
Published by The Psychologist, 9th July 2020

Free Access:

<https://thepsychologist.bps.org.uk/flowunlocked-east-london>

FlowUnlocked in East London

Dr Georgia Pavlopoulou, with the help of Jon Adams and Briony Campbell, reflects on a UCL-funded project to explore autistic people's relationships during and after the lockdown.



We are living through a social paradox: mental health research has proved that social connection is crucial to wellbeing, yet during this pandemic social isolation is crucial to survival. Relationships are one of the most important aspects of our lives, but we can often forget just how crucial our connections with other people are for our physical and mental health and wellbeing.

What about autistic people? There is a common misconception that they prefer solitude to company, yet preliminary evidence has suggested that autistic adults have worried more during the pandemic. Of course, in some cases autistic people have reported experiencing less stress in the ways they interact with others. We need to truly *understand* what has worked and what hasn't. My [recent study](#) on the impact of Covid-19 on family members of autistic people showed how lacking society's understanding is of autistic lives and the wider autistic community.



For that reason, in the past three months we came together as autistic artist, non autistic artist, researcher and a small group of autistic consultants to gain a deeper understanding of autistic people's relationships during and after the lockdown, and to co-devise our objectives and methods. The result is [FlowUnlocked](#).

'The calm that has stolen upon me...'

Like all humans, autistic people need companionship, but society's inability to accommodate their needs causes autistic people to retreat into safer spaces, private places and familiar sensory environments that they can predict and control. Jon Adams, an autistic polymath and autistic artist, told me:

As an autistic person shielding, I have tasted the loneliness of lockdown isolation, something shared by many autistic people. Traditionally the world has seemed unsafe, for many we have sought solace in nature, synaesthetic relationships with 'Sea stones and stars' or animals are common. Nature is often one of our intense interests which help us to embracing belonging in a world that often excludes us. Without that sense of belonging, being a part, not apart from something is vital to our wellbeing and mental health.

Because of Covid-19 I can no longer go out to get objects or 'new friends' so I'm deepening the relationship with those I already have. It's the quality of relationships that resonates with an autistic person, relationships that don't betray or sell us out for something new like shadows on a wall...



Cos Michael, an autistic autism consultant, offers insights of her lived experience as an autistic adult in her [blog](#)

The common belief in the benefits of socialising was a big issue for me, as I cannot understand why participating in large, often loud groups, is fun. I like people, but not all at once. So when coronavirus came to the UK, I had already learned that solitude is not a threat. I need 'alone time', although yes, I can be lonely too. But having no deadlines, no pressure to go out, is strangely liberating. Not having to make up excuses for my reluctance to join in, removes a lifelong, recurring source of anxiety. The calm that has stolen upon me comes as a huge surprise. I will learn from it when this is over [...] There are downsides to enforced isolation. I miss my daily walk into the city, to be among people. I miss my weekly outing with my sister, to stroll along the seafront; I miss the sensory relief of the horizon, the soft tonalities of the sky and susurrations of the sea.

Professor Jacqui Rodgers and colleagues, in their [report](#) on 'coping with uncertainty in uncertain times', say:

Whilst uncertainty can be difficult for everyone for some people a feeling of uncertainty can be particularly stressful and upsetting. Whilst difficulties coping with uncertainty are not specific to autism, research suggests that many autistic people find uncertain situations to be very anxiety provoking.

Similarly, the [Thinking Person's Guide to Autism](#) website has emphasised the importance of planning for transition and changes with autistic people.

A research group at University of Ghent, after running [a survey](#) for autistic and non-autistic people, found that autistic adults reported a greater increase in both anxiety and depression symptoms than non-autistic adults during the lockdown. Considering that autistic individuals ordinarily have higher rates of anxiety and depression than neurotypicals, this increase is particularly worrisome. Autistic people and their parents/carers have agreed long before the pandemic that they often do not receive the psychological help they deserve because those trained in delivering evidence-based therapies feel inadequately trained in adaptations (IAPT, 2016). Autistic people also experience high levels of stigma and often face severe obstacles when trying to access mental health support (Crane et al., 2019). Urgent work is required to improve the accessibility and adaptivity of mental health services in real life settings through collaboration of educational, health and third sector systems with autistic people and their families ([Pavlopoulou et al., 2020](#)).

A creative participatory autism project

When we aim to understand the essence of what it's like for autistic people and their families during the pandemic, we need to consider the fact that everyone's situation is different. So many factors come into play – physical and mental health, access to education, healthcare and employment opportunities, preferences, number of people in the family, demographics, size of house and so on. To be concerned with the individual and wider community uniqueness of lived experiences is to uphold a humanistic view, closely examining their experiential issues beyond focusing on behavioural outcomes ([Pavlopoulou and Dimitriou, 2020](#)). This is central to recent thinking on autism, led by autistic advocates, autistic researchers and their allies, particularly given the fact that dehumanising attitudes (seeing another as less than human) may still prevail ([Cage et al., 2018](#)).

Then there's the 'lifeworld framework', an equally useful conceptual tool based on the idea that disability is embodied and enacted in multiple ways in the life of autistic people and their family members. There will be both agency and vulnerability across lifespan, experiences of wellbeing and suffering in relation to one another ([Pavlopoulou and Dimitriou, 2019](#)).

Ultimately, we need both cultural and structural changes ([Raymaker & Nicolaidis, 2013](#)) in order to ensure genuinely participatory research and public engagement – done *with* autistic people, rather *about* them and without their voices. Sue [Fletcher-Watson and colleagues](#) have identified five elements relevant to building a community of practice in participatory research: Respect, Authenticity, Assumptions, Infrastructure and Empathy. People with lived experience must be at the core of research teams shaping projects, supported both emotionally and financially ([Townsend et al, 2020](#)).

Honest exchanges

Our FlowUnlocked project, funded by UCL Culture and UCL East, aims to explore the experiences of autistic east Londoners (in particular those in Tower Hamlets, Hackney, Newham and Waltham Forest) and their relationships with others during lockdown. Our collaborative is connected by a shared vision of supporting autistic East Londoners to explain how they relate to the world, in order to define their own narratives and erase existing myths.

Our collaborative relationship has continued to strengthen without ever meeting face to face. Though strange, it has been appropriate to feel the limitations of lockdown upon the task of devising this project. This has forced us to be hyper aware of each other's needs and communications styles, which is fundamental to effective relationships between non autistic and neurodivergent people.

Flow Unlocked is a dynamic formulation of roles, interpretations, sharing of power/knowledge. The experts become the participants, the artists learn from the art produced by non artists. The autistic-non autistic world merging, the artist- researcher world merging. It's a respectful and at times provocative approach that brings new understandings. We have had honest, creative and challenging conversations on collaboration, arts in academia, public engagement, allyship, and autistic experiences. We have shared powerful, intimate accounts of an amazing diversity of

relationships. We continue to share our unrefined ideas with each other, and our honest exchanges enable us to examine doubts and find clarity together.

Understanding our local communities' needs is a key part of UCL's role in developing relationships with our neighbours and local people. Professor Alan Thompson, Dean, Faculty of Brain Sciences and Pro Vice Provost at UCL, recently [wrote](#) that the outcomes of our project are *'so important, despite what's going on in the world around us, and aim to highlight autistic people's relationships and help promote autistic acceptance.'* Myself and autistic Coinvestigator, Jon Adams, share a belief in the importance of human relationships as the forgotten foundation of mental health. We dream of a society which not only makes space for, but also offers opportunity to, neurodivergent people across the lifespan, to thrive. I've never met my other co-investigator, Briony Campbell, in person, but our first phone call during the first week of lockdown was a heartfelt exchange about neurodiversity, autistic parity and creative methodologies. The most fundamental myth about how autistic people relate to others was erased from her mind in the earliest conversations with our autistic consultants (see her [video response](#) around 30 seconds).

The FlowUnlocked project took place entirely online, seeking to highlight the importance of relationships to autistic people, while investigating the questions of authorship and representation inherent to the process. The project objectives were codesigned with our autistic consultants. They were invited to share their narratives with other autistic people and families in their preferred ways, to create a greater sense of belonging. For many self-diagnosed and late diagnosed people, this also involved finding their neuro-tribe and promoting autistic awareness and acceptance to the wider population by educating others about how autistic people relate to the world. Through the online meetings we have created safe spaces where creativity and authenticity can shine and flow.



Regents Canal / Lee River was a geographical focal point for the project, as a metaphorical flowing artery of Briony's and autistic participants ever-changing East London neighbourhood. Here I found an inspiring connection to the positive psychological theory of 'flow state' (Milton, 2017). The theory of flow state describes the ability of many autistic people to have extended focus, and to hyperfocus on areas of interest. This optimal experience can help autistic people maintain a positive view of self and the world. We are interested in how the flow of autistic people's relationships is interrupted during pandemic, due to new rules and changes of routines. This idea of flow vs lockdown is echoed in the geography of east London's waterways, with its weirs and locks designed to control flow, travel and ultimately, connection. The canals also provide a plethora of visual stimulations with their inherent combination of natural and constructed elements.

Autistic consultant and co-investigator Jon Adams reports:

Very often autistic people are included but not involved, or have projects done to them not with them... I personally wanted my involvement with 'FlowUnlocked' to break the mould. Reclaiming the autistic narrative from the perspective of lived experience where and when we can is vital to building our culture and understanding. When projects, both artistic and scientific, include autistic people determining the rules, boundaries or participation, methods, measures and outcomes we create safe spaces where creativity, friendship and authenticity can flow.

This project has helped me to see me, and to see where those preconceptions of autistic people which others hold have intersected with defending authenticity. True participation is not a token gesture but a gift.

Our attempts to create a sense of community within the participants, our artists and creators were to identify core commonality and authentic intimacy. Autistic people may be good at reading patterns and finding those traditional boundaries to break. We often know what we need but it's rare to be asked as people just assume; which we've learnt harms us. Once we identified that the group was safe, with all open to each other's authentic voice and need, we opened and blossomed, working in mediums both familiar and new but strangely appropriate.

Authentic participation as a priority

Our preliminary work has demonstrated potential for participatory approaches to inform co-production of knowledge in mental health during the pandemic, reflecting the diversity of identity and experience of autistic people. We have achieved a creative space where community autistic consultants felt safe and empowered to move beyond essentialised 'service user' identities and bring a range of skills and expertise to the design of our project. There was a meaningful balancing of power between traditional university and community roles, although the issues around representation, authorship remained complex... more should be done to explore how our different experiences shape the project.

In May we ran a pilot project with East London Autistic people. We recruited people who would offer their time as consultants to co-establish the project, rather than participants of an existing project. This differentiation was important to ensure that they came expecting to contribute actively and critically to co-designing our project.

This consisted of three online sessions, which aimed to;

1. Enhance our team's understanding of what relationships mean to autistic people, and how lockdown has affected them.
2. Co-establish the key objectives of FlowUnlocked.
3. Understand our consultant's ideal terms of collaboration.
4. Explore and identify potential/ preferred methodologies for collecting personal reflections on relationships.
5. Reflect on the process of this consultation process and pilot project.

We agreed on a personal creative 'mini-brief' for each person in the group (facilitators included), through which we would each reflect on a relationship that was poignant to us during lockdown. Devising the briefs was an organic process of discussion, and ultimately each brief was self-defined. Our autistic consultants each reflected on a relationship with a person or object. GP and BC reflected on their own evolving relationships to autism from their differing professional and personal positions. The results were extremely moving. The personal reflections and group exchanges that took place felt as revealing and rewarding as the wonderful creative outcomes. We were very satisfied to have achieved all five aims with our consultants.

With authentic participation as a priority within FlowUnlocked, we are looking at our approach to collaboration not just as a methodology but also a subject to study in itself. We have been reflecting on our own relationships as facilitators, collaborators and participants simultaneously, and will aim to turn our process inside out so it can be revealed to our audience, in parallel to the core stories of autistic relationships. We have written two interim reflective articles which focus on our collaborative experiences.



As a researcher, I have already experienced a number of benefits by collaborating with autistic and non-autistic artists, including pushing my own by discovering new ways to approach my research passion and to communicate with autistic and non-autistic people in creative ways. Personally, I am hoping that this collaboration will increase my understanding of autistic people's sense of relationships, belonging and culture. Redefining the autistic narrative from the perspective of lived experience is vital to building an inclusive community. When projects involve autistic people in genuine participation, we create safe spaces where creativity, friendship and authenticity can flow. During the last three months we have been doing just that. In Jon Adams words, 'This project has gifted me the opportunity and encouragement to express, through a creative and open peer-led safe space, my hurts and hopes for the relationships I struggle to maintain during Covid-19'.

We have now completed the first round of discussions concerning autistic relationships, mental health, loneliness, connection, sound, space, pattern, and flow, experimenting with creative briefs. In response to our autistic consultants' feedback we will now finalise our proposal for the next stage to explore creative representations of our consultants' relationships with people, places and sensations.

Dr Georgia Pavlopoulou is a Senior Teaching Fellow in Psychology and Mental Health at University College London. georgia.pavlopoulou@ucl.ac.uk

Find [more on autistic people in autism research in our archive](#)

Images: [Briony Campbell](#)

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