



The Association
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THE BRIDGE

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Autism

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a child with autism
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Editorial

Dr Juliette Kennedy
Editor of The Bridge

Welcome to this Autism themed edition of the Bridge. I do hope that some of you will be attending the Jack Tizard Memorial Lecture and Conference in London, on the 7/8 June. Day one focuses on Intellectual Disability, and day two on Autism. The theme is “*Expert analysis, new research: what works*”. Please do look at the program on the ACAMH website. World leading experts will be talking to us about the latest evidence and best practice.

I work in a small CAMHS team in the north of England, we have recently surveyed our caseloads and found that 30% of the young people attending our service have a diagnosis of Autism alongside the mental health problem they are seeking help for. Anxiety and low mood in the context of autism is particularly common, as young people with Autism try to navigate the complex social environment of school. Anxiety and low mood can be very debilitating. Young people with autism often describe to me how difficult it is for them to be in the school environment – busy, social and interactive – for 6 hours a day (as required by law). Despite best efforts it is sometimes difficult for mainstream schools to adapt to meet needs, given current educational pressures. So after careful weighing up of possible benefits and potential risks, sometimes medication is prescribed to help young people with Autism manage anxiety and low mood, so that they can access their education. If medication is helpful, it can then be difficult to find a time to discontinue it, especially as the teenage years are often punctuated by regular transitions between educational stages and the need to meet new people. Research evidence may help to address this – Locke et al’s article highlights the importance of recognising the strengths and abilities of young people with autism and supporting them in schools. The authors stress that there are changeable factors that can increase social success at school. The Molehill Mountain App described here, has been developed with young people with Autism to help with anxiety and among other things hopes to create a forum for online peer support when it is launched. There will be much more discussions at the Jack Tizard Conference day two and I do hope you can attend.

Compensating for ASD: masking the truth?

“Compensation” is a phenomenon by which individuals with Autism Spectrum Disorder (ASD) show improvements in overt symptoms, namely their understanding of others (“theory-of-mind”, ToM), despite persisting deficits at the cognitive and neurobiological levels. Few studies, however, have investigated its mechanisms and impact on mental health. Now, data suggest that those demonstrating a high degree of compensation (i.e. have good social skills) have a better IQ and executive functioning but worse self-reported levels of anxiety compared to those demonstrating a low degree of compensation. The study included 136 adolescents with ASD, who had been recruited to the ongoing Social Relationships Study. The participants were divided into two groups: (1) strong compensators, identified as those with good Autistic Diagnostic Observation Schedule (ADOS) scores despite poor ToM; and (2) poor compensators, being those with both poor ADOS scores and ToM.

Full article is available to be viewed online at <https://bit.ly/2FUMUxo>

Livingston, L.A., Colvert, E., the Social Relationships Study Team, Bolton, P. & Happé, F. (2018), Good social skills despite poor theory of mind: exploring compensation in autism spectrum disorder. *J Child Psychol Psychiatr*, doi:10.1111/jcpp.12886

Early ASD intervention promotes academic achievement

Rigorous screening for learning difficulties is required for adolescents with Autism Spectrum Disorder (ASD), as a significant minority of affected individuals with average cognitive skills show academic delays, according to a new study. The longitudinal study examined early predictors of and changes in academic achievement and class placement in children who had been referred for ASD early in infancy (age 2). The data showed that academic skills varied widely at ages 9 and 18 years, but in general were in-line with or higher than expected based on their cognitive ability. However, a proportion of children with ASD experienced delayed achievement by age 9 (22%) and age 18 (32%) years, despite exhibiting average or above average cognitive skills. Children who stayed in general or inclusive education showed higher academic achievement (in terms of IQ scores) at ages 9 and 18 years, compared to those who moved to special education classrooms. Importantly, early cognitive ability and parent-mediated intervention as early as age 3 years could predict long-term academic outcomes at ages 9 and 18 years.

As such, the researchers conclude that very early interventions that target cognitive skills and parent participation may help later academic development.

Hyun Kim, S., Bal, V.H. & Lord, C. (2018), Longitudinal follow-up of academic achievement in children with autism from age 2 to 18. *J Child Psychol Psychiatr*, 59:258-267 doi:10.1111/jcpp.12808

What might make a child with autism socially successful?

By Dr Jill Locke, Speech and Hearing Sciences, University of Washington, Seattle, WA

Social impairment is a core deficit of children with autism spectrum disorder (ASD). Children with ASD face complex social challenges in school, particularly in inclusive settings. Social impairment may manifest as playground isolation, peripheral inclusion in peer social networks, poor friendship reciprocity, or peer rejection. Although many studies document the ways in which children with ASD differ from typically developing children, few have highlighted the strengths and abilities of children with ASD. The article by Jill Locke, Justin Williams, Wendy Shih, and Connie Kasari argued that many children with ASD are socially successful and have social outcomes comparable to their typically developing peers. The researchers examined the characteristics, both malleable and stable, of socially successful children with ASD.

The researchers conducted a study with 148 elementary-aged children with ASD. Standard assessments were conducted to determine intelligence quotient (IQ), autism symptom severity, as well as playground engagement, friendships, rejections, and social network inclusion. The researchers categorized children with ASD by their social success based on their engagement on the playground as: Group 1 - children with ASD that had high social salience and high playground peer engagement; Group 2 - children with ASD that had high social salience or high playground peer engagement; and Group 3 - children with ASD that were neither high in social salience nor high on playground peer engagement. The researchers analyzed potential predictor variables including: age, sex, ASD severity, class size, received friendship nominations, outward friendship nominations, rejections, and peer connections.

The results indicated that a number of malleable factors significantly predicted playground peer engagement (class size, autism symptom severity, peer connections) and social network salience (autism symptom severity, peer connections, received friendships). In addition, age was the only stable factor that significantly predicted social network salience. Interestingly, two malleable (i.e., peer connections and received friendships) and no stable factors (i.e., age, IQ, sex) predicted overall social success (e.g., high playground peer engagement and social network salience) in children with ASD.

The authors reported that the results of this study suggested that factors that are predictive of social success are malleable, or factors that can be changed and can be prime targets for intervention. In the end, this study revealed two factors that predicted social success: the number of received friendship nominations and peer connections. Both of these factors are considered malleable making them sensitive to change from intervention.

The authors reported that previous research indicated that children with ASD received a higher number of friendship nominations following peer-mediated intervention, indicating that peer-mediated interventions may be critical to improving social success. When considering peer-mediated interventions, the authors noted that there are a number of peer mediated interventions, including clubs, shared activities on the playground, or social groups, that have demonstrated improved playground engagement and may lead to social success.



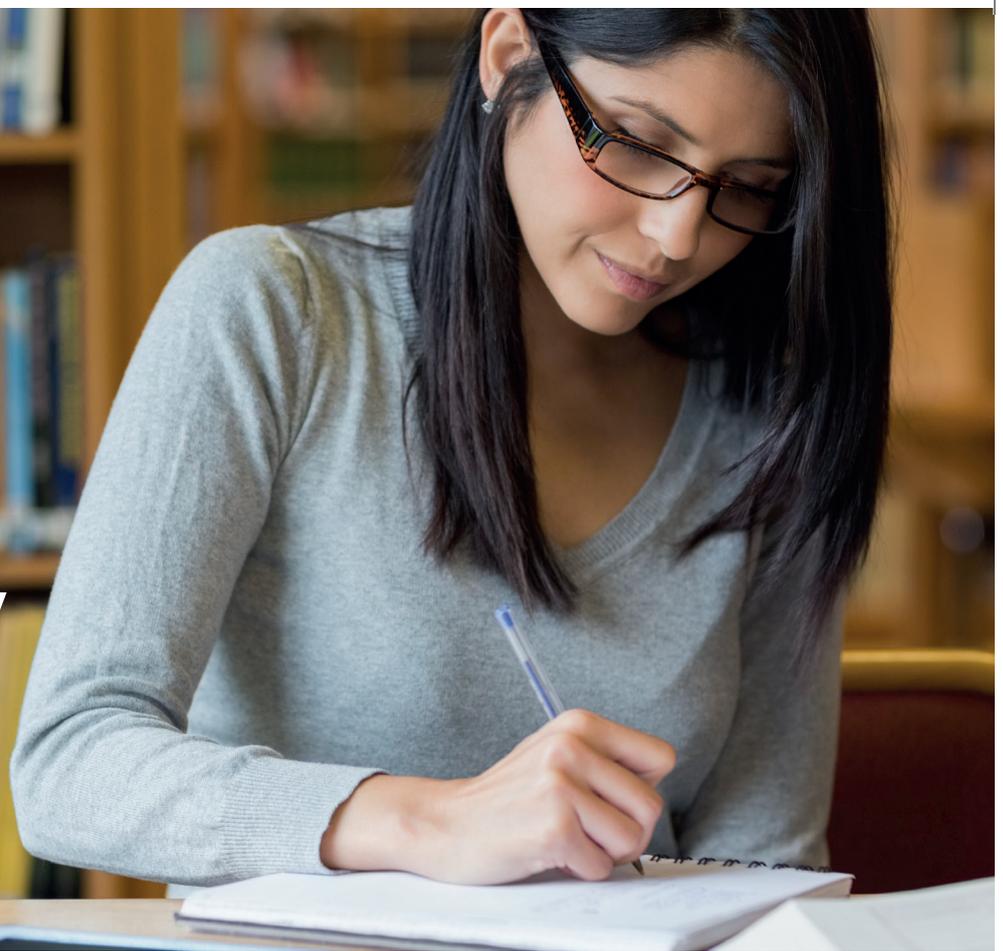
Key points:

- This study examined characteristics of children with autism in public schools from three intervention trials for indicators of social success.
- Children with autism in large classrooms, with lower autism symptom severity, and more peer connections had significantly higher playground joint engagement.
- Younger children, with lower autism symptom severity, and more peer connections showed significantly higher social network salience.
- The number of peer connections and the number of received friendship nominations were associated with highly successful children (on both playground engagement and social network salience).
- Results suggest that there are socially successful children with autism in classrooms with identifiable malleable traits that can be addressed in intervention.

This article is a summary of the paper published in JCPP - Locke J, Williams J, Shih W, Kasari C. Characteristics of socially successful elementary school-aged children with autism (2017) *Journal of Child Psychology and Psychiatry*, 58, 94–102. doi: 10.1111/jcpp.12636

The quality of autism intervention studies must improve to ensure validity

Jessica K. Edwards



The number of studies focusing on early detection of autism spectrum disorder and interventions has increased over recent years. Ensuring consistency between studies and finding a consensus as to the most effective intervention strategies, however, remains a challenge. Earlier this year, Jonathan Green and Shruti Garg compiled an Annual Research Review on the state of autism intervention science for the *Journal of Child Psychology and Psychiatry*. Here, the researchers discuss their key findings and outline where progress needs to be made.

The past decade has seen a rise in the number of international reviews of autism spectrum disorder (ASD) interventions, but confusingly, many of these reviews come to different conclusions or only assess selected forms of intervention. Such discrepancies derive, in part, from the review of different selections of small and/or poor quality studies, and as such, the results can be a hindrance rather than a help to practitioners. “To address these issues, we conducted a wide-ranging review based solely on source papers that were of a reasonable size and quality”, describe Green and Garg. “In doing so, we built on the very valuable 2018 systematic review by French and Kennedy (also published in the *Journal of Child Psychology and Psychiatry*) that independently looked at the quality of methods used in trials for early intervention in ASD”.

A key finding of Green and Garg’s review was that the quality of research into autism intervention is, unfortunately, often poor. This finding was also highlighted by French and Kennedy, who found that only 6/48 studies reviewed met reasonable quality criteria. “Many of the treatments in common use around the world for autism (for example, behavioural interventions such as Applied Behaviour Analysis or Early Intensive Behavioural Intervention) have no robust evidence base for their effectiveness as judged by accepted healthcare standards”, explain Green and Garg. “This finding is really worrying in a condition as important as autism”.

The researchers looked at intervention targets across psychosocial domains and neurological processes, to clarify exactly what kind of effect each intervention is having in relation to ASD development at the mechanistic level.

In terms of psychosocial treatments, the researchers found that most only targeted immediate social interactions, such as those between an affected child and their caregiver. Fewer studies assessed the evidence for generalising such treatments into other contexts or everyday functioning, and only a handful looked at how treatment effects were sustained over time. “We argue that if an intervention is truly to be considered a ‘treatment for autism’, it needs to demonstrate evidence of an effect on autism-specific outcomes in a more generalised way across contexts and time: many claims of ‘effectiveness’ don’t do this”, state Green and Garg. “We did identify, however, that some interventions (mainly those involving social communication) are beginning to show a sustained effect over time, for instance on reducing the severity of autism symptoms when measured in a standardised way”.

Regarding neurological mechanisms, the researchers reviewed a range of new studies aiming to find biological treatments for the underlying neurodevelopmental difficulties experienced in autism. “To the best of our knowledge, this is the first time such an analysis of biological interventions for ASD has been performed”, say the researchers. “The information gathered here gives us a good vantage point to consider neurodevelopmental intervention for autism in an integrated way”.

The researchers found that the number of interventions based on neurological targets (such as neurotransmitters) is increasing and studies of these interventions have promised to inform about the underlying causes of autism. However, as none of these interventions have yet shown efficacy in large-scale trials, they cannot be implemented into mental health practices.

The researchers expect that continued work on neurological and neurodevelopmental targets for ASD intervention will ultimately help improve neural functioning in affected patients. “We also expect to learn a lot more in the years to come as to how targeted psychosocial interventions given at the right time can impact brain development”, suggest Green and Garg. “The notion of ‘brain plasticity’ is commonly invoked in ASD intervention studies, but as yet, this concept has not been studied in depth – we will likely find both exciting possibilities but also limitations here”.

This Annual Research Review emphasized that many questions remain to be answered before evidence-based practice in ASD can move forward. Although practitioners are getting an idea of the long-term effects of psychosocial treatments in ASD, understanding their eventual limits for improvement is lacking. In addition, there are many other interventions promoted for ASD that have not yet been properly tested in rigorous trials. “We do not yet know which interventions that act at the neural developmental level may improve outcomes in ASD; initial progress has been made, but

there remains much work to do”, say Green and Garg. “We hope that it may be possible to combine the interventions that target the brain and cognition with those that target social communication and the environment: this would be an exciting next step”.

An important consideration that the researchers highlight is that autism is an enduring developmental condition; as such, a “one-off” intervention provided at any point in development is unlikely to be sufficient. Consequently, the researchers propose that an evidenced programme of sequenced interventions delivered throughout childhood development, at the right time and according to need, is required to optimise desired developmental outcomes. “Testing combinations of interventions over time is a major challenge”, admit Green and Garg. “But building up this type of evidence step-by-step will ultimately allow us to produce transformative change for autistic children and their families”.

Green and Garg are also actively researching the effectiveness of novel interventions for different groups of patients affected by ASD. “We are currently working to further adapt and implement our psychosocial intervention known as PACT, into low and middle-income countries”, describe Green and Garg. “We have already done quite a lot of work in this area and are now starting a big scale-up study called COMPASS, together with our colleagues in India”. In addition, the researchers are testing the effects of biological interventions (including statins) in those with syndromic autism caused by defects in the gene neurofibromatosis 1 (Nf1). Other work includes further analysis of an early infancy intervention for babies at risk of autism, previously described by Green et al., in the *Journal of Child Psychology and Psychiatry* in 2017. We hope that data from this research project will give us a good sense as to whether intervening in ASD very early in development really adds value”, explains Green. “If it does, there could be major public-health implications as to where we focus our ASD intervention efforts”.

Full article is available to be viewed online at <http://bit.ly/2HYarCX>

Referring to:

Green, J. & Garg, S. (2018), Annual Research Review: The state of autism intervention science: progress, target psychological and biological mechanisms and future prospects. *J Child Psychol Psychiatr*, 59: 424-443. doi:10.1111/jcpp.12892

Further reading:

Stivaros, S. et al. (2018), Randomised controlled trial of simvastatin treatment for autism in young children with neurofibromatosis type 1 (SANTA). *Mol Autism*, 9:12. doi:10.1186/s13229-018-0190-z

Green, J. et al. (2017), Randomised trial of a parent-mediated intervention for infants at high risk for autism: longitudinal outcomes to age 3 years. *J Child Psychol Psychiatr*, 58: 1330-1340. doi:10.1111/jcpp.12728

French, L. & Kennedy, E.M.M. (2018), Annual Research Review: Early intervention for infants and young children with, or at-risk of, autism spectrum disorder: a systematic review. *J Child Psychol Psychiatr*, 59:444-456. doi: 10.1111/jcpp.12828

Pickles, A. et al. (2016) Parent-mediated social communication therapy for young children with autism (PACT): long-term follow-up of a randomised controlled trial. *Lancet*, 388:2501-2509

Infant language development

Parents should keep talking to boost infant language development

Children from low socioeconomic status (SES) backgrounds tend to have poorer language skills when starting school than those from higher SES backgrounds. Now, data shows that increasing the amount of “contingent talk”—whereby a caregiver talks about objects that an infant is directly focusing on—within an infant’s first year of life promotes a wide vocabulary later in infancy. This randomised controlled trial enrolled 142, 11-month-old infants and their caregivers from across the SES spectrum. The participants were randomly assigned to either a language intervention group, which consisted of a video about contingent talk and active practise of the technique for 15 min per day for a month, or a control intervention. At baseline, caregivers of lower SES typically engaged in less contingent talk with their 11-month olds than those of a higher SES. All caregivers in the intervention group significantly increased the amount of contingent talk they engaged in, regardless of SES, and this resulted in reported short-term language learning improvements specifically in infants of a low SES. As the effects of the intervention were visible at 15 and 18 months but not at 24 months, the researchers propose that follow-up interventions are needed to promote vocabulary growth later in early childhood.

Wright, N., Hill, J., Sharp, H. & Pickles, A. (2018), Maternal sensitivity to distress, attachment and the development of callous-unemotional traits in young children. J Child Psychol Psychiatr, doi:10.1111/jcpp.12867

Screening early ASD

European experts develop a new framework to screen early ASD

Early detection of Autism Spectrum Disorder (ASD) can improve outcomes for children, yet the effectiveness and validity of universal screening methods has been questioned. Now, researchers have created a new framework to generate a valid early ASD screening method using a novel approach based on “face and content validity”. Content validity measures the actual extent to which a test measures all aspects of what it claims to measure (in this case signs of early autism), whereas face validity assesses the superficial level by which a test appears to measure the underlying item. A network of European experts first

identified what they considered to be the main factors involved in early ASD. 12 psychological constructs (most notably “social interaction”, “interest in others” and “joint attention”) and eight corresponding test items specific for early ASD (ages 14-36 months) were selected with the highest level of consensus in the group. These parameters were then combined to derive a new theoretical model, based on the DSM-5 diagnostic criteria for ASD, which achieved good face and content validity to diagnose early ASD. The researchers hope that their model will serve as a theoretical framework to develop effective and valid screening tests for early ASD that practitioners feel confident to use.

Magán-Maganto, M. et al. (2017), Measurement Issues: Building a theoretical framework for autism spectrum disorders screening instruments in Europe. Child Adolesc Ment Health, doi:10.1111/camh.12256

Autism in young infants

Early social communication intervention reduces autism severity in young infants

The first, very early social communication intervention for infants at high risk of autism shows promise to reduce the overall severity of early symptoms and a capacity to positively enhance parent–child social interactions. The parent-mediated social communication intervention, known as the iBASIS-Video Interaction for Promoting Positive Parenting (iBASIS-VIPP), was assessed in a randomised controlled trial and compared to a control, no-intervention group. A total of 54 infants at high risk of familial autism were included in the trial and were assessed at four time points: age 9-months (baseline), 15-months (the treatment end-point), and 27 and 39 months (follow-up). Using the Autism Observation Scale for Infants (AOSI), the researchers found that those in the intervention group exhibited reduced severity of early (prodromal) symptoms (such as impaired social reciprocity, imitation, motor, attention and sensory behaviours) in the second and third years of life. The intervention also had a positive impact on parent–infant social communication, as indicated by improvements on the Manchester Assessment of Caregiver-Infant Child Interaction (MACI) and the Dyadic Communication Measure for Autism (DCMA) scales. The researchers are now extending their studies to conclusively determine whether pre-emptive intervention gives added value in terms of autism outcomes and whether this is a valuable area to focus intervention efforts.

Green, J., et al. (2017), Randomised trial of a parent-mediated intervention for infants at high risk for autism: longitudinal outcomes to age 3 years. J Child Psychol Psychiatr, 58:1330-1340 doi:10.1111/jcpp.12728

The challenge: Getting research interventions into community where they are needed

By Dr Stephanie Y. Shire, College of Education, University of Oregon

This article is a summary of the paper published in JCPP - Shire, S. Y., Chang, Y. C., Shih, W., Bracaglia, S., Kodjoe, M., & Kasari, C. (2017). Hybrid implementation model of community-partnered early intervention for toddlers with autism: a randomized trial. Journal of Child Psychology and Psychiatry, 58(5), 612-622. doi: 10.1111/jcpp.12672

What does it take to get effective interventions into the community? This question remains too often unanswered. We tend to accept the 'research to practice gap' endorsing the belief it will take an average of 17 years for effective practices to become integrated into community practice (Morris, Wooding & Grant, 2011). Some researchers, however, are offering solutions to shorten this time period. For example, testing an intervention in the community right from the beginning, thus cutting out many of the years testing in the lab before moving to community (Weisz, Donnenburg,

Han, & Weiss, 1995). Others argue for developing an intervention with community partners to insure greater buy in, and adoption so that community interventions are effective and sustained. This latter practice, known as community partnered participatory research (CPPR), ensures that the interests of the community partners and the researchers are on equal footing (Jones & Wells, 2007).

In moving interventions into community practice, researchers employ implementation science methods with a particular focus on fidelity of the community practitioner (the ability of the practitioner to deliver the intervention as it was intended). An issue with respect to children with an autism spectrum disorder (ASD), however, is the great variability in response to evidence based interventions.

Full article is available to be viewed online at <http://bit.ly/2wsGOVk>

Key points:

- Novel use of hybrid design to look at both children's outcomes and how well the intervention is delivered by community staff
- Paraprofessional TAs can deliver complex social communication interventions in real world environments with toddlers with autism
- TAs learned to deliver the intervention with a mix of local and research team remote support
- This study includes a highly diverse population including staff with diverse background and toddlers who range in developmental skill level and home environment
- Community staff were taught assessments, and delivered the outcome measures, activities that are usually done by research staff

References:

- Jones, L., & Wells, K. (2007). Strategies for academic and clinician engagement in community-participatory partnered research. *Jama*, 297(4), 407-410.
- Morris, Z. S., Wooding, S., & Grant, J. (2011). The answer is 17 years, what is the question: understanding time lags in translational research. *Journal of the Royal Society of Medicine*, 104(12), 510-520.
- Shire, S. Y., Shih, W., Chang, Y. C., & Kasari, C. (2016). Short Play and Communication Evaluation: Teachers' assessment of core social communication and play skills with young children with autism. *Autism*, 1362361316674092.
- Weisz, J. R., Donenberg, G. R., Han, S. S., & Weiss, B. (1995). Bridging the gap between laboratory and clinic in child and adolescent psychotherapy. *Journal of consulting and clinical psychology*, 63(5), 688.



Could a research-based app help ease anxiety in Autism?

By Tim Colebrook, Editorial Assistant, ACAMH

Having worked with people with autism and families to understand their priorities for funding and new research, Autistica, the UK autism research charity, are responding to their community's call for better support to manage anxiety in autism. Their overarching aim is to help build long, healthy, happy lives for every person with autism.

One of the top ten questions to emerge from their recent James Lind Alliance Priority Setting Partnership (2016)¹ was about interventions that could help reduce anxiety in people with autism. In 2008 a study by Professor Emily Simonoff² found that anxiety disorders affect 41.9% of children with autism, and whilst there are a broad range of self-help programmes and therapies for anxiety symptoms already available, these often require further research to ensure that they are appropriate to the needs of a person with autism¹. Indeed, the need for interventions that have either been scientifically shown to work for people with autism or adapted to address the specific

needs of people with autism was the foremost concern of those involved in the Priority Setting Partnership¹.

In order to try and meet this need, Autistica have partnered with Emily Simonoff, Equaleyes, Zobi-Wan and a developer with autism, from IT company Auticon to develop Molehill Mountain, a new smartphone app. The app, due for release this summer, draws upon autism-specific research with the goal to help people with autism better come to understand and manage their own anxiety.

Molehill Mountain is one part of a digital learning package aimed at young people with autism who struggle with anxiety. The package includes an email course, supporting web content and a community of peer support on social media, all intended to provide the user with the knowledge, confidence and skills to understand and self-manage the causes and symptoms of their own, very personal anxieties. It works by allowing the user to track their worries and how they are feeling through a quick daily check-in and activity,

which then unlocks a daily tip about anxiety and autism. At each check-in the user can track their progress up Molehill Mountain and review their journey via a personal dashboard, the idea being that children with autism can learn to identify the situations which trigger their anxiety and develop ways to respond*.

Autistica have been developing the app with an insight team of young people with autism who have shared their experiences of anxiety and apps in order to develop and test an app that is not just user-friendly, but also relevant, engaging and easy to use.

It remains to be seen how useful Molehill Mountain will be to help young people to manage their anxiety, Autistica will continue to carry out research into assessing the app's impact once it is launched. There is a need for effective, evidence-based, autism-specific interventions and tools to help people with autism and their families to deal with anxiety^{1,2}; embracing tech could provide some accessible solutions.

*For more information on Autistica and Molehill Mountain, please visit www.autistica.org.uk.

¹This PSP was a partnership of Autistica, The National Autistic Society, Autism Alliance and the Autism Research Trust: <https://www.autistica.org.uk/downloads/files/Autism-Top-10-Your-Priorities-for-Autism-Research.pdf>

²Simonoff, E. et al., (2008) Psychiatric disorders in children with ASD: prevalence, comorbidity and associated factors in a population-derived sample. *Journal of the American Academy of CaAP*. 47, 8, 921.

