TIME FOR AUTISM

FAMILY NEWSLETTER 2024-2025

Welcome, Time for Autism Families!

As we begin the 2024-2025 academic year, we're excited to share the latest updates to the Time for Autism (TfA) programme at Brighton and Sussex Medical School (BSMS).



INTRODUCING OUR OFFICIAL AMBASSADOR: DAVID BURNS MBE

We are delighted to welcome David Burns MBE as the official Ambassador for TfA.

David is a published author about autism and provides his advocacy and work in education, employment, and healthcare, particularly supporting families of autistic



children. David also delivers lectures about autism at the University of Winchester to undergraduate primary school teachers as part of their mandatory autism module. He is a senior sponsor of the Cross Government Autism Network in the Civil Service.



David's invaluable contributions to TfA, based on his lived experience with autism and healthcare, have shaped the programme since its inception. This year, David continues to play a pivotal role, participating in our teaching sessions, conferences, and the TfA Review Group.



IN THIS EDITION

NEW TFA AMBASSDOR

STUDENT PREPARATION SESSION

NEW FAMILIES

ANNUAL TFA CONFERENCE

STUDENT REPRESENTATIVES

FAMILY RECRUITMENT

EXCITING NEW OPPORTUNITY FOR TFA

KEEPING IN TOUCH WITH TFA FAMILIES

USEFUL LINKS & FURTHER READING

KEY DATES

VISIT 2 WINDOW:

6th Jan '25 - 10th Mar '25

VISIT 3 WINDOW:

7TH APR '25 - 6TH JUN '25

HEALTH PASSPORT

THIS WILL BE RETURNED TO FAMILIES BY THE END OF AUGUST 2025

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ENHANCED STUDENT PREPARATION SEP '24



This year, we extended our student teaching sessions, adding more time for interactive activities and expert-led discussions:

Dr Ann White - TfA Academic Lead / Consultant Community Paediatrician and **Alison Smith -**TfA Development Manager/ Highly Specialist Speech and Language Therapist at SCFT offered a deep dive into autism diagnosis and diverse presentations. Topics included:

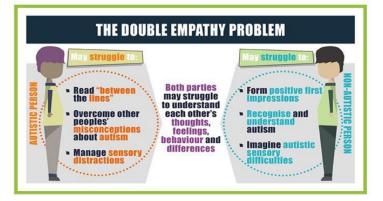
- Why autism education?
- What is autism?
- Context and terminology
- DSM criteria for ASD (ASC)
- Prevalence and causes
- How autism presents in primary care and paediatric teams

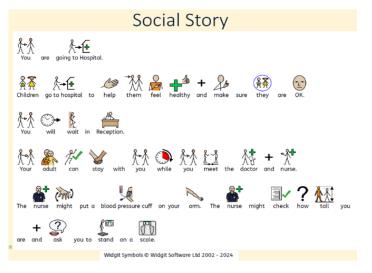
Alison Smith - TfA Development Manager & Highly Specialist Speech and Language Therapist at SCFT inspired students with practical communication strategies, help students feel more confident when they communicate with an autistic person and described methods of communication including discussions around Monotropism, Double Empathy, AAC and the use of sign language and Makaton.

Jane Epthorp - Specialist Nurse at Sussex Community NHS Foundation Trust provided a unique perspective on preparing personalised care plans for autistic children and the use of social stories to assist them to attend clinical appointments.

David Burns MBE shared his personal insights on autism and healthcare.

- Social communication
- Autism in girls
- Autism and co-occurring conditions
- Celebrating neurodiversity
- Purpose of TfA and learning outcomes
- Overview of the TfA programme
- Q&A Session





WELCOMING NEW FAMILIES

At the start of the year, new families joined an online welcome session hosted by Alison Smith and Francesca Rigby. Fleur Tindal, an existing TfA family member and part of the TfA Review Group, shared advice on what to expect during student visits. This was the first new family meeting, and it was a lovely event to share life stories and meet the other families involved. Alison and Francesca are keen to continue to run this event each year and welcome any thoughts on how to develop this further.

Annual TfA Conference 2025

Celebrating Success and Building Community

On January 9th, 2025, we hosted the TfA Annual Conference at the University of Sussex. This event brought together over 40 families, students, clinicians, and researchers to discuss autism in adulthood and evolving perspectives. A copy of the presentation is attached in your email along with some further reading suggestions from our guest speakers.



Highlights Included:

Speaker presentations from David Burns MBE, Professor Bobbie Farsides, Dr Sophie Anns, Dr Gemma Williams, Dr Jess Eccles and Simon Smith.

Workshops encouraging reflection on TfA learning and autism care.

"I felt like my lived experience was valued and that I'd been able to give them real insight. It felt like a genuine opportunity to effect change in the system."

TfA Family Member

"The small group discussion really helped me understand the reallife implications of being neurodivergent." Year 4 BSMS Student

"I think it's definitely really good to actually go and see the family, because I think in a lecture you're not going to get the same insight." Year 4 BSMS Student

Feedback from the conference

"I think it makes you realise that you don't... you won't ever know what to do with a specific person until you ask them, or ask their family, and have a conversation and find out what works for them." Year 4 BSMS Student

"An amazing & informative day" Year 4 BSMS Student "Listening to the doctors speaking about their research. This often isn't what parents hear about and it's good to know what is happening in the medical profession behind the scenes." TfA Family Member

Meet your Cohort 4 TfA Student Representatives









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Charlotte Rose, Maz Keen, Joy Keenan, Georgia Laco, and returning Year 5 representative Mo Shahin will represent the student body this year. Their voices will ensure that feedback, ideas, and concerns are heard and addressed effectively at regular team meetings and the TfA Review Group Meeting.

FAMILY RECRUITMENT

We continue to be thrilled and humbled by the response of local families who are willing to give up their time to teach our students. Alison has recently enrolled the 196th family into the programme and already has 6 new families waiting to be enrolled.

We are always keen to hear from new families, and we are actively engaging in family recruitment initiatives and expanding our support network. Your referrals and connections are invaluable in reaching out to families who can help with our programme. Alison is actively driving recruitment forward, so if you know of anyone who would be interested in joining, please get in touch today.

Could you help future doctors learn about autism?



bsms.ac.uk/timeforautism

EXPLORING AN EXCITING NEW OPPORTUNITY FOR TFA



The TfA team has been in discussions about the exciting possibility of adapting the TfA programme for Education and Social Work students at University of Sussex. There has been significant interest in this initiative, and a small working group has been formed to explore potential funding streams for a pilot project.

While this project is still in its early stages, we are eager to see how it develops and will keep you updated with any new developments on this promising opportunity!

KEEPING IN TOUCH WITH THE TFA FAMILIES

At TfA, we value staying connected with our families throughout the year. Based on your feedback, we're introducing new ways for you to share your thoughts, ask questions, and catch up with us.

This year, Francesca will be leading our family engagement efforts and will be contacting you soon. You'll have the option to:



Join a group feedback session on Teams on Thursday 13th March at 8pm

The group feedback session has been created in response to requests from families for a dedicated space to connect and discuss their experiences. These sessions will provide an opportunity to share feedback from your visits with students and engage with other families in the programme.

We look forward to hearing from you and continuing to build a supportive community together! Look out for Francesca's email with more details, or alternatively, click on your preferred option above to book in.

Thank You

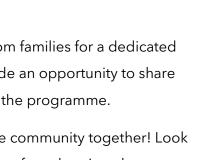
Together, we're shaping a future of compassionate, informed autism care.

Warm regards,

The Time for Autism Team

Dr Stephanie Daley, Dr Ann White, Alison Smith, Francesca Rigby & Rosie Mulgrue





Local Support Groups, Coffee Mornings, Groups and Clubs:

Parent support groups and befriending



Amaze run regular, informal support groups across Brighton & Hove and East Sussex for parents of children and young people with special educational needs and disabilities (SEND). They also offer one-to-one befriending for those parents who need more individual support. For more information visit their website or view the Parent Carer support

groups page at Parent carer support groups - Amaze Sussex

https://amazesussex.org.uk/



mASCot is a support network for parents with autistic children, whatever age your child is. You can join mASCot from the point of recognising your child may be autistic, when they have a full diagnosis or if they are on the diagnostic pathway.

By becoming a member of mASCot, you will be part of their amazing support network and have access to all the things they do. <u>https://www.asc-mascot.com</u>

Being a full member includes:

- access to the private members only Facebook group
- ability to join any of the clubs and groups
- attend mASCot coffee mornings, workshops and talks
- become part of their Skill Exchange
- access to 1-1 sessions
- become part of a collective voice when feeding back to services
- access to resources and information
- and much more......

USEFUL LINKS & FURTHER READING

Other useful links:

Reaching families: <u>https://www.reachingfamilies.org.uk/</u>

East Sussex Parent Carer Forum: https://www.espcf.org.uk/

West Sussex Parent Carer Forum: <u>https://westsussex.local-offer.org/services/195-west-sussex-parent-carer-forum</u>

The Autism Community Research Network Sussex (ACoRNS): <u>https://www.acorns-sussex.org.uk/</u>

Autism Central https://www.autismcentral.org.uk

Further reading and resources:

Oliver McGowan Mandatory Training on Learning disability and Autism:

https://www.hee.nhs.uk/our-work/learning-disability/current-projects/oliver-mcgowan-mandatorytraining-learning-disability-autism

Pulse - The Brighton and Sussex Medical School Magazine (bsms.ac.uk) Celebrating 20 years of BSMS:

https://www.bsms.ac.uk/about/news/pulse-magazine/index.aspx