The path for parents and caregivers from a child’s onset of mental illness to acceptance is often long and difficult. Some are able to take decisive steps right away, while others resist accepting what feels like a life sentence of disability for their child.

The following are guidelines for working to engage parents and caregivers in the early stages of emotional turmoil over their child’s mental illness. These guidelines are based on needs identified by parents and caregivers of children and adolescents living with mental illnesses.

- **Remove feelings of blame.** Parents and caregivers are often consumed with feelings of guilt and react rather sharply to any indication that they are the cause of their child’s condition. Being blamed for their child’s illness makes many parents defensive and distrusting. It is helpful for professionals working with families to offer comments like, “You are not to blame if your child has a mental illness,” or “I know how difficult things must be at home, but that’s because of the strain you are under. It does not cause mental illness.”

- **Acknowledge denial and anger as normal.** Let parents and caregivers know that you believe that anyone facing this crisis would react similarly and that their hesitation and frustration are absolutely understandable.

- **Communicate empathy and compassion for the parent's and caregiver's dilemma.** A warm, nonjudgmental, and accepting attitude goes a long way toward building trust.

- **Recognize parents, caregivers, and youth as treatment partners.** Parents, caregivers, and youth (whenever possible and age appropriate) want to be engaged as equal partners in the treatment planning. This engagement should include a relationship of mutual respect. Youth and families want to know that issues they raise are being heard and adequately addressed. Cultural competence and sensitivity should be a part of all treatment planning.

- **Destigmatize mental illness.** Compare mental illnesses to other childhood illnesses like juvenile diabetes and epilepsy. Stress that thousands of children with mental illnesses receive treatment, and treatment can be highly effective. Emphasize that research advances are underway to help ensure safe and effective treatment for children and adolescents.

- **Emphasize that early identification and intervention are essential protective steps for their child.** Explain that seeking appropriate interventions may lessen the long-term severity of the illness. Stress that intervening with appropriate treatment enables the child to regain lost ground and realize her full potential.

- **Be particularly sensitive to parents and caregivers with special needs and concerns.** Be aware of the unique challenges of single parents, working parents and job demands, families living at or below the poverty level, and parents and caregivers who may be struggling with a mental illness.

- **Provide parents, caregivers, and youth with resources—education and information lead to empowerment.** Share fact sheets, Web-based resources, and related materials with youth and families. Encourage them to contact the local or state National Alliance on Mental Illness (NAMI) organization or other family advocacy groups in their community for information about referrals, support groups, and education classes. Urge them to attend so that they can get the support they need for themselves and to help their child.

The chart on the next page outlines the stages that mark the path that families typically follow in moving from denial to acceptance.
Impact of Mental Illness  
The Predictable Stages of Emotional Reactions Among Family Members

I. DEALING WITH THE CATASTROPHIC EVENT

CRISIS/SHOCK: Feeling overwhelmed, dazed. We don’t know how to deal with it.

DENIAL: A protective response. We normalize what is going on, find reasons for what is happening that don’t involve mental illness. We decide all this is not really serious, there is a perfectly logical explanation for these events, or it will pass.

HOPE AGAINST HOPE: The dawning of recognition and the hope that this is not a life event, that somehow everything will magically go back to normal.

NEEDS: *Support *Comfort *Empathy for confusion *Help finding resources *Early intervention *Prognosis *Empathy for pain *National Alliance on Mental Illness (NAMI) or other family advocacy group

II. LEARNING TO COPE: “GOING THROUGH THE MILL”

ANGER/GUILT/RESENTMENT: We start to blame the victim, insisting that the child should snap out of it. We harbor tremendous guilt, fearing that it really is our fault. We torment ourselves with self-blame.

RECOGNITION: The fact that a mental illness happened to someone we love becomes a reality for us. We know it will change our lives together.

GRIEF: We deeply feel the tragedy of what has happened to the child who is stricken. We grieve that our future together is uncertain. This sadness does not go away.

NEEDS: *Vent feelings *Keep hope *Education *Self-care *Networking *Skill training *Letting go *Cooperation from child-serving systems *NAMI or other family advocacy group

III. MOVING INTO ADVOCACY: “CHARGE!”

UNDERSTANDING: We gain a solid, empathic sense of what is happening with our child. We gain real respect for the courage it takes for our child to cope with this illness.

ACCEPTANCE: Yes, we finally say, bad things do happen to good people. It’s nobody’s fault. It is a sad and difficult life experience, but we will hang in there and manage.

ADVOCACY/ACTION: We can now focus our anger and grief to advocate for others and fight discrimination. We join public advocacy groups; we get involved.

NEEDS: *Activism *Restoring balance in life *Responsiveness from child-serving systems *NAMI or other family advocacy group

Adapted from the NAMI Family-to-Family Education Program and the Parents and Teachers as Allies publication.
To learn more about NAMI and advocacy for children, visit our Web site at www.nami.org/caac.