

Case study: Sheffield ADHD transitions

Summary

South East Sheffield is a socially deprived area of Sheffield. The area includes a number of different communities from former mining communities to large BME communities. An Attention deficit hyperactivity disorder (ADHD) Transition Clinic and a Transition Patient Group 'Living with ADHD' are currently being piloted, working with 16-25 year olds. Their aim is to facilitate a smooth transition for young people into adult services so improving the care of young people with significant needs as a result of ADHD. The Clinic involves Child and Adolescent Mental Health Services (CAMHS) - part of Sheffield Children's Foundation Trust (SCT), and Adult Mental Health Services (AMHS) - part of Sheffield Health and Social Care Foundation Trust (SHSC) in South East Sheffield, working together.

How the service works

The service is for young people with an established diagnosis of ADHD made in childhood, who are thought to need to transition into AMHS for continuation of management of ADHD symptoms.

This group of young people and their parents/carers find the transition to adult services particularly anxiety-provoking. Parents/carers fear no longer being involved in treatment and young people are frequently reluctant to be treated by a different clinician in a different location. These anxieties can interfere with or prevent engagement with services. Young people with ADHD 'dropping out' or not engaging with adult services was previously common before the Clinic was piloted.

Transition Clinic

The Transition Clinic has been running once a month, for six months and has seen 17 patients. The Clinic provides an opportunity for the young people to meet with AMHS staff and learn a little about ADHD in adults and how adult services are organised in Sheffield. Each young person attends a single clinic meeting which can involve a number of staff, including CAMHS consultants, nurses, therapists and AMHS psychiatrists. Parents/carers also usually attend.

Following the meeting, baseline information can be entered onto the Trust record system. This includes standard assessment, diagnosis, risk profile, Health of the Nation Scale (HONOS) and a care plan, usually in the form of a letter to the GP copied to the patient. Further appointments are arranged in accordance with clinical need (a minimum of every six months if medication is being prescribed under the Shared Care Protocol).

The purpose of the Transition Clinic is to tackle the fears and anxieties that young

people may have about AMHS and to reduce the frequency of unattended appointments by young people with ADHD once they have moved to adult services. In order for GPs to continue prescribing for patients with ADHD, patients need to be reviewed by AMHS every six months, in line with the Shared Care Agreement with the PCT. The meeting is used to:

- review the patient's needs, medication, and plan transition
- introduce patients and carers to members of adult services
- provide information (including a leaflet) about adult ADHD services
- to invite young people to join the Transition Group 'Living with ADHD'.

Transition Group

The Transition Group 'Living with ADHD' is made up of clients from the Transition Clinic and other young patients with ADHD under adult services who might benefit from being offered work around psychosocial issues in ADHD. These referrals were mainly from current clients with ADHD on the caseload of clinicians within the other AMHS in Sheffield. All are 16-25 years of age. The first group has been running for eight weeks. In total the group will run for 10 weeks, for 1.5 hours, based at the local adult Community Mental Health Team (CMHT). The sessions are co-run by an occupational therapist and a social worker from the adult CMHT.

Recognising that CAMHS can often be a more parent/carer-orientated service, each session of the Transition Group focuses on specific subject areas of interest to young people, including: medication, anger management, cognitive behavioural techniques (CBT), vocation and education and the psycho-education about ADHD, including positive aspects. They also included a session with an older person with ADHD who uses services. The sessions provide the young people with an opportunity to ask questions, think about ways of developing useful strategies to cope with ADHD and ultimately learn more about their condition and treatment.

Background to project

South East Sheffield's approach to supporting service transitions for young people with ADHD has been influenced by a number of factors. In 2008, the National Institute for Clinical Guidance (NICE) guidelines encouraged a multi-disciplinary psycho-social approach to treating ADHD. These guidelines emphasised the importance of continuity in service provision, encouraging CAMHS and AMHS services to collaborate of creating a seamless care pathway. We were also motivated to improve transitions for young people following findings from Swaran Singh's 2009 work which evidenced the poor transition experience for the majority of clients from CAMHS to AMHS.

Between June 2008 and June 2009, colleagues from CAMHS and AMHS undertook an all-age, cross-Trust audit of ADHD care using NICE standards. The

audit was city-wide (population 600,000) and followed up a cohort of young people with ADHD during the period when transition would be expected to take place. They found deficiencies in the care pathway with many young people not successfully transitioning into adult services.

Prior to the pilot, the most common mechanism for clients was a final meeting with their CAMHS team followed by a discharge letter from the team asking for follow-up to be arranged by AMHS. Staff were keen to develop a more formalised and systems-based approach. Following the audit, the Transition Clinic and Transition Group were piloted in the South East of the city (population 160,000) with one CAMHS and one AMHS team.

Designing the service

The design of the pilot has been influenced by a number of factors. Staff consulted with adults who use services to discuss what services would have been useful to them during transition. The service was also shaped by discussions with the Sheffield Health and Social Care Foundation Trust (SHSC), NICE Implementation Group and the cross-city, multiagency, all-age Sheffield ADHD NICE Group (SANG), which has representation from carers and the third sector (Family Action). There was a universal view that a joint Transition Clinic meeting would be helpful to young people and their families. There was some anxiety that a large meeting would be difficult for some young people and we agreed to monitor views on this. There was agreement that provision of information to young people about ADHD would be valuable.

The views of young people with ADHD who might attend the Clinic were not involved in the initial project design. However, staff collected feedback on an ongoing basis. Staff also consulted people over 25 with ADHD who use services to ask what they thought would have been useful when they were younger and individuals were supportive of the idea of a group. As the service has developed staff also found young people's responses to the Transition Clinic to be generally positive. For example, one older person said 'The best bit was hearing from the woman with ADHD'. Another said: 'It was interesting hearing about the history of ADHD and talking about the medication'. A third commented: 'It was good watching the videos of other people with ADHD and talking about alcohol.'

Some young people said they would not want, or feel able, to join the Transition Group. This was mainly related to anxieties of mixing with others and not feeling that they had the confidence to attend. Some young people who felt the group approach was too much were offered limited individual work. For others, this approach was not thought to be appropriate at this time. Some young people were not interested in any input and were not offered anything other than routine medical follow up if they were on medication for ADHD. A number of young people have been happy to be involved and staff have been pleasantly surprised about how the Group has run.

The design of the Transition Clinic and Group has a number of potential benefits:

- A multiagency approach provides a learning opportunity for professionals. It helps services to better understand patient experiences in order to provide them with higher quality and more joined up services.
- A systematic approach to supporting transitions delivers better transitions for young people with ADHD. It is hoped that the number of appointments not attended (did not attend or DNAs) can be reduced and the necessity of GPs needing to make new referrals when systems have failed can be reduced. Previously some young people who did not successfully transition presented in crisis. It is hoped that if they have a better understanding about how adult services operate this will reduce the number of (more costly) crisis presentations.
- Transition to adulthood is a window of opportunity for helping young people to take on an active part in the management of their mental health problems. This can contribute to improved services and outcomes for young people as they develop a healthy way to relate to services.

Intended outcomes

The pilot has been developed and informed with a number of clear intended outcomes. Overall, the service aims to break down barriers for young people attending adult mental health services. This should improve the proportion of successful transitions and reduce the number of appointments that are not attended. Other intended outcomes:

- to increase knowledge and understanding of ADHD in young people approaching transition
- to reduce re-referrals or crisis presentations of young people who have not successfully transitioned into adult services
- to support young people to take an active interest in how ADHD could affect their lives (particularly in relation to college and employment)
- to introduce ADHD management strategies (medication, healthy lifestyle, CBT techniques, goal setting and planning, managing emotions)
- to increase awareness of support available in the community (including college, employment and self help groups).

Measuring impact

A number of methods are in place to measure outcomes. These will be implemented in the coming months as this new practice develops and include:

- Questionnaires and evaluation forms looking at the quality of service.
- The Weiss Functional Impairment Rating Scale - Self Report (WFIRS-S).

People using services complete this when joining the service and at the end of the Transition Group.

- Reviewing and comparing the DNA rate at adult ADHD clinics prior to introduction of the Transition Clinic.
- To repeat the cross-age ADHD audit of young people with ADHD transitioning from CAMHS to AMHS.

In addition to these methods for measuring outcomes, staff are collecting feedback from young people and their parents/carers about their experiences of the service. So far, feedback from young people and parents/carers has been positive. Attendees of the Transition Clinic have provided unanimously positive feedback both informally, and through questionnaires. Feedback from the questionnaires about the Transition Clinic showed that both young people and parents/carers:

- understood the purpose of the meeting
- thought it was useful to have a joint meeting
- felt that relevant areas were discussed
- found the leaflet and the information about the transition group useful
- felt that the meeting meant it would be easier to cope with the transfer to adult services
- did not find it too much to have a large group meeting.

Feedback around the Transition Group has been on a more informal basis. While staff had concerns that group work may be problematic, this has largely not been the case. Rather, staff have found the group-based environment to have a number of benefits, including more efficient use of resources, providing opportunities for peer support, shared problem-solving and positive modelling of behaviour.

However, a small proportion of young people offered the Transition Group were not comfortable with a group environment. There were a variety of reasons for this. Some people found it difficult to contemplate group work because of issues with confidence and anxiety. For others, it interfered with commitments at work or in education, whilst others declared an interest, but then did not attend. Most of these young people have either been referred to alternative services, or discharged. On average the Group consisted of four people, with a maximum of six attending.

Next steps

It is thought that both the Transition Clinic and Transition Group are sustainable. Based on last year's figures, South East Sheffield AMHS expect approximately 15 transition patients with ADHD per year from their local CAMHS to access the Clinic. They also have transition patients with other diagnoses such as autism,

emerging personality disorders, complex depression and obsessive compulsive disorders. (n=5). Transition patients from neuro-developmental paediatric services (n=5) per year, have not yet been included in the service development work.

Staff involved in the Transition Clinic and Group plan to extend their transitions work to these groups in the near future. In time and with appropriate supervision the team hopes this role will be shared by individuals from other teams. This will be underpinned by a new joint Trust Transition Protocol across the city. SHSC Trust is currently supporting the training of a non medical prescribing specialist nurse to help the project with sustainability.

At the end of the Transition Group pilot, we intend to meet with other local CAMHS and AMHS teams in the city to share our experiences of this model. The team have also been asked to contribute to rewriting the city wide cross-Trust transition protocol informed by this work.

Resources involved

Project costs are primarily in terms of staff time. The Clinic requires one AMHS psychiatrist and one CAMHS psychiatrist to attend a session per month lasting three hours. This is an organisational change rather than a new resource. The Group currently utilises one occupational therapist and one social worker to run the Group per week, for 12 weeks. These sessions last two hours. This resource is currently supported by the AMHS CMHT budget. Other costs are in administrative support to set the programme up such as booking a venue and contacting patients. This is currently split between CAMHS and AMHS teams.

NICE guidelines suggest that a multi-disciplinary approach is more cost efficient in the long run. In Sheffield, a nurse is training as a prescribing nurse specialist in AMHS to lead on the transition work, thus reducing reliance on senior medical staff. This will also make the programme more sustainable in the long-term and spread learning. This has been a model used successfully by CAMHS and paediatric teams to help run services for patients with ADHD for some time, but has not yet developed within adult ADHD services.

There are potential cost reductions by the use of joint meetings for transition. Good transition should also reduce the re-referral rates and crisis presentations. It is also hoped that DNA rates are improved, improving efficiency of services provision.

Contact details

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