

SHORT SUMMARY

Your research ideas

Improve services

- *Designing better services around diagnosis, and transition from child to adult services*

Achieving life goals

- *Providing better support to ensure that goals in education, work and independent living, when present, are achievable.*

Autistic worlds

- *Expanding understanding of autistic worldviews and emotional life, including empathy, and felt connections with the natural world and beyond.*

Autism in the media

- *Critically reviewing how autism is portrayed in the media.*

Your suggestions for improving how research is done

Design it together

- *Research needs to be shaped together with autistic people from the start*

Empower participants

- *Autistic people participating in research need to be empowered as co-researchers and treated fairly and equally*

Reach the hard to reach

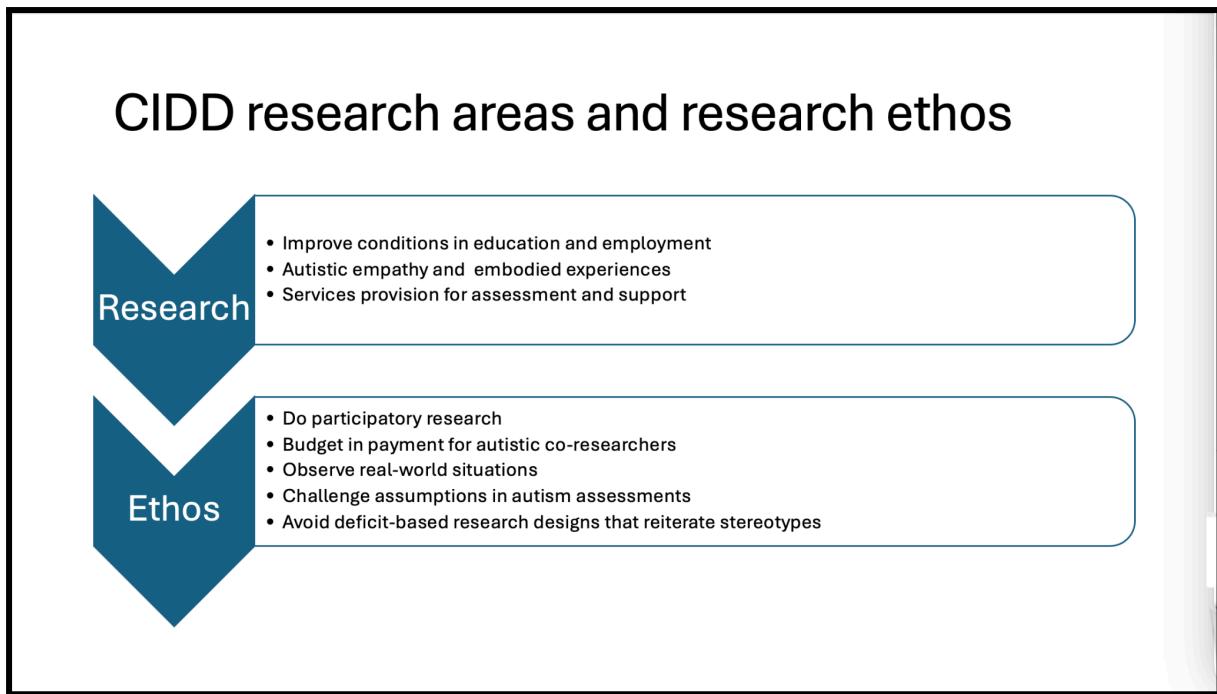
- *Research needs to include voices that are more difficult to be heard, even if harder to reach*

Challenge stereotypes

- *Research needs to avoid being driven by received ideas and stereotypes about autistic people*

Widen access

- *Results of research need to be accessible to as many people as possible*



EXTENDED SUMMARY

1. AUTISM IN ADULTHOOD

You raised concerns around transition to adulthood and how to best support it. Possible research questions for this topic are:

1.a What are the goals when growing into adulthood, and what support is needed to achieve those?

1.b What does success in any of these areas mean or look like for an autistic person?

CIDD: Regarding the transition to adulthood, we have a new paper on the social and emotional experiences of puberty for autistic people assigned female at birth. Regarding autistic adults, Holly Radford and Steven (steven.kapp@port.ac.uk) have a nearly accepted paper on the nonverbal communication experiences of autistic adults.

2. DIAGNOSIS

You mentioned that the autism diagnosis has a strong impact on the autistic person, but also on their family and other relationships: the family history can be rewritten and relations with partners can be seen under a new light .

2a How can we explore the many different effects the autism diagnosis has on the individual and their relations?

CIDD: In a collaborative project with the USA, we are investigating the reasons for seeking or not seeking official diagnosis in self-identified autistic individuals. Please email emine.gurbuz@port.ac.uk or steven.kapp@port.ac.uk if you would like to hear about our

findings.

Furthermore, we have a newly accepted theoretical paper challenging the validity of 'losing' an autism diagnosis.

In our collaborative Project within the Wessex Health Partnership we are planning on working with families from Hampshire to understand their journeys from referral to diagnosis and the ways in which early support such as via an ND pathway might have support the journey. Please email iris.nomikou@port.ac.uk if you would like to learn more.

3. SERVICES

This was a very rich topic. First, you noted that early diagnosis can mean preventing later issues, including mental health difficulties and that there is a need for more awareness in the healthcare services about other commonly co-occurring conditions. It was discussed how the range of gender identities is broad in autism, and this might also require tailored support in certain phases. Finally, it was noted that expectations of support following the diagnosis may lead to disappointment. Among the research questions you raised and for which we have expertise were:

3.a How can we work toward improving services' awareness and provision? Transition to adult public services often comes with disruption and loss of much needed support:

3.b Can we work toward a better understanding of how to have more continuity between services?

Within a research project within the Wessex Health Partnership we aim to bring together different stakeholders, such as parents, schools, NHS professionals, the Integrated Care board, social workers to discuss the design of a pathway that can help capture the needs, support and outcomes for neurodivergent children. Please email iris.nomikou@port.ac.uk if you would like to learn more.

3.c What difference does it make when autistic professionals are the service providers?

CIDD: We have a paper on the experiences of (un)belonging in autistic transgender and non-binary adults, including aspects such as healthcare needs. Please email katie.munday@port.ac.uk for a copy.

4. AUTISM-FRIENDLY EDUCATION ENVIRONMENTS

Autistic people can thrive if given the opportunity to study and develop their skills and passions. However, they face many obstacles. Also sometimes autistic students are older than the average age group at their study level.

Based on this, possible research questions are:

4a. How can we design better education environments for autistic students?

CIDD: We are currently running a research project with Portsmouth City Council exploring the actions put in place in Schools as a result of Neurodiversity Profiling in Schools. Please email iris.nomikou@port.ac.uk if you would like to learn more.

4b. How can we facilitate the transition from study to employment?

CIDD: We are currently collecting data on a questionnaire we co-designed with autistic university students to identify their support needs as well as strengths. Please email emine.gurbuz@port.ac.uk if you are interested in participating.

Please e-mail elinor.lim@port.ac.uk if you are interested in reading a study about the experiences of autistic university students in the UK, or completing a questionnaire about their family support.

Please email steven.kapp@port.ac.uk if you would like a copy of an upcoming encyclopedia entry on education and the autism rights branch of the neurodiversity movement.

5. STEREOTYPES AND REPRESENTATION OF AUTISTIC PEOPLE.

Autistic characters have become more popular in the media, however the representation is rarely realistic (e.g. superpowers and the like), and there are not enough realistic role models for youth to be inspired by, either through media or in education.

5. How can we look at autism representation in popular media and across society, so that we can point out what is missing and misleading on the one hand, and, on the other, what would be good representation?

CIDD: We are very interested in this topic; for example a review by Alessandra Fasulo highlights that the moment of diagnosis is never represented in autistic people's fictional portrayals. Beatriz Lopez supervised a relevant doctoral dissertation on this topic. If you would like more information please contact Beatriz.Lopez@port.ac.uk. We do not have capacity to lead a project on this, but if anyone in the group would be interested in creating a joint Autism in the Media Observatory and start with an online discussion group on different programmes please contact alessandra.fasulo@port.ac.uk

6. EMBODIMENT AND EMPATHY

You suggested it would be good to go beyond the current emphasis on language and include more research on body and material environments. Specifically, you suggested exploring the following research questions:

6.a How can we study not only sensory issues, but the whole sensorial landscape in autism?

CIDD: A PhD student is currently investigating sensory sensitivity and its impact in classroom and learning. If you would like to inform the project please contact Beatriz.Lopez@port.ac.uk.

Steven recently wrote papers on how [sensory issues affect autistic people across the](#)

lifespan, and another one on how visual and auditory sensitivities may relate to speech acquisition divergence in autistic people. Please email steven.kapp@port.ac.uk for a copy of either.

6.b What is autistic empathy, and does it include empathy to the non-human and/or non-living parts of the environment (in ways that may be rare or absent in neurotypical people)?

CIDD: We think this is a highly interesting topic that could open up new understandings of autistic capabilities for connecting with the world. There is anecdotal evidence from autobiographies, but we are going to apply for funding for a participatory project to investigate this. If you would like to offer more insight for a project on this topic please contact alessandra.fasulo@port.ac.uk

A paper by Steven mentioned above also suggests that empathy is underestimated in autistic people.

6. PEER SUPPORT AND ADVOCACY

The most important changes in knowledge and practice around autism have been produced within the autistic community itself, and the activity of advocacy groups.

6.a How can autism advocacy be further fostered to bring societal change?

6.b How can peer support groups be utilized to improve autistic wellbeing ?

CIDD: Steven has a recently accepted paper on neurodivergent researchers' understanding of what neurodiversity advocacy is and should be. Emine (emine.gurbuz@port.ac.uk) has written a book chapter on being an ally to autistic people.

HOW YOU THINK RESEARCH SHOULD BE DONE AND WHAT CIDD IS DOING

This theme is not for separate projects but rather what we will consider when planning research together. Here's a summary of your comments and suggestions, and how we align to them..

YOU- General point: Less emphasis in research on what autism is and more on what autistic people can do and how they can be supported

CIDD: Many of our projects are about developing better support, for example at university, at work and in school.

Instruments: We are working on developing assessments and measures that make sense for autistic people and can pick up the 'can do' part.

CIDD: A recently completed PhD project in CIDD analysed the ADOS assessment (contact Leanne: leanne.chrisostomou@port.ac.uk). In general the study of assessments using natural observation methods is one of our topics. We also are recruiting for a study on autistic adults' experiences with the ADOS (Autism Diagnostic Observation Schedule) autism assessment. Contact steven.kapp@port.ac.uk if interested in participating.

YOU: Inclusivity: Include those who do not feel represented in current debates, discourses,

or approaches such as those with minimal speech or intersecting identities of race and LGBTQ+. Specifically, consider when a strength-based approach (or ways in which it is understood or implemented) could be harmful for some. Consider that masking and generally 'fitting in' behaviours could prevent some autistic profiles from being seen and represented in research.

CIDD: We are interested in understanding all forms of communication beyond verbal performance. We are currently recruiting for a project to understand the social leisure experiences of autistic people who do not rely on speech alone to communicate. Please email emine.gurbuz@port.ac.uk if you are interested in participating.

One of our PhD students, Katie Munday, is looking for community partners to explore health and social care inequities for transgender and gender diverse autistic adults living in the UK. Please email katie.munday@port.ac.uk if you are interested in this research.

Real and equal collaboration: Genuine collaborative research means that budgets and responsibilities should be shared and autistic co-researchers treated equally and fairly (participants as well as co-researchers should be also paid for their work and/or time).

CIDD: Many of our projects are carried out with participatory methods, which means that research questions are developed together with autistic people; when we apply for funding, we include a budget for autistic co-researchers. Please email steven.kapp@port.ac.uk regarding results from a community-based participatory research study on the outcomes that matter to autistic adults.

YOU: Trust: Need to rebuild trust after many decades of autistics being spoken of in terms which you do not think are accurate.

We hope that Autism Day and this document are steps in the right direction!

YOU: Access: Make research accessible using comprehensible language and making research easy to find. Question traditional ways of doing research and develop research procedures and designs that are inclusive and meaningful.

CIDD: Steven co-authored research recently on accessible consent materials for autistic adults and adults with intellectual disabilities.

YOU: "Real world" research: research should be grounded in, and inspired by, experience and difficulties of the widest variety of people in different everyday settings.
CIDD: We adopt an "ecological" approach that means we study psychology in context, with observations in natural settings and interviews

YOU: Stereotype-free, old assumptions-free research: research has been for a long time driven by ideas that have been proven limited if not erroneous; however, research paradigms and design perpetuate these ideas.

CIDD: We have abandoned the research methods that have their built-in biases, like one-to-one group comparisons between neurodivergent and neurotypical people; however, we need your help to continue improving research ideas and plans.

CONTACTING US:

If you would like to keep in touch or find out about our latest work, our e-mail address is cidd@port.ac.uk. We also are on BlueSky (@uopcidd.bsky.social) and Twitter/X (@UoP_CIDD).