

Youth and Family Perspectives on Trauma-Informed Care



Making Sense of the Story

Everybody has a story. Sometimes the story is simple, straightforward and filled with happy memories; sometimes the story is complicated and takes many unhappy twists and turns, as children and families experience violence, poverty, abuse, foster care, substance abuse, neglect or other traumas. Often, when the story is complicated and unhappy, children especially respond in the only way they know how—by internalizing the pain and becoming depressed and withdrawn, or externalizing the pain with aggressive and self-destructive behavior. And all too often, even though they have the best of intentions, family members and caregivers—and even professionals—treat the behaviors with little regard for what the child has experienced.



“Being able to name the trauma was liberating.”

– Brie

Brie, who now works for a youth advocacy organization, describes a childhood in which her parents divorced when she was five years old and she had no contact with her father. After isolating the family from her maternal grandparents, her stepfather emotionally abused her and her siblings and physically abused her mother until they separated when Brie was 14. Brie started acting out and not doing well in school; she was even hospitalized for a time. But no one ever talked about what had happened to her. Instead they focused on her behavior. As a young adult and recent college graduate, in a new job with health insurance, she was finally able to get good therapy. She came to understand that her adolescent behavior was normal for the abnormal childhood she had, but no one had ever told her that before. Brie says that being able to name her childhood experience as trauma was liberating. Using the label of trauma took the focus off of her as a bad person and put it where it belonged—on what had happened to her, on her story.

Understanding what trauma is

Other youth and family members echo the importance of the story when it comes to understanding trauma and what it means to provide trauma-informed care. Sharon, whose daughter died of a drug overdose after Sharon tried for years to treat her addiction, tells of the series of traumas her family experienced both before and after her daughter died. In her current work as a national parent advocate, Sharon emphasizes that the first question professionals should ask when a child comes in with a problem is whether anything has happened at home. Has there been some kind of trauma? This gives the child and family the opportunity to tell their story.



“Professionals should always ask, ‘Has anything happened? Has there been a trauma?’”

– Sharon

The traumas that families have experienced are complex. One parent describes trauma as multi-layered: personal, family, generational, and community. Others who have been foster parents and/or who have adopted children talk about the trauma history their children brought with them. Stephanie, with a personal history of sexual abuse, is a foster and adoptive parent whose children were physically and sexually abused. Stephanie adopted four siblings, not knowing ahead



of time what it would take to unravel the complex nature of the trauma they experienced before and after they joined her family. Foster and adoptive parents recognize that the foster care and adoptive processes are themselves traumatizing for children, given the many transitions children often have to make which can lead to issues with abandonment, loss and grief. Martha, the mother of an eight-year-old she has had since he was two, says it's also important to recognize the trauma in being removed from one's birth home, even when there has not been abuse. "Don't act like nothing ever happened," she says. Jeremy, a young adult with experience in the foster care system, emphasizes the value of educating youth about trauma so they can learn how to manage their own triggers. He also advocates for better understanding of the special issues faced by LGBT youth who often have stigma and stereotypes to deal with on top of the trauma of their mental health issues.



"Don't act like nothing ever happened."

– Martha

Many children who have trauma histories in the form of abuse, multiple foster care placements, or abandonment and neglect also have mental health diagnoses like ADHD or bipolar disorder. Some have a Fetal Alcohol Spectrum Disorder or other neurologically-based disorder. The trauma is part of the

mental health disability, but often not recognized as something that needs to be addressed along with the mental health or physical diagnoses. Sometimes the trauma is not obvious and so it gets missed entirely. Often the trauma is ongoing, not in the sense that the child continues to be abused, but because something happens that reminds the child of the original trauma—like a smell, a noise, a person, a certain kind of vehicle. Trauma is easily re-experienced, sometimes over and over again, leading to Post-Traumatic Stress Disorder.

Repeatedly, parents emphasize that a traumatic experience is not a once-and-done thing. It's not over when the abuse stops and the child is safe in a loving and stable home, but will continue to affect the child for many years. Cassandra's son still relives his sexual abuse and has flashbacks; he had an anxiety attack one time when he saw his perpetrator in the grocery store. Phoebe, a parent and outreach coordinator for a family organization, talks about a "progressive healing process," emphasizing that trauma healing takes time. Understanding the complexity and ongoing nature of trauma is crucial not only for parents whose children have experienced trauma but also for professionals who work with them.

Handling trauma as a family

Trauma is also a family affair, and the child's trauma becomes the family's trauma. Michele was raped when she was six years old. She's now watching her 15-year-old niece Allie grow up. Allie was beaten by her father and lives with her grandmother Constance, who adopted her. Constance is also Michele's mother. Allie is angry and filled with rage. She has multiple mental health diagnoses and has been in the mental health system since she was six. More than once, just when she started opening up and talking to her counselors, they would leave, adding abandonment to the list of traumas in her life.

Sharon's father was an alcoholic and she always felt like she had to fix his problem. His addiction became her trauma. When her daughter began having substance abuse issues, Sharon tried everything she could to fix her problem too. Her daughter's addiction was heaped on her own trauma and also became her sons' trauma. Then when her daughter overdosed and died, that was another trauma, causing one of her sons to attempt suicide just a month later. It hadn't occurred to anyone in the aftermath of their sister's death that the boys' trauma needed to be addressed too, and when Sharon tried to get help for her son, she says that no one asked whether anything traumatic had happened in the family. Her son has spent most of his late adolescence and adulthood in and out of the criminal justice system being punished and re-traumatized. The trauma Sharon suffered as the child of an alcoholic father continued as she dealt with the loss of a child and tried to parent her other children who were also traumatized by that loss. Her advocacy efforts these days are focused on educating families about the nature of trauma and its effect on the whole family.

For Stephanie, one result of being the chief caretaker for multiple foster-to-adoptive children with histories of serious sexual and physical abuse was her own serious depression. She had absorbed all the trauma and stress and still couldn't make sure everyone was okay. Donna counsels parents to ask questions and admit they don't know everything they need



to know about parenting children with trauma histories. She is clear that “it takes a village” to raise these children; it’s the hardest job anyone will ever do, but it’s also rewarding.

Dealing with guilt

Sharon also talks about the guilt that is often part of trauma, stemming from her need to fix first her father and then her children. Her inability to do so, resulting in such tragic outcomes for her family, added to her guilt. Cassandra, the mother of a daughter who was molested and raped by cousins and a son who was molested by a young man the family trusted, expresses her guilt over how long it took her children to tell her what had happened to them. She was shocked, angry and hurt—and also felt incredibly guilty because even though she believed she had open communication with her children, they couldn’t tell her about the sexual abuse. She thinks she should have suspected something, given their behaviors.

Luana’s son, now 17, was sexually abused when he was seven. She didn’t know about the abuse for two years. She says she felt “enormous guilt” about not being able to protect him. He didn’t tell her anything even though the abuse went on for months and months. Over time, with the help of counselors, she has come to understand that often when children experience some kind of trauma, parents have to let them talk about it on their own and not rush them. When they do talk, parents need to try not to fall apart in front of their children because children already fear you’re not going to love them anymore. And, Luana counsels other parents to remember that “it’s not your fault.”

Paying it forward

What many parents of children who have been traumatized have in common, besides the trauma experience itself, is their desire to use the experience to help others. So they tell their stories, as painful as they are, in the hope that the stories will help other parents not feel so alone and promote their own healing.

They form nonprofit family organizations, they get involved in community and governmental advocacy, they attend trainings on trauma and trauma-informed care so they understand it better, and they do whatever it takes to find the best treatments and supports they can not only for their children but for other children and families as well. They form support groups with other parents with similar experiences, and they know that support groups or group therapy can also help their children not feel like they are the only ones who have experienced abuse.

Doing these things is a way of making sense of the stories, and rewriting them into stories of resilience and hope. That’s what Brie has done with her own story. As a

child and adolescent, she was always told what her story was—that she was a bad kid, with a variety of symptoms, diagnoses and negative behaviors. Now that she recognizes and is able to name the trauma she experienced, she can use her new story to help other youth. Tyler, a bullying victim, reflects on his journey and says he has learned that “if you fall, you have to get back up.” Angel, a former foster child with FASD who is now a peer coordinator with a youth organization, looks at the trauma she experienced as how “I learned what I don’t want to be like.” She too has rewritten her story.

Donna likens making sense of the story to taking a ball of unraveled yarn that is stained and tangled and putting it back together again. Shannon, a self-described “beautiful, powerful, spiritual” Ojibwe woman whose son died by suicide when he was 19, uses her native cultural practices to help her make sense of her story. She knows that healing is a process, that grief is not linear but more circular. Participating in a tribal ceremony called “wiping the tears” gave her a better understanding of what had happened to her and her family. When the choice was to allow her story to make her bitter or better, like many other family members she has chosen to become better.



*“If you fall,
you have to get
back up.”*

– Tyler



*Through
trauma, “I learned
what I don’t want
to be like.”*

– Angel



Family Members Talk About Trauma

A Brighter Future



Cassandra's daughter and son were both sexually abused; her daughter was molested and raped by cousins, and her oldest son was molested by a young man the family trusted. When she found out, Cassandra was shocked, angry and hurt; she was surprised that even though she thought she had always had good communication with her children, it took them a long time to tell her what happened.

"Don't beat yourself up. Work with therapists. Remember you're not alone."

– Cassandra

As she describes the journey the family has been on since they found out about the abuse, she is grateful for what she has learned about how trauma affects children and for the support she received from therapists and other professionals. She appreciates the professionals who could explain the effects of trauma and help her know how to deal with what she was going through as a parent, including all the pain and guilt she felt. Cassandra says, "They helped us see a brighter future," and assured the kids that they were not victims, and what happened to them is not who they are.

Cassandra also gives helpful advice to other parents: 1) Don't beat yourself up, or go over and over what you did wrong and why your children didn't come to you right away; 2) Work with therapists and professionals, even if you don't always understand what they're doing (the "method to the madness"); 3) Remember that there are other people out there who have gone through the same thing; you are not alone.

Trauma Is a Family Affair

Wilbur probably had no idea what he was getting into when he married Mechelle. If he had seen his stepdaughter act out before he knew her and what had happened to her, he would have written her off as a "bad kid" and concluded that Mechelle was a bad parent. "Don't judge based on what you see," he says. "You don't know what's going on." Even though Mechelle tried to explain the extent of the trauma her daughter Larissa experienced (sexual abuse), Wilbur didn't really understand and wasn't expecting what he ended up living with. He understands that his stepdaughter is in pain and he wants to empathize, but "it's hard to empathize when she's cussing me out.... I care about her, but my feelings get in the way when she's totally disrespecting me."

Mechelle believes that Larissa ended up in the juvenile justice system because she didn't receive the help she needed. She is concerned about safety for herself and her family because of Larissa's extreme aggressiveness, mood swings and impulsivity. Wilbur admits that people have tried to help but his stepdaughter doesn't seem to want to be helped, and so he wonders what can be done until she's ready. While Mechelle knows that Larissa is going to have issues for the rest of her life, her own trauma is still very real. Wilbur agrees, noting that Larissa's trauma has caused trauma for the whole family. The best kind of help would address not only Larissa's trauma and resulting emotional and behavioral challenges but the trauma the rest of the family has experienced as well.



"Don't judge based on what you see. You don't know what's going on."

– Wilbur



The Hardest Job



“Raising a child who has experienced severe trauma is the hardest job anyone can ever do.” Donna is raising three nieces who were “traumatized in ways no one should ever know about.” They have had multiple diagnoses—including attachment disorder, oppositional defiant disorder, PTSD, and ADHD—and have been in continuous therapy and on various medications.

She continues, “It takes a village to raise a child with a trauma history.” It is emotionally and physically exhausting, and parents have to be committed. As a foster parent, she says, “There will be days when you wonder, ‘What did I get into?’ But you can’t give up on these children. They are not puppies to be given back.” Donna asks questions and admits she doesn’t know what she should do. She talks to friends, but she’s careful not to divulge too much about her children’s trauma history. She doesn’t want to exploit their stories which are private. She uses whatever resources are available to help her cope, and she is part of a support group with other parents. It might be the hardest job, but it’s also rewarding when she can see improvement.

“You can’t give up on these children. They are not puppies to be given back.”

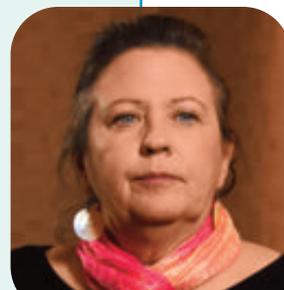
– Donna

Using Cultural Traditions for Trauma Healing

When Shannon went home to her tribal community to tell them about her 19-year-old son’s death by suicide, she focused on what she calls the “trauma narrative.” She emphasized how we “breathe in, breathe out,” and try to “make it to the next moment.” Her son couldn’t make it to the next moment. Because her native community has lost so many to suicide, her son’s death was not just her personal trauma; it was a shared collective trauma.

Shannon repeats the common knowledge about native communities having the highest rates of various social ills, including suicide, mental illness and alcoholism—statistics that tend to reinforce negative associations with race and certain cultures. She points out, however, that they also have the highest rates of complete sobriety, but not much is ever said about that. The positive aspects and protective factors of native culture aren’t often highlighted. These protective factors (or “shields”) include strong connections to culture, language, caring adults, and coming of age ceremonies.

To help her grieve her son’s death, Shannon chose to use traditional practices and tribal ceremonies. She went to tribal elders she trusted and told them she needed help. She learned that there are no cultural or tribal limits on how people should grieve after a trauma or how long healing should take. The elders helped her understand that it was her choice to become bitter or better, and that the circular nature of grief means that something else will always come up to remind you of the trauma when you least expect it. Shannon’s monthly cycle stopped for nine months, which she came to understand as an important metaphor. She had carried her son for nine months, and when she gave birth to him, her relationship with him was different. Now that he had died, she had to learn how to have a different relationship with him again as she birthed him into the spirit world. These understandings, which are embedded in native cultural beliefs and practices but often misinterpreted, provided gentle healing for Shannon from the trauma she and her community experienced.



“There are no cultural limits on how people should grieve and heal.”

– Shannon



What Parents Want

When parents of children who have experienced trauma are asked what they want those who provide services to their children to know, their answers almost always include a strong request for better understanding of the nature of trauma and its impact on children. Parents who have been able to attend training on trauma and trauma-informed care talk about how much it helped them to understand how their child's trauma affected them. The training and increased knowledge about trauma focused their attention where it belonged—on the trauma the child experienced, and not the behavior he or she exhibited.

Ask the right questions and learn about trauma

Now that they understand the impact of trauma on their children, many parents have become strong advocates for “universal precautions.” This term, which has been more common in public health, captures what parents hope will also become the norm in treatment for emotional and behavioral challenges in children. Shannon says it well: “We should be asking, ‘What happened to you?’ not ‘What’s wrong with you?’” Sharon suggests that the initial question professionals should ask when a child comes with a problem is whether anything is happening in the family. Maybe there has been a trauma at home? Sharon continues, “We’re medicating a lot of behaviors that can be traced back to trauma.” Taking the universal precaution of asking the question at the beginning is essential to choosing the best treatment approach—and providing care that is informed by the trauma rather than ignorant of it.

Parents believe that training in trauma and trauma-informed care needs to be available not only for parents but for everyone who might work with children with trauma histories. It should start in higher education so that college graduates entering the workforce are better prepared for what they will inevitably encounter.

Stephanie, a parent with many years of experience caring for children who came to her family with significant trauma histories, is taking her belief in the importance of universal precautions and understanding the nature of trauma to the next level: she is developing her own list of competencies to give to everyone who works with her children. Martha notes that because in her experience therapists often discount the impact of trauma, she has found that parents have to do some of the educating themselves. And even when therapists have been trained or have book knowledge, Mechelle H. suggests that they shouldn't depend on the books for all their answers but should pay attention to what's actually going on with the child.

“Therapists shouldn't depend on books but should pay attention to the child.”
— Mechelle H.



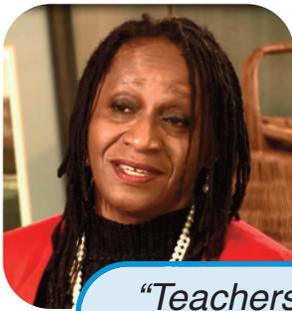
In addition, youth who have trauma experiences need their own training and education so they can learn how to talk about what happened, know what to say and do to protect themselves from experiencing further trauma, and be able to advocate for themselves. Angel in particular wants youth to encourage other youth to use their voice and share their experiences.

Promote more responsive and supportive schools

Asking the right questions, hearing the stories, and identifying the nature of the trauma will go a long way toward developing a system that is trauma-informed, but parents have other recommendations too. Since all children go to school, it's not surprising that the education system is frequently mentioned, sometimes positively and sometimes negatively. On the one hand, Mechelle H. has found that her daughter's school has been more supportive than the mental health system; the school has provided a home schooling option that has allowed her daughter to work at her own pace. Her school, unlike a lot of others, understands trauma. On the other hand, Martha says she has to educate everyone about trauma, including personnel at her son's school. She feels like she's in a constant battle to get the right kind of supports for him, and says, “The school thought of me as a bad person for speaking up.” Luana says that her child's schools haven't offered



anything helpful. Recognizing that communication barriers often exist between schools and parents, Kathy offers practical suggestions for schools, such as texting meeting reminders to parents who may have limited minutes on their cell phones but unlimited texts.



“Teachers need to pay attention to what children can do rather than what they can’t.”

– Phoebe

Parents want schools to be strengths-based and to recognize that even children with significant behavioral issues have strengths. Phoebe tells the story of an Individualized Education Plan meeting with her son and school personnel when he was in elementary school. As she listened to the teachers and others talk, everything they said about her son was negative and she began to wonder what hearing the litany of criticism was doing to her son’s self-esteem. At one point, she interrupted and asked, “Does he do anything right?” Her son turned to her and said, “Mommy, I’m good in math.” She withdrew her son and transferred him to another elementary school where they paid attention to what children can do rather than what they can’t. Cassandra suggests that perhaps teams of parents could work with teachers to help them identify and pay attention to what else might be going on in a child’s life that is affecting their behavior and performance in school.

Create a more effective public mental health system

The public mental health system is also the target of frequent suggestions for what could be done better. “Stop cutting programs,” Luana says. “Provide more funding,” say others. But as Mechelle H. says, “It’s not always only about money.” The system shouldn’t use that as an excuse for not doing something that could be possible if there is the will. Adequate funding is certainly a big issue and could go a long way toward helping the system become more trauma-informed, but parents have other ideas for what could improve the system. Besides her plea to stop cutting programs, Luana asserts, “You can’t treat children as ‘lost souls.’ They are the future.” Constance thinks that children are being pushed aside and says that elected officials need to do more to create a better system. Michelle wonders whether restructuring the whole system is needed, and along with other family members asks that everything possible be done to keep children who have experienced trauma out of the juvenile justice system. Mechelle H., whose daughter has been in the juvenile justice system because she didn’t get the help she needed, calls for training in that system as well.

“Stop cutting programs. Provide more funding.”

– Luana



Continuity of care is important to parents. Often children are re-traumatized by all the moves among programs or when a therapist they have come to know and trust leaves. If it were possible, Michelle F. wishes that a child could be in the same program until he or she ages out to give stability and consistency; she notes that it takes time to develop trusting relationships. Parents also wish for nonjudgmental therapy and compassionate listening. They want to be able to ask questions without fearing that their questions will affect the services their children receive. They want more providers who are able to offer a wider array of services. They point out that especially in rural areas there are frequently not enough providers, and even when providers are available, easy access to transportation isn’t available to get to their offices. Families should not have to travel 45 minutes to get to an appointment.

Another recommendation is to pay attention to the child and family’s culture. Mechele A. emphasizes that foster parents who care for children who come from another culture should do whatever they can to keep them connected to their culture and to help them “embrace who they are.” Admitting that it’s easy to be ashamed of one’s native culture for its negative aspects, Angel, Mechele’s adopted daughter, also says that professionals need to make those cultural connections. She believes that “you can’t truly move on until you know where you’ve come from,” and only recently has been able to accept who she is and the beautiful parts of the culture she came from. Shannon talks about the generational trauma in the native community, and pleads for professionals to emphasize the strengths and protective factors that are also an important part of native culture. According to Shannon, trauma-informed care needs to consider culture and operate on a “do no harm” basis. Some evidence-based programs are not appropriate for native communities and don’t always take into



account some of the protective factors that are inherent in native communities.

Diana, director of a statewide family organization, summarizes the determination with which parents approach getting the right treatment and care for their children. “When parents are dealing with a child in trouble,” she says, “they need to connect with someone who can help. They’ll turn over whatever rock it takes to get help and understand what’s going on.” Sharon, another parent-turned-advocate, reinforces the important role parents play by calling for the system as a whole to focus on families, educate them, and give them the tools they need to help their children.

“When parents are dealing with a child in trouble, they need to connect with someone who can help.”

– Diana



Kathy, whose son is now a young adult successfully managing his serious mental illness, notes that when families are at the table and have a voice, they can help show that mental illness is nothing to be scared about. “It’s all about education,” she says, and notes that she has personally seen how different the system is now that people are more trauma-informed than they used to be. Jeremy echoes the importance of having a voice at the table, in his case referring to youth. “Young people are incredibly intelligent and resourceful,” he says. “They know what works best for them, and parents and professional need to listen to what youth have to say.”

<http://gucchdtacenter.georgetown.edu/TraumaInformedCare.html>

<http://trauma.jbsinternational.com/traumatool>

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