What resources can help families whose loved ones develop SMI while they are still in school?

The onset of severe mental illness (SMI), usually marked by a first psychotic break, most commonly happens when a person is in their late teens or early twenties. From a treatment perspective, the importance of early intervention and the appropriate course of treatment is the same whether a person is 15 or 19. However, a family's options for intervention may depend on whether the young person has reached their state's legal age of consent, which could be anywhere from 13 to 18. Also, if the young person is still in school (including higher education), some additional resources may be available and helpful.

TAC focuses our advocacy work on adults with SMI. However, given the significance of early and robust intervention, we created this resource for families struggling with school age onset of SMI to provide helpful information and to direct you to organizations that can be of assistance navigating those systems.

We will touch on the basics of early intervention programs, age of consent, and other topics relevant to families seeking support for a minor child or young adult in the early stages of a severe psychiatric illness. Some initial places to go for additioin information, training, and support include:
• **NAMI Basics**: The National Alliance on Mental illness provides an online version of this training for parents of children and youth and supports a list of local affiliates for in-person trainings.
• **Parents Like Us Club**: This website includes options for social media networking and is designed for families supporting children and youth with severe mental illness.
• **Child Mind Institute**: This website offers evidence-based information about specific diagnoses and recommendations for care and support at home, in the community, and at school.

**When to seek intervention**

Early signs that a young person may be shifting into psychosis can be alarming. A psychotic break can include hallucinations, delusions, or behaviors that indicate a disconnect from reality. This may indicate that the person is developing SMI — but not always. A medical evaluation is critical for figuring out what may be happening and how to help.

TAC provides an additional resource with information about early signs of psychosis and intervention programs designed to catch SMI early and treat it comprehensively to improve long-term outcomes.

**School services may be available**

A young person still working their way toward a high-school diploma may receive support through the special education system if their mental illness is disabling. Disability related educational services can continue through age 21 for “transition age” students who need additional time and support to prepare for adulthood. By seeking a free educational evaluation from the school, families may be able to pursue school-based options for early intervention.

In the provider world, serious emotional disturbance (SED) is sometimes used instead of SMI when talking about someone younger than 18 with a severe psychiatric condition. This may be due to a reluctance to label a person with a psychiatric diagnosis before adulthood. The important thing to know as a parent or loved one is that when you hear “severe emotional disturbance” or “SED” it’s a term that has significance under the law. Federal law specifically lists schizophrenia within its definitions for the special education eligibility category of Emotional Disturbance (ED). The ED category also might apply for a diagnosis of bipolar disorder, severe depression, an unspecified psychotic disorder, or something else that is serious and disabling.

Note that a medical diagnosis is only part of the information schools use to make determinations about eligibility and services. Families can seek help navigating school-based evaluations and services from the Center for Parent Information and Resources, which provides a [list of parent centers] across the United States.
Find information about age of consent in your state

Families seeking to engage in the treatment of a young person in their care may encounter surprising barriers – even for minor children – if the young person is unable to understand that they are ill and does not choose to engage in treatment. See TAC’s video about anosognosia, a symptom of illness that blocks a person from understanding their illness or why treatment would be helpful.

States have their own medical age of consent laws. To find criteria in your state, type the name of your state and “age of medical consent” into your browser.

If the child is at the age of medical consent, ask the provider about requirements related to releasing information and request a release of information form if one is needed for you to participate in care planning. Information sharing may vary depending on the treatment needs as well as the age of the child. For example, some providers will talk more openly about mental health care than substance use disorder treatment.

If a provider shuts you out because of concerns related to confidentiality, look for ways to learn and collaborate that don’t require them to disclose specific medical details. For example, parents can ask for general information about a diagnosis or tips for managing a certain range of symptoms in the home. You can request general information about how certain substances might worsen psychiatric symptoms or interfere with medications.

Note that you can—and should—share mental health history and your observations with a provider. TAC provides a resource to help you write a concise mental health history. TAC also provides information to help caregivers navigate HIPAA (federal laws that protect medical confidentiality).

Finding ways to partner with the young person you care for will be helpful. In general, learn to ask questions to gain trust and build a partnership. Visit the LEAP Institute for information about communicating with someone you love who may not recognize their illness or why treatment is in their best interests.

Plan ahead for a young person who may be eligible for disability benefits

If a severe and persistent psychiatric condition affects a person’s ability to learn or work, they may be eligible for disability benefits from the Social Security Administration. Those benefits can include access to Medicaid. Information about disability benefits for youth before and after age 18 is provided on a website about Supplemental Security Income (SSI). SSI provides funds for basic needs when someone becomes disabled before starting work and paying into the system.

Note that there is a special designation for individuals whose disability begins before the age of 22. A disabled adult child (DAC) may be eligible for benefits if their parent is deceased or starts
to receive retirement or disability benefits. The benefit for the DAC is tied to the parent’s Social Security earnings record. To qualify the DAC must be unmarried, 18 years of age or older, have a qualified disability that started before age 22, and meet the definition of disability for adults.

What support does my loved one have a right to?

A mental illness can make a person eligible for federal disability protections if it is shown to substantially limit any major life activity (learning, working, managing self-care, etc.). Disability rights apply regardless of the nature or severity of a condition.

Disability rights are upheld by the federal Office for Civil Rights (OCR) and the U.S. Department of Justice. Those protections support a person’s right to be accommodated and supported in order to access what is publicly available (school or vocational rehabilitation, for example).

Two laws support the civil rights of a person with any significant disability condition:

- The Rehabilitation Act of 1973, which includes Section 504
- The Americans with Disabilities Act (ADA)

These laws include protections for people who use coping strategies, medication, or other “mitigating measures” to function as best they can despite their disability-related conditions. Mitigating measures may not be used as a reason to deny a request for evaluation. More information is searchable on a U.S. Department of Education website page of questions and answers about the ADA Amendments Act of 2008.

A public-school student is evaluated to determine eligibility for these protections and to collect data about what accommodations they need to access their right to a free appropriate public education (FAPE). A Section 504 Plan is written to provide FAPE with individualized support. Schools are responsible to protect student civil rights in the ways they manage absences and administer discipline. In July 2022, the Office for Civil Rights published guidance about non-discriminatory use of student discipline to clarify that schools have a responsibility to prioritize help over discipline for students who struggle with behavior related to their disability. Stopping disciplinary practices that feed the school-to-prison pipeline is a goal that matches a larger national advocacy goal to end criminalization of severe mental illness.

A student with an Individualized Education Program (IEP) has their Section 504 FAPE rights further upheld by the Individuals with Disabilities Education Act (IDEA)—the law that governs the IEP process. Schools are responsible to serve students in the least restrictive environment (LRE) that meets their needs. For example, a student with schizophrenia would need to be individually evaluated and an IEP team would make placement decisions.

After a student graduates or leaves the public school system, their school paperwork can support conversations about accommodations in higher education or at work. How and whether to disclose information about a mental illness condition is personal. Consulting staff at
a public office of vocational rehabilitation or within a special services office at a college or trade school is a place to begin.

Families can reach out to a parent center in their state for individualized guidance about navigating special education services and upholding their student’s rights. The Center for Parent Information and Resources maintains a website, parentcenterhub.org, that provides a list of parent centers across the country.