

About Developmental Disabilities (DD)

This toolkit is for members of the primary care team to assist in making practice changes to better support patients with suspected and confirmed developmental disabilities (DD). In our implementation projects we learned that there are different viewpoints about what a DD is.

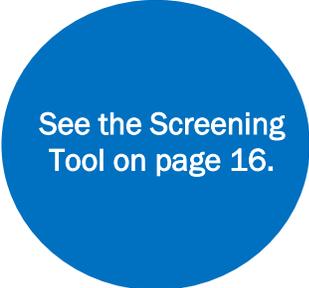
There are some patients in your practice for whom it is very clear from the time they were young children that they had a DD. Chances are, such individuals have been receiving more extensive supports, and perhaps have had greater attention in terms of transition plans into adulthood. They may require help in all aspects of their life on a daily basis, and they may have many comorbid medical issues related to their disability. Their ability to describe and report on their health may be particularly compromised. This group most likely has documentation about their disability on file at your office, as well as in the school record and even in various specialized health care settings. It is important to ask for any of this information when the patient is still in school, so that it is part of your medical file. The sorts of stressors experienced by the individuals and their families can be very different from a second group of individuals - those with more mild disabilities. You may not always know with this second group whether they for certain have a DD as defined in [legislation](#), or in [medical diagnostic criteria](#).

Individuals in this second group may have documentation about their disability in other places, but not your office. Always encourage your patients and families to give you copies of this sort of information from their school setting - anything that documents their need for special education. This may include any annual reviews, such as Identification, Placement and Review Committee (IPRC) notes, Individual Education Plan (IEP) notes, psychoeducational assessments done in school, and psychologists' or physicians' reports done outside of school. This information is an important component of their health record and also useful when it comes to obtaining services.

Even though the disabilities may be more subtle for this second group, we know that their lived experience can still be quite stressful for them and their families. Sometimes, not quite fitting in to one category or another means additional challenges accessing services, which is stressful and can lead to poorer health outcomes. Having independence can also mean having less supervision and support, which can lead to choices that can be harmful to one's health. Not understanding a disability can also lead to interpersonal tensions at home, at school, and work, because expectations are not realistic, and supports are not in place. Individuals in this second group can have a host of physical and mental health issues that develop over time. As clinicians, if we don't recognize the disability, we might only see the health issues and wonder why the patient is having difficulties.

Although we encourage you to look into the various definitions for DD, criteria generally includes the following:

- 1) Originated before the person reached 18 years of age;
- 2) Are likely to be life-long in nature; and
- 3) Affect areas of major life activity, such as; personal care, language skills, learning abilities, the capacity to live independently as an adult, or any other prescribed activity.



See the Screening Tool on page 16.

About Developmental Disabilities (continued)

Why is it important to know whether in fact your patient meets medical or legal criteria for a developmental disability (DD)?



It matters in terms of which services the person may be eligible for. It could matter in terms of strategies that would be most successful.

Suspecting a disability, even without confirmation can be a flag or trigger for you to make some modifications to your standard practice. If these modifications improve the care you provide and ultimately improve the health of your patient, that is what is most important.

Key modifications include:

- Providing information in clear and simple ways; ensure their understanding of these instructions.
- Scheduling appointments around most convenient times; offering additional reminders.
- Screening for additional health issues that are common in patients with DD.
- Linking the patient with supports to help them with follow-up.

Bottom Line:

- ✓ Know your patient. Use a tool like [“Today’s Healthcare Visit”](#) to elicit important information.
- ✓ Don't be afraid to ask if there is a DD ([Screening for Developmental Disability](#), page 16).
- ✓ Even if it takes some time, if you suspect DD, seek services to screen for it.
- ✓ Remember that there are many individuals who have impaired cognitive and adaptive abilities who may not meet criteria for DD. This means they can't access certain services, but they can still benefit from accommodations.
- ✓ Never forget your role as an advocate. If the services are not yet available to meet your patient’s needs, work with your patient and those around him or her to help make that happen.



See the [Resources for Staff](#), and [Resources for Patients & Caregivers](#) for helpful tools to use during your interactions.