EXCLUSIVE:
INTERVIEW WITH DR EMMA GOWEN -
CHAIR OF AUTISM@MANCHESTER

“TELL ME ABOUT YOUR PHD”
INTERVIEW WITH
NEURODIVERGENT PHD-ER.
FREDDIE J.

BLOGS AND BOOKS -
NEW READS IN AUTISM

February 2024

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COVER PHOTO: DIVERSIFYLENS

The editor would like to credit and celebrate Canva portfolio, Diversifylens, for offering freely-available photos representing a diverse range of individuals. The cover image is of an Autistic girl, from Diversifylens' photographer 'Merrysky'.

Above photos by Jayden Becker, Eunice Pais, and Vaneesha by #DepthofV for Diversifylens.

Diversifylens' portfolio can be viewed: https://www.canva.com/p/diversifylens/?utm_medium=referral&utm_source=creator_share&utm_campaign=creator_share

WORDS FROM THE EDITOR: THE CRAFT OF CO-PRODUCTION

I can not believe it has already been four months since I took up the co-production officer role at Autism@Manchester. It felt like just yesterday when I was being interviewed by Dr Emma Gowen and her colleagues for this brand-new role.

As a final-year Education student, my schedule is jam-packed. Therefore, I quit my part-time role at a Manchester charity over the summer between my second and third years. I promised myself that my final undergraduate year would be focused on my studies and dissertation. At that point, I had already published a children's book and lined up a master's degree to follow my undergraduate career. Frankly, I did not need any more experience for my LinkedIn (or, at the very least, I knew I could do a year without the extra work of a job).
However, when I was told about this opportunity of the co-production officer role at Autism@Manchester, I was so excited to see something novel to the Autism research field. I applied and was over the moon to be offered the role.

Four months in, and I am so grateful for the opportunity I was offered. I wish it was more common in the field of Autism Patient Public Involvement and Engagement (PPIE). Actually, I wish co-production and meaningful PPIE is more common in general.

In launching our first Autism@Manchester magazine for this year, I want to take this opportunity to share the 'craft of co-production' - the little tips and tricks I have learnt from the fantastic team at Autism@Manchester.

Firstly, when involving Autistic individuals (like me), researchers need to be direct in asking about our access needs. This was one of the first things Emma and her team discussed with me before I began my role. This meant that I could do my best in my role, and it did not become an uncomfortable 'elephant in the room' later down the line.

Secondly, working as a team without underestimating the Autistic person's capabilities is essential. In working with Emma Gowen (and Alex Sturrock, with Kathy Leadbitter), I have always been involved as an 'equal voice' during meetings and discussions. I have noticed in the past that some researchers are overly cautious about the concepts they bring up near the Autistic person. Sure, it is good to be mindful of ableist language, but oversimplifying concepts can, in turn, be more detrimental to Autistic people's experience of co-production. I always tell people to 'say it as it is', and I will ask if I don't get it.
The most important message here is to involve all individuals equally and get to know the individuals you are co-producing with - truly listen to what they have to say. This can happen 1-2-1 or in focus groups, like the Expert-by-Experience group here at A@M.

Last but certainly not least, you need to get creative. Since starting as the co-production officer, I have been pushed to try new media for disseminating research and different ways we can deliver information accessibly. In co-producing, all stakeholders must make each other creatively rethink ways of doing things. Powerpoint is a bit dated, after all.

It is not just about pushing the co-producers to be creative, though; the craft of co-production is equally offering co-producers with lived experiences to push researchers to become more innovative in their ways, too. It is an ongoing tug of ideas.

I truly hope we have more co-production roles in the future, in every field. I want more individuals to get to experience the joy of bringing their lived experiences to light with research. Co-production is not for everyone, and it can be difficult for many reasons (and you can read more about this in Emma's interview!), but it works for some people. And when it works, it can be liberating.

I hope this short magazine will show you a glimpse of Autism@Manchester and the product of what co-production can do.

EXCLUSIVE: BEHIND AUTISM@MANCHESTER, IN CONVERSATION WITH DR EMMA GOWEN

In an exclusive interview for Autism@Manchester's first 2024 magazine, Dr Emma Gowen, Chair of Autism@Manchester talks about her sensory-motor research, discusses the importance of upvaluing Autistic voices and co-production and shares her hopes for future Autism research.

J: Thank you for being here today, Emma.

I've done another interview before, and it was great to hear about people working in Autism research. Now, obviously, you're someone very important for Autism@Manchester - you literally chair it *laughs*

So, could you please introduce yourself to those who do not know you and briefly explain your role at Autism@Manchester?

E: Well, thank you, Jaja.

I am Emma Gowen, and basically, in my role, I try to develop ideas and galvanise others to help with our main aims of Autism@Manchester and come up with initiatives to help with [Autism@Manchester's aim].

Our aims are around sharing knowledge about Autism research and collaborating on the design and conduct of research, and that is with lots of different people: the Autistic community, academics, clinicians, and practitioners. That's basically what I am trying to do - providing input and galvanising people.

Some initiatives that we are doing at the moment include events. A new initiative at the moment is "Café Autistique", which will run a couple of times a year. I also chair the Autism@Manchester Expert-by-Experience group, which has been running since 2017. We also create educational resources.

And your role (referring to Jaja) as well, the co-production officer, that's another initiative of ours.

J: That's really cool. I think you are doing so much in terms of bringing the Autistic community into research and making that more accessible. It's really important that Autism research is accessible to those who research Autistic people and Autistic people themselves.

J: Now, I think you might have already covered this, but what would you say is Autism@Manchester's main goal?

E: Ultimately, our key goal is to try and help researchers produce quality research that has real meaning for Autistic people, and that's through doing those initiatives we mentioned earlier.

J: Perfect! Here is a fun question. Before we get to the more technical side of this interview, it would be good for people to know you, Emma. If you could meet one person, dead or alive, who would it be and why?

E: I had to think about this one, but it would be Ignac Semmelweis, a Hungarian obstetrician in the 1800s. He worked with women who were giving birth and would then get infections from giving birth. At that time, the women who had their babies delivered by midwives had a far lower mortality rate than the women whom physicians and medical students helped deliver. Ignac noticed that the difference between these two groups was that the medical doctor would go straight from an autopsy to delivering a baby.

This was before we understood bacteria and viruses; this was before the germ theory, but Ignac thought there was something called "death particles" in the hands of the physicians. So, to experiment and find evidence for this, Ignac got medical doctors to wash their hands between patients for a year. And at the end of it, he saw the mortality rates fall. This was great evidence, but his senior colleagues did not want to accept that there could be these "death particles", so they did not accept Ignac's theory.

This took quite a toll on Ignac, and he kept trying to get the theory accepted. He became mentally ill and was admitted into an "asylum" where he deteriorated. And then, it wasn't until 20 years after his death that his contributions were finally recognised. So yeah, I would want to recognise him and say, "No, you were right", thank him for his work, and just give him the due respect and recognition that he should have had. This story is quite sad, and it's a real-life story.

I do take a couple of points from this story.
If others don't believe in what you're doing, you need to keep going. Obviously, it needs to be scientifically backed up and sound. It is no good chasing stuff that you know you don't have the evidence for.

Secondly, the harshness of the environment with his senior colleagues, I think, is quite similar to today's academia environment; it can be quite a harsh environment with lots of bias and criticism. I think we need to strive to make it a more open, accepting, and supportive place, so it's sad that it can still be like that today, as with [Ignac's] days as well.

J: That's a heavy one! Certainly, a difficult story to follow–

E: The one thing I really hate is injustice.
I think that's why that story drew me to it.

J: Of course, I mean for someone to follow what they believe is right when there was evidence and to also go on a year-long journey for what they believe in, especially back then. That sounds difficult.

E: When do you have evidence like that for others not to support you? That is quite sad.

J: That's true.

J: Now that we have touched on Ignac's story and research and why it inspires you, do you mind telling readers about your research? What is the main piece of research that you want to discuss for this interview? I know you do a lot!

E: The area of research that I've been researching for about 20 years now is about "sensory and motor experiences and difficulties in Autistic people", particularly Autistic adults. That area has been given less attention than the social communication and interaction elements of Autism in the past, but it has been gaining momentum. By sensory and motor coordination, what I mean is I study why Autistic people might have difficulties with tying up laces or doing the buttons on their shirts. Hand-eye coordination can also be challenging, so that could be like picking up cups and objects and trying to eat with your knife and fork. Others find that they are "clumsy" or fall over more. And then, there's also kind of the task of walking around, some people can be a bit unstable and so I have been researching these areas.

J: Walking and falling over is so me! *both laughs*

E: Yes, so I have been doing my research with three main streams.

The first stream is trying to describe these difficulties more and explore what impact they have on people.

The next one is understanding the mechanism - so why autistic people might have these motor coordination difficulties?

The third area is trying to get more support [for these problems], thinking, you know, "what can we do to support Autistic people with these sensory/motor problems?"

Recently, we have shifted towards a mix between quantitative and qualitative. I think it's really important to get an idea of what people are saying about their experiences, and then that combines nicely with developing the quantitative work. So, in this, we went and did some focus groups and asked Autistic people about their experiences of motor coordination difficulties and how they impacted their lives. From this work, we got four main themes.

E: The *first theme was that motor coordination difficulties affected many different activities,* such as eating and walking around.

Also, as I mentioned, some have difficulties with balance and increased fall rates, so it's across different activities of daily living. The findings were quite variable; they're variable between people and within people. So, yes, for example, they might have better fine motor control but less good with balance. What we got was what we call “the spiky profile”.

A really nice example of this was one participant who said they could fell run, run and cycle, but on flat ground, trying to walk was really difficult. It was quite interesting because I was like, “But you can fell run - that’s really difficult!”. It’s a really weird, spiky profile because even related activities can be done differently within a person.

Another element was that these problems were lifelong problems as well. Even though, for some, there might be no improvement or slight improvement, they stayed throughout life.

The *second theme was that motor coordination was quite an active process in that [Autistic individuals] really needed to concentrate on performing movements.*

So, for lots of people without coordination difficulties, you don't have to think about picking up a cup or anything, but a lot of our participants said that they really had to think about every movement that they were making. It's not automatic for them, and this then leads to a lot of fatigue and tiredness.

The third element was that these coordination difficulties really impacted emotions and social interactions.

Some participants said that their motor coordination problems would annoy people; for example, spilling something on a carpet or running a supermarket trolley into someone by accident. It wouldn't really do very much for the interaction there.

Then there’s the problem with social exclusion because if they knew they were not very good at motor coordination, they would try to avoid the situation; this would all have a big emotional toll on some people.

Some talked about feeling socially outcasted, having very low self-esteem and also being bullied. So, yes, it has a big impact on the social and emotional aspects, too.

Then, *the final thing was the fact that even though most of our participants had motor coordination problems, none of them had received support for them.*
So, consequently, they developed their own strategies to help themselves. This could be just trying to practice lots or having practical strategies, for example, having zips rather than buttons or making sure the room wasn't cluttered so they wouldn't fall over.

But, sometimes, they would just end up avoiding things, and then by avoiding them, Autistic people miss out on opportunities to make friends and socialise. It was interesting that there was quite a link between motor coordination problems and being socially active as well.

J: That's great. That resonates with me as well. As an Autistic person, I am described as "clumsy" a lot, and I skate better than I walk, so there's that.

E: Yeah, that type of stuff is very fascinating to me. This makes me want to talk to more people, like yourselves, about their spiky profiles.

J: It's really interesting. What would you say were the best bits of completing this research?

E: I really enjoyed it. We did it over lockdown. It was just a really nice experience to be talking to the participants during the focus group.

The data was incredibly rich, which meant that there was so much information that they were giving us, and it felt like a real privilege to be there and listen to people because they were incredibly open with what they had to say. It's the first time I've led a qualitative piece of research, so I was learning a lot about how to do the process properly and analyse the data to the right standards. I was working with two masters students who were very good as well, and it was nice meeting up with them and talking through the data and coming up with the themes.

J: So those were the 'best bits'; what were the more challenging parts of this research?

E: This applies to a lot of research, but it's actually, kind of, setting it up. There's a lot of planning and background stuff that goes on. For this, it was to make sure people were comfortable; we ran video 'Zoom' focus groups and chat focus groups where people could just use the chat function. It just took quite a bit of organisation to ensure people knew how to get Zoom because this was during the early days of COVID; there were other tasks like ensuring people were turning up on time and that the focus group was not too small or large. It was just quite a bit of organisation.

J: For the Autistic community, what do you think is the most crucial part that has come out of this research?

E: We published the paper and got some nice social media comments. People were just saying how they resonated with the comments [from the research] and seemed to like that we were highlighting the problems and issues they face. By highlighting this issue, I hope more researchers will realise the importance [of understanding motor coordination in Autistic people].

We also hope funders will start funding more projects around this topic

> ***"EVEN THOUGH 80% OF AUTISTIC ADULTS HAVE SENSORY MOTOR ISSUES, THEY'RE NOT ROUTINELY GIVEN THESE SENSORY-MOTOR ASSESSMENTS ...***
>
> ***WE ARE TRYING TO PROVIDE EVIDENCE THAT DEVELOPING A PATHWAY FOR SENSORY MOTOR SUPPORT IS NEEDED"***

E: For us, the final thing is that it actually has led to us being able to get funding, so we've got some funding from the NIHR (the National Institute for Health and Care Research), and that's going to hopefully directly support Autistic people.

J: Congrats! That's exciting.

E: Yes, and at the moment, when an Autistic adult is diagnosed in the NHS, they don't routinely give a sensory-motor assessment. Even though 80% of Autistic adults have sensory motor issues, they're not routinely given these sensory-motor assessments.

So, for this project, we're working with some occupational therapists, and we're hopefully going to be showing that there's a need for this. We hope that when somebody is diagnosed, they are routinely given a sensory-motor assessment and support. We are trying to provide evidence that developing a pathway for sensory motor support is needed

We're also going to be developing a toolkit for people like occupational therapists to use and see what kind of assessments and support can be useful.
Support can be quite complex, you know, there are lots of different types of support! And it's best to offer support on an individual level.

It will take a lot of years, but the ultimate goal would be to try and create a pathway in the NHS where when Autistic people are diagnosed in the NHS, they are given a sensory-motor assessment.

J: Yeah, I think it's also about making this information a common knowledge as well, isn't it?

When you can get Autistic people to come in and talk about these issues, many are like, “Yeah, that resonates”. It is more common than people think. It would be great if more professionals were aware of this.

E: Interestingly, it came out from our Autistic focus groups that some people hadn't been aware that they had these issues until they were pointed out by others as well, you know, they were not aware that they would always walk over to the left or something *both laugh*. I think it would be helpful to even just raise awareness for this generally.

J: That’s a good point. That research *has* happened, which is great. But also, what are your hopes for future Autism research?

E: It's a big question!

The main thing is that, in general, there's increased involvement and co-production with Autistic people in research. I think it would be nice to try to get to a place where that becomes a bit more regular and normalised. The key barrier is support, so we need to involve some universities and funders.

There is a movement where things are progressing, but to co-produce takes time, and it takes resources because people need paying and it takes time to train people.

At the moment, the way the research cycle is set up is that as an academic, you’re not often recognised for that increased amount of time, and so there isn't so much value put on co-production. The researchers then have to make a choice and end up not doing co-production so, I think, you know, we need structures to change to support academics as well.

And I think the other point I always add is that I believe that to do good research, you do need a mix of people; you need to mix people with different experiences and backgrounds in different skills working together.

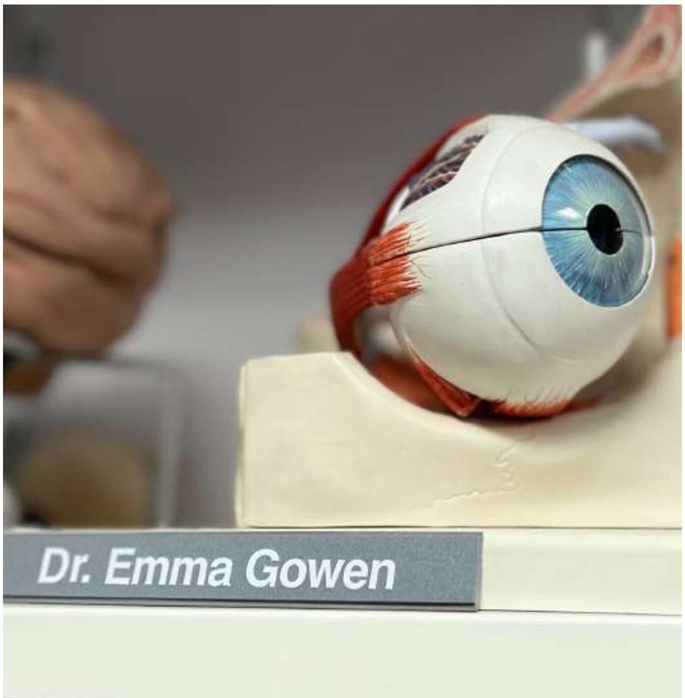
I don't think it works if you have all of the same types of people working on projects - you definitely need to have a mixed group working together.

J: That’s the way to sum it up! Is there anything else you would like to mention or shout out?

E: I think we have covered everything *smiles*

J: Thank you so much for letting me do this today, Emma.

E: Thanks for having me.



With thanks to Dr Emma Gowen for her time.
Photos by Jaja Choktanasiri

READY, STEADY, READ RESEARCH!

There is a constant increase in Autism research and things to read - it can get overwhelming! Lucky you, we've got you covered with some good ones to start with this year.

Reading students graphic by Kiarra from Sketchify Phillipines

Diversity of autistic speech-perception difficulties

Bendo, G. J., Sturrock, A., Hanks, G., Plack, C. J., Gowen, E., & Guest, H. (2024). The diversity of speech-perception difficulties among autistic individuals. Autism & developmental language impairments, 9, 23969415241227074. https://doi.org/10.1177/23969415241227074

Lockdown experiences for families of children with ASD in India

Kaur, A., Lall, G., Abhilashi, M., Naithani, L., Verma, M., Roy, R., Juneja, M., Gulati, S., Taylor, C., Leadbitter, K., Patel, V., Green, J. and Divan, G. (2024). Locked down-locked in: experiences of families of young children with autism spectrum disorders in Delhi, India. Frontiers in Public Health, 12, https://doi.org/10.3389/fpubh.2024.1294538

Eye examination anxiety in Autistic adults

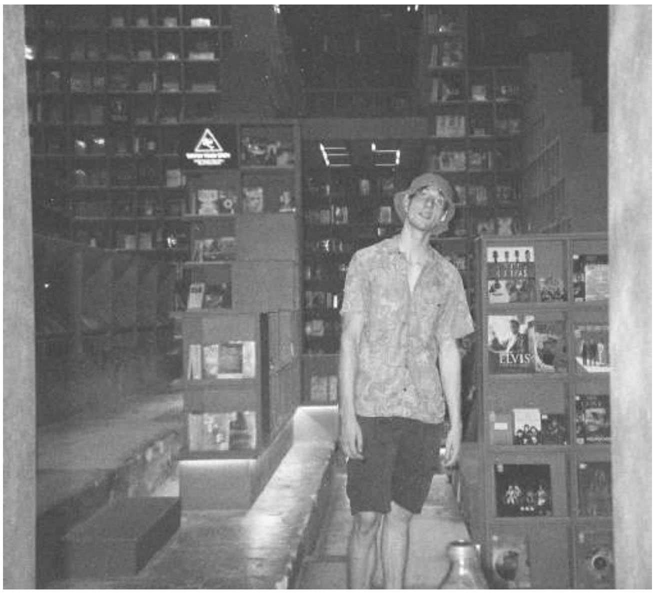
Parmar, K. R., Porter, C. S., Dickinson, C. M., & Gowen, E. (2023). Investigating eye examination-related anxiety in autistic adults. Clinical & experimental optometry, 106(5), 544–550. https://doi.org/10.1080/08164622.2022.2065189

Autistic adults' experiences of motor coordination

Gowen, E., Earley, L., Waheed, A., & Poliakoff, E. (2023). From "one big clumsy mess" to "a fundamental part of my character." Autistic adults' experiences of motor coordination. PloS one, 18(6), e0286753. https://doi.org/10.1371/journal.pone.0286753. See Emma's interview

More blogs, papers and featured project can also be found on **autism.manchester.ac.uk**

FREDDIE JONES:
ABOUT BEING A NEURODIVERGENT PHD-ER AND HIS AUTISM RESEARCH



Freddie graduated from the University of Manchester in Educational Psychology and is now a PhD researcher at the same university. Jaja, our co-production officer, interviews Freddie about his experiences of beginning a PhD, and also, about his own experiences of being neurodivergent.

J: I'm here with Freddie, and obviously, we met through a module that we both took last year. Now, Freddie is actually doing his PhD, so maybe for those who do not know you, can you please introduce yourself?

F: I'm Freddie. I'm currently a PhD student at the University of Manchester. I did my undergrad (degree) here as well in Educational Psychology, which is where we met. You weren't doing Educational Psychology, though, it's weird, but yeah. I just kind of fell in love with Manchester, so when I wanted to pursue a PhD, I was like, I might just still do it here, so yes, that's me. It's my only defining feature, I do PhDs *laughs*

J: Yeah, so, I think before we get to the more technical side of this interview, I think it'd be good for the readers to know you a bit better, so the question is: if you could meet one famous person dead or alive who would it be and why?

F: Actually, my answer to this changed this morning. I was going to say James Acaster because I want to meet him, he is a funny man but, unfortunately, I don't know if you've seen the news but, this morning, it broke that Benjamin Zephaniah died last night at the age of 65. That man is genuine - he is a Dyslexic decolonial author - and was just a heavyweight in the literary world. So yes, he is no longer with us, but I would absolutely love to meet that man. I guess because it's anyone dead or alive. He rejected an OBE, do you know how cool that is?

**J: Yeah, that's cool. Let's get into your PhD though, which is what we're here to do. So, if you were to describe your PhD to a random person on the street -
how would you describe your PhD?**

F: Yes, I quite often do this on a night out. I just like pulling people aside and start talking about my PhD *both laugh*

F: In general, my PhD focuses on the experience of pre-verbal children with Autism, so that is, Autistic people who haven't yet developed the ability to use language as you know those “neurotypicals” do. Oh yeah, I should probably mention I'm neurodiverse - that was something I was going to answer in the first question.

So yes, [the PhD] is going to be using really novel interview techniques to interview that community personally. Typically, proxy informants are used so, like, their parents or teachers, and that doesn't really represent what [Autistic children] actually experience and/or feel. So, the whole point is that rather than me having ownership over the research, it is going to kind of be “their thing” and I'm just asking them questions and being the surrogate to get it out there and raise awareness for their experience and the challenges they face.

J: That's cool. Just out of curiosity, how young are we talking about - about these participants?

F: Currently, we are going through the ethical fight to see how low (in age) we can go. I am going to have to video record [the participants] because they are going to be signing to me most of the time, and there's obviously a lot of red tape around that. We're looking between the ages of about 10 and 16, leaning towards the 16 side.

It's a hefty load of paperwork I am going to do, but it will be interesting nonetheless because their experiences will be valuable regardless of age. For me, I think, almost, a retrospective look back on how you experienced education, as a neurodivergent person myself, will be really interesting to explore. I'm excited.

J: Oh, I'm excited for you too, and it's very interesting for me because I'm also from the Education field.

J: You kind of already covered this, but, what drew you to research in this field, like around Autism?

F: There are both personal and professional factors that drew me to this. Obviously, on the personal side, I am neurodiverse, and I want to represent my community; the metaphorical voice of preverbal children with Autism was just not represented in research at all. So, I was like, that's a community that needs to be heard, so I'm gonna do a thing.

Similarly, there were professional things, so I've worked with children with Autism for four years, and unfortunately, last year, funding was pulled from the charity that I worked for. This means the charity is coming to an end this year, so I had the motivation to make sure that their views were represented and to try and prevent future things like this from happening. It's just awful that funders with a lot of money can decide, kind of, in a removed fashion to withdraw funding from vulnerable individuals who really need support and, now, have literally nowhere to go.

J: Yeah, that's a good, comprehensive answer, I would say. The next question we have here is: what have been the most rewarding and challenging parts of completing a PhD, like the worst and the best bits?

F: The Good, The Bad and The Ugly.

The Bad and The Ugly has really been all the prep. I thought it would be the more enjoyable parts, like, you know, the main character sat in the library reading, but oh no, it was not like that. I have been doing a literature review, and once you've read about 800 papers that you need to read, you are kind of done. I would say those have been the real challenging bits. Again, as someone who is Dyslexic, reading is not one of the top tiers of activities I enjoy.

Still, I guess because I'm Dyslexic, I am more practically-minded, so, weirdly, the writing has come naturally to me as a really enjoyable part, and so has the data analysis. Sure, reading has been awful, but synthesising [the reading] has been so cool. Getting to design a methodology and piloting it has been exciting as well. I'd say the more practical things I enjoyed - and the reading stuff, I have not enjoyed.

J: That's fair. What would you say is the ultimate goal of this research? What impact would you like it to have?

F: Impact, yes - hopefully, if I play my cards right with groups like Autism@Manchester, we will use the experiences of preverbal Autistic children to inform future educational interventions for this group. Currently, educational interventions for Autistic learners are mainly focused on the assumption that everyone can access language and then, from there, we can just build up skills; it doesn't really acknowledge what do we do if someone can't communicate with us clearly in the first place?
How do we know when, say, we're using ABA protocols, and it's too much for them? We don't listen to them enough, so hopefully, from interviews, we are going to formulate interventions, and then that's going to be what is disseminated after the research is finished. So yeah, that's the ultimate aim, but it is a long, long way away.

J: I guess it's all about displaying the range of presentation of Autism, isn't it?

F: Exactly, of course. One hundred per cent.

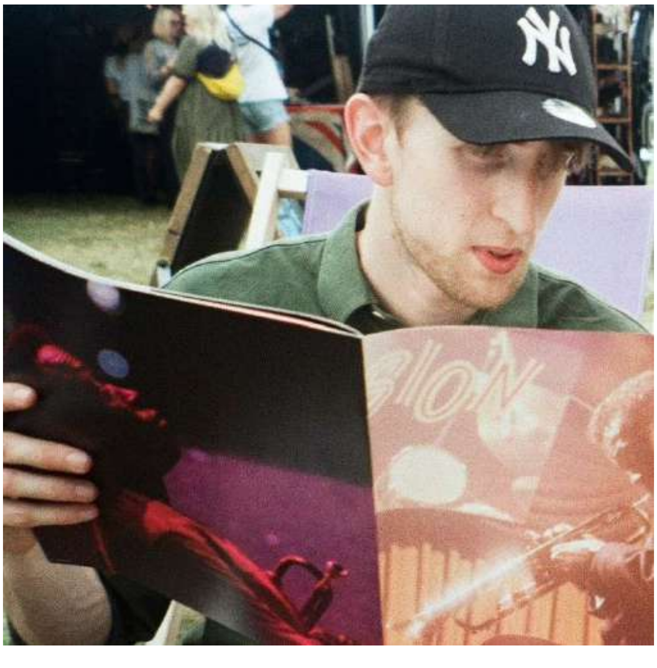
J: Okay, PhD aside, what is your ultimate goal in life? Or a unique goal that not many people know?

F: Right, so this is something that only a few will know, maybe if they have given me enough to drink *laughs*, but I want to build a climbing gym for neurodivergent individuals. For me, to do research with them, too. Maybe if I could put EEGs on Dyspraxic climbers' heads or even study proprioception in Autistic people when they're climbing or look at how ADHD symptoms can be mitigated by climbing; also, it's got to have a a café! I've already started the menu *both laugh*. That's the ultimate goal.
Is it bonkers? One hundred per cent, but that's why it's the ultimate goal. And will I tell everyone about it when I have a chance? Yeah.

J: I actually have always wanted a space for neurodivergent people, like a safe space, and it's a plus that you are putting the sports [element] into it as well. I imagine that a lot of Autistic people enjoy that kind of proprioceptive input as well.

F: Imagine a foam pit, a quiet room and a sensory room - it would be perfect.

J: I will be visiting!



J: Okay, but one last thing for our readers, what advice would you give students thinking about doing a PhD?

F: I think - two things.
First, make sure when you start, even if it's just applying for a PhD, that you have a really clear image of what you want your outcome to be. This is not necessarily like your methods, and whatever, but at least, an outcome. And that's because, trying to find a supervisor is a really key part of the process. If you don't really know where you're going with your PhD, you can't really find the right supervisor for you.

That's the second really important thing. Ensuring that you find the right supervisors for you. For example, I was also offered a place at Cambridge, and I turned it down because the people were not my type of people. They were all about quantifying Autism and looking at it through a very reductionist lens, and I just don't agree with that philosophical position, so, I'm sorry, but I am going to say "no". It's about knowing when to say "no".
Setting your boundaries and choosing a supervisor that gets you is important because four years is a long time.

So yeah, 1.) making sure that you have a clear image of what you want to do and 2.) choosing a supervisor who is right for you.

J: Yes, of course, because you will be working closely with your supervisor, you have to align.

F: And working very closely too. I literally have a desk that adjoins my supervisor's *smiles*

J: That's cool. Anyone you would like to shout out, then?

F: We can shout out Pam (Pamela Qualter). Honestly, she came to me with the offer of the PhD first, and as someone who is neurodiverse and was told that mainstream education is not for them, having someone tell you that you would be good for a PhD, you just go "are you sure?" "are you mad?" "have you had enough sleep?" *both laughs*.

Shout out to my whole supervisor team.
To Rai Fayette, who is an educational psychologist in Autism and also specialises in Autism.

Then, there's Caroline Bond - that's the only Bond better than James - and she also specialises in Autism. The three of them have really given me the confidence to do this.

J: Thank you for letting us interview you and sharing your experience Freddie!

F: Thank you, I enjoyed this.

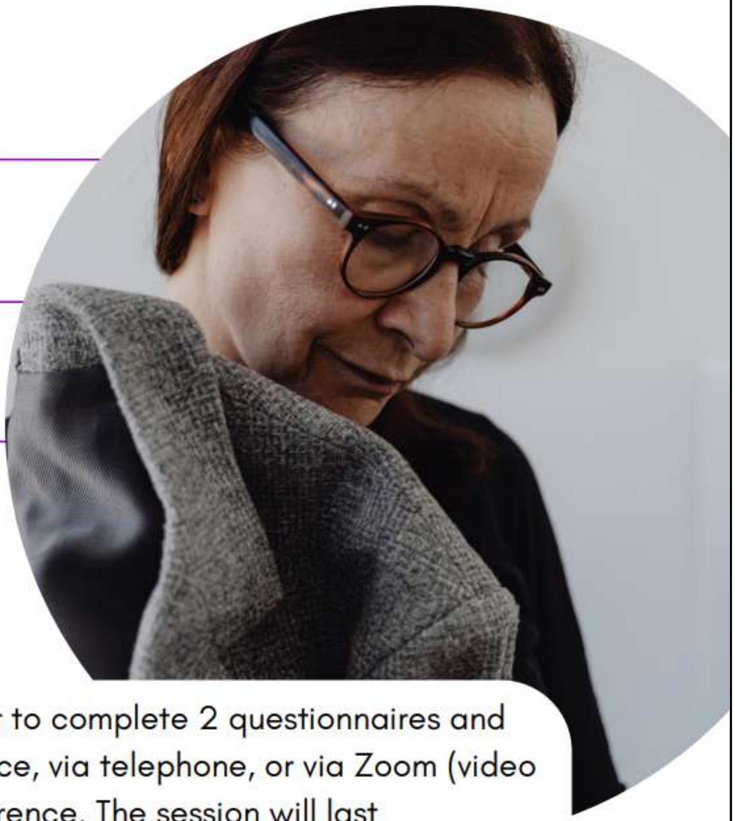
Photo 1, 2 provided by Freddie Jones; Photo 3 by Jaja Choktanasiri

Version 2: 26/11/23

Research Study Opportunity

Researchers At The University of Manchester Seek Volunteers To Take Part In Research Into **Autistic Adults' Experiences of Bereavement, Grief, and Related Support**

ARE YOU:



1. **Age 18 or over?**
   Autistic?
2. **Able to express yourself well in verbal and / or written English?**
3. **Have experienced the death of someone important to you as an adult, more than 6 months ago, whilst living in the UK?**

The study involves meeting with a researcher to complete 2 questionnaires and an interview. This can take place face-to-face, via telephone, or via Zoom (video chat, or text chat) depending on your preference. The session will last approximately 2 hours and you will receive a small reimbursement for your time.

The researchers have obtained advice from the Autism@Manchester expert by experience group during the design of this study and have involved autistic people at all stages of the research project.

If you are interested in taking part, please contact:
callum.rodgers@postgrad.manchester.ac.uk

This project has been reviewed and approved by the University of Manchester Research Ethics Committee.
Project no 2023-17711-32300

AGEING WITH AUTISM:
HOW DO AUTISTIC PEOPLE EXPERIENCE AGING?

Photo by Tatiana Saavedra, Diversifylens
Elderly lady graphic by Sketchify

Our recent interview-based study revealed important insights into the ways that middle to older Autistic adults experience ageing. Seventeen autistic adults (ten women and seven men), aged from 46 to 72 years, participated in the study. A key finding was that current age-related services were generally not considered suitable for autistic adults and that they require adaptations to improve their accessibility.

The participants in our study described a number of ways that their autistic characteristics interacted with other age-related conditions and experiences, such as menopause. They also felt they were more likely than their non-autistic peers to experience age-related diseases, such as Dementia and Parkinson's, although they lacked clear knowledge about this risk. Some participants described how they didn't have access to older autistic role models who could help them understand their own age-related experiences. Participants also felt that some of their autistic characteristics made it difficult to engage in healthy behaviours, such as exercising regularly and eating well.

Participants also felt that some of their autistic characteristics and experiences were changing with age. For instance, some participants felt they were becoming more sensitive to sensory input. Others experienced changes in their ability to mask their autistic characteristics, with some feeling more skilled at this with age and others feeling a reduction in the energy needed to do this. Several participants also reported concerns about how they would cope if key family members, such as parents, died and left them without support. They also worried about not being able to cope with new caring roles themselves and felt at increased risk of becoming socially isolated as they got older.

Participants described several reasons why it could be more difficult for them to access age-related support. This included feeling vulnerable because of previous negative experiences with services and finding it difficult to navigate services due to inertia and difficulties with planning.

Participants also explained how lots of services were incompatible with their autistic characteristics. For instance, participants described the difficulties of sitting in noisy GP surgeries and dreading the social and sensory-stimulating nature of care homes and leisure options commonly offered to older adults. They also reported that professionals within services often lacked accurate knowledge or experience of autism and may misinterpret their behaviour as being rude or deliberately awkward. In general, services were felt not to be designed with autistic people's needs in mind. This was considered to be more problematic as autistic people aged due to the likely increased need for services. Participants hoped for clearer research and ageing services that better understood the links between autism and ageing.

The study has highlighted several recommendations for improving services to support autistic people as they age. Participants wanted support to be tailored to their specific ageing autistic characteristics and to be easier to navigate. In essence, participants wanted support that helped develop autonomy, focused on individual strengths, and that was designed with the input of autistic people. A hub-based model was also proposed, involving flexible and responsive peer and specialist support roles that could help autistic people access appropriate services.

These findings are important as they reveal that autistic people have specific age-related strengths and needs and show that current ageing support is not tailored to the needs of autistic adults. This research emphasises ideas for change to ensure autistic adults can access appropriate ageing support to hopefully achieve improved outcomes in later life. By adapting ageing support for autistic people, people are better able to reach their potential and live better lives.

This research was completed as part of a clinical doctorate thesis project at the University of Manchester.

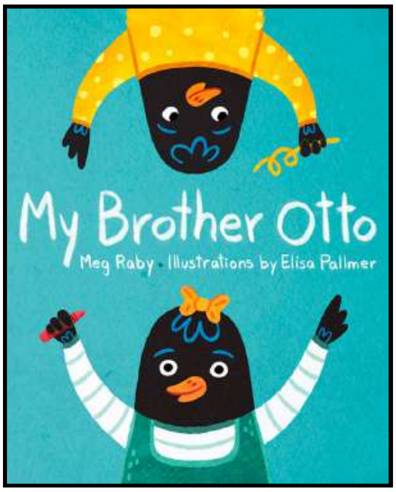
A pre-print version of the findings is available from: https://doi.org/10.31234/osf.io/zw92a .

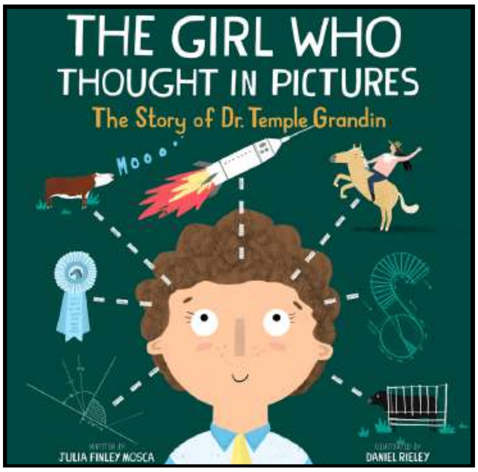
The researchers were Dr Rebecca Aitken, Dr Emma Gowen, Dr Laura Brown and Professor Katherine Berry. For more information, please contact: emma.gowen@manchester.ac.uk.

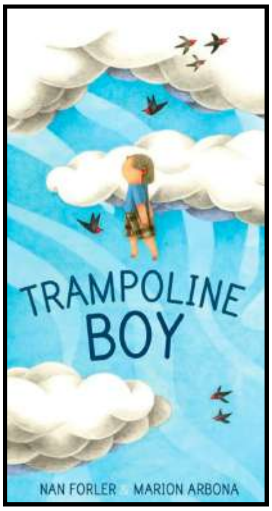
ARE YOU ALL ‘BOOKED’ UP FOR 2024?

Introducing the topic of Autism shouldn’t always have to be complex. There are books for readers of all ages and abilities, here are just some to get you started:

CHILDREN’S

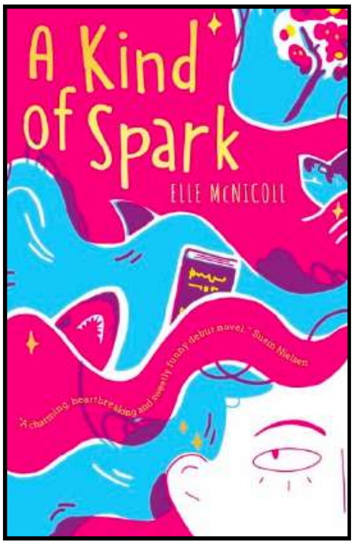


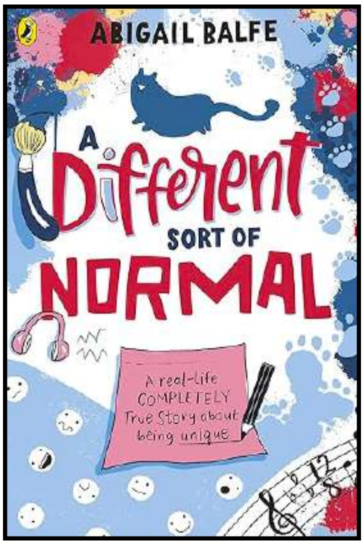


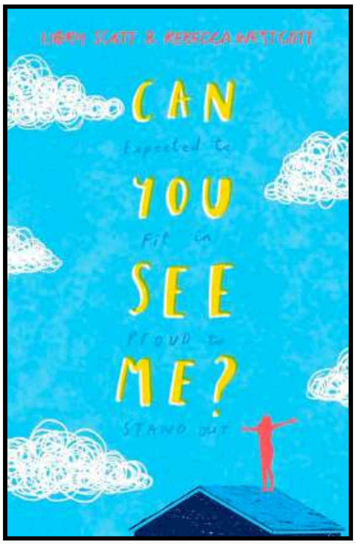


https://www.pbssocal.org/education/families/from-awareness-to-acceptance-10-childrens-books-that-accurately-portray-what-it-is-to-be-autistic

YOUNG READERS’







GENERAL NON-FICTION

- Untypical, Pete Wharmby
- Odd Girl Out, Laura James
- Different Not Less, Chloé Hayden
- Amelia and Me, Heather Stemp
- The Reason I Jump, Naoki Higashida
- Fall Down 7 Times, Get Up 8, Naoki Higashida

Ambitious about Autism

The Autism Transition to Adulthood Group (ATAG) study

In partnership with Ambitious about Autism's peer support course for autistic young people aged 16-25, **Understanding You, Discovering You**

We want to include all autistic young people.
We encourage you to contact us, even if you don't know much about autism or feel nervous about taking part.

UNIVERSITY OF BATH
UNIVERSITY of York
National Autistic Society
UCL

FOR MORE INFORMATION ABOUT
AUTISM@MANCHESTER,
autism.manchester.ac.uk