



Stamping Out Stigma

Rewriting the Script
One Story at a Time

by Peg Nichols



EACH YEAR, ONE IN EVERY FIVE PEOPLE, or about 53 million Americans, experiences some type of treatable psychiatric condition. Yet nearly two-thirds of all people with diagnosable mental disorders do not seek treatment (Regier et al., 1993; Kessler et al., 1996). Tragically, stigma is cited as the top reason for refusing help. Eradicating stigma is perhaps the greatest single challenge to building a social movement that will increase public understanding of AD/HD and other mental health conditions.

In 1999, President Clinton convened a White House Conference on Mental Health, calling for a national anti-stigma campaign. Later that year, Surgeon General David Satcher issued a *Call to Action on Suicide Prevention*. As 1999 came to a close, the Surgeon General made headlines again with his landmark *Report on Mental Health*, which provided for the first time in history a public blueprint of the existing mental health system and objectives for improving it.

When the report was released, Dr. Satcher stated, “Mental disorders and, to an even greater extent, mental health problems can affect anyone. Few Americans are untouched by mental illness, whether it occurs within one’s family or among neighbors, co-workers or members of the community.” Three years later in July 2003, President Bush’s New Freedom Commission on Mental Health released its final report for transforming the nation’s mental health system. One of the

sweeping recommendations was implementation of a national campaign to reduce the stigma of seeking care.

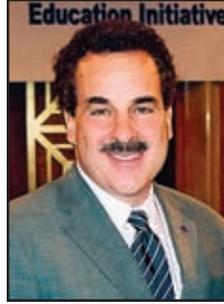
Today we have more knowledge about mental disorders in our arsenal than at any time in history, and still, stigma exists. The good news is that if stigma—and stigmatization—can be viewed as a fluid process, so too can *destigmatization*. Eliminating stigma about mental disorders won’t happen overnight and it certainly won’t be easy. Nevertheless, significant strides *are* being made every day and open, frank discussion about the topic is a vital component of the process.

For this special issue of *Attention!*, CHADD had the privilege of interviewing three prominent individuals in the mental health field—a psychiatrist, a television producer and a marriage and family therapist—who shared their impressions and thoughts about stigma as it relates to both their professional and personal lives.

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Harold S. Koplewicz, M.D., is founder and director of the New York University Child Study Center. He has served as a member of the National Board of Medical Examiners, and as a commissioner of the New York State Commission on Youth, Crime and Violence and Reform of the Juvenile Justice System. Since 1997, Dr. Koplewicz has been the editor-in-chief of the *Journal of Child and Adolescent Psychopharmacology*. He is also a member of a work group organized by the U.S. Assistant Surgeon General and the U.S. Department of Health and Human Services to address the effects of terrorism on children's mental health. Dr. Koplewicz is the author of several books and more than 50 articles on child and adolescent psychiatry, specifically on the treatment of children with anxiety and behavioral disorders. He is routinely interviewed by the nation's leading media outlets.



PN: Dr. Koplewicz, thank you for taking time to speak today about the topic of stigma. Last October you joined CHADD when we took our message of evidence-based science about AD/HD directly to Capitol Hill with an education briefing for members of the U. S. Senate. One of our objectives was diminishing stigma. What message do you hope you left with members of the Senate?

Dr. Koplewicz: Like CHADD, I want to put AD/HD on the radar screens of those who need accurate information about AD/HD and other childhood mental disorders. I want our government leaders to know that AD/HD is a real disorder that unfortunately is very common but fortunately very treatable. Left untreated, our nation faces an enormous public health problem. For example, adolescents with undiagnosed and untreated AD/HD are more likely to use illicit drugs, and are 10 times more likely to drop out of high school. This is alarming and we need to be aware of the long-range societal ramifications when we don't take seriously these highly treatable conditions.

PN: As a treating psychiatrist, you see hundreds—perhaps thousands—of children and families every year. What are some of the ways stigma emerges in your discussions?

Dr. Koplewicz: You cannot underestimate how badly parents want their kids to be normal. They want their child's life to be better than their own. Admitting that your child is in trouble is a very difficult and painful experience. For some parents the fear is so great it actually prevents them from seeking and getting treatment for their child. We know that this fear is exacerbated by the stigma that surrounds diagnosis of a mental disorder. And its results can sometimes be fatal. When not recognized, psychiatric disorders cause other problems such as academic failure, social isolation and substance abuse. All of these behaviors contribute to a downward spiral for the child, making it hard for him or her to cope and succeed in life.

I'd like to share a story from my own family's life. My son, currently a senior in high school, recently obtained early acceptance to an Ivy League college. This accomplishment is awe inspiring to me because he was diagnosed with dyslexia at age four. While my son does not have AD/HD (or to my frustration anything else that I can treat!), his dyslexia is a lifelong disorder with lifelong impact. Like AD/HD, dyslexia can't be cured. But it can be treated. That's the good news. It took my son years to accept his deficit—and it affected our entire family too—but once he did, he became an effective advocate for himself and others. Acceptance doesn't happen in a clean, linear fashion,



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and it certainly doesn't happen overnight. But it *can* happen and when it does the world suddenly looks different. In fact, the paradox of acceptance is that it actually creates room for change. I'm grateful that my son receives the accommodations he deserves and is able to succeed in school. Every child deserves the same.

PN: What about the effects of stigma in some of your young patients?

Dr. Koplewicz: It's not at all unusual for a first grader—an innocent six-year-old child—to tell me that he's a bad boy. This breaks my heart. Kids have a hard time separating their core self from their behaviors. So while children with AD/HD may know that they're not behaving in a way that's helpful—even if they can't stop it—they begin to internalize the message that *they* are bad. This erodes their self-esteem, which is really devastating to see in a person so young.

Another reason stigma gets magnified is our societal fear of medication—particularly medicating children. For many parents, learning that their child needs to take a pill means, in a parent's mind, that their child is sick. I see this a lot. Over time, however, most parents come to realize that the exact opposite is true: they begin to accept—as does the child—that medication and other interventions allow them to function in ways that are positive and productive. This leads to improved interactions with peers and family, which results in increased self-esteem.

PN: Stigma begins with stories—frequently untrue stories. How can psychiatry contribute to the shaping of a new story, one in which mental disorders are seen through a lens of compassion, rather than contempt?

Dr. Koplewicz: Medicine is built around stories. And we live in a world that wants facts, data, and demands proof. As clinicians, we try to explain why things are the way they are. We ask questions. We seek answers. Through this process, we obtain new knowledge...this allows us to "update" the story.

I think one of the most exciting scientific advances made in recent years is the phenomenal work of Dr. Xavier Castellanos.* His recent study on brain size provides definitive evidence that the brains of children with AD/HD who have never been treated are three to four percent smaller in total brain volume than the average child. This is incredibly significant

* See pages 30–31 for additional information on the study conducted by Dr. Castellanos.



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data—it's concrete—and it holds great promise for future research as it sheds light upon questions we have been asking for centuries. In addition, as neuroimaging techniques become less costly and simultaneously more sophisticated, we will be able to see differences in the way children with AD/HD learn and respond to different types of psychosocial and biological treatments.

We are at a very exciting crossroad regarding the diagnosis and treatment of childhood mental disorders. And we have every reason to be highly optimistic as we continue finding significant brain differences in children with disorders and continue developing effective and safe treatments. History shows us that when we have effective treatments for any medical condition and begin openly and non-shamefully talking about it, we reduce stigma. Reducing stigma starts with one person, sharing one story, and grows from there. Talking about real life experiences, coupled with exciting advances in the mental health field, will help millions of children live productive and happy lives. That's our goal—one definitely worth pursuing.



Stories are powerful. They are empowering to the person telling the story. And they are empowering to the person hearing it.



Bill Lichtenstein and his wife June Peoples have devoted their lives to mental health advocacy.

Bill Lichtenstein is company founder and president of Lichtenstein Creative Media, a Peabody Award-winning independent media production company located in New York City. Two of its most well known programs are *The Infinite Mind*, a weekly radio show focused on the art and science of the human mind and spirit, behavior and mental health, and *West 47th Street*, a documentary film for theatrical and broadcast release featuring people living with serious mental illness. Mr. Lichtenstein's award-winning documentary work in television, film and radio spans 26 years, including more than seven years as a producer of investigative reports for the ABC News magazine *20/20* and as a field producer for *Nightline*, *World News Tonight* and *This Week with David Brinkley*, as well as other ABC News programs and specials. In addition to his broadcast experience, Mr. Lichtenstein is a consistently featured writer in a variety of national news and health publications.

PN: Mr. Lichtenstein, stigma is a topic obviously near and dear to your heart. Can you tell our readers about your personal story and how it resulted in a shift in your professional focus?

Mr. Lichtenstein: Mental health became the focus of my life in 1986 when I was working as a producer for ABC News and was diagnosed with manic depression. Had it been any other illness, I would have received a diagnosis, found prompt medical care and gotten better. But that's not the way it happened, which is why we're having this conversation now. The fact is that at that time—and certainly things have gotten better over the years—when I told friends and colleagues I had a mental illness, phone calls stopped being returned and, in one case, a job offer I received completely disappeared. The message to me couldn't have been more clear: this is NOT something you want to have. And it is NOT something you want to talk about. At least that's how I saw it at the time.

PN: Given these circumstances, some people would have moved out of or completely away from their profession. Instead, you opted to use your personal experiences as a professional lens to focus on others with mental illnesses. Why?

Mr. Lichtenstein: Well, I did in fact go through a huge professional transformation. Interestingly, both my parents worked in the public health field. When I was a student they tried to interest me in public health, but my real passion coming out of Columbia where I studied journalism was muckraking—exposing corrupt politicians, putting a spotlight on dangerous products and, as they used to say in journalism school, “just following the buck.”

At that time, stories about the personal and emotional aspects of people's lives held little interest to me as I was focused on a completely different type of reporting. But after I became ill, I took a closer look at others who were heroically struggling and recovering from a mental illness—while simultaneously facing extraordinary stigma and discrimination—and I realized that *that's* where the story really was. That's when we formed Lichtenstein Creative Media. Telling real stories about real people is what we focus on.

PN: Many people with AD/HD, mood disorders and other “stigmatizing” mental health conditions choose NOT to tell others about their disorder for fear of rejection, discrimination, exclusion and other devastating consequences. By contrast, you've often said that you couldn't imagine NOT telling people about your disorder...that the pain required to hold it within is much greater than what could be lost from divulging it. How did you come to this perspective?

Mr. Lichtenstein: Like many people, when I was first

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diagnosed, it seemed logical to tell others I had manic depression. In a way, being able to discuss a medical condition I had came as a relief. Even better was the knowledge that bipolar disorder is treatable. But you learn very quickly from the looks on people's faces or the tone in their voice that mental illnesses are not something universally understood or accepted. That makes sharing even harder.

Conversely though, the burden of holding this personal piece of yourself within is that you begin to feel as if you are withholding a terrible secret. This creates internal stress that can impede recovery. I believe—although it is entirely a personal decision and I won't advise *anybody* on this matter—that it's healthier to be out. When people come to me with questions about whether they should disclose or not disclose, I use analogies. For example, I say, "Are you afraid to tell your boss that you're Jewish because you heard he's anti-Semitic, or that you're African American because she's known as a racist, or that you're gay because he's a suspected homophobic? For me, the answer is clear: if you feel afraid to be you, then that's not a place you may want to work. It may not always be easy to find environments that accept anything deemed "different," but the reality is that there *are* places to work where people have progressive attitudes about a variety of issues—including mental illness.

PN: Any final words of wisdom to our readers about how to reduce stigma surrounding mental disorders?

Mr. Lichtenstein: Tell your story. Nothing, absolutely nothing, is more important than speaking up and speaking out. Stories are powerful. They are empowering to the person telling the story. And they are empowering to the person hearing it. I don't believe that people are by nature mean-spirited. But when it comes to talking about and understanding mental illness, there's a very wide divide. So take a chance. Talk. Share. That's the only way change begins.

Lew Mills, Ph.D., MFT, is coordinator of CHADD of Northern California, serving over 700 members and nine counties. Dr. Mills is a marriage and family therapist working in San Francisco, specializing in adults with AD/HD. He has also worked for many years as an organizational consultant, specializing in teamwork, leadership development and change management. He has a Ph.D. in



If AD/HD helps to explain some of their difficulties—without becoming a crutch—self-acceptance often follows.

organizational psychology from Alliant University where he completed his doctorate in 1997 with research focused on understanding groups and strategies for changing the cultures of organizations. He received his B.A. from Williams College in 1978 and his M.A. in Clinical Psychology from Antioch University-San Francisco in 1984. He has two school-aged children with AD/HD. He was diagnosed with AD/HD as an adult and has since had a passion for serving other adults with AD/HD.

PN: Dr. Mills, thank you for your time. You've traveled a very interesting road in life. You are a marriage and family therapist by profession—and in your personal life your son and daughter both have AD/HD. Shortly after your daughter was diagnosed, you also were diagnosed with AD/HD. Can you tell us more about how one thing led to another, including how CHADD became part of the picture?

Dr. Mills: It's a classic joke—but also very true—that as you study mental disorders in school, you inevitably

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diagnose yourself with the very disorder described in whatever chapter you are reading. I did that, naturally, except that there was no chapter on AD/HD! The catalyst for me recognizing that I might have AD/HD was the realization that AD/HD can be and is experienced by adults—not just kids, as we'd been taught to believe. With this knowledge, it became easier to start looking at specific aspects of my own behavior and see how closely they matched the AD/HD profile.

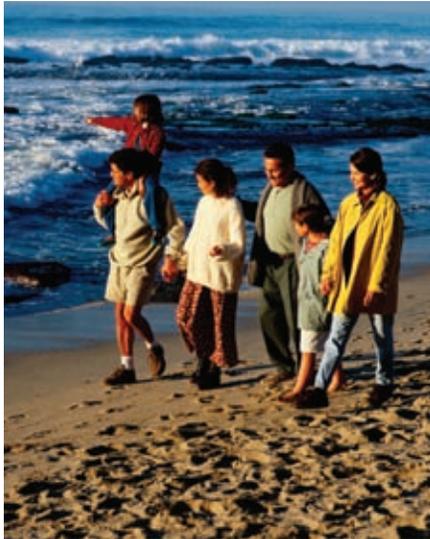
Armed with this knowledge, it still took another two years before I took the diagnosis to heart. Despite having significant struggles with many aspects of my life, I had to gradually let go of the hope that by simply “trying harder” again the next day, I would be able to get over my problems. Accepting the diagnosis—*truly* accepting it—was both intimidating and a relief.

As far as how CHADD came into my life, I became active almost immediately. The huge unmet need of children, adults and families trying to understand and deal with AD/HD drew me right in; so within weeks of attending a CHADD meeting, I volunteered to become a co-coordinator. Serving in this role helped me enormously on both the personal and professional levels.

PN: Every family makes its own decisions about how it wants to handle the sharing of information with family, friends, neighbors and beyond. What works best for your family?

Dr. Mills: Unlike many family cultures where stories are kept in the closet, I grew up in a family where it was easy to disclose our quirks. We have many generations of relatives with bipolar disorder, substance abuse problems, troubles with the law and so on. Interestingly, these were counterbalanced with high points such as a Nobel Laureate, a presidential appointee and a mayor of New York City, among others. So there was always the expectation that if something about us was different, that was okay. Maybe the differences even allowed for a little bit of something special too.

Without the stigma attached to AD/HD, there is no doubt I would have been



diagnosed in 1962. But at that time the disorder was unfortunately named “Minimal Brain Dysfunction.” When an observant first grade teacher suggested that I be evaluated for this condition, my mother immediately came to my defense asserting that there was nothing at all wrong with my brain! And so I waited for another 32 years before I got the treatment I needed.

Now that my two children and I have been diagnosed with AD/HD, I maintain as positive an attitude as possible within our household. I am very open with my kids and involve them in understanding and advocating for themselves. I sometimes get teased about my “obsession” with advocacy, but overall I suspect my children appreciate that I am giving them a positive way to see themselves with AD/HD.

I also have been pretty lucky to work in a way and in a field where disclosing my AD/HD has been an asset, not a liability. I still have experiences where people give me that conspiratorial wink as if to say that we both know AD/HD is an excuse or a non-existent disorder. And that is still very hard to swallow. Some people are more teachable than others, so I put my energy toward them whenever possible.

PN: What does stigma mean to you personally? In your professional role dealing with individuals and couples in therapy, do you find stigma rearing its head in ways that prevent people from living happier lives?

Dr. Mills: The stigma that accompanies AD/HD is truly the biggest thing I treat. I also help clients develop problem solving strategies—for example, how to live well with AD/HD. But a larger part of what I do is help people “revise their histories.” It is enormously helpful to have a new explanation for years and years of difficulty—an alternative to the negative perceptions that individuals and others have made about them. What could be more useful than coming to understand you have a medical condition—not a case of deliberate life-long under performing?

I suspect other therapists would probably agree with me that treating shame and promoting self-acceptance are two enormously important objectives in therapy. The shame that people with AD/HD and other mental health issues experience stems from a deep feeling that there were things they *should* have been able to do, rather than recognizing that perhaps there were things that they simply *could not* do. Without an honest explanation for why they may have “fallen short,” people are left with little else but feelings of profound shame and worthlessness. If AD/HD helps to explain some of their difficulties—without becoming a crutch—self-acceptance often follows.

But as long as our culture continues to shame people (presumably as a motivational strategy to help us be “normal”), instead of helping us discover *why* we are the way we are, stigma will always be present. Shaming people obviously hasn't worked so far. Therefore, I'm all for trying something different...like acceptance.

Attention! is grateful for the stories, insights and reflections shared by Mr. Lichtenstein and Drs. Koplewicz and Mills. Stigma is real. The stories of discrimination, lost jobs, labels, stereotypes, rejection, shame, exclusion, low self-esteem, disapproval and more are endless and no laughing matter. But rewriting the script *is* possible...one truthful story at a time. ■

Peg Nichols is CHADD's director of communications and media relations and executive editor of *Attention!* magazine.