

[“The goal of autism research should be to improve the quality of life for autistic people”](#) Interview with Simon Baron-Cohen

Transcribed by Julie-Ann Lee

December 10, 2020

ABK: You're listening to *Noncompliant: The Neurodiversity Podcast*. I'm your host **Anne Borden King**. We're here in beautiful Canada, where Health Canada has just approved a COVID vaccine today, and it's a good day.

Today, I'm speaking with **Simon Baron-Cohen** who's a professor of Psychology and Psychiatry and the Director of the Autism Research Centre at Cambridge University. He's the author of 600 scientific articles and 4 books including *The Science of Evil* and *The Essential Difference*. Today we'll be discussing his new book, *The Pattern Seekers*, as well as some ideas about how we think about autism ...and how we communicate about autism and how we communicate about science.

It's really a pleasure to welcome Simon to the show. Welcome!

SBC: Thank you, Anne.

ABK: I want to start by quoting from your keynote speech to the United Nations in 2017, where you pointed out that even after the UN Convention on the Rights of People with Disabilities was adopted in 2006, autistic people's rights are not being acknowledged let alone being protected in many places. You said: "People with autism account for a significant minority of the population worldwide, yet we are failing them in so many respects. This creates barriers to their participation in society and to their autonomy that must be addressed. We have had a UN Convention to support people with disabilities for over 10 years now, and yet we still are not fulfilling their basic human rights" – of autistic people.

This is how I'm hoping we can frame some of these ideas in your book, not merely as a descriptive, but also where they are prescriptive towards moving closer to human rights and a clearer sense of compassion towards autistic people.

So let's begin with a summary of your new book entitled *The Pattern Seekers*, and we can take it from there. What's the book about?

SBC: So, the book is kind of exploring this big question about whether there's a **link between autism and the very human capacity for invention**, and I kind of play out a lot of the research evidence showing that there is indeed a link...but the book takes us through a journey about the history of invention, which I argue starts about 70 to 100,000 years ago when we see *Homo Sapiens* producing a whole new range of complex tools, quite unlike anything we'd ever seen before in previous species of our ancestors – *Homo habilis* or *Homo erectus* or the Neanderthals.

The book is really about: *what is invention?* Are we the only species that can do this in the generative way? And then, is there this link with autistic people in terms of how their minds work?

ABK: Interesting. And, are we the only species? Or how does that shake out?

SBC: So I looked at the archeological evidence and although our ancestors were making what I call simple tools, like they were using a rock as a hammer to crack a nut, or they were making stone axes to cut or to scrape, I think the tools were of very limited functions and they didn't tend to invent in a generative way. It tended to be like a one-off ... invention in making something. Whereas what seems to be unique to humans--to *Homo sapiens*-- is that we don't just invent once, we invent unstoppably.

So, 70,000 years ago we see the first bow and arrow – which I argue is a complex tool, the first jewellery – which was a necklace. And 40,000 years ago you see the first musical instrument – which was a flute made out of a hollow bone. And bringing it back to the link with autism, what I argue is that when we invent, we use a very particular kind of logic. We're looking for very specific patterns in the world and I call them **“if and then” patterns**, and I can talk a little bit more about that.

ABK: Yes, yes.

[4:59]

SBC: The idea was that around that time, 70 to 100,000 years ago, there was a revolution in the human brain with a new circuit called the **systemizing mechanism** and what this does is looks for these patterns in the world – “if and then” patterns. If we take the example of the first musical instrument – the inventor – somebody very human, 40,000 years ago would have picked up this hollow bone and would have reasoned in the following way that ‘if I blow down the hollow bone, and I cover a hole, then I get a particular note.’ So it's “if and then.” And then he or she may have thought ‘if I blow down the hollow bone and uncover the hole, then I get a different note.’ Our ancestors 40,000 years ago were experimenting with these “if and then” patterns, and I argue that that's what you see in every human invention. It's kind of a pleasing and simple algorithm that the brain is capable of. We don't see that in other living, non-human species or in the archeological record before *Homo sapiens*.

ABK: Interesting! At what stage in life does that “if and then” pattern of thinking start?

SBC: In human kids, you can see it in 3-year-olds. You may be able to see it in 2-year-olds. It's quite incredible. But in our species, this seems to be natural to us. For example, if a parent is clapping a rhythm--a musical rhythm--a young human child will pick up these “if and then” patterns.

ABK: Mm-hmm.

SBC: Whereas, you can do that to your dog or to a monkey and they just don't seem to understand these kinds of patterns. And human kids will start to experiment, as in their play.

ABK: Mm-hmm.

SBC: It starts very early, and I argue it is one of the unique differences between humans and all other species, which enabled us to basically dominate the planet. When you look around today, our world is full of inventions. I mean here we are talking on Zoom...

ABK: Right.

SBC: ...invented by a human being, but even your coffee cup is an invention. The pen that you're writing with, the glasses that are on your nose-- if you wear glasses (laughter).

ABK: (laughter).

SBC: These are all inventions by somebody over our history. And the environments of other animals are largely unchanged over that 100,000 years compared to ours.

ABK: Mmm. Okay, so there's a dynamic quality to it and that's maybe what you mean by the replicated nature of it?

SBC: Well, I called it *generative* in the sense that we can continue inventing. We just invented a vaccine...

ABK: Yeah.

SBC: ...to combat COVID. So human beings have this capacity but it's still the same logic – this “if and then” logic, and then if we try to link this to autism, autistic people seem to be very strongly drawn to look for these patterns and they're actually above average at spotting these patterns. And in their behaviour they often love to repeat, and psychiatry often looks at this in a negative way...

ABK: Mm-hmm.

SBC: ...that the person is being very obsessive, obsessional and just showing repetitive behaviour. But actually, the trick in invention is that you spot the pattern and then you repeat it and repeat it over and over again to see if the pattern holds true. Engineers do this, scientists do this, people in technology do this, so do musicians. You repeat the sequence and then you can start to play with variables in the sequence. You can change the “if” or you can change the “and” to see if the “then” gives you a new output – a new system, a new pattern.

ABK: Right, and so there's a persistence factor as well. I was really interested in what you wrote about Edison. I mean the whole thing about Edison who I knew very little about...

SBC: Right.

ABK: ...He's quite an interesting character, and you quote him as saying, “I have not failed, I have simply found 10,000 ways it won't work.” So there's that aspect as well, of persistence, which I think also tends to go along with people who are systemizers, and many autistic people who are systemizers.

[9:58]

SBC: Exactly. What people say about autistic people is that they will persevere, they will follow one topic in great depth and go over and over the material really to understand it deeply. But they are looking for these patterns in the information. And for them, it's very pleasurable. For many of us, repetition might be experienced as boring but for an autistic person, I think there's pleasure. When you talk to autistic people there's pleasure in confirming the patterns – they feel kind of safe in the predictability of the world of patterns, and once they can see they've got a predictable pattern, then they can start to experiment with it. And that's when you get invention or even innovation.

ABK: Mm-hmm. You kind of talked about these two concepts of empathy and systemizing. And now, they're not necessarily antithetical...I mean most people have elements of both. Could you talk a little bit about those two concepts?

SBC: Yeah, of course. I said they was a revolution in the human brain 70 to 100,000 years ago, and it wasn't just one new circuit – the systemizing mechanism which allowed this kind of pattern recognition- - there was a second circuit which I call the **empathy circuit** which allowed us to imagine what somebody else is thinking or feeling and also to respond to another person's thoughts or feelings with an appropriate emotion. And again, we can look in the archeological record to see evidence that humans at that time must have been able to empathize. Even the first musical instrument--that flute – we can imagine the inventor was thinking about the logic of how to make this new gadget, but they're also thinking *how is this sound that I'm making going to be experienced or perceived by a listener* – by an audience? And when they were making jewellery....the first jewellery is made of shells that someone has drilled a little hole in and threaded a thread through to make a necklace.

The systemizing mechanism can explain the “if and then,” ‘if I make a hole and I thread a thread through then I can make a necklace from these shells,’ but the empathy circuit would have been allowing our ancestors to imagine *what would someone else think if I wore the jewellery, would they think I was attractive, would they think I was of a higher social status?* Or was the maker of the jewellery intending to give it as a gift in order to make somebody else happy or to please them?

ABK: Mm-hmm.

SBC: So, here we see the kind of empathy side too. And if we kind of jump to the modern day, we can measure empathy and we can measure systemizing as we've done in the population, and what you find is that people fall on a bell curve on both of these. That's to say, most of us are kind of average at each skill, but some people are above average at say systemizing, some people are above average at empathy; or they may be below average, of course. And when we've done our research with 600,000 people online to look at kind of different profiles, you can see that some people lean more towards systemizing and some lean more towards empathy; some people are kind of balanced – they're equally good at both; and then you see these **hyper-systemizers** – people who are looking for the patterns non-stop, but their empathy may just be average or even below average, and that's where we see a lot of autistic people falling into that profile.

The final profile is people who kind of are **hyper-empathizers** – they are kind of worrying what other people thinking or feeling the whole time. But their systemizing again might just be average or below average. This gives us a kind of sense of **neurodiversity**, of different kinds of minds in the population, and it also tells us again that autistic people may overlap with people who are talented at understanding systems, because when we look at people who work in STEM – Science, Technology, Engineering or Math, they have a very similar profile to the autistic people.

[14:56]

ABK: Right, there does seem to be a lot of overlap and Silberman has talked about that too in his early work. I'm wondering, like with school... let's talk about school for a second because there's the tendency in schools to do what they call 'teaching to the middle,' and the idea is they want everyone to be in the middle to some extent. People who are exceptional on one end or the other if you put it on a scale between empathy and systemizing, which we might not even want to do, we might want to call it a spectrum. People that fall towards the edges of that curve tend to have a lot of problems within social institutions like schools, is that right?

SBC: Yeah, I think so. So, if we take autistic people, if you agree with the kind of portrait I've painted that they love patterns but they may struggle in social groups, a mainstream school classroom may be the worst environment for them to learn in...with 25 or 30 kids and there's a lot of background noise and other kids chatting or whispering. Very distracting. Autistic people are often very sensitive to sound but also the environment is very unpredictable. For someone who loves patterns and structure, it's very unpredictable and then you're expected to learn from a teacher who's talking *at* you you're expected to watch his or her face and be able to read facial expressions – these are all things that autistic people and people who are strong systemizers might find really difficult.

You might imagine we should be designing the educational system very differently. The kids who are hyper-systemizers perhaps should be learning in much smaller groups, and to less social kind of chaos. Maybe they should be learning in a much more hands-on way where they can experiment with objects or with systems, and to figure out the patterns on their own. And equally, the kids who are much more towards empathy, maybe for them the mainstream classroom works pretty well, that they like learning in a group, they like communicating and they can switch flexibly very easily.

ABK: Interesting. I mean, you can see that in the workforce. Some industries have actually done that, like the IT industry. For example, Microsoft when they interview people for a lot of their positions they actually have people *doing* something... so they're not prioritizing socialization, they're not giving people a test in socialization but they are really giving them problems to solve and seeing how they can work together in the type of environment that's quieter and a little bit less focused on the sort of hyper-social which seems to have been ramped up more and more in schools over the years. Classrooms are busier and noisier and more social than they were 20 years ago, and that's such a disadvantage for people who are systemizers and for obviously most, if not all, autistic people. So it's really interesting thinking about applying this concept that we've seen in STEM...how that could be applied within classrooms so that people can do better.

SBC: Absolutely. I mean when I went to school...we're talking over 50 years ago, but kids in very-traditional educational-designed classrooms, they were sitting in rows of desks and it was very quiet and very kind of ordered and we've moved away from that, more towards kids kind of working in teams and being able to chat whilst they're working, so it's a much more social environment. Back in the day, if you talked during class you'd get into trouble, whereas now the emphasis is much more to *encourage* kids to communicate and to learn from each other. And of course that works very well if you're the type of person that enjoys communication and understands communication. But, if you're somebody who struggles with communication, maybe the old style would have suited you better.

ABK: Right, like for me like when a lot of different sounds are coming in, like say if I go to a restaurant, or ...I've had to work in environments like the open office, which is taking that concept from school and applying it to like – *oh my God – the rest of our lives*, right? It's a very, very chaotic way of getting anything done and you almost have to ask for--I never did but I should have--a special accommodation.

SBC: Yeah.

[19:56]

ABK: ...to just have peace and quiet, so it's really interesting and I wonder what the social motivation is...why that has shifted *so much* towards these big, noisy groups as a way of getting things done, and

then what the impact that that has on people's ability to learn and work would be. I don't know if anyone has studied it.

SBC: Yeah. Well, I mean again if we look at autistic people the first thing is the majority of them are **unemployed**. Here in the UK, the **National Autistic Society** estimate 85 per cent of autistic adults are unemployed, and that could be because of barriers to finding a job. If the selection process--as you were talking about, how we hire people--is focussed on communication, on social skills, on making eye contact, then that's going to discriminate against anyone who has a disability in those skills.

But it could also be that even if they were lucky enough to get a job and they may not be able to keep the job if they're expected to work in an intensely social environment ...and yet employers could quite easily make these accommodations you talked about. They're called reasonable adjustments – to find a quieter workspace for someone who really can't deal with the amount of sensory overload, and just wants to kind of focus on one topic in depth instead of just in a very superficial way, which is how many people approach their work.

ABK: Interesting, and I think that we need to almost move beyond the idea of individual accommodations because of course people have to know and ask and there's a whole sort of rigamarole around educating people about the accommodations, but to get at the root of *why* we have as a society been prioritizing that approach – the open office, open concept, open classroom and start to, I don't know somehow get educators and employers to acknowledge and understand that that isn't necessarily the best way, and the advantages of allowing these other ways which lead to things like innovation and invention...you're not going to have [innovation] unless you can create a type of environment that's more flexible than the current chaos that most people are facing, especially at school.

SBC: I agree. I would say there are two reasons why we should be adapting the workplace and adapting the educational setting. One is about inclusion, because at the moment, again back to autistic people – autistic kids are dropping out of high school because they find it so toxic. They're getting depressed, they're getting anxious. We're failing them in terms of the **right to education**. And in the workplace as we talked of earlier it's just not conducive to working in this kind of very social environment if that's not how your brain is wired. We want to be more inclusive.

The second reason that you've touched on is that people who are hyper-systemizers, looking for those special "if and then" patterns, could be a real asset to many workplaces basically by understanding a system, whether we're talking about coding, computer programmers and whether we're talking about fixing bicycles or baking bread – they all have systems and an autistic person or a hyper-systemizer could look at the system and think 'maybe I could change one of the variables' so that we can fix the bicycle or bake bread differently then come up with an improvement and then you have an invention. So, it could be good for the company in terms of productivity.

ABK: Mm-hmm.. Yeah, definitely. It's strange that [systemizing] is not privileged a bit more than it is, and one of the things I like about your book is that you don't really privilege empathy over systemizing in that way, but pointing out more that we need systems thinking and systemizing to build our society.

I think we should unpack the concepts a little bit further of empathy and systemizing. Let's talk about empathy first because there's disagreement and even misconceptions about what empathy is. *Empathy*

is actually a really loaded term, I've been discovering, because people equate empathy with kindness a lot, but there's much more to the concept than that. Because if a person is like, correct me if I'm wrong, but if a person has very high empathy they can actually use the empathy to manipulate people and get people to do terrible things.

SBC: Yep.

ABK: So it's not necessarily kind of this binary between Mr. Spock and (laughter) whatever, right?

[25:00]

SBC: No, no. So empathy is a kind of umbrella term and there's at least two components – two types of empathy.

ABK: Hmm.

SBC: In my book *The Pattern Seekers*, I talk about cognitive empathy and affective empathy. **Cognitive empathy** is the ability to imagine what someone is thinking or feeling and it...it literally is like a leap of the imagination. And then **affective empathy** is the capacity to respond to what someone is thinking or feeling with an appropriate emotion.

ABK: Hmm.

SBC: And these two types of empathy do seem to be distinct. We use both of them all the time but if you were just using cognitive empathy without the affective empathy then you could do what you described. You could be manipulating people. You understand what they want, what they think what they feel; but without the affective empathy you don't really care about their feelings. You don't have an appropriate emotional response. And that's probably what the psychopath does, or people with anti-social personality disorder.

Of course, cognitive empathy has lots of positives – it allows us to cooperate, it allows us to teach – because once you can imagine what someone knows or believes you can sort of see what they might need to know and help them learn, so there's lots of positives. But back to autism: a **misconception is that autistic people lack empathy**, but actually the part of empathy that they struggle with is the cognitive empathy. They find it difficult to read people's faces, read people's behaviour and... imagine their thoughts and feelings, but they don't lack the affective empathy. So, once you tell an autistic person that somebody is suffering, it upsets them just like it upsets other people. They want to go over and help and do something about it. So, they clearly have empathy – the affective type -- but the cognitive empathy is one of their areas of disability.

ABK: I think when you talk about going over to help, that's a really interesting way to look at it because it's systemizing – if a person is a systemizer then they might go into something like for example public health, right? People that work in public health tend to be really pretty good at systemizing. They're looking at the whole system and they're looking at what we need to do for example with COVID, they've been looking at it.

The frustration I think with science communication in general, especially from public health, is in melding systemizing and empathizing to communicate around how people stay safe because you can't

just tell people, 'You can't hug Grandma because of the R-factor.' Like most people aren't going to relate to that, even though that is the science, right?

And there even is a break... if you go into, for example, the debates that happen between anti-vax people and people who are pro-vax (and a lot of the people that are debating with anti-vaxers are autistic people)... trying to make a point and trying to communicate about the science but relying on like *logos*, relying on facts when a lot of the appeal of anti-vax is that it pulls on people's emotions and it isn't really focussed on facts. So then it's hard to communicate around science in that way in *either* of those examples.

SBC: Yeah. I agree and I mean first of all back to your example of public health. Public health is basically run by physicians or public health experts but thinking about health – the whole health system and public health relies on systemizing on “if and then” logic. I heard a really clear example of this on television just a couple of weeks ago where a politician was saying ‘*if* the infection rates are doubling every week, *and* we don't do lockdown, *then* more people are going to die.’ So, it's the same “if and then” logic when you think about public health. But obviously with public health the motivation is to save lives and improve quality of life and health, so that's all about empathy. We can care about other people not suffering.

So you can see just in that one example that we need both ways of thinking. We need the systemizers to *understand* how to control the infection rates in that example, but we also need empathy to motivate why we are doing this in the first place. We're worrying about the vulnerable – we're worrying about particularly older people who might be at risk of dying.

[30:14]

ABK: Right, right. I mean would you say there's also a kindness in systemizing? Because if you're looking at the collective good and you're trying to create a system that works the best for everyone then --if you're doing it for good--it would be working for good, whether it's heavily based on systemizing or not it seems like the breakdown would happen in communication...in communicating *why* the systems should be used, which you might have seen with someone like Edison or other inventors who had ideas but they sometimes couldn't communicate them. ...And sometimes they just had bad ideas, as you gave a few examples in your book. But even when someone has a good idea, if there's that communication gap for an innovation or an idea it can't go.

SBC: No exactly, and that's why companies need *teams*, they need the inventors – the people who are great at systemizing, but they need the empathizers to sort of take the new idea and communicate it to a wider market for example, and to explain why is this invention going to be useful. And even to think ‘is this invention going to be useful?’ so they're thinking about people's ordinary lives. This is another great argument to why diversity at work is really valuable.

ABK: That's so interesting. I want to get back to autism for a second and talk about systemizing, but in a different way. I want to talk about the **DSM** – that manual that many providers use to diagnose and treat autistic people and those with other states and conditions or disorders. Now, it seems like in the DSM manual historically it was in a way... like you talk about **Linnaeus** in your book ...we can talk about how we've broken everything down into parts, whether it's plants or animals or just the whole evolutionary map, right?

In the DSM in some sense they've tried to break *people* down and line people up into types. But people--because of a lot of factors--are harder to classify. I mean, you can pin a little moth down and say 'this is an Isabella Tiger moth' or whatever. It's very hard to pin a person down and I think that's one of the points of the neurodiversity argument that I think has had sway within the DSM, because the DSM manual took a step forward and took away some of these restrictive concepts such as "high functioning" and "low functioning" autism and replaced it with a spectrum, to kind of acknowledge that that type of systemizing that they've been relying on --it can work in some circumstances, but we have to remember that when we're talking about *people* that it's informed by the biases of the times and it doesn't really capture the diversity even within a certain neurotype.

So, we're getting into really new territory when it comes to autism around how it's how it's classified, right?

SBC: I agree. The DSM as you've been talking about, this is the kind of manual that clinicians use to classify *psychiatric disorders*, as they call them. First of all, I don't really like the term '**disorder**' in relation to autism and in relation to many conditions, it's kind of a negative word. And certainly in the case of autism we know that autism is a disability, but it also involves strengths and sometimes talents, so the term '**disorder**' doesn't seem to fit. But I think you're right that we're no longer thinking about autism and other conditions as categories, we're thinking about spectra -- the autism spectrum and for me it's not just about a spectrum of differences within the clinical group that we call *autism*, it's a spectrum that runs right through our population -- the general population.

So, we can now talk about autistic traits that we all have, you and I both have autistic traits and we can measure this. In our research, we have a questionnaire called the **Autism Spectrum Quotient**, again we used it in that big study of 600,000 people and we found that there's a bell curve of autistic traits. And only a few have a lot of traits, and [if] those traits are kind of interfering with your everyday life that you might need a diagnosis. In other ways someone like **Edison**, he didn't need a diagnosis, he was functioning perfectly well, and he found a niche for himself...

ABK: Mm-hmm.

SBC: ...as an inventor and he had a very kind of a understanding wife...

ABK: Yeah (laughing)

[34:58]

SBC: So he'd be in his workshop. He was in his workshop day and night experimenting "in 10,000 different ways," as you said, and his wife kind of realized, *okay this is how he's made, this is what he does.*

ABK: Mm-hmm.

SBC: And so she moved the mattress into the workshop so he could just fall asleep at 3 in the morning when he was too tired to keep on experimenting. He was very driven, very focussed...some people would say very obsessional. Came up with some fantastic inventions -- famously the light bulb. Came up

with some other inventions which were not that useful because he wasn't really thinking about whether people really needed them.

ABK: Right, right.

SBC: He was just fascinated by the idea that they *could* be invented.

ABK: I like the examples that you gave about Edison in the book about the different ways that he experimented and some of them that didn't work out. For example, there was the poured concrete home.

SBC: Right.

ABK: Right, where-

SBC: Yeah, he was making furniture out of concrete. Did people really need that? He made a mechanical doll for kids, but actually it sounded really sort of painful to listen to, and so he wasn't necessarily checking on the user...whether they would enjoy it, or want it or need it, but nevertheless, he was having the insight that these things could be invented.

ABK: Right.

SBC: The first phonograph, for example, or recording machine to record sound.

ABK: Mm-hmm.. It's really interesting because there was **a place for him** and people made a space for him and of course it breaks my heart that there are a lot of people, a lot of thinkers where they don't quite find that place or that space. That's really our job, whether we're activists or academics or anyone working in the space of autism, to try to figure out how to get society to carve back those spaces and those places...

SBC: Yeah.

ABK: ...so there is a place for everyone.

SBC: Yeah.

ABK: Not only because of inclusion, which is a good enough reason on its own, but also in terms of recognizing and **valuing** the importance of having that diversity for everyone.

SBC: Yeah, so you started off this podcast talking about my speech at the United Nations on autism and human rights.

ABK: Mm-hmm.

SBC: And one of the basic human rights is the **right to work** – the right to employment. And at the moment as we said, autistic people are falling outside of that human right.

ABK: Mm-hmm.

SBC: And that's largely because we should be a more compassionate society and thinking about the workplace and how we can make sure it's accessible to people with very different kinds of minds, so

we're not just hiring people with autism because they could be inventors, that would be kind of exploitation.

ABK: Mm-hmm.

SBC: We should be doing it because it's their right to work. We all need a purpose in life and without employment many people become depressed.

ABK: Mm-hmm.

SBC: Many people may even become suicidal [thinking] 'what's the point in life if there's nothing to do?' And work gives us that sense of belonging, sense of purpose, sense of being valued. It gives us a salary so that we have autonomy and **independence** in our lives. There's lots of reasons why we should be doing this.

ABK: Right. I mean It kind of goes back to, I think a real shift that's happening in autism research as well, with especially people coming out of Sociology like **Dr. Damian Milton**, and others working in sociology and that sort of stream to say 'we haven't put enough attention,' or- you all, I'm not a researcher- you all – the research field, hasn't put enough attention into quality of life as a research goal, and that research goals can be a lot about again going back to putting that moth down on the cloth and examining it, and "examining the autistic people," but losing sight, ironically though systemizing – through overly-systemizing. Losing sight of that important just really *soft* quality of building people's quality of life and directing research in that direction.

[It] is really exciting to see at ***INSAR** and some of the other conferences – that there's more quality of life research going on, more going into about like what you write about in your book – employment and also making changes in the schools because that's of course the *first* environment and if that's a negative environment, if that's a segregating environment for autistic people or for anyone who is a systemizer, tends towards system thinking...

SBC: Hmm.

[40:04]

ABK: ...then, immediately you're off on the wrong path.

What I like about your book is that you begin to talk about what we can actually do, some of those solutions we've been talking about in this conversation, the *prescriptive* part of all of this, what we can do as a society in scaling up the work force as well.

SBC: Yeah, sure. I mean, I'm glad you mentioned Damian Milton, because I agree with him that the **goal of autism research should be to improve the quality of life of autistic people**. Obviously there's a role for basic science, and genetics is one example of that where we're trying to understand the causes of autism, but all of this should be kind of leading to improved quality of life, and that's really kind of urgent because at the moment if you look across the autism community there are very high rates of **poor mental health**.

ABK: Mm-hmm.

SBC: Most autistic adults and probably teenagers have got anxiety or depression, and that's not necessarily part of autism. That's likely to be through lack of appropriate support or sufficient support. We did a study back in 2014 looking at suicidality amongst autistic adults and we were really shocked by what we found.

ABK: Mm-hmm.

SBC: We published this in a journal called *The Lancet Psychiatry* where we found that two-thirds of autistic adults had felt suicidal, and one-third of autistic adults had attempted suicide – they felt so bad, and they felt that life was just not worth living. Yeah, so we have to look at ourselves, at our own society to think what have we done such that one to two percent of the population, who are autistic, feel so desperate that they no longer want to live? So, my book is not just about an interesting research question – is there a link between autism and invention? It's more a kind of a call to action – what can we do in our education systems as we've talked about, in our workplaces, in our leisure industries to make it more autism friendly, so that people with autism do enjoy a better quality of life?

ABK: Right, right. It's getting at the root of things which ...I see as an activist or as an advocate. I do advocacy with a group **Autistics for Autistics** in Canada and we speak with politicians and sometimes people ask like 'what's the big issue in the autistic community?' and they're very surprised to hear '**poverty**' as an answer. But, it's actually a really central, focal issue for adults, so it's thinking about it in a new way. It's even acknowledging the presence or existence of autistic adults beyond the research field, but into policy and how we can move *policy* because that would be the next place that we need to go.

SBC: I'm very glad to hear you're doing advocacy. I think we do need research, but the research needs to be translated into policy.

ABK: Mm-hmm.

SBC: We published a research paper in 2019 looking at **vulnerability** in autistic people, finding really high levels of vulnerability which included poverty by the way...just asking people, 'Have you ever had a period of your life where you didn't have enough money for food?' and a worrying percentage of autistic people said yes to that question, but also other kinds of vulnerability like domestic violence, and like being exploited financially because of their naivete, being bullied at school – a whole host of really negative experiences.

But doing that research in itself isn't going to change anything, we have to make sure that the research findings gets into the hands of politicians, of policymakers....that one conclusion would be that autistic people need more safeguarding. That they are at risk of being manipulated ah by people who are more socially adept, and- and that could include sexual harassment- all kinds of things and we need to make sure that the safeguards are in place so that they can feel safe, and have dignity and feel respected.

[45:02]

ABK: It does seem like, I mean you're much more involved in the research community – it does seem like there's a newer openness to talking about quality of life. Would you say that it's moving in that direction?

SBC: Yeah, and I think we have to thank the **autistic community** themselves for having kind of made researchers wake up. Researchers were for a long time pursuing interesting scientific questions, a bit like you were saying ‘pinning a moth down on the cloth to investigate it’. That was kind of the old way of doing science, doing research with people, and I think the new way of doing research is that you listen to the people that you’re studying, you work together with them, you co-design your studies, you make sure that the studies are relevant for changing people’s lives, and that’s probably that influence of autistic people talking to scientists, trusting scientists so that they can work together. That’s probably led to this change that you’re describing.

ABK: Right. I appreciate that at the beginning of your book you gave...you did say a thank you to autistic activists and advocates... [change] really has come out in some ways of grassroots effort and of persistence among autistic people whether as individuals or organized – a real persistence to break through and I think that breakthrough has happened now – that it’s really changed the environment in research. It’s definitely changing into the environment in service provision and it’s *very slowly* changing some of the policy, but it’s all taking time. So, it’s interesting to see the way that your work is flowing within that.

I really like the fact that your book included these solutions, and I appreciate it again in your conclusion kind of this acknowledgement of the autistic community...the autistic community is brought in more with research than it certainly used to be, especially with the presence of autistic researchers themselves. It’s really breaking away from those older views and it’s a more humanizing view which comes back to what we were talking about at the beginning and what you talked about in the UN about the need for compassion and understanding.

SBC: Yeah. So, I’d agree with you there. I mean I think although we can see signs of positive change, we still need to be careful not to be complacent.

ABK: Mm-hmm.

SBC: Because we still do have these worrying rates of suicidality, worrying rates of unemployment and so forth, so there’s still a lot of work to do.

ABK: Yes, there’s definitely a lot of work to do. Thank you very much for this discussion and everything that’s coming out of this work, and I’d encourage listeners to check out the book. The book is called *The Pattern Seekers*. Thank you so much, Simon, for being on the show.

SBC: Thank you Anne, for inviting me. It’s been a very enjoyable conversation.

ABK: Thanks. We were speaking with Dr. Simon Baron-Cohen, an autism research whose new book is entitled, *The Pattern Seekers*.

*INSAR – International Society of Autism Research

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