Running Header: Attendance of Deaf children at outreach mental health services

**The impact of mental health services at outreach clinics and non-clinic sites on the attendance of Deaf children and young people and families.**

Aishah Iqbal1, Jared G. Smith2 and Victoria Fernandez1

1. South West London and St George’s NHS Trust, Springfield Hospital, Glenburnie Road, London, SW17 7DJ, UK

2. Population Health Research Institute, St George's, University of London, London, SW17 0RE, UK

**Corresponding Author:**

Victoria Fernandez

Deaf Children, Young People and Family Service

South East Outreach

Heathside, Heathside Road, Coxheath

Maidstone. Kent, ME17 4AH

E-mail: victoria.fernandez@swlstg-tr.nhs.uk

Phone +44 (0) 1622741881

**Abstract**

Deaf children show high rates of mental health disorders, with difficulties getting access to appropriate health care. The National Deaf Child and Adolescent Mental Health Service (ND-CAMHS) was set up to provide specialist mental health care to Deaf young people and hearing children of Deaf adults in the UK. This study retrospectively examined the impact of the introduction of ND-CAMHS at outreach clinics and non-clinic sites on attendance rates at clients and carers’ first and follow-up appointments over a three-and-a-half-year period. In all, 4177 appointments, 372 first and 3805 follow-up, associated with 369 clients were considered for analyses. First appointments were much more likely to be clinic-based than follow-up appointments (78.2% versus 34.3%, *p* < 0.001), which were administered in a variety of sites, most frequently at the client’s school or home. The overall attendance rates for first and follow-up appointments were 68.5% and 79.2%, respectively. There was no significant effect of appointment location on attendance rates for first appointments. However, multivariate analyses indicated that clients at follow-up appointments were more likely to attend when appointments occurred at non-clinic sites compared with clinic-based appointments (81.9% versus 74.1%; odds ratio (OR) = 1.39, 95% confidence interval (CI) 1.17, 1.65). Improved attendance rates were a function of significant decreases in ‘did not attends’ (DNA) and client/carer cancellations at non-clinic sites. There was also an increased attendance rate for follow-up appointments held in outreach clinics relative to hospital-based sites (79.0% versus 72.2%), although this failed to achieve significance after adjusting for other relevant factors (OR = 1.27, 95% CI 0.93, 1.73). The findings indicate that providing specialised mental health services for Deaf children and young people into schools and other locations that are easier to access can improve service accessibility and continuity of care.

**Keywords:** Deaf, Child and Adolescent Mental Health Service, Outreach, Attendance, Engagement

**Introduction**

In England there are a reported 20,160 Deaf children aged between 0-18 years old, 42% who are either severely or profoundly deaf1. Those who are born deaf or acquire deafness in the early years of life can become developmentally disadvantaged as a result2. Delays that can occur include those of a psychological nature as well as emotional and/or educational3. Impaired language development is a serious issue directly affecting social skills and the ability to express oneself, while metacognitive ability, essential for a child’s understanding of the concept that each individual has personal thoughts and feelings, can also be delayed4. Deaf children also have an increased likelihood of developing mental health problems5-7. One study using a screening instrument developed specifically for use with Deaf children indicated that mental health problems were prevalent in 43–50% of Deaf children aged 11-16 years, compared to a prevalence of 25% amongst hearing children8. More recently, Schenkel and colleagues9 reported that Deaf college students demonstrated higher rates of child maltreatment, lifetime trauma, and post-traumatic stress symptoms compared to their hearing peers. In addition, Roberts et al10 observed that 39% of Deaf children and young people in a community sample scored within the abnormal or borderline range using a self-report BSL Strength and Difficulties Questionnaire (SDQ). This figure increased to 46% using the parent version of the questionnaire and to 54% using the teacher version.

Specialist skills, in the form of ability to understand the impact of problems in language and communication as well as the presentation of mental health disorders in the Deaf population, are required when dealing with the mental distress found within this group of children and young people. However, generic child and adolescent mental health services (CAMHS) often lack the specialist experience of working with young Deaf people, with limited understanding of the developmental issues affecting Deaf children as well as the impact deafness has on a patient and their family11-13. Beresford and colleagues12 reported that 89% of referrers believed that the generic mental health services for children were not suitable in meeting the needs of Deaf children. Further, there is evidence pointing to difficulties with access to appropriate mental health support for Deaf children14,15. Van Gent and colleagues15 reported that only three out of thirty-two adolescents with identified psychiatric caseness from expert dossier ratings had any contact with mental health services. These results are supported by the study undertaken by Roberts et al10 demonstrating high percentages of SDQ scores within the abnormal or borderline range, 26% of which were identified as having a probable psychiatric disorder. None of those young people were accessing child and adolescent mental health services. These findings are broadly consistent with evidence suggesting that communication barriers adversely impact on Deaf people’s general health and access to primary care6, 16. For example, a UK study reported that up to 24% of patients have missed an appointment at their GP surgery as a result of poor communication, 19% of whom had missed more than five appointments17. Moreover, a UK report18 found that 70% of Deaf people who hadn’t recently been to their GP wanted to but didn’t because there was no interpreter.

The National Deaf Child and Adolescent Mental Health Service (ND-CAMHS) was set up to provide specialist mental health care to Deaf young people and hearing children of Deaf adults regardless of religion, culture, gender or disability19,20. Previously, only a limited number of isolated services across England were available specifically for Deaf children’s mental health. In 2004, a three-year pilot project was set up intended to investigate the feasibility and effectiveness of a dedicated national service based in London, York and the West Midlands. Subsequently, an independent evaluation by the Social Policy Research Unit12, 13 found that 80% of children believed this specialist service had helped them along with more than 80% of parents agreeing. The use of BSL and skilled interpreters with experience in mental health was highlighted as one of the important barriers removed by the service. In addition to regular access to BSL interpreters just mentioned, the teams making up the ND-CAMHS consist of both Deaf and hearing professionals, all of them trained to a proficient level of BSL. More importantly, clinicians have expert knowledge in the relevant aspects of language and communication that affect Deaf young people and their families. This allows them to consider when this may be a factor contributing to or shaping the mental health presentation and to subsequently make more accurate formulations and diagnosis, and appropriate therapeutic recommendations, including any specific communication needs. Arguably, this increases the rapport the service has with its users. The service now comprises four main teams based in London, South East, North of England, South West and Midlands, three of which have additional outreach teams. Also, an inpatient service is available at Springfield Hospital, London.

Although the introduction of the first three ND-CAMHS teams (ie, York, Dudley and London) increased structured access to specialist mental health services for Deaf children and young people and their families, the pilot showed the relevance of reducing difficulties of geographical access for service users. A primary concern shared by the providers and users of the service concerned the distance many patients needed to travel in order to benefit from the service. Specifically, 47% of respondents reviewing the service commented that children and families found travelling to appointments difficult; 1 in 3 parents expressed difficulties in getting to the appointment12,13. Referrers suggested the service could be improved by increasing the geographical access, through more regional centres and outreach style clinics12. Accordingly, within the South East and London programme, outreach teams in Kent and Cambridge were set up in 2009 to share the workload with London and increase accessibility (prior to this, existing referrals from across the South East Coast and East of England were managed by the London team). The outreach teams delivered mental health support from dedicated (outreach) clinics as well as a wide variety of non-clinic locations, including clients’ schools, homes, GP surgeries and other community locations.

The purpose of the present study was to investigate the impact of the implementation of ND-CAMH outreach services on accessibility by examining attendance rates of clients and carers. Non-attendance of mental health services tends to be more common than in other medical specialities21 and occurs at least as frequently in CAMHS as in adult mental health services22,23. Most estimates indicate that between a fifth and a third of patients referred to a CAMHS miss their first appointment22,24. Aside from representing a waste of (scarce) clinical capacity and potentially increasing waiting times for other service users, non-attendance can lead to treatment dropout and disrupt the continuity of care.25,26 Non-attendance of child psychiatric services typically relates to parental expectancies and/or structural barriers, both of which impact on clients and carers’ willingness and capability to attend22,27,28. Difficulties relating to transport, including access to a vehicle, cost of public transport and distance from clinic have frequently been identified as a major deterrent for appointment attendance in CAMHS12, 13, 29,30. As such, the provision of appropriate, specialised care within the locality of Deaf children and their families may serve to increase service accessibility, ensuring that Deaf children are correctly diagnosed and supported and to minimise the risk of further complications.

This paper reports on the introduction of services for Deaf children and young people and families at outreach clinics and non-clinic sites in terms of non-attendance rates and associated factors. Data on health outcomes are not reported here, however. Given there are likely to be important differences between rates of non-attendance at different stages of assessment and treatment22, 31, first and follow-up appointments were considered separately.

## Method

This study was a retrospective study analysing the change in attendance rates in first and follow-up appointments within the South East branch of the UK National Deaf CAMHS as the service expanded over a three-and-a-half-year period to include outreach clinics and non-clinic sites.

Data extraction

Client appointment data from April 2009 to September 2012 was sourced from the electronic patient record system at the local trust. Only face-to-face appointments with clients or carers were included. In all, 4177 appointments associated with 369 clients were considered for analyses. First appointments were determined by a database classification as ‘first appointment’ or ‘new assessment’ while follow-up appointments were under ‘follow-up appointment’, ‘review’ or ‘treatment’. Of the 4177 appointments, 372 (8.9%) were coded as first and 3805 (91.1%) as follow-up. The majority (215 or 58.3%) of clients had both first and follow-up appointments scheduled in the study period. Seventy-three (19.8%) clients had a first appointment only while 81 (22.0%) had a follow-up appointment only. Just under 5% (186 or 4.5%) of appointments were carer only, 7 (3.8%) of which were first and 179 (96.2%) follow-up. These were associated with 60 of the 365 clients with client appointments and 4 other clients (for which carer appointments only occurred within the timeframe).

The primary outcome measure of interest was whether the client/carer attended or missed their scheduled appointment. For each appointment in the database, the outcome was recorded, and where the client/carer missed their appointment, the reason provided (classified as either client/carer did not attend (DNA), appointment cancelled by client, or appointment cancelled by clinician). Clients could have scheduled appointments at a number of locations. Critically, the focus was on distinguishing between appointments scheduled at a London clinic, the two outreach clinics or a non-clinic site. The latter included those appointments at a client’s school or home, a community site, or any other site (eg, residential schools, GP premises). Subsequently, London and outreach clinic data was collapsed so as to directly compare clinic- and non-clinic-based appointment outcomes. Data pertaining to a range of other potentially relevant variables were also extracted, including details specific to the client (age, gender, ethnicity, number of previous missed appointments) and the appointment scheduling (service year, time of day).

Statistical analyses

Socio-demographic data were presented using means and standard deviations for continuous variables and frequencies and percentages for proportion variables. Chi-squared tests were used to compare frequencies of scheduled first and follow-up appointments across years and the reasons for a missed appointment according to appointment location. Initially, univariate analyses examining associations between appointment outcome and location and other potentially relevant variables were performed separately for first appointments and follow-up appointments using chi-squared test (or Fisher’s exact test) for categorical variables and Mann-Whitney U tests for continuous measures. To control for the possible influence of individuals with high volume of appointments on appointment outcome, (number of) previous missed appointments for the client was also considered. Multivariate analyses were subsequently administered including location and any other variable from univariate analyses indicating at least marginal significance (ie, *p* < 0.10) using Generalized Linear Models. All odds ratios (OR) indicate change in odds of having attended relative to the reference category except the OR for ‘Number of previous missed appointments’ which reflects change in odds per 1 unit (ie, 1 missed appointment) increase. The criterion for statistical significance was set at *p <* 0.05 and all confidence intervals (CI) were 95%. Statistical analyses were completed with the Statistical Package for the Social Sciences, Release 22.0 (SPSS, IBM).

**Results**

Clients

The socio-demographic and appointment frequency data for the 369 clients are displayed in Table 1. Most clients were male and almost 60% were between the ages of 12 and 18 years. Clients were predominantly white although approximately one in five were either black or Asian. The socio-demographic profiles of the client groups with first and follow-up appointments were highly comparable, a consequence of the large overlap between the groups. Across clients, there was a wide range in the number of individual appointments scheduled in the study period. The median number of appointments overall was 5.0 (range 1-91), and just under a third of clients (and/or their carers) had more than 10 scheduled appointments.

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Appointment location

The frequencies of first and follow-up appointments in various sites utilised by ND-CAMHS across the study period are depicted in Figure 1. As indicated, first appointments were much more likely to be clinic-based (78.2% or 291/372) than follow-up appointments (34.3% or 1305/3805; *χ2* = 276.98, *p* < 0.001), which were administered in a variety of sites, most frequently at the client’s school or home. Outreach teams were more likely than the London team to offer appointments at non-clinic sites although this was significant only in the case of follow-up appointments (85.0% 414/487 versus 62.8% or 2082/3313; *χ2* = 92.56, *p* < 0.001). The location of appointments was heavily influenced by the year of service within the study period, as the outreach teams became more established. Specifically, in 2009, all 317 clinic-based (first and follow-up) appointments were at London clinics, whereas in the following years, there was a significant number administered in outreach clinics (2010 22.6% or 104/460; 2011 47.5% or 250/526; January to September 2012 45.1% or 132/293; across years, *χ2* = 254.08, *p* < 0.001). There was also a marked shift from clinic-based appointments towards those at non-clinic sites, with the latter constituting 44.6% (255/572) of all appointments from April to December 2009, 51.5% (488/948) in 2010, 64.7% (963/1489) in 2011, and 74.9% (875/1168) of appointments from January to September 2012 (across years, *χ2* = 204.92, *p* < 0.001). The pattern of change was most obvious in follow-up appointments (non-clinic: April to December 2009 47.4% or 248/523; 2010 55.7% or 468/840; 2011 68.7% or 933/1359; January to September 2012 78.6% or 851/1083; *χ2* = 199.70, *p* < 0.001) than first appointments where changes were less marked (non-clinic appointments: April to December 2009 14.3% or 7/49; 2010 18.5% or 20/108; 2011 23.1% or 30/130; January to September 2012 28.2% or 24/85; across years, χ2 = 4.50, *p* = 0.212).

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Attendance rates at first and follow-up appointments

Of the 288 clients offered a first appointment in the study period, two-thirds (192) attended their appointment. Seventy clients who missed their appointment were re-offered a first appointment within the time period, of which more than three-quarters (53 or 75.7%) attended. As a whole, clients and/or carers were more likely to attend follow-up appointments (79.2% or 3015/3805) than first appointments (68.5% or 255/372; *χ2* = 22.78, *p* < 0.001; OR = 1.75, 95% CI 1.39, 2.21). The higher attendance rate at follow-up was maintained after controlling for whether the appointment was at a clinic or non-clinic site (OR = 1.44, 95% CI 1.13, 1.83).

Associations between appointment outcome and location

More than three-quarters (75.3%) of clients/carers attended their first appointments in non-clinic sites (Table 2). This compared with 70% attendance at London clinics and a little over 62.5% at outreach clinics. But the numerical differences were not significant. There was a significant effect of year, driven at least in part by a very high first appointment attendance rate in the final nine months (2012) of the study (almost 80%) relative to the two years preceding it. However, no other variable significantly predicted appointment outcome, although in some cases this may have reflected low numbers (eg, appointment type, ethnicity). After adjusting for service year, there was almost 50% increase in the odds of having attended’ non-clinic than clinic-based appointments (London or outreach), although the difference was not significant (OR = 1.48, 95% CI 0.85, 2.66).

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The effect of appointment location was highly significant in follow-up appointment outcome (Table 3). Univariate analyses revealed that there was a 45% and 74% increase in odds of attendance at appointments at outreach clinics and non-clinic sites, respectively, compared to hospital-based clinic appointments. Clients/carers were also more likely to have attended if the appointment was administered in the latter half of the study period (ie, 2011 or January to September 2012), scheduled to occur in the morning, and if the client was male and had missed less appointments (in the study timeframe) previously.

Importantly, the positive impact of administering appointments in non-clinic sites on outcome was maintained after controlling for service year and other variables significant in univariate analyses, although client gender and appointment time of day were not significant in multivariate analyses. Overall, the odds of clients/carers having attended non-clinic appointments showed a 40% increase relative to appointments at any clinic site (London or outreach), even after accounting for other significant factors (OR = 1.39, 95% CI 1.17, 1.65).

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Reasons for missed first and follow-up appointments

The reasons for a client/carer resulting in a missed appointment outcome as a function of appointment location are shown in Figures 2a and 2b. For both first and follow-up appointments, ‘did not attend’ (DNA) was the most frequently recorded reason for a missed appointment and constituted 19.4% and 9.9% of first and follow-up appointments, respectively. The respective percentages for appointments cancelled by clients/carers were 7.0% and 5.3% and for appointments cancelled by the clinician was 4.8% and 5.5%. Location had no significant effect on the reason for a missed first appointment. However, DNA and client/carer cancellation rates were significantly less in follow-up appointments at non-clinic sites, while the proportion of clinician cancellations were the same irrespective of appointment location.

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Insert Figures 2a and 2b about here

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**Discussion**

This study examined attendance rates in first and follow-up appointments as a UK National Deaf Child and Adolescent Mental Health Service (ND-CAMHS) implemented treatment at outreach clinics and non-clinic sites over a three-and-a-half-year period. Overall, there was an improvement in attendance across the years studied, a pattern that was evident irrespective of appointment location.

The key finding was that clients/carers were more likely to attend follow-up appointments held at non-clinic sites, a consequence of fewer DNAs and client cancellations. These findings are broadly consistent with research identifying difficulties with transportation as an important factor in families’ non-attendance at CAMHS22, 29 and ND-CAMHS12, 13, and add to the evidence base for the influential role of structural barriers on attendance to CAMHS and paediatric services22, 27, 30,35. Using locations, such as the client’s school or home, appears to improve service accessibility, treatment continuity and reduce the proportion of wasted appointments in ND-CAMHS. More generally, the finding also demonstrates the service being provided is engaging users and strong therapeutic relationships are being formed through offering specialist support to the population of Deaf children that is not regularly available within other general CAMHS teams and related services.

Across the study period, first appointment DNA rate was slightly less than 20%. Comparisons with numbers of Deaf children attending mainstream CAMHS are precluded by a lack of published data. Nevertheless, this compares favourably to previous large-scale reviews of generic CAMHS22, 32, although falls short of the highest quality benchmark (< 13.3%) specified by national performance indicators for missed outpatient appointments in the NHS of the UK33. The DNA rate of 9.9% for follow-up appointments satisfied the Department of Health benchmark33, and was slightly less than the average DNA rate (11%) for (Tier 1-3) outpatient appointments reported in a recent benchmarking report of UK CAMHS providers34, In view of the increased non-clinic and outreach activity, the observed modest improvements over (other) mainstream CAMHS attendance rates likely reflect the great difficulties accessing appropriate health care services generally experienced by this population6,17. Nevertheless, higher follow-up than first appointment attendance rates suggests that once engaging with members of the ND-CAMHS, families are more likely to continue attending.

Attendance at outreach clinics was not significantly better than that at hospital-based clinics. This is surprising given the emerging evidence base for the provision of health care closer to home. McLeod, Heath, Cameron, Debelle and Cummins30 reported that shortened travel distance via the implementation of outreach clinics for general paediatric outpatient services was specifically associated with higher attendance. Qualitative investigations have also indicated that community-based clinics provide a better experience (less disruptive to daily life) for families than hospital visits36. In the present study, the numbers of scheduled outpatient clinic appointments was much smaller than for hospital clinic or non-clinic appointments and the lack of significant benefit for follow-up appointments may simply reflect this (univariate analyses did reveal a significantly higher attendance rate relative to hospital clinic appointments but the effect did not survive multivariate analysis). Further, there was no data available specifically concerned with travel distance so there was no direct examination of this variable. This is likely relevant to ND-CAMHS, because, despite being ‘outreach’, the outreach clinics covered a vast amount of geographical space (8 UK counties between Kent and Cambridge outreach teams). Nevertheless, it is worth considering that first appointments in outreach clinics tended to be (by comparison) poorly attended, and that improved attendance rates were clearly observed for follow-up appointments at non-clinic sites. As such, providing mental health services for Deaf children and young people in their school, home or community locations may be the most appropriate strategy to increase access to specialist care and minimise the number of missed appointments. The potential benefits of child and adolescent mental health services providing health care in settings outside the clinic have been increasingly recognised, with many CAMHS now providing direct work with children in schools, including assessment, observation and individual and group work37,38. This study extends that to the provision of mental health services to Deaf children and young people, at least with respect to attending appointments.

Considering the complexity of organising non-clinic appointments, it is encouraging to see the rate of clinic rate of clinician cancellations remained the same for follow-up appointments scheduled at non-clinic sites compared with clinic-based appointments. Given the service works alongside an array of different agencies and individuals, there may be cancellations from any of these members of the team. This is largely outside of the control of the clinician, as are situations that may arise for the clinician themselves in terms of transport delays and breakdowns. Nevertheless, relevant considerations with regards to additional cost of non-clinic based appointments should be taken into account. In addition to the described gain of reduction in DNA rates, this could also be offset by planning in the most efficient way possible how to best deploy resources within teams (eg, holding mini clinics in school with a number of Deaf children or at a local CAMHS in an area where several families may live).

Although in a recent study Deaf girls evidenced greater emotional difficulties that Deaf boys and their hearing counterparts10, in the present study, boys accounted for almost 60% of clients. Given boys are more likely to be diagnosed with conduct disorders and hyperactive behaviour39 and more likely to suffer from psychosis40, the high proportion of male clients referred to ND-CAMHS may not be surprising. Without clinical details about the reason for referral and subsequent diagnosis it remains difficult to interpret the differential referral rates between boys and girls. Interestingly, although one previous study demonstrated females as being more likely to attend CAMHS referrals41, consistent with an older review of initial appointment non-attendance in CAMHS where males and females failed to attend appointments at an almost equal rate42, in the present study there was no difference in boys’ and girls’ attendance rate once other relevant factors were accounted for.

In fact, after adjustment for factors relating to the year of service and appointment location, no socio-demographic variable predicted attendance at either first or follow-up appointments. Previous studies have indicated that clients belonging to an ethnic minority and/or lower social economic status (SES) are more likely to fail to attend CAMHS22,43, although other studies have observed no such relationship28. In this study, the risk of missing follow-up appointments was greater for clients who had a higher number of previously missed appointments, suggesting that despite the best efforts of the service to engage and support clients by offering appointments (including after non-attendances) in outreach and non-clinic sites, some clients/carers experienced difficulties in accessing and/or engaging with ND-CAMHS. Further work, focussed on specifying characteristics of clients/carers that predict repeated DNAs or cancelled appointments (including client presentation or diagnosis and social care factors), and identifying strategies to facilitate engagement with ND-CAMHS is necessary.

**Limitations**

There are a number of limitations in the current study. First, within the period of study, the service changed in a number of ways other than relocating appointment sites, most obviously increasing the number of appointments available to clients and the introduction of pre-treatment engagement strategies towards the very end of the study period (an informally administered practice of contacting the family of a child via telephone prior to issuing a first appointment to ensure the location and time were suitable, as well as a telephone reminder a few days before appointments), both of which likely impacted on attendance rates. The latter may be especially relevant here, given a recent controlled cohort study in a CAMHS reported that the introduction of a structured, pre-intake contact between a clinician and caregiver significantly decreased DNA rates for the initial and first three scheduled appointments28. Further, the timeframes used to compare attendance rates over years were not always equal in length.

Second, a range of potentially relevant factors were not investigated, including demographic variables known to affect attendance rates in CAMHS such as the possession of a car, socio-economic status, having a partner, employment status, and having to care for other sick children or dependents22, 44. While offering client appointments at home or school likely mitigated the impact of some of these factors, the extent to which they related to missed appointments in either the clinic or other sites remains unclear. Additionally, other potential confounders, such as differences in waiting times and quality of referral letter, which are known to influence attendance of first appointments with CAMHS22, 32, or the impact of regular use of BSL interpreters on BSL users in the service, were not investigated here.

Third, it is unclear why clients/carers did not attend or cancelled appointments, with no reasons recorded. Fourth, although the large number of follow-up appointments allowed for wide-ranging analyses identifying factors related to non-attendance, the number of first appointments was much smaller, possibly precluding significant findings. Finally, we did not include health outcome data (ie, CGAS, HONOSCA) in this audit, nor did we include information on diagnosis, so the impact of missed appointments on clients’ progress or whether the nature of their difficulties may have interfered with engagement is unclear.

**Conclusions**

This is the first (published) study investigating attendance of mental health services over an extended timeframe in the population of Deaf children and young people and their families. The findings of increased attendance rates in follow-up appointments based at non-clinic sites (compared with clinic appointments) indicates that the expansion of ND-CAMHS to work directly with clients/carers in their schools, homes, and community locations was effective in increasing service accessibility. Questions remain about why some clients and their carers frequently miss scheduled appointments and how best to engage these families. Nevertheless, the present study strengthens the case for restructuring mental health services so as to provide health care in local areas to Deaf children and young people and their families.

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