

3 keys for treating patients with intellectual disabilities

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Patients with intellectual or developmental disabilities (IDDs) have unique needs. Two experts outlined what those and what doctors and medical students should know to help meet them during an education session recorded for the November 2021 AMA Section Meetings.

The education session, hosted by the AMA Medical Student Section, featured:

- Priya Chandan, MD, MPH, PhD, an assistant professor of neurosurgery at University of Louisville School of Medicine.
- Douglass Wells, MD, a second-year resident at Baylor College of Medicine in a combined program that focuses on pediatrics and neurodevelopmental disabilities.

Autonomy is important

When working with patients with intellectual or developmental disabilities, it's key to remember that patients themselves are the most important and involved stakeholders in their own treatment.

“At the end of the day, it will always be them playing a key role as a member of our team when we make decisions about them,” Dr. Wells said. “Whether they are an adult and they show up with their parent with them or a caregiver from a home that they may live in, it's always important to make clear indications about their ability to make decisions as we discuss their health care in any setting.”

Find out how the pandemic makes life harder for people with disabilities.

Always address the patient

It sounds like a very basic lesson, but Dr. Chandan said talking directly to a patient who has IDD doesn't always happen. That's especially the case when there may be a caregiver in the room. This also means using any means necessary and possible to understand a patient's needs.

"Don't make the mistake of thinking they don't contribute to their care, because they are your most valuable source of information," Dr. Chandan said. "You might have to get creative. For me, working with patients in physical medicine and rehab—they have some sort of life-altering illness or injury. Many of them do not communicate verbally. So if you get stuck on that and think of it as the only way to communicate, you will miss a lot."

Learn how the AMA is seeking more help for medical students and resident physicians with disabilities

The system of care is a challenge

How and where patients with IDDs receive care can change dramatically based on their condition and where they are being treated. Physicians have to understand that to help deliver better care, Dr. Chandan said.

Care for these patients "is so fragmented," she said.

"There's a big disconnect between the multiple service systems that serve these patients. It varies even from state to state," Dr. Chandan added. "As a physician working with patients in this population, it requires you to learn a lot about service-delivery systems and what that looks like in the context you work in. Through medical training, we move all around. We got to med school, we go to residency, then you eventually settle into practice and the system might look different each place."

Read the AMA's strategic plan to embed racial justice and advance health equity, which outlines the need to center the experiences of people with disabilities, among other historically marginalized groups.