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An Expert Discussion on Autism and Empathy

Damian Milton
University of Kent at Canterbury - U.K.

Noah J. Sasson University of Texas at Dallas

Elizabeth Sheppard University of Nottingham

Melanie Yergeau
The University Of Michigan

Christina Nicolaidis

OHSU-PSU School of Public Health, christina.nicolaidis@pdx.edu

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Autism in Adulthood [Section] Roundtable [Title] An Expert Discussion on Autism and Empathy

[Participants]
Damian Milton, PhD
Lecturer in Intellectual and Developmental Disabilities
University of Kent, United Kingdom

Noah J. Sasson, PhD Associate Professor School of Behavioral and Brain Sciences University of Texas at Dallas, USA

Elizabeth (Lizzy) Sheppard, PhD Assistant Professor, Faculty of Science School of Psychology University of Nottingham, United Kingdom

Melanie Yergeau, PhD Associate Professor College of Literature, Science, and the Arts University of Michigan, USA

Christina Nicolaidis, MD, MPH (moderator)
Professor and Senior Scholar in Social Determinants of Health
School of Social Work
Portland State University (PSU), USA
Editor-in-Chief, Autism in Adulthood

Introduction:

Autism in Adulthood strives to be a home for constructive, inter-professional dialogue on pressing issues that affect the lives of autistic adults. We do this in a number of ways. One is to hold roundtable discussions with experts in the field. Our first roundtable discussion concerns the topic of autism and empathy, a hotly debated construct within and outside academia.¹

As early as 1962, psychologists described children with "autistic psychopathy" as being "unable to achieve empathy." An empathy deficit has since become a core feature in many conceptualizations of autism, including the Theory of Mind (or mind-blindness) model and the Empathizing-Systematizing model.³ Researchers have distinguished between cognitive empathy (or theory of mind; the capacity to understand another person's perspective or mental state) and emotional or affective empathy (the capacity to experience affective reactions to the observed experiences of others), asserting that autistic individuals have deficits in the former, but not in the latter. 4,5 Even this position, however, has been widely criticized by autistic individuals in online forums. For example, purported deficits in cognitive empathy may be a problem of experiencing too much emotional empathy or of needing more time to process empathy's cognitive aspects. 6 Or they may be due to a breakdown in mutual understanding between people who experience the world differently (and may apply just as much to neurotypical people failing to empathize with autistic people as it does in the opposite direction). Autistic adults often argue that the notion that autistic individuals lack empathy or theory of mind is dehumanizing and perpetuates dangerous stereotypes and oversimplifications.⁶

Following is a transcript of our roundtable discussion, with minor edits for clarity.

Christina Nicolaidis:

For decades, researchers have postulated that autistic individuals "lack empathy". This notion has created plenty of controversy, with countless studies, papers, blog posts, and debates. But this idea still affects how we, as a society, conceptualize autism, which in turn greatly impacts the lives of autistic people.

Today, we have brought together four discussants with great expertise on this topic. They each come from different disciplines and have differing perspectives. Two of them are autistic themselves.

My goal is to not repeat the same old debates. I don't expect that we will all agree, but the goal is to help identify some areas of synergy, to trouble current conceptualizations, and to help identify ways that we may move forward - within, between, and outside of our academic disciplines. And perhaps we can make a small, but important step in changing how society understands – and thus treats – autistic adults.

Thank you so much for joining this discussion today. I would like each of you to briefly introduce yourselves. Let's start with Dr. Milton.

Damian Milton: I work part-time for the University of Kent as a lecturer in intellectual and developmental disabilities. I also work as a consultant for the National Autistic Society. I am project leader for the National Autistic Task Force

(http://nationalautismproject.org.uk/national-autistic-taskforce), a new project in the U.K. I work in a number of areas, but, academically, my background is in sociology. I have branched out into other multidiscipline social sciences. I first became interested in autism, specifically, when my son was diagnosed at the age of two in early 2005. Around that time, I was beginning to self-identify as being on the spectrum myself. I was diagnosed formally with Asperger's in 2009.

Noah Sasson: I am an associate professor of psychology in the School of Behavioral and Brain Sciences at the University of Texas at Dallas. For over 15 years I have been studying mechanisms of social disability and autism both in children and adults. These mechanisms include features of autistic people generally—cognitive, behavioral, or social differences. Also, recently, I have been studying mechanisms outside of autistic individuals, things like social environments and perspectives, behaviors, biases of non-autistic people.

Lizzy Sheppard: I am an assistant professor at the University of Nottingham at the School of Psychology and I have been studying autism for a number of years. My research interests are fairly broad in autism and a lot of what I study has not been focused on empathy per se, but the types of studies we are doing recently most related to empathy are in the field of social cognition and, in particular, mind-reading abilities.

Melanie Yergeau: I am an associate professor of English Language and Literature at the University of Michigan. I am a past board chair of the Autistic Self Advocacy Network and past vice president of the Autism National Committee. My home discipline and training are in rhetoric, and my scholarly work is broadly situated across disability studies as well as digital humanities. As a rhetorician, my work around autism largely concerns issues of representation as well as rhetoricity. In other words, I study what it means to communicate and be believed and how autism complicates the ideology and values we hold around language, ethos, and persuasion. I am often the lone autistic person and the lone humanist at autism research gatherings; I am glad I am not today.

Dr. Nicolaidis: Let's start with what it means when we say empathy. I would like you to talk about how you have seen others define or interpret empathy. How would you define it? Do you think there are important distinctions between different types of empathy? What are they? Why is it an important concept?

Dr. Sasson: Generally speaking, I think about empathy as a shared state of being with another person—experiencing what another person is experiencing, or feeling what they are feeling. There's a lot of discussion in non-autism literature and psychology about empathy and what it means.

I found very interesting a recent book on this topic.⁷ It is by the psychologist Paul Bloom, who differentiates empathy from compassion. Compassion, he argues, is a concern for others that doesn't necessitate a shared state or vicarious state of being the way empathy does. His argument is that empathy is more likely to be elicited by like-minded people or it favors ingroup members, which means it can be selective and focused on people you're interacting with in the here-and-now. Compassion can be more generally applied and therefore more rational or at least less prone to bias.

The reason I bring this up is because I often think about that distinction in the context of Damian's work on the 'double empathy problem' where autistic and non-autistic people may often constitute different in- and out-groups, unfortunately, and this might make empathy between them a bidirectional problem. We would probably agree there are a lot of damaging misconceptions about empathy and autism, so I'm glad we are getting a chance to discuss what it means for autism and what it means for autism research.

Damian Dr. Milton: Despite using the term 'empathy' myself, in the 'double empathy problem' theory, I do have some difficulty with what the concept is really referring to. It seems to mean different things to different people in different contexts. The basic dictionary definition would describe it as the ability to understand and share the feelings of others. Though a full understanding of what it means to be someone else is impossible. What empathy is and how it is theorized is open to much debate. I once saw a prominent academic describe a developing theory of mind in a young girl. She was projecting emotions into a toy doll. I had to point out that dolls don't have minds and so the question was on projecting her learned emotions and constructs. I find categories about cognitive and affective empathy of little use. I would prefer a distinction made about compassion and empathy.

I am also interested in concepts opposite of empathy, or 'dyspathy,' the 'othering' of out groups. Prof. Lynne Cameron of The Open University (Milton Keynes, England) explores this concept and so do others. I am interested in notions of interactional expertise⁹, a concept used by Harry Collins and Rob Evans¹⁰ which talks about expertise between groups and understanding.

It's an important topic because of how much weight it has had traditionally in the field of autism. The dynamics of social interaction and personal meaning and everyday disjunctures in meaning are of great interest. This is at least a two-way street.

Dr. Sheppard: You both have done a nice job talking about the different types of empathy or how it has been defined, at least within psychology, and the debate between whether we should think about a dichotomy between cognitive or affective empathy. Empathy is likely to be important in lots of social processes, like the forming of friendships and interpersonal liking.

It is probably also important in many other fields where we have to interact with other people. Being empathic might be advantageous in lots of contexts, like in the workplace. Of course, on the other side of things, if you don't have empathy, this could have very negative consequences. If people did lack empathy, potentially they could be highly manipulative of others.

Dr. Yergeau: I would draw attention to how rhetoric as a field conceptualizes empathy. There are many similarities between discussions in rhetoric and discussions in psychology and philosophy. For instance, Kenneth Burke's concept of identification¹¹ bears a great deal of similarity to how Peter Hobson,¹² and others who study theory of mind, think about empathy; both Burke and Hobson, for instance, describe identification/empathy as connecting with another person by demonstrating commonality with them, whether emotional, personal, or some other mode of relation.

Where I have trouble with empathy is similar to what other people have mentioned. Both within and out of my own field, it seems that 1) empathy is predicated on human relationality, 2) attempts to measure empathy are predicated on what is externally observable and those external behaviors are then interpreted through a normative lens or rubric, and 3) empathy is typically interpreted as a gainful ability. I would like to see more work on how or when empathy, as a practice, can be coopted or marginalizing. This goes back to what Damian and Noah were saying about empathy and compassion. When does putting oneself in another's shoes supplant the other person's identities, feelings, and experiences? This might include being more critical about empathy's limitations and potentials for appropriating another person's experience, as well as thinking carefully about how denying someone's empathic capacity can lead to stigma or harm or even marginalizing a class of people.

Dr. Nicolaidis: Let's connect autism and empathy. Can you summarize the current state of the research or scholarship in your field and offer your opinion about how these two ideas relate? What excites you about it? What troubles you? How do you hope your work informs others? What still needs to be done?

Dr. Sheppard: In psychology, there is a huge amount of research trying to determine whether autistic people are able to accurately recognize or perceive mental states of other people or emotions of others. This research has quite mixed findings, but a lot of research has argued autistic people are less able to do this.

One of the things we have been trying to do is to look at mind-reading ability in natural scenarios. What has typically been done is to present people with a series of facial expressions and ask them to guess the emotion the person is thinking or feeling, which seems quite far from the kind of situations in which we often need to read other minds in real life. Normally, in real life when reading other minds, we do this in the presence of another person or potentially interacting with them. We can use that context to help make those inferences. I agree there is a lot more that needs to be done to appreciate the bi-directional nature of empathy. And we have already started to do work on this, as well; looking at how well other people can read and interpret behavior of autistic individuals.¹³

Dr. Sasson: I think empathy is a broad concept that potentially conflates independent ideas. Autism literature has been rife with these problems and confusions. Damian alluded to the distinction between cognitive and affective empathy and how much meaning there is in that distinction. There has been an increasing appreciation that there are different aspects of empathy; that it might mean something different to infer mental states, which is a more cognitive phenomenon, versus vicariously experiencing a shared feeling with another person—for example, perceiving somebody who is suffering and somehow feeling the pains of that suffering yourself. These things are very difficult to measure and the way these have been assessed in previous research may not fully capture the human nature of that or how it is expressed in autistic and non-autistic people.

It is entirely possible for somebody to be strong in one of those aspects of empathy, but not the other. I am not just talking about autistic people. There's variability across the board and these things might not be always in sync with one another.

In autism research, over the last several years, there is increasing recognition that empathy is a two-way street. Social relationships between autistic and non-autistic people may be difficult not only because autistic people have cognitive or social differences affecting their interaction with non-autistic people, which has been the focus of so much autism research, but also because of another contributing factor, which is starting to get more recognition—that non-autistic people may have difficulty interpreting and interacting with autistic people. One direction of my current research is focused on trying to understand those bidirectional processes. ^{14,15}

Dr. Milton: Much of my own research has been of a qualitative nature. What I've often found in reports from autistic people are comments regarding the lack of understanding they feel they

receive from others—and they far outweigh any comments and issues autistic people have in understanding others. ¹⁶ Particularly for verbally articulate autistic people, one can easily see social awareness and theory of mind not lacking. I would say this can be observed when working with less verbally autistic people too. This suggests the traditional theorizing regarding autism in terms of a social deficit within the autistic mind is quite wrong and needs revising.

The whole way we look at autism needs a bit of a radical rethink. Autism and empathy relate to disposition, perception, the salience of meanings¹⁷ within context and the disjunctures I was talking about earlier. Much troubles me about how autism and empathy are being connected and conceived of traditionally in the field, which can lead to normative and unhelpful interventions, such as how social skills training is often done. I have a lot of issues with that, as well.

I am excited, though, by the work that we are hearing about today from people in different fields looking at this in new and creative ways. One good example is the work of Brett Heasman at the London School of Economics. Is I am excited about how this research can help to redefine what we mean by autism itself in the long run. What needs to be done is more such work from different disciplines coming together for that multidisciplinary effort, such as today. Bringing together research in autistic people to plan ways forward. And to take on board the social context of these issues.

Dr. Yergeau: Disability studies has produced some excellent critical work on autism and empathy. ¹⁹⁻²¹ Many of the problematic issues that have been raised so far provide exigence for disability studies scholars to undertake this work. For example, autistic people often serve as a tidy theoretical foil in philosophy and in literature. We're seen as a limit case for empathy, as a limit case for communication or rhetorical capacity in general. Autistic non-empathy is something that can function as a given for some scholars rather than something they question or try to break down into discrete parts.

Humanists, in particular, rely on scholarship from the social sciences and clinical research quite frequently in their work on empathy. I am thinking of Lisa Zunshine's work on narrative, in particular. It not only informs how humanists come to understand and interpret literary characters and the narrative voice of autobiographers, but this work also informs studies on how people read, write, and conceptualize listening audiences. What I don't typically see is the reverse. I rarely see clinical psychologists, for example, looking to narrative studies when they do work on theory of mind or empathy-in-narrative competence in autistic children. Scholars in clinical and social sciences would gain a great deal from humanistic approaches to empathy, and I think they would have a lot to contribute. There are so many places where all could positively intervene.

Regarding my own work, I am interested in how queer theory might inform how we think about empathy and relationality, especially on sexed-brain research, autism, and gender. I think queer theory forces us to confront how and when empathy is gainful or normative and it can enable us to see parallels between disability histories and LGBTQ histories. I am also excited about work in phenomenology, in particular Erin Manning's work on environmentality and the role of the nonhuman in thinking about empathy.^{23,24}

Dr. Nicolaidis: You all have laid a great foundation for this discussion. Thinking about what your colleagues have said, where are the commonalities and what would you challenge? Did anything anyone say make you reconsider your own thinking? What do you want to learn more about?

Dr. Sasson: My thinking on this issue has changed dramatically over the course of my research career. I was trained in the tradition of social cognition autism research. In graduate school in my early research career as a faculty member, I was solely focused on studying and capturing and characterizing these social, cognitive differences in autism. Things you see an abundance of in the research literature on face processing, emotion recognition and theory of mind issues. I do think there has been value in that line of research and it has produced some insight. At the same time, I think Damian is 100% correct. If you look at the psychosocial interventions that try to build upon those findings with autistic adults and try to improve those abilities, they have produced limited impact on real-life outcomes. You might see some improvement on standardized, computerized tests in the lab, but really it doesn't translate well to improved outcomes and quality of life outside the laboratory. I'm thinking here about a recent review and meta-analysis by Matthew Lerner and Jacquelyn Gates²⁵ that was a powerful sledgehammer to my thinking about this. I have increasingly become curious about other factors that contribute to social disability—social environments, behaviors of other people. So, expanding my focus on social cognitions and not just exclusively hone in on autistic people themselves, but thinking about social dynamics a lot more interpersonally.

What's also been pivotal in this transition in my thinking has been exposure to people in other fields. Damian's writings were very influential and having interaction with autistic people—in my lab as students, autistic people online, self-advocates who raise issues and criticisms about the research literature that I might not be exposed to otherwise. All of these things have had a positive benefit on expanding my thinking about these issues.

Dr. Milton: I have some thoughts and connections I would like to bring up. In relation to what Melanie Yergeau was saying, I would agree about the parallels with queer theory. I recently gave a presentation at a conference on gender and autism and the about the performance of gender utilizing Erving Goffman and Judith Butler. I am also interested in phenomenology and those areas. There's a lot of connection. I have started reading your book,

Melanie,²⁶ and I have found it fascinating thus far. I think it needs to be read more widely because it helps to challenge these long-held notions.

The challenge is the impact of all of this work and where it is leading to. This challenges the notions of what autism is and the diagnostic criteria of autism and social interaction, communication needs more nuance and a better understanding. It challenges how to take this work forward. And to have a wider impact so others who are studying these nuances more, and less from a normative perspective. A lot of traditional psychology centers the norm and so anything outside of that is abnormal and pathologized. That way of thinking can be sometimes quite unhelpful when trying to build mutual comprehension and well-being for all of us in a social sense.

Dr. Sheppard: I agree, and psychology can add to the evidence-base to demonstrate that bidirectionality in social interchange and the role that has in the condition of autism and how we think about it. Some of us have started to do research that has demonstrated that non-autistic people misperceive autistic people in various ways or find it difficult to understand them in certain ways. I think it would be good to do research that tries to link that to the outcomes for autistic people and how this might impact their quality of life. If we can create this evidence, it will, hopefully, help with the challenges we've discussed.

Dr. Yergeau: What is so interesting about this conversation is that we have a lot of commonality even though we are pursuing quite different lines of research. Some of our differences have to do with the field and the methodological approaches we take. We also seem to be working with different major questions as our guiding form of inquiry.

For me, conversations on autism and empathy are essentially questions concerning belief: that is, who will be listened to and who will be believed. Even though scholarship on autism and empathy is multifaceted and varied, when we try to look for narrative through lines, there is always some correlation between autism and lack when it comes to empathy. These narratives about lack filter into real-life practice, whether it has to do with interventions or widely held beliefs about what autism is or represents. That is where my concern tends to lie: how beliefs about autistic empathy function on the ground. What stories are autistic people telling about empathy? How are they perceived? How does this impact relations more broadly?

Something I tend to see explicitly—whether it is in a research setting, a clinic, a social skills group, or even in a book club that consists of autistic people—is that autistic people are less likely to be believed because they are perceived as being unable to intuit what other non-autistic people are thinking. If I disagree with a parent or colleague, I am the one who is read as having failure typically in these exchanges. Somehow having this diagnosis makes me less believable and it is intricately connected to cultural narratives around empathy. It is hard to know what to

do with that. Like other forms of bias, it can be hard to pinpoint and people are less likely to see it as bias. That is why I think empirical research is so necessary. It makes me excited having this conversation and hearing about the work all of us are doing around autism and empathy.

The other thing I would add is the question of double standards, especially in relation to Damian's work. Where have we encountered the double empathy problem previously in history? I often come back to queer and gender studies, as well as ethnic studies. We can also think about what we might learn from Deaf studies. When you work with autistic communities, you will find that autistic people frequently narrate cultural experiences, histories and stories that mirror deaf and queer cultures. That may give us a guiding framework when approaching the question of empathy and relation.

Dr. Nicolaidis: You have made some incredibly interesting observations. They are quite nuanced. <u>Imagine for a moment that If</u>-you are trying to explain <u>these concepts</u> to somebody outside of <u>academia and</u>-your field., <u>wW</u>hat's going on? Do autistic people lack empathy? Can you explain that to a nonacademic audience? What is the relationship between autism and empathy?

Dr. Sasson: Historically, autism research has been dominated by a deficit model in large part because the differences that are found in autism are always in reference to some norm of the dominant group or culture. Increasingly, that assumption should be, and is, starting to be challenged. A big issue has to do with integration, inclusion, and familiarity between group members. Some of the disconnect we see between autistic and non-autistic people, especially from non-autistic people to autistic people, might be a lower familiarity or ability to properly and accurately evaluate social signals based on different kinds of social presentations compared to people who are non-autistic.

In our research, we have found differences in expressivity or social behaviors and try to quantify those in autistic people relative to non-autistic people in how they can elicit evaluative judgments from non-autistic people that were not intended. We have measures of facial expressivity²⁷ or vocal prosody²⁸ and you can quantify that autistic people in general, although there is *a lot* of variability, are characterized by prosodic or expressivity differences relative to typical developing controls. That control group is always seen as a standard and if the autistic group is different, it is often inferred as an impairment. I am glad the people on this panel are starting to question that and other people in the literature are questioning that.

One of the ways we will see improvement is if we expand beyond just treating this as a deficit in individuals on the spectrum that needs to be improved, and focus on the reasons the surrounding environment and other people are misperceiving or forming snap judgments that may affect the social experiences of autistic people. We have several papers ^{14,15} showing non-

autistic people make less favorable snap judgments about autistic people. They are associated with a greater reluctance to even interact with them, meaning autistic people might not have as many opportunities for these social exchanges. More optimistically, we also see evidence that non-autistic people who have more familiarity or understanding about autism do not show those biases to the same degree. That says that with increased interaction and familiarity, just like in any kind of social, psychology aspect study of discrimination or prejudice, those beliefs can be challenged and can diminish over time. Potentially one direction the research can go is to see how integration, inclusion and accommodation can address the double empathy problem that Damian has written about.

Dr. Milton: In understanding an autistic person, or as Melanie has shown, any marginalized minority, will mean putting away one's own assumptions based on one's experiences, if one is not part of that minority or culture. Rather than relying on them, which empathy actually does. Empathy can take you further away, in that traditional sense, in understanding autistic people or other people different to oneself. That means putting in effort to listen and learn.

In this effort, autistic people are putting in frequently to try to survive and navigate the social world. It is something I rarely come across in practice in the other direction. There are some amazing practitioners in the field who do put that effort in, but they are rather rare rather than the norm. That effort needs to be in both directions. That relates to power dynamics in what Melanie was talking about earlier in who is listened to. Another reason I'm quite happy this empirical work is being done by Lizzy and Noah is it has cultural capital and power to influence a wider range of researchers. If it is evidence-based and people listen to it. To see this work being properly tested, as well. It is not just qualitative reports, but high standard empirical work is being done, which is great and needed to unsettle some of the assumptions that are so prevalent.

Dr. Nicolaidis: We have been talking about double empathy and nature of empathy and the difference between cognitive empathy and affective empathy and limitations of those distinctions. One thing that hasn't come up is the notion of being overwhelmed by feelings of empathy. I am not an empathy researcher but in my research and discussions with autistic friends and colleagues, one thing I often hear is this notion of experiencing other people's emotions at such a great level that it almost feels like you have to shut down or it feels like an overwhelming, over-empathy type experience. Has that been studied?

Dr. Milton: It comes up in autism blogs and community discussions. I am not aware of any research, per se, on this topic. I can talk on a personal level that my perceptions of what's meaningful or salient in any given context can be quite idiosyncratic and autistic. When there is connection to something emotionally or physically, it can be a very strong connection—from physical things like knowing that I'm hungry and need to eat, will go from not knowing this at

all to being aware of it to be being hyperaware of it. When something does become salient, of personal meaning, it becomes very meaningful. Autistic interests are often talked about in as very passionate, intense engagement. When there is emotional engagement, it can be extremely intense. When I feel compassion, love, pain, and hurt for myself or others, either I'm not feeling it very much or I'm feeling it very intensely. That is my own personal experience as an autistic person. I know other people are different. It is an area that probably needs more work and nuanced understanding.

Dr. Yergeau: I'm also not aware of direct work on this question around being overwhelmed by feelings of empathy. The first line of scholarship that comes to mind is work on synesthesia, especially phenomenology. It is interesting to consider the ways in which autistic people narrate experiences of sensory overload or being overwhelmed by feelings of empathy. I am also thinking about the ways in which autism is being re-theorized as a condition of sensory differences. In particular, the 'intense world theory' of autism might be another such analog. This goes back to what both Lizzy and Noah were saying that empathy is a broad concept, and it might defy measurement. Studying empathy not only requires self-reporting, but also external observation. If an autistic person is not conveying an expression or form of bodily comportment that is signaling emotional connection with a non-autistic or other interlocutor—how are we thinking about empathy in that context? How do our studies around self-reporting rely on non-autistic or normative conceptions of language?

For instance, I remember when I took the Autism-Spectrum Quotient (AQ)²⁹ several years ago when I was trying to receive services. One of the questions was to react to the sentence: "I am a good diplomat." Then, I had to check off, on a Likert scale, the extent of which I was a good diplomat. I struggled because I didn't know what it was asking me. In some ways, a clinician might interpret this as a classic autistic response, as failing with metaphor. If they take me at my word, I'd say I am not a good diplomat as I never worked for the United Nations. Is this a classic autistic response? Are we operating with different languages, different understandings of what it means to even express an understanding? All these questions come to root here. That question of being overwhelmed with empathy to another interlocutor could look to them as being vacant or absent or silent, when actually the reverse is happening. This affects me personally a great deal. As Damian noted, it is something that reoccurs again and again in autistic life writing.

Dr. Sasson: Have you read the recent paper about autistic traits by Morton Gernsbacher³⁰ about how autistic people and non-autistic people interpret items differently and use a different frame of reference? And just subtly changing wording so that the autistic person taking the questionnaire assumes an autistic person rather than a non-autistic person is the frame of reference can change responses? It is a fascinating look at assumptions made that people are all answering questions the same way, is definitely not the case. Some findings of group

differences could be confounded by these different perspectives and interpretation of items on the autistic trait questionnaires.

Dr. Milton: That doesn't surprise me. In regard to different languages, I would say, yes, and even in quite subtle ways, words and uses in context can mean quite different things for people with different dispositions and perspectives. I am reminded of Ludwig Wittgenstein and his beetle experiment. Everyone has a beetle in a box, but the only one you can see is your own. We don't know other people's experiences whether they are similar or not. What is kind of shared is the symbol or language. What is meant or felt by it can be quite different. I often use the example of an old comedy sketch by The Two Ronnies as they use the same words but are mismatching meanings with every sentence with one of them getting more and more annoyed and upset at the other who is rather deadpan. These kinds of mismatches in language and meaning are happening all the time. The bigger the difference in experience and disposition the harder it is to truly empathize. These issues go beyond autism. They are very human issues. There is diversity and difference in interaction.

Dr. Nicolaidis: I am hearing issues about how broad the concept of empathy is and how challenging it is to do research on it because of differences in how we conceptualize what it means. And a lot of technical problems with how we conduct our research. I am hearing a lot of discussion and commonality around the concept of bidirectional empathy, and how it might be more an issue of two different groups not necessarily being able to understand each other more than a deficit in one group. We have been hearing about lots of areas for future research in terms of truly understanding what's happening and what empathy might look like in autistic individuals and what implications that might have on how we conceptualize autism and if this is related to a social-cognitive impairment, as it is often defined, or if that really begs the question of what autism even is as a disability. I would like each of you to answer two questions: 1) What did you find most interesting or useful in today's discussion? and 2) What is the one most important message you want the world to know about autism and empathy?

Dr. Yergeau: In terms of the first question, what I found most useful is wanting to have more discussions like this or opportunities to speak across position, field, and nation. This is incredibly productive. Following that, how do we maintain that momentum once the conversation ends?

In terms of the most important message about autism and empathy: first, to think critically about what empathy is, including the assumption always that empathy is gainful or positive. We might also question the idea that empathy is a capacity that one can possess or in which one can have impairments. This might involve questioning the ways in which we attempt to measure empathy, whether through observation or self-reporting, as well as questioning the extent to which we conflate empathy with human worth. If an autistic person empathizes with an object,

why is this not seen as empathy? Why are object-relations pathologized? I think this is an incredibly important process. Autistic people have such rich relationships with other people as well as animals, things, and their broader surroundings. I would hate to see that be discounted or seen as an impairment.

Dr. Sheppard: I agree this multidisciplinary discussion has been very valuable. I would really like to see more collaboration like this taking place in the future. Also, the discussion of the idea that the way a person behaves and what may be going on inside might be very different. And this could be creating a lot of difficulty when you think about trying to measure empathy in a systematic way. That has made me think a lot.

As to what I'd like to say about autism and empathy overall: it seems clear that non-autistic people need to try harder to empathize with autistic people.

Dr. Sasson: This has been a great panel and I have enjoyed it tremendously. It may have been even more lively if we had a contrarian view— maybe a hard-core empathy deficit person. I am glad there is consensus here, and I do sense a change occurring in the autism research community. Big picture, a lot of us who have been interested in social adjustments in autism have been concerned by the poor social outcomes we see in the research literature for autistic adults who do not have cognitive impairment. They are intellectually capable with many strengths, but oftentimes do not end up having the social outcomes they desire in terms of having successful relationships and social networks, or employment that is fulfilling as well as financially supportive to live independently. You routinely see lower rates of self-reported quality of life in these adults, though this can and does vary at the individual level. The motivation has always been for trying to highlight or identify characteristics or mechanisms or what aspects are leading to this kind of outcome. Speaking personally, increasingly I have come to a recognition that just trying to improve somebody's theory of mind skills misses the forest for the trees and is not necessarily the way to achieve the outcome that we are looking for. Even people who have conducted autism research historically that has been focused on a deficit model have, perhaps, been limited in their conception of the factors underlying social outcomes. I do think they are well-intentioned, but having this greater conversation with more inclusion of autistic voices becoming more interdisciplinary, I think is seeping into the autism research world. The future is bright in terms of focusing on broader factors that may be more amenable to shaping the future prospects for autistic adults. A lot of that is going to come back to structuring worlds to be more inclusive and accommodating, and maybe treatment needs to focus on non-autistic people as well. This is something where outcomes are often the product of a good fit between person and environment and because the general environment has been structured to be conducive to neuro-typical people, oftentimes it can be challenging for autistic people. We need to think about ways of making our environments more conducive to different types of people.

Dr. Milton: Something that interests me is this link to, and analogies with, other areas like queer theory. Although autistic identities through the displacing of social norms attracts stigma and 'othering', there is also a power in displacing social norms, a kind of subversive power in autistic identities. It is often driving changes in the autism field that come from autistic activists, like sensory needs being highlighted in the first place. There is a power in autistic identities, as well, and building on that as a community.

In terms of overall message, I would say that empathy is contextual and situational. Emotional, in the moment, empathy is not always as helpful as one thinks and can take you further away from understanding, in some contexts. What Lizzy was saying about judgments and assumptions based on appearances from the outside may be quite different from what is happening on the inside for that person and how they perceive things. If you think about that, that has a huge issue in terms of intervention theory and practice. Some are largely based on judgment and appearances from the outside. What's needed is a great deal more humility when working with autistic people and what is going on and not jump to assumptions. That's the message I would like to get out at a practical level.

Dr. Nicolaidis: Thank you to each of you. This has been a really interesting conversation. I hope we can continue to have more conversations on this and other important topics.

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References:

- 1. Engelen E-M, Röttger-Rössler B. Current disciplinary and interdisciplinary debates on empathy. *Emotion Review*. 2012;4(1):3-8.
- 2. Van Krevelen DA, Kuipers C. The psychopathology of autistic psychopathy. Acta Paedopsychiatrica: International Journal of Child & Adolescent Psychiatry. 1962.
- 3. Baron-Cohen S. Autism: the empathizing-systemizing (E-S) theory. *Annals of the New York Academy of Sciences*. 2009;1156(1):68-80.
- 4. Smith A. The empathy imbalance hypothesis of autism: a theoretical approach to cognitive and emotional empathy in autistic development. *The Psychological Record*. 2009;59(3):489-510.
- 5. Blair RJR. Responding to the emotions of others: dissociating forms of empathy through the study of typical and psychiatric populations. *Consciousness and cognition*. 2005;14(4):698-718.

- 6. Cohen-Rottenberg R. Unwarranted Conclusions and the Potential for Harm: My Reply to Simon Baron-Cohen. Autism and Empathy: Dispelling Myths and Breaking Stereotypes 2011; https://autismandempathyblog.wordpress.com/unwarranted-conclusions-and-the-potential-for-harm-my-reply-to-simon-baron-cohen/. Accessed August 8, 2018.
- 7. Bloom, P. Against empathy: The case for rational compassion. Random House (New York, NY) 2017.
- 8. Milton DE. On the ontological status of autism: the 'double empathy problem'. Disability & Society. 2012;27(6):883-887.
- 9. Milton DE. Autistic expertise: A critical reflection on the production of knowledge in autism studies. *Autism.* 2014;18(7):794-802.
- 10. Collins H, Evans R. Rethinking Expertise. University of Chicago Press. (Chicago) 2009.
- 11. Burke K. A Rhetoric of Motives. Prentice-Hall (New York, NY) 1955.
- 12. Hobson RP. Autism and the philosophy of mind. In Fulford KWM, Davies M, Gipps RGT, et al. (Eds.), The Oxford handbook of philosophy and psychiatry (pp. 820–834). Oxford University Press (Oxford) 2013.
- 13. Sheppard E, Pillai D, Wong G, et al. How easy is it to read the minds of people with autism spectrum disorder? *Journal of Autism & Developmental Disorders*. 2016;46:1247-1254. https://doi.org/10.1007/s10803-015-2662-8
- 14. Sasson NJ, Faso DJ, Nugent J, et al. Neurotypical peers are less willing to interact with those with autism based on thin slice judgments. *Scientific Reports*. 2017;7:40700. doi:10.1038/srep40700.
- 15. Sasson NJ, Morrison KE (in press, 2018). First impressions of adults with autism improve with diagnostic disclosure and increased autism knowledge of peers. *Autism: the International Journal of Research and Practice*.
- 16. Milton D, Sims T. How is a sense of well-being and belonging constructed in the accounts of autistic adults?. *Disability & Society*. 2016;31(4):520-534.
- 17. Milton D. A Mismatch of Salience. Pavilion (Hove). 2017.
- 18. Heasman B, Gillespie A. Perspective-taking is two-sided: Misunderstandings between people with Asperger's syndrome and their family members. *Autism*. 2018;22(6):740-750.
- 19. Duffy J, Dorner R. The pathos of "mindblindness": Autism, science, and sadness in "theory of mind" narratives. *Journal of Literary & Cultural Disability Studies*. 2011;5(2):201–216.
- 20. Jack J. Autism and Gender: From refrigerator mothers to computer geeks. University of Illinois Press (Champaign, IL) 2014.
- 21. McGuire AE, Michalko R. Minds Between Us: Autism, Mindblindness, and the Uncertainty of Communication. *Educational Philosophy and Theory*. 2011;43(2):162–177.
- 22. Zunshine L. Why We Read Fiction: Theory of Mind and the Novel. The Ohio State University Press (Columbus, OH) 2006.
- 23. Manning E, Massumi B. A Perspective of the Universe. A Perspective of the Universe. *Inflexions 6*, "Arakawa and Gins" 2013:448-455. www.inflexions.org
- 24. Manning E, Massumi B. Thought in the Act: Passages in the ecology of experience. University of Minnesota Press (Minneapolis) 2014.
- 25. Gates JA, Kang E, Lerner MD. Efficacy of group social skills interventions for youth with autism spectrum disorder: a systematic review and meta-analysis. *Clinical Psychology Review*. 2017;52:164-181.

- 26. Yergeau M. Authoring Autism: On Rhetoric and Neurological Queerness Duke University Press (Durham, NC) 2017. https://www.dukeupress.edu/authoring-autism
- 27. Faso DJ, Sasson NJ, Pinkham AE. Evaluating posed and evoked facial expressions of emotion from adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. 2015;45:75-89.
- 28. Hubbard, DJ, Faso DJ, Assmann PF, Sasson NJ. Production and perception of emotional prosody by adults with autism spectrum disorder. *Autism Research*. 2017;10:1991-2001.
- 29. Baron-Cohen S, Wheelwright S, Skinner R, et al. The autism-spectrum quotient (AQ): evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *J Autism Dev Disord*. 2001 Feb;31(1):5-1.
- 30. Gernsbacher MA, Stevenson JL, Dern S. Specificity, contexts, and reference groups matter when assessing autistic traits. *PLoS One*. 2017;12(2):e0171931.