CB-NSG Nov 2021

PM Workshop 2: *National and Specialist CAMHS Autism and Intellectual Disabilities Intensive Intervention Team (AID-IIT)*

Workshop facilitators: Dr Catherine Sholl, Consultant Clinical Psychologist and Team Lead, AID-IIT, Maisie Krisson (Assistant Psychologist), Linda Hume (CBF)

The aim of the workshop was to gather the CB-NSG's feedback, ideas and opinions to support the development of the AID-IIT service.

Workshop objectives:

• To get ideas, opinions, feedback and critiques from the CB-NSG members to help develop the service to best support young people and families.

• To hear about members' own personal and professional experiences of children and young people with learning disabilities or autism in CAMHS inpatient units (or at risk of a CAMHS inpatient admission) – what helped in this situation or what could have been done differently to support your child/young person?

Despite a wealth of policy and guidance illustrating that inpatient admissions can be unhelpful and at times traumatic for children and young people with learning disabilities and autism, a lack of progress has been made in offering effective community support and alternatives to inpatient care. The AID-IIT service was developed in the context of a lack of progress being made under the Transforming Care Agenda for children and young people with learning disabilities or autism.

AID-IIT is a new service funded by NHS England covering the London region. The aim of the service is to support young people, families and local services to reduce unnecessary CAMHS inpatient admissions for young people with Learning Disability or Autism, and to support successful and timely discharges to the community for those who have already been admitted to inpatient units.

Workshop discussion:

Dr Sholl and workshop attendees discussed the AID-IIT service in boroughs across London.

Firstly, Dr Sholl stated that local, rather than national, offers should be made to AID-IIT as certain boroughs offer greater levels of support and may need to make fewer referrals to the AID-IIT. The AID-IIT service will improve specialist learning disability and intensive support for each area. The difficulty faced has been encouraging local areas to use the AID-IIT service. Where commissioners have identified gaps in the services, the AID-IIT must walk a fine line between recommending that their service is used without criticising the borough, so that they return to AID-IIT in the future. Some boroughs have good early support pathway, whilst there is a 'black hole' of services in others, which require further development before they contact AID-IIT. Sometimes, attendees witness a young person in hospital that would not have been admitted, had they lived in another borough.

Ideally, data from feedback collected by the AID-IIT service would contribute to mapping of learning disabilities, autism and specialist services provided by local authorities across the country. The group agreed that there is a 'postcode lottery', as to whether someone's local authority has learning disability services (such as a community learning disability team), and whether the services are of a good quality. Currently, there is not a 'formal' feedback process amongst provider collaboratives, NHSE and the AID-IIT service to contribute to this data.

The group agreed that once someone is referred to an intensive support team, there needs to be a dialogue opened – amongst family and professionals – on what care decisions need to be made for the future, so that the person is not forced to rely on the intensive support service to keep them safe. In additional, parents often do not receive training in Positive Behavioural Support or psychological therapies, and as a result they must rely on the specialist services from the intensive support team. Parents also often need to fight to obtain good quality care for their children, and as a result the local authority perceives them as 'challenging' and relationships are damaged. Dr Sholl recognised that it is not the role of the AID-IIT to repair damaged relationships between parents and social services – this is up to local authorities. AID-IIT are in a privileged position as they are seen as separate from local services, because they work across London. As a result, the team has better relationships with parents and families.

The group heard that, at crisis level interventions, tiers 1 and 2 are not getting the same support that 3 and 4 receive. Work also needs to be done to unite professionals and families, to identify key issues prior to crisis-point. An 'external manager' to a case may be useful, to improve relationships and 'speak openly' about an individual's care needs and wishes. Families have often been through 'many layers of the system' and not achieved the outcomes they wanted for their children, and may feel exhausted and let down by services at crisis-point. Services, and early intervention and support, must be developed so that families do not have to rely on reactive crisis services like AID-IIT. By the time young people and their families reach AID-IIT, and/or have experienced hospital admission, many have been traumatised. Services should offer to visit people wherever they feel comfortable (Covid-permitting), and not rely on online meetings. Families often do not know about AID-IIT, without a CAHMS referral, so it can take a while before the young person comes into contact with AID-IIT.

Dr Sholl suggested that the AID-IIT are not getting it 'quite right' in deciding which referrals to take on. Many families and children/young people require support but do not meet the threshold of crisis intervention. Accepting cases is a difficult process as the AID-IIT has experiences of rejecting cases and the individual was later admitted. It is also easier to become involved in someone's case when they have already been admitted to hospital.

It varies from area to area how much of what the AID-IIT recommends for an individual is put into a package by their local authority. The CTR process is helpful as it coincides with someone being at high risk of admission, and during the review useful ideas are often put forward on how to avoid admission. It is more of a challenge for the AID-IIT to support young people when there is no CTR or the CTR is unproductive. CAHMS support is also often not of a great quality, with clinicians not understanding the needs of the person and their family.

Schools can also be a barrier to improving someone's care and wellbeing. Schools are often anxious to about young people returning to school, who had been at risk of being admitted to an inpatient unit, and so they decide that the person should not return until their mental health improves. However, returning to school with reasonable adjustments may be essential to their mental health improving. The AID-IIT does not usually connect with schools of young people they are supporting, but if they do it will be with the SENCo, mental health lead and/or headteacher.

Finally, the AID-IIT is attempting to achieve sufficient status to be considered of referred to before every CTR, by NHSE.

Actions:

Action	How will it be done?	Who will do it?	When will it be done?
Local Authorities to create a feedback loop re. service provision (or lack of)	I.e., where outcomes cannot be met due to lack of services/structure/training/being robust enough	Contact Catherine Sholl/ Maisie Krisson and ADASS?	
Develop formal evaluation of intensive support teams	Need quantitative and qualitative data, feedback to NHSE regularly. Develop a performance mark? Commissioners/clinicians to decide if they want/need to commit to the evaluation model. We can then produce mapping of what is needed and where. Use this project to share nationally, it will also provide evidence of the need for such teams (sharing best practice).	Catherine Sholl (to work with Phil Boulter)? Co-ordinating with CBNSG to produce what needs to be in the evaluation/ mark (involving families)	