



Facilitating Transitions to Independence

Best practices when working with adolescent patients

Mark Schmertmann, MSW, a social worker with the Cincinnati Children's Hospital Medical Center, recounts a story about a 14-year-old patient with muscular dystrophy who had been seeing the same provider for years. At this clinic visit, when his mother responded to the clinician's questions, as she always had, he interrupted.

"I have to answer the questions, Mom — I'm becoming a man," he said.

This is one of the bolder assertions of independence Mark and his colleagues have witnessed, but, "it's a great example of how the philosophy of transition can be understood and practiced in a visit," he says.

Helping adolescent patients transition to adulthood, both medically and emotionally, is something providers should help facilitate, even if the patient will remain with the same pediatric provider. "Simply recognizing that patients are becoming adults or that they are adults can go a long way," he says. "It follows that engaging with them as adults in the clinic space should be practiced, even if it is less efficient than getting all of the information from a caregiver."

Ensuring a smoother experience

Mark has identified three points that are especially important when working with adolescent patients:

- 1. Start talking about transitions early.** “Typically, caregivers are hesitant, while the patient is ready to get started,” Mark says. “It’s important for the clinic to give patients a space to identify the challenges they want to take on.”
- 2. Be considerate of caregivers.** It can be hard for parents to go from caregivers to cheerleaders. “To some, the idea of relinquishing control brings safety concerns, feelings of powerlessness, or feeling like clinicians and/or patients want to cut them out of the process,” Mark says. To ease the change, collaborate with caregivers and recognize their reactions are valid and part of the process. This helps to establish mutual understanding and buy-in.
- 3. Be flexible.** “Clinicians should be facilitators, while patients and caregivers are guiding and leading the process,” Mark says. Be prepared to adjust your approach when goals are met or new ideas are introduced.

How can clinicians help?

Make the clinic a safe place for teens to practice self-confidence, independence, and expressing their needs as patients. “These are all skills that require practice to develop and refine,” Mark says.

For many kids with disabilities, it’s not easy to speak up for themselves in daily life. Also, some neuromuscular conditions or treatments can make patients appear younger than they are, which can affect confidence. “The clinic space may be easier to take on, especially with provider encouragement,” Mark says.

He recommends asking patients in high school what their plans are after graduation. Mark did so for one patient and learned that the patient was interested in college. “That was a surprise to his mom, who was hearing that for the first time,” he says. But once they began discussing it, the patient shared ideas on how his family could support him in pursuing that goal, while Mark shared supportive resources available through the hospital and state.

Asking about the future is important, because some kids don’t realize that college or a job could be an option for them. Bringing up these topics can help teens understand their options for living independently as adults.

For patients who have significant cognitive or intellectual disabilities, “transition challenges should always scale to the patient,” Mark says. “You would likely shift transition efforts from remaining caregiver-focused to proactively discussing guardianship and other relevant, attainable concerns.”

To begin discussions about transitioning to independence, have your patient identify a vocational or educational goal. “You as the provider can review or challenge the patient to think about what they would need to be able to do or have in place to make that happen,” Mark says.