Treating Social Anxiety in Autistic Adults with MDMA-Assisted Therapy: An Interview with Nick Walker

IN CONVERSATION WITH ALICIA DANFORTH, PH.D.

Alicia Danforth, Ph.D. (AD): What is your definition of autism?

Nick Walker (NW): Autism is a genetically based human neurological variant. The complex set of interrelated characteristics that distinguish autistic neurology from non-autistic neurology is not yet fully understood, but current evidence indicates that the central distinction is that autistic brains are characterized by particularly high levels of synaptic connectivity and responsiveness. This tends to make the autistic individual’s subjective experience more intense and chaotic than that of non-autistic individuals: On both the sensorimotor and cognitive levels, the autistic mind tends to register more information, and the impact of each bit of information tends to be both stronger and less predictable.

Autism is a developmental phenomenon, meaning that it begins in utero and has a pervasive influence on development, on multiple levels, throughout the lifespan. Autism produces distinctive, atypical ways of thinking, moving, interaction, and sensory and cognitive processing. One analogy that has often been made is that autistic individuals have a different neurological “operating system” than non-autistic individuals.

According to current estimates, somewhere between one and two percent of the world’s population is autistic. While the number of individuals diagnosed as autistic has increased continually over the past few decades, evidence suggests that this increase in diagnosis is the result of increased public and professional awareness, rather than an actual increase in the prevalence of autism.

Despite underlying neurological commonalities, autistic individuals are vastly different from one another. Some autistic individuals exhibit exceptional cognitive talents. However, in the context of a society designed around the sensory, cognitive, developmental, and social needs of non-autistic individuals, autistic individuals are almost always disabled to some degree—sometimes quite obviously, and sometimes more subtly.

The realm of social interaction is one context in which autistic individuals tend to consistently be disabled. An autistic child’s sensory experience of the world is more intense and chaotic than that of a non-autistic child, and the ongoing task of navigat-
ing and integrating that experience thus occupies more of the autistic child’s attention and energy. This means the autistic child has less attention and energy available to focus on the subtleties of social interaction. Difficulty meeting the social expectations of non-autistics often results in social rejection, which further compounds social difficulties and impedes social development. For this reason, autism has been frequently misconstrued as being essentially a set of “social and communication deficits,” by those who are unaware that the social challenges faced by autistic individuals are just by-products of the intense and chaotic nature of autistic sensory and cognitive experience.

Autism is still widely regarded as a “disorder,” but this view has been challenged in recent years by proponents of the neurodiversity model, which holds that autism and other neurocognitive variants are simply part of the natural spectrum of human biodiversity, like variations in ethnicity or sexual orientation (which have also been pathologized in the past). Ultimately, to describe autism as a disorder represents a value judgment rather than a scientific fact.

AD: What are the potential benefits of MDMA-assisted therapy for an adult autistic population? What is the rationale for a clinical study in this area?

NW: Many autistics suffer from social anxiety—a fear and anxiety response around social interaction. Our hypothesis is that MDMA-assisted therapy could help to ameliorate this anxiety.

The crucial thing to understand is that social anxiety is not intrinsic to autism. Intense and atypical sensory experiences, and atypical styles of physical movement, are innate to autistic neurocognitive processing; if one is autistic, such experiences are going to be part of one’s reality to some degree. But that’s not necessarily the case with social anxiety.

To non-autistics, autistic people almost always come across as socially “odd” in some way—sometimes very much so. Indeed, as already noted, it’s become a widespread error in the field of psychology to misconstrue autism as being primarily a set of “social and communication deficits.” A more accurate and less biased way of looking at it is that the communication difficulties between autistics and non-autistics run both ways: Autistics have trouble understanding and communicating with non-autistics, and non-autistics have trouble understanding and communicating with autistics. This makes perfect sense: Of course it’s challenging to understand someone whose mind works very differently from one’s own. But because autistics are very much in the minority and hold less power in society, communication difficulties between an autistic and a non-autistic are always attributed to a deficit on the part of an autistic person. One rarely hears it pointed out that a non-autistic person suffers from an impaired ability to understand autistics. As the political scientist Karl Deutsch said, power is “the ability not to have to learn.”

The upshot of all this is that the vast majority of autistic people experience frequent social rejection and hostility, beginning in very early childhood. Most autistics today constantly receive the message—again, starting in very early childhood—that the ways they naturally think, feel, move, and communicate are all wrong; that who they are is wrong.

This constant social rejection is deeply painful and traumatic. When such experiences are the norm in a person’s vulnerable formative years, of course that person is going to come to see social interaction as a venture into a minefield, a miserable and frightening experience likely to erupt without warning into yet another experience of pain, failure, and humiliation.

Unfortunately, this often becomes a self-fulfilling prophecy, since no one is at their best socially when they’re experiencing overwhelming fear and anxiety. So the early history of social rejection causes social anxiety, which impairs social performance, resulting in further negative social experiences that reinforce the trauma.

And therein lies the key point, and the cause for hope and optimism: that the social anxiety that afflicts so many autistics isn’t inherent to autism—it is, instead, a symptom of trauma. And through the marvelous work that MAPS has done with veterans suffering from posttraumatic stress disorder, it has already been well-established that MDMA-assisted psychotherapy can be extraordinarily effective in treating the symptoms of trauma.

AD: I’ve found that when I tell non-autistic people about the work we’re doing with the autistic community and MDMA, some people have a hard time understanding that we’re not trying to “treat” or “cure” autism—what we’re treating is social anxiety. Some of the journalists who’ve written about what we’re doing have unfortunately misunderstood and misrepresented our work as being about “treating autism.” What are your thoughts on this?

NW: I’ve seen this sort of misunderstanding occur as well. It is of vital importance for everyone connected with this work—researchers, therapists, study participants, MAPS supporters, journalists, and those who wish to cite this research in their academic work—to be clear about the distinction between treating autistic individuals for trauma-induced social anxiety, and “treating autism.”

The best way to put an end to the confusion, I think, is for

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those of us who are involved in this research to make a point of stating very clearly, every time we talk or write about the work we’re doing, that this is not about treating autism. I’ll state it right here: we are absolutely not researching MDMA as a potential treatment for autism. We are researching the potential of MDMA, used in conjunction with therapy, to treat social anxiety in adult autistic clients. We do not endorse the view that autism itself is an illness or disorder, and we do not endorse attempts to “treat” or “cure” it. Our interest is in improving quality of life for autistic people.

Nick Walker is an Autistic educator, author, speaker, transdisciplinary scholar, and martial artist. He teaches in the undergraduate Psychology and Liberal Arts programs at Sofia University, and in the Interdisciplinary Studies program at California Institute of Integral Studies. He holds an M.A. in Counseling Psychotherapy and a 6th degree black belt in aikido. He is the founder and chief instructor of Aikido Shusekai, an aikido dojo in Berkeley, California. Nick has been involved in the development of Autistic community and culture since 2003, and is a leading voice in neurodiversity activism and scholarship, and a sought-after speaker and consultant on autism. He blogs at neurocosmopolitanism.com.

Alicia Danforth, Ph.D. is a clinical researcher at the Los Angeles Biomedical Research Institute at the Harbor-UCLA Medical Center, where she has worked on psychedelic medicine studies with principal investigator, Charles Grob, M.D., since 2004. In 2013, she graduated from the Institute of Transpersonal Psychology. Her dissertation research was on the MDMA (Ecstasy) experiences of adults on the autism spectrum. She is the co-investigator on the new MAPS-funded clinical trial of MDMA-assisted therapy for autistic adults who have social anxiety. Alicia met Nick Walker when they were invited to co-present at a Visionary Voices Salon in San Francisco in 2009, where he gifted her with the life-changing concept of neurodiversity. She currently is accruing postdoctoral hours toward licensure as a clinical psychologist in a private psychotherapy practice at the Los Angeles Counseling Center under the supervision of Dr. Adam Sheck. She can be reached at adanforth@labiomed.org.

MDMA-ASSISTED THERAPY FOR SOCIAL ANXIETY IN AUTISTIC ADULTS
An Exploratory Pilot Study

MDMA-AUTISM.ORG

Location: Los Angeles, California
Clinical Investigators: Charles Grob, M.D., and Alicia Danforth, Ph.D.
Estimated Study Cost: $312,000
Raised by MAPS: $1,000
Raised by Partners: $16,000
Still Needed: $296,000

MAPS is sponsoring this collaborative study between the Los Angeles Biomedical Research Institute at Harbor-UCLA Medical Center and Stanford University.

Based on the known effects of MDMA, as well as individual reports, researchers are developing a clinical study into the safety and effectiveness of MDMA-assisted therapy for the treatment of social anxiety in 12 adults on the autism spectrum who have not previously used MDMA.

The goal of this study is to determine if MDMA-assisted therapy can safely and effectively enhance functional skills in autistic adults, an underserved group which tends to experience greater anxiety, depression, and victimization than typically developing adults.

The protocol for this study was approved by the U.S. Food and Drug Administration on July 18, 2013, and by the Institutional Review Board on October 16, 2013. The U.S. Food and Drug Administration approved a Schedule I license on December 27, 2013, and the Site Initiation visit was completed on February 10, 2014.

STUDY GOALS
• Gather evidence for the safety and effectiveness of MDMA-assisted therapy for autistic adults with social anxiety
• Determine if additional studies in this area are warranted
• Initiate a new program of research into a possible beneficial use of MDMA building on collected case accounts

HOW TO GET INVOLVED

If you are on the autism spectrum and would like to volunteer for our research, please e-mail study co-investigator Alicia Danforth or call (310) 222-1664 for more information.

You can also support non-profit research into MDMA-assisted therapy for social anxiety in adults on the autism spectrum by making a donation mdma-autism.org/donate.