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SCIENCE AND REALITY OF NEURODIVERSITY.

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Contents

Oral Presentations

Attitudes & Priorities

What do parents of nonverbal and minimally verbal autistic children think and feel about genomic studies of autism? (O1)

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Abstract

The PEAPOD (Personal Experiences of Autism and Perceptions Of DNA-based-research) project was inspired by the launch, and subsequent pause, of the Spectrum 10K study in summer 2021. This situation shone a light on the existential concerns that significant sections of the autistic community have about genomic studies of autism. PEAPOD was established to understand these concerns, and to explore whether a co-created approach to genomic autism research is possible.

The PEAPOD project involves studies of both #ActuallyAutistic adults and parents of autistic children. The study presented here asked parents of nonverbal or minimally verbal children in UK primary schools how they felt about genomic autism studies and how their experience of parenting their child affected their views.

We interviewed 20 parents of nonverbal or minimally verbal autistic children and asked them about their experiences of parenting their child, and their feelings about their child participating in genomic autism research. We also asked how they felt about participating in our study of this sensitive topic. Interviews lasted between 30 minutes and just over one hour and participants could choose to provide their data in a range of ways. The interview schedule was designed in conjunction with two autistic experts by experience and the interviews were conducted by a parent of a minimally verbal autistic child.

We are about to code and analyse the data using reflexive Thematic Analysis. We expect our findings to help us to understand how this group feels about their children participating in genetic research, the questions they would like genetic scientists to be asking and the ways in which they would like them to consider nonverbal or minimally verbal autistic children. We

also expect these parent accounts to contribute to thinking around how to include nonverbal and minimally verbal children – and potentially adults – in these important discussions.

Development of a Questionnaire to Assess Attitudes Toward Neurodiversity (O2)

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Abstract

Background: Attitudes toward neurodiversity can impact neurodivergent individuals' daily experiences and affect whether or not support programs and educational settings are neurodiversity-affirming. For example, teacher attitudes toward neurodiversity might impact interactions with students and whether students can access appropriate accommodations. Accurately measuring these attitudes is important for assessment of neurodiversity training needs and studying the effects of different actors' attitudes on crucial outcomes. While diagnosis-specific instruments have been developed, little research has explored instruments encompassing a larger neurodiversity umbrella. This study's purpose is to develop and validate a measure of neurodiversity attitudes.

Methods: An initial set of 31 survey items were developed based on review of academic literature and first-person narratives. Items were reviewed by researchers with expertise in inclusive education and measurement. To assess item quality, three neurodivergent individuals completed cognitive interviews. Response processes were also evaluated by having undergraduates (N=190) answer items and explain their answers and what they thought items meant. Items not well understood were revised or removed. This was repeated until all items were understood by >90% of participants. Next, the measure will be piloted with ~300 individuals. Data will be fitted to a Rasch model and overall model fit and item and person fit statistics will be evaluated. A Wright map, a figure displaying the relationship between items and participants, will be evaluated to ensure items offer an adequate range of attitudes.

Results: If data fits the Rasch model, this would provide evidence of validity. Some items may exhibit misfit, which could require revision or removal of items. Depending on the degree of revision, more piloting may be necessary.

Conclusions: A validated measure of neurodiversity attitudes is necessary for assessing neurodiversity training needs and measuring effects of trainings. Neurodiversity attitudes may also be an important mediator/moderator variable in future research studies.

Identifying community priorities for dyslexia research (O3)

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Abstract

People with dyslexia experience difficulties learning to read and write, and much of the research to date has focused on identifying the causes of dyslexia and characterising differences between those with and without dyslexia. However, unlike in the autism community, it is not yet known what research people with dyslexia would like to be conducted, meaning that there could be a discrepancy between the research priorities of the dyslexia community and current research taking place, and so the research conducted may not actually benefit the dyslexia community it purportedly serves.

In the first stage of our research, we first sorted all research projects funded in the UK since 1999 into six broad categories. We then conducted seven in-depth focus groups (three with adults with dyslexia and four with parents of children with dyslexia) to gather views on current research priorities and identify areas for future research. Preliminary results suggest that members of the dyslexia community are not in agreement with the current focus of dyslexia research (predominantly brain, biology, and cognition) and feel that more research should focus on teacher training and support for children with dyslexia.

Once these data have been fully analysed, we will use identified themes to create an online survey in which we will ask a larger sample of members of the dyslexia community to rank the priorities identified in the focus groups in terms of importance, as well as answering an open question about future research they'd like to see conducted.

We hope that our results will enable us and others researching dyslexia to refocus our research priorities to align with those highlighted by those with a lived experience of dyslexia because it is critical that researchers listen to those people who will be most affected by the work they do.

The Neurodiversity Movement and its Implications for Interventions: Do Community Members' Own Words Highlight Tensions Closed-Ended Scales Miss? (O4)

Patrick Dwyer[1], Steven K. Kapp[2], Ava Gurba[3], Elizabeth Killagon[4], Kristen Gillespie-Lynch[5], Lynnette Hersh[1], Sergey Shevchuk-Hill[5], David S. Chang[1], Susan M. Rivera[1]

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Abstract

Controversies surrounding the neurodiversity movement (NDM) may be exacerbated by uncertainty over its meaning (den Houting, 2019). This study aims to clarify understanding of the NDM so the desires of autistic advocates are known and valued.

275 autistic (51 parents, 33 professionals, 41 researchers) and 226 non-autistic adults (139 family members, 87 professionals, 59 researchers) answered Likert questions about views on NDM (5 items), social (SM), and medical models (MM; single items), autism intervention goals (35 items; factors defined via EFA), and co-occurring conditions (single items).

Participants answered open-ended questions about the meaning of the NDM, SM, and MM, and their similarities and differences.

NDM and SM support were high. NDM support positively correlated with approval of societal reform and supportive environment intervention goals and negatively correlated with endorsement of normalization and adaptive skills goals, p's<.0001. However, adaptive skills were preferred to normalization, p<.0001.

Participants preferred cure-oriented interventions for epilepsy over depression, p<.0001, and depression over anxiety, p<.0001. Support for societal reform was high, with negligible differences between co-occurring conditions.

In-progress thematic analyses will elucidate nuances in participants' opinions on the NDM, SM, and MM, tensions and diversity of opinion within the NDM, and critiques of the NDM not evident in quantitative data. Participants recognized the NDM and SM are related with similar goals. Many stated the NDM does not reject the MM or medical interventions. Some respondents were concerned the NDM might exclude those with intellectual disabilities and other co-occurring conditions.

Overall, participants' views appeared nuanced. Despite high support for the NDM and SM and strong rejection of normalization of autism, participants were open to interventions teaching adaptive (e.g., interpersonal) skills and curing certain co-occurring conditions. These nuances may suggest opportunities for achieving consensus on some issues, while elsewhere, reconciliation between NDM supporters and opponents may be more challenging.

Perception & Attention

Feasibility and acceptability of a new parent-toddler programme to Support Toddlers with a family history of autism/ADHD to develop strong Attention, Regulation and Thinking skills (START) (O5)

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Abstract

Difficulties with Executive Functions (EFs; thinking and self-regulatory skills such as inhibitory control and cognitive flexibility, which are important for day-to-day problem-solving, and setting and achieving goals) are common amongst autistic individuals and those with ADHD, as well as their first-degree relatives. EFs are associated with academic outcomes, mental health and quality of life, which have been identified as research priorities during community consultation. Supporting children with a family history of autism or ADHD to develop strong EFs may therefore help these children to thrive: this is the aim of the START programme. START comprises 12x weekly parent-toddler support sessions. START aims to support EF development through: increasing opportunities for toddlers to practise EF skills in enjoyable, playful ways that can be embedded into day-to-day life; recognising how parents already support their child's development, and empowering them to develop their knowledge and confidence further; and promoting accommodations and adaptations to meet children's individual needs. The hour-long group sessions have a strong peer support element.

The START programme has been co-developed with a Community Advisory Group and is being piloted with two rounds of 7 parent-toddler dyads with a family history of autism/ADHD (confirmed or suspected). Pilots will be complete by December 2022.

We will present the programme Theory of Change, the community consultation process, and pilot data relating to feasibility (e.g. recruitment and attrition rates, summaries of self- and observer-reported fidelity and adherence ratings) and acceptability (e.g. parent- and practitioner-ratings of clarity and suitability of the materials, and enjoyment of the sessions). Lessons that may be applied to other early-years and/or EF interventions will be highlighted.

Autistic and ADHD adults’ experiences of attention, distraction and focus (O6)

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Abstract

Background: Researchers have described problems relating to attention in both autistic people and people with Attention Deficit Hyperactivity Disorder (ADHD) relative to neurotypicals based on experimental studies. However, anecdotal descriptions of attention from these groups suggest attention in everyday life is shaped by context, and that strengths are experienced alongside challenges.

There is a considerable body of experimental work on neurodivergent attention, but there have been no qualitative studies collating everyday experiences. Likewise, we do not know how autistic and ADHD experiences of attention align, differ or overlap. Here, we take a mixed-methods, cross-syndrome approach to explore focus and distraction in autistic adults, adults with ADHD and neurotypical adults.

Method: We are currently conducting an online survey combining open ended and multiple choice responses on experiences around focus and distraction. The survey was co-designed with autistic researchers and through consultation with non-academic autistics and people with ADHD. In addition we are collecting responses on autistic and ADHD traits using standardised questionnaires.

Analysis plan: Data collection is ongoing (current n = 218). We will use content analysis in order to calculate quantitative summaries of responses to open ended questions which can be compared between the groups. Similarly, we will summarise responses on multiple choice items for comparison between groups. We will also carry out a detailed analysis of the responses in autistic and ADHD groups to open ended questions using thematic analysis in order to identify key themes.

What insights do we expect: This will be the first qualitative study to systematically explore attention in neurodivergent populations. This may help to develop new experimental paradigms more closely aligned with everyday experiences. Importantly, improving understanding of the challenges and strengths relating to attention can better enable neurodivergent people to access environments in which they can thrive.

How auditory processing contributes to the Autistic profile (O7)

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Abstract

We, as humans, require the ability to interpret information from our surroundings. Our interpretation of the sensory world entails allocating attention among the often-numerous sources of sensory stimulation in our environments and then processing and integrating the information provided by our senses into something relevant and meaningful. This not only leads ultimately to behavioural responses, but also gives rise to a vivid phenomenological experience, which can have a strongly positive or negative valence, sometimes to the point of inflicting acute distress. Fortunately, there is increasing motivation to fully understand the impact of sensory processing in the Autistic population, and sensory-focused approaches to understanding autism and Autistic experience have become more grounded in evidence over recent years.

Our proposed presentation, led by a group of Autistic researchers, focuses on the auditory modality – differences in which have repeatedly been reported to have a substantial impact on Autistic people with regards to community access and experiences of sensory distress. Specifically, we aim to provide a full description of the Autistic auditory profile and demonstrate how auditory processing shapes Autistic development and influences other aspects of the Autistic profile. To this end, we review the current body of neural, behavioural, and experiential literature regarding how auditory processing impacts Autistic people, demonstrating how the complexity of auditory processing and experience goes well beyond the hyper- and hypo-responsivity and sensory interests described by autism diagnostic manuals. Furthermore, we discuss a growing body of literature suggesting that auditory differences in autism can play a role in shaping behaviour and cognition more broadly, including language, social communication, stimming, and focused interests. Finally, we raise the question of how we, as researchers, can inform our research questions to align with the priorities of people with auditory processing differences to meaningfully direct both basic and applied sensory autism research.

Chasing the conversation: Autistic experiences of speech perception (O8)

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Abstract

Background:

Among the autistic community, atypical sensory reactivity and communication difficulties are well established. Yet the research literature lacks in-depth self-report data on speech perception among autistic people. We gathered detailed accounts of autistic people's abilities and difficulties perceiving the spoken word.

Methods:

Semi-structured interviews addressed interviewees' experiences of speech perception, contributory factors, and responses. Interview transcripts underwent thematic analysis. The team included two autistic researchers, reducing the risk of neurotypical 'overshadowing' of autistic voices.

Results:

Most interviewees reported pronounced yet heterogeneous difficulties perceiving speech in the presence of competing sounds. Difficulties ranged from powerful auditory distraction to auditory overload. Contributing factors encompassed both features of the soundscape and non-acoustic factors such as multisensory processing and social cognition. Participants also identified compounding factors, including lack of understanding of listening difficulties. Impacts were diverse and sometimes disabling, affecting socialising, emotions, fatigue, career, and self-image. They emphasised that listening difficulties are distinct from social difficulties, though the two can add and interact. A wide array of coping mechanisms was described.

Conclusions:

The first in-depth investigation of autistic speech-perception experiences has revealed diverse and widespread listening difficulties. These combine with internal, interpersonal, and societal factors to induce profound impacts. Lack of understanding of listening difficulties, especially by clinicians, appears to be a crucial exacerbating factor. Many autistic adults have developed coping strategies to lessen or mitigate speech-perception difficulties, generally self-taught due to lack of clinical support.

Implications:

There is a need for carefully designed, adequately powered confirmatory research to quantify and disentangle the various forms of listening difficulty. Large samples should explore heterogeneity within autistic groups and potentially trans-diagnostically. More immediate benefits might be obtained through development of self-help and clinical guidance materials,

and by raising awareness of autistic listening experiences and needs, among the autistic community, communication partners and clinicians.

Health & Wellbeing

Interviews with Autistic Adults about Suicide Risk and Prevention (O9)

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Abstract

Suicide is a leading cause of death among autistic people. Even greater numbers of autistic people experience serious suicidal thoughts and attempt suicide. There is growing interest in suicide risk and prevention in the autistic community, but most research has used survey methods to examine risk factors. Survey methods allow for information gathering from large numbers of participants, but pose limits on the depth of exploration. In this project, we aim to conduct in-depth interviews to inductively explore the perspectives of autistic people who have experienced suicidality. We will explore what has contributed to their suicidality, what has supported their mental health, and what ideas they have for autistic suicide prevention. Our project is currently in progress using a community-based participatory research (CBPR) approach. The community research team includes eight autistic adults who are full partners on the project. For this study, we will interview 10-20 autistic adults about their experiences related to suicide risk and suicide prevention. Interviews will be offered through a variety of remote formats including by phone, video chat, text chat, and email. The interview participants will be residents of the United States and we will use a pre-interview survey to help identify and select participants with a wide range of experiences and backgrounds. To date, we have created the pre-interview survey and a semi-structured interview guide using CBPR methods. Interviews will begin in summer 2022 and preliminary results will be available by March 2023. We will analyze the interviews using an inductive thematic qualitative approach. The results will offer an in-depth exploration of the experiences of a group of autistic adults who have had suicidal thoughts and/or behaviors. The results will also inform our team’s development of a community-based suicide prevention education and community empowerment program.

Let’s talk about neurodivergent menopause: building bridges between disciplines to raise awareness of a critical life stage (O10)

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Abstract

Menopause can be a tumultuous time for people with ovaries, when hormone changes can have wide-ranging impacts on the body and mind. People undergoing this life transition may experience uncomfortable physical symptoms, difficulties with memory and executive function, changeable and dramatic emotions, all of which can affect social and work relationships. Emerging research suggests the impact of menopause on neurodivergent people can range from inconvenient to catastrophic. Some autistic adults report heightened neurodivergent features, a loss of coping and independent living skills, reduced social contact, extreme mental illness and suicidality. Others report a challenges AND benefits during the menopause.

Our team of allistic and neurodivergent academics and autistic community research associates are conducting a multi-stage, multimodal and participatory study. Its three phases all feed into three research questions, which aim to understand a) how autistic people experience menopause, b) how information about menopause can be accessibly conveyed, and c) how autistic communities can meaningfully guide research in this area.

In Phase 1, we conducted four focus groups and ten interviews. These were aimed at informing the design of Phase 3, an online survey exploring menopausal experiences and support needs. Phase 2 of the study is underway: participants are invited to submit creative submissions focused on their menopause experiences. This talk/poster will focus on our methodology, the qualitative analysis used for our Phase 1 conversations, and Phase 2 submissions.

Our research aims to bridge disciplinary silos (involving academics from Psychology, Social Work, Communication and Media Studies, English), connect academic and community members, capture cross-cultural experiences (Phases 1+2 occurring in the UK/Canada, Phase 3 aiming for more international reach), and reach and include autistic minority groups (e.g. marginalised ethnic groups, LGBTQIA+ adults). By offering different modes of participation, we aim to push the boundaries of accessibility and recognise intersectionality.

Investigating sleep problems and links to mental ill health in autistic children and adolescents (O11)

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Abstract

Background

Autistic people commonly report problems with sleep, starting in early childhood. They also experience high rates of mental health problems. In the general population, sleep and mental health problems are thought to influence one another bidirectionally. However, the relationship between sleep problems and mental ill health in autistic people remains poorly characterised. Moreover, the underlying causes for sleep problems in autism are not well understood. Gaining a better understanding in these areas could help improve treatment approaches.

Research Aims

1. Characterise the trajectory of sleep and mental health problems in autistic people across childhood and adolescence.
2. Examine whether sleep problems in childhood predict the development of mental ill health later in life for autistic people.
3. Identify candidate biopsychosocial factors which might help predict sleep problems in autism.

Methods

These research aims will be achieved by conducting secondary analysis of data from the Avon Longitudinal Study of Parents and Children (ALSPAC, total n = 14,000). The analyses will be conducted using questionnaire data from this study, as well as linkage data from education and health records. For Aim 1, trajectories will be characterised and compared between non-autistic and autistic participants. For Aims 2 and 3, the associations will first be modelled in the whole sample, with autism-trait scores as a mediator. This will be followed by repeating the analysis in a subset of participants with an autism diagnosis. To maximise the impact of this research, the project is being co-produced with input from a team of autistic people with lived experience of sleep problems.

Potential Insights

The findings from this project might help us gain a better understanding of the extent to which sleep problems might be driving mental ill health in autistic people. It could also provide some insight into the mechanisms underpinning sleep problems in autism.

The feasibility of Shared Experience Interviewing as an inclusive framework for mental health research in neurodivergent young people (O12)

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Abstract

Background: Neurodivergent young people are particularly at risk for mental health conditions, yet traditional models of translational mental health research often rely on concepts defined by non-neurodivergent adults. This study is part of a wider programme, Regulating Emotions–Strengthening Adolescent Resilience (RE-STAR), which places the voices of young neurodivergent people at its heart, through the use of a co-intentional translational model of mental health research.

Aims: In this study we explore the feasibility of co-production and co-delivery of Shared Experience Interviewing, and its impact on a qualitative study exploring emotional regulation in neurodivergent youth.

Methods: Ten young adults (aged 18 – 25 years) with attention deficit hyperactivity disorder (ADHD) and/or autism spectrum condition (ASC) were recruited to form RE-STAR's Youth Researcher Advisory Panel (Y-RAP). The Y-RAP worked with RE-STAR researchers to co-produce an interview schedule for use in a larger qualitative study (n=50). Members of the Y-RAP have now been trained to co-deliver the interview schedule alongside RE-STAR researchers, with a group of 12 young people (aged 11 – 15 years) with ADHD and/or ASC. Post-interview evaluations will be completed to explore what including someone with shared experience adds to the interview process. Analysis: Reflexive thematic analysis will be used with the qualitative interviews and post-interview evaluations. We will explore (i) the feasibility of Shared Experience Interviewing, (ii) whether co-interviewers and interviewees think this approach

could lead to more complete and/or accurate accounts, (iii) how co-interviewers and interviewees experience this approach.

Potential insights: The Shared Experience Interviewing protocol will offer a novel, inclusive and reflective tool for mental health research with (not on) neurodiverse young people.

Implications: RE-STAR, through its co-intentional translational approach, will combine science-based approaches with neurodivergent perspectives to inform the development of future mental health interventions, tailored to the needs of neurodivergent young people.

Inclusive Schools

Creating supportive social groups for neurodivergent high school students (O13)

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Abstract

There is a move away from traditional ‘social skills groups’ for neurodivergent young people. Teaching young people to ‘mask’ (hide) their neurodivergence can have negative consequences for mental health and does not help in developing meaningful social relationships. Instead, neurodiversity-affirmative approaches encourage acceptance and celebration of individual differences and find positive, strength-based approaches to facilitating genuine social connection for those who want it.

The aim of this project was to develop a training package for teaching staff in secondary schools to help them create supportive groups for neurodivergent students, providing them with a safe space to develop social relationships, as well as developing staff and students’ understanding of neurodiversity. This would, in turn, promote acceptance, positive self-esteem and mental wellbeing.

In order to understand the first-hand experiences of neurodivergent young people and to hear their views on the proposed training package, we interviewed 15 neurodivergent young people aged 16-24. We then carried out a thematic analysis to identify and summarise important points made by young people, as well as highlighting responses that were not common, but would be significant in developing the training package.

The views of our participants suggest that it may be beneficial to create groups based on particular interests and activities, incorporating extra support for creating new social relationships in a non-forced way.

Moreover, there should be the opportunity for neurodivergent young people to mix with others, but no expectation or assumption that they will get along just because they are both neurodivergent. School staff and students should not generalise across all neurodivergent people, made evident by the fact that everyone we interviewed had different preferences and views. These results have been shared with the professionals creating the training programme, and this is currently being developed, guided by the opinions and real-life experiences of neurodivergent young people.

The everyday experiences of autistic children in mainstream primary schools: a qualitative investigation using photography and written accounts (O14)

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Abstract

The challenges experienced by autistic children in mainstream schools are well documented in the research literature. However, much of what is currently known about their everyday school lives comes from data collected from parents, teachers and allied professionals, with the subjective experience of being an autistic child in a mainstream school receiving much less attention from researchers. The few studies that have attempted to capture the views of autistic children have tended to focus on the secondary school years and those in specialist educational settings. Currently, little is known about the lived experiences of autistic children in mainstream primary schools who do not meet the criteria for specialist support. The present study aims to contribute towards this gap in the literature by using Interpretative Phenomenological Analysis — a qualitative method concerned with the study of how people make sense of major life events — to investigate the school experiences of 10 autistic children (5 male, 5 female) aged between 9 and 11 years attending mainstream schools and receiving no statutory special educational support. Participants were invited to use photography and written accounts to capture the most important aspects of their school lives. These materials were then used as the basis of a series of online interviews in which participants could speak or type to communicate. The analysis phase is still ongoing, but preliminary findings suggest participants frequently feel overwhelmed by the pressures of spending long periods of time in an environment not designed for autistic ways of being. The data also suggest that the adaptations that make school more accessible for autistic children are environmental, cultural and attitudinal rather than interventionist in nature. It is expected that the results of this study

will call into question the merits of the current interventionist approach to autism support in English mainstream primary schools.

Evaluating the use of Flexible Seating in a Mainstream Primary School for neurotypical and neurodivergent pupils (O15)

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Abstract

Most neurodivergent pupils are educated at mainstream schools. Whilst adaptations to seating are sometimes recommended to accommodate the needs of certain children (for example by occupational therapists), the use of a range of different seating options in classrooms as a whole is not a widespread practice in mainstream schools. In this case study within a mainstream primary school, different seats (e.g., rocking chairs, wobble stools) were trialled in each classroom from reception (ages 4-5) to year 6 (ages 10-11), where all children had open access to seats of their choosing. Halfway through the academic year, 315 pupils (including 57 neurodivergent pupils) completed a questionnaire (guided for younger pupils) eliciting quantitative and qualitative data about their chair preferences and reasons. Older children also completed presentations where they were asked to present in small groups about what furniture they would purchase if they were 'head teacher for a day'. The qualitative data was coded using content analysis. Provisional findings indicate that children positively link the use of different chairs to concentration, productivity and movement. Further, 33 staff including teachers and teaching assistants completed a survey eliciting both qualitative and quantitative data on their views on the use of flexible seating in their classrooms. Provisional findings indicate that staff were overwhelmingly positive about the use of the chairs, and think that their use as a whole class adaptation rather than an accommodation for select pupils is a positive approach. This study has the potential to influence decision makers in schools and applying its findings could provide a simple yet effective way to meet the differing sensory needs of pupils at school, whilst reducing stigma often associated with attaching an adaptation to any one child or group of children.

Designing Sensory Spaces to Improve School Access, Participation, and Achievement of Neurodivergent Students: An Interdisciplinary Approach (O16)

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Abstract

Background: Many neurodivergent individuals experience sensory differences that are associated with difficulties with school access, participation, and achievement. Sensory differences are behavioural and emotional responses to sensory stimuli that disrupt daily functional engagement (Lane, 2020; e.g. reacting aggressively to light touch). While individualised supports (e.g. noise cancelling headphones) have been used to help neurodivergent children with sensory differences at school, attention is turning to the role of the sensory qualities of learning spaces as both inhibitors and facilitators of neurodivergent learning. Currently, however, there are no evidence-based guidelines for the use and design of sensory spaces in schools for neurodivergent learning. Aims: In this paper, we aim to: (1) assess the extant literature examining the use of sensory spaces to support learning of neurodivergent students, and (2) devise an interdisciplinary design framework for sensory spaces in schools. Methods: We conducted a narrative literature review of the use of sensory spaces in schools for neurodivergent individuals with sensory differences. Sensory design experts from Architecture, Building and Construction, Occupational therapy, and Psychology, then synthesised the literature and developed a design framework for sensory spaces for use in schools. Results: The literature assessing the use of sensory spaces in schools and their impacts on neurodivergent student learning is sparse and inconclusive. Within these constraints, however, there was consistency in the reporting of the utility of dedicated sensory spaces to support student emotion regulation, learning, focussed academic work and school enjoyment. An interdisciplinary design framework that considers specific space functions and goals alongside clinical, design and construction elements will be presented. Conclusions: Sensory differences are commonly identified by neurodivergent individuals as a barrier to full inclusion in daily life, including at school. An interdisciplinary approach to the design of sensory spaces in school may improve the school experiences and learning opportunities of neurodivergent students.

Poster Presentations

Session A: Wellbeing & Quality of Life

Sensory, attention and mental health interventions for autism: a technological patient and public involvement study (A1)

David Ruttenberg[1], Oonagh Coleman[2], Joni Holmes[3], Kaśka Porayska-Pomsta[1], Sarah White[1]

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Abstract

The use of digital mediations among autistic individuals has grown dramatically owing to hardware and software availability but there is a paucity of studies describing how technologies might aid sensory-sensitivity, anxiety, and distraction. Heterogeneity complicates but also prompts tuned accommodations that adapt to individual sensory thresholds.

Before attempting to address the needs of those living with sensory, attention, and mental health concerns, we conducted a Personal & Public Involvement (PPI) study to better understand autistic individuals' daily experience, and their potential desire for and tolerance of technological aids. Data was gathered from focus groups with autistic individuals (N=14) and online questionnaires with both autistic (N=187) and non-autistic individuals (N=174).

Focus groups produced six themes ranging from sensitivity cues to technology use. Thirty-three variables were scored using matrix tables, creating 103 autistic-voiced and 48 non-autistic-voiced questionnaire items. Word cloud metadata confirmed that language resonated with autistic participants.

From the questionnaires, autistic adults reported greater visual and physiological sensitivity, combined with increased anxiety. Distractibility was greater for older and less educated autistic individuals, while anxiety was greater for females and for more educated autistic adults. Sensory sensitivity predicted distractibility, with anxiety facilitating the association between the two, indicating that a focus on sensory sensitivity might have downstream benefits. Technology was already a big part of autistic adults' lives, and the vast majority said they would welcome smart devices that responded to their personal preferences and helped reduce anxiety and

distraction, especially in sensory environments. The focus groups also highlighted the desire for smart devices utilizing alerts and guidance.

Creating sensory-alleviating technologies that meet autistic individuals' lived-experience is a significant and non-trivial task. The extensive variability of environmental and physiological stimuli creating discomfort for autistic individuals implies that meaningful and personalized digital mediations may have significant and widespread benefits.

An exploration of the association between metacognition and quality of life in a sample of older autistic adults (A2)

David Mason, Karen Glaser, Patricia Howlin, Francesca Happé

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Abstract

BACKGROUND: Autistic people often display atypical cognitive processing (e.g. eye for detail) compared to non-autistic participants. Recent research has found that metacognition (i.e. "thinking about thinking") is different in autistic compared to non-autistic samples. Better metacognition has been linked to better self-reported Quality of Life (QOL) and associated constructs (e.g. well-being). However, this association has yet to be examined in autistic participants. Thus, this study examines how self-reported decision-making style, and metacognition (assessed behaviourally) is associated with self-reported QOL in a sample of older autistic people.

METHODS: We recruited a sample of 30 older autistic adults (mean age 56.7 years, 40–72; 10 females, 16 males, 4 with other gender identity or not reported) who were all diagnosed in adulthood (mean age of diagnosis 49.3 years, 35–67). Each participant completed a range of psychological measures (including decision making style, cognitive insight, depression, anxiety, and autistic traits), self-reported QOL, a brief measure of cognitive ability, and a metacognitive behavioural task.

RESULTS: Preliminary results suggest that QOL is not correlated with autistic traits, nor with self-reported cognitive insight. However, Social QOL is positively correlated with a self-reported intuitive decision-making style; however, other decision-making styles are not correlated with QOL. Analyses are ongoing to examine how behavioural metacognitive ability is related to QOL.

CONCLUSIONS: These preliminary analyses suggest that, overall, QOL is unrelated to self-reported decision-making style, or cognitive insight (which can be considered a subset of metacognition). However, these findings must be considered in light of the small sample size, with low statistical power. Subsequent analyses with the behavioural (as opposed to self-

reported) measure may help identify an alternative mechanism linking cognition and QOL. If supported, this may shed light on how autistic individuals construct QOL appraisals.

Supporting the Mental Health of Autistic Students (A3)

Emma Jenks, Felicity Sedgewick

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Abstract

Autistic students are currently ~2.4% of the UK university student population. These students are particularly vulnerable to stressors within a university environment and are more likely to experience poor mental health than their non-autistic peers. Despite this, there is a lack of tailored support for autistic students at university.

The current project assesses a six-session training course, co-created with autistic students, staff, and relevant experts, for university staff who work directly with autistic students (e.g. personal tutors, disability support staff, careers advisors), focused on debunking stereotypes, educating on the autistic experience at university, and highlighting the differences in mental health presentation between autistic and non-autistic individuals. It also aimed to provide practical strategies and tips for these staff members to help make interactions with autistic students as accessible and beneficial as possible.

We anticipate between 40 and 60 staff taking part from three universities. The Autism Stigma and Knowledge Questionnaire (Harrison et al., 2017) will be administered before and after the training, to examine changes in their understanding and acceptance of autism and autistic people. The differences in responses between time points will be analysed through a repeated measures ANOVA. The project also involves diary entries from participants over the following academic year, tracking the use of strategies and how the training has impacted their interactions with autistic students. These will be analysed through either thematic analysis or frequency analysis, depending on the quantity and quality of data we receive through this method – data to date will be reported at ITAKOM.

It is hoped that, following evaluation, the course can be refined and made available to a larger body of university staff. Our project has the potential to develop a set of good practice guidelines for co-creation of resources, trainings, and autism education materials in higher education settings.

Anxiety and Prayer: Listening to Autistic Experience about Prayer, Anxiety and the Relationship Between the Two (A4)

Helena Cundill

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Abstract

In anxious times, Christian communities often encourage prayer and religious practice as a way to reduce anxiety and to promote inner well-being. Underlying this are certain theologies of prayer, and assumptions about human-God communication, which have never explicitly considered the viewpoint and experience of Christians who are autistic.

Using a participatory method called Theological Action Research, this (doctoral research) project sought to listen to the experiences of autistic Christians, and to ask this question: are the current teachings and practices of the Church inclusive and beneficial to autistic people of faith?

Steered by an all-autistic Research Advisory Group, data was gathered using semi-structured interviews with 12 autistic Christians (ages 18-76) and two online focus groups. Participants represented a range of Church backgrounds, both Catholic and Protestant. The project obtained approval from the Committee for Research Ethics and Governance at the University of Aberdeen and was supervised by Dr Léon van Ommen (University of Aberdeen) and Dr David Simmons (University of Glasgow).

Initial analysis of the data found that, rather than alleviating anxiety, prayer can become an anxiety-inducing area for autistic Christians. This was mostly attributed to three sources:

i) A sense of inadequacy because a person's habits of prayer did not conform to certain structures or routines that were promoted by their Church or Christian community.
ii) Feelings of uncertainty about the role/necessity of speech and language in prayer.
iii) Anxiety about the 'correct' way to pray, particularly in 'intercessory' prayer, (where Christians ask God to act or intervene in situations or life events.)

This paper considers the impact of these research findings, both for Church teaching, but also for therapeutic practice in the secular world, given that prayer shares many characteristics with recommended activities such as Mindfulness, and with treatment pathways such as Cognitive Behavioural Therapy.

Communicating distress: a qualitative study considering the language autistic adults use to describe their mental health needs (A5)

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Abstract

There is a known association between autism and mental health difficulties however autistic adults with mental health needs are less likely to seek formal support than non-autistic adults. Communication difficulties is a known barrier for autistic adults seeking to access mental health services. This study proposes to better understand this issue, with a view to developing future recommendations stemming from the research. This study will therefore consider the following research question: “What words and phrases do autistic adults use to communicate psychological distress or mental health concerns to health care professionals?”

A qualitative methodology will be used for this project. The data will be analysed using content and linguistic analysis. 12 participants were recruited and have taken part in semi-structured interviews. Descriptions of specific mental health diagnoses will be taken from recognised manuals such as the Diagnostic and Statistical Manual of Mental Disorders and the International Classification of Diseases. These descriptions will be matched to the language used by the participants in order to develop groups of words and phrases for each diagnosis.

It is anticipated that the analysis will show a disconnect between the words and phrases used by autistic adults describing their mental health, and the words and phrases that a clinician (e.g. GP) would expect to hear in order to diagnose mental ill-health or recommend appropriate treatment. It is hoped that this study will support future training to be provided to professionals working with autistic people in psychological distress. In addition, this could support health literacy education and promotion amongst autistic adults (e.g., if you feel X and say Y then you will be offered Z).

Gathering perspectives from a diverse group of caregivers about anxiety in autistic children who speak few words (A6)

Molly McCabe[1], Tamsin Green[2], Laura Crane[1], Anna Melissa Romualdez[1]

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Abstract

Background: Research suggests anxiety is common among autistic people. Despite growing research about anxiety in the autistic community more widely, there is less known about anxiety within specific groups within the autistic community, such as autistic people who speak few words and autistic people from minoritized ethnic backgrounds.

Aims: This study sought to better understand the experiences of caregivers who support their autistic children with anxiety. The study aimed to elicit perspectives not typically represented in research such as caregivers of autistic people who speak few words and are from minoritized ethnic backgrounds within the UK.

Methods: Caregivers were recruited through community groups and primary schools throughout London. Semi-structured interviews were conducted with three caregivers on their perceptions of their child's anxiety and experiences of supporting their child with their anxiety.

Results: During interviews, caregivers talked about difficulties with relying on different behavioral cues to determine if their child was feeling anxious. They also described effective preventative strategies and difficulties with supporting their child with anxiety in the moment. Worries about children's isolation, safety, and mental health due to their anxiety were expressed. Finally, they described their own difficulties including increased stress and feeling drained.

Impact: This study adds to the story of how anxiety affects autistic people and their families. Our results show several areas within management and impact of anxiety that would benefit from more focused research. Going forward research must seek to explore these perspectives by working with the community with the goal of creating sensitive supports that address the needs of all autistic people.

Community Collaboration: Our research focus was created in collaboration with Autistica, a research charity. The interview schedule and final analysis was carried out in partnership with a collaborator who has lived experience of caring for an autistic child who speaks few words.

Self, parent and teacher assessments of depressive symptoms in children with Attention-Deficit Hyperactivity Disorder (A7)

Emily Williams[1], Victoria Powell[2], Olga Eyre[2], Frances Rice[2], Lucy Riglin[2]

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Abstract

Little is known about the abilities of schoolteachers to identify depressive symptoms in their pupils with Attention-Deficit Hyperactivity Disorder (ADHD). This study aimed to compare reports of depression symptoms in a non-ADHD group and an ADHD group of young people identified in a population sample and to compare teacher-, parent- and self-reported depression symptoms within the two groups. Investigations were conducted in a sample of 1960 children aged 11-12 attending a mainstream school. The non-ADHD and ADHD groups were defined using a cut-point applied to teacher's responses to the hyperactivity-inattention subscale of the Strengths and Difficulties Questionnaire (SDQ). The children, their parents and their teachers provided information on depressive symptoms in the children by completing the Short Mood and Feelings Questionnaire (SMFQ). T-tests were used to compare mean total SMFQ scores from each reporter type between and within the two groups. Results showed that depressive symptoms were scored more highly in the ADHD group than in the non-ADHD group by parents (difference=7.04, SE=1.41, p=<0.001) and teachers (difference=4.74, SE=0.42, p=<0.001), however, children in the non-ADHD and ADHD groups scored themselves similarly (difference=0.87, SE=0.88, p=0.29). Within the non-ADHD group, children scored themselves most highly for depressive symptoms, teachers scored them the lowest and parents scored them intermediately (child-parent difference=1.86, SE=0.25, p=<0.001, child-teacher difference=3.05, SE=0.16, p=<0.001, parent-teacher difference=1.56, SE=0.21, p=<0.001). Within the ADHD group, depression symptoms were rated similarly across all respondent types and the trend observed across raters differed: children scored themselves the lowest for depression symptoms, parents the highest and teachers scored them intermediately (child-parent difference=1.67, SE=4.81, p=0.74, child-teacher difference=1.18, SE=1.27, p=0.36, parent-teacher difference=3.67, SE=4.42, p=0.45). The results of this study indicate potential utility in approaching schoolteachers as part of assessments for depression in children with ADHD.

An international study on experiences of discrimination and well-being among autistic adults (A8)

Yulin Cheng

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Abstract

The neurodiversity movement has shifted the way we think about and construe autistic experiences, communication, interaction and behaviour with far-reaching implications for not just how autism research is conceptualized, conducted and analyzed but also the changes it brought to the lives of autistic people. However, like most autism research, discussions of neurodiversity are primarily led by and centered on Western perspectives. Its implications for

global autism research and relevance to the lives of autistic people from non-Western cultures and regions are less known and seldom discussed, particularly in countries or regimes where autistic people remain largely out of the picture, where autism remains poorly understood and highly stigmatized. The aim of this research is to compare the lived experiences of autistic people from amongst a socio-demographically diverse background to examine how discrimination affects their identity, mental health and well-being. Building on the premise that a stressful social environment leads to poorer health outcomes, do autistic people from cultures with high autism stigma report a higher level of emotional distress? What is the role of the social environment in this regard? These are some of the questions this study seeks to address using a mixed method design involving an online survey and semi-structured interviews with autistic adults. The findings are expected to shed light on the commonalities and differences influencing mental health and well-being in autism. In addition, the implications of the findings for the neurodiversity movement will be considered.

Understanding the impact of learning about wellbeing on Autistic adults and their allies taking an online course run by Autistic people (A9)

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Abstract

Since September 2021, the Australian, Autistic-led charity, Reframing Autism, has run courses designed, delivered and facilitated by Autistic experts on fostering Autistic wellbeing. These 6-module courses cover aspects of Autistic lived experience impacting on wellbeing, and are tailored to the needs of different cohorts: the Autistic population, families of Autistic individuals, and professionals. The expressed outcomes of the courses are for participants to build the theoretical and scientific knowledge, and the practical application, to build Autistic wellbeing and resilience, foster community engagement, and experience improved mental health and quality of life outcomes.

This presentation will offer some early insights into the impact of these courses on the participants compiled from evaluation and qualitative data collected within the course, and a formal research project analysing their impact on wellbeing. Participants have been invited to participate in research measuring their personal wellbeing, self-esteem, family quality of life (if applicable), Autism acceptance, self-acceptance and implicit bias at both the beginning and completion of the course, to understand participant growth and change in these areas. Whilst our early qualitative analysis has indicated significant growth in personal wellbeing for Autistic adults taking the course, we were especially interested to understand the impact of the courses on internalised ableism and implicit bias across cohorts. For non-autistic participants we are

also interested in understanding qualitatively their experiences of Autistic facilitation and map correlations between Autistic-led education and implicit bias.

This research seeks to establish early evidence to argue for a focus on wellbeing rather than remediation, and for Autistic-led interventions. Implicit bias is traditionally considered difficult to ‘move’, but is also an acknowledged driver behind the exclusion, marginalisation and oppression of Autistic communities. Understanding any changes in implicit bias through Autistic-led, strengths-focussed education may offer insight into how broader social acceptance of Autistic individuals might be achieved.

Being able to fulfil oneself or live one's interests: The impact on the quality of life of autistic adults (A10)

Vicky Caron[1], Nuria Jeanneret[2], Guerrero Lucila[2], Mathieu Giroux[2], Mélanie Ouimet[2], Baudouin Forgeot d'Arc[3], Isabelle Soulières[1], Isabelle Courcy[3]

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Abstract

Traditionally, autistic individuals’ intense interests have often been perceived as harmful and interfering with learning and daily functioning. However, some researchers are questioning this view of autistics' interests and current trends in autism research and practice are moving away from a focus on impairments to recognizing the unique abilities and strengths that autistic people may possess. This strength-based approach suggests that characteristics of autism such as special interests can be potentially useful and contribute to their quality of life (QoL). Indeed, it has been suggested that interests could be targets to promote employment, which has been associated to better QoL. As this hypothesis remains to be verified, we asked: what are the relations between quality of life, employment status and interests among autistic adults?

Using a participatory research approach, we developed an online questionnaire in partnership with three autistic expert collaborators. In this questionnaire, QoL was assessed with the WHOQoL-BREF. Participants also answered questions about their interests/passions and sociodemographic characteristics. A total of 226 autistic adults (19 to 74 years old, officially diagnosed or self-identified) took part in the study.

Statistical analyses confirmed that having enough time to pursue one's interests had a significant positive effect on QoL. On average, participants who reported having someone to share their interests with reported better QoL than those who reported having no one to share with. Among employed participants, being able to fulfill one's interests through one's job had a significant positive effect on QoL. Qualitative analysis of types of interests led to the

understanding that interests are not as restricted as once thought and could contribute to promoting employment in autistic individuals. Altogether, these results demonstrate that autistic individuals who do not have a life context allowing them to pursue their interests report a lower QoL.

Evolving job satisfaction over the first three months for new employees on the autism spectrum and/or with intellectual disability: Employee, employer, and job coach perspectives (A11)

Flavio Murahara[1], Valérie Martin[2], Cynthia Di Francesco[1], Tara Flanagan[1], Aparna Nadig[1]

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Abstract

Job satisfaction contributes to social inclusion as it is related to higher employment retention and subjective well-being (1). We extend the literature on the job satisfaction of employees on the autism spectrum and/or with intellectual disabilities (ID) who receive employment support services (2,3). Specifically, we use a novel approach that explores job satisfaction from a triad of perspectives: employee on the autism spectrum and/or with ID, employer, and job coach, during the critical first three months of employment (4).

A multiple case approach (5,6) was used to explore participants' experiences and identify commonalities and differences among nine case triads (employee, employer, job coach). Data were obtained through field notes, short interviews, an employee job satisfaction questionnaire, employer evaluation of the employee, and an evaluation of specific job coach services, collected at two timepoints (immediately after hiring and 3 months later).

Three independent reviewers conducted a qualitative analysis of the nine case triads, and through discussion, found three major themes. 1) Establishing an optimal match between job seeker and prospective workplace, 2) Developing a supportive employer-employee relationship, 3) Engaging in a proactive approach to job coach support over time.

Based on this triadic (employee, employer, job coach) multiple case approach, we reflect upon the influential elements of job satisfaction in the workplace for employees on the autism spectrum and/or with ID. Working with employees' and employers' expectations during the training process may promote more consistent job satisfaction in the three initial months of employment. Moreover, promoting clear communication between employers and employees throughout these initial months7 may facilitate job satisfaction. Job coaches must also continue to offer support proactively, even after the initial employment integration period as issues may arise between employees and employers, who may struggle to identify and express their needs and, in turn, solve issues.

The findings from a systematic review and meta-analysis investigating the impact of play-based interventions on the mental health of autistic children and children with developmental language disorder (A12)

Gill Francis, Emre Deniz, Carole Torgerson, Umar Toseeb

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Abstract

This systematic review and meta-analysis is published in the Journal of Autism and Developmental Language Impairment (Francis, et al., 2022). The review aimed to assess the impact of play-based interventions on mental health outcomes from studies of children with developmental language disorder (DLD) and autism (ASD), as well as to identify the characteristics of research in this field. The study selection process involved a rigorous systematic search of seven academic databases, double screening of abstracts, and full-text screening to identify studies using randomised controlled trial (RCT) and quasi-experimental (QE) designs to assess mental health outcomes from interventions supporting children with DLD and ASD. For reliability, data extraction of included studies, as well as risk of bias assessments were conducted by two study authors. Qualitative data were synthesised narratively and quantified data were used in the meta-analytic calculation. A total of 10 papers met the criteria for inclusion in the review. There were 8 RCTs and 2 QEs using 7 named play-based interventions with ASD participants only. Meta-analysis of 5 studies addressing positive mental health outcomes (e.g. positive affect and emotional functioning) found a significant overall intervention effect (Cohen's d = 1.60 (95% CI [0.37, 2.82], p = 0.01); meta-analysis of 6 studies addressing negative mental health outcomes (e.g., negative affect, internalising and externalising problems) found a non-significant overall intervention effect (Cohen's d = 0.04 −0.17 (95% CI [-0.04, 0.51], p = 0.88). A key observation is the diversity of study characteristics relating to study sample size, duration of interventions, study settings, background of interventionists, and variability of specific mental health outcomes. Play-based interventions appear to have a beneficial effect on positive, but not negative, mental health in children with ASD. There are no high-quality studies investigating the efficacy of such interventions in children with DLD.

Success, Enjoyment and Mental Health Differences between Neurodivergent and Neurotypical Higher Education Students in Australia and New Zealand (A13)

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Abstract

Neurodivergent students are enrolling in higher education in increasing numbers, but completion rates remain low. Most research focuses on autistic students attending university, however, research including other neurodivergent conditions, i.e., attention deficit/hyperactivity disorder, specific learning disorders, communication, tic and developmental coordination disorders, remain understudied. Success has been linked to the enjoyment of higher education and mental health conditions for neurotypical students but has not been investigated in neurodivergent students as a group.

The aim of this study was to examine neurodivergent students regarding enjoyment of higher education, completion of units studied and mental health conditions. Understanding these phenomena may enable the provision of more tailored supports for neurodivergent students to increase their retention and higher education completion rates. The research question asked was “For neurodivergent students, does mental ill-health affect enjoyment and completing units?”. The study was informed by lived experience advisors.

204 Australian and New Zealand current and past higher education students (2015-2021) completed an anonymous online survey. There were 131 neurodivergent (Mage = 31.34) and 73 non-neurodivergent (Mage = 33.16), majority females (70.4%). The survey captured diagnosis, disclosure and support experiences, autistic traits, and anxiety and depression symptoms. There were statistically significant differences in enjoyment and passing of units between neurodivergent and neurotypical students. However, clinical levels of anxiety, depression and autistic traits were not significantly associated with enjoyment or passing of units for neurodivergent students. The implications of these findings suggest that while neurodivergent students have significantly lower enjoyment and pass fewer units than neurotypical peers, poor mental health may not be the reason for this. Explorations into alternate factors associated with higher education enjoyment and success are warranted.

Session B: Creativity & Sensation

Benefits of Improv for autistic adults: a short 4-week course (B1)

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Abstract

Introduction

This study investigated the benefits of improv comedy for autistic adults attending their first course. Specifically, the research queried whether the participants believe there had been any benefits from participating in the sessions.

Methods

This study has 17 participants with a range of ages (20 – 56 years old), but most participants are Caucasian (76%). Genders were beyond the binary split of male and female. This study used focus group and analysed the data using Qualitative Content Analysis.

Results

Seven themes emerged from the data. These were: 'Being accepted as and with other autistic people'; 'Autistic valued skills, and allotted time to practice'; 'Quality of Life and Mental Health benefits'; 'Provides a way into or inspire an activity I want'; and 'Not every autistic person will perceive or gain benefits'.

Discussion

This study indicates that even from a short four-week course, elicitation of a variety of benefits can be achieved or noticeable. Participants often seemed to require an autistic space in classes, which relates to the autistic people occupying neurotypical space (akin to the concept of spatial imaginaries). Skills were preferred to be additive not replacement. The QoL gains (as per Schalock et al., 2002) are possible even within a short space of time. Nevertheless, it is noteworthy that not all autistic people will gain benefits.

Conclusion

Improv comedy seems to have benefits for autistic adults. These include being accepted, learning valued skills, and QoL. However, not all autistic people will gain, or perceive value in or from improv. Nonetheless, this study adds to understanding regarding how autistic adults may gain through a specific activity, i.e., improv comedy.

Watch me first: Replication and innovation in a tower-building task with autistic and non-autistic adults (B2)

Harriet Axbey[1], Catherine Crompton[2], Sue Fletcher-Watson[2], Alisdair Tullo[2], Nadin Beckmann[1]

[1]Durham University, Durham, United Kingdom. [2]Edinburgh University, Edinburgh, United Kingdom

Abstract

Whether we choose to replicate or innovate depends a lot upon our relationship with the person we are looking to. If we trust that person and their methods, we may follow their lead; whereas if we feel a disconnect, we may take matters into our own hands and create our own way of doing things. Evidence from previous studies suggests autistic people have greater rapport with those sharing their diagnosis than with non-autistic individuals (Crompton, Ropar, Evans-Williams, Flynn, & Fletcher-Watson, 2020; Crompton, Sharp, et al., 2020). This can be linked to the theory of the double empathy problem causing a disjuncture in reciprocity between autistics and non-autistics (Milton, 2012). In this study, 71 adults (35 autistic) took part in a tower building exercise as part of diffusion chains that were either autistic, non-autistic, or alternating autistic and non-autistic. The research questions asked whether there would be more replication within single-neurotype chains than in the mixed chains. Using images of the towers built in the task, 351 independent raters judged the similarity of these towers through a matching task. Results showed there was the greatest similarity between towers built by the non-autistic participants, and the least similarity between towers built in the mixed chains. These findings could inform the way support is delivered, as it reinforces the evidence that autistic individuals interact well with other autistics. More research could be done to look at the thought processes behind those taking part in such tasks, to see to what extent they are aware of their replication or innovation choices.

Using storytelling skills to describe everyday events: investigating areas of strength and challenge for autistic young people (B3)

Anna Harvey, Helen Spicer-Cain, Nicola Botting, Lucy Henry

City, University of London, London, United Kingdom

Abstract

Aims: To investigate how coherently autistic adolescents are able to describe everyday events and to determine which linguistic and cognitive factors predict narrative ability.

Background: Spoken narrative (storytelling) skills are important for young people across many different contexts and have a significant positive impact on both academic attainment and social outcomes. Previous research into the narrative skills of autistic people has produced conflicting findings, with some studies indicating strengths in producing coherent narrative accounts when compared to well-matched neurotypical comparison groups. Other studies, however, have highlighted areas of challenge. Most previous work has focused on fictional narratives and there is little research into whether autistic adolescents show strengths in recounting real-life events.

Methods: This study compares the narrative abilities of 50 autistic adolescents (11-15 years) with a non-autistic comparison group closely matched on age, cognitive ability and language skills. Participants are asked to describe ‘what happened’ in two videos, chosen to replicate real-life instances of narrative. A novel framework for assessing narrative coherence has been developed as part of this project and will be used to score participants’ narratives alongside more established methods. In addition to group comparisons, regression analyses will be used to investigate underlying factors contributing to narrative ability across both groups.

Findings: This study is still in progress (projected completion date: October 2022). If no group differences are observed, the findings will be disseminated as further evidence for communicative strengths in autism. However, if everyday narrative skills are found to be an area of challenge for autistic adolescents, these findings can be used to better understand challenges that these young people may face in daily life and inform new ways of supporting functional communication skills. By investigating predictors of narrative ability, this study will also contribute to our understanding of the relationships between language and cognition.

‘FND Stories’ - Capturing the stories and lived experience of those diagnosed with the neurological condition Functional Neurological Disorder (FND) through multidisciplinary art (B4)

Andrew Brooks

Creative Informatics (Funders), Edinburgh, United Kingdom. University of Edinburgh (Architecture Tutor), Edinburgh, United Kingdom

Abstract

I exhibited ‘FND Stories’, a multidisciplinary art exhibition, at Inspace, University of Edinburgh, June 7-26. The project was funded by Creative Informatics and independent from but supported by FND Hope UK. It is based on 6 in-person interviews from around the UK with people living with Functional Neurological Disorder (FND) along with contributions from over 90 diagnosed people from around the world.

FND is a common and disabling cause of neurological symptoms. The symptoms are not caused by a structural disease of the nervous system but a problem with its functioning. Symptoms are highly varied and can cause impairment in quality of life.

Working with online surveys and the videos and transcripts of the interviews, I used text mining and data analysis (Python and Excel) to interpret the stories and data.

The artwork includes video, word and ink-based art, to represent different facets of stories. Ink and gold leaf pieces encode words and information which slows the understanding of subject matter enabling a more nuanced perception by the viewer. The interview films are shown silently in pairs, one showing the subject's reaction while listening to their favourite childhood story and the other explaining about their life with FND - the contrast and silent presentation allows the viewer to emotionally engage with the teller.

In presentation or poster I would discuss the methods involved in the creation of the work (encoding and data analysis) as conduit to presenting the stories and then the responses to the exhibition and participants being involved in the project.

This is an ongoing project that raises awareness and portrays lived experiences of those diagnosed with FND. I intend to present and exhibit this work in as many places as possible: medical, scientific, data and artistic conferences as well as in gallery, NHS and shopping centre contexts.

Arts-based methodology for understanding neurodivergent and ADHD learning journeys (B5)

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Abstract

Participatory based research methods, which include neurodivergent voices in developing research questions are still lacking. Moreover, new technologies and other forms of support for neurodivergent people are often developed by neurotypical populations, which compromises the effectiveness of such support and can creates an environment of epistemic violence (Ymous et al., 2020). Previously Khanolainen and Semenova (2020, 2021) used graphics vignettes to explore school bullying. This arts-based method engages children and their teachers in a collaborative creative process to describe experiences and feelings that might be left out of a traditional interview, and helps pinpoint areas of support for teachers, teacher educators and researchers. Importantly, arts-based research methods proved to be a particularly valuable tool to explore sensitive topics and negative experiences with vulnerable groups (Coemans et al., 2015; Dickson, 2021). The goal of this project-in-progress is to extend the method of graphic vignettes in order to review currently available support for neurodivergent students in school. We plan to pilot this in a small adult sample (n=20) and encourage creative reflection on childhood and adolescence events and support systems, by asking participants with ADHD to complete graphic vignettes with school-related prompts. Our research question focuses on school challenges, teacher and peer support, as well as various self-coping mechanisms. This way we aim to help our participants voice what they found to be most helpful on their learning

journeys and what was missing from the support system that was offered to them as neurodivergent students. The vignettes will be analyzed through thematic analysis (Braun & Clark, 2006) in order to identify common experiences that could inform stronger support for children with ADHD.

How being an autistic poet and synesthetic (thinking in rhyme and feeling in colour) aids my single minded and detail focused research (B6)

Wenn Lawson

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Abstract

As an autistic researcher, who is also a synesthetic, this presentation illustrates how autistic cognitive differences can be very helpful in research. As well as previously being a participant in another's research that focussed upon autistic poets and imagination (see: Ilona Roth (2020) Autism, Creativity and Aesthetics, Qualitative Research in Psychology, 17:4, 498-508, DOI: 10.1080/14780887.2018.1442763) and suggested autistic imagination was real, authentic and unique, I have continued to both see this in other autistic researchers as well as in my own research. Therefore, this paper will use poetry, in particular, to paint a picture of qualitative research I have co-produced. It will directly highlight the importance of using autistic strengths in coproduction and emphasise the quality of autism research as coproduced with autistic researchers. It should always be 'nothing about me without me'. Originally this approach led to the creation of a suite of resources that were developed to aid teachers and pupils in South Australian Schools. These are now 'on line' and are available as free downloads

Sound(e)scapes: Representing Sonic Sensitivity and Synesthesia in Middle Grade Novels (B7)

Jennifer Slagus

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Abstract

Neurodivergent middle grade literature (intended for 8-12-year-old readers) is commonly written by authors who are not neurodivergent themselves. This lack of embodied experience leaves ample space for tokenism, misrepresentation, and misunderstanding on the page.

Though the children's publishing industry has seen slight improvements across their disability offerings in recent years, neurodivergent young people are still most often left to be storied by a neurotypical's best guess.

My work is in-progress and seeks to question whether research is enough to tell authentic neurodivergent stories. Approached from the intersections of sonic and disability studies, I will explore two sound-centric contemporary middle grade novels written by neurotypicals: *Tune It Out* by Jamie Sumner (2020) featuring sensory processing disorder and *A Mango-Shaped Space* by Wendy Mass (2005) featuring sound-color synesthesia.

Both works have received general praise and inclusion in classrooms and libraries and have been added—likely without having been read—to a slew of "Best *Blank*" recommendation lists. However, I question from a neurodivergent perspective, whether the novels share positive, honest depictions of sonic-sensitive neurodivergence or rely on tokenism and stereotypes to drive the plot. Through an analysis of their (mis)representation of sensory seeking/avoidant stims, their imposed notions of normalcy, and their discussions of therapy and neurologist care, my paper will determine whether Sumner and Mass do justice for their characters and what that (in)justice means for their young readers too.

We all perceive the world differently: Sensory reactivity differences across neurodevelopmental conditions (B8)

Teresa Tavassoli

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Abstract

Background: We all perceive the sensory world around us differently. Sensory reactivity differences such as hyperreactivity (stronger response to sensory stimuli such as sounds), hyporeactivity (slower or less of a response) and sensory seeking (an unusual sensory interests) are currently only listed as a diagnostic criterion for autism. In this study we challenged the assumption that sensory reactivity should be seen as a diagnostic symptom, and rather be seen as a feature cross neurodevelopmental conditions. We also tried to identify best ways to measure sensory reactivity across neurodevelopmental conditions.

Methods: This study included children from a mixed neurodevelopmental condition cohort including autism and sensory processing disorder (n = 176) as well as neurotypical children (n = 128). The Short Sensory Profile (SSP)) and a direct sensory assessment the Sensory Processing-Three Dimensions: Assessment (SP-3D:A)) were used.

Results: Across conditions sensory reactivity differences did not significantly differ. Using direct assessment, 31% of the children with neurodevelopmental conditions had auditory hyperreactivity and 27% had tactile hyperreactivity. The inter-test agreement between SSP and SP-3D:A for auditory hyperreactivity was 65% and tactile hyperreactivity was 50%.

Conclusion: Sensory reactivity differences are seen across neurodevelopmental conditions. A combination of questionnaire and direct observation measures should be used in clinical and research settings.

Surveying autistic adults about their experiences of sensory overload and what affects it (B9)

Elliot Millington, David Simmons

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Abstract

A common theme of autistic accounts of autism is sensory overload. Despite this, sensory overload is poorly defined and underexplored. Sensory overload, as well as the resulting meltdowns and shutdowns, reduces quality of life directly by disrupting everyday activities and indirectly through their impacts on mental health. Not yet directly studied, it is possible that sensory overload and anxiety have a circular relationship, each increasing the other over the short and long term.

This research will be a qualitative study exploring the lived experience of autistic people. The first stage is an online survey, asking participants about their typical experience of sensory overload, how their emotional state affects their sensory processing, and about any other factors which affect their sensory experience. The second stage will be a focus group where participants can volunteer to return and talk through the data with the researchers, ensuring that they have been correctly interpreted.

The data will be analysed using grounded theory techniques. It is hoped that this study will firstly record some of the diversity of experiences of sensory overload in one place. Secondly, it is expected that participants will report that they are more likely to be overloaded when they are anxious, as well as encountering anxiety before events if they think they will be overloaded. Finally, we expect to identify several factors which increase the likelihood of sensory overload, particularly everyday practices and sensory environments designed for neurotypicals.

Using autistic bilingual children’s voices to fill in the silent space in research (B10)

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Abstract

Background

There are unfounded concerns among parents and practitioners that bilingualism may be harmful fo autistic children, resulting in many autistic children being denied access to their familial language. However, there is a growing body of research that disputes these concerns. In fact, some findings suggest that bilingualism could confer some cognitive advantages. The current research to date however is limited, as it disregards the child’s own perceptions on bilingualism, focusing solely on cognitive outcomes. Important questions therefore remain about how autistic children view the impact of bilingualism on their cultural identity, societal inclusion and quality of life.

Aims

The aim of this study is to learn the perspectives of autistic bilingual children (ABC) on their cultural and linguistic experiences being bilingual. In order to do this, we will create an autism-specific interview tool in collaboration with members of the autism community, families, and practitioners.

Method

The interview tool will be co-produced using feedback from parents, practitioners, and autistic bilingual adults and a Young Researcher advisory group, who are autistic bilingual young people aged 19-21 years.

The questions in the tool can be altered to accommodate the communication needs of each participant. There will be 3 versions of the interview tool: talking interview, activity-based interview in a clinical setting, and activity-based interview in a home setting.

The research is keen to learn each participant's perspectives on the following topics, which are underlying themes in the interview questions: being bilingual and autistic, family dynamic, sibling discrepancies, friends and hobbies, situation-dependent language use, and emotion-dependent language use.

In-depth, qualitative data will be collected from 12-16 participants aged 9-16 years. The interview data of speaking participants will be analysed using thematic analysis, and non-speaking participants' data will be analysed using interpretive phenomenological analysis. Themes and subthemes will be generated from the data.

Session C: (Neuro)Cognition

Capturing Individual Differences reflecting the Diversity of Visual Attention in Autistic and Non-autistic people: a Statistical Method applied to Eye-Tracking (C1)

Teresa Del Bianco[1], Luke Mason[1], Tony Charman[2], Julian Tillman[2], Eva Loth[2], Hannah Hayward[2], Frederik Shic[3], Jan Buitelaar[4], Mark Johnson[5], Emily Jones[1]

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Abstract

One limiting issue in research is the range of statistical models that use averages for case-control comparisons. To capture individual differences in mechanisms reflecting diversity, we need novel methods in relevant dimensions; here we illustrate potential value of one approach through application to a commonly studied topic (face-looking).

We developed a model of face-looking measured with eye-tracking of 764 autistic and neurotypical participants aged 6-30 that took part in the Longitudinal European Project, and watched photographs of people in various situations on a screen for 20 seconds. To model the underlying process and dissect its variation, we used Growth Curve Analysis applied to a mixed model that, in addition to the traditional case-control comparison, contains 1) polynomial coefficients modelling the variation of face-looking over time 2) individual coefficients of varying intercepts and slopes representing individual gaze-paths and their deviations within the same group, moving away from comparing to controls. We used these individual coefficients as indexes of variation of the process underlying face-looking, and applied hierarchical clustering and partial correlation with questionnaires within the autistic group.

We found a cluster encompassing 8% of the autistic participants showing less focus on the face over time, whose curvature correlated with autistic traits (SRS-2; $r = 0.71$, adjusted $p = 0.01$). Deviations correlated inversely with adaptive communication (VABS; $r = 0.17$, adjusted $p=.03$),

meaning that autistic participants that were more consistent with the average looking behaviour of other autistic, had less divergent communication scores in what would be expected for their age group (as captured by higher VABS scores).

These results pave the way to individual coefficients from mixed models as indexes of variation in underlying processes rather than raw data. Next steps should discuss maximising their utility and extending the application domains to map out differences between people rather than groups.

Family history of ADHD associates with stronger problem-solving skills amongst 2- to 3-year-olds (C2)

Alexandra Hendry[1], Emily Jones[2], Mark Johnson[3], Tony Charman[4]

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Abstract

Objectives: Difficulties with inhibitory control and other executive functions (higher-order skills critical for analytic problem-solving) are common amongst individuals with autism or ADHD, and their first-degree relatives. However, adolescents/adults with ADHD show advantages in insight-based problem-solving. In a general-population sample of 1.5- to 4-year-olds, low inhibitory control is associated with stronger problem-solving performance. We investigate whether toddlers with a family history (FH) of ADHD or autism show differences in problem-solving.

Methods: 129 children (FH-autism-only, n=67; FH-ADHD-only, n=22; FH-Autism-&-ADHD, n=16; No-FH-autism/ADHD, n=24) completed an open-ended problem-solving task (Problem-Solving Box) at ages 2 and 3 years. Videos were coded for Success (cumulative time to retrieve 3 rewards, inverted), Generativity (count of goal-directed strategies attempted), Persistence (proportion of time spent on goal-directed manipulation) and Perseveration (time spent on the dominant strategy as a proportion of goal-directed manipulation). Differences in performance by FH-Autism/ADHD were tested using ANOVAs.

Results: FH-ADHD 2-year-olds had higher Success scores (M=307.66,SD=235.84) and greater Generativity (M=6.12,SD=2.85) compared with No-FH-ADHD 2-year-olds (M=159.49,SD=170.00; M=4.50,SD=3.09) (F(1,106)=13.813,p<.001,η2p=.115; F(1,103)=6.849,p=.010,η2p=.062). FH-ADHD 3-year-olds had higher Success scores (M=453.05,SD=291.15) and lower Perseveration (M=0.40,SD=0.14) compared with No-FH-ADHD 3-year-olds (M=345.53,SD=226.27;

M=0.48,SD=0.17) (F(1,109)=6.231,p=.010,η2p=.054; F(1,93)=6.393,p=.013,η2p=.064). No significant FH-autism or FH-ADHD/FH-autism interaction effects were found.

Conclusions: Toddlers with FH-ADHD are more-efficient problem-solvers, generating more unique strategies (aged 2) and perseverating on a single strategy for less time (aged 3) than peers with no FH of ADHD. Identifying positive attributes of heritable cognitive profiles associated with autism and ADHD will allow clinicians and researchers to better understand and support children at elevated likelihood of neuro-divergence.

Are the social abilities of neurodivergent individuals measured accurately? An intergroup bias in smile discrimination in autism (C3)

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Abstract

Genuine and posed smiles are important social cues. Neurodivergent individuals, including autistic people, struggle to reliably differentiate between the two smiles, which may contribute to their difficulties in social communication. An intergroup bias has previously been found in neurotypical adults in identifying genuine from posed smiles. However, it is not clear whether this bias also exists in neurodivergent individuals. If so, given previous studies likely used neurotypical actors (i.e. out-group members), past results might not measure their real social ability. Thus, the current study was first designed to investigate whether autistic individuals would show an intergroup bias when differentiating smiles for in-groups and out-groups. Fifty-nine autistic adults were compared with forty-nine non-autistic adults, matched on sex, age and nonverbal reasoning. Participants viewed videos of people making genuine or posed smiles and were informed (falsely) that some of the actors were from an in-group and others were from an out-group, using a minimal-groups manipulation. The smile distinguish ability was assessed. Both autistic and non-autistic adults rated genuine smiles as being more genuine than posed smiles and in-groups as more genuine than out-groups. Autistic participants generally rated smiles as less genuine than non-autistic participants. Both groups identified themselves more similar to the in-group than out-group members, but this tendency was weaker in autistic individuals. These results indicate that autistic adults are capable of identifying genuine smiles from posed smiles, unlike previous findings; but they may be less convinced of the genuineness of others, which may affect their social communication thereafter. Importantly, autistic adults were also influenced by a social intergroup bias which implies that they might fail to rate smile stimuli as 'genuine' because they perceive most actors as belonging to a neurotypical 'outgroup'. This indicates the need to re-evaluate past finding of social abilities in neurodivergent individuals that used neurotypical actors.

Identifying profiles of inattention and hyperactivity/impulsivity, and their links with cognitive abilities, in a neurodiverse sample (C4)

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Abstract

Background and Aims

Elevated levels of inattention and hyperactivity/impulsivity are key diagnostic features of attention deficit hyperactivity disorder (ADHD), yet they are experienced by a wide range of individuals, including autistic people and those with diagnoses of specific learning difficulties. The aim of this study is to use a data-driven approach to identify children with similar profiles of inattention and hyperactivity in a large sample with a diverse range of needs.

Research questions

Can we identify subgroups of children presenting with distinct symptom profiles? Do their symptom profiles correspond to the primary ADHD-subtypes identified by DSM-V (inattentive, hyperactive/impulsive, combined type)? Do these data-driven subgroups differ in terms of cognitive performance, learning, or mental health? Are children with a particular diagnosis over-represented in any of the subgroups?

Analysis Plan

A data-driven community detection algorithm will be applied to child-by-child associations across item-level (symptom level) data from the Inattention and Hyperactivity / Impulsivity subscales of the Conner's Rating Scale to identify subgroups with similar profiles. Demographics and diagnostic characteristics, cognitive function, mental health, and learning will be compared across subgroups.

Kinds of Insights

These analyses will determine whether transdiagnostic profiles of inattention and hyperactivity/impulsivity exist among a heterogeneous neurodivergent group, and whether symptom profiles correspond to DSM-defined distinctions between hyperactive/impulsive, inattentive, or combined-type profiles. We anticipate the profiles will not be disorder-specific, neither in profile nor composition. If so, these data will add to accumulating evidence for a shift away from conceptualising additional needs as nosological entities, and towards the use of transdiagnostic approaches that allow more refined phenotypes to be delineated and interventions to be tailored to individual needs rather than potentially ill-fitting diagnostic labels.

The blind men and the elephant: The need for a coherent transdiagnostic approach to volition (C5)

Karen Leneh Buckle

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Abstract

Difficulties with initiating voluntary action have a substantial impact on quality of life for people with various psychiatric and neurological conditions, yet they are largely neglected by formal research (Buckle et al., 2021). Understanding of these widespread difficulties is impeded by: i) the arbitrary distinctions between neurological, psychiatric, and neurodevelopmental conditions, ii) the biases arising from the most obvious or 'primary' symptoms, and iii) the enormous diversity of terminology.

The ancient Indian parable of the blind men and the elephant (Saxe, 1884) can be useful for understanding the way volition is viewed across different neurological and psychiatric conditions. Just as the blind men describe the elephant as a snake, a tree or a fan depending on whether they are touching the trunk, a leg or an ear, so our present day health care providers, educators and researchers have difficulty seeing beyond their expertise and the primary features of a condition. A neurologist sees initiation impairments in Parkinson's Disease, attributes them to a neurological deficit and calls them apathy; a psychiatrist sees lack of goal directed activity in schizophrenia and calls it avolition; and a behaviour therapist sees a lack of initiative in autism, considers it behavioural, and does not acknowledge it as a separate issue at all. In a review of the literature, at least 28 terms were found for deficits in initiative, sometimes describing identical or near-identical syndromes.

Lack of understanding of difficulties with motor initiation can lead to punishment or inappropriate interventions for evident 'non-compliance' (Ming et al. 2004). This paper begins to unite the disparate theoretical perspectives and terminology, drawing out common features of initiation impairments in neurological and psychiatric conditions. This has the potential to facilitate research into the cognitive and biological mechanisms underpinning voluntary action and to develop more appropriate and informed interventions.

Neurodiversity in neural maturation and cognitive abilities in the first three months of life and interactive effects of environmental risk-factors (C6)

Rebecca Barbosa[1], Karen Moreira[1], Raquel Santos[1], Monike Teixeira[1], Ana Luiza Polimeno[1], Caroline Vieira[1], Juliana Bonizzi[1], Laís Vasconcelos[1], Leticia Borges[1], Ricardo Fernandes[1], Adriana Argeu[1], Daniel Fatori[1], Guilherme Polanczyk[1], Elizabeth Shephard[1,2]

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Abstract

There is considerable neurodiversity in the rate of neural maturation during the first months of human life. Yet, few large-scale studies have examined factors that may influence this variability, nor how neurodiversity in neural maturation affects the development of overt cognitive abilities in infancy. The aim of this study is to examine (1) how inter-individual variability in neural maturation relates to infants' developing cognitive abilities, and (2) how environmental factors, such as poverty and psychosocial stress, influence neurodiversity in neural maturation. These questions will be addressed in a sample of 500 infants taking part in a longitudinal study investigating neurodevelopment across the first 36 months of life in São Paulo, Brazil. All infants complete the first study assessments at age 3 months. Neural maturation is measured with electroencephalography (EEG) recorded during a visual evoked potential (VEP) task, in which infants are presented with black and white checkerboard patterns that are known to stimulate basic sensory processing in the visual cortices. Environmental factors are measured with questionnaires assessing family socioeconomic level, food insecurity and parental experiences of stress. The current analyses will use regression and structural equation modelling statistical methods to examine bidirectional associations between event-related potential component (P1, N1) markers of neural habituation during the VEP task and (1) infants' overt cognitive abilities on the Bayley and (2) measures of poverty and family psychosocial stress. The findings of this study will be important in understanding early neurodiversity in neural and cognitive development and how environmental factors affect this variability.

Executive function as a predictor of emerging psychopathology: Dimensional associations between EF and symptoms of ADHD, ASD, oppositional defiance and anxiety in young children with diverse mental health problems (C7)

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Abstract

Background: Executive function (EF) impairments (i.e., working memory, inhibition, cognitive flexibility) are transdiagnostic and implicated in different neurodevelopmental conditions (NDDs). For example, EF impairments are shared between Autism Spectrum Disorders (ASD), Attention Deficit Hyperactivity Disorder (ADHD) and/or externalising problems, and it is unclear which symptom profiles are associated with unique or more typical EF impairments. Most

studies examining EF in NDDs use a case-control approach; this relies on diagnosed samples and fails to account for the complex heterogeneity of comorbid symptoms that are highly prevalent in conditions such as ASD and ADHD, which may alter the presentation of EF impairments.

Method: The current study utilised a sample of young children (n=311, aged 4-8) referred to Cardiff University's Neurodevelopment Assessment Unit (NDAU) by classroom teachers for emerging neurodevelopmental problems. Children completed computer-based measures of EF, while parents took part in a clinical interview assessing symptoms of anxiety, oppositional defiant disorder, ADHD and ASD.

Results: A high proportion of our sample showed clinical levels of neurodevelopmental symptoms, such as ASD (n=144, 46%), ADHD (n=140, 45%), oppositional defiance (n=106, 34%), and/or anxiety (n=98, 32%). Comorbidity was prevalent (n=150, 48%) and so was EF impairment (n = 154, 51% being impaired in at-least one EF domain). Preliminary analyses indicate that attention problems and oppositional defiance are specifically associated with impaired inhibition and cognitive flexibility, respectively, which will be explored further using multiple regression. Controlling for comorbid disorder symptoms, severity of autistic traits was associated with better memory and cognitive inhibition performance.

Conclusion: Children identified as having emotional, cognitive or behavioural problems display diverse and comorbid neurodevelopmental symptoms and impaired EF. Our approach to assessment and analysis can identify how EF impairments are associated with different neurodevelopmental symptom profiles. This can inform the development of tailored interventions to improve outcomes in children.

Association between behavioural and neural measures of social-communication skills and environmental variables in young children growing up in socioeconomic disadvantage in Brazil (C8)

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Abstract

Social-communication abilities and their underlying neural mechanisms vary widely across children. These skills play an important role in protecting against the emergence and severity of mental health difficulties in children exposed to environmental risk-factors, such as socioeconomic and psychosocial deprivation and suboptimal parental practices. However, social-communication development is itself affected by these adverse environments. The aim of this study is to investigate these bidirectional associations between behavioural and neural measures of social-communication skills and environmental variables (style of parenting care, synchrony and sensitivity in parent-child interactions) in a sample of young children growing up in adversity in Brazil. Participants are 160 children aged 2-4 years and their primary caregivers recruited from public early childhood education centres in impoverished urban regions of the city of São Paulo, Brazil. All parent-child dyads are participating in a randomized controlled trial (RCT) of a parent-mediated therapy to support social-communication development for vulnerable children. The current analyses will focus on data from the baseline assessment. Children's social-communication skills are assessed behaviourally with the Communication domain of the Vineland Adaptive Behavior Scales and neurally with indices of oscillatory electrophysiological (EEG) activity recorded during a live social interaction paradigm. Environmental variables are measured during a 10-minute parent-child free-play interaction, which is coded for interaction synchrony, and the parent-report Parenting Scale questionnaire. Multiple regression will be used to examine associations between all variables. We predict that lower children's social-communication abilities on the Vineland will be associated with lower oscillatory neural activity in the live social interaction paradigm and with poorer synchrony in the parent-child interaction and the presence of dysfunctional discipline practices in parents on the Parenting Scale. We expect the results of this study to improve our understanding of the bidirectional relationships between young children's social-communication development and environmental risk-factors.

Filling in the gap between social cognition and behavior in neurodivergent children and youth (C9)

Iciar Iturmendi-Sabater[1,2], Meng-Chuan Lai[1,2], Hsiang-Yuan Lin[1,2], Evdokia Anagnostou[1,3], Marc A. Fournier[1]

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Abstract

Background. Social behavior differences occur across neurodevelopmental conditions (NDCs) (e.g., autism, attention-deficit/hyperactivity disorder, obsessive-compulsive disorder, intellectual disability). Opposing previous hypotheses, social cognition explains limited social

behavior variance in autistic persons. This social cognition-behavior discrepancy has been operationalized as an indirect measure of social coping, described in lived experiences as “camouflaging”/masking. Camouflaging has not been studied across NDCs beyond autism. Since social situations elicit anxiety in some neurodivergent persons, anxiety may be associated with camouflaging and explain further variance in social behavior across NDCs.

Aim. This secondary data-analysis study aims to (1) assess whether social cognition-behavior discrepancy (i.e., “camouflaging”) varies with NDC diagnosis and anxiety and to (2) examine the role of social cognition and anxiety in explaining social behavior across neurodivergent children and youth. We hypothesize that (1) social cognition-behavior discrepancy is present across NDC diagnoses and vary with anxiety, and that (2) anxiety explains variance in social behavior beyond social cognition.

Methods. Over 300 typically developing and over 2000 3-18-year-olds with NDCs from the Province of Ontario Neurodevelopmental Disorders (POND) Network dataset constitute the sample, with available measures of social cognition (Eyes Test, NEPSY-II Affect Recognition and Theory of Mind, SandBox False Belief), social behavior (CBCL Social Problems, ABAS-II Social) and anxiety (CBCL Anxiety, RCADS/Spence). First, linear regression with elastic net regularization will identify correlates of social cognition-behavior discrepancy (i.e., camouflaging) among NDC diagnoses, NDC dimensional traits, and anxiety. Second, structural equation modelling will test the mechanistic relations of social cognition, anxiety, and social behavior across this transdiagnostic sample.

Implications. This work will extend the understanding of camouflaging across neurodivergent children and youth. Since anxiety is often contextually-bounded, the findings will inform ways to shift the focus from individual deficits within NDCs transdiagnostically onto how contextual factors influence social behavior and adaptation.

Improving detection and assessment of dementia in the autistic population (C10)

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Abstract

This research project addresses the detection of dementia among autistic individuals. Such an association has been the subject of little scientific exploration. This research is a priority because of:

- Scarce and scattered literature
- Lack of reliable data
- An overlap in cognitive profiles of autism, and dementia
- This area of research being neglected

This research project seeks to explore the subject in a Scottish context and improve detection and assessment of dementia amongst the autistic population. The overall aim of the research is broken down into four key objectives:

1. Identify the risk factors and profiles of dementia in autistic people
2. Characterise the problem by identifying prevalence rates of dementia amongst the autistic population in Scotland
3. Evaluate current dementia detection methods for effectiveness in autistic population
4. Formulate a potential customised dementia assessment package for this population.

This presentation will demonstrate a suggested cognitive profile of autism and dementia developed using current literature. Factors of note within autism are the specific differences in cognition that autistic people may have, for example executive functioning movement and memory and sensory processing. Using mind mapping software, a visual tool is being developed to identify aspects which are sensitive only to dementia and to determine those aspects which are sensitive to autism, or autism and dementia as they may impact outcomes of screening and assessment. The results of this will be presented. This same approach will be used in relation to the dementia risk factors as identified by the Lancet Commission, along with other components of the dementia profiles. These profiles will form the methodological basis of the bespoke assessment toolkit.

The presentation will also give an overview of future direction of the research and will discuss the participatory approaches being taken.

Looking at a large group of neurodiverse children to understand how differences in cognitive control across structured and unstructured situations are related to school and socio-emotional functioning and brain organisation (C11)

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Abstract

Executive functions are associated with cognitive, behavioural, and socio-emotional development, and atypical executive functioning has been implicated in numerous

neurodevelopmental disorders. There are two different conceptualisations of EF. The first views EF as a set of higher-order cognitive skills that enable us to engage in flexible thinking and regulate our thoughts, behaviour, and emotions (e.g., Miyake et al., 2000 Pennington et al, 2005). The second proposes that EF relates to the integration of knowledge, beliefs and values when applying cognitive control in unstructured everyday settings (Doebel, 2020). These two perspectives map onto the ways in which executive functions are measured in childhood. One relies on performance on structured laboratory tasks, the other on ratings of everyday behaviours. There is ample evidence that functioning in these two situations is dissociable and makes independent contributions to clinical and academic outcomes in both neurotypical and neurodivergent populations (Soto et al., 2020; Toplak et al., 2013). Considering both conceptualisations of EF, the present study aimed to identify subgroups of children with different EF profiles in a large neurodiverse sample drawn from the Centre of Attention, Learning, and Memory (CALM, N = 805). We looked at both performance and rating-based assessments of EF and aimed to address the following questions: 1) can we identify robust subgroups of children presenting with different EF profiles; 2) do these profiles relate to the two dissociable conceptualisations of EF or diagnostic labels such as ADHD and ASD; 3) how do these profiles differ in terms of academic and socio-emotional functioning, and functional and structural neural organisation. Analyses are currently ongoing. The findings could have implications in terms of understanding the origins and consequences of different profiles of EF and devising appropriate support strategies for individuals presenting with distinct strengths and difficulties across different situations involving EF.

Do experience-dependent changes shape synapse architecture? (C12)

Hanan Woods[1], Zhen Qiu[1], Noboru Komiyama[1], Frank Sengpiel[2], Seth Grant[1]

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Abstract

The neuronal activity triggered by sensory stimulation arriving at our peripheral sensory organs allows for appropriate connections in the brain to be altered and refined (Baroncelli & Lunghi, 2021; Levelt & Ḧubener, 2012). This process is referred to as experience-dependent plasticity (Faust et al., 2021). Many studies have employed two well-established paradigms to study how experience modifies synaptic properties, environmental enrichment (EE) and monocular deprivation (MD). Changes in synapse number, shape and size have been reported using these paradigms (Sun et al., 2019; Wegner et al., 2022; Yusifov et al., 2021).

Recent studies of the molecular composition of individual synapses reveals a great diversity of synapse types. The synaptome describes the diversity of brain synapses and the synaptome architecture describes the spatial distribution of these synapses in neurons, brain regions and

the whole brain. Systematic mapping of the molecular and morphological properties of individual excitatory synapses on a brain-wide scale in the mouse reveals high synapse diversity (Zhu et al., 2018). How much the synaptome architecture of excitatory synapses is controlled by activity and experience is poorly understood, especially for large parts of the brain that remain unexplored. We asked if the development of the synaptome architecture was modified in MD or EE.

Synapses in the mouse brain can be visualised using mice expressing fluorescently labelled post-synaptic proteins. These mice underwent MD from P25-31 or EE rearing until P30 and P90 and synaptome mapping was performed on a brain-wide scale. In contrast to existing studies, preliminary results indicate no significant differences in excitatory synapse number in any brain regions. Analysis of synapse types, subtypes and synapse diversity will be presented.

Clarifying experience-dependent changes at the synapse will demonstrate how genetically driven neuronal structure is modified by our environment and sensory experience such that individual-specific variance in human cognition and behaviour is generated.

Transdiagnostic Neural Pathways to Inattention and Hyperactivity (C13)

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Abstract

Inattention and hyperactivity are regarded as the cardinal symptoms of Attention Deficit Hyperactivity Disorder. These features have also been observed across a range of other neurodevelopmental conditions, such as autism and dyspraxia, suggesting that they might best be studied across—or regardless of—diagnostic categories. Here, we evaluated how inattention and hyperactivity behaviours are associated with features of the structural brain network (connectome) in a large transdiagnostic sample of children (Centre for Attention, Learning, and Memory; n = 392). We began by conducting an exploratory factor analysis on data from several behavioural questionnaires, which revealed that variations in inattention and hyperactivity are best represented by one latent factor, rather than two.

We conducted several exploratory analyses to determine how variations in inattention and hyperactivity relate to properties of 100-node connectomes derived from DTI and resting-state fMRI data. K-means clustering analyses revealed that two structural 'neurotypes,' differentiated primarily by nodal communicability, are capable of generating the same behavioural phenotype of extreme inattention and hyperactivity. These ‘neurotypes’ are further differentiated by cognitive ability.

We conclude that there may exist multiple neural trajectories that lead children to express high levels of inattention and hyperactivity, which is reflected in the organisation of structural brain networks.

Session D: Supports & Innovations

The effect of task instructions on visual processing in autistic and non-autistic children (D1)

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Abstract

Many autistic people experience sensory symptoms, for example, sensitivity to visual stimuli such as flickering lights. As such, exploring sensory processing has been identified as a top research priority by autistic people and their families. Motion coherence tasks can be used to explore visual processing, and these tasks require participants to discriminate the coherent direction of moving signal dots amongst randomly moving noise dots. Multiple previous studies have found reduced sensitivity in these tasks in groups of autistic relative to non-autistic participants. This means that autistic participants required more dots to be moving coherently to perceive the coherent motion. However, it is possible that task instruction may impact upon performance, with equivalent performance found across groups in a more recent study that included clear instructions on how to respond. This study is currently ongoing, and aims to investigate potential differences in motion coherence task performance between groups of autistic and non-autistic children (aged 6-14 years, around 50 per group), and whether performance is impacted by asking children to emphasise speed or accuracy when responding on a motion coherence task presented as a child friendly game. We plan to fit the task data using hierarchical drift-diffusion models, which incorporate both accuracy and reaction time in order to break down task performance into distinct processing stages. We will then determine whether there are group differences in the model parameters and explore the influence of task instruction. If autistic participants are able to successfully modulate their performance with instruction, we will expect to find similar task performance across groups, which could call into question some of the previous findings reporting group differences in motion coherence processing.

Interviewing autistic adults to find out how autistic peer support groups affect their social connections and wellbeing (D2)

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Abstract

Background: Autistic peer support groups are reported by autistic people to improve the wellbeing of participants, providing support and solidarity, however there is little published research on this topic. The research question explored is: 'What is the experience of autistic adults who engage with autistic peer support groups, particularly in relation to their social connections and wellbeing?'

Materials and Methods: Semi-structured interviews were completed remotely with eight autistic adults who had engaged with autistic peer support groups, whether face to face or online. A reflexive thematic analysis of the data was completed.

Results: Four themes were identified: 'autistic identity, 'respecting diversity', 'functions of peer support' and 'factors of success'. 100% of participants would recommend autistic peer support to other autistic people, but felt strongly that not every group could suit everyone so people should choose the group that was right for them as an individual.

Conclusions: Autistic peer support groups improve wellbeing and social connections, providing a sense of community based on an autistic identity. Commissioners and others seeking to develop support for autistic people should take into account the diversity of the autistic population and provide a range of peer support options. Autistic people should be provided with appropriate administrative assistance to deliver peer support.

Overcoming disability prejudice: The use of indirect contact and knowledge interventions to improve relations in the disabled/nondisabled intergroup context (D3)

Rebecca Dole, Lindsey Cameron

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Abstract

Purpose: This systematic review analysed experimental trials and education programmes using knowledge and/or indirect contact methods with the aim of improving non-disabled attitudes and behaviours towards disabled children and adults

Background: Much stigma and prejudice still surround those with disabilities. Observational and experimental studies with disabled children and adolescents show increased verbal aggression and isolation by peers. This extends into later life with higher levels of unemployment, poverty, workplace discrimination, and isolation and violence commonplace for disabled adults.

Method: Following PRISMA guidelines an electronic search of PubMed, Psychinfo and Google Scholar retrieved 26 studies published between 2001 and 2021. The criterion included: (1) Published in English, (2) Published after 2001, (3) Used indirect contact and/or knowledge interventions (4) Analysed primary data only. Of the 26 results, 10 focused on indirect contact methods, nine on knowledge-based interventions and seven on a combination of indirect contact and knowledge.

Conclusions: This research was characterised by skewed focus on child participants, lack of baseline data and control groups, minimal consideration of mediation and moderation variables and no collaboration with disability groups. Despite this, our narrative synthesis of the literature highlighted small but promising outcomes of prejudice reduction. Increases in outcomes such as attitudes, behavioural intentions and more are seen throughout results encouraging future research to expand and develop the field.

When, How, and Who to Tell: Developing and testing a new programme to support decisions around disclosing an autism diagnosis/identity (D4)

Emeline Han, Katrina Scior, Eric Heath, Kana Umagami, Laura Crane

University College London, London, United Kingdom

Abstract

Autistic adults often face a dilemma of whether to conceal or reveal their autistic identity due to the stigma surrounding autism. Clearly, to improve autistic adults' experiences of disclosure, it is crucial to reduce stigma and create more inclusive environments. There are other programmes already trying to do this. However, as change can be slow, we believe that autistic adults should also be empowered to make informed, strategic disclosure decisions. So, we are developing and testing a programme that seeks to support autistic adults in deciding when, how, and to whom they want to talk about their autism diagnosis/identity.

First, this programme is being designed based on research evidence, including a systematic review we conducted on autistic people's experiences of stigma and coping strategies. The programme is also being developed with direct input from autistic people, including our autistic team members and a consultation survey we conducted with the autism community.

Next, we plan to conduct an initial assessment of how feasible and acceptable our programme is. We aim to recruit around 20 autistic adults to take part in the programme, which will involve them working through a self-help guide with the option to contact an autistic facilitator for one-to-one support or participate in an online peer forum. We will ask participants to complete a survey before and after the programme, as well as an interview at the end of the programme, so they can tell us whether they liked the programme and what they found most or least helpful about it. We will then carry out descriptive analysis of quantitative data and thematic analysis of qualitative data.

These findings will help us to further refine and improve our programme, which we hope will contribute towards better support for autistic adults' mental health and wellbeing in the future.

Managing and supporting young people with Attention deficit hyperactivity disorder (ADHD) in Primary care (MAP) study: mapping current practice, and working with people with ADHD and health workers (such as GPs and nurses), to jointly produce guidance to improve healthcare for this underserved group of young people (D5)

Anna Price, Tamsin Newlove-Delgado, Jane Smith

University of Exeter Medical School, Exeter, United Kingdom

Abstract

Background:

Attention deficit hyperactivity disorder (ADHD) is the most common childhood neurodevelopmental disorder. It affects around 5% of children and adolescents, and up to 40% continue to experience symptoms into adulthood. Primary care practitioners (e.g., general practitioners (GPs), nurses, and pharmacists) play an important role in the healthcare of young people (YP) with ADHD, particularly due to long waiting times in adult mental health services, and patchy provision of specialist services. However, many practitioners feel unsure about how to support YP at this vulnerable stage in their lives. They report concerns about prescribing ADHD medication and a desire for more guidance. Currently, little is known about how YP with ADHD are supported in primary care, the strengths and weakness of existing care pathways, and how care can be improved.

Aims:

To map current service provision and co-create evidence-based guidance to improve and better co-ordinate primary care for YP aged 16-25 years with ADHD.

Methods:

Phase 1: A national survey of primary care practitioners, people with ADHD, and organisations providing and funding ADHD services, to map current care pathways, learn about practitioner roles and prescribing practices, and identify underserved areas.

Phase 2: Interviews with 10-15 YP with ADHD exploring their experiences, information needs, and expectations of primary care management of ADHD. Focus groups with 10-15 practitioners, to consider the information they need in their roles managing ADHD in YP, and the information and support they need to provide care.

Phase 3: Building on findings from phases 1 and 2, workshops with all stakeholders will co-produce key messages and guidance for improving primary care support.

Insights:

We will report on findings from the national survey. Also, on the role of our two research advisory groups (made up of young people with ADHD and health professionals) in shaping the delivery of this research.

Common cognitive barriers in virtual reality environments and how they overlap with daily life (D6)

Jamie Knight

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Abstract

3 years ago the BBC accessibility team where starting to work on a wider and wider range of VR, AR and MR projects. We were reaching an audience of millions, however we didn’t have a great idea of where the accessibility barriers would be for these emergent platforms

This led to a three year project to find and understand the most common barriers in virtual reality and augmented reality environments (known collectively as XR)

We worked with over 100 participants across 15 sessions who each entered our VR environment (based on a model of a small library) and took part in activities exploring navigation, interaction and information gathering. We observed the sessions to identify the barriers experienced and also developed and used an inclusive feedback form to gather additional thoughts from participants. To check the system was safe we also build a VR performance testing robot!

Our data analysis pipeline had four stages.

1. Observations (we collected > 1700 observations)
2. Deduplication
3. Thematic analysis (Identify 70 common barriers)
4. Grouping by impairment (Identifying the 14 most common barrier across mobility, cognitive and low vision groups)

The project was published in 2022 at: https://www.bbc.co.uk/accessibility/forproducts/xr/

Of the 14 common barriers identified, 6 related to cognitive accessibility and neurodiversity. (See this section of the barrier browser for details: https://www.bbc.co.uk/accessibility/forproducts/xr/barriers/#cognitive-barriers)

This session would discuss these barriers in the context of the research and how they impact the development of VR / AR tools in the future.

One of the surprises emerging from the project was how well the barriers identified also provide a good framework for ‘real world’ barriers. The session will also include some reflection on how understanding these barriers can be used to improve life for neurodivergent people in general.

Reframing neurodiverse universities with Specialist (Autism) Mentoring (D7)

Brian Irvine

University of Birmingham, Birmingham, United Kingdom

Abstract

Reframing the student's experience of themselves as failing (by some normative standard) – inviting them to look at things differently, think about what their values are, how awesome they are as they are, rather than constantly punishing themselves for not being 'good enough'. Claire.

Universities in the UK have seen a remarkable increase in the number of autistic students. These students can receive funded Specialist (Autism) Mentoring to “remove barriers to learning”. Prior research recounts barriers, challenges, and cultures of success that autistic students encounter but little on the transformative journey of Higher Education.

A guided diary format was developed from questions posed by mentees as autistic hypothesisers. 28 mentors, of whom 8 themselves were autistic, kept diaries over the academic year 2020/21. Adding to themes of prior research, a process of framing and reframing emerged as a key pillar of mentoring autistic students through diagnostic framing, prognostic framing, and motivational framing. The addition of a motivational aspect positions Specialist (Autism) Mentoring akin to the frame alignment of social movements. Through the nurturing of advocacy autistic students are not simply inducted into university culture, they are equipped to change it.

Interventions to promote verbal language in autistic people: a review of existing evidence alongside community views and priorities (D8)

Audrey Linden[1], Kurinchi Gurusamy[1], Courtenay Norbury[1], Freya Elise[1], Jade Davies[1], Molly McCabe[1], Aaron Giuliano[1], James Cusack[2], William Mandy[1], Laura Crane[1]

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Abstract

Many autistic people struggle with language, and around a quarter speak few or no words. Identifying interventions focused on language and communication for autistic people is a top priority for the autism community. We focused our work on verbal language because there is a significant impact of verbal language difficulties on autistic people, for example in terms of employment, social disadvantage, and mental health.

Currently, there is uncertainty about which interventions lead to long-term improvements in verbal language among autistic people. We are conducting a systematic review and network meta-analysis of randomised controlled trials (RCTs), searching multiple databases and trial registers. We will include RCTs reporting verbal language outcomes in a suitable format. We estimate that around 40 RCTs will be eligible for inclusion. Following this review, we will work with community collaborators to conduct a survey of autistic people, their parents/carers, and the professionals who work with them. The survey will gather opinions on verbal language interventions and the current state of research. Survey data will be analysed using thematic analysis to determine key themes about how the research evidence aligns with the priorities of the autism community, and to develop recommendations in the area of verbal language interventions.

We expect to be able to offer insights to the research community in terms of recommending research directions. We also expect to be able to develop recommendations for clinical practice in terms of which interventions are best supported by research evidence, and which are considered acceptable to the autism community. As such, our findings may influence how speech and language therapy services are delivered.

Is Parents' ADHD Symptomatology Associated With the Clinical Feasibility or Effectiveness of a Psychoeducational Program Targeting Their Children's ADHD? (D9)

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Abstract

Background: Families where both parent and child have a neurodevelopmental disability such as Attention-Deficit/Hyperactivity Disorder (ADHD) tend to face many co-occurring challenges. A growing number of studies indicates that parental ADHD symptoms may complicate the administration of and adherence to interventions for children's ADHD, whether they be medication, parent training or a combination. Considering the familial aggregation of ADHD, it is important to find out if this also applies to parent-received psychoeducation.

Objective: To examine if the clinical feasibility and effectiveness of a psychoeducational program targeting children's ADHD differ between parents with varying ADHD symptom severities.

Method: In an open trial, we analyzed data from 549 parents of children with ADHD (aged 3 to 17 years) who participated in psychoeducation at an outpatient habilitation/disability clinic. In all analyses, parents were stratified into three symptom severity groups (low, middle and high) based on scores on an ADHD screening scale. Clinical feasibility was evaluated based on program completion rates and ratings of program acceptability. Effectiveness was examined by self-report questionnaires, administered before and immediately after psychoeducation.

Results: Across the entire sample, we observed high program completion rates, positive acceptability ratings and large increases in parental knowledge about ADHD, its treatment, and parenting strategies. Parental ADHD symptom severity was not associated with results on any outcome, although the odds of having incomplete data were higher in parents reporting higher symptom severity.

Conclusions: The results are encouraging, as they suggest that psychoeducation delivered with general adaptations to promote program accessibility for adults with ADHD may indeed have the potential to be beneficial regardless of the participating parent's ADHD symptomatology. However, further research is needed to examine whether these results are generalizable to parents diagnosed with ADHD, an underrepresented group in our study.

Online post-diagnostic autism interventions - an initial evaluation of the Healios service (D10)

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Abstract

Background: Despite improved provision of autism assessment, immediate post-diagnostic support for families is often lacking. Healios is a UK-based digital provider of NHS-commissioned online autism assessments and currently offers a Post-Diagnostic Intervention (PDI) service for families immediately following autism diagnosis, whether by Healios or other clinical services. PDI is structured around idiosyncratic goal-setting focused on the needs of the family with dedicated online resources ('slide decks') covering topics such as communication, sensory processing and emotional wellbeing. The current project examined how families engaged with, and used, the PDI service.

Methods: PDI is currently provided to referrals from two NHS trusts in Scotland and England, and sessions scheduled between January-May 2022 were selected for the initial evaluation. Pseudo-anonymised data was extracted from Healios' digital platform, Panacea, and included number and date of sessions, cancellations, non-attendance, goals and goal attainment, and qualitative feedback from families. A preliminary analysis of N=25 families who had completed PDI was conducted, with N=71 due to complete sessions between June-August 2022. The data for these will be added and included in final analyses.

Results: N=25 families completed a mean of 2.76 (sd 0.88) with a mode of 3 sessions and a total of N=3 non-attendances and N=5 cancellations. Key themes from the goals set included psychoeducation on autism, communication strategies, understanding emotions, sleep strategies, understanding of sensory processing and strategies for anxiety management. Feedback from families was positive with parents reporting the sessions provided "lots of helpful information and strategies" and young people with autism saying what they liked about Healios was "people listened to me".

Discussion: The initial evaluation demonstrates the feasibility and acceptability of online post-diagnostic support and supports further developments including service improvements, such as additional therapeutic materials and more fine grain measurement of outcomes.

Online social support by and for autistic adults – assessing needs and interest of francophone Autistics in Canada (D11)

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Abstract

Background : While many autistic adults are neglected by formal support services, online exchange groups are numerous and initiatives aiming to provide online support by and for autistic adults are being implemented all around the world.

Aim: To assess needs and interest for online social support offered by and for Autistic adults to inform the implementation of such a service.

Methods: Participants (≥ 18 years old Autistic) were recruited through social media. This study is based on a citizen participatory approach. A survey was launched using a four sections online questionnaire: 1) sociodemographic; 2) current social support; 3) specific area of needs; 4) interest in an online platform to provide or receive social support by and for autistic peers. Data analysis relied on descriptive statistical tests.

Results: 116 participants responded to the survey. While use of formal social support services (mostly offered by non-autistic) was limited due to their inadequacy with participants' needs and preferences (32.0%), cost (30.9%), and obstacles in their access (47,4%), participants mentioned needing social support in regards with personal life experiences (73.5%), professional or academic life (57.1%), place and role within society (57.1%), family life (48.0%), friendships (45.9%), couple or romantic relationships (41.8%). Participants (80.9%) were mostly to very favourable to using an online support service offered by Autistics, as well as to volunteering to offer such support (62.2%). Regarding communication, they mentioned online chat (72.3%), videoconference (51.8%), emails (49.4%), telephone (44.6%) and text messages (43.4%).

Conclusion: Findings show various obstacles limit Autistic's access to social support, while suggesting a need for diversifying social support offered to them. According to this study's participants, an online social support service for and by Autistic adults would receive a very strong support by the community.

A living environment adapted to the needs of autistic adults: What does literature offer? (D12)

Anne-Marie Nader[1,2], Mylène Charette[3], Estellane St-Jean[3,2], Virginie Lasalle[3], Baudouin Forgeot D'Arc[3,2], Isabelle Courcy[4,2], Roger Godbout[3,2]

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Abstract

A majority of autistic adults either live with their family or in one form of residential care while many autistic adults wish to acquire a certain residential autonomy. What is a good living environment and what should be consider when conceiving home for autistic adults? This study wishes to identify the best practices in the conception of living environments for autistic adults by 1) describing the current scientific literature and 2) identify environmental factors associated with the quality of life (QoL) of autistic adults in residential living regarding both the built and the social environments. A transdisciplinary systematic literature search was performed combining information from health, human, social and architecture fields. 35 studies met the inclusion criteria (aged ≥ 18; residential living environment; empirical studies, French/English). Content analysis was done following a systemic model (factors related to the a. individual; b. physical and relational environment; c. community). Results show that most studies focus on autistic adults considered as having behavioral challenges and living in group-home. The most assessed outcome was behavior profile and adaptive functioning through questionnaires completed by proxy (parents, staff). Only three studies addressed the subjective perception of autistic people on what they consider a good living environment. 5 relevant key themes were identified: 1) sensory issues; 2) social regulation; 3) communication; 4) security; 5) social participation. Those themes were mainly addressed in the context of architectural design principles and much less in the context of relational environment, nor the role of community. This review reveals that little is known on the impact of the living environment on the QoL of autistic individuals, nor on factors to consider in the context of living facilities. A better understanding of conditions associated to QoL when designing living environment is a starting point to conceive homes *with* and *for* autistic adults.

Autistic women's experiences of university (D13)

Sophie Phillips

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Abstract

Autistic students are at particular risk of marginalisation in society. The number of students with autism attending university in the UK is ever increasing, and now exceeds the numbers declaring a physical disability (Higher Education Statistics Agency, 2017). Gaining a degree is often assumed to assist in gaining future employment, but this seems to not be the case for autistic people. With growing numbers of autistic people going to university, it seems necessary to ensure that the experience is still fulfilling.

In order to fully understand the barriers autistic students face at university and the support they receive, it is necessary to gather their lived experiences of university. These experiences could offer insight into how autistic women students not only experience university, but also experience wider society as an autistic person.

11 autistic women students (who were studying at a UK university) participated in the research. All created up to three pieces of artwork documenting experiences at university where they felt their autism had impacted. Each participant then completed a follow up online interview. Interviews were analysed thematically and with reference to participants' artwork.

Participants talked about how they had, or were having, both positive and negative experiences at university. They cited how other people's knowledge of autism had a noteworthy impact on their experiences and that 'human support' was either the most helpful or most unhelpful support they had had from university. In addition, participants focused on how the sensory environment impacted their experiences.

Overall, ingrained societal attitudes and stereotypes towards autistic women and a lack of autism knowledge by others can hinder autistic women's experiences at university.

Session E: Learning & Inclusion

Interviewing Autistic teachers to find out about their experiences in the Irish Education System (E1)

Claire O'Neill

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Abstract

This qualitative study explores the experiences of Autistic teachers in the Irish Education system. Autism has received attention in the past three decades in Irish educational practice, policy, and research, but Autistic teachers have not. This is an Autistic-led study as the teacher-researcher is Autistic and her lived experience is used in the research. A literature search uncovered that the experiences of Autistic teachers is a underdeveloped but growing area of research internationally. There is no literature available on Autistic teachers in Irish research or policy and therefore the study exposed a significant gap in the existing literature. Interpretative Phenomenological Analysis was the primary methodology used and also informed the research design. Four Autistic teachers participated in semi-structured interviews over Zoom. The interviews were transcribed and analysed using the structured and systematic IPA process. Several findings emerged from the study that have implications for future practice, policy, and research. Participants described strengths including using monotropism to advantageously in their teaching and the ability to form strong and empathetic relationships with their pupils. Experiences with colleagues were often influenced by lack of Autism-related understanding and sometimes stigma and negative biases. The physical, sensory, and organisational environments of schools had an overall negative impact on participants' experiences. Recommendations resulting from the study include the need to increase whole school knowledge of Autism and neurodivergent-friendly environments. The findings suggest that more awareness is needed across the Irish education system including initial teacher education (ITE), professional development (PD) and support services. What support to provide, how to provide it and who to provide to are areas for future study emerging from the research.

Keywords: Autism, Autistic teachers, neurodivergence, neurodiversity, Irish Education, inclusion, Autistic advantage, support, monotropism, stigma, embodiment, IPA, qualitative, lived-experience, role model, relationships, empathy, embodiment, sensory environment, space and place, expertise, insider-perspectives.

Co-designing peer support materials for neurodivergent young people in mainstream secondary schools (E2)

Francesca Fotheringham

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Abstract

To date, studies examining support interventions for autistic young people have involved non-autistic students playing a mentoring or befriending role to autistic students. Such models risk promoting a normalisation agenda, rather than supporting autistic (and other neurodivergent) students to thrive on their own terms (Kim & Crowley, 2021; Crompton et al., 2022). Our

preliminary work shows that some young people would prefer a neurodivergent approach to encompass pupils with different diagnoses. Neurodivergent peer support (where neurodivergent pupils provide support to one another) allows for experience-sharing, friendship-building and developing pride in their neurodivergent identity, without needing to adhere to 'neurotypical' social norms (Cresswell & Cage, 2019).

We will co-design a peer support materials package for use in mainstream secondary schools. Our co-design group includes 6 neurodivergent 13–16-year-olds, with a range of diagnoses, and 6 neurodivergent adults/education professionals. Using a participatory paradigm enables neurodivergent pupils to design their own support so it is authentic and accessible, unlike most support approaches which are developed by neurotypical adults. We will use Rapid Evaluation and Assessment methods to collate co-design outputs into a designed package of information to give to schools.

Co-design groups are scheduled for Summer 2022. Pilot work suggests that materials are likely to focus on: nurturing a positive outlook on neurodivergent identity; a sense of belonging; and self-advocacy skills. We will consider group activities, the nature of staff involvement, and how peer support is embedded within the wider school community. The findings presented will include both the co-design groups' outcomes and reflections on the process. A pilot trial of the materials will commence in Autumn 2022.

The longer-term aim is to make the co-design peer support package available to UK secondary schools and future research may investigate the viability of a peer support package for neurodivergent children in primary schools.

Developing and testing strategies for UK Primary schools to better support children with traits of ADHD (E3)

Abigail Russell

University of Exeter, Exeter, United Kingdom

Abstract

There has been a lot of research about what works to support children with traits ADHD in school, however lots of what we know is not used or 'implemented' in schools. This is because the existing evidence-based programmes include lots of complicated parts, whereas in reality school staff use short and brief strategies to try to manage any problems that arise, based on the individual needs and traits of the child.

In this talk, I will describe how we are developing a toolkit of strategies for school staff to use and the process of testing this with eight Primary schools and about 20 children with traits of

ADHD. The toolkit is being developed using a method called "Intervention Mapping", which involves working with real people who have relevant experiences (people with ADHD, families, school staff and others), considering theories about ADHD, school systems, and how people learn new behaviours, and combining this with what we know from existing evidence from previous research. The toolkit will be tried out with eight schools in staggered way (a case series design) to assess whether the toolkit is acceptable and feasible, making any changes needed between schools, and to see if any indications are seen that using it is improving the school experience for children with traits of ADHD. This will be analysed using a combination of qualitative and quantitative methods.

I will report findings from the first schools to try the toolkit, and talk about the process of developing and evaluating it. Should this work be successful, I will go on to test the toolkit to see if it is effective at improving school experiences for a much larger group of children with traits of ADHD and then plan to roll this out to be available to Primary schools across the UK.

An exploration of the embodied everyday lives of autistic children in a UK primary school (E4)

Jill Pluquailec

Sheffield Hallam University, Sheffield, United Kingdom

Abstract

The fieldwork for the study is in its early stages and will continue through Summer 2022. The study is an ethnographic exploration of a UK mainstream primary school with an Integrated Resource for autistic children. Taking place over two half-terms, data is being gathered through participant observation, interviews, and the collation of field notes in and around the school site. This includes time spent in classrooms, in the Integrated Resource, playgrounds and social spaces, and alongside teaching and leadership staff.

The claim that the UK education system continues to fail autistic children is well evidenced (Ofsted, 2021; Autistica, 2019; House of Commons Education Committee, 2019; Ambitious About Autism, 2018). The aim of the study is to focus attention on the everyday, embodied experiences of autistic children from a perspective situated within the neurodiversity paradigm (Walker, 2021) - that is, it is not centred on documenting or analysing autistic traits or deficits, nor measuring children’s educational outcomes or behaviour, but instead, centres analysis on the features of the education environment (including broader social and political contexts) that enable, or disable, autistic flourishing. This is an approach intended to further the call for autistic children having meaningful childhoods (Pluquailec, 2018; forthcoming; Curran and Runswick-Cole, 2014) rooted in social justice for neurodiverse communities, rather than autistic children as disembodied containers of impairment in need of educational intervention. Ongoing

insights from current fieldwork might be expected to highlight how much of autistic flourishing is deeply relational (Crompton et al., 2020; Milton, 2012), highly embodied (Pluquailec, forthcoming; 2018; Smith, 2016), and dependent on the prevailing attitudes of beliefs of adult figures such as school leaders and school practitioners.

Defining Neurodiversity in the Context of Algerian Teacher Education: Perspectives from the Global South (E5)

Imene Zoulikha Kassous, David R. Simmons, Ines Alves

University of Glasgow, Glasgow, United Kingdom

Abstract

How well is the concept of neurodiversity understood across the world? In the Global South, little has been written about neurodiversity, and most of the relevant definitions used are borrowed from the Global North. This questions the extent to which teachers of these countries are acquainted with this concept.

This paper focuses on a small part of a wider study on teacher education and inclusion of autistic children in Algeria. This study is based on qualitative methods principles where we used both interviews and focus group discussions. Thirteen teachers of English as a foreign language took part in this study and were asked about their knowledge of autism which we then subjected to critical thematic analysis. Two interview questions asked what participants knew about the word “neurodiversity” and how it related to autism.

Of those who answered the question, seven tried to explain the word using their own knowledge. Some participants explained the word “neurodiversity” as variations or differences in the human brain/mind. One participant suggested that it was to do with different intelligence. While most participants had a neutral perspective, one participant suggested that it implies “autistic people [maybe] have some problems in the brain”. This neutrality can be linked to participants’ unfamiliarity with neurodiversity. Our findings also demonstrate the way some participants relate autism to neurodiversity. One participant explained that autistic people are included under the umbrella of this diversity as “[t]hey have particular understanding of some things that's what makes them different unfortunately from us”.

The idea that autistic people are “different” was directly/indirectly declared when answering this question in particular, and sometimes throughout the entire interview. As the area of neurodiversity is still globally new, participants’ definitions based on their own understanding reflect its novelty in Algeria.

Genuine inclusion in organisational decision making through the Scottish Autism Inclusive Governance Project (E6)

Yo Dunn[1], Karen Leneh Buckle[1], Kabie Brook[2]

[1]National Autistic Taskforce, National, United Kingdom. [2]Autism Rights Group Highland, Inverness, United Kingdom

Abstract

The majority of large autism charities and care providers are governed by neurotypical professionals and/or parents/family members of neurodivergent people, rather than by neurodivergent people ourselves. This project develops and pilots methods to genuinely include autistic people in governance and decision-making, including those with the highest support needs, who are rarely meaningfully involved.

Scottish Autism is the largest provider of autism-specific services in Scotland. In March 2021, they issued an invitation to tender seeking autistic consultants to deliver a programme of change by developing an inclusive governance approach at Board and operational level. The National Autistic Taskforce is autistic-led, and focusses on autistic voice in matters affecting those with highest support needs and, often, least autonomy. Together with two Scottish autistic-led organisations, Autism Rights Group Highland and Autistic Mutual Aid Society Edinburgh, they submitted a successful bid to deliver the project.

The project includes case studies of approaches to inclusive governance from a diverse range of contexts. The case studies span governance at all levels from individual autonomy and supported decision-making; through the frontline organisation and delivery of care services; up to board and senior leadership level decision-making. Alongside this work, we are finding out about the experiences of and attitudes to decision-making and governance across stakeholder groups including staff at all levels, supported individuals and their families. We are developing accessible materials to communicate about the project and consult directly with those supported individuals who face the most barriers to their involvement.

These developing ideas and understandings will be shaped in co-production with all stakeholder groups, exploring opportunities and seeking to overcome barriers to implementing meaningful organisation-wide change. The team expects to produce comprehensive models of how governance at all levels of organisations can be made genuinely inclusive of neurodivergent people right across the spectrum.

Barriers to social inclusion faced by autistic youth at school and in employment: comparing the perspectives of autistic youth to those of parents and professionals (E7)

Aparna Nadig[1,2], Catherine des Rivières-Pigeon[3,2], Valérie Malboeuf[3,2], Marie-Hélène Ayotte[4,2], Isabelle Courcy[3,2], Tara Flanagan[1,2], Lucila Guerrero[2], Nadia Lévesque[2], Valérie Martin[3,2], Josée Moreau Moreau[5,2], Lili Plourde[6,2], Nathalie Poirier[3,2], Marie-Hélène Poulin[4,2], Isabelle Soulières[3,2], Alena Valderrama[7,2]

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Abstract

Autistic youth face significant challenges both in realizing their academic potential[1] and in integrating into employment.[2] Our project engages people with lived experience of autism to identify barriers to the inclusion autistic youth in the domains of school and employment, allowing to us to co-develop strategies to promote their social inclusion.

We employ a participatory research approach aimed at recognizing and using the expertise of people directly affected by autism.[3,4] Until now, strategies to promote social inclusion have predominantly been developed by clinicians or researchers, while the perspectives of autistic youth who face these barriers have rarely been studied. Our team, working in co-construction, developed a qualitative design using an asynchronous online focus group (FG) method.[5] As with traditional, in-person FGs, the aim is to encourage interactive discussions on a predefined topic, but in the case of asynchronous online FGs, the exchanges take place in writing, on a closed online platform to which only the participants and facilitators have access. These are asynchronous because the discussions do not require a real-time exchange: they can take place at any time during a defined period, which was 4 weeks in our study.

We conducted 27 asynchronous FGs using private groups on Facebook, involving a total of 147 participants from the Montreal area (Quebec, Canada; FGs were conducted in French). Nine of these FGs (involving 49 participants) were conducted with autistic youth aged 13 to 25 years. Using the technique of reflective thematic analysis, we will be able to identify the barriers to inclusion identified by these autistic youth and compare them to those perceived by parents and school and employment professionals. This research will uncover the valuable perspectives of autistic youth on the challenges they face and identify mitigation strategies that incorporate their lived experience.

Exploring belonging: the views of autistic people collected through online focus groups (E8)

Krysia Waldock, Michelle McCarthy, Jill Bradshaw

University of Kent, Canterbury, United Kingdom

Abstract

Although it is known within social sciences that autistic people have smaller social networks, less attention has been paid to how autistic people experience and understand 'social inclusion' and 'belonging'. Within the academic literature, 'social inclusion' and 'belonging' have been interchangeably used, but with no clear consensus on how autistic people define them. The aim of this research was to explore how autistic people understand and conceptualise the terms 'social inclusion' and 'belonging'. This study was an exploratory, qualitative study. Focus groups were selected as the method of data collection. Three focus groups, lasting 2-2.5 hours, were held over Zoom, with written and verbal communication options available. Thematic analysis (Braun & Clarke, 2006) was used to analyse the data. Four themes emerged from the data: 'nebulousness', 'a bidirectional relationship', 'degrees of belonging' and 'barriers'. Both being socially included and feeling a sense of belonging were considered to be bidirectional and intersubjective, with autistic lived experience an important dynamic (theme: 'a bidirectional relationship'). Breakdowns in this relationship seemed to be a result of the double empathy problem (Milton, 2012). Furthermore, social inclusion and belonging were not clearly defined by participants (reflecting the academic literature; theme: 'nebulousness'), but belonging was seen as a 'human need'. Experiences shaped participants' views, and metaphysical environments, e.g. online spaces, were referred to as spaces that were accessible (theme: 'degrees of belonging'). Participants reported multiple experiences of exclusion and oppression due to being autistic and 'different', including experiences of stigma and group dynamics as barriers to being included and a sense of belonging (theme: 'barriers'). Suggestions for further research and implications for practice will be provided, including the implication of physical (e.g., sensory) and intersubjective (e.g., communicative, attitudinal) dimensions to inclusive environments for autistic people, and the importance of the double empathy problem in inclusion.

Understanding camouflaging in neurodivergent (autistic, ADHD and/or dyspraxia) and neurotypical girls (aged 11-14 years) (E9)

Ailbhe McKinney[1], Jacqueline Maybin[1], Stella Chan[2], Sarah O'Brien[3], Sinead Rhodes[1]

[1]University of Edinburgh, Edinburgh, United Kingdom. [2]University of Reading, Reading, United Kingdom. [3]Kings College London, London, United Kingdom

Abstract

Background:

Many neurodivergent people learn to ‘camouflage’ their difficulties by imitating others and hiding aspects of themselves. Girls and women are more likely to do so. Camouflaging has not been examined in teenagers with ADHD or dyspraxia. Gaining a better understanding of camouflaging in girls with ADHD and dyspraxia is important given its association with poor mental health outcomes. This research was co-produced with 15 neurodivergent women and sits within a larger project aimed at understanding the transition into adolescence in neurodivergent girls using a two-wave longitudinal design.

Aims:

1) examine if diagnostic label (autistic, ADHD, dyspraxia, neurotypical) can predict camouflaging scores.
2) examine if camouflaging scores are associated with anxiety and depression.

Methods:

An adapted version of the Camouflaging Autistic Traits Questionnaire (CAT-Q) will be used to assess camouflaging. The CAT-Q questions were adapted for this age group by interviewing four teenage girls. Anxiety and depression will be assessed using the Revised Child Anxiety and Depression Scale-25 and the Anxiety Scale for Children – ASD. The project is currently under ethical review and due to launch in June 2022.

Results:

To determine if camouflaging scores are different across the four groups, a one-way ANOVA will be conducted. A generalised linear regression will be used to determine the association between camouflaging and mental health scores. A priori sample size analysis indicated that 128 girls (recruited at age 11-13.5) was sufficient to detect effects.

Potential insights:

This study will provide evidence on the extent to which this age group is camouflaging, across different diagnostic groups. The association between camouflaging scores and depression and anxiety, and whether it is mediated by diagnostic label, will be demonstrated. Understanding how much young girls are camouflaging and its relationship to mental health will be important for parents, clinicians, and school staff to provide appropriate support.

Exploring the impact of a school-based autism screening protocol using interviews with autistic young people, their parents/carers and teachers (E10)

Hayley Edwards, Adam Rumble

University of Manchester, Manchester, United Kingdom

Abstract

In a mainstream all-girls secondary school in England, autism was often not considered as a potential underlying cause of pupils' difficulties until pupils were aged between 14 and 18 years, or after involvement from educational psychologists. The need to identify autistic pupils earlier was recognised, which led to the development and implementation of an autism screening protocol at the school.

Prior to commencing the present study, the researcher conducted a case study with an autistic young person who attended the school before the screening protocol was introduced and received an autism diagnosis after leaving the school. The study explored experiences of autism identification, the impact of late autism identification and the potential impact of earlier autism identification. Findings demonstrated how lack of identification of autistic pupils can contribute to their needs being unmet in school and how this can impact on their ability to engage with learning and to experience positive emotional wellbeing.

Following this, the researcher consulted with autistic pupils at the school, to design the present study. The aim of the present study is to explore experiences of the school-based autism screening protocol, using a multiple case study design with three autistic pupils, with three embedded units of analysis: pupil experiences, parent experiences, and staff member experiences. Data gathering using semi-structured interviews has commenced and will be analysed using thematic analysis.

It is expected that the data will provide information about how a school-based autism screening protocol may affect the outcomes of autistic pupils. The data will also highlight if and how the protocol supports staff to identify potentially autistic pupils and make more informed, well-evidenced referrals to autism diagnostic pathways. Therefore, findings are expected to contribute to our knowledge of how schools may use autism screening protocols effectively to support the earlier identification of autistic pupils.

Predictors of Autism Understanding in Autistic Teenagers (E11)

Kyle Gravitch[1], Sinéad O'Brien[1], Bella Kofner[1], Eliana Grossman[2], Ariana Riccio[3], Kristen Gillespie-Lynch[1,2]

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Abstract

Prior research suggests that parental decisions about if and how to tell their autistic child they are autistic impact autistic identity development. No prior research has examined if autistic people’s own characteristics influence how autistic youth understand autism. Our study examines how parental discussions about autism and autistic youths’ self-determination and cognitive skills (i.e., fluid intelligence, perceptual abilities, and grammatical reasoning) affect youths' autism understanding. The lead author, an autistic honors student, hypothesized that the following individual differences would be associated with heightened autism understanding: inductive logic skills, detail orientation, grammatical reasoning, self-determination, and age. His hypotheses were informed by how he and his autistic friends figured out they were autistic. He coded interviews with 40 autistic students in an informal technology program and parental surveys. He coded the teen question “What is autism?” in collaboration with an autistic graduate student and the parent question “What have you told your child about their diagnosis/diagnoses?” with his advisor. Youth completed Cambridge Brain Sciences' tasks which assessed cognitive skills such as fluid intelligence, perceptual abilities, and grammatical reasoning, as well as a self-determination inventory. Findings revealed that parents commonly told their children about unique child characteristics, but less commonly told them about their autism. Parental disclosure of unique characteristics, but not necessarily autism, was associated with less youth difficulty defining autism. Parents were more likely to tell a teen they were autistic if the teen was older and had higher grammatical reasoning skills. Teens with higher fluid intelligence were more likely to define autism in connection with themselves. Higher self-determination was associated with less difficulty defining autism, but more misconceptions. These findings highlight individual agency as a key predictor of autistic identity development. Future research should examine if these associations replicate for autistic persons of different ages and abilities.

“But it doesn't really have to do with bilingualism”: Family language policies in transnational families of bilingual autistic children (E12)

Anna Metreveli

Stockholm University, Stockholm, Sweden

Abstract

Family language policy (FLP) investigates language ideologies, practices, and management strategies among family members. With the growing number of autistic children exposed to bi- or multilingual environments, there is a gap in the existing body of research that has not focused before on speaking and non-speaking autistic children from transnational families. This study therefore aims to determine to what extent existing FLP frameworks can adequately capture the lived experiences of families with bilingual autistic children, especially in the case of non-speaking or minimally speaking autistic children who require additional support. This mixed method study uses an online parental questionnaire and semi-structured interviews to investigate which language and modality policies and practices are prevalent in transnational families with bilingual autistic children. Eight parental interviews also explore other potential factors that affect parental decisions about bilingualism. The study further aims to determine if there are any other broader ideologies and discourses about autism and bilingualism in the parental accounts. The results suggest that parents of bilingual autistic children share positive views about their children's bilingualism. Their language practices and management strategies, however, were not always consistent with their views on bilingualism. The results of the parental interviews indicate that additional diagnoses, spoken language proficiency, the amount of additional support the child requires, misrecognition of early diagnosis, recommendations from professionals, and access to socioeconomic resources were other factors influencing parental decision about bilingualism. As a result, I argue that FLP as a theoretical framework fails to capture certain aspects of the families' lived experiences, address ableist injustices and offer any remedies against them. Thus, this thesis highlights the importance of developing an innovative framework that can incorporate FLP, social class, and the neurodiversity movement as a transformative remedy to ableist injustices experienced by bilingual autistic children and their families.

The Impact of Identity-First Language on Undergraduates' Perceptions of Autism Spectrum Disorder (E13)

Lauren Bacchus

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Abstract

Linguistic choice plays a critical impact on our identities and social relationships. Recent literature suggests a disagreement amongst autism researchers in favor of person-first language (PFL) use, such as a "person with autism spectrum disorder" (Vivanti, 2020) or identity-first language (IFL) use, such as an "autistic person"(Botha et al., 2021; Bottema-Beutal et al., 2021; Dwyer, 2022; Kapp et al., 2013, etc.). The majority of surveyed autistic individuals, however, tend to prefer identity-first language to promote neurodivergent self-identities (Kapp et al., 2013), reflect diversity (Bury et al., 2020) and reduce stigma (Bury et al., 2020). This is the first study to investigate the impact of identity-first language on undergraduate students' perceptions of autistic individuals. Participants were randomly assigned to a treatment group using either identity-first or person-first language, and rated statements about autistic individuals. Overall, identity-first language impacted undergraduates' perception of autism

spectrum disorder and autistic individuals. Further implications and limitations are discussed for further research and application.

Session F: Research Culture

A participatory approach to creating a Neurodiversity Resource Hub for staff and postgraduate research students within the University of Glasgow. (F1)

Leigh Abbott, Chris Halsey, Peter Hastie, Elliott Spaeth, Karin Oien, Margaret Sutherland, David Simmons

University of Glasgow, Glasgow, United Kingdom

Abstract

We have been funded by the Wellcome Trust to create a Neurodiversity Resource Hub (NRH), intended to facilitate an inclusive community for staff and postgraduate research students (PGRs) at the University of Glasgow.

The purpose of this hub is to supply information on:

1. Terminology surrounding neurodiversity
2. Inclusivity and allyship
3. Creating and maintaining positive working relationships
4. Accessibility
5. Accessible interviewing processing
6. Disclosure of a condition and staff and PGRs access to support
7. Support within the University
8. Internal and external resources

Content was identified by the internal team using the research literature, attendance at workshops, and training from disability and neurodiversity specialists.

We wanted to use participatory involvement so that members of staff and PGRs across the University could give their thoughts on the NRH through revising its contents. This was to ensure that the NRH was understood across the neurodiversity spectrum. Thus, we invited staff via email and PGRs via a survey to be contributors to the NRH.

The survey asked participants if they identified as neurodivergent, neurotypical or disabled. Names of those who completed the survey were chosen via a random name generator. As the Neurodiversity Resource Hub has 7 sections (excluding the internal and external resources section), 7 neurotypical people and 7 neurodivergent or disabled people were asked to revise its contents. 4 neurodivergent, 1 disabled, and 4 neurotypical people responded and provided their insight.

We are editing the document based on the contributor's suggestions. Once edits are complete, the team will issue a draft webpage to the contributors along with a survey to gather people's thoughts on the NRH before it is launched.

The Neurodiversity Resource Hub is anticipated to encourage others to amplify accessibility, acceptance of neurodiversity, and overall practice inclusion at the University of Glasgow.

How do late-diagnosed autistic people feel about genomic studies of autism? (F2)

Rebecca Ellis, Umar Toseeb, Kathryn Asbury

University of York, York, United Kingdom

Abstract

Background: The stated aim of the Spectrum 10K study, led by researchers at Cambridge and UCLA and funded with £3 million from the Wellcome Trust, was to study the genetic and environmental underpinnings of autism and co-occurring health and wellbeing challenges. However, this research was paused indefinitely due to a substantial and sustained backlash from the autistic community, including accusations of eugenics (Sanderson, 2021). The current research seeks to understand this situation and addresses some of the ethical, philosophical, practical, scientific and social concerns about genetic research into neurodivergence and disability, and about participation in this type of research (Sabatello et al., 2021).

In our interdisciplinary, qualitative study we will elicit personal autism narratives and explore how they relate to individuals' views about participating in genetic studies of autism, and about the potential prospect of DNA-based autism screening.

Primary aims are:

1. How do late-diagnosed autistic individuals experience being autistic?
2. How do late-diagnosed autistic people feel about genomic studies of autism?

(Plan for) Method: 20 autistic individuals who were diagnosed in adulthood will be invited to take part in semi-structured interviews. Options include: an in-person interview; an online interview; a phone call; a video interview conducted by a trusted other (with schedule provided by the research team) or providing written data or an audio recording in response to written questions; email and social media correspondence.

(Plan for) Analysis: All recorded data will be transcribed and anonymised by a professional transcription company. Data will be coded and thematically analysed using Braun and Clarke's methodology (2021).

Insight Expectations: There is a current gap in research surrounding the opinions of autistic individuals regarding genomic studies into autism. This research hopes to contribute towards this understanding and to work towards a situation in which genomic autism research is co-created with the autistic community.

Investigating how we summarise evidence from fundamental neurodevelopmental disorder research (F3)

Emma Wilson, Gillian Currie, Peter Kind, Emily Sena

University of Edinburgh, Edinburgh, United Kingdom

Abstract

Background

Fragile X Syndrome (FXS) and Rett Syndrome (RTT) are two extensively researched neurodevelopmental disorders (NDDs). It is important that researchers and other stakeholders have access to up-to-date information and can make decisions based on the highest quality evidence.

Systematic review is a method used to summarise evidence and assess its quality. However, they are time-consuming to conduct and often results are out-of-date by the time of publication. Living evidence summaries are a new type of resource which provide an up-to-date, searchable database of research on a given topic. They build on systematic review methods but use automation technology, such as artificial intelligence, to keep up with new research as it is published, providing real-time overviews.

Aims

To inform the development of a living evidence summary of fundamental NDD research, our project aims to (1) identify previously conducted systematic reviews of fundamental FXS or RTT research, (2) summarise their focus, and (3) assess their reporting quality.

Methods and analysis

We will search three bibliographic databases (PubMed, Embase, and Web of Science) to identify relevant systematic reviews. We will not restrict searches by publication date or language.

Two independent reviewers will screen the search results to ensure relevance. We will then provide a descriptive summary of each reviews' scope and score each reviews' reporting quality using an adapted version of the PRISMA (Preferred Reporting Items for Systematic reviews and Meta-Analyses) checklist. Reporting quality is used as a surrogate to measure how well each review was conducted.

Impact

This meta-research project will help us understand how well previous systematic reviews of fundamental NDD research were conducted, and inform the development of a living evidence summary. Once completed, this resource will provide researchers and other stakeholders with an up-to-date overview of research and an indication of the overall evidence quality.

DO read the comments: reflecting on and learning from participant feedback on an autism-focused genetic literacy survey (F4)

Nicola Sugden, India Little, Amy Wang, Maddie Piper, Chris Gunter

National Institutes of Health, Washington, D.C., USA

Abstract

We will present a qualitative analysis of participant feedback from an autism-focused online survey about genetic literacy, based on thematic coding of a database of 424 text comments and in-depth engagement with select examples. The survey project sought to replicate and extend previous analysis of genetic literacy and opinions on genetic testing. It also tested the efficacy of a short online educational intervention explaining that autism has a mix of genetic and environmental causes. We surveyed both the general population and participants of SPARK, a large study on the genetics of autism. Preliminary analysis has indicated that the comments from SPARK participants raise a series of questions relating to research design and methodology, including how to balance evolving best practice with the replication of older studies; whether there is a fundamental tension between dominant norms of survey design and the inclusion of neurodiverse participants; and the need to critically evaluate the necessity, promises, and limits of different kinds of community feedback on research. We intend to use a mixed methods approach by combining these qualitative data with quantitative analysis of associated demographic data to characterize groups of participants and their views. We will also reflect on the implications of this learning on the results of the main research project. The “free space” of a comment box created room for participants to pose criticisms, corrections, questions, and praise; serious analysis of this unstructured feedback allows us to hear and elevate neurodivergent and minority voices. Ultimately, we emphasize the importance of incorporating insights from research participants whenever and however they are communicated and demonstrate how our team is taking forward work that builds on the issues raised.

Revisiting the "Anthropologist on Mars": Questioning the assumptions that support Participant Observation from the perspective of an autistic anthropologist (F5)

Will Tuladhar-Douglas

Situgyan Consulting Ltd, Aberdeen, United Kingdom

Abstract

After decades of doing participant observation fieldwork and consistently not getting the answers that my colleagues did, I now finally understand that for us autistic folk, social life is almost continuous participant observation. However, we lack the social scaffolding of an internalised social norm that is presumed by the method as we teach it. In the famous essay from which I draw my title, neither Oliver Sacks nor Temple Grandin knew enough about formal theory within anthropology to understand either the methodological reflexiveness of participant observation, or its implicit cultural norms. In the work of an autistic anthropologist --- a person who is professionally adrift among different cultures --- participant observation becomes both a network of reflecting jewels and an embodied critical theory. In this presentation, I will juxtapose (a) Sacks' encounter with Grandin, (b) standard texts on how to do participant observation, and (c) some reflections from my own, bewildering, failed efforts to reproduce correct participant observation for anthropological papers and conferences. I will argue that the dominant mode of autistic anthropology is not comparison but empathy.

Authentic coproduction: utilizing research networks to enhance participatory research (F6)

Rebecca Poulsen[1,2], Melanie Heyworth[2,1]

[1]Macquarie University, Sydney, Australia. [2]Reframing Autism, Sydney, Australia

Abstract

Recent literature demonstrates autism research does not reflect the priorities of the Autistic population or their families, and does not fully adopt inclusive, coproduced, or participatory methodologies that in turn increase Autistic community engagement in autism research. Although some organizations and institutions have pioneered a broad commitment to inclusive, coproduced research, a disparity exists between current research funding and output, and community priorities and needs. In our discussion, we define and describe authentic Autistic coproduction from the literature. Next, we will review the disparities between the research priorities of the Autistic community and current research outputs and funding. Then, we investigate broad strategies to assist in bridging the gap between the researchers and the researched. Finally, we will highlight how research networks can help facilitate coproduction, increasing the “voice” of the Autistic community and their allies in research.

Our review suggests that although there is a shift in the participatory research landscape, there is a need to identify ways to facilitate an environment where authentic coproduction is standard practice and inclusive of Autistic contributors regardless of support and communication needs, including marginalized and otherwise silenced populations. One emerging community-based solution is research networks. Networks such as PARC (UK), ICCR (US) and ARN (Australia) aim to facilitate an environment where coproduction is standard practice. As the founder of the ARN and a member of the INSAR Autistic research committee that is driving the ICCR, we discuss the aspirations of these networks, and how they support Autistic coproducers and enable their participation in autism research. This is done through sharing opportunities, tools, and resources within a community-based network. Networks will equally work alongside autism researchers to foster and facilitate inclusive coproduction processes.

Inclusion of autistic research assistants in the subjective coding of social interaction (F7)

Nida Latif[1], Avleen K. Mokha[1], Kouro-Maïram Baro[2], Alyssa Di Cesare[3], Aparna Nadig[1]

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Abstract

There have been many calls for the meaningful involvement of autistic people in all stages of autism research, to both ensure respect of and acceptability by autistics, as well as to increase real-life impact of the research (Nicolaidis, 2019). The inclusion of autistic perspectives would be particularly informative for research on social interaction and cognition, which has traditionally been viewed through a deficits-based lens (Davis & Crompton, 2021). Such a lens has resulted in research outcomes that have limited efficacy for improving social functioning for those on the autism spectrum (Paynter, Keen, & Rose, 2016). Here, we share reflections on our first attempt at including an autistic research assistant in the implementation phase of research on social interaction. In this project, an autistic and a non-autistic research assistant were collaboratively involved in applying an observational coding scheme in order evaluate Interactive movement coordination (IMA) during naturalistic social interactions. IMA is the tendency for conversing individuals to become more similar in their overall movement, including postures, gestures and facial expressions, and is thought to be a metric of the efficiency and success of a social interaction (Miles et al., 2009; Marsh et al., 2008). We present autistic and non-autistic reflections on the individual and collaborative experience of applying a coding scheme and finding consensus amongst team members. We conclude that neurodiversity within research teams serves as a strength within the research process, creating space for the exchange of perspectives that is mutually beneficial to all team members. However, we suggest that some "common-practice" research methods, as they currently stand, are not conducive to creating inclusive research environments. We offer several concrete recommendations to support the inclusion of autistic research assistants in research on social interactions.

What are the common issues and motivations discussed when autistic people, family members and professionals come together to talk about priorities for autism research? (F8)

Tori Haar[1], Elizabeth Pellicano[2,1], Charlotte Brownlow[3,4], Melanie Heyworth[3,5,1], Wenn Lawson[3,1], Rebecca Poulsen[1,5,3], Gabrielle Hall[1], Tamara Reinisch[6]

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Abstract

There is mounting pressure for autism researchers to focus on areas of priority and everyday practical relevance to autistic people and those who support them. Founded in Australia in 2018, the Australasian Autism Research Council (AARC) is a diverse group of community members (including autistic people, parents, advocacy and service organisation representatives, researchers etc.), who worked together to consult the broader autistic and autism communities about their priorities for autism research. The AARC operates under the auspices of Autism CRC, a charitable research organisation which has enacted a collaborative approach to autism research across the lifespan.

In 2020, the AARC conducted an in-depth consultation with community members to identify key research questions under five key topic areas: Communication, Education, Employment, Health & Wellbeing and Justice. Each group consisted of autistic people, family members and professionals with experiences relevant to the topic area (total n=55). Intense online text-based focus group discussions were held over a 10-day period yielded the 10 top research questions for each of the five topic areas.

In this study, we conducted a secondary analysis of these data, focusing on participants' views of *how* autism researchers should go about addressing these research questions. Using reflexive thematic analysis – and adopting an inductive (bottom-up) approach to identify patterned meanings within the dataset – our initial examination has revealed that participants want autism research to shift away from a model that prioritises research objectives by external experts alone, to a model that supports the autonomy, wellbeing and engagement of autistic people and their allies throughout the lifespan. These findings highlight the new possibilities for research that arise when autistic people and their families are listened to, approached with understanding, and are respected and valued as individuals in the research process.

Autistic-Led Emancipatory Research: Enabling Autistic Voices to Enhance Access to Cultural Heritage (F9)

Aimee Fletcher

University of Glasgow, Glasgow, United Kingdom

Abstract

Growing up as autistic, it seemed to me the research in the field of Psychology *spoke about* people like me, rather than being *led by* the neurodivergent minds it is fascinated by. Now the neurodivergent community is finally being heard in research, but is it being actively listened to? There has been a shift in the autism research field towards embracing paradigms which are participatory and open to the involvement of autistic and neurodivergent people. Whilst this shift is welcomed by the neurodivergent community, ongoing criticisms about how truly representative participatory practice is when not autistic-led, and the risks of "tokenistic involvement", suggest that researchers need to adapt their practice to reflect community needs more closely. I argue for the importance of autistic-led, community-informed research that can shape future practice.

The scope of my PhD research crosses the disciplines of Psychology and Museum Studies, though I do not have a traditional background in Psychology. My research is about enabling the voices of autistic adults in identifying and addressing the barriers to museum visiting in Scotland. I have developed a methodology focused on involving autistic people meaningfully from the beginning – such as holding focus groups to inform research questions – through to

continually adapting my surveys, focus groups and interviews to meet the specific needs of each individual person. The research aims to promote the experiences of the autistic people involved to develop guidance for the museum sector, with the aim of improving visitor accessibility for neurodivergent people.

Using lived, professional and research experience, I will discuss the significance of encouraging and creating space for autistic researchers in the field. I will argue for the importance of ensuring access needs are met through reflective practices, and how such practices can produce meaningful findings that can benefit the neurodivergent community and wider society.

Towards Revelatory Research in Neurodiversity (F10)

David Simmons, Aimee Fletcher, Elliot Millington, Sarune Savickaite

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Abstract

In recent years, members of the autism and neurodiversity research communities have been at the forefront of developments in participatory research paradigms. The key feature of participatory research in neurodiversity is that those who identify with the neurotype of interest are, as far as possible, fully active and “true” participants in all elements of the research process: conception, design, implementation, analysis and dissemination, rather than being passive “patients” or “subjects”.

A further recent development has been “emancipatory” research paradigms, in which the aim of the research is to overcome a perceived barrier for participants, such as, for example, access to leisure facilities or a breakthrough in societal understanding of the impact of the neurotype on daily living. What we want to argue for here is the potential benefit of “revelatory” research into neurodiversity, which constitutes another development in the participatory research agenda. In revelatory research, something is revealed to participants about which they, and their co-researchers, were previously unaware and which can have a positive impact on both their own and others’ understanding of the neurotype.

One example of this in our own research is using Virtual Reality drawing tools to allow neurodivergent individuals to share their perceptual experiences (i.e. how they see the world). By analysing and interpreting these drawings, and the way they are drawn, together we can achieve a greater joint understanding of neurodivergent perception and explore the implications both for daily life (emancipatory) and for deeper self-knowledge (revelatory). Using further examples from our own research, and that of others, we will argue that revelatory research has the promise to make participation in research an extremely engaging and rewarding experience for all concerned, and not just the experimenters.

Researcher insights into the effects of neurotype and cognition on doing research interviews and analysing transcripts about personal relationships in a mixed neurotype study population (F11)

George Burrows

None, Edinburgh, United Kingdom

Abstract

Interviews about personal issues, such as relationships, need sensitivity and rapport. Interactions between people of different neurotypes is notably harder than between people of the same neurotype (e.g. Crompton, Milton). Neurotype may therefore affect the interview as well as a researcher's interpretation of data about relationships.

Through integration of the sociological concept of 'positionality' and use of a formal reflective model (e.g. Gibbs), I will use written accounts to identify the influence of my neurotype in research with participants of the same and different neurotype.

Expected findings include differing levels of rapport and flow of interview, as well as insights into data not shared by others in the research team.

This will produce insights into cross-neurotype and within neurotype interactions from beyond the field of neurodiversity research. These findings may help to give voice and value to neurodiversity in other fields of relationship research.

Autistic adults' views on commonly-used measures for assessing loneliness: an online survey (F12)

Kana Umagami, Anna Remington, Jade Davies, Laura Crane

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Abstract

There has been increasing interest in research on loneliness in autistic adults. Commonly, this has involved giving autistic adults widely used measures of loneliness that have been developed for the general population. We do not know whether such measures accurately capture autistic experiences of loneliness.

In this study, which was led by an autistic researcher, 203 autistic adults completed an online survey that included two commonly used loneliness questionnaires: the UCLA Loneliness Scale Version 3 (Russell, 1996) and the Social and Emotional Loneliness Scale for Adults (SELSA; DiTommaso & Spinner, 1993). We asked our participants to share their views on how well these questionnaires captured their experiences of loneliness.

As seen in previous research, our findings suggested that autistic adults' scores on the UCLA and SELSA questionnaires were higher than those typically seen on these questionnaires, when they are used with the general population. Encouragingly, however, participants' scores on the UCLA and SELSA appeared to align with their subjective experiences of loneliness.

Our participants identified several ways to further improve the measures. This included: (1) better distinguishing the characteristics of loneliness from the characteristics of autism; (2) acknowledging the role of autistic camouflaging; (3) addressing implicit assumptions about loneliness that may not apply to autistic people (e.g., that being alone equates to being lonely); (4) better reflecting the contextual and time-dependent nature of loneliness; (5) changing unclear phrasing that can make it difficult for respondents to answer (e.g., to whom the term 'family' applies); and (6) improving formatting/user-experience (e.g., removing compound questions).

We conclude that existing, widely used measures of loneliness appear to correspond with autistic adults' subjective experiences of loneliness, but that there are several ways that these measures could be improved for use with autistic adults.

Lessons from conducting co-production for a PhD project on the transition from childhood to adolescence in neurodivergent girls (Autistic, ADHD, and/or Dyspraxia/Developmental co-ordination disorder) (F13)

Ailbhe McKinney[1], Jacqueline Maybin[1], Stella Chan[2], Sarah O'Brien[3], Sinead Rhodes[1]

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Abstract

Background: Co-producing research with neurodivergent people leads to a more feasible and acceptable design. Furthermore, co-produced research has become a critical agent for change in how people with disabilities can advocate for their rights, after a history of being excluded from decision making.

Aims: Within the scope of a PhD, with small funds, a lack of training, and a short timeframe, it can be difficult to commit to a co-produced project and instead revert to traditional methods.

This presentation will aim to give early career researchers strategies on how to conduct co-production for a PhD project.

Methods: Co-production for this PhD thesis was designed in three phases: 1. connecting with relevant groups, 2. setting research priorities, and 3. designing a feasible project.

Results: Lessons learnt included recruitment strategies (through social media, contacting individuals, collaborating with charities), how to design co-production activity workshops, how to include feedback and how to evaluate impact.

Conclusion: While there are barriers to designing a co-produced PhD thesis, the following strategies can be helpful in overcoming them: creating connections early in a PhD programme, committing to training in the first semester about the principles and practice of co-production and conducting co-production in parallel with a literature review. Useful strategies for carrying out co-production using interviews/workshops and measuring impact will also be discussed. Finally, the benefits of a co-produced PhD will be highlighted such as a higher quality PhD project, better employability and the opportunity to spend time with the relevant population before ethical approval.

Session G: Relationships & Communication

Alone-time for autistic wellbeing: asking autistic adults about how and where they spend alone-time, and why (G1)

Florence Neville

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Abstract

Although mental wellbeing is generally acknowledged to be disproportionately low in the autistic population, research seeking to understand how autistic people experience and self-manage their wellbeing is scarce. Recent studies showing the importance of autistic community, stimming, and engaging in intense interests, indicates that autistic wellbeing needs and priorities may be different to those of non-autistic people.

Anecdotally, autistic adults discuss how time when they are not distracted by other people is vital for wellbeing. However, this need is rarely discussed in the literature. My PhD research

includes a mixed-methods study exploring how and where autistic adults choose to spend alone-time, and why. My approach to developing personal understandings and research practice is informed by the social model of disability, the neurodiversity paradigm, monotropism theory and the double empathy problem.

To date, I have run and analysed (reflexive Thematic Analysis) qualitative interviews with 16 autistic adults about alone-time, from which I identified four themes: “Reacting to social and sensory overwhelm,” “Retreating from social and sensory distraction,” “Regulating, recovering and recharging” and “Ready to reconnect with others.” Based on these findings I developed online quantitative questionnaires which I will have run and analysed by the end of 2022.

I intend for 250+ autistic adults to take part in these questionnaires to show (1) what activities are engaged in and what spaces are preferred during alone-time, and (2) whether alone-time average daily hours have an association with self-reported wellbeing, using the Warwick-Edinburgh Mental Wellbeing Scale. I will outline the qualitative and quantitative findings from my PhD research and discuss the implications of these findings.

Early life attachment in term and preterm infants (G2)

Lorena Jiménez-Sánchez[1,2], Lorna Ginnell[2], Sinéad O'Carroll[2], Victoria Ledsham[3], Amy Corrigan[3], David Q. Stoye[3], Gemma Sullivan[3], Jill Hall[3], Ann M. Clemens[4], James P. Boardman[3,5], Sue Fletcher-Watson[2,5]

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Abstract

Preterm birth is associated with atypical neurodevelopmental outcomes in childhood, including attention problems, impaired language development and delayed socioemotional competence. Secure infant attachment relationships can attenuate some of these challenges, but could be modified by alterations in the early caregiving environment inherent to essential neonatal intensive care or co-morbidities of preterm birth. We aim to test the hypothesis that preterm birth is associated with differences in infant attachment compared with infants born at term, and to identify clinical, neurodevelopmental and socioeconomic variables that are associated with infant attachment. Preterm and term infants will complete the Still-Face Paradigm (SFP) at nine months of corrected age. Attachment dimensions and categories will be obtained from infant responses to the SFP using a published coding scheme, and an alternative principal component and clustering strategy. Clinical variables will be collected through medical records. Neurodevelopmental variables will be assessed using the Vineland Adaptive Behaviour Scales. Socioeconomic status will be operationalised as neighborhood deprivation. Attachment dimensions and the distribution of attachment categories in the term and preterm groups will be compared. Correlations between clinical, neurodevelopmental and socioeconomic variables and attachment dimensions across the study sample will be investigated, suggesting upstream and midstream pathways to infant attachment. This study will contribute to understanding the relationship between preterm birth and attachment, identify clinical and socioeconomic factors that may contribute to attachment, and patterns of neurodevelopmental outcome that are associated with attachment. Ultimately, addressing these questions will be essential to support early relationships between preterm infants and their caregivers, which in turn, are important to foster infants' socioemotional resilience and parental wellbeing.

Listening to autistic children's voices to explore their experiences of friendships (G3)

Laura Fox

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Abstract

Having friends has been found to be a source of social support. However, studies show that autistic children typically have fewer mutual friends than their non-autistic peers. Although these findings may suggest that having fewer friends could negatively impact on autistic children, most studies gather this information through parent/teacher reports, or observations. This means that we know very little about how autistic children feel about their own friendships and if they believe that having close friends is important to them.

This study explored the following research questions:

- How do autistic children describe their experiences of friendships and their ability to make and maintain friends?
- Do autistic children in mainstream school experience friendship differently to children in specialised settings?
- Are there gender differences in how autistic children experience friendships?
- Do teachers and parents perceive children's friendships differently to each other, and to the children themselves?

The study used novel arts-based methods. A scrapbook was designed to allow children to engage with activities in multiple ways to ensure that the study would be accessible to a majority of autistic children. Scrapbooks were then used to facilitate parent-led interviews to

explore the child’s experiences. Qualitative surveys gathered parent and teacher perspectives of children's friendships.

Data is currently being analysed using reflexive thematic analysis. Three separate analyses are being carried out to explore the experiences of children, and the perceptions of parent and teachers. Each analysis will be discussed, and differences and similarities between groups will be explored.

It is hoped that this study will provide an insight into autistic children’s experiences of friendships, and how arts-based methods may be a more accessible way of working with autistic children and their families. Listening to the experiences of autistic children may help us to provide better informed social support in schools.

“Autistic kids do get a little lonely”: social interactions and friendships in autistic adolescents (G4)

Rhys Proud, Deborah Riby, Mary Hanley

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Abstract

Differences in social interactions have been reported for some autistic teenagers relative to neurotypicals, particularly in domains such as eye contact, initiating friendships, and social interactions with neurotypicals. However, existing research has predominantly emphasised social interactions with unfamiliar people or has examined eye contact outside everyday social experiences (e.g., using experimental contexts). Furthermore, existing research often excludes autistic participants that may not be accommodated in research set-ups; for example, autistic people with few or no words. This necessitates the inclusion of the ‘autistic voice’, and to ensure it is provided by a range of autistic adolescents, when exploring potential difficulties in everyday social interactions, friendships, and eye contact.

To aid providing this voice, 15 co-constructed online semi-structured interviews were conducted via Microsoft Teams with autistic adolescents (ages 12-17, mean age 15) about their lived experiences of social interactions, friendships, and eye contact. In addition, the researcher worked with autistic adolescents with additional communication needs and/or social anxiety and their parents to explore capturing their perspectives using a variety of methods. These included flexible data collection formats (e.g., written formats, adapted interviews) and led to suggestions for future studies (e.g., training parents as data collectors). Taken together, our results, analysed through reflexive thematic analysis, indicated a need for shared understanding; emphasising that a shared neurotype may facilitate but be neither necessary nor sufficient for successful friendships. We also highlight the nature and complexity of implicit

social rules within neurotypical communication, and uncertainty regarding the 'cost' of breaking them. Findings will be explored in relation to notions of double empathy, equifinality in social interactions, the role of neurotypical behaviour in facilitating social interactions with autistic people, and communication across and within neurotypes.

How do autistic adults describe their interactions with other autistic people? A systematic review (G5)

George Watts[1], Catherine Crompton[2], Joseph Long[3], Catherine Grainger[1], Mark Somerville[2], Eilidh Cage[1]

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Abstract

Background:

A growing body of research suggests inter-autistic interactions are associated with more effective communication and better rapport than is experienced in autistic relationships with non-autistic people (Crompton et al, 2020; Rifai et al., 2022). This research supports the Double Empathy Problem, which suggests social-communication difficulties result from a mismatch of social-communication styles between autistic and non-autistic people (Milton, 2012) and challenges the theory that autistic social-communication is "defective". Most research on autistic social-communication focuses on non-autistic perspectives which risks contributing to epistemological injustice (Bottema-Beutel et al., 2021). It is vital that research knowledge is informed by autistic perspectives, therefore, this review focuses on literature which includes first-hand accounts of autistic people.

Methods:

We will carry out a systematic review to identify qualitative research which includes autistic adults' descriptions of their interactions with other autistic people. We will use a tool, such as the Critical Appraisal Skills Programme Checklist, to assess the quality of the papers and use a thematic meta-synthesis to analyse the data and identify key themes.

Results:

We will complete the systematic review by March 2023 and I will present identified themes. This may provide insights into the nature of inter-autistic interaction, how this contrasts with interactions with non-autistic people and how this relates to autistic wellbeing. Themes may

also identify the contexts in which inter-autistic interactions take place and factors which facilitate or create barriers to inter-autistic interaction.

Discussion:

I will discuss the themes in relation to the wider literature and how this informs our understanding of autistic social interactions. Additionally, I will explain potential implications for future research and practice. For example, if interacting with other autistic people is described as beneficial to wellbeing, this suggests more research is needed to explore this phenomenon and has implications for services which seek to improve autistic wellbeing.

Gender differences in pragmatic abilities of autistic adolescents (G6)

Marie Belenger, Mikhail Kissine

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Abstract

ASD is more frequently diagnosed in males than females, with a 3:1 ratio. There is growing evidence that diagnostic tools are less likely to identify autistic females. There are only few studies that focus on how gender may interact with pragmatic abilities within the autistic population. These studies found fewer pragmatic difficulties in autistic females when compared to autistic males, but more difficulties when compared to non-autistic females. Furthermore, autistic females seem to be more likely than autistic males to camouflage their autistic behaviors—including pragmatic functioning. As pragmatic difficulties are considered as a manifest and robust characteristic of autism, gender differences in this domain could have a significant impact on diagnosis. This project aims to further delineate the pragmatic profile of autistic females. Participants will be autistic and non-autistic adolescents (9-16 years old). The existence of a possible diagnosis bias against females also warrants the inclusions of adolescents presenting a high risk of autism (i.e. an autistic sibling in their family). Pragmatic abilities will be studied through a narrative task based on a wordless picture book. Narratives will be transcribed verbatim. Detailed discourse analysis of the transcript will be performed. Parents will complete questionnaires assessing pragmatic abilities of their children. Our main hypothesis is that narratives of autistic females will differ from narratives of autistic males and non-autistic females. Data collection is still in progress. For discourse analysis, outcome variables will be counts thus analysis will be conducted by means of linear regression. Camouflage (disfluencies ratio) will be analyzed by means of cumulative link regression models as well as parents' questionnaires. We expect that giving more insight on how autism presents in females, would enable clinicians to better identify autistic females. We hope this work will contribute to the current effort of improving autistic females' quality of life.

An exploration of how caregiver experiences are related to emotional expressions towards autistic children (G7)

Sophie Langhorne

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Abstract

Expressed emotion (EE) is a measure of the emotional climate expressed by one person toward another. High levels of caregiver expressed emotions have previously been shown to be related to poorer social and behavioural outcomes in autistic children (Benson et al., 2011). EE is believed to be modifiable via intervention, thus suggesting that a range of caregiver experiences may influence EE. Indeed research has shown consistent links between heightened levels of parenting stress and higher EE in caregivers of autistic children. However, little research has been conducted to explore if further experiences are related to high EE in caregivers of autistic children.

This exploratory study aims to assess to investigate relationships between: parental mental wellbeing, parenting stress, family experiences, demographic variables, and child adaptive behaviours, on caregiver expressed emotion towards autistic children. 120 parents and carers of autistic children have completed measures of parental wellbeing, family experiences, child adaptive behaviours, and the Autism Five Minute Speech Sample (AFMSS) interview. We plan to analyse data using correlational analyses to explore the relationships between caregiver experiences and EE.

We hope such research will help us to explore how caregiver experiences affect EE in more depth. As a consequence, our research will provide insight into areas of focus for future interventions, which can target and support caregiver experiences to reduce EE, and consequently improve outcomes for autistic children in the future.

Academic and Social Interactions between Autistic University Students and their Non-autistic and Autistic Instructors (G8)

Jacquie Ballantine

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Abstract

Increasing numbers of autistic adults are enrolling at universities worldwide (White et al., 2016). Their academic and social interactions with non-autistic instructors impact their successful participation in learning and knowledge construction which universities aim to foster. And yet, there is limited understanding of the nature of these interactions. This study is informed by Milton's Double Empathy Problem (DEP, 2014) which posits that frequent "mutual incomprehension" (p. 800) occurs between autistic and non-autistic people, both of whose ways of communicating are equally valid. We also use the lens of Rhetorical Genre Studies (RGS) which defines genres as typified and recurrent ways of acting socially in response to perceived and constructed social needs (Bakhtin, 1986; Miller, 1984). More specifically, RGS provides conceptualized elements of social interactions (viz., recognition of rhetorical situations, exigences, uptake, and timing) which help to more deeply explore the nature of autistic and non-autistic interactions. We use a mixed-methods, community consultation design to explore the lived experiences of autistic university students' and autistic and non-autistic instructors' interactions. Semi-structured interviews with autistic students and autistic and non-autistic lecturers informs the design of an online survey resulting in collection of both qualitative and quantitative data to investigate the nature of these interactions. A consultation group of autistic graduate students informs the research, acting as participants, coding and survey consultants, and editors. Results suggest that RGS concepts are highly useful in understanding differences in autistic and non-autistic ways of thinking, learning, and communicating and provide important ways for students and academic staff (autistic or not) to understand each other's' experiences. Further, the RGS concepts supply potential strategies so that different ways of thinking, learning, and communicating can be bridged to support the success of autistic students and instructors as well as all who seek to construct knowledge within university contexts.

Understanding the impact of neurotype on parenting experiences (G9)

<u>Melanie Heyworth</u>[1,2], Cathy McMahon[1], Elizabeth Pellicano[1,3]

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Abstract

Parents of autistic children often report finding their child's autistic behaviours challenging. Indeed, the more "autistically" a child behaves (usually termed "severity of autism symptomology" in the research literature), the higher a parent's stress, and the lower their quality of life and mental health outcomes. In families of typical children, a parent's ability to mentalise – their propensity to be aware of and reflect on their own and their child's mental state – is a significant predictor of the quality and security of a parent-child relationship. Yet, there are no studies looking at autistic parents' mentalisation capacity for their autistic children, and remarkably few focusing on the role of non-autistic parental mentalisation in parenting their autistic children. Those few studies that do exist indicate that non-autistic parents mentalise their autistic children differently from their non-autistic children. These

differences may occur as a function of the ‘double empathy problem’, since non-autistic parents may lack access to intrinsic Autistic processing and neurology (Milton, 2012).

This study, developed in collaboration with key stakeholders and led by an autistic parent, addresses this gap, focusing on the mentalising process of insightfulness. We are using quantitative and qualitative methods to (1) discern whether any difference exists between an autistic and a non-autistic parent’s insightfulness into their autistic child, (2) ascertain whether there are differences in parents’ insightfulness capacity and propensity as applied to their autistic children and their non-autistic siblings, and (3) determine the potential effects of parent insightfulness capacity on mental health/quality of life.

This study is ongoing. The presentation will report on analyses examining whether parent neurotype (autistic, non-autistic) moderates the ways parents experience parenting autistic children. By considering whether cross-neurotype parenting is a moderator in quality of life and wellbeing, we identify areas to improve parent-child relationships.

Examining rapport between autistic and non-autistic people during online interactions (G10)

Leanne Naudusevics, Lauren Marsh, Ellen Howard, Danielle Ropar

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Abstract

Several studies have reported that autistic people may experience greater rapport with an autistic interaction partner, compared to a non-autistic partner (Crompton et al., 2020; Morrison et al., 2020). However, current research does not yet provide a clear understanding of how or why this improved social connection is achieved. In this study, we investigated whether such benefits extend to online interactions, and whether the amount of social information available to partners has an impact on self-reported rapport.

Twenty autistic and 20 non-autistic participants engaged in a series of online, one-to-one conversations. Half of the conversations were with a same-neurotype partner and half were with a different-neurotype partner. In addition, half of the conversations were video calls and half were voice-only. In study 1, participants rated their experienced rapport with their partner. Initial analyses indicated that autistic participants rated their rapport similarly across different neurotype partners. Notably, they did not report improved rapport with an autistic partner in these online conversations. Non-autistic participants also rated their experienced rapport with autistic and non-autistic partners similarly. The amount of social information also had no impact on rapport ratings. Follow-up work is underway to explore how dialogic features of the conversations might predict rapport. In study 2, conversations between different neurotype partners were rated by a third-party observer. Contrary to previous work with in-person interactions, results indicate that observer ratings of rapport were higher for mixed-neurotype conversations.

In all, it seems that rapport between autistic and non-autistic people may be appraised differently when they result from online, rather than in-person interactions. Indeed, online interactions may provide a 'level playing field' which minimises the bidirectional disconnect experienced between autistic and non-autistic people. Differences in the sensory demands and social etiquette for online interactions will be discussed.

Exploring research priorities for autistic and neurodiverse romantic partnerships (G11)

Claudia Preuss

Newcastle University, Newcastle-upon-Tyne, United Kingdom

Abstract

Autistic adults and adolescents often describe difficulties with the initiation and maintenance of romantic relationships but research has shown that many enter into romantic relationships with autistic as well as with non-autistic partners. Higher levels of relationship satisfaction have been reported by couples with two autistic partners than couples with one autistic and one non-autistic partner. Partners in both autistic and neurodiverse (neuro-mixed) romantic couples report facing unique challenges in their relationships. As part of participatory research, focus groups were run with autistic adults who are in relationships, non-autistic adults who are in relationships with autistic partners, and counsellors and relationship coaches with experience of working with autistic and neurodiverse couples. Each focus group consisted of three to five participants and lasted between 30 and 90 minutes. Each group explored challenges surrounding relationship maintenance and communication through open ended questions. Participants also had the opportunity to discuss topics relating to romantic relationships that they felt were important for research on neurodiversity. Resulting data were analysed using thematic analysis and findings show both similarities and differences in the way autistic and non-autistic individuals perceive and approach romantic relationships. More challenges were reported by neurodiverse couples, and counsellors reported working mostly with neurodiverse rather than autistic couples. Differences between the way autistic people interact and accept their partners, compared to non-autistic individuals were also identified. Both autistic and non-autistic groups commented on the therapeutic value of being able to share their thoughts with peers in the focus groups. Findings from this study are expected to contribute to the development of a brief intervention for couples in which one or more partners are autistic and will help to raise awareness of the need for counsellors and other professionals to consider neurodiversity when working with romantic partners.

Investigating the effect of neurotype-matching on communication efficiency and first impressions of verbal interactions of autistic and non-autistic adults (G12)

Philippine Geelhand, Fanny Papastamou, Mikhail Kissine

Université libre de Bruxelles, Brussels, Belgium

Abstract

More and more studies show that neurotype mismatching (e.g., autistic-non-autistic pairing) rather than being autistic leads to interaction difficulties in autism. This study further tests this assumption by investigating communication efficiency and first impressions of verbal interactions across three dyad types (autistic, non-autistic and mixed (autistic-non-autistic) dyads). To address this aim, we used an online version of the Director Task (DT) - a task in which dyads need to organize unlexicalized images in a specific order across several turns. To do so, they need to create novel referential expressions for these images. Dyad members communicate about these images across several rounds, prompting them to negotiate shorter descriptions and therefore taking less time to complete a round. The DT thus provides objective measures of conversation outcome which can then be related to more subjective measures (ratings). Following the DT, dyads engaged in an unstructured, get-to-know-you task. Afterwards, they rated each other's discourse abilities (coherence, fluidity & efficiency), interaction quality and likelihood to hang out. Preliminary results from 52 dyads (23 non-autistic dyads/16 autistic dyads/12 mixed dyads) indicate that turn duration and expression length decreased for all dyad types, suggesting that all dyads became increasingly efficient as the task proceeded. Furthermore, during the DT, perceived discourse coherence, fluidity & efficiency did not differ across dyads. However, during the get-to-know-you task, in non-autistic dyads, ratings of coherence and fluidity were higher than in autistic and mixed dyads. Finally, in mixed dyads, ratings of likelihood to hang out were lower than those in same-neurotype dyads. These results suggest that neurotype mismatching does not influence impressions of the discourse and interaction quality but does seem to influence future behavioural intentions (e.g., likelihood to hang out). This study will help us better understand interactional dynamics between different neurotypes, and how these can influence future interactions with autistic people.

Session H: Identity & Diagnosis

The Attention Deficit Hyperactivity Disorder: How specific are its diagnostic element? (H1)

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Abstract

Many children with Attention Deficit Hyperactivity Disorder (ADHD) have behavioural, cognitive and emotional difficulties that are also present in other neurodevelopmental conditions. Patterns of features that cross-cut conventional diagnostic categories are shared across the broader field of psychopathology and are widely viewed as reflecting transdiagnostic dimensions of neurodevelopmental conditions that yield complex and highly variable patterns of difficulties. A systematic literature search was conducted to establish the extent to which characteristics of the ADHD phenotype extend across other neurodevelopmental conditions. The first aim was to identify the phenotypical characteristics of cognition, behaviour, and social and emotional aspects of children with ADHD through a comprehensive evaluation of recent evidence, supplemented by key findings from earlier research. The second aim was to assess the extent to which these elements of the ADHD phenotype are also prevalent in other neurodiverse conditions with high degrees of co-occurrences with ADHD: Autism Spectrum Disorder (ASD), Learning and Language disabilities (LD), and Oppositional Defiance Disorder (ODD). This review identified evidence for a broad range of cognitive, behavioural, social, and emotional difficulties in children with ADHD. Contrary to a narrow diagnosis-bounded characterisation of these features, this review indicated that most of them were also found in one or more of four neurodiverse conditions – ASD, LD, DLD, and ODD. This overlapping constellation of characteristics favours a transdiagnostic approach that replaces distinct diagnostic categories with multiple and potentially co-occurring features. It offers benefits for research by informing the underlying mechanism of complex neurodevelopment and for practical assessment by providing suggestions for tailored support to neurodiverse children with and without a diagnosis.

Interviewing professionals who work with children and young people to find out what they think about strengths-based autism diagnostic assessment (H2)

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Abstract

Descriptions of autistic people in diagnostic reports often focus on difficulties and deficit-based comparisons to non-autistic 'norms'. The neurodiversity paradigm challenges this approach through its emphasis on centering autistic voices and advocacy for a holistic perspective on difficulties, differences, and strengths.

We want to know more about how clinicians can apply a neurodiversity-informed, autistic-positive perspective to diagnostic assessments for autism. We believe a way of thinking about assessment that is known as the ‘strengths-based approach’ could help with this.

So, we designed a study to help us understand what professionals involved in autism assessment think about the strengths-based approach and how it might (or might not) apply to the way they carry out and report on autism assessment.

We are consulting autistic adults and parents or caregivers of autistic people about the topics and questions that should be covered in our study. In June/July 2022 we will carry out interviews with 10-20 professionals involved in autism diagnostic assessment. We will focus the interviews on assessment for children and young people. The interviews will likely cover what a strengths-based assessment could involve and its benefits and limitations from the professional’s perspective. We will analyse the interviews in August-November 2022 using a qualitative method called thematic analysis. This will help us to identify patterns or themes relating to the professionals' views.

The findings will tell us how professionals view a strengths-based autism diagnostic assessment. This may suggest areas to focus on for future research. In practice, the findings could help professionals to make changes that mean autism diagnostic assessment is more in-line with a neurodiversity-informed perspective. This could improve diagnostic assessment in ways that allow autistic people to thrive.

The Autistic Immigrant in the UK: an exploration of overlapping identities in the context of diagnosis (H3)

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Abstract

The last decade has seen a significant increase in adult autism diagnosis in the UK with the numbers of females and cognitively able people who receive a diagnosis increasing. There are no studies that identify immigrants among those adults or examine their experiences of diagnosis which may be complicated by relocation to a culturally different place and by social biases. Ethnicity, theorised as a social identity, is routinely discriminated against in the healthcare system. Autism is theorised as an identity too. However, there is a limited understanding of lived experience and identity issues through cross-cultural adaptation, specifically the alienated quality of being both an immigrant and an autistic. As the first to study the intersection between autistic and immigrant identity, this research involves the development of new concepts and call on intersectionality to address the question of perceived otherness and discrimination towards autistic and ethnically diverse minority groups. Using a mixed method approach the study will examine the views and experiences of officially diagnosed autistic adults who have ethnic minority status, and the qualitative work will follow those immigrated to the UK. The sample of participants for qualitative work will be recruited through contacts with community groups, NHS support groups and networking. A second quantitative study will utilise the longitudinal ESRC Millennium Cohort Study to model key outcomes and how they are differentially affected by single and interaction terms between minority autistic/ethnic status. The research aims to explore an interaction between the impact of immigration and of being autistic for ethnic minorities. It will also provide an insight into a diagnostic experience influenced by sociocultural norms, disability and racial bias.

Happiness is “a giant heart with a big smiley face”: Adolescents’ insights into their experiences of being autistic (H4)

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Abstract

Young people’s personal experience of having ASD is often underrepresented in clinical research. Existing research often explores young people’s experiences through parents, caregivers and schools.

This research aims to provide young people with a voice. It has given young people the opportunity to demonstrate insight into their strengths and challenges in relation to their unique experience of ASD.

Qualitative data is being collected from at least 20 individuals aged 11–18 years using a semi-structured interview, which is completed as part of their neurodevelopmental assessment. The interview questions correspond with the diagnostic criteria for ASD, enabling young people to discuss their experience on each criterion. To be included in the study, the young person must have been diagnosed with ASD.

Consent is sought from the young person and their family to include their information. The notes from their interviews are uploaded to their medical record and accessed by the raters once the assessment has concluded. Data collection started in April 2021 and is ongoing.

Thematic analysis will be used to identify themes within the dataset. We plan to have independent raters to assess the reliability of themes generated from the analysis.

Understanding these themes and hearing the voices of young people enables a better understanding of their lived experience of ASD. The interview maps directly onto the ASD criteria, making questions more deficit based, however strengths, skills and interests were also discussed, allowing the young person to express various aspects of their experiences. It will allow others to have a better understanding of adolescents' insight and thoughts on their own experiences. Findings can be fed back to families, schools, and professionals to help create person-centred adaptations and improve accessibility to a variety of settings. However, we acknowledge that findings are only representative of some young people with ASD.

Talking about their autistic identity: Intersection of biomedical, neurodiversity and social disability models in French-speaking Autistics' discourse (H5)

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Abstract

Social representations of autism are diverse. The "autism spectrum disorder" category proposed by the biomedical model has been criticized for the deficient vision it conveys. Alternative discourses have emerged and offer other ways of conceiving autism. Neurodiversity model considers autism as a neurological variation within human diversity. The social disability model puts forward the social and structural contexts that produce situations of discrimination and stigmatization for Autistic people.

This paper focuses on Autistics' conceptions of autism and their relation (complementary or oppositional) with these three models (biomedical, neurodiversity, and social disability). Using a participatory research approach, we developed an online questionnaire in partnership with three autistic expert collaborators. It was completed by 460 French-speaking autistic adults (18-74 years old) from France, Belgium, Switzerland, Senegal and Quebec (Canada). A majority had received a diagnosis of autism (69%) and 31% were self-identified. Participants were asked: "Is autism part of your identity?". A qualitative analysis was conducted to identify emerging categories, code the data and compare the coders' interpretations. Results show many aspects interweaving in the participants' representations of autism: autistic identities (e.g. inseparable from the person), autistic differences (e.g. neurological functioning; strengths; experience of the world; spectrum diversity), diagnostic-related (e.g. diagnosis as explanation or resistance), challenges (e.g. limitations or impairments, health problems, disorders; difficulties in relationships; social barriers and "non-adapted society") and strategies (e.g. passing, masking, camouflage; use of support, coping) in fulfilling social role and participation (e.g. as parent).

The current results show that individual representations of autism mobilized different aspects of biomedical, neurodiversity and social disability models. Thus, these models seem to be often complementary instead of mutually exclusive. Overall, there is an agreement that autistic individuals share an understanding and experience of the world which, if not acknowledged by society, can lead to exclusion, threatening people's rights and well-being.

'The Human Spectrum' - a shared participatory phenomenological self-investigation of lived experience across the autistic/non-autistic divide (H6)

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Abstract

Autism has historically been defined by external manifestations rather than lived experience; something which impacts on both research and practice. There have been increasing calls for a phenomenology of autism, but little actual work reported. As four participating authors (three autistic, one non-autistic), we began therefore a formal in-depth phenomenological self-investigation into our lived experience across the autistic/non-autistic divide. We asked; "How to characterize a difference like autism without constraining the freedom of identity or action of those falling on either side of its definition?" In monthly 1.5 hr meetings, we rehearsed our lived experience in domains of social relationships, physical environment, development, and adult life; opening them then to formal phenomenological investigation between us by

alternating roles of ‘researcher’ and ‘interviewee’ in a ‘dialogical’ method. We then synthesised these observations across individuals into themes of continuity and difference.

Emergent themes such as the need for trust and reliability, and the impact of context on regulation of emotion, sociability and empathy, showed striking commonalities between all participants. Other themes, such as primary sensory experience and social joining, showed more difference between autism and non-autism in development and the adult world. Themes of interest-focus and attention showed both commonalities and difference.

This form of shared in-depth enquiry is we believe quite novel, and represents one valuable route towards developing an autistic phenomenology. Our detailed results suggest hypotheses for new understandings of autism within the broader “human spectrum”. They highlight the common basic need for trust and social connection, but striking differences in sensory experience. They suggest that some characteristics long thought intrinsic in autism, such as social mis-perception and reduced empathy, may be better understood as state-dependent outcomes contingent on specific contexts and interactions. We will suggest implications from this work for further research, developmental theory and intervention practice.

Autism is a Humanism: Journey to an Autistic Identity in Women (H7)

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Abstract

Background: There is a growing body of literature on late diagnosis, self-discovery, and self-identification of autistic adults, particularly in women. There is no research specifically exploring how women arrive at a sense of autistic identity. This study sought to explore the nature of the autistic self-discovery journey in women, and what insights this yielded about being autistic.

Methods: Twenty-two women who identified with “figuring out that they were autistic” were recruited for a semi-structured interview or qualitative survey on lived experiences associated with their autistic self-discovery experience. Eleven participants completed a semi-structured interview on Microsoft Teams, and 11 participants completed a Qualtrics survey with open-text boxes. Reflexive thematic analysis was used to analyse the data.

Results: A journey comprising four stages was identified, represented by four semantic themes: “I always felt a bit different”, “a spark to set the wheels in motion”, “the truth will set you free - community knowledge as catalyst” and “self-acceptance, community acceptance”. Four latent themes were also identified regarding the meaning of being autistic: “autistic lens: reflecting on

myself and the world", "a sense of responsibility to pave the way for others", "being autistic is a different way of being in the world" and "the electric fence of power-backed norms."

Conclusion: The journey towards an autistic identity can be conceptualised as a set of discrete elements, a finding with epistemic and clinical utility. Insights into the meaning of an autistic identity were existential-humanistic in nature, raising the issues of acceptance, power and social norms.

A photo-based study with young people with Fetal alcohol spectrum disorder (FASD): exploring views on FASD disability identity and preferred support (H8)

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Abstract

Fetal Alcohol Spectrum Disorder (FASD) is a neurodevelopmental disability that is caused exclusively by prenatal alcohol exposure. Low diagnostic rates of FASD in the UK are associated with multiple factors: health professionals' confidence to diagnose; the negative discourse of stigma towards biological mothers and the perception of limited or positive value of a diagnosis for individuals with FASD. However, little research has explored the experiences of adolescents with FASD regarding their disability or their views about this diagnosis. A Photovoice study was therefore conducted online with 8 young people (age 12-19 years; 2 female, 6 male) in the UK. Parents (n=7 : 4 adoptive, 2 foster carers and 1 birth parent) completed a screening measure of Intellectual Disability and a background questionnaire regarding their children's FASD assessment process. The Photovoice procedure included group training followed by episodes of thematic photo-taking. It also included individual interviews with young people about: home, school and community activities; views of FASD diagnosis and support; discussion of their photos; and concluded with a group interview. Participant-led analysis of photos suggested the significance of adult/family relationships in terms of nurture, support, and daily living activities, and a continuous need for reasonable adjustments across school, home and the community. Researcher-led analysis will use Interpretative Phenomenological Analysis to explore the distinct phases of disability identity development for young people with FASD. While parents play a significant role in educating their children on FASD, there are also implications for the role of professionals in supporting children's understanding and disability identity. The dissemination of the photos from this study has been constructed jointly with the young people and highlights the importance and benefits of young people with FASD being actively involved in self-advocacy and contributing to a wider academic, public, and professional understanding of FASD as a disability.

The Representativeness of the Longitudinal European Autism Project: High Income and Education, but also Diverse Geographical Heritage of Participants (H9)

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Abstract

The large multinational Longitudinal European Autism Project (LEAP) aimed to estimate medium-to-small effect sizes and parse variability between and within autistic and non-autistic people, however, voluntary-based recruitment with limited community involvement raises the question of its representativeness. Therefore, we descriptively compared essential demographic characteristics with official country demographics (EUROSTAT).

We examined the % of parents with primary/secondary/tertiary education, employed, and born outside the country of the study, the domestic average annual income, the % of families with one/two/three/four+ components of 453 autistic and 311 non-autistic, 6-30 years old participants in 6 cities - London and Cambridge (United Kingdom), Nijmegen and Utrecht (the Netherlands), Mannheim (Germany), Rome (Italy). We averaged by country and group and differenced the official country average. Based on these preliminary comparisons, we comment on the direction of differences in terms of over/under-representation.

Compared to country norms, in all countries and both groups, families with 1) parents below tertiary education 2) unemployed 3) less than 4 members were under-represented. Average annual incomes were higher in all countries and groups (+25k on average, with the highest deviance in the UK). Instead, parents born abroad were overrepresented compared to country norms: with 95 parents, and 146 grand-parents, the LEAP dataset sampled 66 different countries.

At a glance, the LEAP data represent people of higher socio-economic status, compared to countries' distributions; under-represented small families may include single-parents and autistic people living on their own. Leaving out families of lower socio-economic status represents a real loss of insight, and calls for re-designing sampling and recruitment strategies. The relatively higher frequency of parents born abroad may flag a difficulty in recruiting locals,

maybe due to the study locations; however, it may also offer insight into cultural diversity of autistic traits and expressions - a field where large multidisciplinary datasets are rare.

How to lobby government successfully: a guide for autistic people (H10)

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Abstract

This research develops an outline lobbying strategy for autistic people based on what has worked well for autistic self-advocates in England to date. It focuses on *how* to ask for policy change at the national level. This paper combines theoretical ideas from lobbying, collective action, disability studies and psychology with data from an online survey, focus groups and, crucially, in-depth interviews with successful autistic self-advocates. It uses process tracing to assess the presence or absence of certain behaviours, and a semi-inductive, iterative approach with several phases of analysis. The resultant data identifies behaviours clearly associated with lobbying success for autistic people. These behaviours can be developed into a strategy which could change the policy landscape for autistic people. As a neurotypical ally, it is my hope that autistic people will further develop this strategy and adapt it to their needs.

Medicine needs all kinds of minds: autistic doctors are changing culture in healthcare towards a neurodiversity-affirmative approach (H11)

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Abstract

Autistic Doctors International (ADI) is a peer support organisation involved in advocacy, research and education. We are changing the culture within medicine towards a neurodiversity-affirmative approach to autism, with benefits for autistic doctors and medical students, as well the autistic community more widely.

Medicine selects for autistic traits. High achieving autistic individuals are intensely focused perfectionists with high attention to detail and often have particular strengths in pattern recognition; skills which are clearly advantageous in medicine. Autistic people are often creative thinkers and problem solvers, and contrary to stereotypes, can exhibit high degrees of empathy. Doctors are over-represented among parents of autistic children and increased recognition means more students are entering medical school with an existing autism diagnosis. Autistic doctors thrive in all areas of medicine. Increasing visibility facilitates recognition, diagnosis and disclosure therefore reducing the need for masking of autistic traits, which is associated with poor mental health and increased suicidality. For far too long autism has been defined as a disorder with terminology of deficit and impairment. Successful doctors may struggle to recognise themselves within this pathology paradigm, therefore remaining undiagnosed and unsupported.

As insiders to both the world of medicine and the neurodivergent community, the power of our voice is increasing. A strategic approach to advocacy, including building an evidence base of peer-reviewed publications and alliances with key clinical, educational and regulatory bodies has positioned us well to leverage our collective experience to influence current thinking around autism and in particular, to achieve our goal of reframing the tragedy narrative towards a neurodiversity-affirmative approach. Current research projects focus on the experiences of autistic doctors and medical students, and disclosure decisions by autistic psychiatrists. This presentation will include an overview of our current research projects and advocacy work, including preliminary results from several projects.

The Ableist Conflation in Canadian Public Health Discourse (H12)

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Abstract

The understanding of autism has grown exponentially over the past several decades. Critical autism studies (CAS) provide a reflexive means to examine how we pursue questions concerning the health of autistics. Applying a CAS lens reveals how Canadian public health officials conflate disability with misery in their representation of autism. The conflation of disability and misery occurs because of an overly simplistic pathologized lens that views autism through a deficit paradigm. My primary method for this work combines anthropological document analysis and Foucauldian discourse analysis to examine two Canadian Federal Government publications: Autism Spectrum Disorder: Highlights from the 2019 Canadian Health Survey on Children and Youth (ASDH) and the underlying instrument, the Canadian Health Survey on Children and Youth, 2019 (CHSCY). This paper tracks the collection and transformation of medical data into deficit approaches to autism in the Canadian landscape. I argue that the translation of data by the Public Health Agency of Canada (PHAC) has two issues. First, the data that was applied in the ASDH flattens the discourse of autism and second, opportunities to introduce other data from the CHSCY were omitted. Compounding this problematic dynamic between documents, the CHSCY is a general population survey instrument that features accessibility issues for autistics. This paper concludes with a call to action for better representation of autism in government documents and the use of more accessible instruments that allow greater autistic participation in health research.

Keywords: Autism, ASD, public health, ableism, document analysis, discourse analysis

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