

Fergus

Hi, you're listening to the AMASE research podcast. I'm Fergus Murray.

Sonny

And I'm Sonny Hallett.

Fergus

And we're talking to Cameron Maitland, PhD student at the University of Edinburgh and Heriot Watt. Cameron, would you like to tell us a bit about your research?

Cameron

Yes, I'm in the third year of my PhD with the Salvesen Mindroom Research Centre, which focuses research on learning difficulties. My specific research is looking at depression in autistic people, and why some autistic people might be more likely to be depressed than others. And I focus on kind of social factors. So things like social motivation and social connection, and the role they might play in mental health.

Fergus

The idea being that people are probably more likely to be depressed if they lack social connections?

Cameron

Essentially, yes, I'm taking some theories that have evidence in the general population, and seeing if they apply to the specifically autistic population. So there's lots of evidence that feeling socially connected, and feeling not lonely, are related to better mental health and less depression and less anxiety, and positive mental health. So actually feeling good about yourself, rather than just a lack of depression. And I want to examine whether that still holds for autistic people.

Fergus

You're looking at social identification in particular.

Cameron

Yes.

Fergus

...in the sense of identifying with a group?

Cameron

Yes. So social identification, in some ways, is akin to feeling connected and belonging with a group. But as part of the measures, it's important you feel similar to that group. So it can explain why, say an individual feels lonely and that's related to depression and anxiety. The automatic thought might be okay, put them in a group, they'll feel connected, and they'll feel better. But it doesn't always work like that. If you take an individual at school who is isolated, doesn't connect, they're surrounded by people they shouldn't be lonely, in some senses, but they are. So social identification includes this feeling of similarity.

Fergus

So it's the feeling that you can identify with members of a group, right?

Cameron

Mm-hmm. So by being part of a group where others are similar to you, you enjoy being part of that group, you say, "Oh, hang on, other people are like me. I like these other people, they are really cool. All these positive things about them. If I'm like them, then I must be...I must have all these positive things. I've seen in other people." And so in that way, provides the link to mental health, which other measures of social connection don't.

Sonny

Have you looked at how this is related to representations as well? Because if you're talking about people sort of feeling socially connected to others who are similar to them, then that's sort of similar to representations of autistic people as well, and therefore them feeling connected to these representations.

Cameron

I haven't directly looked at that, no. That is the underlying hypothesis that I haven't really spoken about because I haven't collected evidence to support or refute it. But essentially, I'm thinking that a lot of the groups that my autistic participants might report being socially connected to, so that they socially identify with, will be kind of pro-autistic, pro-neurodiversity communities, and the positive representations within those communities are the key to better self esteem better mental health,

Fergus

...which is not necessarily autism-specific, right? Some communities are more accepting of people just generally being quite weird.

Cameron

Oh, yes, certainly. But for some individuals, their autistic identity is often the most important part. Or it's the identity that's kind of been reinforced the most, in that it might colour an awful lot of someone's experience. And it's also perhaps a label that's been thrown at them all the time - you're autistic, you're autistic, you're autistic - and not allowed to explore other identities. So that's why I think specifically autism and neurodiverse groups, may be particularly helpful.

Cameron

But you're right, sometimes just more accepting groups and communities of difference might be the key. So it's this thing, it's this balance of, "okay, I'm similar to these people. But I'm also different to these people. And because we're all going to be different from each other in some level." So it's, it comes down to... almost a philosophical argument into how are we similar, how are we different?

Cameron

So again, is there a slight point where you need to feel that level of similarity, have your core identity recognised? So if that identity's particularly central to you, perhaps that's the identity that's most important you socially identify with. And perhaps the other groups are supplementary, and still excellent for your mental health because it endorses other parts of your identity. And there's a bit of research showing that a multifaceted identity is also better for your self esteem and mental health, perhaps in terms of a protection thing in that, say, one aspect of identity is being attacked, or you feel negative about that identity for a small period of time, you've got your other identities to fall back on. So you might say, okay, I'm not feeling good about being male right now. But I'm also let me say, a member of a choir, I really enjoyed that. And that's not related to me being male.

Sonny

One thing that a lot of people who've worked extensively with the autistic community and members within the autistic community as well, have observed, is how autistic people seem, if anything to be more diverse in many ways than non-autistic people. I'm wondering if you found that has impacted your research at all, the fact that there may be so many multifaceted identities in there?

Cameron

It's not something I've directly looked at. But it's something I do keep in the back of my mind. One of the key studies that my research is based on, is one of the first looking at social identification in autistic people. I think 50% of their sample was LGBT, I think, by chance, and the study wasn't looking at anything to do with LGBT identity, but 50% was. So as you said, there does seem to be a high level of diversity within the autistic community. Perhaps that's because it's a relatively new community. And that perhaps as it goes on, and grows from strength to strength, smaller communities will break out. So I'm autistic and LGBT, I'm autistic and female. And we're starting to see some these communities developing now. And going back to the earlier point of, perhaps the more and more similar you get to other people, that's why these communities are forming, because 'Oh, hang on, the whole community might be similar to me! But this even smaller community might be more similar.' So you kind of get breaking it down into smaller and smaller communities. So allowing people to form these kind of more niche identities I suppose.

Fergus

The overlap between autism and neurodivergence more broadly. And various, sort of, more or less outsider communities is very interesting. Science fiction, and bisexuality, gender divergence, the kink community, role playing. All of these things, attract a lot of people whose brains seem to work a bit differently from the rest of the population. And some autistic people, for example, obviously feel more at home in the Doctor Who fan community than they do in the autistic community at large.

Cameron

I agree with that, and of all the research that's going on around these communities, I think the key thing might be take away is how do we get people to more accepting of difference? How can we foster that feeling in, let's say, schools? How can we get kids at a very young age to be accepting of difference and not to either discriminate against others and bully

against others, and just instantly assume difference is a bad thing? So how do we bring that feeling of accepting and celebrating difference into as many different organisations, workplaces, schools as possible? On that point, it's obviously excellent we have all these initiatives to be more inclusive of every kind of difference, so race, sexuality, any kind of difference. But there's always going to be specific differences, let's say a medical condition that affects one in a million. That is a difference which, if we have like an initiative to include every single... it's impossible, essentially, to have that work. So if we foster the sense of accepting difference on a whole, I think that may be a key in that.

Fergus

Yeah! And not just accepting but appreciating.

Cameron

Yes, exactly: celebrating.

Fergus

A big part of what people who differ from this society's mean or norms need is understanding that actually, it's a good thing for people to think differently, for there to be people who think differently and experience the world differently.

Cameron

Mm-hmm. Unfortunately, I think it is a lot easier in society to follow the status quo if you can, a lot of people spend a lot of time and effort to follow the status quo and fit within their boxes. Whether they're ultimately happier for that or not is again, again a wider question, I think.

Fergus

And of course, some communities who've made the greatest strides in societal acceptance, have done that partly by presenting themselves as being really a lot like everybody else.

Cameron

As a gay man, I think I've seen that in the gay community, certainly: I'm gay, but I'm not this type of gay, I still want to get married and have children 2.4! I'm still everything else. Yeah, at the same time, often discriminated against other minority identities. So the gay community is often very racist, still ableist in a lot of ways, getting better, but still very slow progress, I think.

Fergus

Yeah. And even bi-phobic a lot of the time..

Cameron

Yes, exactly. There's a lot bi erasure.

Fergus

So what attracted you to autism research?

Cameron

I kind of fell into it really, I started off volunteering at a social club for autistic teens. And when I was doing my undergrad, and really enjoyed it, I really enjoyed getting to know autistic people, and working with them and just having fun with them really. And then it got to the time when I realised I wanted to do a PhD, some focused research. And it was kind of this perfect mix of, I've got some face to face experience with autistic people. From a psychological research point of view it's very interesting for me. And also, I felt it was a way that I could really, well, help the world. I think what really keeps me interested is that my perception of - I suppose it's the neurodiversity phenomenon, in that through my engaging with the neurodiverse community, I've really got on board with it. It's just a different way to be human, there is no better way, there is no poorer way. And there is no reason why autistic people should have a less happy or successful life than anybody else.

Cameron

I'm a gay man. And there's also a lot of parallels between homosexuality and autism, both in the past have been seen as disorders, as a deficient way of being human. Whereas now it's just a different way of being human. A lot of both autistic people and gay people often have to come out. So, revealing you're either autistic or gay. And whether to do that, when to do that, how to do that. The fact there's also both autistic and LGBT Pride now as well, as a nice mix, quite different events, I think. I like autism research because it supports the idea that being different isn't a bad thing, really. And I'm trying to find ways of supporting that view.

Sonny

Would you say that your personal insights in sort of seeing parallels between the LGBT community and the neurodiversity movement has been a particularly personal way of giving you insight into how to connect with the autistic community?

Cameron

In a lot of ways, yes. In these kind of slight feelings of being an outsider, and the autism community treading a lot of the same paths that the LGBT community has treaded before. And hopefully, perhaps we can use some lessons in the LGBT community and apply them to the autistic community, of how to make people autistic people feel happier and more accepted. And so, hopefully speed up the process. Hopefully, we'll do that. And I have to realise that I'm not autistic, I don't have any lived experience, I really have to be a sounding board for the autistic community, I have to listen to what you're saying, because I don't have that experience.

Fergus

So what have you done in your research to make sure that you're listening to autistic people?

Cameron

I've made a few efforts. So my first study that I ran, and I've just finished data collection for, I put out a study proposal of the things I was going to measure, and the theories I was using. So this is the study I did looking at feelings of social identification and feelings that seemed to have an association with depression, anxiety and mental health.

Cameron

Before I did that, I put together a short proposal of what I was going to do and distributed to the autism community via Twitter to get feedback. It was a short presentation, explaining the theories on using what I was going to measure and what the autistic community felt from it. And it changed a few things in my study. So for example, I wasn't actually going to look at the autistic community originally, because a study's already been done looking at that. And it found that autistic social identification was associated with lower anxiety and depression. But I decided to include it because in the feedback the autistic people gave me, it was such as ringing endorsement it was such an important thing that I'm really needed to study it. And actually investigating anxiety and positive mental health came from autistic feedback in that anxiety it seemed was a really important aspect of mental health autistic people want me to examine, and also positive mental health in that being mentally healthy isn't just about a lack of depression, anxiety: it's about feeling actually good about yourself and feeling you can do things and accomplish things.

Cameron

So I ran that investigation looking at autistic people's opinion on the theory of it, where I realised I fell down upon was I didn't include any autistic people in the actual design of the study: in the exact questions I was using, the online survey tools I was using. And so for example, the survey software that I used, there are different ways to answer questions. So you can use like a slider bar or drop down or tick the box. I didn't keep those consistent between my different questionnaires and that caused an issue for a couple of people. So I got a little bit of the way there to having autistic involvement, but going ahead, I've learned some things for future studies that I need to do to really get autistic involvement in the nuts and bolts and things.

Fergus

Do you feel that there are barriers to including autistic people in autism research? And if so, how could they be reduced?

Cameron

Definitely, I mean, I'm facing them myself at the minute, there's a study that I'm planning, and want some autistic input and involvement with it. And I'm very lucky that AMASE have agreed to consult with me and discuss it. But at the same time as a PhD student, I don't have any funds to pay anyone. So I feel slightly guilty that I can't afford to pay anyone. Also, the input researchers get from autistic people is usually from the autistic community that is very much engaged with research. So whether that's on Twitter, or through research networks, it's an autistic community that's very much interested and able to interact with the research community. We're not getting the input of, perhaps, people that aren't as connected to those communities.

Cameron

So perhaps we need to make some efforts to try and broaden autistic input from people of different levels of connectedness to the research community, in that it's almost a self-selecting sample. I think a lot more involvement from autistic agencies that work directly

with autistic people, or having people involved, to a kind of practice based research. So let's take Number 6, for example. Let's say they're running a group, they've encountered a problem within a group time and time again, there's a research question that's perfect. If they had a researcher involved they could say, right, here's my question, can you help me answer this question?

Cameron

What we can do as researchers in the field of autism, is provide the nuts and bolts for answering those questions. So someone comes to me with a question, I can say, 'Oh, well, we can measure that using this questionnaire or using this test. And, oh we need to get this many participants to really be able to answer this question, how are we going to recruit our participants?'

Cameron

So we provide the nuts and bolts. We are the research element, the research expertise, whereas most of the questions and often the interpretation of results, needs a lot more involvement from the autistic community. And so autistic organisations and organisations that work and have autistic people involved directly, I feel they should have a much stronger role in driving research objectives.

Sonny

So leading on from that, where do you see the future of autism research? And what would you ideally like to see as well?

Cameron

Ideally, I think I would like to see autism research heading in the direction of, again, increased collaboration. So I've mentioned the autism-focused organisations, but also collaborating in other ways. So I think Autistica's got quite a nice initiative at the minute where they get a researcher and they team them up with an autistic person to directly consult with them about that research, and that autistic person is paid for their experience and expertise.

Cameron

So any initiatives like that, which promote collaboration between autistic people, and researchers in autism is excellent, and those things need to become a staple of research grants, and any research that's being conducted, and slowly build up so that no research about autism is conducted without autistic input. So for example, I'm imagining all the undergraduate psychology projects that have been done around the country this minute, possibly about autism, a way of getting autistic inclusion in those projects. So whatever way that would be, I mean it sounds quite intense now for the hundreds of thousands of projects they'll be doing. But I'm sure there will be a way, and there should be a way, of getting autistic input. Because then right from the ground up, all our ...I'm restricting it to psychology, because I'm a psychologist... all our psychology researchers going ahead from that point, we'll know, oh this is what needs to be done

Fergus

Back to your own research. Once it's all wrapped up and written up and hopefully published, what kind of impact would you hope it would have on the world, and what benefits for autistic people?

Cameron

I think I said before, that my main motivation was to put some numbers behind something that a lot of autistic people have said for a long time, that interaction with other autistic people is important for them. And I wanted to frame those results in terms of numbers, in terms of standardised mental health measures, so I can take this to policymakers, anybody that's making decisions and say 'Look, this is important in numbers.'

Cameron

Some people are very close minded to, let's say, qualitative research, which is what inspired a lot of my own research. So I wanted to put a quantitative spin on it, I guess, for those people who are looking at 'Well, I want something that helps this many people, I want to help the majority' in terms of politicians what's going to get you the most votes? In that context. I want to show this helps this many people.

Cameron

I realise that my theories won't apply to everybody at all, certainly not. I don't believe that everybody does need social identification, autistic or non-autistic. There are some people that won't be depressed if they don't have any social identification. But I believe there are enough people to justify funding for autism-specific social clubs and initiatives and organisations like the Highland One Stop Shop, and show how important they are for mental health.

Fergus

That's great. Thanks for talking to us Cameron.

Cameron

Thank you for interviewing me. It's been a pleasure.

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