B IS FOR BIOMETRICS

Tim Webb’s film *A Is For Autism* delivered a touching insight into what life is like for people with the condition. A new wristwatch that scans biometric data might open another window into it.

**WORDS:** PAUL PARSONS
even years ago, I had one of the worst conversations of my life. A paediatrician delivered the news to me and my partner that our 18-month-old son, Callum, had a severe developmental delay and was presenting symptoms consistent with autism spectrum disorder (ASD). The diagnosis of ASD was later confirmed. Callum has since attended a specialist pre-school and now goes to a special educational needs primary. His progress has been good, but his condition remains moderate to severe, and it’s likely he’ll require continued support into adulthood.

Knowing that your child probably won’t achieve independence in later life throws up many unpleasant questions. What’s going to happen when I’m gone? Who will care for him? Who will love him? But, as we were to find out, that wasn’t the worst of it. Autism is a lifelong developmental condition characterised by difficulties with language and social interaction, and a tendency for repetitive behaviours. The disorder often manifests itself with other mental health issues, including learning disabilities, depression and anxiety. It is a spectrum condition, meaning that its symptoms and their severity vary greatly from one individual to the next. Those who experience autism range from high functioning, such as naturalist and television presenter Chris Packham, the high functioning, to being profoundly disabled. Depression and anxiety. It is a spectrum condition, meaning that its symptoms and their severity vary greatly from one individual to the next. Those who experience autism range from high functioning, such as naturalist and television presenter Chris Packham, to being profoundly disabled.

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The US Centers for Disease Control and Prevention estimate the autism prevalence to be 1 in 59 children, with approximately five times more males being diagnosed than females. In the UK, the rate is thought to be around 1 in 100. The precise cause of autism isn’t fully understood. Research points to a combination of environmental factors, such as air pollution and conditions in the womb, and genetics – although, despite many genes being implicated already, we’re only just beginning to identify all of those that contribute to autism risk, and we’re only just beginning to identify all of those that contribute to autism risk, and we’re only just beginning to identify all of those that contribute to autism risk, and we’re only just beginning to identify all of those that contribute to autism risk.

It has also emerged that many autistic parents process sensory information differently – the point that some sensations, loud sounds, for example, can cause pain. The frustration of not being able to communicate their predicament to others, or to regulate the resulting emotional distress, can lead to a meltdown.

EARLY WARNING SYSTEM

My partner and I have witnessed countless meltdowns, during which Callum will scream as if he were being tormented, sob uncontrollably, break anything within reach, hit and bite us, and self-harm – punching himself and banging his head into walls and floors. It’s one thing when these episodes occur in the privacy of home, but when they take place in public – as they inevitably will – the consequences can be dire. There have been times when, in fury, he’s almost run out into traffic. Visits to the barber’s or the dentist became impossible. Pubs, restaurants – anywhere noisy and in close proximity to other people – equally so. And then there’s the spectacular of full-on public meltdown – and the disapproving looks and the muttered remarks from those who don’t understand, and who write us off as inept parents of a disobedient child. Whatever the long-term outlook, when day-to-day life becomes such an unrelenting struggle, it does drive you to the proverbial depths.

Callum was non-verbal until the age of six. He’s now eight and, happily, his meltdowns have subsided somewhat as his communication skills have improved. But while they lasted, they kept us under effective house arrest much of the time.

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The researchers chopped this data up into intervals, each 15 seconds in length. For each interval they calculated summary statistics – the average, minimum, maximum and the variability within the interval – for each of the biometric markers that the wristband records. Finally, they added a label – essentially a yes/no indicator – from the carers’ notes, to show whether or not there was a meltdown episode in each interval.

Next, they looked for patterns in the biometric marker data that presaged the onset of the aggressive episodes recorded by the labels. They did this by crunching the processed numbers through a machine learning algorithm – a piece of computer software that uses statistical methods to extract knowledge and insights from an abstract mass of data. In this case, it was trying to construct a model that could forecast whether or not a meltdown was going to occur in any given 15-second interval, based on the biometric readings in the preceding intervals. In fact, they built a number of different models – a person-dependent model for each patient, using just that individual’s data, plus one ‘global’ model pooling together the data from everyone.

“If we used three minutes of past data, that gave us the highest accuracy of prediction one minute into the future,” says team member Professor Matthew Goodwin, of Northeastern University. “For the global model, that accuracy was 71 per cent. Out of every 10 times that you would make a prediction that an aggression is going to happen in the next minute, then roughly seven times it will come to that.”

Of course, that also means that 3 times in 10 it’ll be a false alarm. However, Goodwin says that clinicians – and, indeed, most parents – would rather deal with those ‘false positives’ than for genuine meltdowns to go undetected. “They would rather have their attention triaged and nothing occurs than have a false belief that they don’t have to attend and something does.” He also believes there’s room to improve the model’s accuracy, both in the way the data is pre-processed and by employing more sophisticated machine learning algorithms. And this work is ongoing. Already, for the person-dependent model, the accuracy is higher, averaging around 84 per cent.

Goodwin and his team are about to trial the technology at a residential care facility for autistic people in the UK. The charity Autism Together operates the Ruby Hall care home in the Wirral. From July they’ll be trialling biometric wristbands on a group of residents, the first time the technology has been applied in a residential care setting. But it won’t just be biometric systems on test. Goodwin’s team will also be installing technology has been applied in a residential care setting. But it won’t just be biometric systems on test. Goodwin’s team will also be installing video and audio monitoring equipment, as well as devices to record light levels, ambient temperature, humidity and barometric pressure.

“The hope is that all this extra data will assist in understanding how an autistic person’s immediate environment can exacerbate their condition,” says Goodwin. “The hope is that all this extra data will assist in understanding how an autistic person’s immediate environment can exacerbate their condition.”

As Goodwin imagines that, in the coming years, this technology may combine with the Internet of Things to enable automated safeguards in the care of those on the autism spectrum. “Somebody starts to escalate physiologically,” says Goodwin. “Might the lights in the room automatically dim down? Might some quiet music come up?” With so many people now receiving autism diagnoses, the demand for care is increasing – automated solutions such as this could help triage the attention of human carers more effectively.

STATES OF MIND

The technology also represents a potential sea change in how we measure someone’s emotional state generally. Other aspects of health and development can be determined quantitatively – by, for example, a brain scan, an X-ray or a genetic test. But assessing behaviour, mood or overall state of mind, is comparatively imprecise. It might, for example, involve them filling out a questionnaire, the answers to which are naturally subjective. And even if you could put patients in some kind of laboratory-based ‘behaviour scanner’, obtaining an accurate picture in such an unnatural and potentially stressful environment seems unlikely.

Biometrics, on the other hand, offers an unobtrusive window to look inside a patient and quantify those nebulous aspects of human health objectively, in a way never before possible. And for people on the autism spectrum – who are often intellectually impaired, or who may lack the language skills necessary to express how they’re feeling – the benefits could be even more profound. “These are the folks that we understand the least,” says Goodwin. “These are the folks that we need to support the most.”

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