

Evaluation of the neurodiversity support pathway in Hertfordshire: Stage 1 Final Report



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Executive summary

Overview

In the summer of 2023, Health Innovation East was asked by Hertfordshire County Council (HCC) to evaluate the neurodiversity support services for children, young people, parents and carers in Hertfordshire. The evaluation, overseen by both HCC and the Mental Health Learning Disability and Autism Health and Care Partnership, aims to assess the effectiveness of the neurodiversity support centre, referred to as the Hub, in (a) supporting parents and carers, (b) serving as a central point for professionals, and (c) facilitating data collection for informed planning. The first stage of the evaluation, completed in January 2024, focused on analysing data on Hub usage and conducting interviews and focus groups to address the initial research questions. The report outlines findings from this first stage, which emphasises understanding the use and impact of the Hub, its role in family life, and its acceptability to various stakeholders.

Methods

A mixed-methods approach was employed, combining data on service users from the Hub with qualitative insights gathered through focus groups and 1:1 interviews conducted in November and December 2023. The quantitative analysis of service use data utilised Microsoft Excel, focusing on changes in service use over time. Qualitative research involved engaging parents who utilised the Hub's helpline, Hub staff, and professionals from various support agencies. Focus groups and interviews, guided by a thematic framework, addressed specific evaluation questions related to the engagement of parents, the acceptability of the support centre to staff, and the viewpoint of professionals from referring agencies. NVivo software facilitated the coding and analysis of transcripts, identifying key themes and emergent codes. The qualitative work was guided by a logic model (Appendix 1) describing three phases of support: start-up, delivery for parents and carers, and delivery for children and young people. The first stage of the evaluation primarily focused on delivery for parents and carers, with reflections on the start-up phase. The second stage of the evaluation will centre on the delivery of support for children and young people.

Findings

The analysis of service use showed a consistent rise in calls to the Hub helpline with an increase from 113 to 186 monthly calls from May 2022 to November 2023. This upward trend aligns with an increase in helpline staffing levels, reflecting the growing demand for the helpline service. Monthly variations, notably following school holiday periods, were observed. Calls predominantly originated from parents, although they were also received from health and social care professionals with few calls being unanswered. The helpline catered to diverse needs, addressing both child-related and caregiver-related concerns.

Positive user feedback highlighted the value of engaging with professionals who have firsthand experience, effective crisis support, and high-quality follow-up emails. Additionally, the Hub extends support through various digital channels, including emails and an active Facebook group, which saw increased stated demand over the time period for which data was supplied.

The focus groups and interviews raised several themes related to the support service. These were:

Urgency of need:

- Parents expressed feelings of helplessness during crises, seeking guidance for neurodivergent children.
- Referral agencies played a crucial role, often connecting families with the Hub during diagnostic waiting periods.

Support received:

- The Hub offers comprehensive, flexible, and supportive assistance tailored to families' evolving needs.
- Call handlers' personal experiences with neurodivergence contribute significantly to empathetic support.
- The Hub staff's training in coaching techniques enhances their ability to handle challenging calls.

Quality of service:

- Parents praised the Hub's valuable, easily accessible, and personalised services, emphasising its role in resolving problems.
- The personal experiences of Hub staff contribute to the quality of service, fostering understanding and empathy.
- Strong team support, information sharing, and collaboration with other organisations enhance service quality.

Impact:

- Parents reported improvements in psychological well-being, parenting skills, and overall family functioning after receiving Hub support.
- The Hub's positive impacts led to reduced reliance on additional services and improved family dynamics.

Demand for service:

- Increasing demand for the Hub's services was noted, driven by greater awareness and changes in diagnostic practices.
- Concerns were raised about the potential overwhelming of the Hub and the need to manage increasing demand.

Wider system:

- The Hub simplifies navigation of support services, but parents face challenges in the educational system.
- Consistency and predictability in managing neurodiversity were highlighted as essential, with a call for increased training for educators.
- Suggestions were made for online services to bridge geographical gaps and ensure equal access to resources.

Future development:

- Parents expressed a desire for extended helpline hours, and the Hub team proposed an interactive chat service.
- Challenges in accessing information about the Hub were identified, suggesting a need for proactive promotion in various settings.

Conclusions

The evaluation indicates that the support Hub effectively offers high-quality and personalised assistance to parents and carers of neurodivergent children and young people in Hertfordshire, especially amidst extended waiting times for formal diagnoses. The Hub is a valuable resource, alleviating pressure on the broader health and social care system. Stakeholder discussions and service use data highlight the increasing demand on the Hub, emphasising the need for sustainable strategies as the service expands. Managing the surge in demand while maintaining the quality of tailored services poses a challenge to the Hub, requiring careful resource allocation and strategic planning to meet a growing need.

Introduction

In the summer of 2023, Health Innovation East (formerly Eastern Academic Health Science Network) was commissioned by Hertfordshire County Council (HCC) to deliver an evaluation of the neurodiversity support offer for children, young people, parents and carers in Hertfordshire. The evaluation is being overseen by staff HCC and the Mental Health Learning Disability and Autism Health and Care Partnership. The overall aim of the evaluation is **to assess how well the neurodiversity support centre (hereafter the Hub) is: supporting parents and carers; providing a single point of contact for professionals; and enabling data collection to inform dynamic planning.**

This report considers the findings from the qualitative data collected during Stage 1 of the evaluation as well as a quantitative dataset supplied on use of the Hub by service users. In the context of this work, neurodiversity is taken to mean attention deficit hyperactivity disorder (ADHD), Autism, or a related condition, which aligns with the services provided by the Hub. The Hub is run by a Hertfordshire-based charity called ADD-vance (the ADHD and Autism Trust) on behalf of HCC. The funding for the Hub was initially allocated for a two-month pilot program from August to September 2021, and additional funding was granted in May 2022. As of August 2022, the helpline service had three call handlers, up from two since May 2022. The team expanded its workforce to five call handlers in November 2023.

The evaluation has five objectives, which are to understand:

1. *Use and uptake of the Hub (including number of calls, reasons for calls, follow-up needed, needs identified and feedback).*
2. *The role the Hub has played in a young person's care and the impact this has had on them and their family – through analysis of routine data and additional qualitative data where needed, to develop individual case studies.*
3. *How well the Hub is meeting the needs of parents, carers and families, and where additional support may be required.*
4. *How acceptable the Hub's approach is to staff working in it – including with reference to workload, confidence, training, perceived usefulness and ability to deal with referrals.*
5. *How acceptable the Hub's approach is to staff from referring agencies – including perceived ability to deal with referrals and meet need.*

In line with these objectives, there are three overarching research questions:

1. *How has the neurodiversity support Hub been adopted by children and young people and their families?*
2. *How acceptable is the neurodiversity support Hub to:*
 - a. *Parents and carers*
 - b. *Neurodiversity support centre staff*

- c. *Staff from referring agencies*
3. *What role has the neurodiversity support Hub played in a child or young person’s care, and what impact has this has on them and their family (including what they would have done if the hub was not there)?*

The evaluation process consists of two stages. The first stage, which began in October 2023 and completed at the end of January 2024, focused on assessing the core service provided by the Hub run by the charity ADD-vance. This first stage has focussed on the first research question, via an analysis of a supplied secondary dataset on use of the Hub; and the second research question, via a series of interviews and focus groups. The second stage of the evaluation will assess the range of support offers developed from the core service and will focus on the third research question.

Methodology

Stage 1 of the evaluation comprised a mixed-methods approach, which combined data on service users collected by the Hub and qualitative data collected through focus groups and 1:1 interviews in November and December 2023. Service user data was provided to Health Innovation East on the 21st December, 2023.

Table 1 shows the schedule of data collection that was used to address the research questions that governed this evaluation.

Table 1: Schedule of data collection used for research questions

Research question	Data collected
1. <i>How has the neurodiversity support Hub been adopted by children and young people and their families?</i>	<ul style="list-style-type: none"> Quantitative data on service use
2a. <i>How acceptable is the neurodiversity support Hub to parents and carers?</i>	<ul style="list-style-type: none"> Two focus groups (6 parents in total) with a sample of parents of young people who are neurodivergent and used the helpline provided by the Hub Five 1:1 semi-structured in-depth interviews (5 parents in total) with a sample of parents of young people who are neurodivergent and used the helpline provided by the Hub
2b. <i>How acceptable is the neurodiversity support Hub to Hub staff?</i>	<ul style="list-style-type: none"> One focus group with 5 Hub staff who run the helpline service One 1:1 semi-structured in-depth interview with the CEO of ADD-vance
2c. <i>How acceptable is the neurodiversity support Hub to staff from referring agencies?</i>	<ul style="list-style-type: none"> Three 1:1 semi-structured in-depth interviews with health and social care professionals who, in their professional capacity, work with children, young people and their parents or carers who make use of the service

Quantitative work

The analysis of the quantitative service use data was undertaken using Microsoft Excel. Comparisons were made based on mean values and differences. As there was no intention to undertake hypothesis testing, measures of statistical significance were not computed.

Qualitative work

Focus groups and 1:1 interviews (depending on convenience and preference of participants) were undertaken with:

- A sample of parents of young people who are neurodivergent and who have used the helpline for parents and carers provided by the Hub.
- The Hub staff who operate the helpline, along with the CEO of ADD-vance.
- A sample of staff who, in their professional capacity, work with children, young people and their parents or carers who make use of the service and hence form part of the wider support network in the county. Contact details were supplied for staff representing East and North Hertfordshire NHS Trust (a paediatrician), Hertfordshire Community NHS Trust (a referral hub manager), and the Special Educational Needs and Disabilities Information Advice and Support Service (a SENDIASS representative).

Parents and caregivers were invited to express their interest in participating in the focus groups and interviews via the Hub. The 1:1 interviews lasted around 45 minutes each, while the focus groups were just over an hour long. All interviews and focus groups were guided by a topic guide that covered the themes outlined in Table 2.

Transcripts were imported into NVivo (qualitative data analysis software), where the data was coded and analysed for key themes for the purpose of analysis. Initial codes were generated in relation to study objectives and the topic guide; emergent codes were also identified and incorporated into the analysis.

To guide the qualitative work, the evaluation team's early task was to finalise a logic model describing the support provided. This model was co-developed during the summer of 2023 and finalised during an online workshop on November 3rd, 2023. The logic model is presented at Appendix 1 at the end of this document. It divides the service provision into three phases: the initial start-up phase, which includes setting up the Hub, recruiting staff and establishing services; the delivery of the support service for parents and carers; and the delivery of a support offer for children and young people.

Table 2: Themes explored during focus groups and 1:1 interviews.

Stakeholder group	Themes explored
Parents and carers of neurodivergent young people	<ul style="list-style-type: none"> -What were the needs that led them to use the service? -How did they engage with the service and what support was received? -How easy was the service to use? -What was the quality of support provided by the service? -Where there any areas for improvement? -What was the impact on the service on the parent/carer, the young person they were caring for, and on wider family functioning? -What were the mechanisms by which any impacts arose, such as improved knowledge and understanding, learning of practical skills, feeling listened to and validated? -How might the Hub evolve in the future to continue to meet potentially changing needs?
The CEO of ADDvance	<ul style="list-style-type: none"> -How was the service developed in terms of identification of need, ways of addressing need, and implementation of the service? -How might demand for services like those provided by the Hub evolve in the future? -How challenging is it to provide the service in the context of considerable diversity in need in the community? -What are the critical requirements for successfully delivering the service? -How is the success of delivery internally assessed? -How might the services offered by the Hub evolve in the future?
Staff operating the helpline run from the Hub	<ul style="list-style-type: none"> -How acceptable is the approach adopted to the Hub to staff, including workload, confidence, training, support for themselves? -How well does the Hub work with various partner organisations to deliver services? -How well does the Hub meet the needs of the community, including how are needs identified, what gaps are there, what challenges do they face? -How might the services offered by the Hub evolve in the future, such as range of services offered, level of provision, links with other organisations, digital offers?
Staff who work with children, young people, and their parents and carers who may use the Hub	<ul style="list-style-type: none"> -What is their role? -What is their experience with signposting people to the Hub, including how to identify need, how to determine if need is met? -What impact has the Hub had on knowledge and support options for neurodivergent individuals and their families? -What impact has the Hub had on the time they have available to support their own service users such as diagnosing neurodivergence, dealing with calls, providing support?

	<p>-What impact has the Hub had on work satisfaction and needs of the organisation?</p> <p>-What, if any, changes could be made to improve your relationship with the Hub, including range of services offered, closer links with other teams, formal referrals, accessibility improvements?</p> <p>-How might demand for services like those provided by the Hub evolve in the future?</p>
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Quantitative findings: Analysis of data on service use

Health Innovation East was supplied with a dataset (in Microsoft Excel), which consisted of data on various elements of service provision, and the data provided is set out in Table 3. The data were supplied variously over the period 1st December 2020 – 30th November 2023, with the November cut-off representing the most recent complete data that was available at the time of supply. This time-period coincides with a considerable expansion of the service, which includes the Hub being commissioned by Hertfordshire Community NHS Trust in May 2022, following an initial period of piloting along with subsequent evaluation in August and September 2021. Over the period the number of staff employed to deliver the telephone helpline service increased from an initial one worker to two in May 2022, three in August 2022 and then five in November 2023.

Table 3 shows that data were supplied covering four domains of service use; the volume of calls made to the helpline, the identification of needs discussed amongst the callers, the contacts made with the other services offered by the Hub as well as written feedback provided by users of the helpline. For all datasets, the period covered extended earlier than the month ADD-vance were commissioned to deliver the services of the Hub. In the analysis of this data, differentiation is therefore made between the pre-and post-commissioning time periods where appropriate.

Table 3: Service use data supplied.

Dataset	Time period covered
-Number of calls made to the helpline	1 st December 2022 – 30 th November 2023 (with detail on call characteristics) 1 st December 2020 – 30 th November 2023 (monthly call numbers)
-Identification of needs amongst helpline callers	1 st October 2022 – 30 th November 2023
-Contacts made with the wider Neurodiversity Support Hub helpdesk service	1 st October 2022 – 30 th November 2023
Feedback from service users of the helpline	1 st May 2022 – 30 th November 2023

(i) **Use of the helpline service**

According to the data, there has been a sharp rise in the number of calls the Hub helpline receives in recent years. This is illustrated by Figure 1. The number of calls made in December 2020 was 18, which increased to 186 in November 2023.

Figure 1: Calls made to the Hub by month, December 2020-November 2023

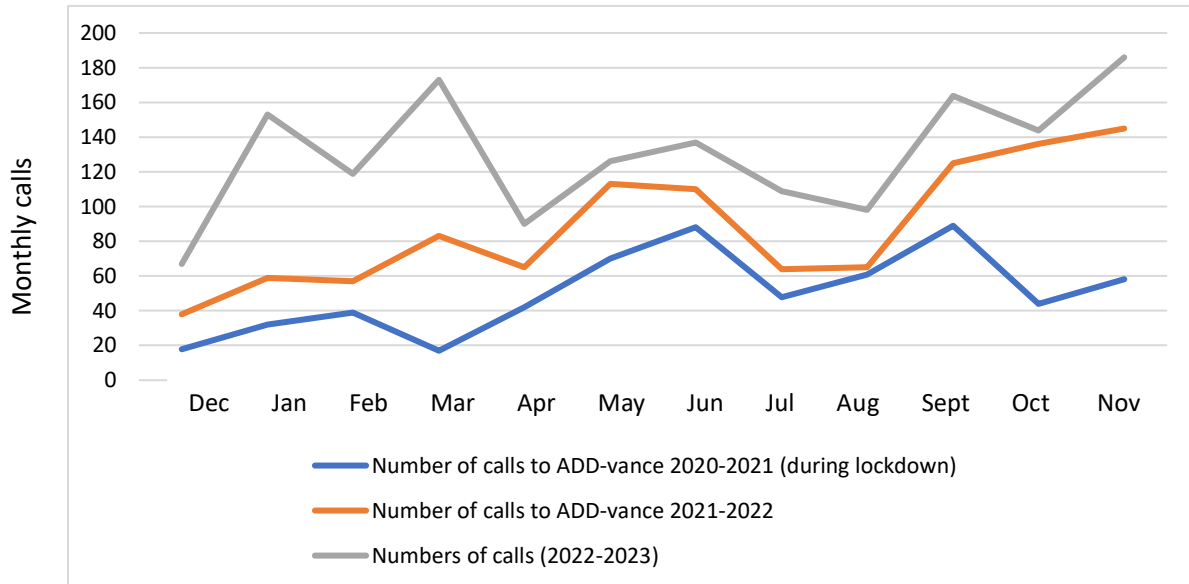
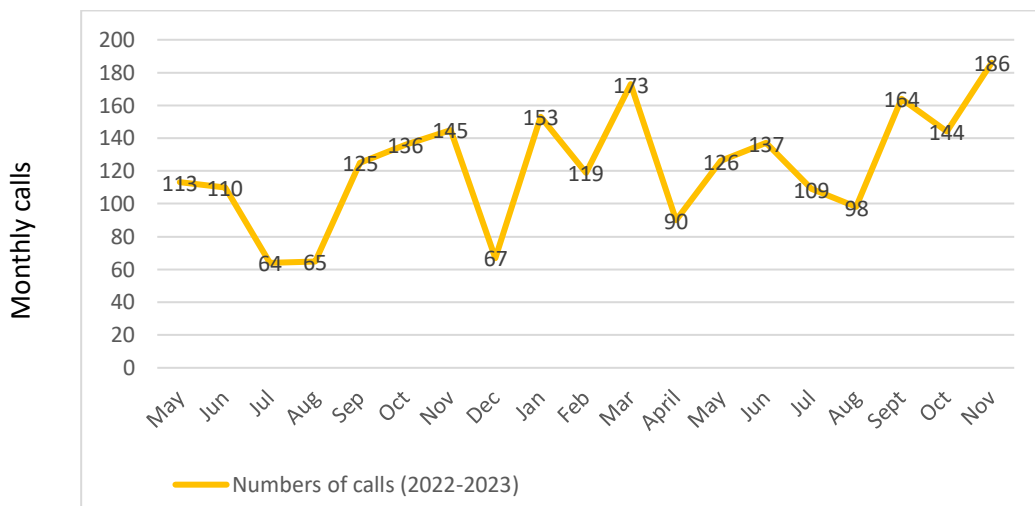


Figure 2 shows the volume of calls made to the Hub helpline between May 2022 and November 2023 (when the Hub was commissioned). The graph depicts a steady upward trend in the number of calls received, with a total of 113 calls made in May 2022, which rose to 186 calls by November 2023. The figures suggest a growing demand for the Hub helpline service which has been relatively constant over the period for which data was available and did not appear to be particularly impacted by the commissioning of the Hub in May 2022 and any associated increase in promotion.

Figure 2: No. of calls made to the Hub by month, May 2022 - November 2023



Analysis was undertaken to look at the number of telephone calls received relative to the number of staff working on the helpline. This shows that there was an average of 53 calls per month when there was one staff member, 88 when there were two, 123 with three and 186 with five (with the latter value being based on just one month of data). The appointment of new staff to deliver the helpline service has therefore aligned with increased demand on it. Similarly, there has been a considerable increase in the monthly number of calls to the service in the post-commissioning period (May 2022 onwards) compared to before, with mean monthly telephone call numbers of 53 and 122 calls pre- and post- commissioning respectively.

Both Figure 1 and 2 show the overall trend of increasing demand for the helpline over the time for which data was supplied. There is however quite substantial monthly variation around this trend, the pattern of which is suggestive of an association with school holiday periods. For example, over the three years of data, the mean number of calls received in December was 50% lower than the following January (post new year return to school) value. Similarly, the volume of calls received in August (summer holiday period) was just 53% of that received in September. There was less evidence of a post-Easter holiday peak in calls, but this may be because only monthly values were available and the changeable dates of the Easter holidays, which can span more than one month, may obscure any increase in demand following the return to school. Nevertheless, the data provides evidence that periods of return to school are associated with increased demand for the helpline. This triangulates with the findings from the qualitative work reported elsewhere in this report, where parents of neurodivergent young people talked about a range of challenges around schooling as well as the needs identified from the Hub use data below.

The data show that calls are typically around 25-30 minutes in duration, with a mean duration of 26 minutes over the most recent 12-month period December 2022-November 2023, although the range was considerable; between two minutes for the shortest calls and over two hours for those of the longest duration. Around 94% of calls came from the parents of neurodivergent young people, whilst around 2% of calls came from other family members or carers or other neurodivergent adults. The remaining 4% of calls came from health care, social care, and education professionals.

In December 2022, 42% of calls received were from existing users, with this percentage increasing to 63% in November 2023. The callers were also asked how they found out about the service. Most of the new users discovered the service through an online search (35%), word-of-mouth (20%), or an educational setting (8%), whereas referrals and signposting from other organisations were less common. It is notable that 20 helpline users reported hearing about the service from an organisation recorded as the "Peace Centre" in September 2023, which may have been associated with a publicity event.

Most of the calls were promptly answered, with an average of just 8 calls per month being redirected to the answerphone with the option of a callback if contact details were left. Conversations with the CEO of ADD-Vance suggested these calls were received at the times when the helpline was closed, rather than being unanswered calls during staffing hours.

(ii) Needs identified amongst helpline callers

A very wide variety of needs were identified from the callers making use of the service, and most calls were associated with more than one need. These are shown in Table 4, ordered according to overall frequency, for the most recent year for which data was available. Given the focus of the helpline, it is unsurprising that the need to understand ADHD and/or autism was identified in most calls. Additional groupings of needs that were commonly identified included addressing the needs of the parent or carer themselves (e.g. self-care), those of children and young people (e.g. managing self-esteem, depression, and anxiety), the challenges of managing the wider support system (e.g. working with schools and Special Educational Needs (SEN) workers, rights and benefits, obtaining a private diagnosis), dealing with the challenges of managing particular situations or behaviours (e.g. toileting, distressed behaviours, communications) and understanding the challenges young people were facing (e.g. puberty, preparing for adulthood, relationships and bullying).

(iii) Feedback from helpline callers

Callers to the helpline are sent a follow-up email, when an email address is provided, providing them with an opportunity to give feedback on their experience with the service. In May 2022, feedback was provided by just 5 callers (4.5% of the total number of callers), whilst this had risen to 42 callers (22.6% of the total) by November 2023.

Callers who provide feedback are asked to rate their satisfaction with the service they received on a scale of 1 to 5, with 5 indicating the highest level of satisfaction. The data shows that levels of satisfaction were consistently high during the period for which data was collected, with the monthly mean score ranging from 4.72 out of 5 to 5 out of 5 in several months. Additionally, callers were asked whether they would recommend the service to others, and the responses indicate a high level of satisfaction, with 93% responding 'yes' and 7% responding 'maybe' in one month, and 100% responding 'yes' in 16 out of the 19 months for which data was provided.

In addition to scoring their satisfaction with the service, callers are given the opportunity to provide written feedback on their experience. This feedback was supplied for the 380 callers who chose to provide it between June 2022 and November 2023. The feedback supplied is generally very positive. Based on the feedback received, some key themes have emerged, which include the following:

- Numerous benefits, including feeling truly understood and not feeling the need to explain a complex back-story, were reported by individuals who spoke with staff members possessing professional and personal experience of neurodiversity.
- Amongst over 350 responses provided for this evaluation, there was no evidence of any negative feedback
- The ease of contacting and utilising the service was appreciated by those who used it.
- The support provided by the service was deemed critical in helping individuals during times of crisis.
- The continuity of service offered by the helpline was much appreciated, and individuals felt reassured knowing that support was available when needed.
- Follow-up support provided by the service after the end of a call was considered helpful by those who used the service.

The themes raised by service users in their feedback align with those that arose during the interviews and focus groups undertaken with parents of neurodivergent young people and are explored in detail in that section of this report.

Table 4: Needs identified (by number of instances overall) during calls to the Hub Helpline, December 2022 – November 2023

Needs Identified	Dec '22	Jan '23	Feb '23	Mar '23	April '23	May '23	June '23	July '23	Aug '23	Sept '23	Oct '23	Nov '23	Total
Understanding ADHD and/or Autism	41	85	72	92	58	66	82	58	63	86	84	73	1029
Anxiety/Depression/Phobias	42	90	78	93	49	65	86	47	47	67	63	62	955
School/Learning/SEN Support Process	21	60	52	68	33	44	56	34	10	68	57	78	713
Anger/Aggression/Distressed Behaviours	35	50	47	70	32	49	62	40	45	44	51	51	683
Diagnostic Pathway	20	39	37	48	29	38	42	19	28	39	36	51	500
Recommended Resources	23	43	33	39	22	29	39	25	31	44	56	25	480
Self-esteem	18	38	31	39	20	23	42	0	0	0	0	30	325
Everyday Transitions	10	33	17	24	12	14	31	15	15	31	30	20	300
Sensory Differences	7	24	22	33	14	11	29	14	14	20	34	29	300
Puberty/Adolescence	23	20	14	24	12	19	18	13	13	19	14	11	241
EHCP Support	7	16	16	22	8	13	22	14	5	21	26	33	234
Self-care	21	25	13	33	11	15	32	0	0	0	0	19	223
Communication	14	22	17	16	5	7	4	5	4	6	14	14	174
Rights & Benefits e.g. DLA	9	11	8	12	7	14	9	12	11	15	18	2	144
Private Diagnosis	8	8	13	12	7	12	11	6	8	9	14	9	143

Social Activities/Social Skills	9	17	10	7	2	7	13	11	5	13	9	15	140
Sleep	1	16	5	15	3	12	13	5	8	16	8	12	135
Relationships/ Bullying	9	13	15	19	6	8	15	4	4	4	11	9	134
Preparing for Adulthood	10	8	7	9	6	6	5	4	5	7	0	3	97
Siblings	5	9	6	6	3	4	12	4	5	5	6	10	95
Other unclassified	1	5	9	10	4	4	8	5	5	3	2		65
Toileting	3	5	0	3	1	2	2	1	0	2	5	9	40
Eating/Diet	1	1	2	2	2	2	2	6	2	0	6	6	39
Transition to Secondary School	2	5	2	2	3	2	2	0	0	2	3	2	32
Specific Learning Difficulties	0	3	0	0	0	1	2	0	1	0	0	2	16
Learning Disability	0	0	0	3	1	0	0	1	0	2	1	2	12

(iv) Use of the Hub helpdesk service

Over the most recent 12-month period for which data was available (December 2022–November 2023), there were an average of 13 monthly email enquiries received via the website and 27 sent to the general email address. There was growth in the number of email enquiries received, with 12 being recorded in April 2022, 30 enquiries received in December 2022, and 51 in November 2023. For each email received, the needs identified were logged. Unsurprisingly, these were diverse and primarily aligned with those identified amongst callers to the support helpline, with help understanding ADHD and/or autism being most common (34% of emails), followed by help with diagnostic pathways (10%), support with anxiety, depression and phobias (10%), and requests for recommended resources (10%).

Around 50 people were typically added to the Hub mailing list each month. Ninety three percent of people being added were parents or carers, with 7% from healthcare professionals. ADD-Vance maintain an active Facebook discussion forum, with data illustrating how well the Facebook site is well used. Over the most recent 12-month period (December 2022–November 2023) there were a monthly average of 4252 active members, 119 posts, 1229 comments and 1322 reactions. Although the number of active members increased over the period for which data was supplied (2933 in April 2022, 4261 in December 2022 and 5111 in November 2023) there was no clear corresponding trend in the number of posts, comments or reactions. The messenger service was used relatively infrequently; between six and 21 times for each month that data were provided. As no information on identified needs was available for the Facebook site, it is not possible to assess the needs that are met via this service.

Qualitative findings: Parent and carer, Hub staff and referring organisation conversations.

Findings from the focus groups and interviews are presented in the order in which they were explored within the topic guide. These are grouped within the following subthemes identified from the data: (i) Urgency of need, (ii) Support received, (iii) Quality of service, (iv) Impact, (v) Demand for service, (vi) Wider system, and (vii) Future development.

(i) Urgency of need

During our conversations with parents, the majority described feelings of helplessness and having no other options for seeking guidance and emotional **support during times of crisis**.

Many parents contacted the service through referrals, signposting, or word of mouth. Parents often contacted the service while the young person was on a waiting list for specialist diagnostic services.

"I was introduced to ADD-vance (the Hub provider) through the team I contacted to see whether they would be prepared to assess my son. There was a waiting list, that was the problem, so there was quite a long waiting list at the time that I first contacted them, and I needed a little bit of help in the meantime while we were on the waiting list, so they said they'd put me in touch with ADD-vance." (Parent focus group 01).

One challenge from the perspective of referring agencies is that families often wait for a formal diagnosis of Autism or ADHD when, in fact, they could proactively implement management strategies to support their children while on a diagnostic waiting list. One staff member from a referring organisation acknowledged the critical role of services such as the Hub in supporting families on waiting lists.

"And this is where things have improved dramatically for us to be able to give some information to the parent when they call in, some light at the end of the tunnel [the improvement has been driven by] ADD-vance, it's been a lifeline to a lot of parents." (Referring organisation, 02).

A staff member from a referring organisation mentioned that they felt less like they were abandoning their service users when they could not provide the **required support**.

'It's easier for the staff as well because we feel like we put the phone down, and basically, we've abandoned them as well. So, we had nothing before, whereas now we've actually got something to say to them and to give them and, like I say, it seems that they always answer the phone when they're open and "it's a very good service" is what feedback we get.' (Referring organisation, 02).

Parents described struggling with **managing complex behaviours** at home and school, as well as dealing with risk management **without specialist input**, as one parent highlights below.

"High school has been particularly challenging for him with a lot of disruptive behaviour and things like that, and I had got to the stage, or me and my husband had got to the stage where, I really felt quite helpless because I was being told that my son was going to be expelled and they didn't know what to do and, and all of this." (Parent interview, 04).

(ii) Support received

Parents have reported that the Hub provides **personalised support** and adjusts to their needs at different stages of their journey. They value the support that is on offer at various points in time, such as before the young person receives a diagnosis, and how it continues to provide varying types of support throughout the young person's stages of development.

"I've been using them for a few years now and I used them right at the very beginning of our journey before we had a diagnosis and then both my kids have now got their diagnosis, and then I used them again for refreshing and also because situations change." (Parent focus group 01).

Parents described the support offered by the Hub as:

- **Comprehensive:** which included a wealth of educational resources and consistent follow-up contact.
- **Flexible:** associated with comprehensiveness, which also means that family members who may not have otherwise engaged could do so.
- **Safe and supportive:** parents felt the helpline provided an environment where they felt understood.

"Someone for the first time was listening to me, and it sort of...it was over an hour's phone call, and she just...she was wonderful, she had, she explained that to work there they sort of all had either neurodiversity themselves, experience of neurodiversity and things like that and she made me feel like a mum and not a bad parent or someone that didn't know anything or like I was making my son's things up or whatever, she made me feel valued by a professional, which was just amazing." (Parent interview, 06).

(iii) Quality of service

Parents praised the quality of the services provided by the Hub as being **valuable, easy to access, and tailored** to the parents' specific needs. This **person-centred approach** made them feel they could resolve their problems in a way that suited them.

"They just, they get it, and they know, and they sympathise, and it's not just like a shrug you off kind of service, it's really detailed, really targeted specifically to you and your family's needs, not just ASD or ADHD, it's your family's needs. They

listen to everything that you say and then they follow up with very targeted detailed responses of actions that you can take, and I just find, I find it vital for us.” (Parent focus group 01)

Based on feedback received from multiple parents, the quality of services provided by the Hub is primarily attributed to the personal experience of the call handlers with neurodiversity. This experience is believed to allow them to understand the callers' situations better and offer empathetic support. The call handlers' **lived experience** is perceived to have a significantly positive impact on their interactions with callers.

“I think because a lot of the...well, all of the staff there and people on the helpline are going through similar experiences, you kind of feel like they understand what you are going through, and a lot of the times, you don't talk to other parents and things like that because you feel like there's a bit of a stigma or a little bit of a taboo and people don't really understand it. And so, it is important that you have somewhere that you can access that understands what you are going through as a family, can understand the support that we need to give to our son to be happy, healthy, and all the rest of it.” (Parent interview, 04).

According to the staff working in the Hub, there are several critical elements that support them to deliver the service effectively. These include:

- Having team members who have **lived experiences of neurodivergence**.
- The **diversity of experience** among staff allows for clients with specific needs to be referred to a relevant staff member.
- This variety of experiences also allows staff to **share knowledge, resulting in team growth and support**.
- The Hub staff have been trained in **coaching techniques**, allowing them to feel they handle challenging calls with confidence and impartiality.
- The **trained coaches in the community network** provide invaluable support to Hub staff.
- The Hub staff reflected a **strong sense of team support and camaraderie**.
- The organisation described a **strong culture of information sharing and network building**.
- The Hub staff described establishing partnerships with various organisations promoting each other's services. The Hub was well-known for collaboration, prioritising assisting parents and avoiding interfering with other organisations.

- The staff at the Hub express a **strong sense of support** from leadership and **value the supervision** structures that have been established.

"We are not just supporting each other here and making the tea and all of that. It's really important that we are supported, and actually (name omitted) will always make time available for us if we want to talk to her. It also makes it available if we want to be sort of supported by one of the coaches. So she'll arrange for a separate session for us. And then supervision is run twice a month. So we can tap into supervision with the other coaches and get supervision and maybe share something. So we are lucky that we are not just us five supporting each other and finding our way. We've got that." (Hub staff focus group).

(iv) Impact

Numerous parents expressed feelings of being overburdened and stressed due to their present circumstances, leading to a decline in their overall well-being and family functioning. After receiving support from the Hub, they described improvements in several areas:

- The Hub call handler's coaching and educational resources provided valuable support and assistance, improving **these individuals' psychological well-being.**
- Parents credit helpline staff and courses offered by the Hub (and others) with teaching them valuable skills to manage their children's behaviour, leading to **positive changes in their parenting.**
- Parents highlighted the importance of learning that caring for their mental health **positively impacts the young person's lives.**
- They expressed how the Hub has made them feel heard and understood and helped them **establish new strategies** to ensure their **children feel heard, understood, and supported.**
- They expressed that the Hub is a valuable resource for parents to navigate their children's unique journeys, **reducing their need for additional services,** as the Hub's **direct support to families has made it accessible.**

- Parents report that the Hub's positive impacts have led to **improved family functioning**.

"I think it's had a massive impact in lots of different areas. I feel like it's, it's almost like a service that incorporates so many different aspects, like mental health, occupational therapy, speech therapy and it just kind of ticks so many boxes in a way that it gives you a little bit of power back and a little bit of control because it gives you the knowledge and knowledge is power. And also it's that reminder of the perception of the, if kids aren't sick, you know, they don't need a doctor to come in and say, right you know, like if you had a cold or flu, this is just their brain is just different and the way that our world is that we want everybody in this box, and their brains aren't in that box. And so, it's giving us parents a way of helping them navigate through their path and their journey to make them feel stronger and it gives them that mental health support as well through us to them, so that you know, you don't have to send necessarily all the services and you're giving it straight through the family into the home, helping everybody." (Parent focus group, 02).

According to a referring organisation staff member, evidence shows that increasing community awareness of the Hub may reduce **the burden on partner organisations**.

"We were saying about the amount of calls (about neurodivergence), and we don't actually keep a running total, but it has dropped off recently. Now, I think it's because the Trusts have been actively sending letters and communications, giving people the information regularly. And I think they should be commended for that, to be honest, because they really have made a difference." (Referring organisation, 01).

(v) Demand for service

From the Hub's team perspective, **demand for services** was sharply increasing, partly driven by the strain **on the wider system**. They described how, with the increased demand, guidelines have been implemented to assess the service's capacity. The service is considered at full capacity if they cannot respond to messages within a day or emails within 48 hours.

"I think what we're doing at the moment, obviously, the demand has increased.... and it's a case of I have put red flags in the ground to say, if we're not getting back to people within the day, if they leave a message, then that's

when we're at capacity, if we're not able to do the ring backs that we want to or if we're not able to do the emails back, we want to within 48 hours. So, I've kind of got my this is where we'll get to, I can see when it's going to get to roughly there, and then I will kind of say, well, okay, that's work capacity. We can't start advertising any further." (Hub staff interview).

According to the Hub team, managing the time callers spent on the helpline was necessary to manage the load and prevent inappropriate dependency. Some callers were described as having specific issues they wanted to discuss, but others used the helpline as one of their only sources of social contact.

"We put boundaries in place. So, we will say... we're talking to you today on a Monday. "How about you phone us next Monday [And tell us how you are doing]"? Because otherwise, they would be phoning us every day to update. So, we give them that timeline." (Hub staff focus group).

From the hub team's perspective, a particular consideration in managing the increased demand for the helpline was the need to protect the **well-being of the call handlers** and give them the space and time to manage the impact of difficult calls.

"I am aware of situations where, after the call, our call handlers have just gone, I need space. Yeah. And then we'll go and have a chat and talk it through. And I'll bring the call handler down." (Hub staff interview).

When we asked staff from referring organisations, they highlighted **concerns about growing demand in the system and the volume of work a centralised Hub would face.**

"I would say my biggest concern about the Hub is it is going to be utterly overwhelmed. It will be overwhelmed as soon as word gets out. It's not going to be able to manage what it's got, it won't have the capacity, and it needs a huge amount of input because we know, from the numbers that are being referred to us and our waiting list, that the numbers are just overwhelming really." (Referring organisation, 01).

Increasing demand for the services offered by the Hub was seen as being driven by a combination of greater awareness of the services offered by the organisation plus changes in diagnostic practices, meaning more young people were being diagnosed as neurodivergent.

"I think it will continue to increase, but that's based on... I know that there's work going on around pathways and wait lists and all of those things, but I think we see the demand still going up for our service, and I just assume that's probably reflective of the system." (Referring organisation, 03).

(vi) Wider system

Professionals from partner organisations, who may direct service users to the Hub, have spoken about how the Hub **simplifies the navigation of support services**, which can be complex and confusing.

"I think the one-stop shop or the concept of the Hub as a 'the place you go to' because the list of resources we send family is huge, and it's mind-boggling." (Referring organisation, 01).

Notwithstanding the positive outcomes reported by parents, many of them encountered difficulties when **navigating the educational system**, such as facilitating the return of a young person to school or managing the disruption that comes with changing schools.

"I think for us, we are also in that stage that my son's got a diagnosis now. Great, okay. But it's still not going to help him go back to school, and I've just had, that's why I was late was on the phone to the school and she was saying, "I don't know, I think we've done everything we can do to help you now and we just don't know what to do now." And, and I'm like, yeah, he's still home. And then yeah, where do you go from there? And I think it's just a real, there's a real unknown." (Parent focus group 02).

From the parent's perspective, an essential aspect to consider while managing neurodiversity was the need for **consistency and a predictable environment**, where expectations, consequences, and management of situations remain the same, irrespective of the location. This consistency in approaches was seen as **crucial for ensuring a stable and supportive environment for individuals with neurodiversity**.

"That's like one of the first points for dealing with ASD, it's that continuity for them to have that prediction and everything is the same, so it's the same at school, it's the same at home. Same consequences, it's the same expectations, and it's the same way it's going to be dealt with." (Parent focus group, 01).

Many parents suggested that **schools receive more training on neurodiversity from the Hub**, as their expertise could help educators provide individualised support that meets each child's unique needs.

"I was going to say it would be great for some of the courses to be extended into schools. Or enable schools to have a greater understanding (...) it will help schools provide children with greater understanding and say, why are you doing this way, and schools will be better at working with parents and also these organisations, especially ADD-vance to say, actually we know how to work with this child, and rather than bucketing children (...). They're individual, but it is an issue. If ADD-vance can go into schools and support schools in a greater understanding, that would be absolutely amazing." (Parent focus group, 01).

One parent believed that educational providers are making the best of the available resources to support children with neurodiversity. However, there seems to be a gap between what parents learn and what teachers are trained to do, which makes it difficult for them to work together effectively. To avoid misunderstandings and conflicts, our findings suggest that **care is taken to align the content of training offered to both parents and teachers to ensure that both groups are on the same page and have access to consistent information.**

"So the teachers do get, as a professional body gets education and training in autism, in ADHD, (...) the problem is that at the moment generally, (...) parents have training and access in their way but it's different. It's not by the same provider, and there are no connections. In a lot of cases, everybody's trying to do the best thing for that child. (...) but it's not necessarily connected, and they're not necessarily singing from the same hymn sheet, so maybe there's a place for the same provider to be providing the training for the schools and the parents, so everybody gets the same message. So, you've got somebody that can see it from both points of view, and those that, the messages that they're giving to one party are the same as the messages they're giving to the other party rather than there being a little bit of conflict." (Parent focus group, 01).

One staff member from a referring organisation saw the **importance of supporting school staff** in managing challenges related to neurodiversity in their student populations.

"I have huge sympathy for schools because they also are very much on the front line of managing a lot of really difficult behaviours and really difficult presentations of children where I think the effects of the pandemic and lockdown are really proving to be very... we're really seeing the outcome of that now and it is very profound." (Referring organisation, 01).

A few participants highlighted that access to **resources and support systems may not be equal across different geographical locations**. Suggestions included that online services and courses can be leveraged to extend support to other regions, thereby ensuring equal access for all, making resources more widely available and helping bridge the gap between different areas.

"(...) I have friends in Essex who can't access this. I've got friends who are facing similar issues but in different parts of the country, and they don't have anything like this (...). If other parents had access to this (...), I think you'd have fewer children being taken into care throughout the country if the parents had the tools to be able to because people want to help their kids; generally, people want a happy home life. And if you gave them that, if it was more widely available across the country, I'm sure we would all be in a better place. Even if they just had a southern, like a hub, like a southern England hub, a middle England hub and a northern England hub, because most of what we've talked about, you don't need to be geographically close. We're accessing services online; we're doing courses on Zoom." (Parent focus group, 01).

(vii) Future development

We asked parents about areas where the Hub could be improved. Many parents expressed their desire for the helpline service to be **available for longer periods, potentially at different times of the day**.

"I've got to say, and this is going to sound really greedy, the only thing that I think that could improve it is if the number of hours that they operate could be extended slightly because as long as I have my crisis in a morning, it's fine, okay. But if we have a crisis after school, it's less fine, okay, because they're not open at that point in time. It would be lovely if there were a way of facilitating an afternoon service in the same way that you've got the morning service because they're brilliant, but it is for quite a specific window

of time. So, we have to plan our family crisis to make sure it fits.” (Parent focus group, 01).

The team at the Hub suggested the helpline's operating hours be extended to improve the service but would require **a different service model** where the extended hours would be used to address specific issues service users face. Additionally, the team has proposed introducing **an interactive chat service** as another **potential way to expand the service.**

“I like the idea of potentially doing something outside of the nine to one hours. (...) But, I think, for me, having that as more of an appointment space service works.” (Hub staff interview).

According to some parents, finding information about the Hub can be challenging, and **promoting their services more proactively** could prevent some families from falling into a state of crisis before becoming aware of the Hub.

“But I think earlier on it would be useful to have the information, and maybe it is available. I know it's on the Hertfordshire local offer page, but that is, well, that's a whole different story. That's really hard to find. But just to have it more widely available in schools and in libraries and anywhere where there's parenting or doctor surgeries and that sort of thing as well.” (Parent focus group, 02).

Summary of themes according to research questions

Table 5 below summarises the findings of the thematic analysis according to the research questions (2a-2c) that governed the development of the topic guides. As the table shows, the neurodiversity support centre was found to have high levels of acceptability to parents, staff working in the Hub, as well as professionals who referred their service users to it. For many parents the Hub was described as a 'life-safer', although with this there were calls for longer helpline opening hours. Hub staff clearly had much satisfaction from delivering the service in a supportive and collegiate environment. Health and social care professionals praised the service as making an important contribution to the support options available in Hertfordshire although concerns were expressed about how well the Hub would be able to manage ever-increasing demand for its services.

Table 5: Summary of findings from qualitative work according to research questions

Research question	Key findings
<p>2a. <i>How acceptable is the neurodiversity support centre (Hub) to parents and carers?</i></p>	<ul style="list-style-type: none"> • The work of the Hub was praised by all those spoken to. • The Hub provided a point of contact when parents and carers were in crisis and felt they had no other options. • The Hub was often a lifeline when parents were waiting for formal diagnoses, offering an informed, comprehensive, and personalised support service. • The fact that Hub staff had their own experience of neurodivergence was much appreciated. • Parents felt they gained new skills in managing difficult situations from the support they received, and they saw this benefitted the quality of life of their children and well as improving family functioning. • Hub support was felt to be particularly helpful when navigating complex environments, such as education settings. • The availability of online resources, such as Webinars, offered by the Hub was appreciated and helped overcome access barriers to in-person events. • The opening hours of the Hub helpline were felt to be restrictive and the need for longer availability was discussed.
<p>2b. <i>How acceptable is the neurodiversity support centre (Hub) to Hub staff?</i></p>	<ul style="list-style-type: none"> • Staff felt that their work in the Hub was rewarding. • Hub staff drew upon their own lived experiences to support their service users. • The Hub staff's training in techniques gave them the confidence to handle challenging calls impartially. • There was a strong team ethic amongst Hub staff who supported each other, and that extended out to their work with coaches in the community. • Staff keenly felt the need to manage demand for the service to maintain the standard, particularly in light of increasing awareness of the services. • Potential evolutions of the service in the future included the extension of hours to include pre-booked appointments.
<p>2c. <i>How acceptable is the neurodiversity support centre (Hub) to staff from referring agencies?</i></p>	<ul style="list-style-type: none"> • Staff recognised that the Hub formed an important part of the network of support available to the parents of neurodivergent young people. • The "one stop shop" nature of its offering was felt to be very valuable. • It was felt that the Hub helped take the strain off other services and helped referral partners support parents when they could not offer appropriate support themselves.

	<ul style="list-style-type: none"> • The Hub was felt to potentially play a key role in supporting external professionals who came into contact with neurodivergent young people such as those working in education. • Concern was expressed that the Hub could be overwhelmed by future demand, particularly from parents.
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Discussion

Overall findings

The quantitative data on service use showed an ongoing increase in calls made to the Hub over the period for which data was supplied. For example, the commissioned Hub, which was active between May 2022 and November 2023, received 113 calls in May 2022, and this number increased to 186 calls by November 2023. These findings indicate a growing demand for the Hub helpline service which was matched by sequential increases in the number of staff running the service. There was some monthly variation in call numbers around the general upward trend, with evidence that this was associated with peaks in demand when children returned to school from holiday periods.

Calls to the service came from diverse sources, but the majority were from the parents and carers of young people. Notably, most calls are picked up, with very few going to answerphone. The helpline service deals with callers with a diverse range of needs, which cover the needs of their child or young person and their own needs. Written feedback from service users was generally very positive, including the benefit of speaking with professionals with lived experience, how the service helped when callers were in crisis, and the high quality of follow-up emails. The service use data also shows that the Hub provides much support via digital means other than the telephone line, with a significant volume of emails being responded to and maintaining a very active private moderated Facebook group.

A range of themes emerged from the qualitative data. It was clear that many families were at the point of crisis when contacting the Hub helpline, with no apparent alternative source of help. They were often on waiting lists for formal diagnosis and felt they had no other place to turn to. The service provided by the Hub was praised as meeting their needs by being person-centred and high quality, and the combination of the helpline as well as on-line training options and the Facebook forum were felt to meet different requirements of families at different times. The fact that helpline call handlers had lived experience of neurodiversity themselves was felt to be very important, and the support service also

benefited from the network of trained coaches in the community as well as an information-sharing and supportive culture within ADD-vance. Parents spoke about the significant positive impact of the help they had received, which often went beyond just the management of the neurodivergent child to the whole family. Professionals from partner organisations spoke about how they had seen evidence that helped alleviate the burden on the wider support system, and it was also apparent how the work of the Hub helped the parents of neurodivergent young people manage situations with schooling as well as supporting school staff although it was recognised that there were still many problems associated with navigating education settings and this was a source of considerable stress for families.

The quantitative analysis showed how demand for the Hub services was sharply increasing, which was reflected in the conversations with Hub staff and referral partners. The team spoke about the need to manage demand to protect their own welfare as well as to continue to provide a high-quality service. There was some concern expressed by referral partners that ever-increasing demand, as well as latent demand being stimulated from unmet need, might eventually overwhelm the Hub. In terms of future evolution there were calls from parents to make the helpline available for longer time periods, although it was felt by Hub staff that extended periods might use a different service provision model, possibly based on appointments. The introduction of an interactive chat service was also being considered as this might attract service users who would be reluctant to call the helpline.

Strengths and limitations of the evaluation

In terms of strengths, Stage 1 of this evaluation used a mixed methods approach to provide both a general overview of levels and characteristics of service use of the Neurodiversity Support Hub as well as detailed insight into the role the Hub is playing for parents of neurodivergent young people, staff working for the Hub, and healthcare professionals who may refer their own service users to the Hub. The qualitative work has provided a rich insight into the experiences of key stakeholder groups, giving insight into the evolution of the Hub as well as the significant impact it has had on the lives of parents and families of neurodivergent young people. Further, the availability of quantitative time series data on patterns of Hub use over time has meant that some triangulation was possible between the quantitative and qualitative datasets.

In terms of limitations, the service use data was provided at the monthly level, which meant it was not possible to examine how use of the service varied over shorter time

scales. Whilst the qualitative data provided a rich insight into the experiences of key stakeholders, we were only able to have conversations with three professionals who worked for organisations and then signposted their service users to the Hub. This group had good diversity in terms of their roles, but it may be that a wider diversity of opinion might have been captured had more professionals been spoken with.

Conclusions

Evidence from this evaluation shows that the support Hub is providing a high-quality and person-centred approach to supporting the parents and carers of neurodivergent young people in Hertfordshire. The services provided are particularly welcome in the context of long waiting times for formal diagnoses, and the Hub clearly appears to be relieving pressure from the wider health and social care system. The service was much valued by all those who were spoken to. Data on service use, as well as discussions with stakeholders, showed how pressure on the service was increasing with rising demand. As the Hub expands, awareness of the services it provides will increase, which may further drive-up demand. A key challenge for the Hub will therefore be finding ways of continuing to provide their high-quality bespoke services in an environment where demand for those services risks outstripping current resources.

Appendix 1: The Neurodiversity Support Service Logic Model

Inputs	Activity	Mechanism for change	Output	Shorter term outcomes	Medium term outcomes	Longer-term outcomes (impact)
Initial service start-up phase of the NDSC						
Produce business case. Identify staff resources.	Set up and implement a single access hub (The Neurodiversity Support Centre, or NDSC).	A single point of access (the NDSC) will help simplify the system and overcome barriers to accessing support for parents and carers of neurodivergent young people.	Number of training materials, manuals, SOPs, developed.	Families of neurodivergent young people across Hertfordshire report consistent support being available.	Partner organisations report fewer complaints associated with a perceived lack of support.	A higher percentage of neurodivergent people are in employment.
Obtain funding (contractor NDSC). Procure software.	Develop Hertfordshire branding for the service. Recruit call handlers.	The use of branding will ensure there is a consistent message across the system with regards to the support offer, supporting service users' confidence and engagement.	Number of referral pathways set up. Number of call handlers recruited.	Those working within the support system report better working between organisations to meet need.	Family support workers who work with neurodivergent young people report having more time to do their job effectively.	There is a wider societal acceptance of neurodivergence leading to reduced referrals to diagnostic services.
Procure hardware. Identify physical infrastructure	Establish a telephone number and call handling system (the helpline), as well as a web system. Establish a call logging	An efficient intelligence	Number of staff trained. Number of calls to the helpline.	Professionals supporting	Staff in the	Schools can meet the needs of

<p>(buildings).</p>	<p>system to identify needs.</p> <p>Develop pathways for signposting parents and carers to support.</p> <p>Provide a follow-on call back service to small numbers of parents and carers (those in most need, most complex cases).</p>	<p>driven approach to running the Hub will lead to an effective, efficient, and agile service.</p> <p>The development of a portfolio of referral pathways will provide flexible and tailored follow-on support for parents and carers.</p> <p>Providing a follow-on call back service gives some longer-term support to ensure that the needs of people who are the most complex cases are best met.</p>	<p>Amount of time that the helpline (and associated support) is live.</p> <p>Number of service users referred to other services.</p> <p>Number of follow-on call backs made.</p> <p>Number of parents and carers using follow-on call back service.</p>	<p>neurodivergent children, young people, or their parents and carers report being more knowledgeable about how to access information & support.</p> <p>Professionals report having more time to diagnose neurodivergence because of the NDSC services.</p> <p>Those providing the service have a better idea of need based on geography, ethnicity, and</p>	<p>autism and ADHD teams report improved job satisfaction.</p> <p>Data from A&E departments show fewer visits from neurodivergent young people due to self-harm/ crisis.</p> <p>Those working in the system report that messages to young people and their families are more consistent and evidence-based.</p> <p>Fewer young</p>	<p>neurodivergent young people without statutory assessment.</p> <p>Available therapies are better targeted as universal knowledge is more accessible.</p>
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				<p>other population characteristics.</p> <p>Those providing the service report being more confident, well trained, and knowledgeable, in supporting neurodivergent young people and their families.</p>	<p>people with autism appear on the Dynamic Support Register.</p> <p>Referrals to CAMHS/PALMS/ Step 2 are reduced (reduced inappropriate referrals).</p> <p>Additional support interventions are commissioned to fill identified gaps.</p> <p>A reduction is observed in the number of appointments at</p>	
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					<p>PCN services for autism and ADHD.</p> <p>Reductions are observed in the number of EHCP requests/ approvals.</p>	
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Inputs	Activity	Mechanism for change	Output	Shorter term outcomes	Medium term outcomes	Longer-term outcomes (impact)
Delivery of parent/carer support service						
As above	<p>Provide extended 1:1 support (involving referral to a suitable offer depending on need) for parents and carers who need on-going support after accessing the Hub. Up to 15 hours initially (up to 220 families).</p> <p>Commission organisations to record and provide access on demand digital webinars for parents and carers to use (e.g., understanding autism, understanding ADHD).</p>	<p>The development and delivery of a bespoke support service for the parents and carers of neurodivergent young people will support the needs of parents and carers as well as of their young people.</p> <p>The provision of extended 1:1 support will help ensure that parents and carers with more complex needs are properly supported.</p> <p>The provision of longer-term support for at-need families will help avoid crisis in the lives</p>	<p>Number of 6-week courses delivered.</p> <p>Number of parents attending 6-week courses.</p> <p>Number workshops for parents delivered.</p> <p>Number of parents attending parent workshops.</p> <p>Number of parent carers accessing 1:1 support.</p>	<p>Parents and carers report having better knowledge on how to access information & support on neurodiversity.</p> <p>Parents and carers report having a better understanding of the needs of neurodivergent young people.</p> <p>Parents and carers report being better able to support</p>	<p>Families of neurodivergent young people report family life is improved.</p> <p>Parents of neurodivergent young people report that their family experience is normalised, and the incidence of crisis declines.</p> <p>Parents of neurodivergent young people report being less likely to</p>	<p>Fewer families with neurodivergent young people in them have family breakdowns.</p> <p>Parents and carers of neurodivergent young people are more confident of supporting their young peoples' future needs.</p>

		<p>of neurodivergent young people and their parents and carers and support 'long game' activities like getting young people back into school.</p> <p>The provision of access on demand webinars will mean that parents and carers of neurodivergent young people have a resource they can conveniently access when they need it.</p> <p>Supporting & empowering parents and carers of neurodivergent children and young people will help alleviate pressure on the wider system.</p> <p>Supporting &</p>	<p>Number of on-demand webinars provided.</p> <p>Number of views of on-demand webinars.</p>	<p>neurodivergent young people (including asking for reasonable adjustments, explaining their needs).</p> <p>Parents and carers of neurodivergent young people report feeling more listened to and validated.</p> <p>Parents and carers of neurodivergent young people report having an improved quality of life and better wellbeing.</p>	<p>experience poor mental health.</p>	
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		empowering parents and carers of neurodivergent children and young people will support the good functioning of families.				
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Inputs	Activity	Mechanism for change	Output	Shorter term outcomes	Medium term outcomes	Longer-term outcomes (impact)
Delivery of support offer for young people						
As above	<p>Develop, promote, and deliver an “Understanding my autism and ADHD” offer (for up to 900 young people with a diagnosis). Format to be determined.</p> <p>A digital “wrap-around” offer is developed and provided which includes a text-chat service and a website.</p>	<p>Providing a service directed at neurodivergent young people will directly address their needs and empower them for life, directly supporting their mental and physical health and helping them reach their long-term potential.</p> <p>Supporting neurodivergent young people will remove pressure from their parents and carers and support better family functioning.</p> <p>Providing a digital offer</p>	<p>Number of young people making use of the peer-support service.</p> <p>Number of “Understanding” courses delivered.</p> <p>Number of young people attending the “Understanding” courses.</p> <p>Number of visits to wrap-around offer website.</p> <p>Number of young people making</p>	<p>Neurodivergent young people report having a better understanding of themselves.</p> <p>Neurodivergent young people report better ability to advocate for themselves (i.e., express their needs, access what they need etc).</p> <p>Neurodivergent young people report improved</p>	<p>Neurodivergent young people achieve better school outcomes.</p> <p>Neurodivergent young people report being better able to access appropriate healthcare.</p> <p>Health professionals report a reduction in the number of neurodivergent young people</p>	<p>Across society, neurodivergent young people can achieve their full potential in education.</p> <p>The societal needs of neurodivergent young people are more proactively anticipated and met.</p> <p>Fewer neurodivergent young people are seen as</p>

		<p>including a text-chat service ensures that modes of communication that are familiar to young people are used, reducing barriers to uptake and use and maximising service impact.</p> <p>Supporting neurodivergent young people will enhance their autonomy and help take pressure off the wider support system.</p>	<p>use of the text chat service.</p> <p>Number of text chats undertaken.</p>	<p>wellbeing (mental and physical health).</p> <p>Neurodivergent young people report feeling better supported with their needs.</p> <p>People supporting neurodivergent young people report experiencing fewer instances of challenging behaviour.</p>	<p>who develop diagnosable mental and physical health conditions.</p>	<p>offenders in the judicial system.</p> <p>Neurodivergent young people exhibit life expectancy more in line with the general population.</p> <p>Neurodivergent young people in society require residential or hospital placements.</p>
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