

ADHD Parallels with Other Misunderstood Causes

by Barbara Luther

HOSE OF US IMPACTED BY ADHD or working in the field of supporting people with ADHD can learn a great deal by looking at other misunderstood communities and their success in raising awareness and combatting discrimination. Some of the most misunderstood neurological conditions are autism, Tourette syndrome, dyslexia, and ADHD. Also misunderstood is the gay/lesbian/bisexual/transgender (GLBT) community.

Members of each of these communities have long experienced misunderstanding, discrimination, and stigma. The rates of suicide in each community are much higher than the general population, especially for youth.

| Condition | Number of Times the Suicide Rate is Higher than in the General Population |
|------------|---|
| Autism | 6 to 28 |
| Tourette's | Unknown |
| Dyslexia | 10 to 14 |
| GLBT | 2 to 4 |
| ADHD | 3 to 4 |

Sadly, in a recent study in Los Angeles, fifty percent of the students who committed suicide had been diagnosed with some sort of learning difference.

The prevalence of suicide in these communities can be attributed to many factors, such as not getting properly diagnosed or not getting diagnosed at all, little or no education to understand how their brains are uniquely wired, and the pressure individuals put on themselves to succeed. One other key factor is “minority stress,” which stems from bul-

lying, teasing, and not being able to see positive examples in their world. Another contributing factor is “institutional discrimination,” the lack of specific laws and regulations to ensure equal benefits, opportunities, and protections. Negative media representations are yet another factor.

We have many excellent reasons for looking to other misunderstood communities for what we can learn to help our own ADHD community. Let's briefly look at each.

Community parallels

The autism community has come together, crafted a message of awareness and acceptance, and put that message and vision forward to change the world. As an example, let's look at Autism Speaks, founded in 2005. In the space of less than ten years, Autism Speaks has become the leading autism science and advocacy organization, dedicated to supporting research, increasing awareness of spectrum disorders, and advocating for the needs of individuals with autism and their families. They have created an organization that magnifies the impact of individual efforts and funds to speed up increased awareness and bring educational and advocacy initiatives to fruition much faster.

I love the memorable phrase, Autism Speaks, because it represents something that is often thought not to happen



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to people with autism—speaking. And it takes what is perceived as a negative trait and transforms it into a proactive message of advocacy. I would love to see the ADHD community find a phrase like that for us to all get behind. One example for us might be the ADD Coach Academy’s vision statement: Launching ADHD Success.

The National Tourette Syndrome Association, like Autism Speaks, is dedicated to supporting awareness, education, advocacy, and research on **Tourette syndrome**. It provides one place for resources and support. Also, based on an HBO documentary, they have embraced a positive message for their members to support better understanding. That message is proactive: “I have Tourette’s but Tourette’s doesn’t have me.” It distinguishes clearly that a person is more than just his or her Tourette’s. They offer an upbeat newsletter titled *That Darn Tic*, which contains stories by and for children dealing with Tourette syndrome. Such a newsletter can directly combat potential suicidal thoughts by creating community and offering hope through examples.

The **dyslexia** community formed an International Dyslexia Association to promote education, advocacy, and research. Like the other organizations, they offer resources, publications, research support, and conferences. They also have developed teacher practice standards. They created a *Celebrate!* pin to create awareness, and a Forward Movement bracelet to encourage “validation, support and advocacy for all people that are coping with dyslexia and learning disabilities by providing opportunities for success for all struggling readers and support for their families.” Like some of the other organizations, they offer or support such resources as *Dislecksia*, the documentary film and book. In

the ADHD community, we have many individuals creating wonderful resources, but there is no coordination or organization support or funding for creating one clear, compelling message through these disparate resources.

The last misunderstood community (**GLBT**) has gone from a closeted, unfocused minority to a movement that has called for acceptance of diversity and equal civil rights. Due to the proactive Gay Pride message and civil rights activism, awareness and acceptance have grown dramatically.

The GLBT community had many factions with their own agendas and ideas for how to go about obtaining equal rights. Ultimately, the groups found common ground under the Gay Pride message and vision. The GLBT community crafted the message that GLBT folks were everywhere, and every person—whether they realized it or not—knew someone who was gay. But for this to work, the GLBT community had to go to its own members with a message of bravely coming out so that the world could see that they did, indeed, know someone or have someone in their own family who was GLBT. This took a lot of courage on the part of many people who truly weren’t safe to publicly acknowledge who they were.

Internalizing external judgments

Dr. Stephen Hinshaw, a Berkeley psychology professor who researches stigma, explains that when we communicate and share our personal struggles, rather than ignoring or trying to hide them, those around us can have empathy and even want to help rather than judge. When people feel they know a person and his or her challenges, the fear of difference diminishes.

In an Attention Talk Radio interview (April 10, 2013), Hinshaw pointed out that the mental health profession “in some ways is looking for an identity that arises out of stigma. We professionals are inadvertently contributing to the whole problem. The very profession supposed to be caring for and treating people with mental and emotional problems needs to get our act together and look at the stigma we ourselves receive.” He said, “A big contributor to stigma is silence.” He admonished professionals who have ADHD to own their own challenges and talk about them as a model to help others speak about their symptoms.

The ADHD coach community models this as we share personal challenges and experience through talks, websites, and articles. The more we matter-of-factly talk about our personal challenges, the more people can appreciate the very real day-to-day struggles we face.

One of the ways all these communities are similar is that their members have to deal with labels and internalized self-judgment.

Hinshaw speaks about “internalized stigma,” where we fall into the vicious cycle of accepting societal messages of not being good enough, feeling demoralized, then not feeling worthy or deserving of seeking help. I see so many people with ADHD who have internalized the external judgments they’ve received to the point that they disapprove of themselves and treat themselves very harshly. They don’t like their ADHD brain wiring and only see it as a negative they would like to deny, ignore, or get rid of. Hinshaw has called ADHD internalized stigma a “double whammy.” He explains that “we tend to blame and stigmatize when we feel the person could have, would have, and should have had it under control.” So, people with ADHD experience a great deal of external judgment then add to it as they internalize those judgments and turn on themselves.

In the past, there were many labels for GLBT folks that were used in very derogatory ways, just as there were labels that stigmatized individuals with autism. The GLBT community has embraced those labels and

taken them back in an empowering way, much like the Tourette syndrome community proclaiming Tourette’s doesn’t have them. We in the ADHD community might learn from this. ADHD is too often used to put people down or to convey a snide judgment. How might we embrace the label or create empowering ones we can put forward confidently? Dr. Hallowell talks about our Ferrari brains; I’ve seen other terms like Fast Brains or Bright Brains. What label can we embrace and own for our empowerment?

What can we do now?

Exciting opportunities await the ADHD community. As a diagnosed condition, ADHD falls under the mental health umbrella, and one of the last frontiers for civil rights is the stigma against mental health conditions.

Our first step is to face head-on our internal judgments and misperceptions that people with ADHD are broken, need fixing, and somehow deserve mistreatment. When we have self-stigma, we are not likely to stand up for ourselves or seek the treatment we need. Too many of our professionals and organizations are working from a broken/fix-it perspective that does not empower individuals dealing with ADHD. We must embrace our uniqueness, celebrate our neurodiversity, and learn the environments and situations in which we thrive and excel. We can have a huge impact through helping people to appreciate the incredible individuals with ADHD around them.

It will take many years and multiple initiatives to significantly reduce stigma. Hinshaw proposes a multi-pronged approach that begins with helping people with ADHD get the best evidence-based care and diagnosis, come out of hiding and confidently advocate for ourselves, develop and pass good legislation to provide equal services and prevent discrimination, and upgrade media representation to portray our day-to-day struggles as very human and worthy of empathy.

We must also bring together our service professionals, researchers, visionaries, and mavericks to shape a message. Only then will we begin to speak and act with one cohesive voice to challenge prejudice, create appreciative awareness and understanding, and work for adequate support for all people with ADHD and their families. What do you think our ADHD message should be? 

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