

**A research project to explore how Participatory Research Methods can develop capacity with articulate individuals with autism to enable effective skills as co-researchers and skills as peer advocates for people with profound and multiple needs and autism**

*Keywords: autism, participatory research, stress sensor, ethics, advocacy*

Autism is a condition which affects people in different ways. Some are able to live relatively 'everyday' lives; others need a lifetime of specialist support. Yet, the right support at the right time can make an enormous difference to people's lives and help them to lead the life they choose (Bancroft et al., 2012). Aylott (2010) argues that an alternative way of understanding autism is through the 'social model of disability', where a person is disabled by barriers in their environment as opposed to disabled by the limitations and restrictions of their impairment.

This presentation will explore ways to engage with people with a diagnosis of autism through Participatory Research Methodologies. In the first instance this will be to facilitate their participation in a research project to measure and account for their own stress using simple wrist sensors that can identify when stress levels are rising.



Figure 1: The Stress Sensor

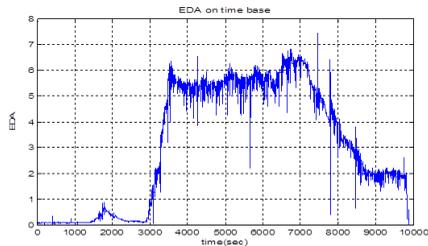


Figure 2: EDA on Time Base

This is carried out with the collection of personal diary records to correlate with the stress sensor data. This talk will demonstrate how the feedback from collected data about their own stress can make a difference to their lives and if they change or control their environments in light of this new knowledge.

Activity experience and mood diary					Researcher name: [redacted]
Date	Time activity happened	What were you doing when this happened?	What happened and how did this make you feel?	Who-time did you complete this form?	How did you cope?
10/1/2	9:00	Spoke with a 'Buck' group	A member of the group approached me and said 'Gosh, it's a bit noisy here'	2	None in some 'distressful'
10/1/2	19:00	W/1:1	Over 'how ever' I'm going to be a member of 'Buck' group and I'm going to help	10:30	By using my coping strategies, these were not a problem
10/1/2	19:00	Spoke up	How 'Buck' group was 'Buck' group	10:30	By using the sensor and data to help

Figure 3: Mood Diary Record Sheet

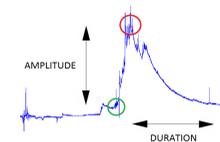


Figure 4: Signal Characteristic

This talk will argue that a level of engagement will enable the development of skills and knowledge of stress, measure what difference engagement with the project has made to them in terms of contributing to the self-monitoring of stress for self-management. This research aims to examine how it can inform and generate a greater understanding of the needs of people with autism who do not have verbal communication and explores how this new knowledge generate new theories in engaging people with autism in research- with people who have verbal communication and those who do not and contribute to the theory of advocacy particularly 'peer advocacy'.

**References**

Aylott, J. (2010) Improving Access to health and social care for people with autism. Nursing Standard. 24 (27). p. 47-56.  
 Bancroft, K. et al. (2012) The way we are: autism in 2012. London: National Autistic Society.