
Participatory Autism Research
A STARTER PACK:
SHAPING AUTISM RESEARCH UK

PARTICIPATORY EXPERIENCE IS NOT SIMPLY A METHOD OR SET OF METHODOLOGIES. IT IS A MINDSET AND AN ATTITUDE ABOUT PEOPLE. IT IS THE BELIEF THAT ALL PEOPLE HAVE SOMETHING TO OFFER

(Sanders, 2002)

This Starter Pack is a guide for ensuring that research is carried out collaboratively with autistic people and their allies. It offers practical guidance to working with a diverse range of people at all stages of the research process.

This Pack is for anyone involved in autism research – in any discipline, in any capacity and in any stage of their lives. It covers principles for doing research *with* autistic people, rather than *on* or *about* them.

In 2013, a project called A Future Made Together (Pellicano, Dinsmore, & Charman, 2013) demonstrated that academics had not been taking enough notice of the everyday issues - with regard to services, interventions, supports and education - that affect autistic people and their families. Instead, they had been focusing heavily on "basic science" - understanding the neural and cognitive systems, genetics and other 'risk' factors related to autism.

One reason for the mismatch between what was being researched and what people wanted to be researched was a lack of autistic involvement in the decision-making processes that shape research and its applications.

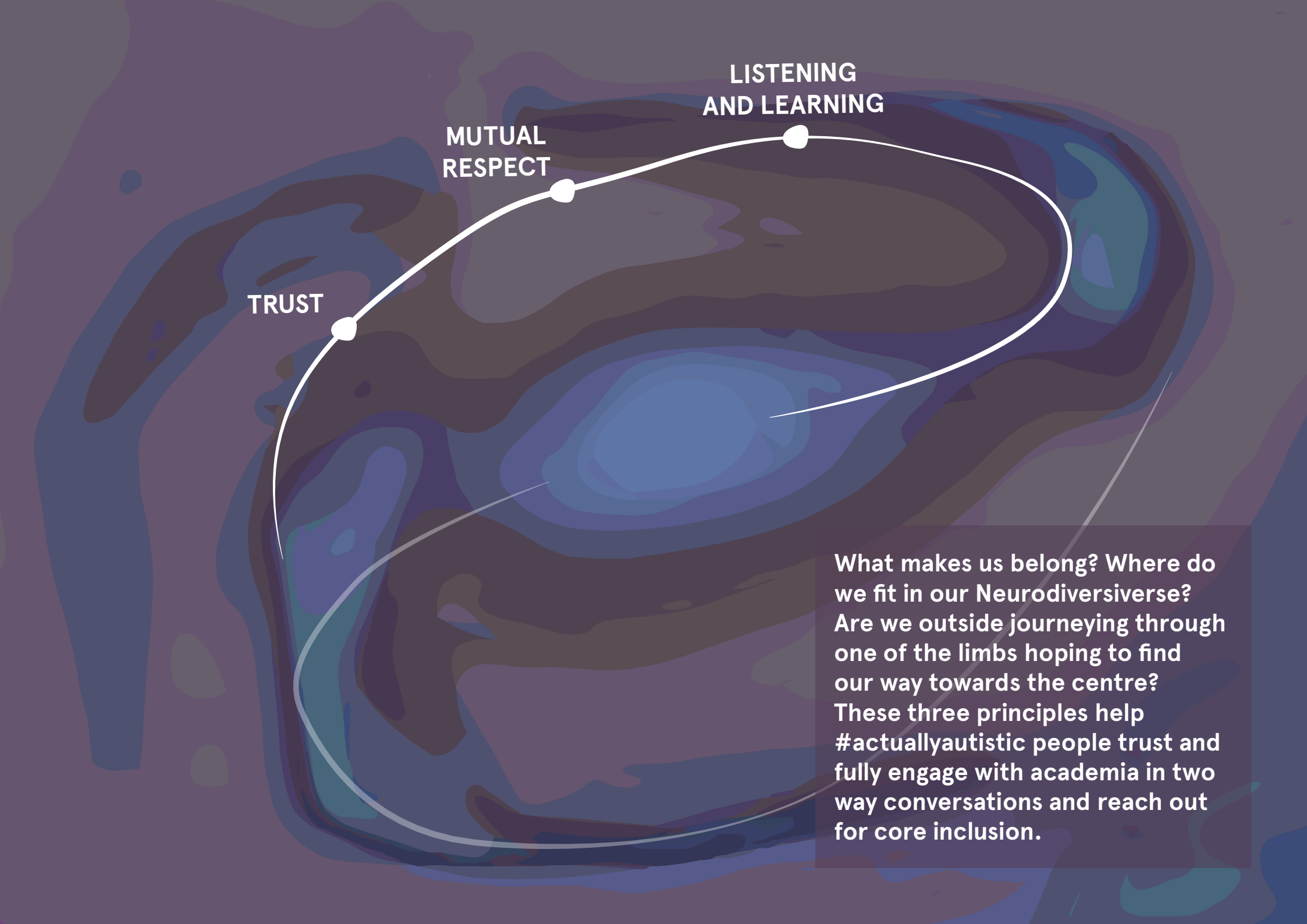
Researchers, both autistic and non-autistic, need to connect with the people that they 'study'. They need to listen in order to appreciate the diversity of what it is like to be autistic, to support for someone who is autistic or to work with someone who is autistic. And autistic people, their family members and those who support them (their allies) need to join together in innovative new partnerships to ensure that the research that gets done is the research that matters most to people, and that makes a real difference to their lives.

This Starter Pack provides some practical ideas about how autistic people and their allies can work together in research. The ideas presented are not meant to be prescriptive. Not everything will work for everyone or every type of research. But they should nevertheless get you thinking about possible ways of working more collaboratively.

We understand that some of these ideas and ways of working might be new - and slightly daunting - to some people, but don't be put off!

Autistic people and their allies have so much expertise and experience to offer to the research process. Working together will lead to research that is more relevant to people's lives, tailored to their needs and consistent with their values.

THE FUTURE OF AUTISM RESEARCH MUST BE SHAPED TOGETHER



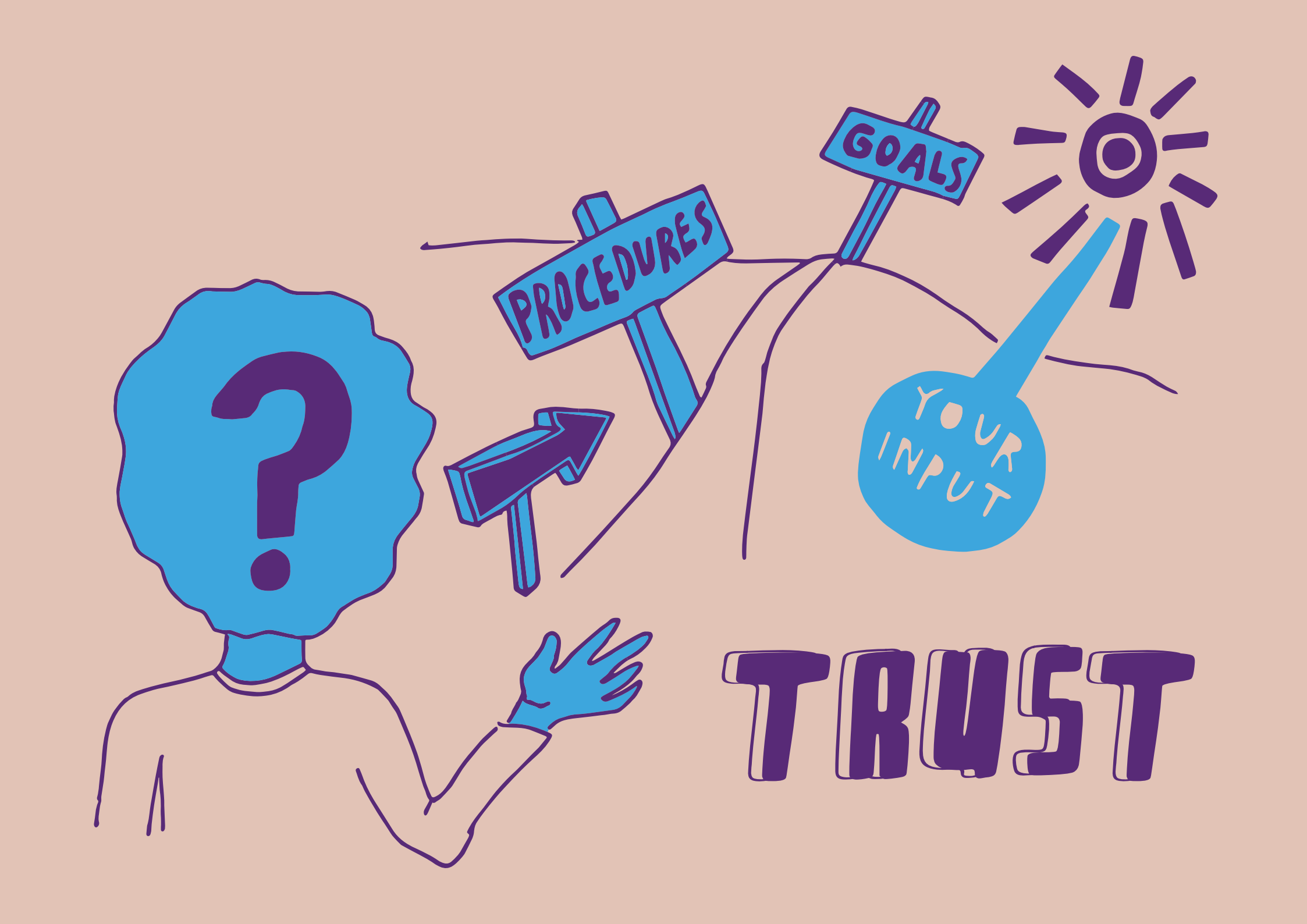
What makes us belong? Where do we fit in our Neurodiversiverse? Are we outside journeying through one of the limbs hoping to find our way towards the centre? These three principles help #actuallyautistic people trust and fully engage with academia in two way conversations and reach out for core inclusion.

TRUST

"WHATEVER I SAY IS IT REALLY GOING TO INFLUENCE ANYONE?"

Many autistic people and their allies who have taken part in autism research report a lack of trust regarding the research process. Researchers, both autistic and non-autistic, must be honest and committed in their interactions - saying what they mean and meaning what they say.

Are you being honest and transparent about your research (its goals and procedures)? Have you told participants about the outcomes of the research and how their information has been used? Have you taken on board constructive feedback about your work?


GOALS
PROCEDURES
YOUR INPUT
TRUST

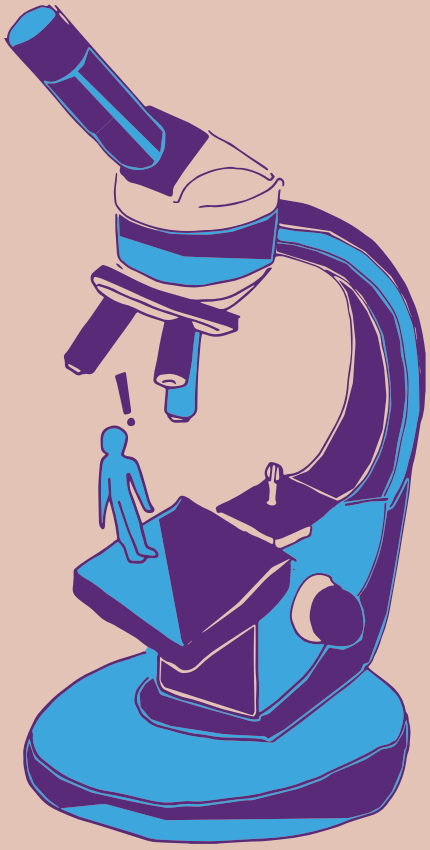
MUTUAL RESPECT

"THE AUTISM RESEARCHERS THAT I HAVE DEALT WITH PERSONALLY WERE ALWAYS INTERESTED IN WHAT I HAD TO SAY AS WELL AS MY WELL BEING."

Autistic people and their allies are happier with their experiences of contributing to research when they feel respected - and their views have been valued - by researchers, both autistic and non-autistic.

Are you treating your participants as people (as collaborators), rather than just subjects in your research? Have you asked for the participants' views on your research at all stages of the process? Have you thought about how the research impacts upon those being researched?

MUTUAL RESPECT



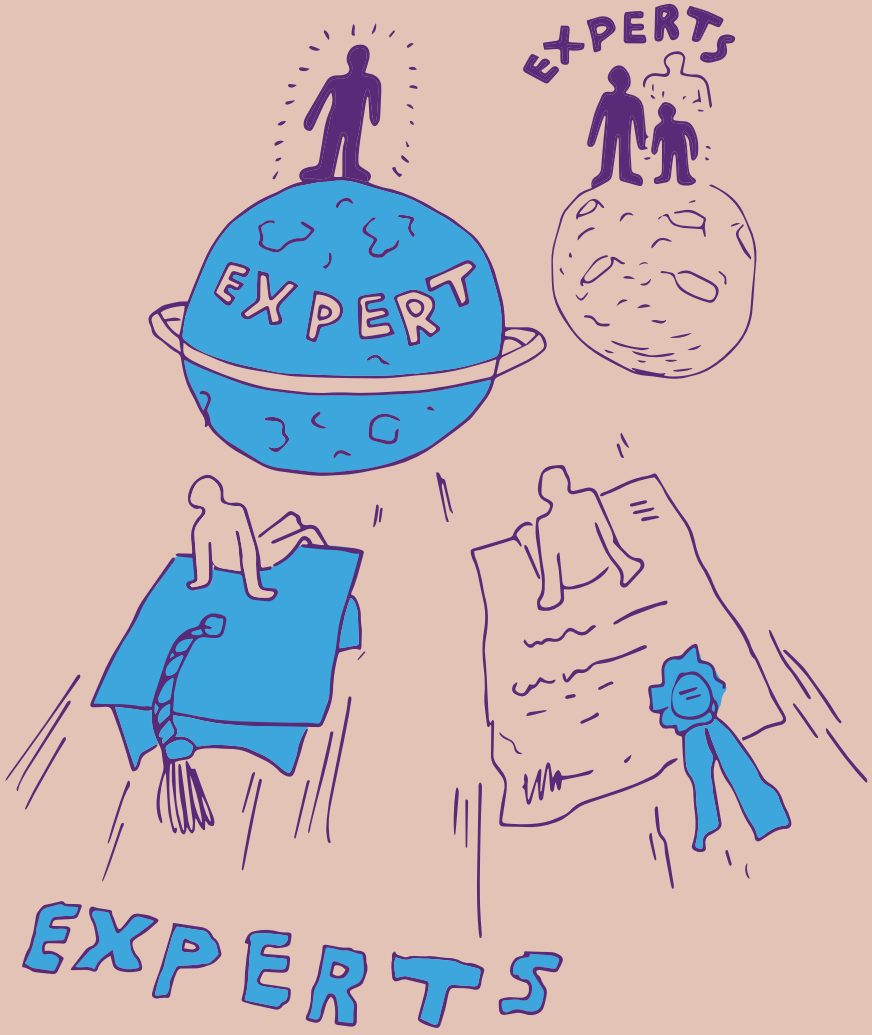
LISTENING AND LEARNING

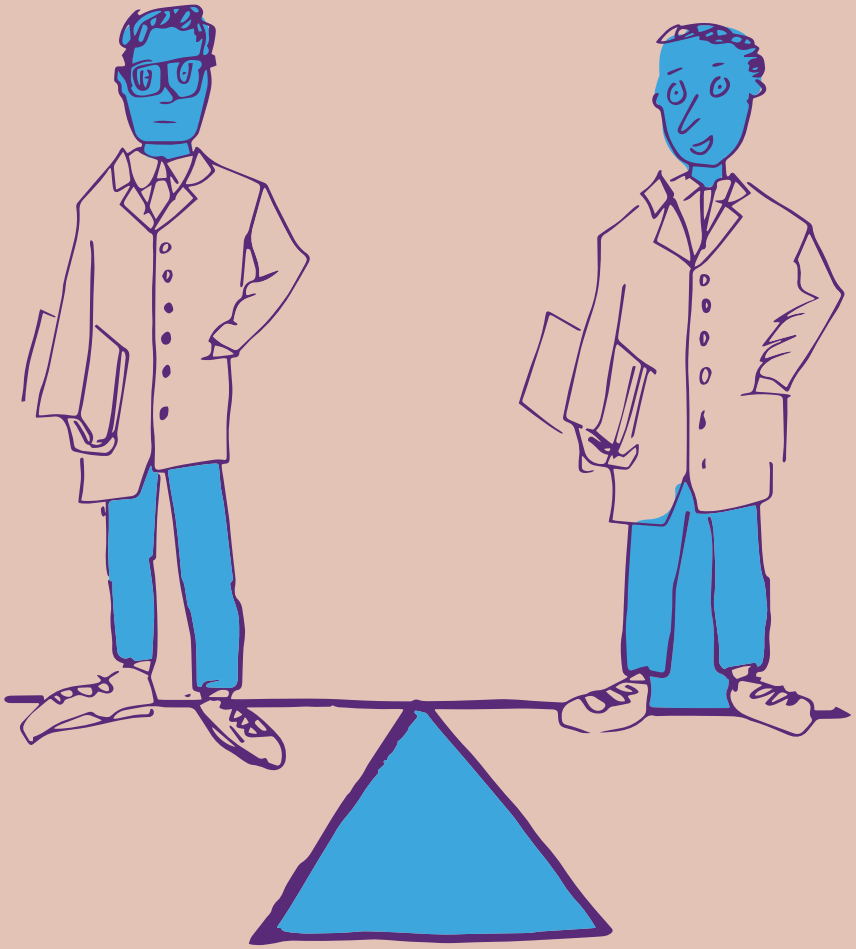
"YOU HAVE YOUR AREA OF EXPERTISE WHICH IS NOT MINE AND WE HAVE OUR AREA OF EXPERTISE. YOU HAVE TO LOOK AT US ON A SIMILAR LEVEL."

Researchers have expertise in designing and implementing research. Autistic adults have expertise gained from their lived experience of being autistic. Parents of autistic children have expertise regarding living with and caring for someone on the autism spectrum. Professionals have expertise regarding working with a range of autistic people on a daily basis. And some people benefit from expertise in more than one of these areas. It is crucial for different kinds of expertise to be acknowledged and valued. By learning from other people's expertise, we can ensure that the research taking place is relevant to those it directly affects.

Have you thought about the benefits that an alternative type of expertise might bring to your research? How has your research changed following consultation or partnerships with autistic people and/or their allies?

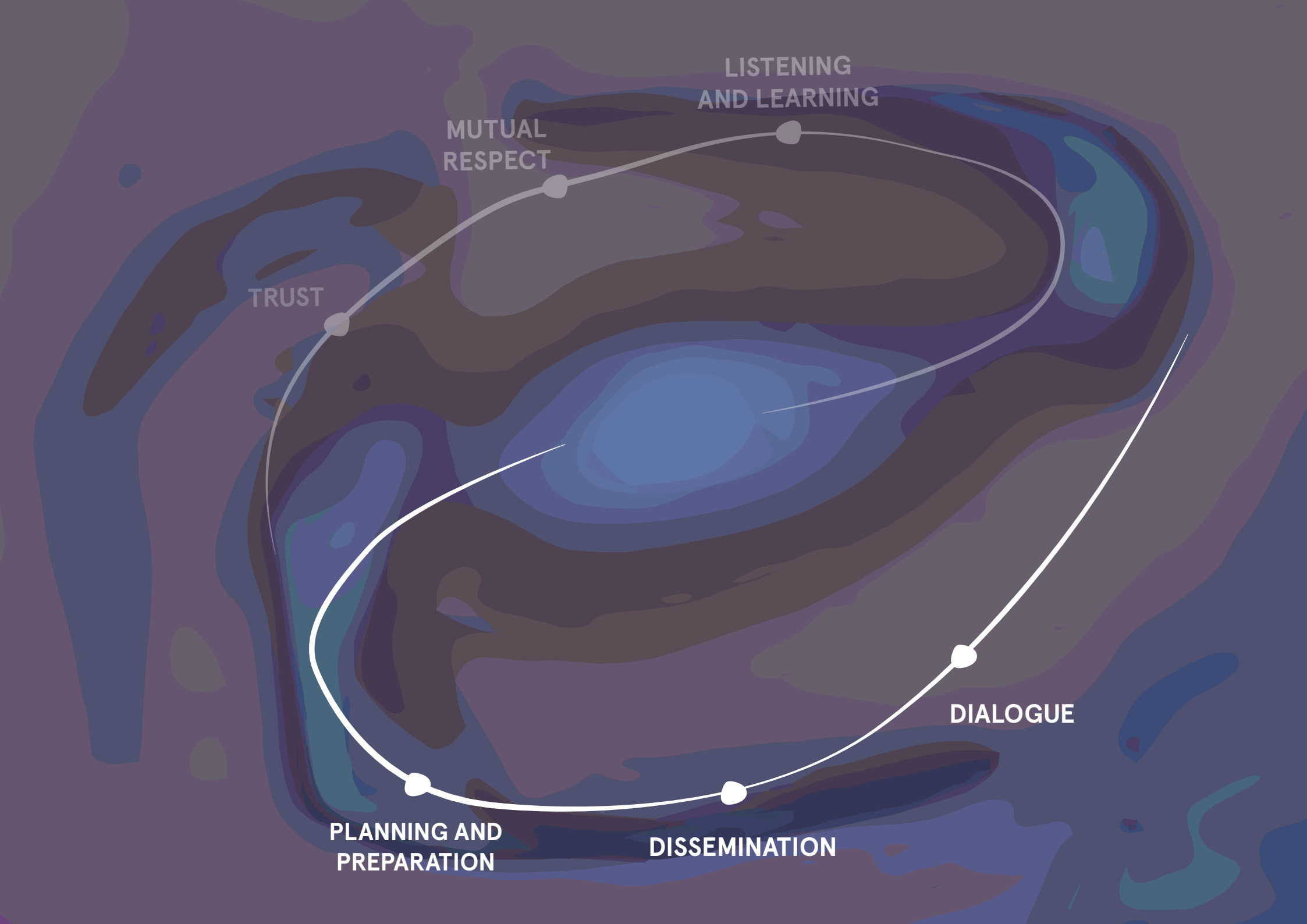
LISTENING AND LEARNING





GUIDANCE FOR WORKING TOGETHER

The following guidance includes recommendations for how to ensure that we approach our research in such a way that it promotes trusting relationships, is built on mutual respect, and involves listening to, and learning from, one another.


LISTENING
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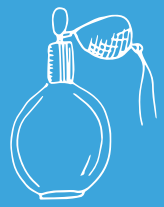
PREPARATION
DISSEMINATION

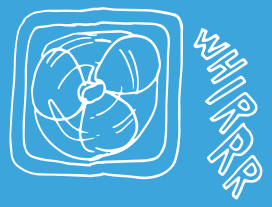
Creating an enabling environment:
Different autistic people experience the world in different ways. As researchers, we should seek to understand the specific needs of the people involved in our research and, where possible, adjust our behaviour and environment accordingly. How do we know a person's specific needs? We can usually ask them or someone who knows them well like a parent/carer or teacher.

Here are a few, more general tips to get you started...



Don’t wear products with a strong scent like perfume.

Respect people’s use of aids to cope with the sensory environment (e.g. ear defenders).



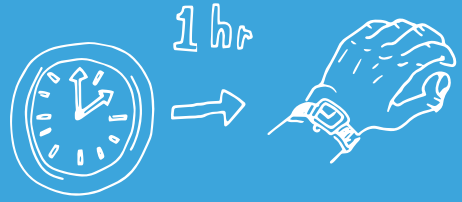
Try to reduce distracting noises such as air conditioning or projector sounds.

Be mindful that people might not like you touching them or touching certain materials (e.g., the material on the seat you offer).

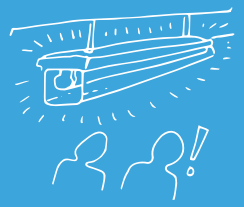
Allow opportunities for a person to ‘stim’ or move around when you are working together.

Avoid clothes with distracting patterns or ‘loud’ colours.

Know that not everyone likes eye contact.



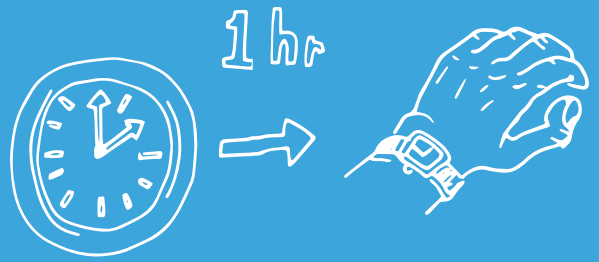
Give advance notice of loud noises that might occur like fire alarm testing or hand dryers.



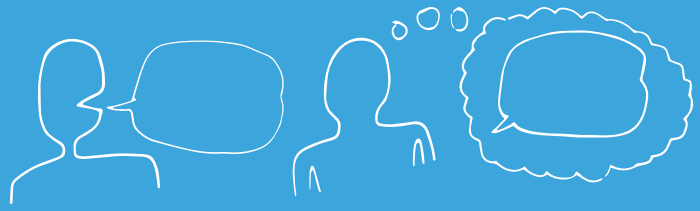
Avoid harsh, flickering lighting in the room, where possible.

Most of us feel more comfortable when we know what to expect in new or unfamiliar situations. Autistic people can find such situations, like coming to a university for the first time, unsettling. As researchers, we should do our best to make their experience of research, whatever it is, as positive as possible.

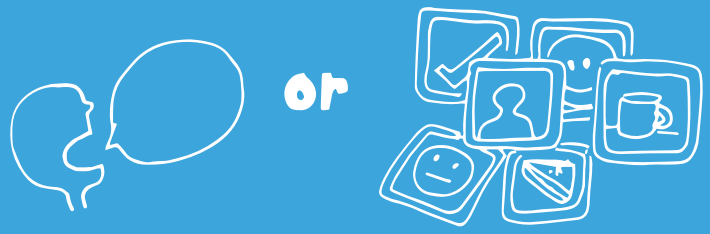
Here are some ways to do this...



Give plenty of warning of any changes to the setting or situation.



Allow the person the time it takes to process what you are saying before repeating an instruction.



Find out about the way that the person likes to communicate - through spoken or written language, symbols or pictures - and accommodate this as much as possible.

Be clear about what is expected of the person with whom you are working - what is going to happen during their time with you and how long will it take. Use concrete language.

Be clear in your use of language - say what you mean and mean what you say - and be sincere in what your offer. Wherever possible, promises should be kept, expectations met, and outcomes fulfilled.

DISSEMINATION

"I WOULD LIKE MORE DETAILS OF THE RESULTS OF RESEARCH PARTICULARLY WHEN I HAVE GIVEN TIME AND EFFORT TO HELPING WITH IT."

Dissemination is the process of sharing information and knowledge – in other words, spreading the word. Traditionally, research dissemination has focused on publishing the results in academic journals, which are typically read by other academics. But we know that getting our results out there and ensuring that they make an impact with as large an audience as possible requires a great deal more. We need to ensure that we communicate our findings in such a way that the people we want to reach (our 'target audiences') can understand, reflect on, and use them in their everyday lives.

To achieve this, we need to think about....

The content:
Is the content easy to understand (i.e., jargon free), written in a clear and accessible manner and tailored to the target audience?

The medium:
Is the medium (e.g., face-to-face communication, social media, hard-copy newsletter) easily accessible to the target audience? Is it the most effective medium for the people we want to reach?

The audience:
Who is our target audience(s) (e.g., parents, autistic people, practitioners, policymakers) and what is the most appropriate way of communicating with them?

Ideally, we should disseminate our research findings in a variety of forms to ensure that they have the greatest impact. This is particularly important since many research articles are not freely available to view and are not written in a way that is accessible to a broad audience.

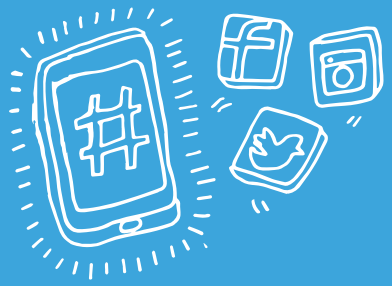
At the very least, communicating the results to those who took part in the research should be at the forefront of our dissemination strategy – our participants deserve to know what we found, presented in a way that is meaningful to them. Doing so can be difficult, especially when research often takes a long time to conduct, but it is essential to promoting trusting, respectful relationships with the people with whom we work.

In every research project, you should aim (at some point) to get autistic input into your plans for dissemination. You could also consider getting an autistic person to help create a novel and interesting way of presenting your research. Whatever strategy you decide, researchers should actively promote their research. We have listed a few practical ideas...

Workshops
Participating in (or even organising) a workshop can be a helpful way of bringing together a small group of people to discuss a specific topic. If you are organising a workshop (or other public event), consider how best to involve autistic people and their allies, ensuring that they are appropriately represented, and that the event is accessible (e.g., might people be able to wave their hands rather than applaud?). Partnering with autistic-led organisations is a fantastic way to achieve this.

Newsletters
Consider developing a short, engaging newsletter to showcase what you did, how you did it and what you found.

Public events
Might you, or your research team, be able to host a public event linked to autism? This could be a conference, seminar, lecture, film screening or any other event open to the public. There are often funding opportunities available to support such activities, and they can be a great way of engaging people with research.



Social media

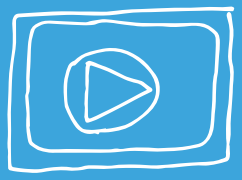
Do you, your research team, or your institution have social media (e.g. Twitter, Facebook, Instagram, LinkedIn) accounts? You can use social media to promote your research (at all stages) and engage in dialogue with autistic people and their allies. Use hashtags that autistic people will see on Twitter.

Podcasts

Some organisations have regular podcast series where researchers can discuss their work and its implications. These tend to be around 10-15 minutes long. Consider putting yourself forward for one of these, or even recording your own. Vodcasts (video podcasts) are also becoming increasingly common.

Lay articles and blogs

Writing for open access lay publications are a great way of disseminating your research beyond academia. Alternatively, consider a personal blog as a great way of disseminating your research. If you don't have time to maintain your own blog (you'll need to post fairly regularly to keep people interested) consider contributing to a departmental/University/ charity/campaign group blog (where different contributors write each post).



Video abstracts

Try making a short video summarising your research. You don't need any fancy equipment - just the ability to record a video and an Internet connection! If the video is two minutes or less, it is likely to have even greater reach!

IMPORTANTLY GET FEEDBACK ON YOUR PLANNED DISSEMINATION ACTIVITIES FROM AUTISTIC PEOPLE AND THEIR ALLIES

DIALOGUE

"I FEEL THAT IT CAN OFTEN BE TOKENISTIC I.E. ASKING THE SAME OLD PANEL OF AUTISTIC PEOPLE TO CONTRIBUTE TO POLICY PRACTICE AND DECISION MAKING, ALMOST TO TICK THE BOX TO SAY THAT PEOPLE WITH AUTISM HAVE BEEN INVOLVED."

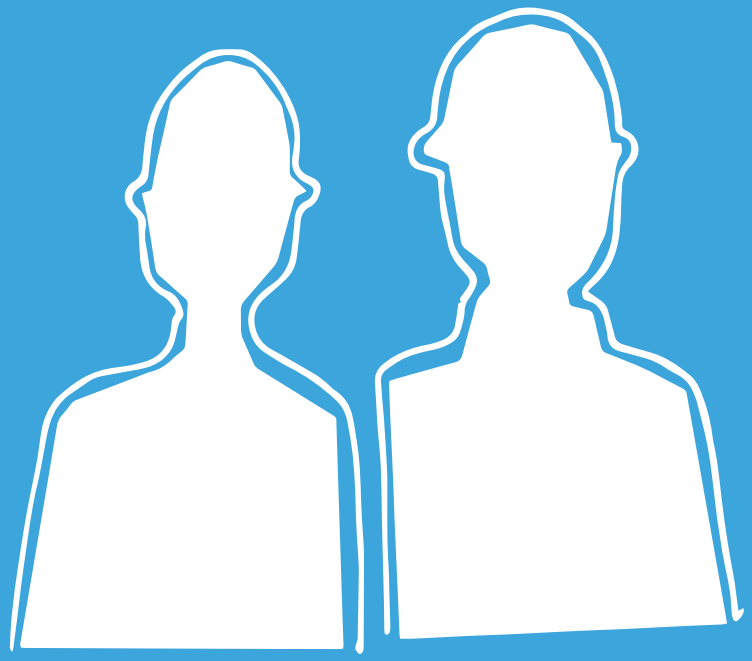
For too long, researchers have set the agenda for research on their own, without asking autistic people and their allies what they would like researched or whether they would like to be involved in the process. Today, more and more researchers want to engage in dialogue with the autistic community whilst conducting their research. However, many non-autistic researchers are often too nervous to do so, or don't know how to get started.

Importantly, engaging in dialogue with autistic people and their allies doesn't have to be difficult, expensive or time consuming! You might just want to consider asking your research participants a few key questions before, during and at the end of your study, to get their understanding of the experience.

Basic dissemination of the research may lead to helpful discussions and dialogue with autistic people and their allies or, eventually, to partnerships and collaborations.

Other forms of dialogue that researchers might like to experiment with can take the form of...

Focus groups
From time-to-time, it's good to discuss your research agenda and your research findings with selected groups of autistic people and their allies. Focus groups can be formal events (with well-developed methodologies and impartial facilitators) or less formal gatherings (via open discussion in a more relaxed setting). Either way, they give the autistic community the opportunity to reflect on the nature of ongoing research in a safe setting, away from pressure.



Mentorship
Over time, you may find that you seek the advice and guidance of certain autistic people or allies, whose interests closely align with yours and with whom you have a strong professional relationship. If so, you may want to consider formalising this into a mentor relationship. Such relationships can be mutually beneficial.

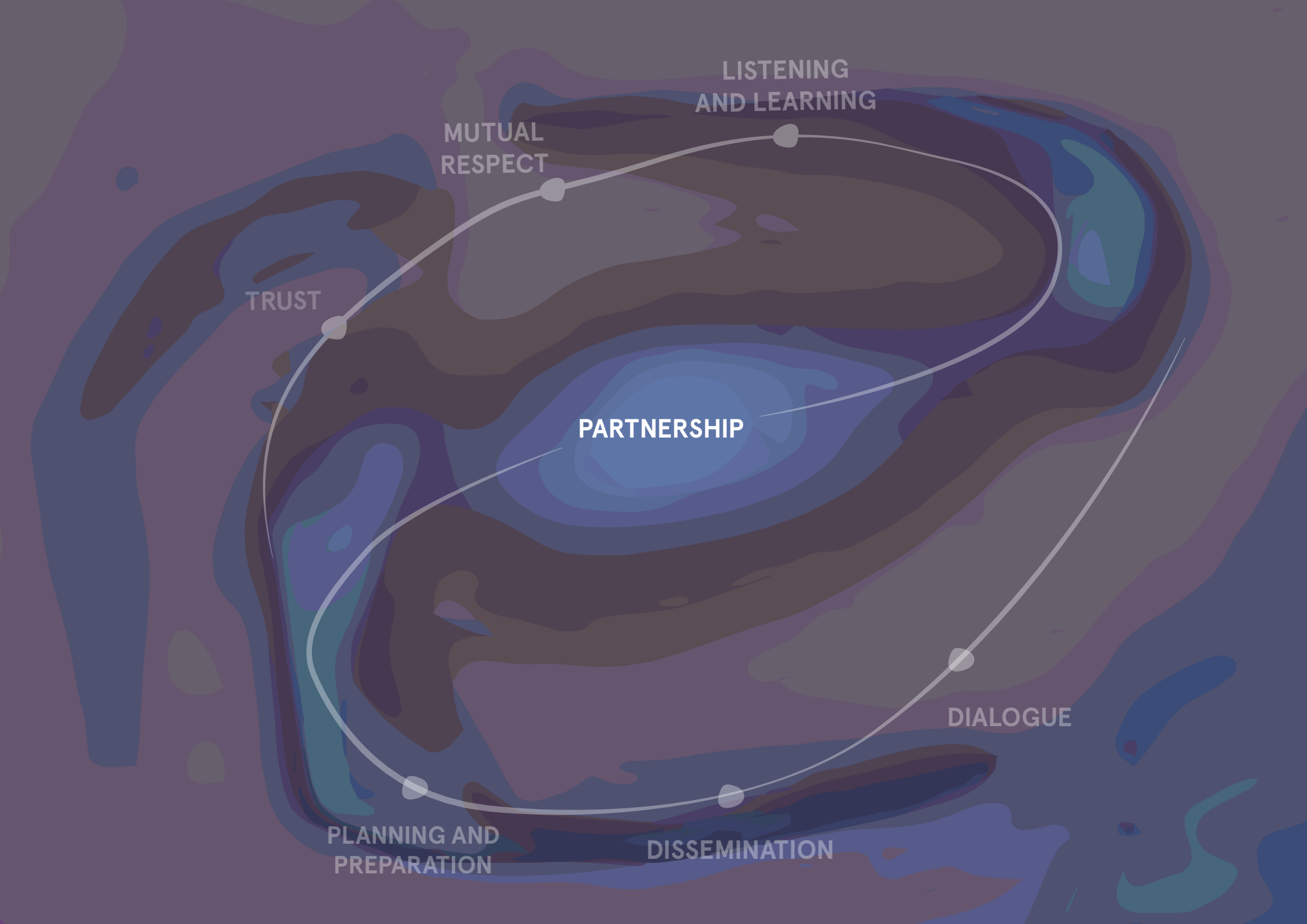
Research review
Some universities, funding agencies and research centres have developed internal research review processes, whereby researchers can submit their research plans to get feedback from autistic people and their allies as those plans are being developed. This is a helpful way of receiving constructive feedback at early stages of the research process.

PARTNERSHIP

"I WAS A LITTLE NERVOUS ABOUT CO-PRODUCING RESEARCH FOR THE FIRST TIME, BUT THE INPUT OF MY AUTISTIC CO-RESEARCHERS WAS INTEGRAL TO THE SUCCESS OF THE PROJECT, I'D RECOMMEND IT TO EVERYONE."

Genuine research partnerships are what we hope all researchers will aspire to in the future. It includes joint working between researchers (autistic or non-autistic) and autistic people, family members or practitioners, where research is carried out *with* or by community members rather than *about* or *for* them. Research that is produced in this way may involve researchers joining forces with autistic researchers to conduct original and exciting work.

This approach is seen in many areas of research - not just the field of autism. The methodologies, practices and techniques used to achieve this are becoming ever more subtle and sophisticated. Some organisations exist to conduct research and deliver services entirely along these lines (e.g., exclusively employing researchers who have both experiential and community knowledge and expertise), while others are just beginning to draw these methods into their work.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Genuine partnerships often take time to form. Even those researchers who are most experienced in the approach say that it can often take years to develop the necessary trust and relationships.

Key questions to ask at the start of any such work are...

Who are the partners going to be?

How are they going to be recruited and why would they want to be involved?

What kind of partnership research methodology is going to be employed?

Have all the researchers (autistic or non-autistic) got the necessary experience, expertise or training to begin building the partnership?

Is there support and funding in place not only for the research partnership itself but for all of the work that will be required to develop and shape it in the early stages?

Are all parties clear that partnerships involve give-and-take and that research agendas, approaches and processes will have to be genuinely debated and discussed during the partnership?

Do you know to appoint someone external to the partnership to keep an eye on how it is going and to mediate if any disputes do come up?

Can you employ an autistic researcher who has experiential and community knowledge and expertise in your team?

There are many sources of advice that you might like to turn to in order to develop these partnerships, these include:

INVOLVE
www.invo.org.uk

The Examining Community:
Institutional Partnerships for Prevention Research Group (2006)

Developing and Sustaining Community-Based Participatory Research Partnerships:
A Skill-Building Curriculum
http://depts.washington.edu/ccph/cbpr/

NICE Patient and Public Involvement Policy:
https://www.nice.org.uk/about/nice-communities/public-involvement/patient-and-public-involvement-policy

The Participatory Autism Research Collective (PARC):
PARCautism.co.uk

A FINAL NOTE ON TERMINOLOGY

The language we use to talk about autism - in research labs, clinics, schools and communities - is important. Yet, there is much disagreement about the way autism is, and should be, described. In 2016, the UK's National Autistic Society surveyed people, about the terms they prefer when talking about autism. The following guidelines are based on these results.

These guidelines are not agreed by all. But researchers should be sensitive to the preferences expressed by the #actuallyautistic community.

Preferred language:
The research highlighted that there is no one preferred way to talk about autism, and researchers must be sensitive to the differing perspectives on this issue. Amongst autistic adults, the term 'autistic' was the preferred term. (Kenny et al., 2016; see also quote to the right from Sinclair, 1999). Across all stakeholder groups (clinicians, educators, family members all taken together) the most preferred term was 'on the autism spectrum'. If possible, ask the person you are speaking to which term they prefer.

"IN DESCRIBING SOMEONE WHO'S AUTISTIC AS "A PERSON WITH AUTISM/PERSON WHO HAS AUTISM/(OR WORST OF ALL) PERSON WHO SUFFERS FROM AUTISM" YOU IMPLY THAT AUTISM IS SEPARATE FROM A PERSON, AND BEHIND THEIR AUTISM IS A "NORMAL" PERSON "

Terms to avoid:

`Suffers from' or is  a `victim of' autism
Use `is autistic', `is on the autism spectrum', or `has a diagnosis of autism' instead.

Referring to autism as a `disease' or `illness'
Use `autism is considered a disability' or `autism is a condition' instead.

`Retarded', `mentally handicapped', `backward'
These terms are derogatory and offensive and we would suggest avoiding these terms all together. Use the terms `intellectual disability/difficulty' instead.

Referring to Asperger's syndrome as a `rare' or `mild' form of autism
Just because someone appears to be verbally or cognitively able, does not mean they cannot be severely affected by their autism.

`Low-or High-Functioning Autism'
Dividing autistic people into categories of low or high functioning does not fully represent the diverse pattern of ability and challenges faced by individuals on the autism spectrum. Use a more precise description of people's abilities (such as referring to their cognitive or verbal abilities) instead.

Referring to `normal', `normally developing' or `healthy', non-autistic, comparison groups
Use `typical adults' or `typically developing children' instead. In some cases, the term `neurotypical' may also be appropriate.

Referring to a `control' group
Use `comparison' instead as it is almost always unclear what is being `controlled' for.

READING LIST

General information on participatory research
Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Planning Association*, *35* (4), pp. 216-224.

Israel, B., Schultz, A., Parker, E., & Becker, A. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*, *19*, 173-202.

Priority setting in autism research
Pellicano, E., Dinsmore, A., & Charman, T. (2013). *A Future Made Together*. London: Institute of Education

Autistica and James Lind Alliance - https://www.autistica.org.uk/research/top10/

Describing autism and language
Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, *20*, 442-462. doi: 10.1177/1362361315588200

Autistic expertise
Milton, D.E.M. (2014). Autistic expertise: a critical reflection on the production of knowledge in autism studies. *Autism*, *18*, 794-802. doi: 10.1177/1362361314525281

Milton, D., & Bracher, M. (2013). Autistics speak but are they heard? *Medical Sociology Online*, *7*, 61-69.

Involving autistic people and their allies in research
Nicolaidis, C. (2012). What can physicians learn from the neurodiversity movement? *Virtual Mentor 14*, 503–510. doi: 10.1001/virtualmentor.2012.14.6.oped1-1206

Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Ashkenazy, E., et al. (2011). Collaboration strategies in nontraditional community-based participatory research partnerships: Lessons from an academic-community partnership with autistic self-advocates. *Progress in Community Health Partnerships: Research, Education, and Action*, *5*, 143–150.

Pellicano, E., Dinsmore, A., & Charman, T. (2014). Views on researcher-community engagement in autism research in the United Kingdom: A mixed-methods study. *PLOS One*. doi: 10.1371/journal.pone.0109946.

We hope this Starter Pack has provided some ideas about how you could meaningfully engage autistic people and their allies in the research process.

You can find out more at:
shapingautismresearch.co.uk

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