocational

Rehabilitation, Centers for Independent Living, County Boards, Missouri Job Centers, etc.) that may be needed and ensure appropriate referrals have been made; Match career interests, skills and academic coursework with real work experiences in the community; Develop and improve job interviewing skills, resume development, expertise in completing job applications; Identify accommodations that may be needed; Describe how the individual will learn about what benefits and services (Social Security, Medicaid, Personal Assistance Services, etc.) he/she are currently receiving and how to manage him/her.

The guide explains how an ISP should help ensure the individual's right to receive physical, emotional and mental health care from the practitioner of their choice. It should also ensure that individuals receive information and education on ways to maintain their health and well-being.

However, despite these laudatory aspirations about ensuring individual choices are respected, the guide is conspicuously silent on how the ISP process should assist youth to transition from parents making medical decisions to the youth making such decisions, with appropriate assistance, upon reaching adulthood.

According to the Information Specialist Statewide Director for the Developmental Disabilities Division, although the Division provides materials and encourages staff to have conversations surrounding transitioning to adulthood, and provides materials explaining supported decision making, the materials do not mention medical transitioning.

The guide states that individuals must be provided information on their legal rights upon entry to the waiver and annually during the individual support planning process. The support coordinator will provide a rights brochure, developed by the division, to the individual and guardian. The brochure is titled "Knowing Your Rights: A Guide for Individuals with Developmental Disabilities to Understanding Rights and Responsibilities."

The brochure explains: \* You have the same legal rights and responsibilities as any other person unless the court says you do not. \* You can choose someone to help you make decisions or act in your behalf. \* If you believe any of these rights have been violated, you may file a grievance with the agency providing your supports.

The following authorities in the Missouri Code of State Regulations are cited in the brochure:

9 CSR 45-3.030(2) Adults who do not have a legal guardian have the right to designate a representative to act on one's behalf for purposes of receiving services from the Division of DD.

9 CSR 45-3.040(1)(A) Designated representative—a parent, relative, or other person designated by an adult who does not have a guardian. The designated representative may participate in the person-centered planning process and development of the individual support plan, at the request of, and as directed by, the individual.

9 CSR 45-3.040 (4) Adults who have not been declared legally incapacitated may give their written consent for parents, relatives, or other persons to serve as their designated representative to advocate for and advise, guide, and encourage the individual and members of the individual support plan team in developing and implementing individual support plans. Written consent for designated representatives shall include written authorization to disclose protected health information.

9 CSR 45-3.040(4)© Individuals may revoke their consent in writing at any time and the Division of DD and all parties responsible for the implementation of the ISP shall recognize the revocations immediately.

The brochure explains that it is based on various components of “Missouri Quality Outcomes,” including that: “People are able to choose health/mental health resources and are supported in making informed decisions regarding their health and well-being.”

If there is a restriction of rights of an individual receiving services funded by the Division on Developmental Disabilities, an ISP must explain the reason for the limitation and document how less restrictive means of meeting the individual’s need have been tried and did not work. Further, the ISP must describe what it will take for the restriction to be lifted / how the individual and team will know when the restrictive support is no longer needed or could be reduced in intensity/frequency.

These requirements should be followed when medical decision-making rights of an adult have been restricted, such as when a medical provider will not honor the individual’s right to make their own health care decisions, to have a support person assist them in medical settings, to designate a patient representative, or to designate a health care agent through a medical power of attorney.

Crystal Amini-Rad, Executive Director of Adair County SB40 Board, explained that the issue of medical rights is only tangentially involved in the ISPs that her agency develops with their transitioning clients and that inclusion of medical rights is not mandated by law.

“Our Targeted Case Management Team is not aware of any specific statutes or regulations around education about medical rights in the transition planning process. . .

“Within the ISP, specific issues around the Health & Safety of individuals are included. Individuals also are given information about the Rights. However, there isn’t specific requirement to provide education or information regarding Medical Rights. Client’s rights generally include legal rights to self-determination, ensuring individuals are free from abuse, neglect and exploitation and includes information about general rights – but not specifically medical rights. Requirements of the TCM Contract address the importance of least restrictive alternatives, understanding of the guardianship vs self-determination process and client’s legal rights, but does not specifically require inclusion around medical rights or medical decision making. . .

“Throughout the ISP process, and especially during the transition years, Service Coordinators are encouraged to discuss alternatives to guardianship with parents. We have recently made it an internal priority (not a codified policy yet) that all individuals without guardians consider having an MPOA to be maintained on record. We also recently began working to assure that MPOA is addressed starting around age 17-17 ½ (prior to turning 18). These are voluntary priorities with our agency practices and not required or regulated anywhere that we are aware of. . . .”

To ensure that youth are prepared to assume medical rights when they turn 18, the Division on Developmental Disabilities should develop a brochure specifically about the medical rights of adults with developmental disabilities and options available to such adults and their family supporters to exercise those rights and complain if they are violated. Anyone involved in the ISP planning process, especially for transitioning youth, should be required to read such a brochure and agree to incorporate this information in the ISP planning process.

Such a brochure should explain the right to medical self-determination for all adults who have not been placed in a guardianship, the legal presumption of capacity to make medical decisions, that disability discrimination is prohibited in health care services, that individuals with disabilities have the right to a support person to assist them in health care settings, that supported decision-making is authorized by Missouri law, that patients have the right to designate someone to have access to their medical records, and that patients have the right to designate someone to make medical decisions for them in the event that they cannot do so themselves. Most importantly, the brochure should emphasize that a guardianship should not be used unless less restrictive alternatives have been tried and do not work.

*Thomas F. Coleman is the executive director of Spectrum Institute and a legal consultant to the Alternatives to Guardianship Project. He has written extensively on disability rights, capacity assessments, medical decision-making, and alternatives to guardianship.*

## **Resources**

Transitioning to Adulthood: Resources for Patients, Families, and Health Care Providers  
<https://alternativestoguardianship.com/transitioning-resources.pdf>

## **References**

Code of Federal Regulations – 34 CFR 300.43 – Transition Services Defined  
<https://alternativestoguardianship.com/transition-services-defined.pdf>

U.S. Department of Education – Guide to Individualized Education Program  
<https://alternativestoguardianship.com/guide-to-iep.pdf>

Missouri Code of Regulations – Individual Support Plans  
<https://alternativestoguardianship.com/Mo-Code-Regs-ISP.pdf>



Missouri Code of Regulations – Rights of Designated Representatives, Parents, Guardians  
<https://alternativestoguardianship.com/Mo-Regs-Rights-of-Designated-Representatives.pdf>

Missouri Division on Developmental Disabilities – Individual Support Plan Guide  
<https://alternativestoguardianship.com/ispguide.pdf>

Missouri Division on Developmental Disabilities – Knowing Your Rights  
<https://alternativestoguardianship.com/knowing-your-rights.pdf>

MODDC – My Health Decisions: Supported Decision-Making and Health Care  
<https://alternativestoguardianship.com/moddc-SDM-booklet-5.pdf>

MODDC – Transition to Adulthood Position Statement  
<https://alternativestoguardianship.com/MODDC-Transition-Position-Statement.pdf>

FloridaHATS – Role of Schools in Health Care Transition  
<https://alternativestoguardianship.com/FLHATS-Role-Schools.pdf>

Got Transition – Health Care Transition  
<https://alternativestoguardianship.com/Got-Transition-Gaps-and-Barriers.pdf>

Federal Partners in Transition Workgroup – Youth Transition Plan – Interagency Strategy  
<https://alternativestoguardianship.com/2020-Youth-Transition-Plan.pdf>

National Association of School Nurses – Position Statement on Health Care Transition  
<https://alternativestoguardianship.com/school-nurses.pdf>

Adolescent Health Transition Project – Role of School Nurse for Special Education Students  
<https://alternativestoguardianship.com/importanceofhealth.pdf>

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