

Supporting Young People with a Diagnosis of Intellectual Disability or Autism at High Risk of Inpatient Admission – Early Outcomes from the National and Specialist CAMHS Autism and Intellectual Disabilities Intensive Intervention Team (AID-IIT)

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1. Service Context

- The **co-occurrence of mental health problems for young people with an Intellectual Disability (ID) and Autism** has increasingly become well-documented as well as an **increased suicide risk** in this population¹²³⁴⁵
- Transforming Care⁶** aimed to end **over-reliance on inpatient settings and a lack of effective community support for young people with an ID and Autism**.
- Review by Cooper⁷ **criticised the lack of progress** since the post-Winterbourne View investigation, which **led to the development of AID-IIT**.
- AID-IIT aims to offer a **short-term bespoke package of care** in addition to local and/or inpatient services to ensure young people and families are receiving robust support that meets all aspects of a complex neurodevelopmental presentation, in order to **reduce unnecessary or overly lengthy CAMHS inpatient admissions**.

2. Service Model

Multi-disciplinary team (MDT):

- Psychiatry, Clinical/Counselling Psychology, Occupational Therapy, Speech & Language Therapy, Specialist Nursing, and Educational Psychology.

Intervention Process:

- Network support:** Consultation with the professional network to learn about the young person, support the local network and advocate for robust local multi-agency community support in addition to AID-IIT if this is not in place.
- Bespoke MDT assessment:** A formulation-driven clinical psychology and psychiatry-led initial assessment takes place. This may lead onto further assessment and/or intervention from multiple disciplines.
- Outreach intervention:** AID-IIT travel to the young person wherever they need to be seen (e.g. family home, inpatient unit, community settings).
- Joint working with parents/carers and local network throughout:** Parent/carer and local network support and collaboration to improve multi-agency care, so the young person is effectively supported by their parents/carers and local services once AID-IIT input ends.

3. Demographics: June 2020 – March 2022

90 accepted referrals (55 inpatients and 35 in the community):

- All were at **imminent risk of admission or already admitted to an inpatient unit**: self-harm/suicide attempt (58%), challenging behaviour (21%), eating disorder (7%), anxiety/low mood/withdrawal (7%), psychosis (7%).
- Average age was **14.9 years old**
- Population were **largely females** (61%), 30% male and 9% transgender.
- 81% diagnosis of Autism, 2% diagnosis of an ID and 17% had both ID and Autism**

4. Findings

- 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**).
- Pre and Post Intervention Outcome Measures:** Pre and post CGAS scores were completed for all 90 young people. Paired measures data was also available on the SLDOM for 20 cases.
 - CGAS: This difference was found to be statistically significant ($z = 6.85, p < .001$). A large effect size (0.51) was found for the change in raw scores on the CGAS, as rated by clinicians. These results suggest that **young people’s global functioning had improved following intervention**.
 - SLDOM: This difference was found to be statistically significant ($z = -3.36, p < .001$). A large effect size (0.53) was found for the change on total SLDOM scores, as rated by parents. These findings show that **parental self-efficacy and knowledge/understanding of their child’s needs had increased after direct input from AID-IIT**.



5. Qualitative Feedback

“...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[s] 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)

6. Reflections

Strengths

- Promising early outcomes and feedback
- Large number of referrals accepted
- Co-working and strong links with parents/carers and with local and inpatient CAMHS teams and other services
- Links with charity sector (e.g. NAS, CBF, FPLD) and service user involvement
- Clear care pathway and bespoke model of support
- Robust service evaluation and publication of outcomes

Challenges and next steps needed

- Local and national picture of fewer referrals of young people with ID vs Autism – improvement of care? Or are these young people ending up elsewhere (e.g. residential care)?
- Impact of COVID, cost of living
- Local CAMHS, social care, education over-stretched/under-resourced
- More specialist training needed to other community services
- Better development of interventions for this cohort of young people
- Publication and dissemination of the AID-IIT model and outcomes

7. References

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