

Newsletter

10 Year Anniversary Special
Spring 2025

Editorial

Welcome to this special issue of Autism@Manchester's newsletter celebrating over a decade of autism research and co-production. Autism@Manchester works with autistic people in the Manchester area and beyond to inform research projects at every stage, to ensure that research is relevant and meaningful to the people involved.

In this issue, we look back at how Autism@Manchester began and key milestones along the way. We share 'birthday' messages from our friends and colleagues, reflecting on how we work together. We meet one of A@M's PhD students, Divya Gosain, who explains her work with caregivers of autistic children in India. There's also a special celebration of Amanada Haydock-White's contribution to the autistic community written by Kathy Leadbitter.

Research for and with parents and carers is a sub-theme across this issue. Colleagues in Stockport share reflections of their first year delivering iBASIS, supporting families of neurodivergent babies (pre-diagnosis) using a needs-led approach. We also feature an excerpt from a newsletter about the University of Manchester's REACH ASD project, which developed and trialled the 'Empower-Autism' course for parents and carers. Lastly, you can find calls for volunteers to support our latest projects on the Easy Eyecare Pathway, and research on autistic experiences of mindfulness.

You can find more news on our website and blog: <http://www.autism.manchester.ac.uk/>
<https://sites.manchester.ac.uk/autism-at-manchester/>

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I am currently working as the group's autistic co-production officer, and it has been a pleasure getting to know the growing network of autistic experts by experience, colleagues working in every nook and cranny of the University of Manchester exploring different facets of autism, and the lovely team at Autism@Manchester. I hope you enjoy finding out more! - Erin Beeston



A brief history of Autism@Manchester

Dr Emma Gowen developed the idea for A@M in 2014, taking inspiration from Elizabeth Pellicano's research that highlighted that autism researchers were not involving autistic people in research. The first steps towards establishing A@M began with University of Manchester Research Institute (UMRI) pump prime funding, this gave Emma opportunities to build the network.

Building Bridges, the first major project funded by Wellcome, aimed to increase involvement of autistic community in the lifecycle of research and produced guidelines for delivering this. Findings from Building Bridges and relationships developed with the local autistic community became a springboard for our regular Autism by Experience lived-experience group, and later the Co-producer position with the A@M team.

Public and Patient Involvement and Engagement (PPIE for short!) is central to the ethos of Autism@Manchester, from projects in the Body Eyes and Movement (BEAM) Lab to research into autistic experiences of aging, people are involved throughout the research cycle. This is not without challenges; A@M researchers seek to continually improve practices around including people in research and communicating our research.

Currently, A@M researchers and colleagues working in health and social care are developing a grant application to tackle health inequalities. A key output from this current UMRI pump prime funded project is a toolkit of resources to help autistic people learn about and get involved in research. We're delighted to share that we've received support from the NIHR to evaluate this, and we will be seeking feedback on the toolkit from autistic people in the autumn.

Links for the projects discussed:

The Building Bridge Project

<http://www.autism.manchester.ac.uk/research/projects/building-bridges/>

Guidelines for conducting research with the autistic community

<http://www.autism.manchester.ac.uk/research/projects/research-guidelines/>

BEAM Lab's blog

<https://blogs.manchester.ac.uk/beamlab/>

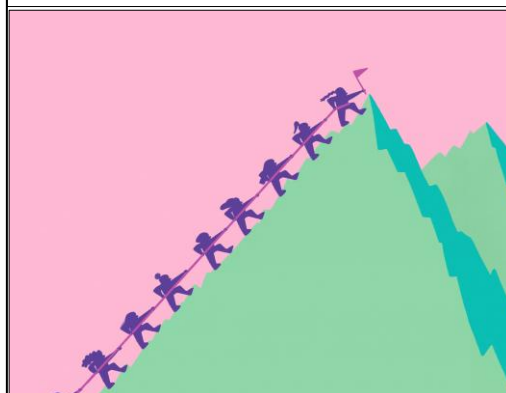


Our founder, Dr Emma Gowen photographed at an Autism@Manchester event

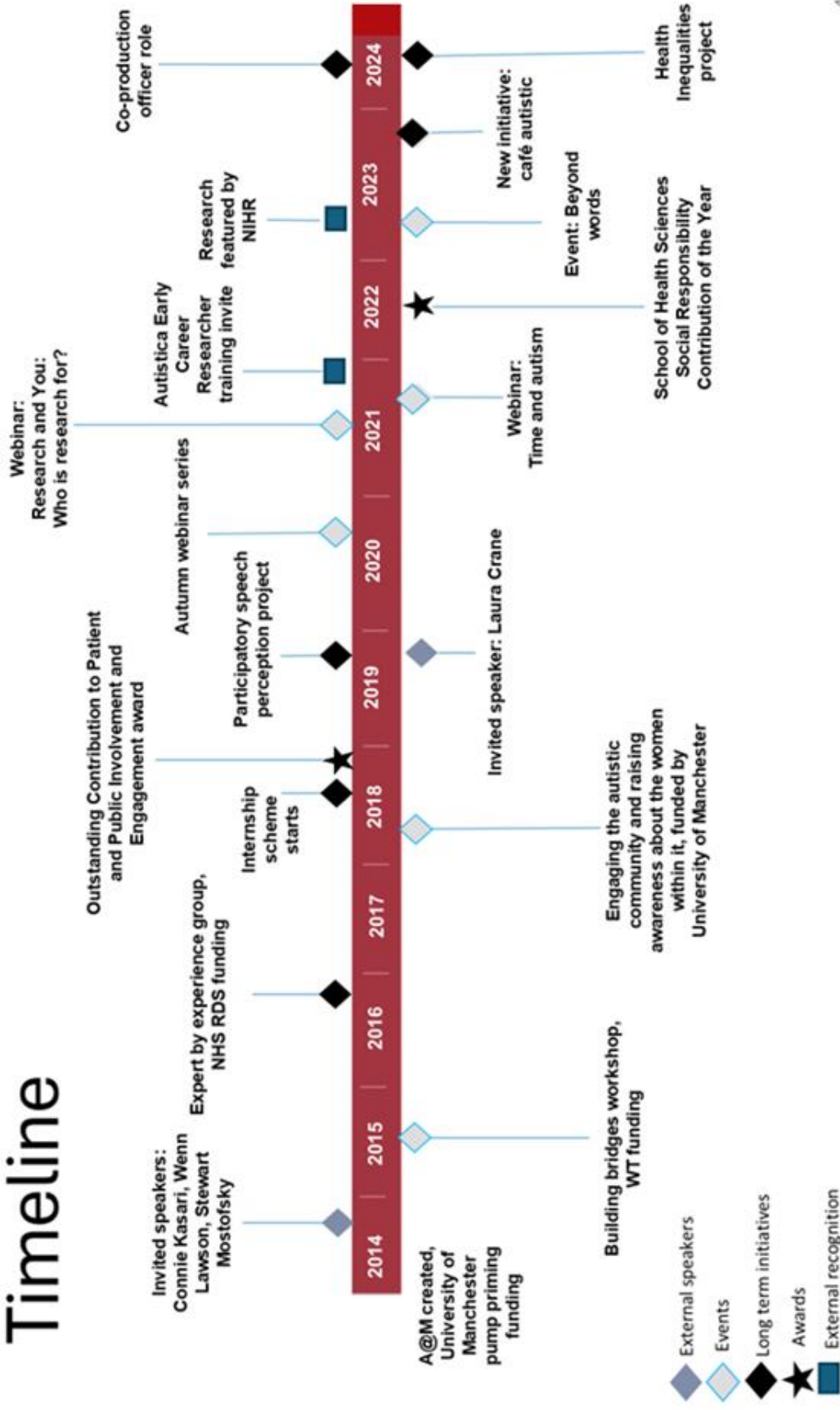


Emma would like to thank some key people who have been involved in contributing to events and activities over the years:

Daniel Poole, Kathy Leadbitter, Alex Sturrock, Katie Twomey, Lisa Miles, Peter Baimbridge, Hannah Guest, George Bendo, Ellen Poliakoff, Jaja Choktanasir, Kelly Birtwell, Elizaveta Nosova & members of the expert by experience group



Timeline



News

Kelly Birtwell will be giving the following online talk for Cheetah House on 8th April, 6.00-7.30pm:

Does mindfulness suit all kinds of minds? An exploration of neurodiversity and the evidence on mindfulness for autistic adults.

Cheetah House is a US organisation led by Dr Willoughby Britton (Brown University), that supports people who have had adverse experiences from mindfulness and meditation. Kelly will be speaking about what neurodiversity means, the research evidence on mindfulness for autistic adults including her own recent qualitative research, and adaptations that can make mindfulness courses more accessible for autistic adults.

Cheetah House charge a fee (on a sliding scale) for their talks, which provides valuable support for the work they do. Talks are recorded and made available on their website along with other training. To find out more and book a place, see here: <https://www.cheetahhouse.org/upcoming-lectures>

Kelly Birtwell, Christine Rowland, Claire Planner and team have started work on a project about autistic people's experiences of dance: **The Ada study (Access to Dance for Autistic adults)**.

The aim of the project is to understand how autistic adults experience dance in different settings (e.g. at home in, in a social environment like a nightclub, or in an organised class), and why people might choose not to dance. The findings will be used to create resources to support autistic people to dance; to support link workers to make referrals to dance; and for dance teachers and organisations to be more aware of the needs of autistic people. This could help to support the health and wellbeing of autistic adults in the future. The resources will include written materials and short films. The first part of the project will be an online survey for autistic adults aged 18+ and living in the UK.

This will be available in the next couple of months. You can find out more about the project here: <https://www.spcr.nihr.ac.uk/research/three-research-schools-mental-health-programme>

Ketan Parmer has recently begun a 9 month project asking: **Is the “Easy Eyecare Pathway” autism-informed?**

The Easy Eyecare Pathway is available in South East London, North West England and Durham. It aims to provide accessible eye tests for autistic people in community and is delivered by accredited eyecare clinicians. Ketan would like to interview autistic people who have had an Easy Eyecare Pathway eye test to understand their experiences, and if the pathway is autism-informed.

Contact ketan.parmar@manchester.ac.uk for more information (and see posted on page 17)

Talks

Emma Gowen recently gave a talk for the School of Health Sciences on 'Co-production in autism research: Examples from Autism@Manchester'

you can see this online here:

<http://www.autism.manchester.ac.uk/connect/events/previous-events-speakers/>

New Publications

"Our Existence as Whole Individuals Does Not Evaporate at Age 50": A Mixed Methods Study of Autistic Adults' Perspectives on Growing Older

Authors: Kelly Birtwell, Donna Bramwell, Emma Gowen, Laura J.E. Brown, Lucy Hulme, Emily Corsellis, and Christine Rowland

Publication: *Autism in Adulthood*, Published Online: 12 February 2025

<https://doi.org/10.1089/aut.2024.0028>

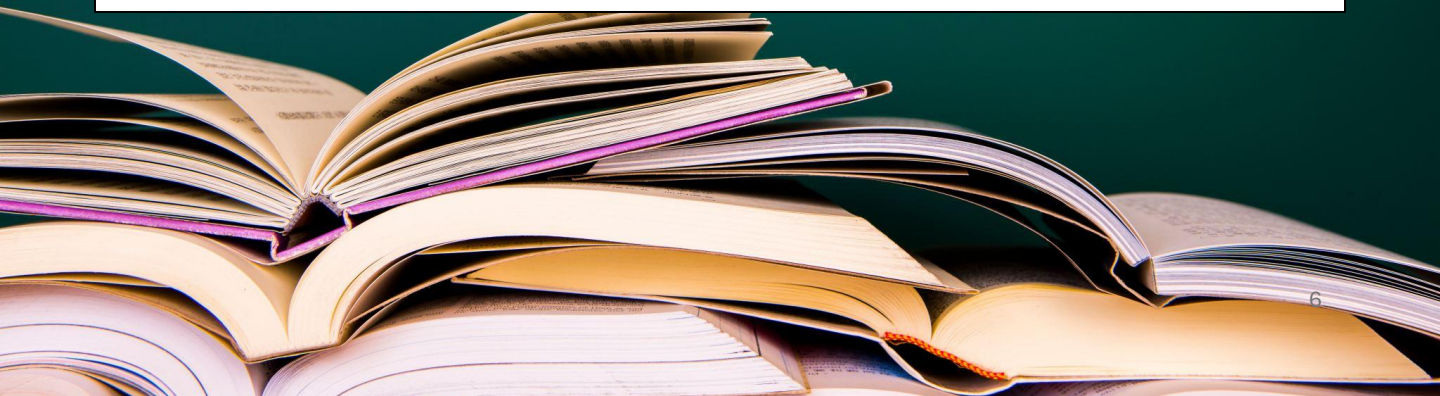
If you would like a copy, please email Kelly.birtwell@manchester.ac.uk

'Clinical effectiveness of an online psychoeducational and psychotherapeutic programme for caregivers of children newly diagnosed as autistic: a parallel, assessor-masked, randomised controlled trial in the UK (REACH-ASD)'

Authors: Kathy Leadbitter, et al.

Publication: *The Lancet Psychiatry*, Volume 12, Issue 4, 289 – 302

[https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366\(25\)00036-7/fulltext](https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(25)00036-7/fulltext) **Open Access**



Happy 10th Birthday A@M!

We asked our friends and colleagues to share their thoughts about Autism@Manchester

I would like to extend a very big "thank you" to Autism@Manchester. The group has supported me since the beginning of my PhD and continues to do so. I really enjoy coming along to the Expert by Experience Group meetings and am very grateful for all your help!

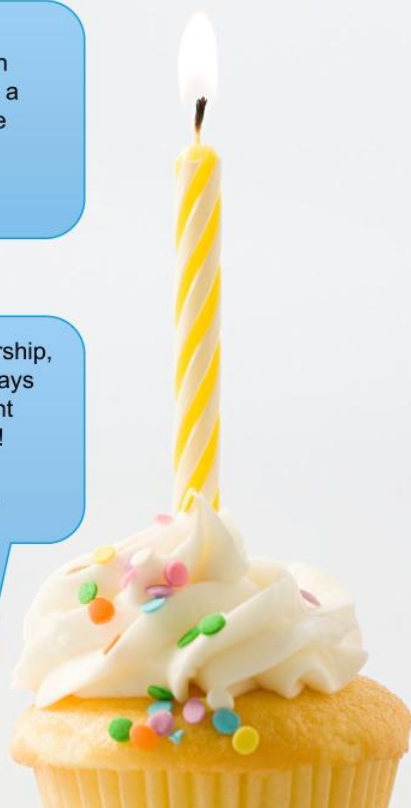
Ketan Parmar

It's made me feel part of an important group that makes a difference to autistic people

Rosalyn Paterson

You demonstrate ethical leadership, and this is absolutely not always evidenced in neurodivergent research. All power to you!

Shirley Woods-Gallagher



I am very grateful for the opportunity to have worked as a co-production officer and meet world-class researchers. Not only have I gained and shared skills, I have also made lifelong connections in the field of autism, which is something I care deeply about.

All the best wishes for the next decades to come!

Jaja Choktanasiri

I have met so many amazing people through Autism@Manchester. It is these connections, and the experiences people share that keep me fired up about autism research and grounded in the issues that really matter. The highlights for me over the years have been the events – they always have an inclusive and welcoming vibe, and I come away feeling energised and inspired. Thanks to Emma for all her leadership over the past 10 years and to all the Autism@Manchester crew for being just so Au-fully Au-some!

Kathy Leadbitter

Mixing and working with the academics and other Experts by Experience at Autism@Manchester has helped me nuance my understanding and perceptions of autism, the experience other individuals may have of their own condition and how I might better support those who come to me for assistance. I hope my observations and discussions have helped others in a similar way

Peter Baimbridge

I stumbled across autism@manchester in my search for information when my son was diagnosed with autism in 2014, so we started our journeys at the same sort of time. It was fantastic to find autism@manchester where I feel the research teams are engaged with and keen to involve the autistic community at every stage of the research.

Meeting members of the community, discussing and hearing experiences has provided me with invaluable insights into my son, helping me to advocate and support, so the world can see the brilliance we see in him.

Lisa Miles

My involvement in the group at an early career stage has shaped my career as a researcher.

On the Building Bridges project, I engaged in co-production and participatory research when these ideas were first gaining traction. I've gained better understanding of experiences and becoming aware of autistic culture transformed my understanding of autism and human diversity. A@M is a rare insight into how we can work together across disciplines, practices, and understandings to do good work

Dan Poole

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Supporting Caregivers of Autistic children in India

by Divya Gosain

PhD student, Autism@Manchester

Caring for an autistic child can often come with unique challenges, particularly in low-resource settings like India. As a PhD student at the University of Manchester, my research focuses on supporting the emotional and mental health needs of caregivers in India- an often-overlooked aspect of autism care. I had the opportunity to spend three months in Manchester last year. This experience was both insightful and inspiring, allowing me to connect with researchers dedicated to strengthening autism support in Manchester.



Photograph of Divya sharing her research

Consistent with the research in the UK, studies in India also show that for many caregivers, receiving an autism diagnosis for their child can be an overwhelming experience. They go through a range of emotions- confusion, sadness, guilt and denial to sometimes even a deep sense of fortitude and purpose. Beyond emotional struggles, families also face some practical challenges. Reliable information is scarce, trained specialists are few, and navigating multiple appointments with long waiting times can be exhausting. Negative attitude in society towards autism further isolates caregivers, leading to increased stress.

Research shows that caregiver’s wellbeing directly impacts their child’s development and overall family wellbeing. However, most autism interventions focus only on the child, with little attention to the parent’s emotional resilience. Stress and burnout can lead to disengagement from therapy, making it difficult for caregivers to fully support their child.

Recently, Acceptance and Commitment Therapy (ACT) has emerged as a promising approach to addressing caregiver wellbeing. ACT helps individuals manage difficult emotions while focusing on actions that align with their personal strengths and values.



Photograph of Divya (right) with non-specialist health workers working with NAMASTE

My research aims to develop an ACT-based intervention tailored for caregivers in India. I plan to use a participatory approach, ensuring that caregivers themselves shape the intervention, including its content, mode of delivery, and accessibility.

My PhD is part of NAMASTE, a larger research programme being implemented across India, Sri Lanka, and Nepal. NAMASTE aims to improve access to autism care by training non-specialist community workers to screen for developmental disabilities and provide early interventions. In regions where professional services are limited, this approach ensures more families receive the support they need.

While caregivers of autistic children face challenges worldwide, families in low- and middle-income countries face additional cultural and financial barriers. Many autism interventions have been developed in high-income western countries, where social structures, cultural beliefs and healthcare systems differ significantly. In South-Asia, autism awareness remains low, and outdated beliefs such as blaming mothers for their child's autism, attributing developmental disabilities to bad karma, or assuming boys naturally speak later than girls still persists.

A celebration of Amanda Haydock-Wright and all she gave to the autism community

By Kathy Leadbitter (University of Manchester)



I first met Amanda in April 2019 in 'Milk and Honey', a veggie café on the University of Manchester campus. My research at the University focuses on early supports for autistic children and I became aware of Amanda's work initially through Facebook. She was running a specialist support service for young autistic children from her home in Irlam, called the Rainbow Project. I was in awe of Amanda from the moment we met. She was so knowledgeable and passionate about therapeutic approaches for autistic children. The Rainbow Project was fantastic both in its innovation – I've never heard anything like it before or since – but also in its values of radical acceptance, autism-positivity, respect, and fun.

We would meet intermittently from then on, often in cafes around Chorlton with tea and cake. Amanda had completed a Masters in Autism in Children at the University of Birmingham and I would try to persuade her to come and do a PhD with me at the University. She would have been brilliant, such an original and astute thinker, but she was adamant this wasn't the right path for her, and I eventually had to stop mithering her about it.

A celebration of Amanda Haydock-Wright and all she gave to the autism community

Amanda went on to complete training in Paediatric Autism Communication Therapy (PACT), a therapy that supports parents to communicate in a respectful and attuned way with their autistic children. Our team at the University of Manchester have done a lot of research into PACT and I was delighted that Amanda was adopting and spearheading this approach. Amanda was trained and supervised by my colleagues Louisa Harrison and Hannah Danvers who saw her wide range of talents immediately. She was compassionate, articulate and would always quickly and accurately get to the heart of any matter.

Amanda then founded a community interest company called Spectrum Connection and was awarded National Lottery funding to offer free PACT therapy to Manchester families on a low income. This was classic Amanda: committed to making the therapy accessible to all who needed and wanted it. She also initiated a piece of work with other PACT therapists to make the approach as neurodiversity-affirming as possible. Her ideas for doing this were dynamic, smart and insightful, both in a theoretical sense but also in their relevance to – and respect for – autistic people and their families.

Amanda, perhaps thanks to her being autistic, never had a half-baked interest. She became an expert in any topic she was interested in, and, because of this, I learnt so much from her. One such topic was gestalt language development - how some autistic children learn to talk by copying chunks of language they have heard. We wrote a journal article together, with colleagues Louisa Harrison and Katy Baldwin, about embracing gestalt language development as part of neurodiversity-affirmative practice.

Read it online here: <https://journals.sagepub.com/doi/10.1177/13623613241234598>

This article has promoted a lot of conversation around how professionals and parents can best support their autistic children to communicate in ways that are both effective and authentic.

Amanda became a wonderful friend and a true comrade in the struggle to make the world a better place for autistic people. We had many a grand plan. Amanda was a blend of confident authority, absolute integrity, and a human fragility which made working with her a beautiful and unique experience. She was incredibly perceptive and her frank responses to people - and observations of people - were both refreshing and often hilarious.

My colleagues and I are devastated that Amanda passed away in February 2025. Her flame will burn bright and long. Her knowledge, values and fiery drive for change will live on through the many people whose lives she touched. We are committed to keeping Amanda's legacy alive through our work and turning some of her brilliant ideas into reality.

Parent focus group favours early neurodevelopmental pathway for under 2s

by Susanna Vosper, Liz McNeillie & Emily Hoare, members of IBASIS therapy team



A neurodevelopmental pathway for under twos that launched last year in Stockport is celebrating its one-year anniversary. The pathway is now being piloted in Bury. The pathway is designed to support families of neurodivergent babies and toddlers pre-diagnosis, using a needs-led approach. It was developed in recognition that the first two years of life are a critical stage in both brain and early communication development, as well as for child and parent/carer bonding.

Under the pathway, the babies are identified by health visitors and early year workers using an observational tool called SACS-R, currently referred to as MoSAIC (Monitoring of Social Attention Interaction and Communication). Families are then offered an early communication programme individually tailored to their child's communication style called iBASIS, delivered by a specialist team.

iBASIS supports parents to better understand their babies through video feedback and shared discussion with the iBASIS practitioner, usually offered in their own home. The evidence-base shows that babies become stronger communicators when parents and carers find it easier to recognise, understand and respond to their baby's communication signals. These changes last across time (Green et al, 2017), (Whitehouse et al, 2019).

Following the programme, children presenting as neurodivergent join the neurodevelopmental pathway accessing multi-disciplinary support and access to assessment services, where appropriate.

Our team carried out focus group sessions with five parents of neurodivergent children, some of whom identified as neurodivergent themselves. Their previous healthcare experiences and their views of the new pathway were discussed, most of these parents had not experienced the new pathway themselves. Their input was sought to co-produce and influence the design and delivery of the pathway. All parent and carers' names have been changed.

Views of parents who have experienced the new neurodevelopmental pathway
In a different coproduction meeting, the views and experiences of 5 parents with neurodivergent infants who had experienced the new pathway and iBASIS programme were also gathered. These parents felt it was helpful to have support before age 2 rather than spending this time waiting for support.

“It’s lots of early intervention at an earlier age. As parents it helps instead of worrying, it puts you in a better place having help.”

One parent compared the experience of their younger child receiving iBASIS to that of their older child who would have to wait till age 7 for support.

“Speaking as a parent who’s child was missed, this iBASIS is going to make my life much easier with my younger child. It’s already in place. We’ve been seen early on and we’re having early conversations about my child.”

They were pleased that their child would be followed up with the SACS-R in another 6-9 months after iBASIS and liked knowing they would be receiving ongoing support.

“You know you’re not alone, your child will be seen again which makes you feel better”
One parent said she “jumped at the chance of having the screening and iBASIS due to the experience with my other child, who was missed.”

Parents felt iBASIS helped them to better understand their child and they felt empowered to support their child. They said iBASIS supported their child’s communication and relationship with their child.

Parents emphasised the importance of professionals taking the time to fully understand their child and their family’s experience to the appropriate support.

“Unless you actually support the family, support the child and unravel...you know the ball of elastic bands, you can’t always tell what the diagnosis is and the...pathways” (Cara)

Receiving holistic and joined up care was important to parents. Use of neuro-affirming language when communicating was also key.

“So only last week I had my nine-month review with my son and I mentioned my daughters on the [autism] pathway... she was like, oh, looking at your son, I don’t see any red flags and referred to things like ASD and stuff, using quite negative language... there needs to be some like language awareness about it because I don’t see it in that way. ” (Abi)

All parents highlighted frustration from previous health care experiences with delays and long waiting times for appropriate support, assessment and diagnosis, particularly when the child’s presentation was less clear or accompanied by other needs In comparison, parents were strongly in favour of the early identification and support provided by the new under 2s neurodevelopmental pathway.

Parents who participated in the focus groups, highlighted the importance of having early open neuro-affirming conversations about their child's development and the possibility this pathway opened for earlier identification, discussions and support. Following the focus groups, the views of these parents have informed the language used by practitioners in the pathway and materials given to families, as well as the design of the pathway such as changing the review point post-iBASIS.

References

- Green, J., Pickles, A., Pasco, G., Bedford, R., Wan, M. W., Elsabbagh, M., ... & McNally, J. (2017). Randomised trial of a parent-mediated intervention for infants at high risk for autism: Longitudinal outcomes to age 3 years. *Journal of Child Psychology and Psychiatry*, 58(12), 1330-1340.<https://doi.org/10.1111/jcpp.12728>
- Whitehouse, A. J., Varcin, K. J., Alvares, G. A., Barbaro, J., Bent, C., Boutrus, M., ... & Hudry, K. (2019). Pre-emptive intervention versus treatment as usual for infants showing early behavioural risk signs of autism spectrum disorder: a single-blind, randomised controlled trial. *The Lancet Child & Adolescent Health*, 3(9), 605-615.

Some parent comments:

"iBASIS helped me focus on what I could see was happening with my child. It helped me see things from a different angle. It's beautiful. It's a good idea"

"To begin with I found the video a bit embarrassing. I felt my baby was always crying. But from the filming, I now understand he's making different sounds. From there I got more understanding. When you're in it you don't always see how yourself or how you are acting / responding to your baby. Like seeing how you give your baby your attention."

"Doing this as an early age, helped me understand her a lot better. I used to speak to her the same way as my 6 year old. I didn't understand her social cues. Now I do"

"It's made such a difference to our relationship"

"It's given me the power to know how to continue helping my child."

"I'd say to other parents - Do it - you'll be fascinated!"



News!

We are excited to share our results with you! We will briefly summarise the study and then discuss our findings, what they mean, and where you can read the research paper and find out more.

Methods

Empower-Autism was a new trial for parents of autistic children. Parents' progression through the programme was monitored at baseline, 12 weeks, 26 weeks, and 12 months through questionnaires and interviews. This allowed the research team to measure and compare aspects of caregiver and family wellbeing over the 12-month period across the two groups.

The programme provided autism psychoeducation about behaviour and sensory needs, strategies to support communication, and navigating the education system. It also included the mindfulness-based Acceptance and Commitment therapy to support parents' mental health and adjustment.

Thank you!

Welcome to this special edition newsletter to celebrate the release of our paper! Thank you to everyone who supported the REACH-ASD trial to make this possible, either through referrals or delivering the interventions.

Participants

The REACH-ASD trial involved 379 families who were randomly assigned either to the Empower-Autism group or to their usual post-diagnostic support available locally, allowing us to comparatively evaluate the effectiveness of the Empower-Autism programme.

Results

Compared to treatment-as-usual, the Empower-Autism programme significantly improved caregiver mental health. It also improved caregiver wellbeing, autism knowledge, adjustment to the diagnosis, and family wellbeing.

The study did not find significant improvements in parenting stress, confidence in parenting skills, family emotional environment, child adaptive behaviour, or child emotional and behavioural difficulties.

Both groups experienced similar numbers of adverse events, which were unrelated to the intervention.

What does REACH-ASD mean?

Excerpt from the
REACH-ASD
newsletter

Take home messages

Empower-Autism is the first fully powered trial to show a statistically and clinically significant sustained effect on mental health in caregivers of newly diagnosed autistic children.

We recommend the use of the Empower-Autism programme to clinicians and policy makers as a clinical intervention for parents.

Future implications

Interventions that improve the health of parents may have beneficial long-term impacts on the child and wider family. Future research should continue to address the long-term impacts of parent-focused interventions on family outcomes.

Overall, our study highlights the need for the implementation of programmes such as Empower-Autism. We hope that aspects of Empower-Autism can be utilised not only in interventions but also on smaller scales, for example through support groups and provision of online parent-facing resources.

We thank once again the families and professionals who contributed to the research, and hope these findings bring positive insights.



If you would like to read the paper, you can find it here:
[https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366\(25\)00036-7/fulltext](https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(25)00036-7/fulltext)

You can find more information on the REACH ASD Website:
<https://sites.manchester.ac.uk/reach-asd/>

If you have any queries or feedback about the research, please contact kathy.leadbitter@manchester.ac.uk.

This study was funded by the NIHR [NIHR – Health Technology Assessment Programme (HTA Project 17/80/09)]. The views expressed are those of the author and not necessarily those of the NIHR or the Department of Health and Social Care.



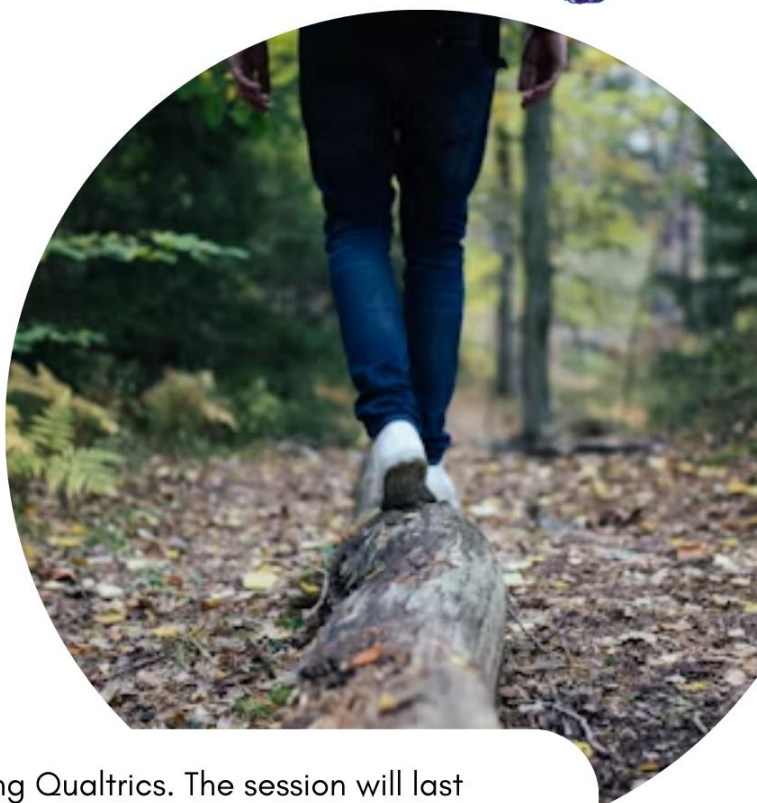
Research Study Opportunity

Researchers At The University of Manchester
Seek Volunteers To Take Part In Research Into
Balance and Falls.



ARE YOU:

1. **18+? and Autistic**
2. **Able to express yourself well in verbal and/or written English?**
3. **Free from neurological movement problems (e.g. Parkinsons, Multiple Sclerosis, etc.)**



This study involves a questionnaire, using Qualtrics. The session will last approximately 30-60 minutes and you will receive a small reimbursement for your time. The researchers have obtained advice from the Autisme@Manchester expert by experience group during the design of this study, and are from the Body, Eyes, and Movement (BEAM) lab.

Please contact: courtney.nabb@postgrad.manchester.ac.uk
or scan the QR code



Is the “Easy Eyecare Pathway” autism-informed?

The Easy Eyecare Pathway is available in South East London, North West England and Durham. It aims to provide accessible eye tests for autistic people in community and is delivered by accredited eyecare clinicians.

We want to interview autistic people who have had an Easy Eyecare Pathway eye test to understand their experiences, and if the pathway is autism-informed.

To take part, you must:

- Be diagnosed OR self-identified as autistic, without a diagnosis of learning disabilities
- Be aged 18 years or over
- Have had an Easy Eyecare Pathway eye test

Interviews will require approximately 45 minutes, and can be in-person at The University of Manchester, by video call or by text chat. You will be reimbursed for your participation.

This study is being conducted by Dr Ketan Parmar, Dr Emma Gowen, Dr Sarah Rhodes and Dr Kathy Leadbitter (The University of Manchester), and Lisa Donaldson (SeeAbility).

For more information please contact: ketan.parmar@manchester.ac.uk

This project has been reviewed and approved by the University of Manchester Research Ethics Committee.

Version 1, 16/12/2024

Kelly Birtwell and Christine Rowland are running a survey about autistic adults' experiences of stimming, mindfulness and other contemplative practices. The survey is open to autistic adults aged 18+ based anywhere in the world.

To find out more and take part, visit <https://tinyurl.com/Aut-Mindful>

