Reducing unnecessary CAMHS inpatient admissions for Autistic children and young people

The National & Specialist CAMHS Autism & Intellectual Disabilities Intensive Intervention Team (AID-IIT)
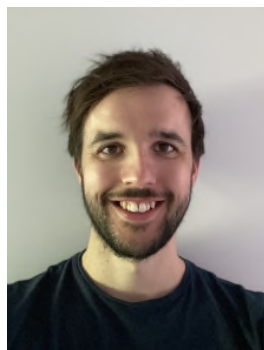
Dr Catherine Sholl

Consultant Clinical Psychologist and Team Lead

NAS Conference 2023

Meet the team

Changing Lives

NHS
South London and Maudsley
NHS Foundation Trust

Dr Catherine Sholl
Consultant Clinical Psychologist

Dr Dominic Wrein
Senior Clinical Psychologist

Dr Georgina Barnes
Senior Clinical Psychologist

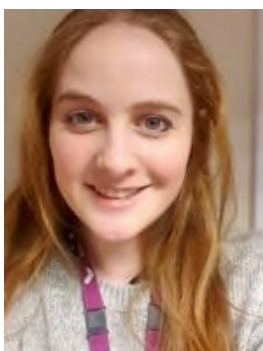**Dr Marinos Kyriakopoulos**
Consultant Psychiatrist

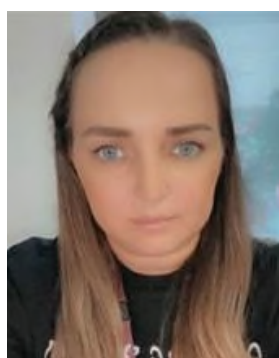**Dr Laura Wilby**
Senior Educational Psychologist

Scott O'Hare
Clinical Nurse Specialist

Millie Pittam
Speech & Language Therapist

Sarah Gilbert
Occupational Therapist

Rachel Isaku
Occupational Therapist

Jess Gash
Trainee Counselling Psychologist

Emma Jewitt
Assistant Psychologist

Tharaney Puvanachandran
Assistant Psychologist

Becca Kingston
Admin & Assistant Psychologist

What is AID-IIT?

- Tier 4 N&S outpatient CAMHS Team.
- Based at the Maudsley working closely with other N&S teams e.g. the SCAAND.
- Cover all London Boroughs.
- Co-work with local and inpatient CAMHS.
- Funded by NHS England.
- Work with young people both in the community and in inpatient settings to improve support.

What is AID-IIT?

Our core aims for autistic young people and young people with an intellectual disability

Reduce or **prevent unnecessary** inpatient admissions

Support young people to live sustainably in the **community**

Support to make unavoidable inpatient admissions as **useful as possible**, and support successful and timely **transition back** to the community

Why AID-IIT?

Autism, ID and Mental Health

Increased risk of mental health problems for autistic people
- As many as 7 in 10 autistic people may have a diagnosable mental health problem such as anxiety, depression or OCD (Autistica)

Increased risk of mental health problems for people with ID
- Well documented in research
- Rate of mental health problems up to double that of typical population (Cooper, 2007; Emerson & Hatton, 2007; NICE, 2016)
- Between 15-52% prevalence (Cooper *et al.,* 2007; Emerson & Hatton, 2007; Hatton *et al.* 2017; McCarron *et al.* 2017)

Why AID-IIT?

Autism, self-harm, and suicidality in the literature

Autistica summary of the research:
- Around 1 in 100 people in the UK have a diagnosis of autism
- Autistic adults are 9 times **more likely to die from suicide**
- **Autistic teenagers are 28 times more likely to think about or attempt suicide.**

Maddox et al (2016)
- **Young adults with autism are much more likely to self-harm than the general population, even more common in autistic women**
- Variety of factors likely to contribute to this increased risk e.g.:
  - Difficulty expressing emotions and masking
  - More likely to experience adverse events/relationships (being misunderstood in a 'neurotypical world')
  - More likely to not receive or struggle to access the right help.

Blanchard et al (2021)
- **Meta-analysis found autistic children and adults have increased risk for self-harm and suicidality**

Why AID-IIT?

A response to the need to improve community support

- **Transforming Care (now LDA programme)** aimed to end over-reliance on hospital admissions for people with a diagnosis of LD or Autism and improve community support.

- **Lack of progress** post-Winterbourne View abuse scandal investigation (Cooper, 2021/2)

- Continued **inappropriate admission and over-use of** mental health hospitals, and a need for more robust community support.

- Hospital reported by many Autistic young people and their parents as a **negative, rather than helpful, experience** (Childrens Commissioner report, 2019)

Why AID-IIT?

Changing Lives

NHS South London and Maudsley NHS Foundation Trust

Abuse Scandals

20+ years

National Responses

"Cruel, callous, and degrading"

"Never again!"

- Valuing People (2001) & Valuing People Now (2009)
- Mansell report revised (2007)
- Aiming High for Disabled Children (2007)
- Exposures of abuse e.g.,
  - Winterbourne View (2011)
  - Whorlton Hall (2019)
  - Cawston Park (2021)
- Transforming Care: A national response to Winterbourne View Hospital (2012)

- Building the Right Support (2015)
- STOMP/STAMP (2016)
- Lenehan & Geraghty (2017)
- NHS long term plan (2019)
- Children's Commissioner Report (2019)
- NHS England Learning Disability and Autism (LDA) Programme (ongoing)
- Building the Right Support (2022)

What does good community support look like?

Mansell et al (2007) principles for good community-based services...

- Being **person-centred,** tailored to the individual's needs, wishes and aspirations and flexible in adapting support over time.

- Being **supportive to the person, their family and wider network** augmenting resources rather than disrupting or displacing them.

- **Adopting a social model of disability** - recognising that the experience of impairment is mediated by social structures and processes and addressing these.

- **Taking a holistic approach** - addressing all of people's lives. Not pretending people can manage without extra help, but providing the support needed to overcome the effect of impairment and disability to enable people to have a good quality of life.

What can AID-IIT do?

AID-IIT support depends on the needs of the young person, family, and their professional network

- AID-IIT **works in addition to local and/or inpatient CAMHS services** (not instead of). Aiming to add to and not replace existing services.
- Offers short term (e.g. 4 to 12 months) additional input and expertise, but expects/**advocates for a robust longer term local community care plan.**
- **Local teams continue to manage day-to-day risk** and providing treatment as usual
- This allows AID-IIT to work with the network/YP/family to help them better **understand the young person in the context of LD/ASD** and how to tailor approaches/community support to better meet their and their family/carer's needs.
- Brings an **additional set of expertise and 'fresh pair of eyes'** to complex situations.
- **Supports the network and family in addition to the young person.**

12

What can AID-IIT do?

AID-IIT support is bespoke depending on need but can include…

Consultation and advice

MDT interventions

Out-reach, and in-reach support

Professional & network meeting attendance

Parent/carer support

Training

MDT and 2nd opinion assessments

Advice on schooling and provision

What can AID-IIT do?

Changing Lives

NHS South London and Maudsley NHS Foundation Trust

Overview of the AID-IIT intervention process

Network/system support

- Consultation always offered as 1st step
- Within 1-2 weeks
- Familiarise with network
- Bring together
- Encourage LD/ASD informed thinking

Bespoke MDT package

- Clinical psychology & psychiatry led initial assessments
- Formulation driven
- Intervention and/or further assessment from multiple MDT disciplines
- Adapted intervention for YP/family needs

Outreach work

- See the young person where they need to be seen
- Family home
- Ward
- CAMHS clinic
- School
- Residential home

Close joint working

- Regular liaison with local and inpatient staff throughout
- Planned step-down when stable / more effectively managed locally

AID-IIT assessment

- A detailed assessment of the **young person's mental health needs and presenting difficulties in the wider context of their diagnosis of ASD or ID.** Info gathered from the young person, parents/carers and professional network to gather information **aiming to get a clearer formulation including understanding how they ended up in inpatient care/at high risk of admission, and how to prevent this in the future.**
    - **Family and social history**
    - **Developmental history**
    - **Educational History**
    - **Cognitive and neurodevelopmental needs**
    - **Mental health history and current presentation/difficulties**
    - **Risk assessment**
    - **Protective Factors**
    - **Goals and hopes**
- Leading to a collaborative and detailed **formulation considering Predisposing, Precipitating, Perpetuating and Protective Factors**, and **clear multi-agency recommendations for support**

15

AID-IIT Interventions

- A **bespoke and multi-agency approach to intervention**, working closely with the existing local multi-agency network (and advocating for more local support where needed).

- AID-IIT may then **offer interventions in additional to a robust local plan** which may draw on/utilise:
  - **Outreach approach, flexible approach** with additional time spent building trust and rapport.
  - Attachment and **trauma informed** working
  - **Psycho-education** about Autism for young people, parents and networks
  - **Parent/carer support and interventions** – drawing upon e.g. Positive Behaviour Support (PBS), Non Violent Resistance (NVR)
  - **Adapted psychological therapies** – CBT, DBT, ACT…incorporating interests and working creatively!
  - **Occupational Therapy**
  - **Speech and Language Therapy**
  - **Medical and Medication advice**/consultation to local or inpatient professionals
  - **Education advice and support**.

16

Who do AID-IIT see?

Summary of clinical caseload June 2020 – March 2022

Tend to be older adolescents and female

Largely diagnosis of autism without intellectual disability

Repeated self-harm and suicide attempts (incl. restrictive eating)

Significant challenging behaviour also present, some psychosis

Admission had typically already occurred, this is changing to more proactive referrals

Community referrals usually on background of multiple previous admissions

Demographic information

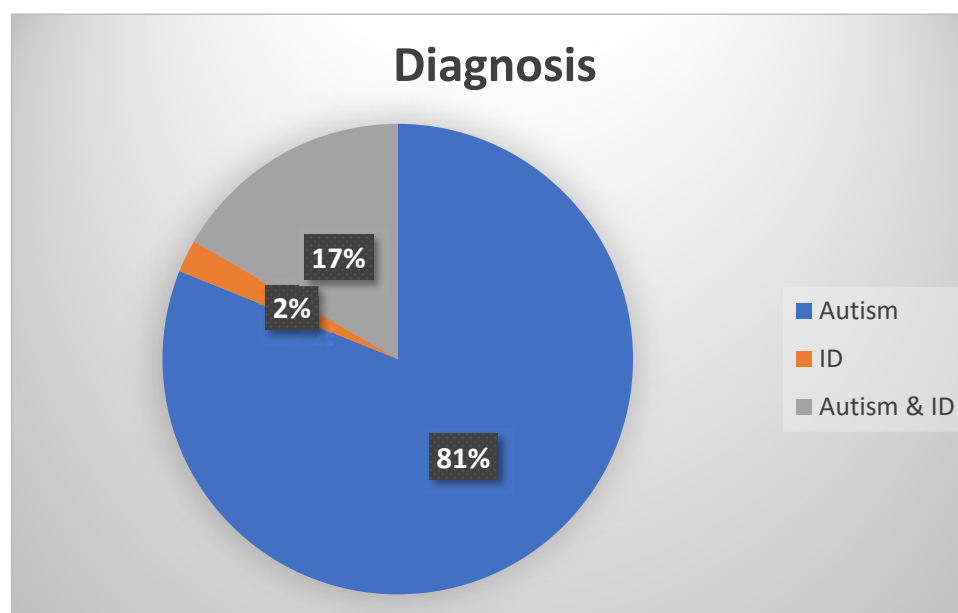## 90 young people accepted for input by AID-IIT June 2020-March 2022

Gender

- Female — 61%
- Male — 30%
- Transgender — 9%
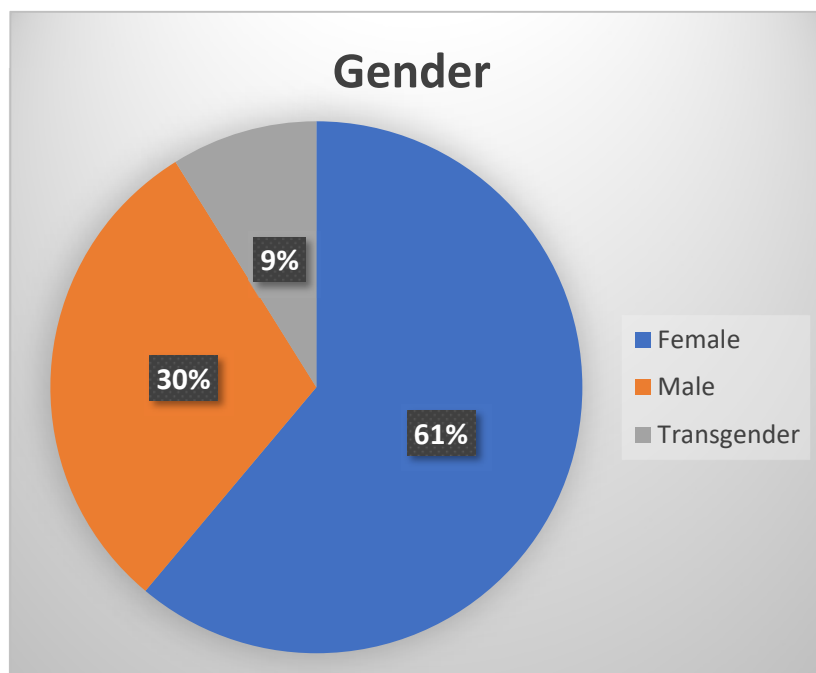
Average age was 14.9 years old (range 10-18 years old)

Diagnosis

- Autism — 81%
- ID — 2%
- Autism & ID — 17%

Demographic information

90 young people accepted for input by AID-IIT June 2020-March 2022

Ethnicity
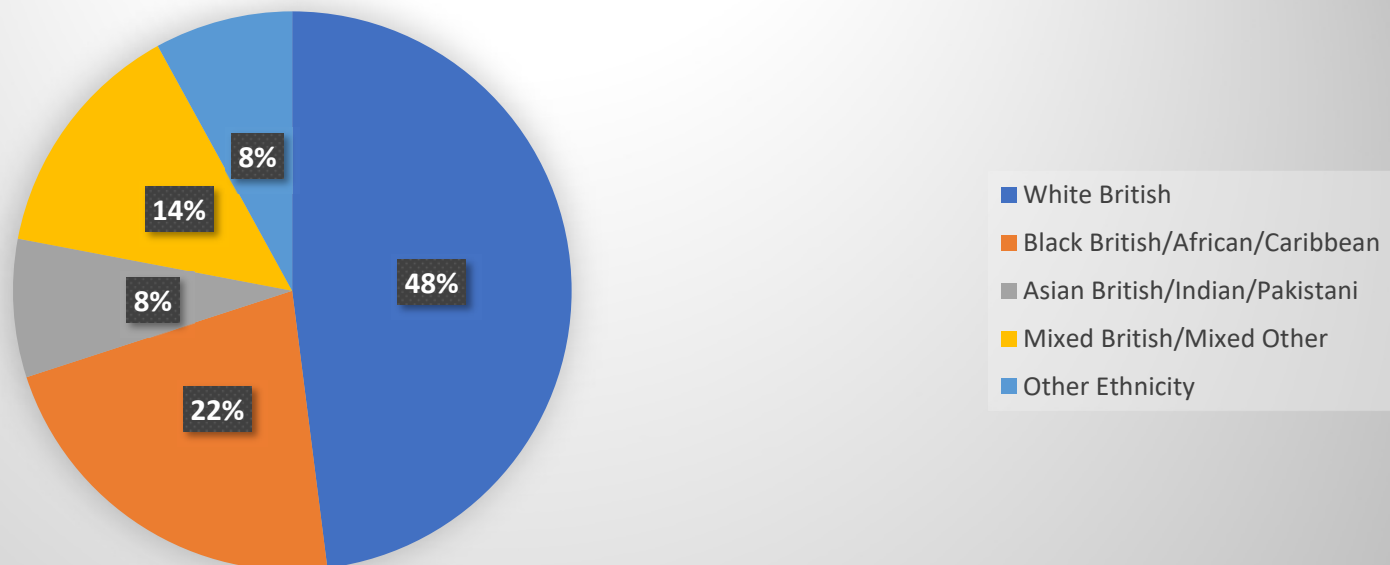
Pie chart segments:
- White British: 48%
- Black British/African/Caribbean: 22%
- Asian British/Indian/Pakistani: 8%
- Mixed British/Mixed Other: 14%
- Other Ethnicity: 8%

90 young people accepted for input by AID-IIT June 2020-March 2022

Reason for risk of admission

- 58%
- 21%
- 7%
- 7%
- 7%

Legend:
- Self harm/suicide attempt
- Challenging behaviour
- Eating disorder
- Anxiety/low mood/withdrawal
- Psychosis
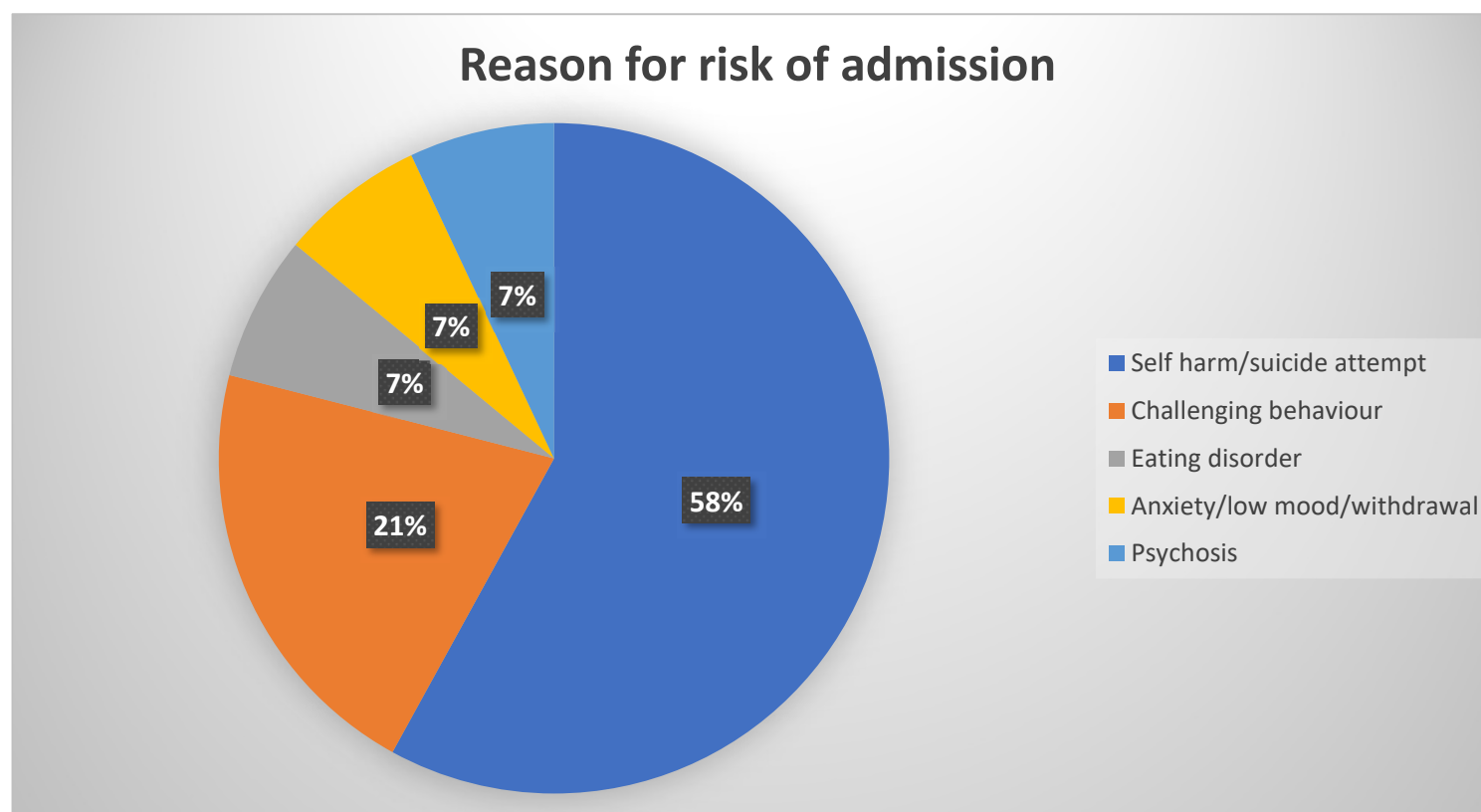
Admissions avoided and discharges supported

For the young people we started seeing between June20 & March22:

90 new referrals accepted: 55 inpatients and 35 in community at imminent risk of admission.

Preventing admissions: Of the 35 referrals who were at imminent risk of admission – 6 (17%) of these still went to an inpatient setting, 29 remained in the community (**83% admissions prevented**)

Supporting discharges: Of the 55 referrals already in an inpatient setting – 52 (95%) were discharged into a family home or placement, and 3 (5%) remained in inpatient settings (**95% supported to be discharged**).

Measuring outcomes

Evaluation and outcome monitoring…results are in publication:

Quantitative feedback:
Location of YP at referral and discharge (inpatient unit, family home or placement)

T1 and T2 ROMS:
Children's Global Assessment Scale (CGAS) – significant change
Sheffield Learning Disabilities Outcome Measure (SLDOM) – significant change
Strengths and Difficulties Questionnaire (SDQ)
Revised Children's Anxiety and Depression Scale (RCADS)

CHI-Experience of Service Questionnaire

Qualitative feedback:

From professionals, families and young people

How have AID-IIT done?

Family and professional experience of service

"Thank you everyone for such passion and thoughtfulness on a complex case. Really helps with our capacity to attempt containment." (professional)

"…I appreciate how much you have helped me over the past months. I honestly would not be where I am now if it wasn't for you! I found your organization really useful, and I loved how you incorporated my hyper-fixations into sessions." (young person)

"As a family, our lives have changed beyond all recognition. X [young person] still requires a lot of support, prompting, structure and routine in his life but he now see that he has a life worth living and is no longer trying to end his…..[AID-IIT staff] saved X's life and I cannot thank you enough for having this specialist service." (parent)

What do AID-IIT think?

Next steps and reflections so far

Strengths:

- Promising early outcomes and feedback
- Larger number of referrals accepted
- Co-working and strong links with local & inpatient CAMHS, brings additional expertise to system
- Links with charity sector (NAS, CBF, FPLD) and PPI
- Clearer care pathway & bespoke model of support
- Collecting evaluation data and publishing

Challenges and next steps

- Continuing to manage clinical demand while working intensively
- Impact of COVID and cost of living on CYP
- Local CAMHS overwhelmed/lack of neurodevelopmental teams and expertise
- More training/support to other services to improve community support
- Better development of interventions for Autistic people for suicidality/self harm
- Dissemination and publication

Thank you for listening
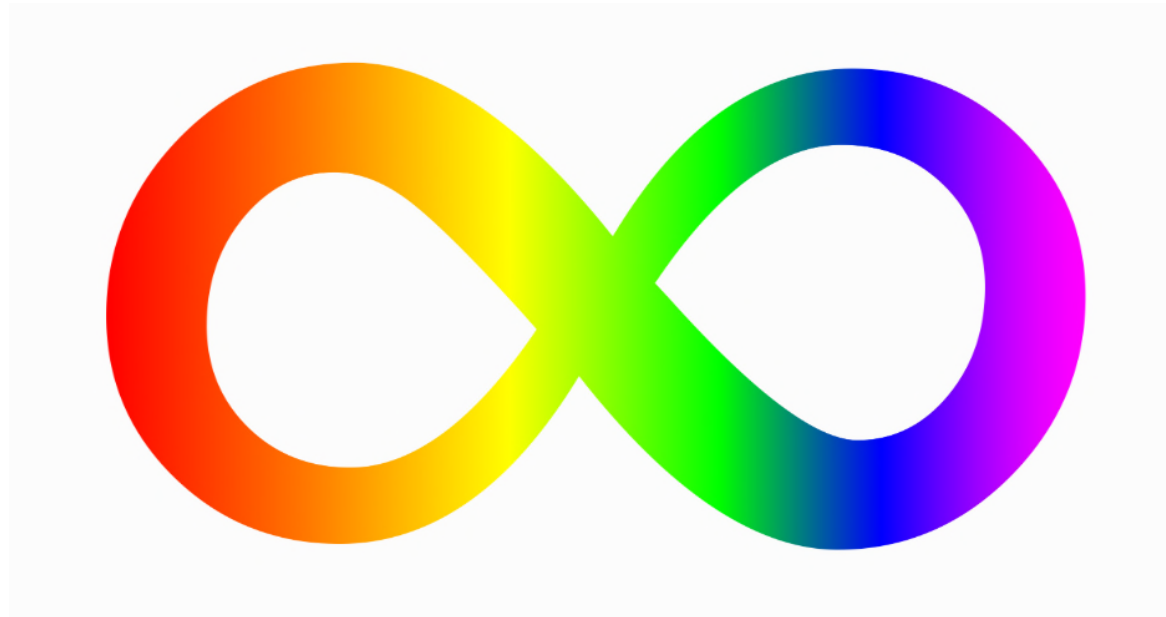
Contact details:

For more information please contact:

AIDIIT@slam.nhs.uk

Dr Catherine Sholl, Consultant Clinical Psychologist and Team Lead

Catherine.Sholl@slam.nhs.uk