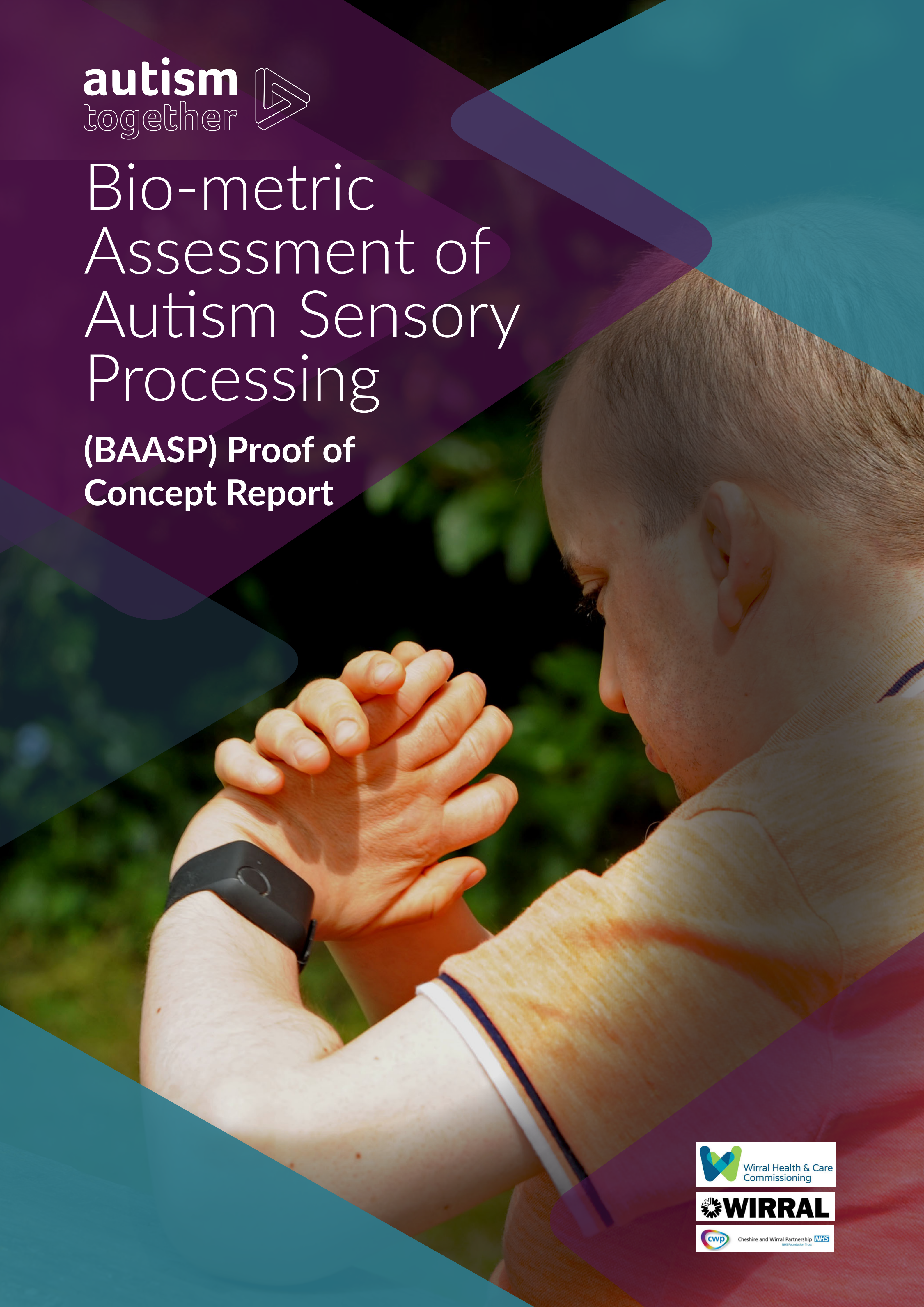
autism together

Bio-metric Assessment of Autism Sensory Processing

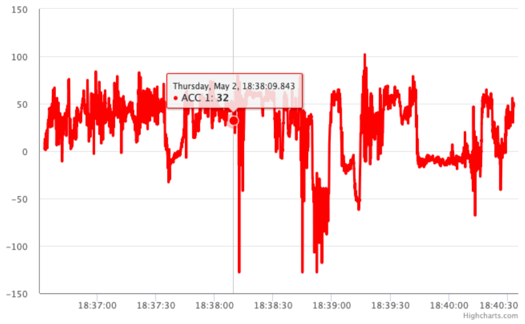
(BAASP) Proof of Concept Report

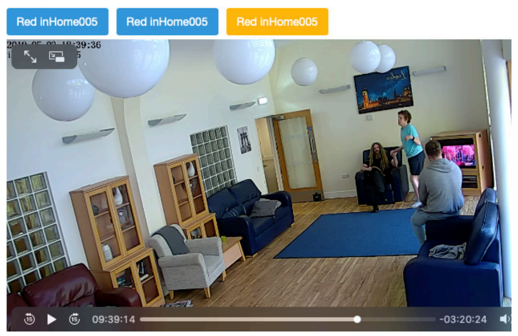


Wirral Health & Care Commissioning

WIRRAL

Cheshire and Wirral Partnership NHS Foundation Trust





BAASP
Proof of Concept Report

Autism Together (AT) has been providing services to the autistic population for over 50 years, during this time we have developed experience of how best to support people with this complex condition. However, as a learning organisation we wanted to do more, we recognise that technology has a key role to play in the future of support provision. In 2014 we were already using iPads to facilitate communication but it was by chance that we came across the work of Dr Goodwin and his application of bio-metric technology in a classroom setting.

We quickly identified the potential of this technology for the adults that we supported and began designing our Biometric Assessment of Autism Sensory Profiling Project (BAASP). Despite some promises of funding it wasn't until Wirral Council invited us to deliver this project on their behalf, through a successful funding bid they applied for from the LGA, that the project became a reality.

After years of planning, testing and negotiation we are very excited to have proved the concept that it is possible to capture multiple environmental and bio-metric data streams simultaneously, outside of a laboratory and in services. The potential for this system still remains untapped but having demonstrated what is possible, we are hopeful that we can develop the system further and thereby improve the quality of life outcomes for people on the autism spectrum.

1 The history

Many individuals with autism experience sensory processing difficulties, whereby they are either hyper- or hypo-sensitive to light, sound, taste, touch, temperature, smell, and/or own spatial awareness. These processing difficulties can cause significant distress, physiological arousal, and anxiety that are putatively thought to occasion behavioural events including self-injury, aggression to others, property destruction, tantrums, meltdowns, and taking flight (collectively referred to as 'challenging behaviours'). Sensory processing and anxiety are considered so significant for the autistic population that they were recently included in the DSM-V as accompanying diagnostic features.

Based in part on the above, Autism Together built two new residential services designed to be more sympathetic to the sensory needs of autistic people. Anecdotally, we observed reduced incidents of challenging behaviours in these newly designed settings, and thus sought to determine how we could more quantitatively capture the effects of the sensory environment on our service users.
Around this time a staff member from Autism Together attended a technology and autism conference in Paris (2nd Annual Innovative Technology for Autism Spectrum Disorders (ITASD), Institut Pasteur, Paris, France, Oct 3-4, 2014) and saw a keynote address from Dr Matthew Goodwin from Northeastern University (Boston, MA, USA) showcasing work he was doing developing and deploying synchronized biometric and video capture sensors to support individuals with autism in home and classroom settings. Subsequent to that conference, Dr Goodwin and AT began discussing applications of his technology and their extension across services at Autism Together. Those conversations resulted in the design and execution of the present pilot study testing the feasibility of simultaneously capturing biometric and environmental data at Autism Together. However, it wasn't until Wirral Council successfully bid for NHS Digital Money through the Social Care Innovation Fund (through the LGA) that this project could finally become a reality. We have been exceptionally grateful for the opportunity to partner with Wirral Council on this project. We feel that learnings from this pilot, described more fully below, will facilitate future research that quantitatively identifies potential root causes of and remedies for remediating challenging behaviours in individuals with autism in clinical and residential settings.

2 Bringing the three components together - a collaborative approach

AT reached out to Dr Goodwin in 2014 and after some initial discussions we agreed to develop a pilot feasibility study at Autism Together using an extended version (i.e., adding ambient environmental sensing capabilities) of his existing data capture system. We ran an initial study with one individual to gauge tolerability and utility and then sought funding to broaden the scope of the proof-of-concept. A number of avenues were explored for funding and eventually we were able to secure resources with Wirral Council from the LGA. Dr Goodwin had run similar projects in North America and had at his disposal contacts who could support the development of hardware integration and analytic platforms bespoke for Autism Together.

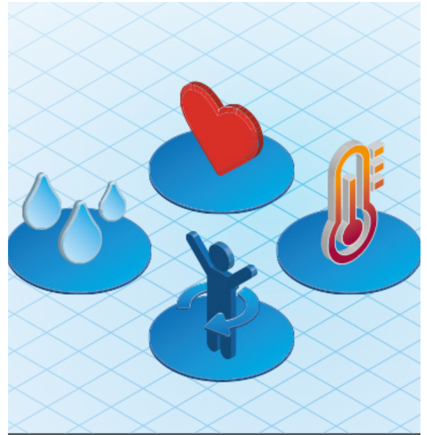
We wanted to ensure that any potential outcomes from this project were congruent with the commissioning models locally and we sought to develop a multi-disciplinary approach to the project implementation. Representatives were identified from Cheshire Wirral Partnership and Wirral Council to act in a "critical friend" capacity. A nominated individual was allocated to support the implementation partner (Autism Together) and they worked closely with them to monitor the project deliverables.

A number of information sharing meetings were held with the families and advocates of those people who were identified as being potential participants in the project. These meetings demonstrated elements of the technology, Matthew Goodwin was in attendance and was able to answer any question that the families had. We developed an ethics review committee which included independent academic representation from local universities as well as trustees of Autism Together and a representative from Healthwatch Wirral.

We held a number of meetings with staff at Autism Together to discuss the project and get them engaged with the study. Additionally, we undertook an extensive internal ethics review to ensure we were acting within an acceptable and appropriate framework. Participants in the project were assessed as to their level of mental capacity and those who were unable to consent were subject to a best interest meeting with stakeholders and advocates present.

THE CHALLENGE

THE TECHNOLOGY



THE RESULTS

3 The system in practice

The following is based on regular meetings with 15 support workers, 3 service managers and IT staff at Autism Together during and after the pilot project period.

"I can see its potential, it would be good if we could use it for more people, perhaps for those people who are in the bedrooms and withdrawn from other spaces." SUPPORT STAFF MEMBER

Support staff generally reported that the overall system was useful (e.g., "I can see its potential, it would be good if we could use it for more people, perhaps for those people who are in the bedrooms and withdrawn from other spaces."). Specific to system components, they reported that once they got accustomed to putting the E4 biosensor onto service users it soon became part of their early morning routine. However, they felt the sensor could be made to be more user-friendly through alternative form factors (they suggested making a sweat band with embedded sensors for more comfortable wear on the wrist or ankle or as an adhesive patch); could provide an easier way of indicating when it was recording and its battery life status; and suggested it would be easier if the device could automatically sync to a cloud server rather than having to manually plug it into a computer to upload data. With respect to the ambient environmental sensors, they reported that they were unobtrusive, although extended battery life was an issue. For the behavioural annotation buttons, staff reported that they were useful for time-stamping clinically relevant behaviours they observed, but that since the device was remote it was not always easy for them to remember to press it. Furthermore, they reported that placing the annotation button in the environment made them a target for service users' attention, leading to the buttons being damaged. Finally, they reported that it was difficult to tell whether the button was transmitting their annotations or not. Their suggested remedy was to source an alternative annotation device that they could wear as a keyring type fob that clearly indicates when a button has been pressed.

From an IT perspective, the IT technician reported an issue wherein Teamviewer (a remote system access platform) did not keep a consistent connection, requiring him to travel to deployment sites to reboot the laptop to reconnect. He also felt that more regular updates indicating whether system data was being received in the Amazon S3 data repository would have been helpful. His concluding remark was that if he had a better understanding of the system, he may have been able to provide better and more timely maintenance onsite and not been dependent on remote support from someone offsite in a different time zone.

4 The initial data and analysis

Over the course of the pilot, consisting of 4 months of system data collection from 3 service users, beginning January 17th and ending May 7th 2019, we obtained 335 hours of video and audio (67 days x 5 hours average recording), 130 hours of ambient environmental data (temperature, relative humidity, light, UV index, barometric pressure, sound noise, discomfort index, heatstroke risk factor, battery voltage across 26 days x 5 hours average recording), and 459 hours of biometric data (cardiovascular, electrodermal activity, physical activity through 3-axis accelerometry, and skin surface temperature across 51 sessions x 9 hours) all time-synchronized. All of these data streams were processed and uploaded to an Amazon S3 bucket, daily. We generated one video file per recording session accompanied by all the environmental and biometric data captured during that session, including behavioural annotation button presses. Using this infrastructure and organization allows other programs to access this data for post-processing in a way that is both interoperable and secure.

335 hours of video and audio

130 hours of ambient environmental data

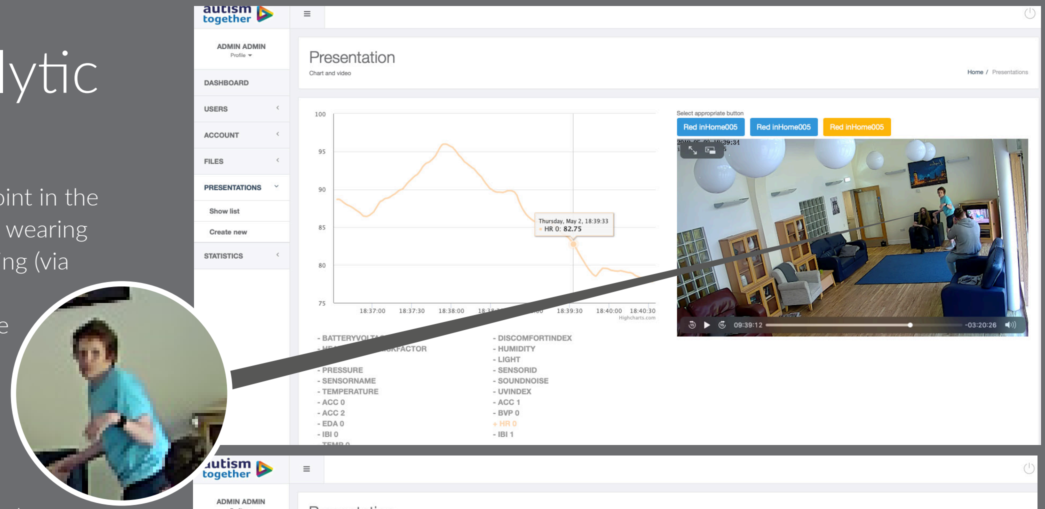
459 hours of biometric data

For data visualization and analysis, we developed a Web-based tool capable of displaying all obtained data in a secure, simple, and effective manner, wherein users could easily log-in with a password to navigate each data type and discern clinically significant events. The application was built using Angular on the frontend and Python on the backend (we selected Python because it is compatible with many scientific libraries that can be leveraged for statistical analysis in future projects). Backend development involved implementation of video uploading from cloud storage, environmental and biometric data uploading from storage, and features supporting data presentations. Frontend development covered designing a dynamic chart capable of displaying all data types with the user option of toggling data sources on/off to achieve desired visibility, and color coding of different data sources. The data visualization chart works to display raw sensor data time-stamped with a video player. Selecting a point of interest (either using behaviour annotation button presses, points of interest selected in a data chart, or an open field ad hoc annotation feature in the data viewer) makes the video automatically skip to and display 2 minutes of recorded footage and accompanying environmental and biometric sensor data surrounding the point of interest (note: the duration of display before and after a noted event is user-customizable). The tool also allows data presentations to be edited, curated, or removed at any time. Using this approach, we believe we achieved simplicity of user interface while enabling end users to efficiently and accurately track, annotate, and query interactions between all recorded data types surrounding clinically relevant behaviour.

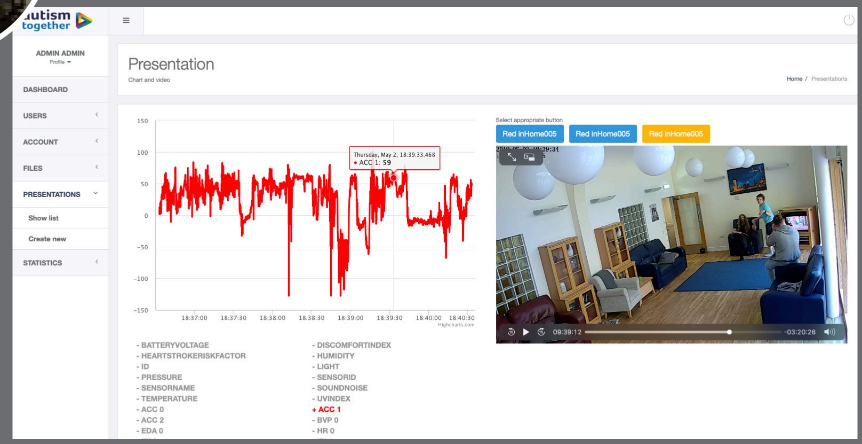
In summary, we feel our pilot project demonstrates both feasibility and utility of ongoing system use at Autism Together. We achieved good buy-in from clinical and IT support staff, had good compliance from all service users, obtained a sizable corpus of all data types, and created a user-friendly webtool for data access and hypothesis generation.

Visual Analytic Platform

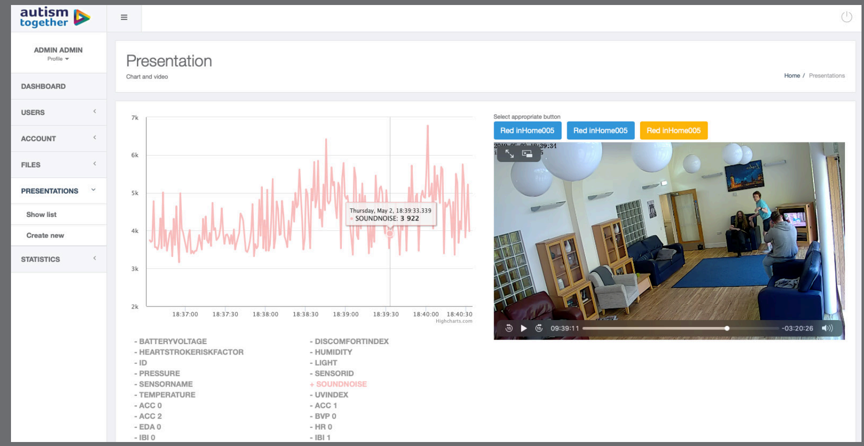
We can see that at this point in the video when the individual wearing the device is communicating (via physical contact) with his support staff his heart rate continues to decrease, this reduction begins when the individual starts to initiate communication with the staff in the room earlier in the video



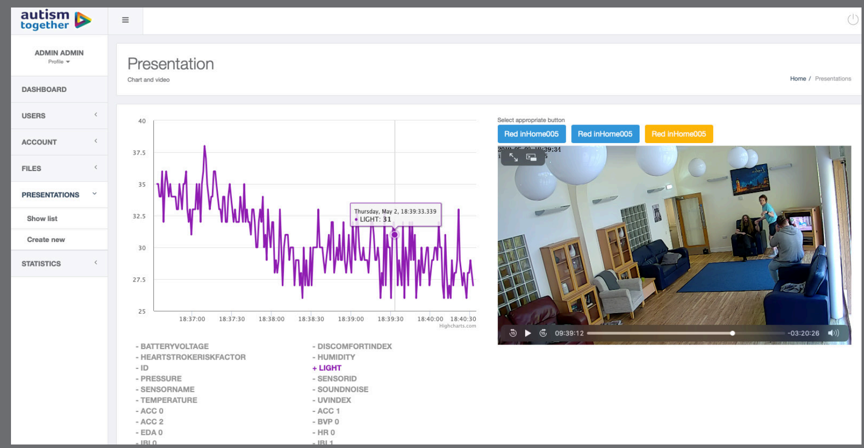
The data in this image shows the movement of the wrist on which the device is being worn



At approximately the same time we are able to see that there is a reduction in noise level in the room



We are also able to assess the light level in the room using the same time stamp



Whilst we are unable at this stage to prove the hypothesis, that environmental sensory processing has an impact on levels of anxiety and related behaviours; we are able to demonstrate that it is possible to capture multiple environmental and bio-metric data sets in a service provider (non-laboratory) setting. Increasing the cohort of participants and developing the system using the learning from the proof of concept stage will allow for us to analyse increased volumes of data and interrogate any correlations that exist.

5 Effects on assessment and treatment

ASD is one of the most common childhood disorders (1 in 59) (Baio et al., 2018) and it is associated with high health care cost (Amendah, Grosse, Peacock, & Mandell, 2011). While ASD is characterized by social communication impairments and restricted, repetitive behaviors and interest (American Psychiatric Association, 2013), youth with ASD are also at increased risk for a range of co-occurring psychiatric and behavioral issues compared to the general population (Gray et al., 2012; Joshi et al., 2010; Leyfer et al., 2006; Salazar et al., 2015; Simonoff et al., 2008). Aggression is one of the most frequently observed problem behaviors in youth with ASD (Kanne & Mazurek, 2011; Matson & Cervantes, 2014), especially in the more severely affected (Bronsard, Botbol, & Tordjam, 2010; Matson & Rivet, 2008; McClintock, Hall, & Oliver, 2003; Tsiouris, Kim, Brown, & Cohen, 2011), and ranks among the most common causes for referral to behavioral healthcare services (Arnold et al., 2003). Physical aggression, including hitting, biting, scratching, and throwing objects at others, is particularly debilitating because it often occurs without warning, sometimes long after any observable trigger, creating an environment of unpredictability.

> "Unpredictable aggression can create a barrier to accessing community, therapeutic, medical and educational services"

Unpredictable aggression can create a barrier to accessing community, therapeutic, medical, and educational services. For instance, families report that aggression increases their stress, isolation, and financial burden, and decreases available support options because they are understandably afraid to put their child with ASD into potentially stressful environments that might lead to aggression without warning (Davis & Carter, 2008; Hodgetts, Nicholas, & Zwaigenbaum, 2013). Frequent aggression can also have deleterious effects on professional support providers, leading to increased sick days, higher turnover rates, and compensatory payments for injury (Allen, 2000; Kiely & Pankhurst, 1998). This predicament can demoralize parents and providers, accelerate negative patient trajectories, and lead to homebound or residential living placement, collectively decreasing quality of life while increasing healthcare costs (Jewett, 2017; Price & Price, 2016). Cross-sectional and longitudinal studies suggest that even though aggression may decline in ASD over the lifespan, it can persist into adulthood and remains heightened in comparison to typically developing and intellectually impaired populations without ASD (Farmer & Aman, 2009; Farmer & Aman, 2011; Gray et al., 2012; Woodman, Mailick, & Greenberg, 2016).

The purpose of this proof of concept study was two fold, primarily it sought to establish the feasibility of collecting environmental, video and physiological data in a non-laboratory environment from people with a complex learning disability and autism. A secondary objective was to establish whether the data that was collected was able to better inform the understanding of behaviours and specifically how any environmental factors may affect these behaviours leading to the development of different intervention models to better support people in their lived environments.

As already discussed in this paper the BAASP system managed to successfully capture multiple environmental data streams, video imagery and 5 different physiological markers simultaneously. A further refinement was added to the system whereby staff could "flag" the data when there was a behaviour of interest was present. Flagging was achieved by staff physically pressing a button that was situated in the living spaces where the environmental technology was deployed.

The development of a bespoke analytic platform where simultaneous environmental and bio-metric data feeds could be reviewed concurrently with video images has allowed the staff teams in services to apply a more detailed and evidence-based assessment when reviewing behaviours. Using this tool, initial manual analysis of the headline data did reveal some potential patterns in behaviour that have led to a better understanding of root cause and, importantly, more effective interventions.

Reviewing the data for one individual enabled the support team to establish which of his behaviours appeared to be associated with an increased level of anxiety and which did not.

By reviewing the historical data, the support team were also able to establish patterns when these anxiety-led behaviors were more likely to occur. Staff have also been able to identify from further data anyalsis which interventions appeared to be more effective in reducing the level of anxiety for this individual. Applying this analysis the staff were better able to predict the likelihood of certain behaviours and use appropriate interventions to reduce the anxiety which has seen a reduction in behaviours at these key times.

When reviewing the data for another individual, in conjunction with the video images, staff observed that the participant (images page 7) whilst externally not displaying any behaviours that would indicate he was becoming anxious had a physiological markers that indicated that there was increasing levels of anxiety. On further analysis of the data staff were able to hypothesize that the different key low level behaviours displayed by this individual communicated his increase in anxiety. Further detailed analysis seemed to indicate that this individual engaged with staff as a mechanism of self regulation to reduce their anxiety. Subtle changes were also detected in the decibel level in the environment, encouraging staff to trial the use of noise-cancelling ear defenders.

> "the support team were also able to establish patterns when these anxiety-led behaviors were more likely to occur."

Although the BAASP system is still at the prototype phase these examples demonstrate that the system has the capacity to provide a more detailed evidence-based assessment of behaviours at service level. It also allows through the manual analysis of data staff to ask questions of the information available and test their hypothesis, reviewing in real time any effects that different interventions may achieve. This approach to assessment could have significant advantages within a multidisciplinary forum where behaviours can be observed and external factors assessed simultaneously.
Already BAASP has been instrumental in allowing support staff to provide more effective interventions to people with a complex learning disability and autism. This has been achieved through using the data provided to gain a better understanding of behavioural patterns, potential cause and then reviewing the efficacy of their interactions with the people supported.

A larger cohort of participants would be required to gain enough quantative data, to conclusively test the hypothesis that (a) specific changes in the ambient environment lead to (b) changes in physiological arousal that lead to (c) subsequent engagement in challenging behaviours.

However, when considering how the BAASP Proof of Concept study has already started to inform the intervention strategies for the small number of participants involved in the project, it is possible to envisage how at a larger scale this system can benefit significant numbers of people on the autism spectrum who display behaviours that challenge.

In summary, cutting-edge technology combined with multidisciplinary clinical experience has the potential to further inform what has been a largely intractable problem for a sizable segment of the ASD population, who are arguably most in need of innovative approaches. By focusing on reducing the unpredictability of challenging behaviour, we hope that the knowledge, data, and algorithms we are generating will ultimately facilitate reductions in the occurrence, duration, and impact of aggression in those with ASD, enabling them to more fully participate in their homes, schools, and communities.

6 Costs and savings

NHS figures from 2015 show that as many as 24,000 people with learning disabilities or autism were at risk of admission to hospital, revealing the large number of people at crisis point at any one time. Later figures, from autumn 2017, show that a third of people with autism in hospital had been there for two years or more. Many staff do not have the expertise to help support this client group.

We know that many people on the autism spectrum experience high levels of anxiety and that this can increase as a result of the things that are happening around them. We also know that autistic people can be either very sensitive (hyper) or really un-sensitive (hypo) to light, sound, taste, touch and temperature. Because some of the people who we support do not use words to communicate, currently the only way they can tell us they are anxious is through displaying risk behaviours.

> **“**With the average cost of a secure hospital admission spiraling upwards, reduced admission would have a substantial savings to the public purse**”**

Most organisations currently undertake visual sensory profiling assessments to gauge how a person with autism processes environmental stimuli. Whilst these tests are useful, it is not possible to quantitatively assess long term levels of stress and anxiety, especially the extent to which different stimuli and settings are processed. As a result, these profiles are subjective and vary in accuracy, thus we are unable to gauge precisely what baseline stress and anxiety is being experienced, and which sensory inputs reduce/increase these levels.

This form of behavioural profiling prevents a true appreciation of the role and response of the nervous system in people with autism. As a result, individuals run the risk of reaching crisis, admission to psychiatric services, and/or incorrect discharge because the cause(s) of stress and anxiety have not been fully understood. Thus, there is a risk of the crisis re-occurring as the contributing factors may not have been identified and, therefore, effective interventions and support are not provided, increasing the vicious circle of crisis admissions and discharge often leading to heavy pharmaceutical interventions. Often with medication the root cause is rarely identified and a lasting reduction in symptoms is not achieved. Furthermore, and importantly, the therapeutic benefit of medication diminishes with time and negative side effects can increase with the duration of medication.

By using the biometric wristbands and room sensors, we are hoping that we will be able to tell exactly what it is in the environment that is causing stress and anxiety in the individual. We can then support them with strategies to reduce their anxiety and hopefully reduce risk behaviours.

With the average cost of a secure hospital admission spiralling upwards, reduced admission would have a substantial savings to the public purse.

Additional benefits would be realised in terms of quality of life outcomes for individuals with an autism diagnosis, who instead of requiring secure accommodation, could be supported in their communities

7 What is the next step?

Further work needs to be undertaken to develop a user-friendly and high-throughput data collection system for use at Autism Together, and we are taking the following steps to scope this next phase of the project:

Discussions are now at an advanced stage with Professor Ian Craddock who is the Institutional Lead for Digital Health and Director at the EPSRC Centre for Doctoral Training in Digital Health & Care; he is also the Head of Digital Health Engineering Research Group and Director of SPHERE at the University of Bristol and Francesca Happe who is a Professor of Cognitive Neuroscience and Director & Head of Department at the MRC Social, Genetic & Developmental Psychiatry Centre at King’s College London. We are currently developing a funding proposal to take forward the project to the next phase.

In addition CEO of Autism Together is working locally with the Transforming Care Team to look at how the NHS may be able to provide some additional funding to roll out the development of this technology.

Autism Together has also launched a Fundraising Appeal, a part of which is designed to raise funds to continue with the development of the system.

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