



Family Matters

Elizabeth Ahmann, ScD, RN, and Deborah Dokken, MPA

Making Meaning When a Child Has Mental Illness: Four Mothers Share Their Experiences

Elizabeth Ahmann

According to American Psychological Association (APA) (2013) estimates, approximately 15 million children in the United States can currently be diagnosed with a mental health disorder. While there is controversy about its characterization as such, attention deficit hyperactivity disorder (ADHD) is included in this designation. Data from the late 1990s indicate four million children and adolescents in the United States suffer from a serious mental disorder, causing significant functional impairments at home, at school, and with peers (U.S. Department of Health and Human Services [DHHS], 1999). Additionally, 21% of children 9 to 17 years of age have a diagnosable mental or addictive disorder that causes at least minimal impairment. Many more children are at risk of developing a disorder due to biology, genetics, and/or challenges faced at home, in schools, in their neighborhoods, or among peers (APA, 2013).

Despite these numbers, even though nearly half of all Americans will meet criteria for a mental illness at some point during their lives (National Federation of Families for Children's Mental Health, 2012), and despite increasing social awareness of mental illness, stigma around persons with mental health concerns has remained significant (Link, Phelan, Bresnahan, Stueve, & Pescosolido, 1999). Both children and teens and the family as a whole are subjected to stigma (Mukolo, Heflinger, & Wallston, 2010). In fact, families of children diagnosed with mental illness not only experience the challenge of managing the illness but also social rejection, misunderstanding, grief, and a resultant sense of isolation (Godress, Ozgul, Owen & Foley-Evans, 2005; IU Newsroom, 2007; MacGregor, 1994; National Federation of Families for Children's Mental Health, 2012).

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Author's Note: Names marked with an asterisk (*) have been changed to protect the individual's identity.

Approximately 15 million children in the United States can currently be diagnosed with a mental health disorder (APA, 2013). Families of these children experience not only grief and the challenge of managing the disorder, but also stigma, including rejection, misunderstanding, and a feeling of isolation. Nonetheless, some parents find or develop approaches for "making meaning" from the experience. Interviews of four mothers of children with mental illness demonstrate "making meaning" in ways that provide for personal growth, fulfillment, and support, while engaging in efforts that ease the journey for others in similar circumstances.

Some parents find a way to reach out of their grief and isolation to find a larger purpose or meaning to their experiences, often by helping others. Parental efforts to "make meaning" can include developing support groups, providing community education, writing a book, or other avenues. *Pediatric Nursing* "Family Matters" Co-Editor Elizabeth Ahmann, herself the parent of a child with mental health challenges, interviewed four mothers about their paths to "making meaning" from the experiences of their children's mental health diagnoses.

Rose Jones

Rose Jones*, a psychiatric nurse, is experiencing the challenge of parenting a daughter with an increasingly common diagnosis: ADHD. She has become determined to educate others about ADHD, especially the often overlooked diagnosis of ADHD, inattentive type, in girls.

"When my daughter Nicole* (now in 8th grade) was in pre-school," Jones recounts, "the teachers said they noticed things about her behavior but didn't say much more. Her first grade teacher commented that Nicole had trouble with reading and writing. So, wondering whether she might be dyslexic, I decided to home-school her to work on her

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Gina Gallagher and Patricia Konjoian

spelling, reading, and writing. Over the year, we saw improvements in her reading, and when she took the required “end-of-grade” tests for home-schoolers, she did quite well, though it took her a long time to complete the exams.”

When Nicole was in 5th grade, and had more independence with her home-school assignments, “she needed frequent reminders to stay on-task and to follow through with assignments. I also found she was often interrupting conversations. Something was off. Although by now, we saw that Nicole clearly wasn’t dyslexic, we just didn’t know what to make of her behaviors.”

“My husband wanted Nicole to go into public school for 6th grade, but I was concerned, given what I had been observing at home, so we got psycho-educational testing and learned that she had ADHD, inattentive type. Since she hadn’t been hyperactive, ADHD hadn’t crossed my mind. But it explained her challenges with organization, focus, delayed acquisition of reading, and impulsiveness (interrupting). That diagnosis was the missing piece to the puzzle!”

Nicole tried many medications to help manage her ADHD but experienced a wide range of side effects – from tics and insomnia, to frightening thoughts, to a depressed/sedated state – before finally having success with a medication patch. Despite a diagnosis and several medication trials, says Jones, “she still struggled with school and had difficulty organizing her materials, managing her time, and keeping up with assignments. She was physically and emotionally exhausted much of the time.”

Jones felt “torn up inside,” watching all this happen to her daughter. “I knew that Nicole was working hard but that ADHD was impacting her ability to organize, plan, get started, sustain attention, and manage her time. But I didn’t really know how to develop strategies or set up systems to help her.” Turning to teachers for help, Jones discovered that although they found her daughter respectful, kind, and sweet, some thought Nicole was being lazy and not trying hard enough. Some teachers did not even follow Nicole’s 504 educational plan, and no one offered Jones strategies for helping Nicole succeed. “Looking back, the doctors we saw didn’t even give me a pamphlet about ADHD. I was left on my own to figure things out. It hurt me so much to be unable to help my daughter. I felt alone, and I was so frustrated! At the same time, I knew I couldn’t be the only mom feeling that way.”

“Education is my passion,” Jones says, “and it hurts me that ADHD education is lacking, particularly education about inattentive ADHD, which is often overlooked. I want to make it easier for people to find information that will be helpful. I have so many ideas: developing an educational Web site about ADHD with links so that parents can access useful materials; putting pamphlets in local doctors’ offices; getting connected with psychiatrists, pediatricians, and family doctors to help educate families with whom they work; and improving the way study skills are taught in schools.” Over this past year, while continuing to research ways to help her daughter, Jones learned about and decided to pursue training as an ADHD coach to better help her own family as well as to meet her goal of eventually educating parents, teachers, and others in her community about ADHD. (To learn more about ADHD coaching, or to find a coach, visit the Web site of the ADHD Coaches Organization – <http://www.adhdcoaches.org>)

“Shut up about your Perfect Kid!” say Gina Gallagher and Patricia Konjoian, sisters who are both raising children with emotional and behavioral disorders, and authors, together, of a poignant, funny, and courageous book by just that title.

Gallagher, the mother of two girls, Katie and Emily, was a high achiever as a child – she had lots of friends, played sports, and excelled academically. When Katie, her oldest daughter, was in first grade, Gallagher was devastated to learn that she had Aspergers’ syndrome. Her heart broke as she watched Katie get few birthday invitations, be called “weird,” and struggle with tremendous anxiety. Gallagher mourned for the “perfect” daughter she had imagined and became depressed as books, professionals, and even an advocate she had hired told her again and again about all her daughter would not be able to achieve in life. Several years later, learning that Emily had non-verbal learning disability, fighting a “terrible legal battle” with the school system for appropriate services, and continuing to worry about the futures her daughters would face, Gallagher, who loved her daughters very much, nonetheless struggled further with feelings of anger at being somehow “cursed.”

Konjoian, a more easy-going personality than her sister, had her hands full as the mother of three children – the oldest, neuro-typical, and the middle child having ADHD – when she experienced escalating concerns about the behavior of her youngest child, Jennifer. On a family trip to Disneyland, “the seemingly happiest place on earth for a child,” as Konjoian notes, Jennifer, then 8 years old, began “screaming and crying for no apparent reason during a parade.” This, coupled with periods in which Jennifer had intense sadness as well as separation anxiety, and an episode in which she nearly jumped out of a window, led to an eventual diagnosis of bipolar disorder.

Konjoian experienced many ER visits and hospitalizations alongside Jennifer. As this went on, Konjoian began joking with her sister, Gallagher, that she could “become a newspaper critic rating hospitals: which had the best magazines in the ER waiting room, which had the best food choices!” Konjoian jokingly said she was going to write a humorous book about bipolar disorder. This sparked an idea in Gallagher, a writer. All the books she had ever seen about children with special needs had been negative and/or clinical. She had always imagined she would write a book one day and was struck with the idea: what about writing a humorous book together? Friends, relatives, and members of support groups, parents of typical children, and parents of children with disabilities all loved the idea of the book. When Gallagher coined the title “Shut Up About Your Perfect Kid!” many she knew thought it was brilliant.

Both Gallagher and Konjoian found writing the book to be therapeutic. However, the benefits of the book did not stop with the personal release experienced in the process. The sisters began to get speaking engagements, exposing them to numbers of other parents of children with special needs, many of whom felt isolated, lonely, and as though no one understood their parenting experiences. Audience members would often both laugh and cry during their speeches, and after each speaking engagement, Gallagher and Konjoian received numerous emails in which other parents shared their own stories and expressed gratitude for the hopeful message the sisters had shared. Over time,

Gallagher and Konjoian recognized that the book and the speaking engagements were not really about their two families anymore. The message of their efforts, which they now call the "Movement of Imperfection," had become a process of sharing their experiences; helping others feel understood, and as a result, less alone; and "offering humor and perspective, a reminder to look for the good, and yes, hope, to other families."

Parents can join Gallagher and Konjoian's "Movement of Imperfection" by visiting their Web site (www.shutupabout.com). Their "Shut Up about Your Perfect Kid!" Facebook page has over 15,000 "Likes" as well as many more readers who stay under the radar. The Facebook page, Twitter feeds, and Linked-In page offer humor, honesty, sharing, and 24/7 connection and support among parents of children who are "different" in some way.

Linda McDonough

Remember hearing about a woman who sent her adopted child on a one-way trip back to Russia? Linda McDonough is a mother with a similar child from Russia who, instead, transformed the challenges she has faced in parenting her son into an opportunity to help others.

McDonough and her husband were parents of two young children when they experienced a series of miscarriages. Wanting a larger family, they adopted Victor*, a 13-month-old from Russia, "a darling boy who had spent all of his young life in orphanages." By the time Victor had turned 2 years of age, McDonough knew that something was not right. Another adoptive mom mentioned the term "attachment disorder," and McDonough jumped into action, finding a therapist who specialized in attachment issues.

Several years in family-based attachment-oriented therapy helped a great deal with managing Victor's behaviors, but his symptoms recurred at age 7 with "awful, out of control behaviors" when McDonough, by now the mother of four, gave birth to a fairly demanding baby. After trying to manage for a year or so, McDonough says, "I looked for respite care for my son, expecting to get a break for a week or two. But the therapeutic respite provider recognized Victor's attachment issues and encouraged me to leave him in respite for several months during which she would work hard to 'settle him down.'"

Four weeks into the arrangement, McDonough joined the respite care provider in therapy with her son. "I sat Victor on my lap, and he sat calmly, facing me, and looking into my eyes." Victor was almost 9 years old, but McDonough recalls thinking, "Wow! We have never been able to experience this before!" although it had been normal to share calm, loving moments with her other children. She then spent days in the respite care setting observing and being coached in therapeutic parenting techniques.

As Victor was leaving respite care, McDonough met another mother whose adopted son was just entering therapeutic respite. Having learned a great deal herself during Victor's two months in respite, McDonough began coaching and supporting this other mom. As she recalls, "For years, as I struggled with parenting Victor, I had listened to a psychology radio show. I would imagine what they might say to me if I called in: 'Go to a support group!' But it didn't exist for this diagnosis. I had a strong desire, even a need, to share what I had learned so that I could help others have an easier time with their children than I did. It was only natural to me to want to help this other mom."

That first experience of coaching another mom developed over time into running a small parent group, and eventually, an education and support group that McDonough calls a "therapeutic parenting group" for mothers of children with reactive attachment disorder. At each meeting of the group, McDonough or invited speakers address an issue, resource, or skill pertinent to parenting children with attachment disorder. The monthly meetings of this group have a core group of 12 to 14 regulars who also share experiences, information, and support. The group's list-serve, used for sharing resources as well as announcing meeting dates and topics, reaches 140 parents, many of whom show up for meetings on occasion, especially for the periodic guest speakers. New people typically learn about the group through word of mouth, but sometimes therapists will refer parents of children with attachment disorder because it supplements their work with families.

McDonough's "therapeutic parenting group" keeps a lending library of pertinent resources, and one mother in the group started a Web site to collect and share information and resources both from and for group members (<http://radicalmoms.wordpress.com>). Recently, recognizing the unique issues and needs of parents having adopted teens with more extreme behaviors, McDonough started a spin-off group to support these parents and give them space to address issues particular to their concerns. "One mom who has been in both of these groups has said that her family and friends don't really understand her experience or the way she needs to parent her son with attachment disorder. She often feels isolated. But when she comes to the support group meetings, she feels understood and affirmed. It helps her keep going."

Making Meaning

While the stories of each of the mothers interviewed are unique, it is clear that they all have faced challenges in parenting their children. McDonough shares: "For years...I struggled with parenting my son.... Parenting a child with difficult behaviors can be isolating; it is easy to feel misunderstood and even judged." Gallagher describes having experienced "anger, hurt, and fear" about her parenting situation. In a similar vein, three years after her daughter's diagnosis, Jones says, "I am still in the thick of it. I still feel the hurt and pain."

Despite, or perhaps because of, these difficulties, Jones, Gallagher, Konjoian, and McDonough all found ways to "make meaning" from their experiences, meaning that has both helped others and benefited themselves. Two key themes emerge from their stories: 1) Finding meaning and purpose through easing the parenting journey for others and 2) Experiencing personal fulfillment, growth, and support as a result of their own efforts to help others.

Theme 1: Finding Meaning and Purpose Through Easing the Parenting Journey For Others

McDonough acknowledges many personal benefits of the therapeutic parenting group she started. Among them: "Doing this makes what I have gone through in parenting my son worthwhile. It's almost redemptive; somehow the pain I've experienced feels worth it if I can use my experience to help someone else."

Gallagher recounts, "Through our book, our speaking, our products, our Web site, and our Facebook page, I feel we can help other parents at the beginning of their journeys, or parents who have lost hope, avoid the negativity and depression I personally experienced. Hope is so important!"

"I want to be able to help others lift the cloud of confusion and loneliness I have felt around my daughter's ADHD," says Jones. "Part of lifting my own cloud about parenting a child with ADHD is through creating ways I can help others have an easier time."

Theme 2. Experiencing Personal Fulfillment, Growth, and Support as a Result of Their Own Efforts to Help Others

Jones' journey to reach out to others with ADHD education is just beginning. As she explains, "Learning about ADHD coaching is opening up my eyes and changing my own thinking about ADHD. I am also making many helpful and supportive connections. For example, at a coaching conference I learned about a new program of study skills designed specifically for children with ADHD; this might be beneficial in our schools. I was also talking with a woman who told me how to apply for [contact hours] for educators for classes I might offer on understanding ADHD. This year of coach training is just a starting point for me in my passion to improve access to education about ADHD. I am so excited about it all!"

McDonough recognizes that the group she started "can't be all things to all people" but acknowledges that it has been many things to her. "I have personally benefitted so much from this group! Teaching and sharing with others forces me to re-examine my own parenting and helps keep me on track and accountable for what I want to be doing for and with my son. Since parenting Victor has been very overwhelming and hasn't left me a lot of time to get involved in the community, I can give back this way and I can connect with others. A plus of this group is that all the moms here have suffered with their kids, and we can relate at a deep level. I have made some very good friends in the group. I've been able to share information and resources, but I have also gotten great resources from the group; the amazing therapist we are working with right now is one example! Not only that, but I have benefitted a lot from hearing other people's heart-breaking stories; I've become wiser as a parent but also more accepting of others and myself through running this group."

Reaching out to others through their book has been beneficial for Gallagher and Konjoian as well. Gallagher emphasizes, "We personally get so much joy from what we are doing!" They describe being inspired and moved by the impact of their work on others. "At a recent talk we gave, a woman came up to us in tears telling us that our book had changed her life. She had been struggling with her son's disability as well as her own disabilities and had lived in silence. She said that the humor in our book gave her the courage and strength to openly talk about her struggles. Before reading our book she had required pain medication to manage, but because of her changed outlook after reading our book, she told us that she is now 'med-free.' Another mother, one who found the Facebook page when she had been despairing and lonely, wrote: "This page has saved my life."

Conclusion

Research suggests that for mothers like Jones, Gallagher, Konjoian, and McDonough, whose children are diagnosed with mental illness:

Wanting to help [their children] but feeling powerless to do so, feeling like things are happening outside of their control, lacking supports and having to "sit back" and watch things unfold exacerbate feelings of helplessness (Ozgul, 2003, p. 5).

All four mothers interviewed had experienced a feeling of helplessness or something similar at one point or another in parenting their children. But despite the challenges they faced, not one of these mothers was willing to settle for helplessness as an outcome. In fact, Jones, Gallagher, Konjoian, and McDonough each had a desire to assure that other families would not feel as helpless as they had. Each of these mothers found a way to "make meaning" by reaching out to share what they could with other families. In this way, they offered both herself and others the following important gift:

Those that feel heard and listened to, supported, and receive timely and accurate information about the nature of their child's illness and its treatment feel empowered to take action (Ozgul, 2003, p. 5).

By making their own meaning from the experience of parenting a child with a mental illness, each of these four mothers has found a way to empower not only themselves, but also many others.

References

- American Psychological Association (APA). (2013). *Children's mental health: How many children have mental health disorders?* Retrieved from <http://www.apa.org/pi/families/children-mental-health.aspx>
- Godress, J., Ozgul, S., Owen, C., & Foley-Evans, L. (2005). Grief experiences of parents whose children suffer from mental illness. *The Austria and New Zealand Journal of Psychiatry*, 39(1-2), 88-94.
- IU Newsroom. (2007, April 30). *Making a difficult situation worse: Stigma and mental health in children*. Retrieved from <http://news-info.iu.edu/web/page/normal/5488.html>
- Link, B.G., Phelan, J.C., Bresnahan, M., Stueve, A., & Pescosolido, B.A. (1999). Public conceptions of mental illness: labels, causes, dangerousness, and social distance. *American Journal of Public Health*, 89(9), 1328-1333.
- MacGregor, P. (1994). Grief: The unrecognized parental response to mental illness in a child. *Social Work*, 39(2), 160-166.
- Mukolo, A., Heflinger, C.A., & Wallston, K.A. (2010). The stigma of childhood mental disorders: A conceptual framework. *Journal of the American Academy of Child and Adolescent Psychiatry*, 49(2), 92-103.
- National Federation of Families for Children's Mental Health. (2012). *Executive Director of the National Federation visits the White House, advocating on behalf of children, youth, and families*. Retrieved from <http://fedfamsc.org/2013/01/16/executive-director-of-the-national-federation-visits-the-white-house-advocating-on-behalf-of-children-youth-and-families/>
- Ozgul, S. (2003). *Parental grief and serious mental illness* (draft). Retrieved from http://www.nami.org/Content/Microsites374/NAMI_Glendale/Home375/Resources209/parentalgrieffdraft.pdf
- U.S. Department of Health and Human Services (DHHS). (1999). *Mental health: A report of the Surgeon General*. Rockville, MD: Author.