

What families need you to know:



An open letter to AOT judges, providers, and others with jobs that serve people with severe mental illness

When a person has a severe mental illness, families like ours want our loved ones to receive compassionate care and effective treatment. We want to serve as respected collaborators while professionals do their jobs as judges, AOT monitors, case managers, and other providers.

During a national conference on assisted outpatient treatment, family caregivers openly, honestly, and vulnerably shared insights about the broken mental health care system, including ideas about how AOT can become an essential part of a renovated system.

Our families have expertise and creative ideas. **This document highlights what we learned that every family wants from providers and AOT teams.** This list is not exhaustive, and we welcome input from within our community:

Acknowledgement that our families are “normal,” and that family dysfunction is an outcome of SMI – not its cause.

Timely communication and mechanisms to share information promptly so adjustments can be made, and recovery can stay on track.

Our loved ones to be as healthy as possible, and to continue treatment.

Not to be abandoned; treatment providers who are in it for the long haul and can help us grow in acceptance and ability to participate.

Evidence-based problem solving and treatment solutions leading toward long-term recovery.

Language and cultural access support so that we are respected for our differences and our loved ones receive care in the language, and with the sensitivity, required.

Empathy as we envision and embark on cautious steps toward a different future.

Recognition that we are not the problem, but rather a crucial part of the solution.

Freedom from the blame that makes our trauma worse, such as people telling us we were too permissive or too strict.

Responses that respect and honor us and show that the team is working to support the best interests of our loved ones.

Understanding about difficult decisions we must make, such as being forced to file civil protection orders, because the system has required our loved one to get so dangerously unwell before intervening.

Recognition that the onset of SMI tests the strength and stability of the entire family.

To partner with providers to ensure that treatment choices are properly informed by our knowledge about what has or has not worked in the past.

To be asked about history and thus be able to provide our previous experiences and records of hospitalizations, incarcerations, homeless episodes, and more.

The terrible truth is that by the time our loved ones meet eligibility criteria for AOT, most have endured negligent or abusive medical treatment, incarceration, arrest, homelessness, suicide attempts, and more. We want providers and AOT teams to meet us where we are, with grace and understanding, at what is often the worst point in our family's journey.

As family members and supporters of people living with SMI, we continue our advocacy work because we know our loved ones are not the enemy; their illness is. We know their baseline personalities, and we relish days when we see glimmers of who they truly are. We want providers to recognize those glimmers with us and to shine light on the path that will lead us to a place where our loved ones can be their best selves.

We also want providers to know that we appreciate them. We value their expertise, education, and willingness to roll up their sleeves to do the hard work. With mutual respect and shared expectations, we believe that outcomes will improve; physical and human costs will drop significantly; and we will be able to step back into our roles as mothers, fathers, siblings, and family members equipped to help our loved ones live with as much health and independence as possible.



Illustrated in a graphic depiction by artist Erica Bota, we prompted family members to talk about how and where we fit as part of a care team; why communication is important; and how it feels to be a family member of someone who cannot comprehend their illness and therefore often stops treatment and deteriorates.