

# Findings from a Collective Case Study of the MDMA/Ecstasy Experiences of Adults on the Autism Spectrum: Transcript from Psychedelic Science 2013

ALICIA DANFORTH, Ph.D.



Alicia Danforth, Ph.D.

*METAPHORS AND SYMBOLS FROM *The Wizard of Oz* were guiding tools for me on many levels when I was analyzing interview transcripts and identifying emergent themes for my dissertation. In the slides for this presentation, I supported the literal, verbal content with images from the film, in support of visual and figurative thinkers. Here are some of the Oz-inspired concepts that helped me make sense of what the research participants shared with me:*

*The black-and-white to color transition in the film reminded me of the impression lots of folks have of their pre- and post-MDMA perceptions of the world. Even more so, I felt that the juxtaposition of Kansas and Oz was relevant as a before-and-after comparison.*

*I don't think it's a coincidence that Dorothy and her companions have a mind-altering experience in a poppy field just before arriving at the gates of the Emerald City. Sure, they are sedated instead of energized, but the consciousness shift precedes access to a dreamlike, transformative world.*

*The America song, "Tin Man," by Dewey Bunnell inspired me: "No, Oz never did give nothing to the Tin Man that he didn't, didn't already have." Those lyrics were a reminder that, despite stereotypes about ASD, the study participants did not lack empathy, feelings, heart, soul, compassion, caring, or other higher human attributes. They struggled with perception and processing, similarly to how the Tin Man was frozen until he got support from companions.*

*The balloon that leaves the Emerald City has the words "Omaha State Fair" printed on it, which reminded me of the return from non-ordinary states of consciousness to default reality, a transition that can be like returning from Oz to Kansas. So, the question remains when one is back in Kansas: What to do with exposure to the wonders of Oz? You've seen "a horse of a different color"—now what?*

## TRANSCRIPT FROM PSYCHEDELIC SCIENCE 2013

Good afternoon.

I'm going to begin this talk by addressing any members of this audience who might be on the autism spectrum. I want to let you know that what I am about to do is to support any members of this audience who are not autistic but are challenged with experiencing empathy for the conditions of others. That comment was only mildly sarcastic.

For those of you who are neurotypical, non-autistic, typically developing, I want to invite you for a moment to imagine the following. Imagine that you are as intelligent as you are today, you have valuable marketable skills, you engage with life through your deep and passionate interests, however your personal processing system prevents you from correctly interpreting social cues of the dominant culture in which you are expected to function every day.

You want a relationship, but you don't have any idea how to flirt. You want employment, but you have difficulty securing and maintaining employment. Sometimes you have emotional meltdowns that look like temper tantrums, but they are absolutely out of your control. Eye contact is distressing for you. You cannot interpret facial expressions or body gestures. Figurative language, such as metaphors and sarcasm, is just lost on you. You don't know how to dance. You are more like Mr. Spock from Star Trek, in a world that expects and sometimes demands that you behave like Captain Kirk, and you have no idea how to do that nor do you particularly want to.

*You are more like Mr. Spock from Star Trek, in a world that expects and sometimes demands that you behave like Captain Kirk, and you have no idea how to do that nor do you particularly want to.*

One day or evening you have an opportunity to take MDMA. What might that experience be like for you? That was the primary research question that informed my dissertation research. The emphasis in this talk today will be on my qualitative findings; the quantitative data will be presented elsewhere in future presentations.

Here's a closer look at the research project: It's primarily qualitative with an embedded quantitative component, that's represented by the smaller circle at the bottom. It's exploratory, not explanatory. The purpose is pragmatic, to inform future clinical investigations. It's data-driven, based on the comments and survey results of individuals on the spectrum. It's inductive, intended to cast a broad net, to capture all sorts of specific instances, different data points that are then used as part of the scientific method to inform hypotheses for later research. It's also intended to be atheoretical. I did use an actual method; this isn't a matter of cherry-picking data to serve my purposes. I used *applied thematic analysis*.

Three of the most important points I'll make today are that [1] this research is not about treating or curing autism, [2] it's not about children or teens, and [3] it's not about individuals who lack empathy. I am a biased researcher. I am a psychedelics researcher. I study psychedelics and empathogens. I am not an autism researcher, nor do I intend to speak on behalf of autistic individuals. That's a brief list [referring to presentation slide] of some of the processes I implemented to offset my bias, so that I could stay true to what they told me and represent that data to you accurately, minimizing the influence of my bias. This research was made possible by support from the Betsy Gordon

Foundation and the James Fadiman Dissertation Support Fund.

For the smaller, quantitative portion of this research, 150 online surveys were collected, four assessments were used, 100 MDMA-experienced individuals participated, and 50 who were MDMA-naïve served as a comparison group. Those are the instruments I used [The Autism Spectrum Quotient (AQ), The Empathy Quotient (EQ), The Interpersonal Reactivity Index (IRI), and the Cambridge Friendship Questionnaire (FQ)]. I won't say a lot about them today but I'll come back to one of them a little bit later. Thirteen countries contributed data to the final data analysis.

The data are still being analyzed, and I'm going to defend this thesis next month, so some things might change. One important thing I'd like you all to know [is] that as of May 2013, the definition of autism in the DSM-V [Diagnostic and Statistical Manual of Mental Disorders, 5th Edition] is going to change in a very significant way: There will be no more categories that

distinguish one level of autism from another. It will all be "Autism Spectrum Disorder."

Relevant to this study, Criterion A states that autism is a condition in which there are persistent problems in social communication and social interaction across context. Most participants in this research would meet the criteria for Asperger's Syndrome.

There were early studies working with minors with autism, with LSD, UML, and psilocybin. A very significant finding from that early research is that none of the mute children suddenly acquired language or were instantly not autistic anymore. This was our first indication that psychedelics do not treat or cure autism.

A note about the AQ score (one of the assessments): It's the Autism Spectrum Quotient, and it's not a diagnostic measure, but it is an indication of the likelihood that an individual may be on the spectrum. Using independent samples T-tests, I was able to determine that there was a statistically significant difference between the MDMA users and the non-MDMA users. But that only gives us a correlation; it doesn't say anything about cause. It doesn't indicate that MDMA somehow made some individuals less autistic, but it does tell us something about a trend we might see in a future study, if we could acquire baseline data.

One interesting finding: 41% of participants for this study used MDMA 11–20 times. No one reported using it 21–50 times, and using it over 50 times was an exclusion limit for this study, but it was an indication to me that most of the people who participated in this study showed some common sense about how often they used MDMA/Ecstasy. Sixty-nine percent of the participants in this study reported that they were highly confident that the substance that they took contained MDMA.

Only one individual said that he was not confident at all.

Here is a brief look at some examples of key findings: Seventy-two percent of survey respondents reported feeling “more comfort in social settings” as a result of using MDMA/Ecstasy, and for 12% of them, that change persisted over two years. Seventy-eight percent of them reported “feeling at ease in my own body.” For 15% of them, it lasted more than two years. Seventy-seven percent reported that it was “easier than usual to talk to others,” with effects lasting up to a year or more for 18%.

One interesting exception to the other participants was one individual who submitted a survey on June 10, 2012, and filled out all of his data as an MDMA-naive participant, then came back after having used MDMA/Ecstasy for the first time a couple of weeks later. On all of the outcome measures, his scores showed a trend toward increased social adaptability and prosocial behaviors.

When I first began this research I knew very little about autism. Early on I came across an image of a pin on the internet. It said, “You don’t get to talk about autism if you won’t listen to autistics.” I printed it out on a big piece of paper and posted it by my computer as a guidepost to follow when I began the interviewing process.

I spoke with 22 males and two females. The mean age was about 30 years old and the mean AQ score was 37.6. The mean score for “typically developing” individuals is about 16. In addition I interviewed two third-party observers, a best friend and a girlfriend of two of the participants, to see if they observed any change before and after MDMA/Ecstasy use.

This slide [of images of snowflakes] just serves as a reminder that autism is a spectrum. I can’t disclose the identity of my participants, so these snowflakes will stand in as representative of the people with whom I spoke. All of the individuals who I spoke with were as individual and unique from one another as these snowflakes.

I asked everyone essentially three open-ended questions:

[1] Describe your experience of taking MDMA/Ecstasy, [2] What led you to try it?, and [3] describe what if anything changed for you after your experience. As a result, three meta-themes emerged.

The first of those was “Change.” What I’m going to do now is read to you excerpts from the actual interview transcripts to give you an idea of how the individuals expressed their experience. To give you a sense of how people expressed the changes that they experienced, first I’ll mention that everyone in the study assigned themselves his or her own pseudonym, and sometimes they made kind of whimsical choices. I’m going to present this data using literal words and terms as well as symbols, images,

and more visual ways of describing what was conveyed to me.

A first comment under the broad heading of **change** in general came from Meri, a 24-year-old male. *“It feels nice to be able to change as a person; it was not something that I was expecting very much; for most of my life, I did not change.”*

The first subtheme [to emerge from the interviews] is **courage**. Pertaining to courage, Haus, a 21-year-old male, said, *“I guess it broke down barriers, is how I would describe it. Yeah, it felt like up until that point, I just sort of always lived in a shell, like in a bubble. The way I isolated from people, and, yeah, I just sort of tore that down, I said, ‘There’s no need for there to be a barrier.’”*

On **communication**, George, who is 24, said, *“I wanted to talk to people, but not in the way I usually do, i.e., lecture them. I listened to other people and cared deeply about what they were saying. I was actually enjoying making eye contact. Suddenly, there was no discomfort at all. Not only no discomfort, but suddenly, it was like I could see the person behind the eyes, and I wanted to sort of know who it was. And I was sort of just looking in there*

*to look for a slight reaction, slight sort of changes just to see how he was reacting to me.”*

Regarding **social conversation**, Begrimed, a 25-year-old male, said, *“MDMA didn’t make me unafraid of it, unafraid of conversation. It made me want to actually converse and make friends and*

all that. It was...it was something else.”

On **connection**, Sylvan, a 24-year-old male: *“There were actually certain friends I had made months previous to that that I really wanted to get to know better, but due to my social anxiety, I was really just, well I was intimidated by them. I really looked up to them and thought they would never really want to be my friends, so I kind of stopped talking to them out of shyness. But for a while I really wanted to make a connection with them. It felt really important. So the day after that experience, I was still feeling so open and so changed that I made an effort just to get past my shyness, and make a call to them and I actually ended up seeing them that day and it was really kind of great. It was a great connection, and I told them about my experience, and since then we’ve been pretty much best friends. And we do all of these things together, and it’s been one of the best places I’ve ever been in my life, to reconnect, and I really feel that that was because I was so changed by that experience.”*

One important note: You hear a lot of talk about empathy and autism. I just want everyone to remember how complex the various domains of empathy are; we need to be very careful what we mean when we say empathy. The individuals with whom I spoke did not lack empathy in terms of concern for others. However, often they were challenged in interpreting the cues that would help them understand the condition of someone else.

Sometimes the connections that were made were on a deeper and more profound level of **communion**. Michelangelo felt as if *“the mystery of other people had been dissolved a bit.”* Fuzzy, 23, said, *“I felt more emotionally connected to my friend, and I could understand his situation better.”* Jules, 32, said, *“I found people much more interesting to be around. I wanted to connect with people. I want to be around people, I want to hang out and commune with like, some aspect of community.”*

Tony, age 36, was a classic non-responder. He took MDMA several times and he only experienced the amphetamine-like effects; he didn’t experience the empathogenic effects. It’s a good reminder to remember that some people have that experience. This is what he had to say: *“I’m a little bit skeptical of some people’s impressions of Ecstasy, because Ecstasy is also an amphetamine, and while it increases your sense of empathy, it probably increases your delusions of empathy at the same time,”* and he laughed, and I think

**Siobhan: “I don’t think MDMA changes your nature at all. I think it just brings it out to the forefront.”**

he’s right.

One unexpected finding that caught me off guard: When we talk about ecstasy, most often we hear about the empathic heart opening, the love drug, the feel-good drug. The majority of participants in this study emphasized mental clarity, a sort of straightening out, a clearness in their thinking that was new and novel for them, more than we’re accustomed to hearing from neurotypical reports.

Examples [of this kind of report] include Morton. He was 49. *“It gave me a complete clarity about things that I didn’t have prior to that. And the reason that I didn’t have clarity prior to that was because I was always worried and anxious.”*

Fuzzy, 23: *“I have a tendency to just get stuck in thought loops about things, usually things that I don’t want to be thinking about, and this kind of seemed to just not make that happen while I was on it. It didn’t seem to happen at all.”*

Begrimed, age 25: *“For the first time, it was very, [sigh], like, like I finally got it. Like, you know how, I guess, autistic people, they don’t really know those unwritten social rules and all that? You know, the nuances in conversation and stuff like that? Like, I got it. Like, it was just like, bing!”* And George said, *“my thoughts were flowing lucidly.”*

Fifty-eight percent of participants in this study reported experiencing what they described as *epiphany*: significant new insights, or revelation.

There were undesirable effects and outcomes. I want to acknowledge that very forthrightly.

No one had any severe persisting outcomes. I didn’t hear any horror stories that came after the fact, but here are some examples: distress, disappointment, being overwhelmed, overdisclosure or the fear that one might overdisclose to others by talking too much, and some people had a bumpy come down, but none that lasted more than a few days.

An example from Tony, the non-responder: *“I just kind of wanted the general happiness feeling of it because I don’t naturally feel much of that at all. My general sensation is neutral*

*to cold, I would say, and so I was hoping it would have some effect there, and I got, you know, I got pretty upset that it didn’t, that it, nothing, it’s like, am I ever going to have that?”*

Sylvan, 24, said, *“It was a bit hard to find a kind of ground in myself for a while, because all these kind of new thoughts and new kinds*



*of new feelings were flooding into me, and it was disorienting for a while. It was, I was just stuck to my bed, not knowing what to do, you know?"*

Descartes, age 30: *"I find it a bit too overwhelming, and too different from the autistic wiring. If I had to pick any substance as the preferred substance for treating autistic symptoms, I'd suggest methylene or methedrone. The impact on empathy and overall intuition is similar to the impact of MDMA, but the serotonin release is a lot milder, which allows a lot more introspection and analysis."*

The second meta-theme was one of **transformation**, a positive change that persisted long after the actual MDMA experience. Some brief examples of what that sounded like:

BioDrinx, age 33: *"The person I went with noticed the old me is definitely way gone, and much more confident and happy."*

Sylvan, 24: *"I'm actually a totally different person since, well, I would say, yeah, since I did it...It was one of the best places I've ever been in my life. I was so changed by that experience."*

David: *"Comparing how I was and what I am now, there's a big difference."*

Jules, age 32: *"It's definitely helped. My life would be very different if I had not had this experience."*

Meri: *"For most of my life I was a very consistently depressed person and very much a hateful person, and I'm fairly certain that MDMA made me a very loving person."*

So what are we to make of these comments about profound transformation? Another theme that came through loud and clear was **"I am still me."** Like Dorothy when she returned to Kansas, she had her profound experience in Oz, but then you come back to your ordinary life and you are still you. Here is what that sounded like:

Sylvan: *"I was completely myself, except inverted, just very social for once."*

Siobhan: *"I don't think MDMA changes your nature at all. I think it just brings it out to the forefront."*

Begrimed: *"It just felt like there was more added to what was already there."*

David: *"Even after taking the MDMA and all that, it's not that it made me normal or anything, but it made me much more aware."*

How long did these benefits last? It varied from indi-

vidual to individual. But there were many comments that kind of quantified how long the changes lasted. Here are some examples:

Meri: *"I can sort of recall that one moment, that memory, and it's fresh in my mind, and it's a very necessary thing in my life now...With the MDMA moments, I remember them very vividly, and they fill me with a very great joy."*

George: *"I was always, sort of, you know, slightly critical of myself. You know, 'You can't keep a conversation with other people because you just can't. Don't even bother trying.' Whereas now, I've got this memory*

*of, well hang on a minute, one night there a week ago I went out and I talked to a bunch of strangers and they enjoyed my company, and I enjoyed their company, you know, this is one step really, isn't it? At the moment, it's really helping that."*

David: *"By giving me that perspective, I can bring a lot of that back when I, you know, to my normal day-to-day life."*

I'm going to read for you a portion of a case history about George's experience on the train. By including a photo of an adorable small child, I'm really not trying to manipulate your emotions or make you feel a certain way. I'm trying to give you a sense of George's embodied experience.

At sunrise on the morning after he took MDMA/Ecstasy at a dance club for the first time with little idea of what to expect,

George boarded a commuter train for the journey home. He was still feeling exhausted yet stimulated from his night out when a man with a child in his arms sat down beside him. The child started grabbing at George's water bottle. He explained why such a situation normally would "scare the hell out of him," to quote him.

He said, *"I have no idea how to engage children. They sort of look at me in the eye, and I have no idea what to do or say back at them. They look at me in the eye, and they don't get the reaction they normally get from other people. And you can sort of see it in their faces. They just go,*

*'I don't trust you,' and move away from you. I'll have none of that."*

However, in his post-MDMA experience afterglow state, George was able to interact with the child in an empathic and engaged way. *"And it was really interesting to me, because when this kid looked at me, I was directly looking back, in the eye. I was intrigued*

*Michelangelo: "I feel like I understand people just a little bit better, and that pushed me into the area of confidence that I needed to be in, and that stayed with me ever since."*



by it and interested by it and I was sort of happy for the child.”

George contrasted this sense of communion with how he usually perceived children. “Ordinarily, I would just not see the appeal of it at all. I would see nothing nice in it. All my mind would be telling me is ‘great, here’s another human being in the world, that’s overpopulated as it is, and we’re here doting over, you know, it’s just a child. It’s going to grow up to be an investment banker or something.’ You know, this is the thing people don’t see. All they see is the big eyes of the child, and it’s just the most amazing thing in the world, to them. And to me, it’s just totally abstract. It’s arbitrary. It’s totally meaningless for me.”

In addition to achieving some sense of communion with a child, George also became aware that he was participating in a unitive experience with others who were enjoying the child’s antics on the train.

“But as I sat there, I looked at everyone else, looking after the child, and suddenly, as a result of the effects of the ecstasy, I could understand, I could see peeping out, I could look at the child and I could just see the sort of curious, innocent wonder of the child. And suddenly it wasn’t a sort of a stupid, arbitrary thing. Suddenly I could understand it. Suddenly I was one of those people actually looking after the child, going, ‘How cute!’ I just found out. And that was just so totally uncharacteristic of me, like, I mean, if you ask anybody that[sic] knows me, and told them that I’d done that, they wouldn’t believe you.”

The final and probably most significant meta-theme was all about **healing**. I’ll zip through to show you the categories without reading the quotes. Many of the themes supported the potential of MDMA-assisted psychotherapy for individual and couples therapy. Here are a few examples of areas in which it may be helpful [referring a slide that lists Affect Awareness, Therapeutic Rapport, Alexithymia, Improved Mood, Problem Solving, Optimism, Insight, and Social Adaptability].

Three participants spontaneously reported that they had PTSD (Posttraumatic Stress Disorder) that was helped by their MDMA/Ecstasy experience. Fifty-eight percent of participants

in this study commented about how MDMA/Ecstasy affected their social anxiety.

BioDrinx: “Socially, all the anxiety I had, completely gone.”

Sylvan: “I’ve credited that one experience to nearly wiping out my social anxiety, which at that point had been strong.”

Morton: “I used to experience terrible anxiety before I took Ecstasy, and this disappeared completely while I was actually high on the drug, and I was able to communicate much more openly.”

Doc Star: “I just felt comfortable talking about everything, and so it was kind of a relief of the anxiety of holding things back.”

David: “It reduces social anxiety for me, I guess. I feel like I can step onto a dance floor and have a lot of fun.”

Isabeau: “It’s a little easier just being around the whole press of people, without still feeling like, oh my God, there’s all these people, and they’re all around me, and I don’t know how any of them think.”

Michelangelo: “I feel like I understand people just a little bit better, and that pushed me into the area of confidence that I needed to be in, and that stayed with me ever since.”

To conclude, I’ll just state, that it’s my hope for the future that that proportion we saw in the beginning, with a big Qual[itative], with a small embedded Quant[itative] will reverse,

that we’ll start seeing double-blinded, randomized, placebo-controlled studies applying the scientific method, but that we won’t lose that piece of the qualitative that informs us about the population with whom we’re co-researching. So that’s my hope for the future, and thank you. 🎧

The full video of this presentation is available at [psychedelicsscience.org](http://psychedelicsscience.org).

Special thanks to our volunteer transcription and translation team at Amara.

 amara

*Alicia Danforth, PhD.*, is a research associate at the Los Angeles Biomedical Research Institute at the Harbor-UCLA Medical Center. She can be reached at [adanforth@labiomed.org](mailto:adanforth@labiomed.org)

