Accessing CAMHS: The Inclusion Initiative pilot study to enhance access of young people with social and communication difficulties with and without an autism diagnosis

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Editorial comment

Autistic children and young people are often referred to CAMHS (Child and Adolescent Mental Health Services) for support and therapy but struggle to attend or to engage in what is offered. This pilot study undertaken by a CAMHS Mental Health practitioner sought to address this difficulty by offering home-based CAMHS services based on principles from Acceptance and Commitment Therapy (ACT). A small sample of five young people aged from 12 to 16 years with social and communication difficulties who were on the waiting list for an autism assessment or had a diagnosis of autism, were recruited. The findings are very positive and encouraging and showed that all five increased their contact hours, felt the sessions were valuable and took part in both online and face to face meetings. A case study is presented on one of the young people. All the young people became involved and happier with their education plans. The first author plans to do a larger study to ascertain whether the findings can be replicated.

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Conflict of interest/ funding for the study
As a service improvement pilot, funding came from existing CAMHS provision and there was no external evaluation of the pilot.

Introduction

One of the major problems reported by children and young people to the Children's Commissioner (2021) is being 'turned away' from mental health services without receiving any therapeutic intervention. Their referral may be closed without any contact, or their initial session does not lead to further intervention. The Children's Commissioner (2021) reported that of the 148 CAMHS services sampled in England, 70 services closed 30 per cent or more of their cases before the young person accessed any therapeutic support. There is no national data on why this occurs, but locally one of the primary reasons is that many of those referred find it very hard to attend regular clinic appointments. This, and a lack of understanding about the needs of this group, mean that children with social communication difficulties or autism diagnoses struggle to access CAMHS (Autistica Action Briefing, 2019).

The Mental Health Act White Paper (DoH, August, 2021) made several proposals to improve the availability of community support and to prevent avoidable hospital admissions. This included new legal duties on NHS and Local Authorities to ensure an adequate supply of

community services. It also proposed a duty on local areas to monitor the risk of crisis for autistic people and people with a learning disability and began a trial of monitoring 'reasonable adjustments' for this population.

Efficacy of approaches for addressing social anxiety in autistic children and young people

It is estimated that one in four children with diagnoses of autism experience social anxiety (Simonoff et al., 2008). According to NICE guidelines, the primary intervention for anxiety in autistic children is adapted Cognitive Behavioural Therapy (CBT). In a meta-analysis of studies using adapted CBT protocols for autistic children (Sharma et al., 2021), CBT was found to be effective. However, parent and child reports of efficacy were significantly lower than the clinicians' ratings and the gains recorded were not maintained on follow-up. Furthermore, most of the children in these trials had less systemic complexity and co-occurring conditions than children who are typically accepted by CAMHS services (Gibbons et al., 2021). In the Government's 2021 review of the National Autism Strategy 'Think Autism', only eight per cent of respondents felt that the mental health support they received was effective.

Importance of the therapeutic relationship

Across all talking therapies, the quality of the relationship between the therapist and the person receiving the therapy is considered to be essential to a good outcome (Shirk et al., 2003). However, by definition, children with social communication difficulties and diagnoses of autism typically struggle in making and maintaining relationships. Clinicians and therapists often also struggle to engage them. This is compounded by the likelihood that many more of these young people compared with their peers have experienced significant bullying (Kald et al., 2022) and so find it hard to trust others. As such, these children are likely to need a more pro-active approach to enable them to build the relationship with a mentor/therapist that is necessary to support them to make valued changes in their lives. If they are not able or willing to come to a clinic and engage with talking therapy, then one reasonable adjustment that CAMHS can make is to meet them at home and to invest time in getting to know them before supporting them to understand and manage their mental health.

Acceptance and Commitment Therapy (ACT)

Acceptance and Commitment Therapy (ACT) is an intervention designed to help people accept their thoughts and feelings and to move forward through difficult emotions towards what is important to them. It is based on personal values and evidence based processes of change and is designed to increase psychological flexibility. ACT has been found to be more accessible for young people who struggle to build relationships and talk about how they feel. It has been demonstrated to be effective across 14 randomised control trials (RCTs) and numerous conditions including anxiety, Obsessive Compulsive Disorder (OCD), depression, chronic medical issues and eating disorders (see Fang and Ding's meta-analysis, 2020). ACT is a strengths-based model that takes a skills-building approach to therapeutic intervention, coaching and self-help to empower children and young people to lead more values-based and prosocial lives. The focus on moving towards a valued life and learning skills in vivo means that it fits within a mentoring framework and skills can be taught whilst doing valued activities within the home.

Aims of the pilot study

The Inclusion Initiative pilot proposed a model of intervention to include young people with social communication difficulties with and without diagnoses of autism who had not previously been able to engage with the mental health services offered by community CAMHS. It investigated the feasibility, effectiveness and costs of delivering an ACT-informed, home- based CAMHS intervention for these children and young people.

The main aims were:

- To investigate how to deliver home-based therapeutic programmes which enable the development of a therapeutic relationship.
- To evaluate the effectiveness of therapeutic programmes in the young people's homes.
- To produce a cost analysis of the service.

Participants

Prior to the pilot, Bristol CAMHS clinicians were asked to identify children and young people who were on their caseloads who had social communication difficulties, either on the waiting list or with an autism diagnosis, who were isolated and not engaging meaningfully with CAMHS. Eight partnership workers contributed and identified 29 young people who met these criteria. A request for a more formal referral was made and used Likert scales to rate the level of engagement with their family, education, friendships and CAMHS (1 low to 5 high). A total of 14 referrals were received with three identifying as male, 10 as female and one identifying with them/they pronouns. Referrals who did not currently have a partnership worker in CAMHS (2) or who had recently been offered a specialist service (1) were not included in the pilot. Due to resource limitations, the service was offered to the first five young people whose parents gave their consent.

The five young people who were involved with the pilot:

- had a diagnosis of autism or were on the waiting list for an autism assessment;
- were rated by the clinician as not engaging well (i.e., Likert scores of 1 or 2) with CAMHS, and/or with education, family and friends;
- had been open to community CAMHS for between 1.5 to 3.5 years (see *Table 1*);
- were aged between 12 and 16 years old (12, 15, 15, 15 and 16yrs);
- were referred to CAMHS for eating disorders, including ARFID (2), Low mood (3), Anxiety (5), Self-harm (2), Suicidal ideation (3), Suicide attempts (2), School refusal (4); and
- had received between 8 and 58 clinical hours of support (mean 33 hours) over the time they were with CAMHS, prior to starting the pilot (see *Table 1*).

Table 1. Participant's contact with CAMHS prior to and during the Inclusion Initiative Pilot

	Period open to CAMHS prior to the pilot	Therapeutic contact hours prior to the pilot (average hours/month)	Therapeutic contact hours during 6 months pilot (average hours/month)
Child 1	1y 11 m	58 (2.5)	54 (9)
Child 2	1y 11m	36 (1.6)	52 (9)
Child 3	1y 6m	41 (2.3)	56 (9)
Child 4	3y 6m	20 (0.5)	41 (7)
Child 5	2y 11m	8 (0.2)	41 (7)
Total		**163**	**244**

Note: Contacts logged prior to the pilot include a high number of appointments with parents alone. The appointments logged by the pilot are predominantly with the young people alone.

Methodology

Five Band 4 Recovery Navigators/Assistant Psychologists were employed through the NHS bank to work directly with the young people. They were given training in the model and in ACT skills and were supervised weekly by a qualified CAMHS practitioner including group supervision with a clinical psychologist on alternate weeks. The Recovery Navigators delivered ACT based interventions in the home. They visited the young people at home twice a week for up to 24 weeks. During that time the young people were offered access to online and face to face group sessions.

Parents were offered a six session online support group. There were regular consultations and liaison (at least three meetings per child) with the community CAMHS team. Recovery Navigators and the pilot co-ordinator liaised with the wider network, where appropriate, to ensure a smooth transition when the pilot ended.

Measures

The efficacy of the approach was measured by:

- Feedback taken from parents and the young people following the pilot. This was done using semi-structured questions either in an interview or questionnaire.
- Feedback from the CAMHS partnership clinicians using a social validity questionnaire (adapted social validity scale; Witt et al., 1985).
- The Revised Anxiety and Depression Scale (RCADS) (Chorpita et al., 2000) was given to parents before and after the pilot. This scale has 47 items designed to assess anxiety and depression symptoms in eight to 18 year olds.

Standard outcome measures including the RCADS were also given to the young people to complete before and after the pilot. Due to the inconsistency of completion and the importance of prioritising engagement with the young people, we were not able to collect sufficient data from these.

Findings

Increased engagement

Prior to the pilot, despite being open to CAMHS for between 18 months to three and a half years, none of the young people were engaging meaningfully with CAMHS therapists. There were frequent appointments not attended (DNA's), very little or no speaking during appointments or a refusal to attend appointments completely. During the pilot study, the average time spent engaging with the therapists increased nearly six-fold, from 1.4 hours a month (range 0.2-2.5 hours) to 8.2 hours/month (range 7-9 hours). As a result, all five young people were able to build a relationship with their Recovery Navigator and actively engage with therapeutic conversations to build their psychological skills. In their feedback following the pilot, all five young people said that they would have liked to see their Recovery Navigator for longer, indicating a positive and meaningful therapeutic relationship.

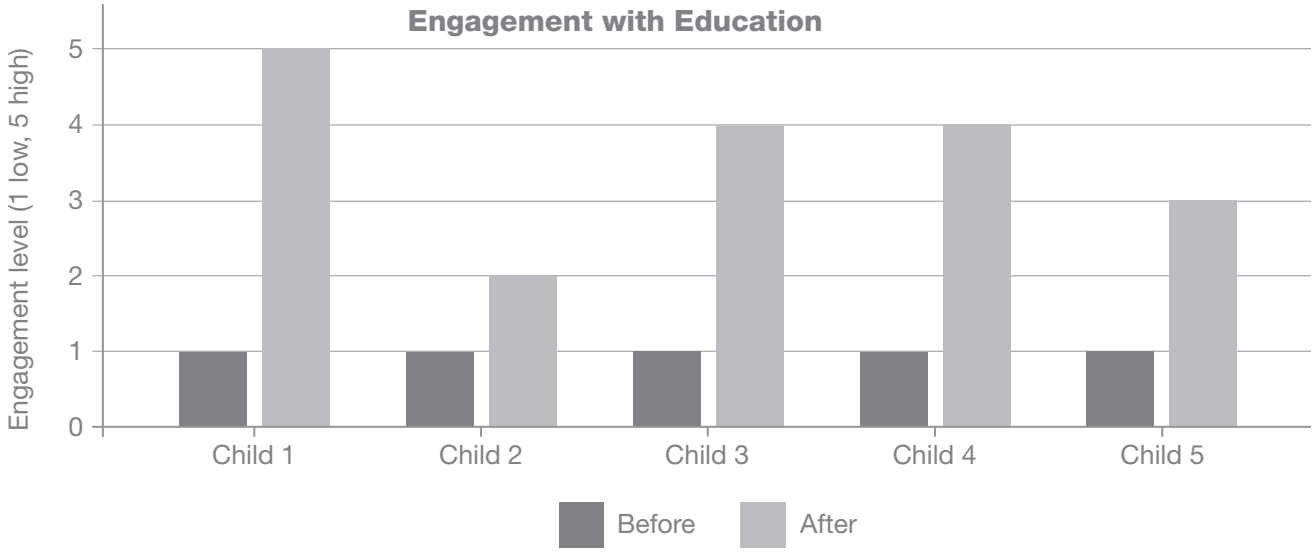
Reduced isolation

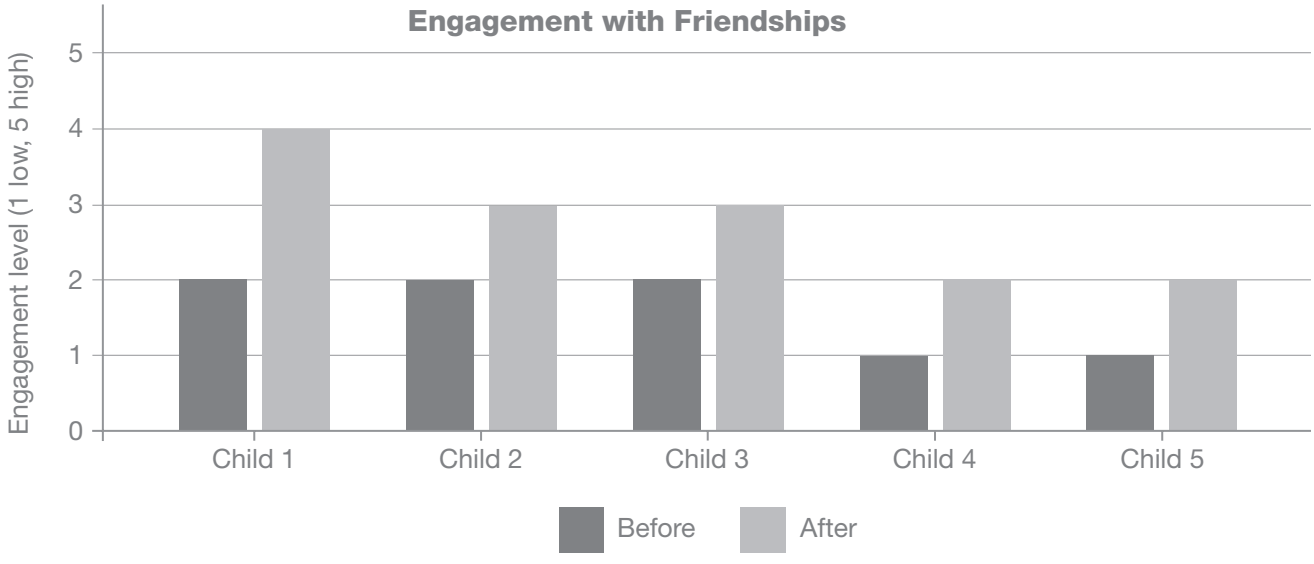
Prior to the pilot, all five of the young people were socially isolated and had limited contact with friends or peers. All five attended at least one of the four online group sessions. Four of the young people engaged in at least one of the three face to face groups run as part of the pilot and three of these expressed their intent to continue to attend this or another group when the pilot ended. Four of the young people now have an education plan in place which they are happy with and engaging with. The fifth participant is applying for an EOTAS service (Education Other Than At School) around valued activities. *Figure 1* shows the change in the CAMHS clinicians' ratings of the children's engagement levels before and after the pilot.

Reduced need for ongoing community CAMHS services

Two of the young people were discharged shortly after completing the pilot. Two others no longer needed therapeutic treatment but remained open to CAMHS for medication monitoring. The final young person had refused to see any CAMHS clinicians prior to the pilot but is now engaging with the CAMHS partnership worker during home visits. Prior to the pilot, the RCADS total T-scores rated by parents for all five young people scored above the clinical threshold for anxiety and depression. Following the pilot, three of these scored below the clinical threshold.

Figure 1: Clinicians' ratings before and after the pilot study

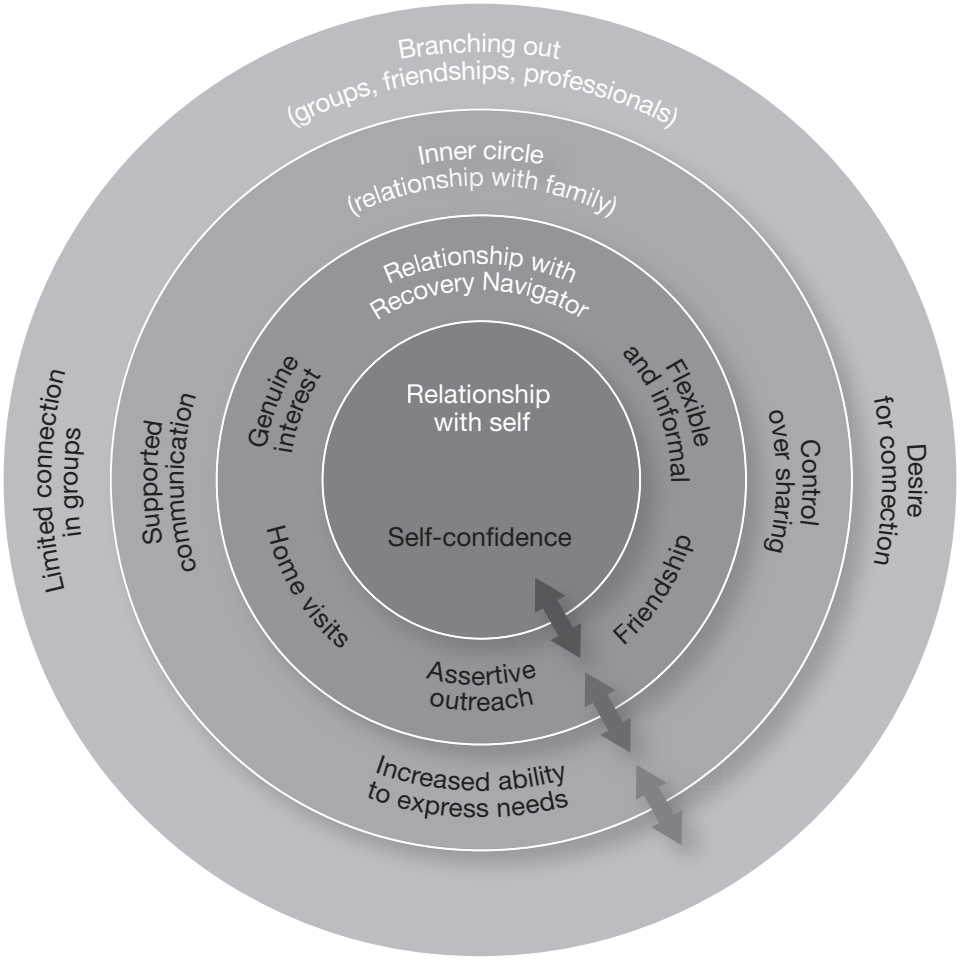




Increased satisfaction with the service

In the feedback following the pilot, all five young people and their parents said that they felt the approach was helpful and that they would recommend it to other families in a similar position. While only a small sample, this outcome stands in contrast to the eight per cent satisfaction levels in the Government's 2021 review of the National Autism Strategy.

Figure 2: The themes raised by parents and young people in their feedback following the pilot



Increased confidence in the young person

An inductive thematic analysis was carried out on the transcribed interview data and self-reported outcome questionnaire data from the young people and their parents. The themes and subthemes are represented in *Figure 2*, with concentric circles expressing the young people's growing confidence to relate to themselves, the Recovery Navigator, their families and wider social situations.

At the level of the young person's relationship with themselves, the intervention appeared to build their confidence to recognise and name internal states and emotions. Furthermore, the data suggests that the nature of the young people's relationship with their Recovery Navigator was an important bridge between this inner confidence and more outward expressions of confidence. Several contributing factors were identified, as follows:

- a model of home visiting;
- taking a flexible and informal approach guided by a genuine interest in the young person; and
- the young people positioning the Recovery Navigator as 'friend' (rather than clinician/therapist).

Table 2: Frequency of subthemes in the feedback data for each young person (YP)

	YP1	YP2	YP3	YP4	YP5
Self-confidence	3	1	4	1	-
Genuine Interest	4	4	2	2	-
Home visits	2	1	1	2	2
Assertive outreach	2	4	-	5	-
Friendship	7	6	4	2	1
Flexible and informal	8	1	4	1	1
Control over sharing	-	2	2	-	-
Supported communication	1	7	2	3	2
Increased ability to express needs	-	2	-	1	1
Limited connection in groups	2	6	4	2	1
Desire for connection	2	3	3	1	4

Table 2 shows the number of times each of the five young people identified each of the themes and subthemes.

The data suggests that the young people's relationship with their Recovery Navigator facilitated stronger communication with immediate family members. This was captured by repeated occurrences where the Recovery Navigator supported communication between the young person and their family; where the young person expressed their needs independently; and the young person showed an increased sense of control over what they would like to share with their families. Finally, at a wider social level, the data suggest that young people on the pilot developed a strong desire to connect with others on the pilot and beyond. However, the group settings facilitated by the pilot did not effectively enable the young people to make these connections. Factors such as virtual settings and the over-involvement of Recovery Navigators were considered to hinder this.

Case study of a 15 year old participant - Sam (fictitious name)

Sam lived with their mother and older siblings who were also involved with CAMHS. Sam's mother was unable to work due to her own mental health difficulties, but was dedicated to supporting her children. Sam first met with CAMHS through a school consultation with a Primary Mental Health Specialist (PMHS) in March 2019. Sam presented with anxiety, self-harm and school refusal. Despite a parental comment that Sam "didn't feel helped", the case was closed. The next referral to CAMHS followed an admission to hospital after taking an overdose with an "intent to end (their) life". The referral to Community CAMHS was declined and a recommendation made for a local authority parenting support programme.

In March 2020, Sam was referred to CAMHS again and allocated a partnership worker. Despite being brought to most partnership and family therapy appointments, the

clinician's notes made frequent reference to Sam's lack of engagement (e.g. Sam "was not talking", "was pushed to engage", and "does not contribute verbally"). Sam was open to CAMHS for 2.5 years and Sam and their mother's sessions amounted to a total of 20 clinical hours. During this time, Sam was unable to access education and had little contact with their friends.

When Sam was referred to the Inclusion Initiative Pilot, it took the Recovery Navigator approximately five weeks of repeatedly attending the house (nine visits) before Sam began to engage with them. Sam was supported to focus on and talk about things that were important to them and gradually built a relationship with the Recovery Navigator. In the time that they have been working together, Sam has started to take their dog out alone, has re-engaged with a friend and is planning a trip with them. In addition to this, with the support of the Recovery Navigator, Sam has been able to speak in a recent education review which led Sam to being offered an education plan that they are happy with. Since ending with the Inclusion Initiative Pilot, Sam has started meeting with a member of staff from the Hospital Education Service whom they like. Clinicians and Sam have agreed that they do not need to attend any other sessions at CAMHS and instead will continue to monitor medication and hold reviews.

Sam's mother said during the mid-point of the pilot,

> *"After (clinic based community) CAMHS appointments [Sam] would scream and shout as they would not have got across what they wanted to say. In contrast, the Recovery Navigator "has a brilliant approach and has done really well with them."*

Learning from the pilot study

From the feedback from the young people, their parents, their CAMHS clinicians and the Recovery Navigators, there are a number of changes we would like to make if we were to run the pilot again.

Adjusting consent

Several of the young people meeting the criteria for the pilot who were invited to take part by their CAMHS clinicians, declined to take part saying they did not want to meet a new clinician. As a result, the initial approach was changed by asking for consent initially from the parents and then on a session by session basis from the young person themselves. This gave the young person the opportunity to meet the Recovery Navigator who would be working with them and to make informed consent about taking part.

Adapting or removing the online group

Several of the young people said in their feedback that they found the online group difficult as other young people did not speak. They made suggestions of ways to adapt this or suggested just having a face to face group.

Reducing the size of the face to face group

The face to face group in the pilot was held in the youth drop-in hub. Whilst some of the young people liked the setting, others commented that they found the number of young people there overwhelming and would have preferred it if the group was exclusively for the young people in the pilot.

Greater flexibility in the length of time working with each young person

Due to the varying lengths of time it took to engage the young people, it was felt it would be helpful for the length of the intervention to be flexible.

Improving the Recovery Navigators' role

It was recommended that the Recovery Navigator has protected time to work in the pilot rather than working in addition to their substantive role.

Concluding comments

The pilot demonstrated that the young people were able to engage with and make use of therapy when the CAMHS offer was adapted. Central to the pilot was the importance of relationship building, that is, the time spent on building a meaningful, trusting relationship between clinician and young person before engaging in therapeutic work. Recovery Navigators adopted a unique, person-centred approach and made a considerable effort to engage with the young persons' interests and to explore their values. The majority of young people within the pilot fed back that their Recovery Navigators were genuinely interested in them and that they had developed a sense of 'friendship' by the end of the pilot. The Recovery Navigators offered regular, home-based appointments meeting the young people in their home environment where they felt safe. This was highlighted by feedback from every family as being important.

By the pilot's end-point, all five participants were able to engage in therapeutic conversations, using principles based in ACT. The Recovery Navigators were able to help the young people to identify their values and to support them to do more of what mattered to them without having a strict focus on wellbeing work and typical 'therapy.' By making reasonable adjustments to CAMHS provision to enable the delivery of effective therapeutic support, the pilot demonstrated the potential for significant savings relative to the more usual, clinic-based offers.

Next steps

This pilot demonstrates the feasibility and potential of a home-based CAMHS service for children with social communication difficulties and autism who are unable to engage with current CAMHS therapies. It can be delivered by Band 4 practitioners under the supervision of an experienced practitioner. As a next step, we would like to replicate this service model within CAMHS areas across the city. We would use a more robust, multiple baseline, experimental design in which young people still act as their own controls, so the impact of the intervention model can be systematically evaluated. This would enable a larger and more robust data set to be collected and thereby further evaluate the promise shown in this initial proof of concept pilot.

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