

**Title:** ADHD One Stop Shop. The impact of nurse-led, multi-agency drop in service for children and young people with Attention Deficit Hyperactivity Disorder: a repeated measures observational study

## **Abstract:**

ADHD is a neurodevelopmental disorder. It is one of the most prevalent psychiatric disorders in children. Access to high quality, integrated healthcare services is inconsistent.

Due to the nature of the diagnosis; ongoing support and care needs vary dramatically and can have a huge impact on the child and family unit. It can also mean that attending routine fixed time medication reviews is difficult. Clinical guidance recommends access to a bio-psychosocial package of care including parent training and social modelling support services. Working in collaboration with a charitable organisation, the ADHD One Stop Shop incorporated all aspects of the recommended package of care in one clinic venue.

**AIM:** To implement and evaluate a nurse-led, multi-agency drop in clinic for young people with ADHD.

**METHOD:** Repeated measures observational study over 12 months evaluating the impact on access to services during 'crisis' situations, regular attendance at medication reviews, adherence to NICE guidance, service design benefits and service user feedback.

**RESULTS:** 62 service users participated in the study. A significant improvement in service user experience pre, during and post implementation  $p=0.001$ . The number of crisis management attendances pre and post implementation significantly increased  $p=0.005$ . Service users attended for their medication review on or before their actual due date  $p=0.011$ . By previous comparison those who needed additional clinic time were able to spend more time with the staff  $p=0.001$ .

CONCLUSION: The clinic improved accessibility and flexibility of services. It allowed adherence to clinical guidance, including an uptake on psychosocial interventions. There was an overwhelmingly positive improvement in service user experience, compared to the traditional clinic model. There was a significant reduction in the waiting time from identified crisis and service users to be seen. Importantly, as contact with the ADHD Nurse Specialists increased, this significantly reduced the amount of time Consultant Community Paediatricians spent with clients. Further research should examine the cost effectiveness and longitudinal impact of the drop in model.

**Keywords:** ADHD (Attention Deficit Hyperactivity Disorder), CAMHS (Child and Adolescent Mental Health Service), Service Design, Service Development, Mental Health and Young People, Engagement, Drop in Services, Nursing, Mental Health.

## Introduction

National Institute for Clinical Excellence (NICE) guidance for Attention Deficit Hyperactivity Disorder (ADHD) (2008) stipulates that a bio-psychosocial model of care is utilised, comprising of pharmaceutical and psychosocial interventions, including behaviour management. Children, young people and their families should have access to specialist teams. An emphasis is placed on a positive child-parent relationship, with parent training programmes recommended; as well as access to self-help groups and support in the community (NICE, 2008). Within the specialist ADHD Service for Families, Young People and Children's Service (FYPCS), and due to pressure on waiting times, clinical work centred around medication monitoring. A small number of families had access to a psychosocial package of care on a 1:1 basis with an ADHD Nurse Specialist. Psychosocial interventions were implemented at the family home, the cost of implementing psychosocial packages of care within a National Health Service (NHS) setting is dramatically challenging. In addition, crisis management was accessed via home visits by ADHD Nurse Specialists.

ADHD Solutions is a local charitable organisation that provides services to children, young people, their families and adults who either have ADHD or are suspected of having ADHD. All families of children and young people who are diagnosed with ADHD by the trust are provided with information about their services. Families can access support groups, social events and parent training programmes. The uptake of parent training programmes was low, with not all families accessing the services offered.

In collaboration with ADHD Solutions, the ADHD One Stop Shop project aimed to provide a "drop in" service for children and young people with ADHD. The clinic was accessible to all children and young people in Leicester City. It was the first clinic of its kind locally and, from literature searches, possibly nationally. The ADHD One Stop Shop provided a safe environment in which clients were able to access ADHD Nurse Specialists, who were able to review medication and ADHD Specialist Coaches, who were able to provide advice on behaviour management and refer to more formal parenting

programmes, such as 123 Magic. The bio-psychosocial model of care was accessible in one clinic venue.

## Project rationale

ADHD is a neurodevelopmental disorder characterised by the core symptoms of inattention, impulsivity and hyperactivity (NICE, 2008). In the UK it is estimated that 5% of children are diagnosed with ADHD (ADISS, n.d.) Poorly managed ADHD can lead young people into crime or result in suspension/exclusion from school. There is an increased likelihood of co-morbid mental health problems, personality disorder and drug/alcohol misuse. Of those who do not fully meet the diagnostic criteria for co-morbid mental health problems, 78% of them have symptoms of mental health problems (Kooij *et al* 2012). A recent health economic study in Denmark suggests that adults with undiagnosed ADHD compared to same sex siblings from the same biological parents, cost society on average £10,000 per annum more (Daley *et al* 2015).

Whilst NICE guidance recommends a bio-psychosocial model of care using collaborative interventions and service design to optimise health outcomes for ADHD; it is recognised that parents often do not engage with the behavioural training and support available. Therefore they do not receive the best quality care; which in turn can compromise the prognosis for the child/young person. This may be due to situational or economic factors or perceptions of behavioural training/education. In addition, medication reviews, on-going support and management are essential in ensuring the best quality care, however many parents fail to attend mandatory reviews due to fixed appointment times and the generally 'stressful' and unpredictable family life associated with ADHD.

Caring for or living with ADHD can cause great anxiety and stress for the family. Many families often reach 'crisis' point where urgent support and intervention is required. Currently, locally there may

be a 4-8 week wait for this, due to clinic waiting lists and specialist availability, by which time the problem may require more intensive intervention which could have been prevented.

A range of literature has identified that 'One Stop Shops' and drop in clinics may be some of the most suitable forms of providing services to young people by improving accessibility, reducing time away from school to attend routine appointments and improving engagement with services for 'hard to reach' or vulnerable groups. In addition, such services have been shown to reduce 'risk' taking behaviours, enable identification of 'unmet' needs and provide care in the right place, at the right time; fitting with the *You're Welcome* quality criteria (Wilf-Miron *et al*, 2002; Austerberry *et al*, 2008; Advocates for Youth, 2008; WHO, 2012; RCPCH, 2003).

## Aims and Objectives

### Aims

Here, a One Stop Shop drop in clinic was implemented for children and young people with ADHD to improve access, flexibility, efficiency and satisfaction. This project aimed to reduce the waiting time in a crisis situation and thus, enabled access to the 'right service at the right time' with early intervention.

A 'family centred', drop in 'One Stop Shop' was established every two weeks, which enabled service users to attend for mandatory medication reviews at a more flexible time. In addition, this service allowed individuals to access a specialist healthcare professional more quickly in case of 'crisis' or urgent support regarding their condition.

The collaborative approach of this project meant that service users could access both medication reviews and psychosocial intervention services at a single point of access. Additionally, it allowed individuals to meet others in similar situations and obtain support.

## Objectives

- i. Implement a drop in clinic service for children and young people of 6-18 years of age with a diagnosis of ADHD
- ii. Evaluate the impact of the drop in clinic through service user feedback and satisfaction
- iii. Evaluate the impact on service delivery by comparing baseline and post implementation DNA (Did Not Attend) rates, crisis management intervention time [from contact to consultation] and Consultant Community Paediatrician time spent with service users
- iv. Inform local policy on the potential value of 'One Stop Shops' for children and young people, and hard to reach groups

## Primary Research Question

Can the implementation of an ADHD One Stop Shop improve access to services and reduce DNA rates for mandatory medication reviews in a Community Health Service setting?

## Secondary Research Questions

- Does the use of a 'One Stop Shop' improve access to specialist care in a crisis situation?
- What is the comparative benefit(s) [in this context] of implementing a One Stop Shop to that of the traditional method of service provision?
- Was Service User satisfaction positive after implementation of the ADHD One Stop Shop?

## Design & methodology

This observational study employed a pre-test post-methodology using a four phase Plan, Do, Study, Act (PDSA) framework for project management and design.

## Sample population & sampling frame

The research population comprised of children and young people with a confirmed diagnosis of ADHD, who required regular mandatory 6 monthly medication reviews or who required crisis management intervention. The service was aimed at a caseload of 200-250 children and young people. Participants were identified by the ADHD Specialist Nurse and the Principal Investigator through her caseload.

### *Inclusion Criteria*

- Parent of child or young person aged 6-18 years diagnosed with ADHD and choosing to attend a One Stop Shop service
- A young person of 16-18 years of age diagnosed with ADHD choosing to attend a One Stop Shop service accompanied by their parent/carer
- Child or young person required mandatory medication review or crisis management
- Parent/carer willing to provide informed consent

### *Exclusion Criteria*

- Person diagnosed with ADHD is more than 19 years of age
- Limited spoken and written English
- Deemed to be inappropriate for inclusion by their lead clinician

This project operated over 12 months. Retrospective and anonymous data collection occurred from electronic record reporting systems for the preceding 6 months, followed by a 12 month implementation and data collection period. Recruitment took place over the first 6-9 months (ending at the end of month 9). Months 9-12 were a follow up period for included participants.

## Sample size

Sample size was calculated using an alpha  $\alpha$  0.05 to establish a power of 0.8 ( $1 - \beta$ ). Cohen's d was used to determine minimum sample size. A Cohen's d of 0.4 was deemed to be suitable in order to detect a small to moderate effect on DNA rates and user satisfaction (Cohen, 1988). There was not a need to standardise pre and post test data for the purpose of this analysis. A minimum of 52 participants were required as per the calculations.

## Intervention

Table.1 illustrates the service provision prior to the 'One Stop Shop' and compares this with the 'One Stop Shop' service intervention.

*Insert table.1*

All participants were expected to have six monthly mandatory medication reviews, including measuring of height & weight, blood pressure & pulse. NICE Guidance (2008) recommends blood pressure and pulse monitoring at three monthly intervals, this was not feasible under the existing service and the old style of appointments. Patients were offered a monthly review to check physical observations where there had been a change to the medication to comply with NICE guidance.

A flowchart of study procedures and flow of participants can be seen in figure.1.

*Insert figure.1*

## Data Collection and Recording

Service user satisfaction questionnaires using Likert scores of 1-5 were utilised to gain feedback on the service along with secondary data collection through anonymous electronic patient record reporting systems. Once consented into the study participants electronic medical notes were used to gather data on medication reviews and DNA rates.

As shown in figure.1 the following data were collected:

- DNA rates for mandatory reviews:
  - Baseline, retrospectively for preceding 6 months
  - Collected at 12 months following implementation
- Patient Satisfaction and feedback on first contact with the service and any subsequent contact up to the 12 month end date.
- Self-reported use and comparison of access rates for psychosocial interventions training/education at baseline [first contact] and 12 months.
- Crisis point intervention at baseline [retrospectively for the preceding 12 months] and 12 months following implementation, participant medical notes were used to obtain data on the time from crisis point to clinical contact and the number of contacts through the clinic for crisis point intervention.
- Open qualitative feedback comments following each visit and during the three month follow up period

## Data analysis

Pre-post implementation DNA data was assumed to be normally distributed. Normality was tested using Spearman's Rho. Paired t-tests were used to detect any significant differences in pre and post implementation DNA rates. Pre and post Likert scores that examined user satisfaction and

experience were analysed using Mann Whitney U tests for non-parametric ordinal data. The Statistical Programme for Social Sciences (SPSS) v22.0 was used to analyse data.

## Ethical and institutional approvals

Ethical approval was obtained through the NHS Research Ethics approval service (Reference: 13/SC/0415). Institutional approvals were also obtained from Trust Research and Development and Derby University ethics committee. This study was also accepted onto the National Institute for Health Research Portfolio (CSP reference: 129323).

## Results

### Participant characteristics

Table.2 provides an overview of the participants. Of 94 people approached to participate, 62 consented to the study. Children included were aged between 6 and 17. The average age of the children whose parents/carers took part was 10.87 (s.d. 3.29). Males comprised 88.7% of the sample children. Of the participants, 43.3% had been diagnosed less than 12 months before attending and 50% had received a diagnosis over 12 months ago. The remaining 6.7% were undergoing assessment. Of those who completed the questionnaires 14.8% were male and 85.2% were female. 80.3% were mothers, 12.1% were the father of the child and 4.9% had another role e.g. sister, aunt. Of the carers 23.3% were in full time work or education, 30% were part time and 46.7% recorded no employment or education. The average number of visits to the clinic was 2.47 s.d. 1.43.

*Insert table.2*

## Clinic attendance and user satisfaction

Participant's main reason for attendance was mandatory medication review (74.2 %) followed by crisis management (9.1 %), other reasons and three monthly observations (e.g. blood pressure and pulse check) (6%).

The ADHD One Stop Shop improved the overall experience of our patients compared to the previous services, a paired T-Test at 95% confidence level showed  $p=0.001$  suggesting a significant improvement in the overall clinic experience pre and post implementation of the ADHD One Stop Shop. The length of time patients waited for an appointment showed a significant improvement in acceptability,  $p=0.024$ . There was a significant improvement in the convenience of appointment times following the project,  $p=0.031$ . The overall time families waited to be seen in clinic showed a significant improvement post implementation,  $p=0.001$ . Our service users felt that the service was flexible to their needs, compared to previous clinics,  $p=0.009$ .

## Crisis Management and DNA Rates

The number of crisis management attendances significantly increased after implementation of the clinic,  $p=0.005$ . This may be linked to the accessibility of the clinic and the ability of the service to assess those in crisis within a 2-3 week time frame, rather than having to wait for a standard consultation, which could take 4-6 weeks. The number of face to face consultations required from any professional related to ADHD care significantly increased pre and post implementation of the clinic,  $p=0.000$ . This is likely to reflect the accessibility of the clinic and its role in meeting the needs of clients. The total number of ADHD related telephone conversations, as for face to face consultations, significantly increased,  $p=0.011$ .

DNA rates did not reduce significantly,  $p=0.057$ . However, this may be skewed by participants who missed a planned appointment (recorded as a DNA) but then attended the clinic as a drop in later the same day.

### Consultant time spent with patients for ADHD

After implementation of the ADHD One Stop Shop, there was a significant reduction in the amount of time spent on the telephone by Consultant Paediatricians to clients,  $p=0.038$ . The contact with Paediatricians significantly reduced, as contact with ADHD Nurse Specialists increased, as well as an uptake on access to psychosocial interventions.

### Benefits to quality of care

A one-way T-Test measured the days between date of visit and date the review was due. The test value was 21 days, which would mean that participants completed their review during the month it was actually due and accounted for the pattern of clinics of every two weeks. For visit one, participants were significantly likely to attend for a medication review before or on their due date:  $t=-2.731$   $df$  28  $p=0.011$   $CI$  [-29.99, -4.29]. This suggests that the majority of participants attended for their review earlier than scheduled. For visit two, participants were also significantly likely to attend for medication review before or on their due date:  $t=-6.768$   $df$  16  $p=0.000$   $ci$  [29.74, -15.55]. This may suggest that participants felt able to attend when convenient rather than following a fixed appointment time. It may also mean that they felt able to attend the clinic during a crisis situation between appointments for review, given that the service was more accessible. Given that most participants only attended for two appointments this analysis was not possible for further visits.

The days between appointments were also assessed. The mean time between appointments was 49.83 days s.d. 37.44 suggesting that most participants attended between one and three months

(mode 91, 28, 42, 28 for visits 1-4 respectively). Taken with the data for measuring physical observations this reaffirms that the clinic enabled adherence to NICE guidance.

Of the attendees, 53.3% had accessed the psychosocial intervention service prior to attending the clinic. At the end of the 12 month period this increased to 57.8%. However, 94.9% indicated they would be likely or highly likely to access this support in future. Of those who had not heard of this service on their first visit to the clinic, 88.5% stated they would go on to access such support in the future. At the end of the 12 month period, 41.2% had gone on to use them. This suggests that over 40% of participants accessed parent training or behavioural support that had not done so previously. It should be noted that many participants did not attend the clinic until the end of the 12 month data collection period and may well have gone on to engage with psychosocial interventions even if they had not done so by the time of our final follow period.

### Flexibility and wide impact of the One Stop Shop

The average time spent with the clinician was 34.46 minutes s.d. 13.95. The range was 55.50 minutes (min.14.5 max. 70 minutes). A Shapiro Wilk test for normality showed that the time spent with the specialist was not normally distributed 0.923, df 59,  $p=0.001$  with the majority of participants spending 14.5-30 minutes with the staff. As the clinic was a drop in service, appointments could be tailored to the needs of the individual.

Interestingly, the time taken away from work significantly improved post implementation of the project meaning that there was evidence of wider benefits to the child and family unit. The mean time taken from school prior to the clinic was 2.71 days, s.d.1.60 and post implementation 1.71 days s.d. 0.82. The time taken away from school was significantly reduced following implementation of the clinic  $p=0.002$   $t=3.33$ , df 30, CI [0.39, 1.61]. As the CI crossed 1, bootstrapping was used to assess against median values, BCa Mean 1.000, bias 0.00029, std error 0.305,  $p=0.008$  CI [0.43, 1.60]. Conversely, the pre BCa CI [2.19, 3.26] mean 2.71 and post 1.71 [1.48, 1.97] suggests that there is a

significant decrease in time spent away from school when using the One Stop Shop. Conversely, participants who were in employment took significantly less time away from work due to the flexibility of the clinics Pre mean 2.48 days s.d. 2.12 and post mean 1.22 days s.d. 0.52  $p=0.015$ .

Over the first four visits the mean time people arrived was 13:20 s.d.2:12. The most common time people arrived in clinic was 10:55 or 14:30. The earliest time anyone arrived was 8:40 and latest 18:20 there were also some peaks between 14:30 and 16:30, which coincides with school finish times. Most of the visits were during school hours: lower quartile 11:52, median 13:10 and upper quartile 15:05. The times people entered the clinic was normally distributed identified through a Shapiro Wilk 0.986 df 63 0.717 illustrating a relatively even spread throughout the 12 hour period.

The waiting time from an identified crisis to access to specialist ADHD Services significantly reduced from 18.5 days pre project to 6.5 days post implementation  $p=0.05$ .

## Discussion

The literature search informed the service design, with the most suitable forms of providing services for young people to improve accessibility and engagement are 'One Stop Shops' or 'drop in clinics'. This kind of approach has shown to reduce risky behaviours (Wilf-Miron *et al* 2002; Austerberry *et al* 2008; Advocates for Youth 2008; WHO 2012; RCPCH 2003).

Service user satisfaction significantly increased post project implementation; our clinic was flexible to the needs of clients. The service design was aimed to improve patient satisfaction and accessibility, which was proven.

NICE Guidance (2008) recommends that patients with ADHD who are treated with medication should have height & weight measured at six monthly intervals and after each dose increase. Blood pressure and pulse rates should be monitored every three months and after each dose increase. A

yearly review by a specialist is indicated as a quality standard. Our local Shared Care Agreement with primary care does not include the monitoring of blood pressure and pulse rates at three monthly intervals, thus patients on drug therapy require three monthly reviews to monitor physical observations. The service standard prior to the implementation of the One Stop Shop with regards to medication monitoring, was monthly after a medication change and six monthly to check physical observations. The ADHD One Stop Shop enabled Clinical guidance to be met with regards to medication monitoring and access to the recommended bio-psychosocial model of care. The results indicated that most participants attended the clinic at one-three monthly intervals. Although DNA rates did not significantly reduce, the above highlights the improved access to specialist services and seeing the right people at the right time.

In the UK, NICE guidance (2008) is the standard worked towards; on checking the Summary of Product Characteristics (SPC) of all ADHD medications, it is recommended by manufacturers that physical observations are checked at six monthly intervals (Eli Lilly 2015; Flynn Pharma 2015; Jansen Cillag 2016; Shire Pharmaceuticals 2014 accessed online through electronic medicines compendium). The ADHD One Stop Shop more than allowed for adequate and safe monitoring of medications, whether measuring against national or international guidance.

Further research is indicated to look at health outcomes for individuals who attended the ADHD One Stop Shop, compared with service users who did not have access to the clinic.

## The ADHD One Stop Shop framework of care

*Insert Figure 2*

The ADHD One Stop Shop framework of care is a model that can be adapted for clients in other areas of the country or for other hard to reach groups. As highlighted in figure 2, primary care were able to refer directly to all tiers of our clinic model (referrals made by primary care to ADHD

Solutions were only made if the patient had a confirmed diagnosis of ADHD). As tier one and two provided the drop in clinic at the same venue, it was easy to move from tier one to tier two and back to tier one again. The ADHD Nurse Specialists provided ongoing consistent care for clients, as well as crisis management. The Nurse Specialist acted as the Care Co-ordinator, providing a link to the wider Multi-Disciplinary Team, as well as with tier three services- such as specialist CAMHS and clinical psychology. Hence, creating a fluid framework of care that ensured a smooth transition from each tier shown.

*Insert Table 3*

Table 3 highlights the specific clinic design for the ADHD One Stop Shop.

### Scientific rigour & methodological limitations

This study was limited to a small region of an East Midlands city, over a 12 month period with small numbers of participants, and there were limited numbers of those from Black, Minority and Ethnic groups. This limits the wider generalisability of the findings. However, participant demographics do reflect the overall prevalence of ADHD nationally and internationally.

This clinic model and approach to care has been shown to have value and a wider, longitudinal cohort and/or Randomised Controlled Trial that examines cost-effectiveness and clinical outcomes more closely and robustly could be built on the findings presented here. In the absence of baseline data on this type of service model in this field, this study has demonstrated the potential feasibility of this approach to ADHD services and will inform the design and delivery of further research and service provision in this field.

## Conclusions

The results of the research project were overwhelmingly positive in terms of patient experience and satisfaction. The service was flexible to the needs of our client group; there was a reduction in the amount of time our client group had to take away from work/school. There was an increase in access to ADHD Solutions, thus indicating an uptake on the recommended bio-psychosocial model of care suggested by NICE Guidance (2008). The majority of our service users attended clinic at one-three monthly intervals which allowed safe and adequate monitoring of ADHD medications. The time taken from identified crisis to face to face contact with a specialist significantly reduced; this was measured against contact with ADHD Nurse Specialists, it was a four-six week wait to see a Consultant Paediatrician.

The clinic had great benefits to the NHS, on occasions the number of people who 'dropped in' could be as high as 12 children/young people per clinician. Prior to the ADHD One Stop Shop, crisis management was offered in the form of home visits; the maximum number of home visits that could be offered in one day was three; taking in to account travelling time and administrative tasks. The service was nurse-led and it was proved that Consultant time was freed up post implementation of the project.

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