

## **The Emotional Consequences of Environments, particularly School Environments, on the Mental Health of Neurodiverse Adolescents**

The overarching theme of this symposium is the role of environmental factors in reducing the risk of depression in neurodivergent adolescents. Neurodivergent adolescents, for example those with a diagnosis of autism and/or ADHD, are at high risk for depression, self-harm and suicide. It is broadly acknowledged that this risk arises through interplay of individual characteristics and environmental factors. However, prior research studies have mainly focused on the former while largely overlooking the latter, individuals' difficulties with negotiating stress and emotion regulation being identified as contributing factors for depression. The alternative possibility, that such behaviours are a response to ADHD- and autism-related differences in the exposure to, and the experience of, environmental provocations and stressors and associated challenges to emotion regulation, has not been sufficiently explored. In this symposium we set out to explore this emotional burden hypothesis theoretically and empirically, through qualitative and quantitative methodologies, principally in school environments.

Key words: Emotional responding; ADHD/autism; environmental stressors; young people; school staff

### **Paper 1 – Deepening Participation of Neurodivergent People in Qualitative Research to Understand Emotions in School**

**Georgia Pavlopoulou**, Sylvan Baker, Susie Chandler, Steve Lukito, Myrofora Kakoulidou, Beta Balwani, Tiegian Boyens, Zoe Glen, Luke Harvey-Nguyen, Issy Jackson, Elisa Ly, Maciej Matejko, Dorian Poulton, Archie Wilson, Edmund Sonuga-Barke and the RE-STAR team

There is a growing acceptance that neurodivergent young people should play a central role in shaping research into neurodevelopmental conditions. However, currently, their involvement is typically limited to arms-length advice. To address this, the *Regulating Emotions-Strengthening Adolescent Resilience* (RE-STAR) programme has co-developed, co-delivered and tested the feasibility of a new protocol for deepening neurodivergent young people's participation in qualitative research. Building on the track record of successful RE-STAR collaboration between a neurodiverse group of academic researchers and the Youth Researcher Panel (Y-RP), a cycle of meetings was co-convened to co-develop the participatory protocol. RE-STAR academic researchers and Y-RP researchers co-designed the interview schedule and co-delivered interviews with 12 young people with diagnosis of ADHD and/or autism. After the protocol implementation, all participants shared their experiences through interviews (N=36) and qualitative surveys (N=22) and themes were generated. The framework included the co-design, co-delivery and co-analysis processes. Our results showcased the overall benefits of academic and Y-RP researchers working together to improve the interview experience for interviewees by creating interview tasks that enable capturing emotional experiences specific to those with a diagnosis of ADHD and/or autism. Additionally, all parties expressed that this protocol brought personal benefits such as enhanced self-understanding and a sense of validation via working with other neurodivergent people. Success pre-conditions were identified, such as a trusting relationship, a good balance between flexibility and structure. Time management and navigating university structures were the key challenges identified. This new RE-STAR protocol for participatory qualitative research proved feasible to implement.

## **Paper 2: My Emotions and Me: A Co-produced Qualitative Study Exploring the Everyday Emotional Experiences of ADHD and Autistic Adolescents**

**Myrofora Kakoulidou**, Georgia Pavlopoulou, Sylvan Baker, Susie Chandler, Steve Lukito, Beta Balwani, Tiegan Boyens, Zoe Glen, Luke Harvey-Nguyen, Issy Jackson, Elisa Ly, Maciej Matejko, Dorian Poulton, Archie Wilson, Edmund Sonuga-Barke and the RE-STAR team

Research on emotional regulation in autism and ADHD primarily relies on concepts defined by or for neurotypical young people and adults. The perspectives of neurodivergent young people with diagnoses of ADHD and/or autism have been systematically overlooked. This qualitative study is part of the wider *Regulating Emotions–Strengthening Adolescent Resilience (RE-STAR)* research programme, which places the voices of neurodivergent young people at its heart, by employing a deep participatory research model. In this study, we worked closely with a Youth Researcher Panel (Y-RP) of autistic and ADHD youth researchers (aged 18 to 25 years). We co-designed a neurodiversity-sensitive interview schedule to interview 24 young people with a diagnosis of ADHD and 21 young people with a diagnosis of autism (aged 11 to 15 years). We wanted to understand from the interviews: a) what triggers strong emotions in young people b) how young people experience these emotions and c) what helps them to manage their emotions. We generated interview themes from the two groups using reflexive thematic analysis. In this talk, we will primarily present the findings about young people’s experiences of external everyday provocations that trigger difficult emotions. Themes include: 1) social dislocation, alienation and conflict 2) the need to mask 3) self-doubt, loathing, embarrassment and 4) over stimulation/sensory mismatch. We found qualitative differences between the two groups in the content of these themes. We will discuss key findings and how these can inform future mental health interventions to support autistic young people and those with ADHD with their emotions.

## **Paper 3 - Emotionally Healthy Schools – Pupil and Staff Perspectives**

**Jane Hurry**, Myrofora Kakoulidou, Georgia Pavlopoulou, Sylvan Baker, Lauren Low, Susie Chandler, Tiegan Boyens, Zoe Glen, Amber Johnson, Anya Rose, Edmund Sonuga-Barke and the RE-STAR team

Existing research consistently documents a relationship between school belonging/connectedness and student mental health. The school environment can be a challenging setting since it exposes autistic students and those with ADHD to numerous daily stressors, physical, academic and relational. All of these stressors require an emotional response. In this presentation we explore how the school environment impacts the emotional worlds and responses of students and school staff, from the points of view of students and school staff respectively, comparing and contrasting their accounts and their suggested solutions. The study was qualitative and involved a series of online focus group sessions delivered separately with a School Researcher Advisory Panel (S-RAP) and a Youth Researcher Advisory Panel (Y-RAP). S-RAP consisted of 12 staff in English schools, selected to represent senior and junior school staff, school counsellors, special educational needs coordinators (SENCOs) and learning support staff (LSA). The S-RAP took part in 10 sessions. Y-RAP included 11 young people aged 11 to 16 years old with diagnoses of Autism, ADHD or both. They all attended English mainstream secondary schools. The Y-RAP took part in 10 sessions. All the sessions were recorded and thematically analysed. Themes covering the following broad headings will be presented, exploring the similarities and differences between S-RAP and Y-RAP groups: *School-related emotion triggers; Experience and expression of big emotions; Impact on school staff professional practice; Impact on staff well-being; Impact of school staff on student well-being; What is helpful for staff and students to support well-being.*

## **Paper 4 – Architecture to Enhance sense of Belonging in Schools for Autistic Youth**

**Carolien Rieffe**<sup>1,2</sup>, Alexander Koutamanis<sup>3</sup>, Dennis Reidsma<sup>2</sup>, Els Blijd-Hoogewys<sup>4</sup>, Maedeh Nasri<sup>1</sup>, YungTing Tsou<sup>1</sup>

1. Leiden University
2. University of Twente
3. Technical University Delft
4. INTER-PSY

School is a place where youth meet their peers, form groups, socialize, and make friends. All this contributes to feeling welcome and valued at school. However, many autistic pupils miss out on school on a daily basis, because they feel unwelcome, neglected or even rejected. In this presentation, I will discuss outcomes of the project we run in our research group on how autistic youth experience their daily school environment; and what factors in the social and built environment can either contribute or hinder pupils feeling welcome and their right to equity within the school environment. In our project, we focus on playgrounds, schoolyards, canteens and hallways, which are the places where youth meet and socialize. Actual peer interactions on schoolyards are captured during recess via new wearable sensing technologies and combined with their' self-reports. These new techniques also give the opportunity to examine the effect of different interventions. Finally, outcomes of different studies within our project point at the importance of architecture in creating equity in schools for all youth.

**Discussant: Graham Moore**