



Evaluation of the Sandwell Helping Hands Service

Final Report

January 2022



Building
stronger
families



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We would like to thank the families and professionals who gave up their time to take part in this evaluation, to tell us their stories, and who talked so openly and honestly about the challenges they face and their experiences of the Helping Hands service in Sandwell. We are also incredibly grateful for the support from the Helping Hands team throughout this evaluation, the effort that went in to facilitating engagement with families, and for us to be able to see first hand the way the service operates and the impacts it can have on families, schools, and across the wider health and care system.

This report presents the findings of an evaluation of Family Action's Helping Hands Service in Sandwell. The Helping Hands Service supports families who have a child diagnosed with ASD or ADHD (and/or other conditions that result in particularly challenging behaviours), or where they are waiting for a diagnosis, a context within which there are potential gaps in access to appropriate intervention and support.

Current estimates show that around 1.8% of school aged children are autistic, while around 3 to 4% of boys and just under 1% of girls are diagnosed with ADHD. The prevalence of other conditions that affect sensory processing among children is not known, although sensory processing difficulties are thought to affect up to 16% of the whole population. More recent evidence is also starting to paint a picture of much higher rates of sensory processing difficulties (or sensory integration) than previously thought (including ASD and ADHD).

Despite this, there are well known gaps in the support available for children, parents and carers, and professionals working with these children and their families to effectively support the best possible outcomes. While a number of different support options do exist for parents, including through SEND practitioners in schools, Children's Services, dedicated condition specific charities (nationally and locally across the UK), generic education and parenting support programmes and, for some families, through CAMHS, much of this is either suitable only for those children and families living with the most severe and enduring mental health conditions, or for those who are able to successfully navigate and understand the complexities of sensory processing conditions with minimal professional help.

The Helping Hands Service in Sandwell aims to provide support that bridges this gap. Along with helping parents to develop a better understanding around sensory processing and challenging behaviours, the service aims to increase parents' social networks, improve wellbeing, and to reduce the impact of ASD and ADHD on the whole family.

This evaluation was undertaken to explore:

- The effectiveness of the Helping Hands service and the impacts for families and the wider local health and care system, both before and after the coronavirus pandemic, and
- The extent to which the service achieved its intended aims, and the opportunities for future developments of the service model to improve its effectiveness and to potentially replicate the model in other areas.

The evaluation was commissioned just prior to the final year of the service (2021/22) and was therefore undertaken during the period of the coronavirus pandemic. Owing to this, and the effect that the pandemic had had on the service model, the methods used to evaluate the service focused primarily on exploring the views of (a) professionals who had referred families to the service, and (b) those families who had recently taken part in one of the (virtual) PBS courses.¹ We also undertook session observation and analysed referral, activity and outcome data collected by the service.

Overall, there is strong evidence that the service delivers a number of positive outcomes for parents, and some promising evidence that there are positive impacts on children and the whole family, including over the longer term. There is also promising evidence in relation to awareness and trust in the service among professionals. In terms of whole system impacts, we believe that there is some initial evidence from this evaluation of the potential to improve partnership working for children and families experiencing ASD/ADHD, and to potentially reduce demand elsewhere in the wider health and care system (including within schools), however, further research on this is needed.

This evaluation has shown that Helping Hands has the potential to transform the lives of families living with ASD or ADHD (or other sensory processing conditions), and to generate longer lasting benefits through knowledge and skills transfer, the development of action plans that are specific to each family context, and by supporting a calmer, more confident, and less stressful family environment. There is especially strong evidence that parents feel better equipped to manage behaviour, that they are more confident advocating for their child (especially within school and with healthcare professionals) and more confident in their parenting ability. Parents were also less stressed and worried about the future. There is some promising evidence of a positive impact on wellbeing and the potential for this to be sustainable over the longer term, especially given the lower than population average for wellbeing that parents recorded when they started using the service.

However, there is a need to develop better insights into which families are most likely to engage with and benefit from the service, whether that be in relation to the diagnosis of their child, the child's age and/or time since diagnosis, or different family situations. This would require more systematic capture of this type of information from families, and more robust data on engagement in different aspects of the service and the reasons why people do and don't engage. Such evidence would help to inform any changes that could be made to the referral criteria and/or the service delivery model in order to increase the effectiveness and impact of the service, within the context of the wider health and care system.

Notwithstanding this, the evidence from this evaluation has shown that there are opportunities to both strengthen the service offer around follow up support (following participation in a PBS course) and to build in measurement of longer term outcomes, such as school engagement and learning, and in relation to the creation of sustainable support networks. We also believe that the future funding model should rely less on volunteers to deliver the more specialist aspects of the service (the PBS course and TIM workshops) and look to use volunteers primarily as a 'value add' and as a key part of the wider support to parents that the service provides. This should be factored in to any future funding models.

¹ See section 3 of the main report for a description of the different elements of the Helping Hands service offer.

There are also opportunities to extend the reach of the service across the wider health and care system, including more work in schools and consideration of how Family Action could work in partnership with other condition specific charities. It would also be useful to raise awareness of the service (and of sensory processing conditions more generally) outside of the traditional support structures.

Alongside this, we believe there is a strong case for Family Action to work with commissioners across Integrated Care Systems to establish the service as a more formal part of the care pathway for families that are at an early stage along the diagnostic pathway. This would help to better manage demand on more specialist care services and ensure that these families receive appropriate and meaningful support that can prevent problems escalating (including the potential for family and/or relationship breakdowns). It would also ensure that children are supported to maximise their engagement in learning and development at the earliest opportunity.

1 About this report

This report presents the findings of an evaluation of Family Action's Helping Hands Service in Sandwell. This was a mixed method evaluation which looked at activity and outcome data gathered by the service over the last three years, information from participant interviews and session observations, and interviews with professionals who have referred families to the service.

The report is presented in four parts:

- Part 1 sets out the context and scope of the evaluation, including a description of the Helping Hands service and Theory of Change
- Part 2 provides an overview of the evaluation methods
- Part 3 describes our findings and the supporting evidence, and
- Part 4 sets out our conclusions from this evaluation.

2 Key terms and definitions

The following terms and definitions are used throughout this report. While we recognise that the terminology around those with additional needs does change from time to time, and which therefore means that the Helping Hands service may use different terms and definitions in the future, these are the terms and definitions used by the service during the period of this evaluation.

ADHD: Attention Deficit Hyperactivity Disorder

ADHD is a mental health condition characterised by persistent patterns of inattention and/or hyperactivity/impulsivity that interferes with day-to-day functioning and/or development.

ASD: Autism Spectrum Disorder

Autism is a lifelong developmental disability which affects how people communicate and interact with the world.

CAMHS: Child and Adolescent Mental Health Service(s)

NHS funded community health services for children and young people who have difficulties with their mental health or wellbeing.

PBS: Positive Behavioural Support

A three week (6 session) course for families with a child with ASD or ADHD which forms the main intervention offered by the Helping Hands service. Note that Family Action has recently changed the name of the PBS course to TIM (This Is Me) in order to align with the terminology used for the children's workshops and to minimise potential association with Applied Behaviour Analysis (ABA) which refers to specific types of interventions for children with Autism. However, for the purposes of this report, we have elected to continue to use the term PBS to refer to the parents' sessions for ease of distinction.

TIM: This Is Me

A series of workshops for children aged 4 to 11, designed to mirror some of the content covered in the PBS course and to help children better understand and manage their behaviours.

Sensory Processing Disorder

A range of conditions that affect how the brain processes sensory information/stimuli. Note that we use this term throughout this report to refer to a number of possible conditions (including ASD and ADHD), rather than the specific disorder which has been described in the medical literature.

3 The Sandwell Helping Hands service

3.1 Overview and referral criteria

Family Action was awarded funding from the Big Lottery Reaching Communities Fund in early 2019 to deliver the Helping Hands service in Sandwell for a period of three years, ending in March 2022. The service was officially launched on 10th April 2019 with an event that was attended by parents, professionals working with children and families, and Sandwell Council. The service model builds on the successful course 'Positive Behaviour Support (PBS) - Managing Behaviour in Children with Different Needs' developed by clinical psychologists Dr Melanie Bruce and Dr Stephanie Summers, and the experience of Family Action's Health Champions pilot in Peterborough, Swaffham and Sandwell. It also incorporates workshops for children aged 4 to 11, 'This is Me' (TIM) Workshops, which support children to better understand and manage their own behaviours.

The Helping Hands Service supports families who have a child diagnosed with ASD or ADHD (and/or other conditions that result in particularly challenging behaviours), or where they are waiting for a diagnosis, a context within which there are potential gaps in access to appropriate intervention and support. Along with helping parents to develop a better understanding around sensory processing and challenging behaviours, the service aims to increase parents' social networks, improve wellbeing, and to reduce the impact of ASD and ADHD on the whole family.

3.2 Service provision

The service is delivered by a service co-ordinator and volunteers, who are themselves parents of children with additional needs. A service administrator was also recruited to help with processing referrals, scheduling, and to support data collection and recording. The service is overseen by a Family Action Operational Manager, and receives support from central Family Action teams, particularly in relation to communications and data systems.

Prior to the coronavirus pandemic, much of the service was delivered in person. The physical space for this was made available at the Burnt Tree Children's Centre in Oldbury, Wednesbury Library, in schools, and at CAMHS in West Bromwich. Office space was also available at Burnt Tree Children's Centre. Following the start of the coronavirus pandemic, a number of online platforms were used to make content available for parents (YouTube), build connections between parents (Facebook) and deliver virtual course sessions (MS Teams). The service also received some additional funding during this time from Family Action's Covid Response fund to create and disseminate resource packs to families already known to them. Course materials and other resources which could be used at home were also distributed to parents by email, along with the wellbeing and feedback surveys.

3.3 The service pathway

There are four main elements of the Helping Hands service model in Sandwell.

1. Referral
2. Welcome appointment
3. Intervention
4. Closure/ongoing support

Referral

Referrals are received by hand, by post, or by email² using an agreed referral form. They come primarily from schools, local children's services, and self-referral, although the latter of these may happen following a recommendation from CAMHS or other statutory service. Each referral is then reviewed to ensure it meets the referral criteria with a decision letter sent to the family and the referring agency. Rejected referrals are offered alternative support and advice, either directly with the family or through the referring agency.

Welcome appointment

For those families that are accepted, a welcome appointment is arranged. Prior to the pandemic this was held in person at CAMHS in Wednesbury and undertaken by one of the volunteers, who were all trained by a Family Action staff member to conduct these appointments. Welcome appointments were conducted by the service co-ordinator over the phone following the start of the pandemic.³

The main aim of the welcome appointment is to gather more information about the family, parents' concerns and challenges, and to provide advice on and agree next steps. It is also an opportunity to talk about what Helping Hands could offer the family, the purpose and content of the PBS, and, where possible, to secure agreement from the parents for them to attend a future PBS course.

Interventions

The Helping Hands service offers all families access to the following support, although not all families will access all of the support options available:

- Attendance at six PBS group sessions (over three weeks), with supporting videos and other resources
- Completion of a PBS action plan
- 1:1 support outside of the PBS sessions
- The sharing rooms (in person drop-in sessions before the pandemic, and 1:1 telephone calls with the service co-ordinator and access to an online sharing room during the pandemic)
- Signposting to other agencies and advocacy as needed

² By email only since the start of the coronavirus pandemic.

³ The shift away from volunteers conducting the welcome appointments during the pandemic was primarily because of reduced availability of volunteers during this time, and the challenges associated with volunteers working remotely.

In addition to this, the service ran targeted workshops for children in schools (TIM workshops) to mirror some of the content being covered by their parents in the PBS, and family sensory sessions with families (summer 2019 only) and GPs (November 2019 only).

Closure and ongoing support

A key feature of the Helping Hands service is that, while more intensive support concludes once the PBS action plan has been developed (typically towards the end of the PBS course), parents are able to continue to seek advice and guidance on an ongoing basis. This includes direct contact with the service co-ordinator and volunteers, and continued access to the Facebook group and sharing rooms. This provides families with an opportunity to access further help and support as needs arise.

3.4 Intended outcomes

The service aims to deliver positive outcomes for parents, for whole families, and across the wider health and care system.

For parents, the knowledge and understanding they gain from the PBS, along with the connections they make, plus the opportunity to develop an action plan specific to their own family situation, is intended to enable parents to:

- Be better prepared to prevent and manage challenging behaviours
- Be more aware of the different support available to them
- Feel more equipped to advocate for their child and to communicate with other family members, friends, and professionals.

It is expected that this will lead to greater confidence in parenting ability, less anxiety and stress, improved self-esteem, and improved wellbeing among parents.

For whole families, the service intends to facilitate more open and effective communication between family members, and to help children (either directly through the TIM workshops, or through the strategies being used by parents) become more equipped to understand and manage their behaviours, and to communicate their feelings with others. This, in turn, should lead to better family relationships and improved engagement in school over the longer term.

For professionals and the wider health and care system, the service aims to build greater knowledge and understanding about sensory processing disorders/conditions, the help and support available to families, and for professionals to see Helping Hands as an important and integral part of the care pathway for children (and their families) who are showing signs of some type of sensory processing disorder. This would mean that families would be more likely to receive help earlier, and at a point when longer term developmental, social and learning outcomes can be maximised.

3.5 Moderating factors

There are a number of potential factors that may moderate (or limit) the extent to which the service is able to achieve the intended outcomes.

At the referral stage these include changes among the staff teams from those agencies making referrals, and the knowledge that new staff may have about Helping Hands and the families that

are most suitable for referral. This may lead to an increase in the number of inappropriate referrals and/or a reduction in the number of referrals coming through to the service. At the welcome appointment, the confidence that parents feel in terms of opening up about the challenges they face may influence what they can gain from attending the PBS and engaging with other parents.

In terms of effective service delivery, lack of engagement in all of the PBS sessions may result in parents developing only a partial understanding about how best to manage their child's behaviour. Volunteer capacity and technology barriers (including confidence to engage in PBS sessions online) could also impact the effectiveness of online service delivery during the pandemic.

3.6 Evidence underpinning the Theory of Change

While there is some evidence of positive outcomes from the Health Champions pilot evaluation,⁴ from which the Helping Hands service has been adapted, much of the evidence underpinning the Helping Hands Theory of Change is based on professionals' experiences and expertise, and knowledge of the challenges that many of these families face. This current evaluation therefore provides an important opportunity to test the extent to which a service such as Helping Hands is able to achieve the intended outcomes for parents, whole families, and the wider health and care system, and to begin to better understand what it is about the intervention that drives these outcomes.

3.7 Impact of the coronavirus pandemic

The service adapted quickly to the impact of the coronavirus pandemic in March 2020, and moved the core elements of the service online. This included the establishment of a private online sharing room and the introduction of 1:1 telephone calls in place of the in person drop-in sessions. Given the challenges associated with running successful online workshops with young children, the TIM workshops were paused until November 2021, at which point the service was able to secure agreement for them to begin again in at least one local school.

⁴ Available at: <https://www.family-action.org.uk/content/uploads/2018/07/Health-Champions-Evaluation-Final-Report.pdf>

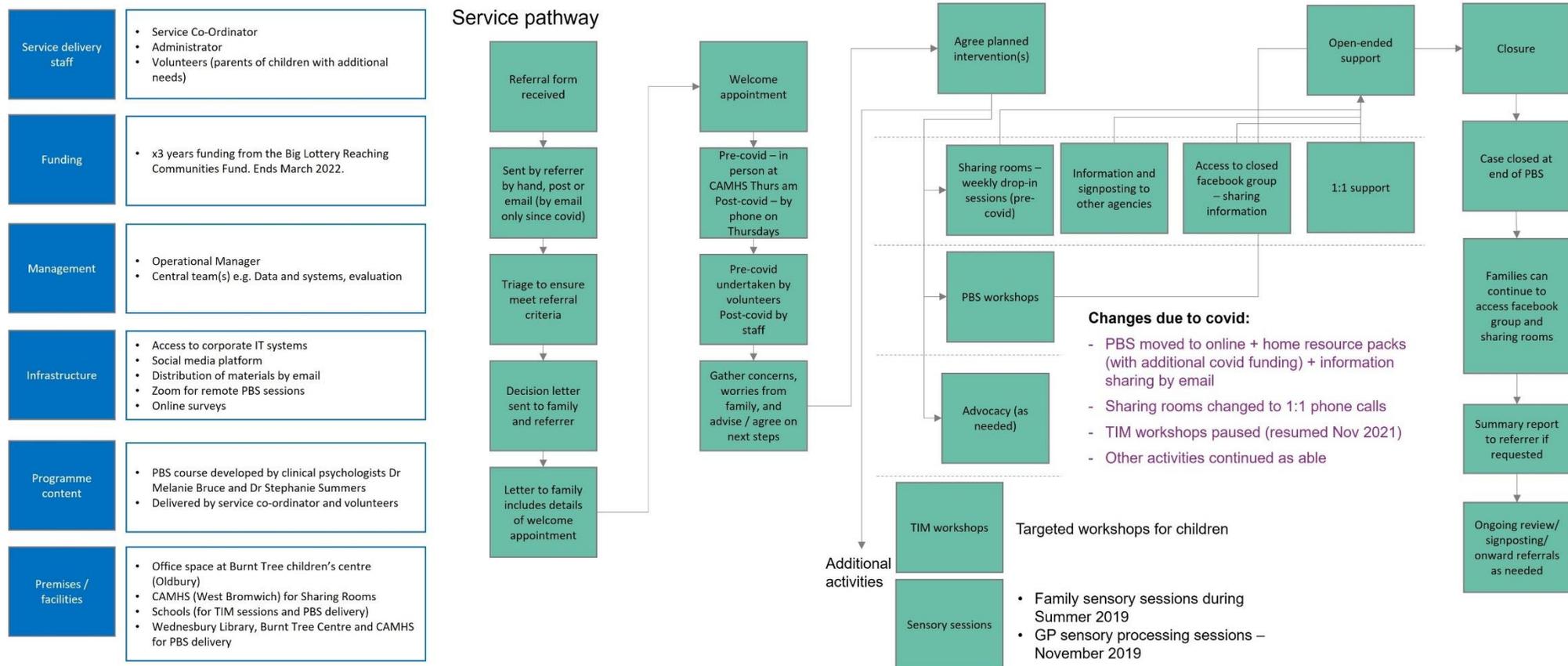


Figure 1a: Helping Hands Theory of Change – Resources and Service Pathway

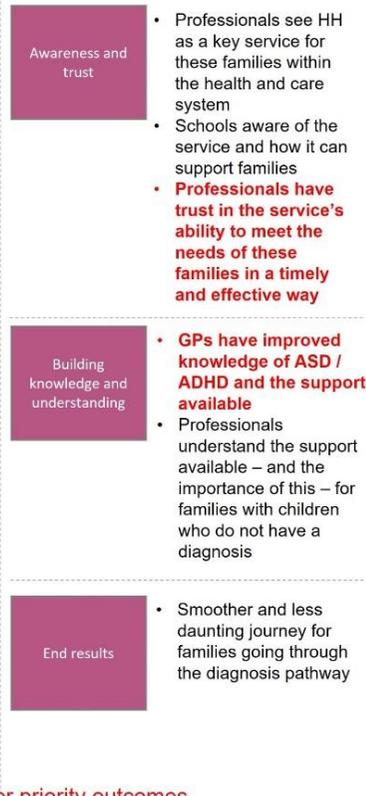
Parents



Children & whole family



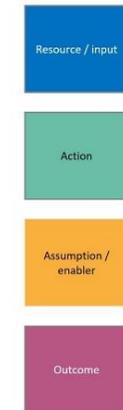
Professionals



Whole system

- Improved partnership working for ASD / ADHD (pre- and post-diagnosis)
- Reduced need for escalation to higher level support services – leading to:
 - Reduced demand
 - Reduced waiting times, esp CAMHS and Paeds

Key:



→ Process steps / links

****Statements in red indicate higher priority outcomes**

Figure 1b: Helping Hands Theory of Change – Intended Outcomes

4 The support system for families with a child with ASD or ADHD

It is estimated that there are around 700,000 people in the UK (1% of the population) who are autistic, and three million family members and carers of autistic people. Around 40% of autistic people also have a learning disability. The prevalence among children is thought to be similar (one child in every one hundred), although recent evidence shows that rates of autism among school aged children could be as high as one child in every 57 (1.8%) and significantly higher than previously reported.⁵ Around three to four times as many boys as girls are likely to be diagnosed with autism.⁶

In terms of ADHD, a study undertaken between 2004 and 2013, and published in 2015, showed that 3.62% of boys and 0.85% of girls between the ages of 5 and 15 years in the UK had ADHD.⁷ It also showed that incidence rates were highest among those from more deprived areas and lowest among those from the least deprived areas. The authors concluded that ADHD may be associated with socioeconomic deprivation. And while the incidence of ADHD in children was relatively stable between 2004 and 2013, it peaked in the last two years of that study. Global prevalence of ADHD in children is estimated to be between 2% and 7%, with an average of around 5%.⁸

More recent evidence has also started to paint a picture of much higher rates of sensory processing difficulties (or sensory integration) than previously thought (including ASD and ADHD), with up to 16% of the UK population experiencing difficulty with sensory processing.⁹ Linked to this, the researchers found that a third of UK adults had never heard of sensory integration or sensory processing difficulties. As the Chair of Sensory Integration Education points out: 'Think what this poor awareness of sensory integration means for people with sensory differences when they come into contact with employers, teachers, civil servants, customer service staff, etc, and their behaviours are not understood and their needs are not properly catered for.'¹⁰ A recent study in Finland found the prevalence of sensory abnormalities to be around 8.3% among 8 year old children.¹¹

Despite these relatively high (and seemingly growing) rates of prevalence of ASD, ADHD and other sensory processing difficulties, there is limited support available for children, families and carers, and professionals working with these children and families to effectively support the best possible outcomes. This is particularly the case when problems are only just starting to become apparent, and in the time leading up to and following a diagnosis. With respect to children's mental health services, the Children's Commissioner noted in early 2021 that 'the sad truth is that, in spite of progress, services are still nowhere near meeting the level of need and hundreds of thousands of children are being left without help as a result.'¹²

⁵ Available at: <https://www.ncl.ac.uk/press/articles/archive/2021/03/autismratesincrease/>

⁶ See: <https://www.childautism.org.uk/about-autism/what-is-autism-symptoms-of-autism/>

⁷ Available at: <https://journals.sagepub.com/doi/abs/10.1177/1087054715613441>

⁸ Available at: <https://www.sciencedirect.com/science/article/abs/pii/S2215036617301670>

⁹ See: <https://senmagazine.co.uk/content/specific-needs/sensory-impairment/15906/sensory-integration-or-processing-difficulties-are-common-so-why-have-over-a-third-of-the-uk-population-never-heard-of-them/>

¹⁰ Ibid.

¹¹ Jussila K., Junttila M., Kielinen M., Ebeling H., Joskitt L., Moilanen I., et al. (2020). Sensory abnormality and quantitative autism traits in children with and without autism spectrum disorder in an epidemiological population. *J. Autism Dev. Disord.* 50, 180–188.

¹² Available at: <https://www.childrenscommissioner.gov.uk/report/mental-health-services-2019-20/>

A number of different support options do exist for parents, including through SEND practitioners in schools, Children's Services, dedicated condition specific charities (nationally and locally across the UK), generic education and parenting support programmes (such as the Triple P online parenting programme), and, for some families, through CAMHS. However, much of this is either suitable only for those children and families living with the most severe and enduring mental health conditions, or for those who are able to successfully navigate and understand the complexities of sensory processing conditions with minimal professional help. Furthermore, there is a noticeable difference between the amount of information and advice available in relation to autism, versus the many other behavioural or sensory processing conditions that families may be faced with.

Unfortunately, many parents with a child with additional needs are scared to speak out about the problems they are facing, for fear of being judged by others as incapable or irresponsible parents. Or they have tried and failed in the past, because professionals are not equipped to understand and support them. A recent report published by the All Party Parliamentary Group on Autism (APPGA) found that while awareness of autism had improved substantially over recent years, 'there is still a significant lack of understanding about autism amongst the public, including what it means to be autistic and the diversity of the autistic community.'¹³ The Chair of the APPGA noted that 'every day, I and my MP colleagues are contacted by autistic constituents or their family members who struggle to get a diagnosis, or have to wait several years for one. Too often, they cannot get support from social care or in school. It is clear that there is still much to be done.'¹⁴

Indeed the UK Government, in its current five year strategy for autistic children, young people and adults, sets out a number of key priorities for autistic people, including significantly improving public understanding and acceptance of autism, and enabling autistic children and young people to access the right support, both within and outside of school.¹⁵ However, this is a strategy for autistic people. What remains are potentially significant gaps, both nationally and locally, in terms of funding and service provision, and plans for system-wide transformation, that could benefit all families with a child with additional needs (and in particular those with sensory processing conditions), irrespective of the diagnosis.

13

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1004528/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026.pdf, p. 14.

¹⁴ <https://pearsfoundation.org.uk/wp-content/uploads/2019/09/APPGA-Autism-Act-Inquiry-Report.pdf>, p.1.

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https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1004528/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026.pdf

5 Objectives of this evaluation

The overall aims of this evaluation were to:

1. Explore the effectiveness of the Helping Hands service and the impacts for families and the wider local health and care system, both before and after the coronavirus pandemic,¹⁶ and
2. Explore whether the service achieved its intended aims and the opportunities for future developments of the service model to improve its effectiveness and to potentially replicate the model in other areas.

The evaluation was commissioned just prior to the final year of the service (2021/22) and was therefore undertaken during the period of the coronavirus pandemic. Owing to this, and the effect that the pandemic had had on the service model, the methods used to evaluate the service focused primarily on exploring the views of (a) professionals who had referred families to the service, and (b) those families who had recently taken part in one of the (virtual) PBS courses.

There were limited opportunities to engage with families who had been part of the service prior to the pandemic. As noted above, all families also had access to 1:1 discussions with the service co-ordinator, resources and information provided by email, the Facebook group, and the virtual sharing room. Face to face PBS and TIM sessions did begin again just prior to the end of this evaluation, and some of the data included in our analysis is from these sessions. However, we have been unable to draw many firm conclusions as to the overall effectiveness and impact of the service before the pandemic compared to the delivery model after March 2020.

6 Overall approach and evaluation methods

6.1 Evaluation methods

The work for this evaluation was undertaken as follows:

Phase of work	Methods/evaluation activities	Timescale
Inception, scoping and evaluation design	<ul style="list-style-type: none"> • Inception meeting • Theory of Change design session with Family Action staff • Development of evaluation framework 	January – February 2021
Fieldwork	<ul style="list-style-type: none"> • Recruitment of participants (service users and professionals working with families in other settings) • Interviews with families • Interviews with professionals • Interviews with volunteers involved in running the service • Session observation (virtual and in person PBS, and in person TIM session) 	March – November 2021

¹⁶ The coronavirus pandemic first affected service delivery in March 2020.

Phase of work	Methods/evaluation activities	Timescale
Data analysis and synthesis	<ul style="list-style-type: none"> • Data cleaning and analysis – service activity and outcome data • Coding and analysis of interviews, observation and ad hoc feedback from professionals, service users and volunteers • Development of draft findings and recommendations 	November – December 2021
Reporting	<ul style="list-style-type: none"> • Preparation of final report 	January 2022

Table 1: Summary of evaluation methods

6.2 Sample sizes and data limitations

Activity (referral) data was available for 274 referrals accepted by the service between April 2019 and November 2021. This included the following information for all referrals:

- Data of referral
- Referring agency
- Diagnostic status of the child/children in the family (including diagnosis if available)
- Age of the person (parent) named on the referral form
- Gender of the person (parent) named on the referral form.

There was also information for some referrals as to the status of the referral (such as whether or not the family had accepted an offer to attend the PBS), however, this was incomplete. No data such as time since diagnosis, number of children in the family, or other contextual information was collected routinely by the service for each referral, although these were discussed at the welcome appointment.

Monitoring reports were used to determine the total number of referrals received (including the number of rejected referrals), the number who were offered a place on a PBS course, and the number who attended. These reports also provided information on the total number of PBS courses that were held (both in person and virtually) during the period.

Other quantitative data available for the evaluation included:

- Short (7-item) Warwick Edinburgh Mental Wellbeing Scale (SWEMWBS) scores for 66 parents at the beginning of a PBS course, and scores for 34 of those parents at the end of their course
- 13 survey responses from parents who completed a PBS course
- The number of people ‘following’ the Helping Hands Facebook page
- The number of members in the virtual sharing room
- The number of families who attended the weekly in person sharing rooms prior to the pandemic.

In terms of qualitative data, we successfully engaged with 10 families for an interview and one service volunteer. All families had attended the online version of the PBS course. Two of these mentioned that they had also previously attended face to face sessions. Five of the families were also interviewed a second time, around three to four months after the first interview. This is

despite considerable efforts on the part of the Family Action team to seek consent from families and to provide contact details, and repeated efforts by the evaluation team to make contact with those families and to arrange interviews. Contact details were provided for 20 families and two volunteers in total. Interviews were also undertaken with five professionals who had referred families to the service.

In order to supplement the information gathered from the interviews, we also observed two virtual PBS sessions and one in person session, and one session with children (TIM). The service co-ordinator also provided a document with various ad-hoc comments and feedback that had been given directly to her by parents and professionals.

The findings presented in this report therefore need to be seen within this context. While the sample sizes are large enough to provide a good indication of the potential of the service to lead to positive impacts, they do limit the extent to which we can compare the service model pre- and post-pandemic. And they give us limited information on the different profiles of families who might benefit more or less from being referred to the service. Notwithstanding this, we are able to reach a number of conclusions about the effectiveness and impact of the service, both for families and across the wider health and care system, which will be important to consider in the context of further funding in Sandwell, and potentially other local areas.

7 The effectiveness of the delivery model

7.1 Reach and engagement

A total of 294 families were referred to the Helping Hands service between April 2019 and November 2021 (around 9 referrals per month). Of these, only 20 (7%) were assessed as not being suitable for the service. 274 families were therefore offered a 1:1 introductory session (to determine suitability for the PBS and/or to identify alternative support options), and 208 families engaged in that initial meeting. A total of 140 families went on to start one of the 23 PBS courses run between April 2019 and November 2021, an average of 6 families per course.¹⁷

60% of accepted referrals were from some type of children’s service (Children’s Centre or family centre, early help, or Children’s Social Services). 18% were self-referral and 14% were from schools. The remainder were from CAMHS (3%), or from some other referral source (4%) such as GPs or from an NHS community mental health team.

Referral source - accepted referrals

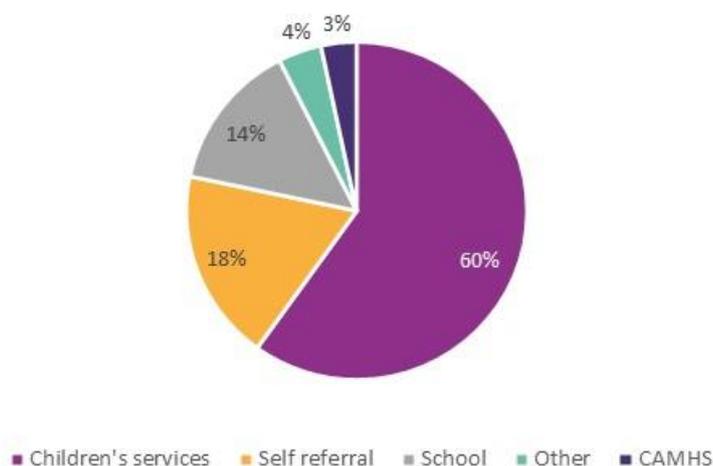


Figure 2: Source of accepted referrals

While attendance data is not available for the whole period, data from May 2020 (just after the start of the coronavirus pandemic) to September 2021¹⁸ shows a high level of attendance after the first session. 83% of those who started the PBS attended all sessions and completed a PBS plan. The biggest challenge, however, was in relation to the number of families who agreed to attend and who then felt that they couldn’t commit the necessary time. Around 40% of those who agreed to take part in the course didn’t subsequently attend a session. It is important to recognise, however, the additional pressures that were on families during this time, in particular in relation to home schooling, or being able to access their usual childcare due to the coronavirus restrictions.

While the virtual delivery model was easier for some families in terms of attendance, we know that the pandemic has had far reaching impacts on families, and we recognise the challenges they face to set aside even a small amount of time once or twice a week when it is not part of the usual routine.

¹⁷ 9 PBS courses were held in person, while 14 were run virtually.

¹⁸ All PBS sessions were delivered virtually during this time.

All families were also given information about accessing the sharing rooms (in person sessions before March 2020¹⁹ and online after March 2020) and the closed Facebook group. 70 families attended sharing room sessions between April 2019 and March 2020 (pre-pandemic) and, as at September 2021, there were 253 followers on the main Facebook group page and 60 members of the private online sharing room.

In addition to the PBS sessions for parents, 22 children attended the TIM sessions held in local schools. Eight families attended both the PBS and the TIM sessions. It is important to note, however, that the TIM sessions were not held between March 2020 and October 2021 due to coronavirus restrictions.

Three families also attended the family sensory sessions prior to the pandemic and resource packs were provided to all families known to the service for them to use during lockdown. These contained a range of indoor and outdoor sensory activities. 18 professionals also took part in education sessions on sensory processing and managing behaviours in children with additional needs. These sessions did not run after March 2020 due to the coronavirus pandemic.

Output	Number
Number of families referred	290
Number of families accepted	274
Number of families engaged in initial assessment	208
Number of families attending PBS courses	140
Number of families (children) attending TIM courses	22
Number of families who attended in-person sharing rooms	70
Number of people in the online sharing room	60
Number of families attending in-person family sensory sessions	3
Number of professionals attending in-person sensory processing education	18

Table 2: Key service delivery outputs

7.2 The profile of service participants

43% of the families referred to Helping Hands had a child with a confirmed diagnosis of either ASD (23%), ADHD (12%), some other behavioural condition (3%), or a diagnosis of more than one condition (5%). 36% were, at the time of referral, going through some sort of diagnostic process, while 7% were yet to start that process. 14% of referrals did not have a diagnostic status recorded.

¹⁹ The in-person sharing rooms (held at CAMHS in Wednesbury) were stopped in March 2020 as a result of the coronavirus pandemic.

Diagnostic status / diagnosis of children in families with an accepted referral

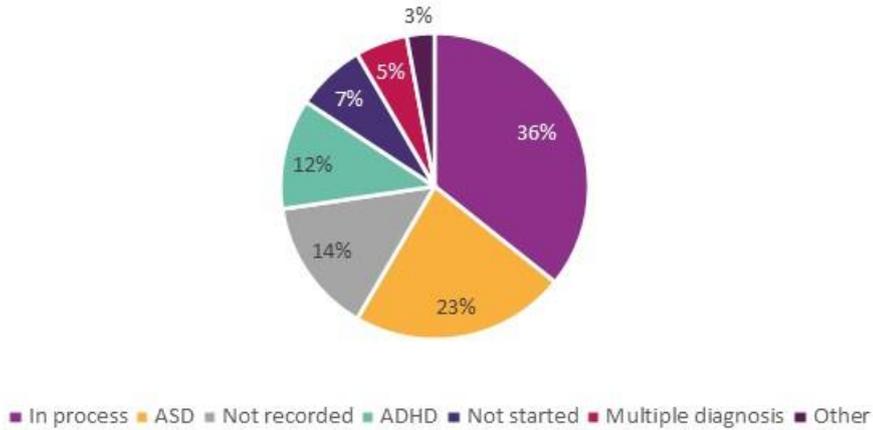


Figure 3: Diagnostic status/diagnosis of children in families with an accepted referral

In terms of age and gender, the service captures this information only for the person named on the referral form and not for any other parents or carers (or children) who may subsequently attend the PBS or TIM, or benefit from the service in some way. The data shows that the vast majority of people named on the referral were between the age of 25 and 44, with 34% of accepted referrals being people aged 25 – 34, and 48% people aged 35 – 44. 19% were 45 and over (Figure 4).

Age of person referred (accepted referrals)

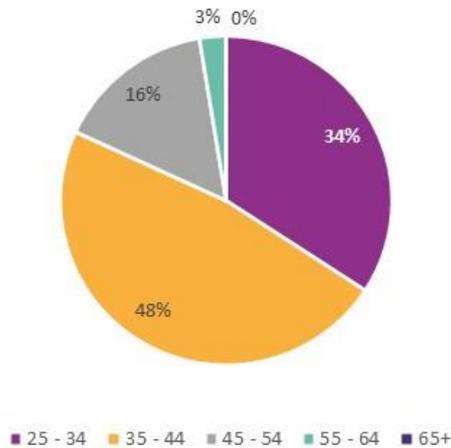


Figure 4: Age of person referred – accepted referrals

With regard to gender, 95% of those named on the referral form were female (Figure 5).

Gender of person referred (accepted referrals)

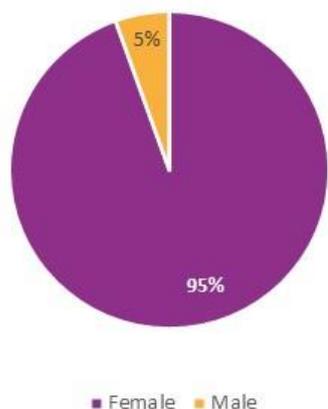


Figure 5: Gender of person referred – accepted referrals

While we don't know the extent to which these age and gender profiles reflect the profile of those who subsequently attended the PBS (and/or engaged in other aspects of the service), there is some anecdotal evidence to suggest that many more mothers than fathers attended the PBS. This difference could be the result of a number of different factors, such as the timing of the sessions (during daytime work hours) and the division of parenting roles among families from the local population. It will be important for the service to better understand any opportunities to more effectively engage with both mothers and fathers in the future, given the many social and cultural factors that may make this particularly challenging across the target population.

It will also be important to consider how additional information about the family, such as time since the child's diagnosis (where relevant), number of other children in the family, other parents or family members living with or involved in the child's care, and other contextual information about the family, could be routinely and consistently captured in the activity database, given that the initial discussion at the welcome appointment typically covers these areas. This type of information would provide valuable insights into the different factors that may influence which families are more likely to engage with and benefit from the Helping Hands service, and what could be done differently to support those who are less likely to access the support available.

This could include, for example, continuing to provide welcome appointments by telephone, and running virtual PBS courses alongside face to face sessions, as the service has noticed a higher level of engagement in these (and lower levels of drop out during the PBS) since the start of the pandemic.

7.3 The key challenges facing parents who attend the service

The parents we interviewed described a number of challenges associated with looking after a child with a behavioural condition such as ASD or ADHD. Most often this was about feeling isolated and unsupported, the length of time it takes for a diagnosis, and getting meaningful help from other agencies and from their child's school.

'There's not enough of this type of support for people. It helps you to stop feeling that what you are doing is wrong. And you don't feel so isolated, and so alone.' – Parent of a child with a sensory processing disorder

'The school really wasn't backing me. I felt really isolated. And the thing is parents shouldn't have to feel that way.' – Parent of a child with multiple behavioural conditions

'My daughter was having problems at school, hitting, screaming, and then meltdowns when she came home. The school wanted her to go to special school. But it was as if they just weren't interested in looking after her. She had been going there since she was 2 and a half, and things were much different when the previous headteacher was there.' – Parent of a child with ASD

Many parents were under enormous pressure, both to deal with daily routines and to meet perceived expectations from family and friends. Many also grappled with feelings of self-doubt and guilt.

'I feel like I'm a bad parent, and that this is all my fault.' – Parent²⁰

'We are at a bit of a standstill now. We don't know if we have an open case with CAMHS. We are trying to get an appointment with the paediatrician, but it seems to take forever. It is just so difficult to get professionals to work together.' – Parent of a child with a sensory processing disorder

'We had reached a point of total family breakdown. And even when we did have a diagnosis, we didn't feel that it was enough. We needed to speak with professionals and other parents. Just to get any extra advice about how to deal with the problems we faced.' – Parent of a child with ADHD

'When she was diagnosed, I thought 'we can do this'. And I'm so glad I asked for help. I was scared, I was afraid. And I felt ashamed.' – Parent of a child with a sensory processing disorder

7.4 Experiences of service participants

All participants were asked to complete a short survey at the end of their PBS course. Unfortunately only a small number of these were received, largely due to the challenges associated with remote data collection during the coronavirus pandemic.

Among those who did respond ($n=10$), 8 parents gave a score of 7 or more in response to the question: 'How much progress do you feel you have made towards your goals, where 1 is none and 10 is achieved them all?' Only 1 person gave a score of 5 or less.

Those who were interviewed also spoke very highly of their experience, both of the PBS course and of other aspects of the service, in particular the sharing rooms. Parents most often identified the following as the reasons for why they found Helping Hands beneficial:

²⁰ Note that some of the quotes included in this report were provided anonymously and therefore we do not know the diagnosis of the parent's child.

- The opportunity to meet and talk to other parents facing similar challenges, many of whom had not had such an opportunity before, nor had it been suggested by other professionals they were in contact with.
- The positive, safe and enjoyable environments within which parents could talk openly about their situation, without the fear of being judged.
- Learning about strategies that are specific to their child and their situation. This was particularly important for those who had previously attended more generic parenting courses.
- Learning to understand sensory processing, and how this is linked to behaviour in children with ASD or ADHD (or other similar conditions), a concept which for many parents had never been introduced by other professionals, including mental health professionals.

The relative strength of these benefits are shown in Figure 6 below.²¹ These aspects of the service were also most commonly seen in our session observations.

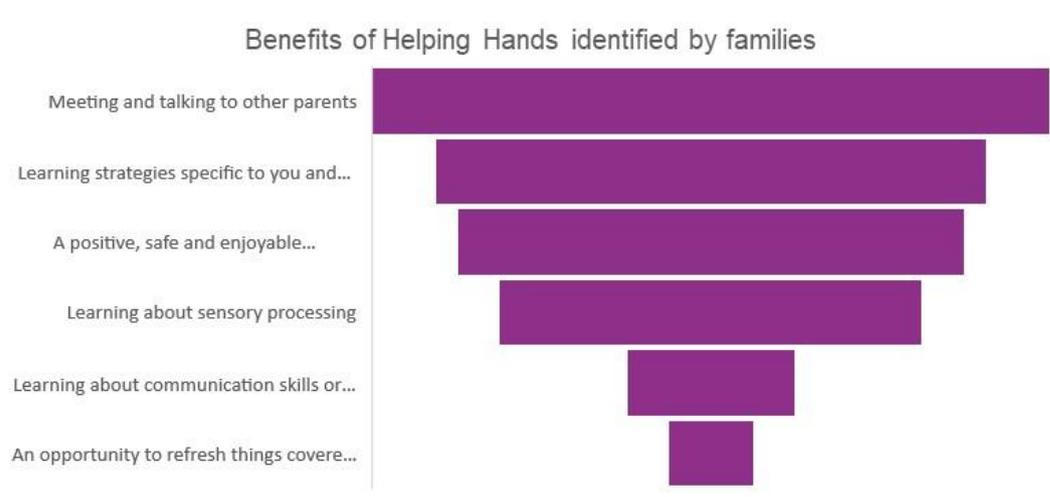


Figure 6: Relative strength of the benefits of Helping Hands identified by families

'I liked the group atmosphere, you learn so much from the others. Everyone was really nice, and you realise you're not the only one dealing with this.' – Parent of a child with a sensory processing disorder

'By the end of the course, I became friends with the others in the group. Hopefully we can have coffee mornings soon and continue to meet up. But I got loads of tips from the other parents on the zoom sessions.' - Parent of a child with a sensory processing disorder

'It's just so nice to have a group like that. To speak to the other parents, and to get ideas and information from them.' – Parent of a child with ASD

²¹ Funnel charts (such as Figure 6) are used in this report to present the relative strength of different themes (codes) identified in our qualitative analysis, which was undertaken using an inductive coding methodology. The more often a theme is identified in the data, the stronger that theme is.

'I had been to lots of events before, presentations mainly. But with this one, you could ask about specific things that you were struggling with at home. And other parents had tried things I hadn't.' – Parent of a child with ASD

'[The facilitator] is lovely, she does such a great job, handing out information and making everyone feel like they are doing their best. This gave me just what I needed. The way she delivers it is amazing, it's like talking to a friend.' – Parent of a child with ASD

'The course was really enjoyable. It was clear that they really wanted to help us and the way they put everything across meant that it was on the same level as us.' – Parent of a child with a sensory processing disorder

'I was a bit hesitant at first. People have talked about parenting courses before and I've gone to various things, but this has given me a much different perspective on how my child is feeling and why he behaves the way he does. That has been so helpful. I just wish I'd heard about it before!' – Parent of a child with ASD

8 Outcomes for parents and their families

8.1 Mental wellbeing

Mental wellbeing of service participants (parents) who completed the PBS was measured using the 7-item (short) Warwick Edinburgh Mental Wellbeing Scale (WEMWBS) at the beginning and end of each cycle. The scale is used widely, both nationally and internationally, for monitoring and evaluating the impact of projects and programmes on mental wellbeing. Each item is scored from 1 to 5, giving a total score of between 7 and 35.

A total of 34 parents completed the scale at both the beginning and end of their PBS course and 66 parents completed the scale only at the beginning. While these numbers are much lower than the total number of parents who attended the course, it reflects the challenges of collecting this type of data remotely and in a timely and consistent way. It also reflects the limited staff and volunteer time (especially during the coronavirus pandemic) that was available to support more complete data collection, and this would be worth considering as part of the future service delivery and funding model.

Overall, there was an average improvement in the SWEMWBS score of 3.5, moving from 21 (out of 35) at the beginning of the PBS course and increasing to 24.5 at the end (Table 3).

Average SWEMWBS score at the start of the service	Average SWEMWBS score on service completion	Change in average score
21.0	24.5	3.5

Table 3: Average SWEMWBS scores at the start and end of the PBS course (n = 34)

For comparison, the average wellbeing score across the population in England is 23.6, while the score at the 25th percentile is 21.5. This means that the parents who were involved in the PBS started with an average wellbeing among the lowest 25% of the population and were just above the population average at the end.²² This suggests potentially sizeable improvements in wellbeing among PBS participants – improvements that could be directly attributable to the service given the short period of time between the start and end scores being taken (typically no more than six weeks) and which could make a considerable difference to the lives of those families.

Table 4 below shows the average scores (out of 5) for each of the seven wellbeing statements at the start and end of the PBS course, along with the average change. While in all cases there was a small improvement, it is particularly notable that improvements were greatest in relation to feeling close to others, feeling optimistic, and feeling relaxed (Figure 7). These were also the only statements which had an average starting score below 3.

SWEMWBS statement	Average starting score	Average end score	Average change
I've been feeling optimistic	2.79	3.50	0.71
I've been feeling useful	3.06	3.35	0.29
I've been feeling relaxed	2.47	3.15	0.68
I've been dealing with problems well	3.24	3.44	0.21
I've been thinking clearly	3.03	3.50	0.47
I've been feeling close to others	2.88	3.65	0.76
I've been able to make up my own mind	3.59	3.94	0.35

Table 4: Average SWEMWBS scores by wellbeing statement

²²

https://warwick.ac.uk/fac/sci/med/research/platform/wemwbs/using/howto/wemwbs_population_norms_in_health_survey_for_england_data_2011.pdf

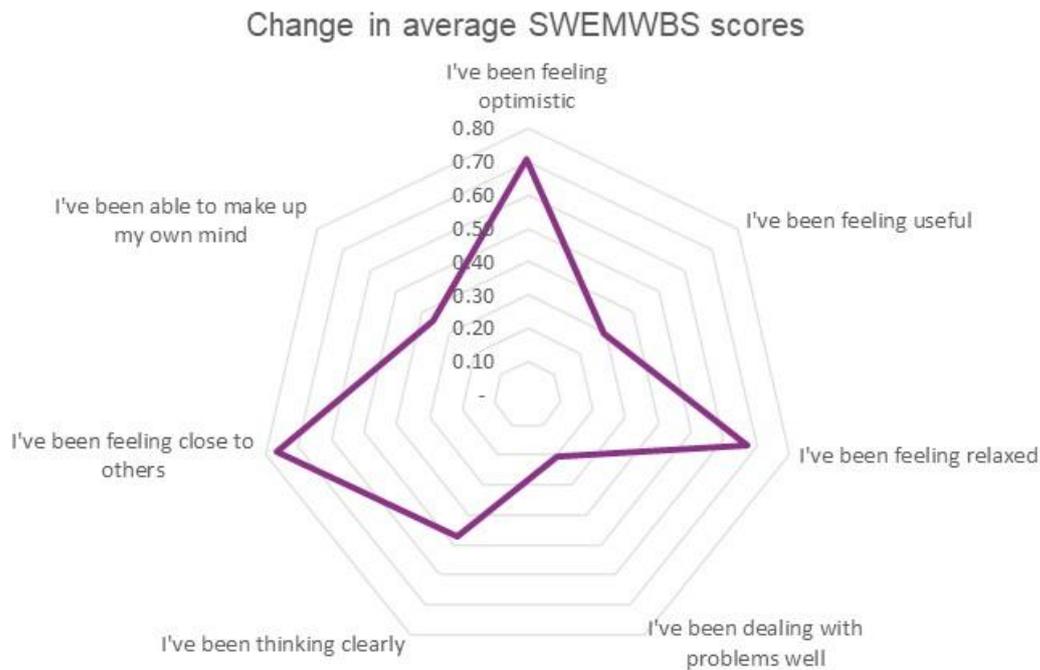


Figure 7: Change in average SWEMWBS scores

This aligns closely to the key challenges that parents were facing when they were referred to the Helping Hands service (feeling lonely and isolated, feeling stressed, and being frustrated by a perceived lack of support from other agencies), and demonstrates that the service is particularly effective at helping parents to address those challenges and the underlying causes. We discuss the likely drivers of positive change in section 8.2 below.

Also notable in these results is the small number of parents who reported a lower level of wellbeing at the end of the PBS course (Table 5), although it is important to note that the coronavirus pandemic had a substantial impact on levels of personal wellbeing across the UK population, and during the early stages of the coronavirus pandemic they were among the lowest seen since 2011 (when data collection started).²³

²³ See: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/coronaviruscovid19latestinsights/wellbeing>

SWEMWBS statement	% of parents improved	% of parents staying the same	% of parents worse
I've been feeling optimistic	62%	35%	3%
I've been feeling useful	38%	50%	12%
I've been feeling relaxed	59%	35%	6%
I've been dealing with problems well	29%	56%	15%
I've been thinking clearly	44%	50%	6%
I've been feeling close to others	62%	38%	0%
I've been able to make up my own mind	44%	41%	15%

Table 5: Proportion of parents whose SWEMWBS scores changed or stayed the same between the start and end of the PBS course

While the overall changes in wellbeing reflected by these results might appear to be relatively small, it is important to recognise the short amount of time between the first and second scores (typically no more than six weeks). This gives us some confidence that the changes observed are likely to be directly attributed to taking part in the PBS course, along with the effect of other support provided during this time including 1:1 discussions (both for general support and to develop an action plan specific for each family), the sharing rooms, and the information packs and resources provided to parents.

8.2 Other outcomes for parents and families

In terms of outcomes that participants described in the interviews and through informal feedback, and which we identified from our observations of both online and face to face PBS sessions, these were most commonly:

- Feeling calmer and more positive as a result of being supported by Helping Hands
- Feeling more confident
- Being in a position to better manage difficult behaviours (in particular, meltdowns), and
- Being able to adopt a parenting style that suited them and their family, rather than following preconceptions about being a 'good' parent.

Some parents also said that their whole life had changed as a result of their learning and their interactions with other parents during their time with Helping Hands.

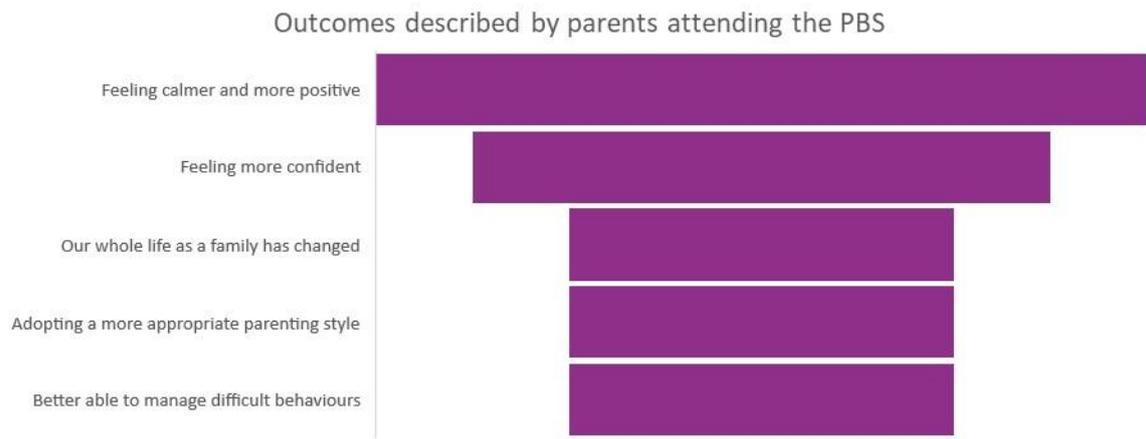


Figure 8: Other outcomes for parents attending the PBS

‘Since doing the PBS course I don’t feel so negative about things. I’m in the right frame of mind to deal with things. Before, I couldn’t think clearly and I just shut the world out. The course has helped me to feel calmer, and made me feel that I can deal with things. I follow through with things and I just feel so much different.’ – Parent of a child with a sensory processing disorder

‘The course taught us a lot about the meltdowns. How to deal with them in a much better way. How to deal with other people when they happen outside of home. And importantly how to try to prevent them happening in the first place.’ – Parent of a child with a sensory processing disorder

‘The workshops have helped me change my approach to managing my son, I took a step back and observed him, stopped nagging him and allowed him to do things and to choose my battles.’ – Parent

‘My daughter has meltdowns during which she screams. This can go on for an hour or so. I used to get very agitated and not want to leave her. But I’ve learnt that leaving her for a few minutes, gives me a chance to calm down and to manage the situation better. It also helps my daughter because she doesn’t want human interaction when things get like that. No-one had ever told me that that was ok to do. That I shouldn’t feel bad about leaving her. But it has helped so much.’ – Parent of a child with ASD

‘I feel much more confident. I used to feel like I was winging it. Now I’m more confident that I know why she is acting the way she is, and that it’s a normal part of the process for her.’ – Parent of a child with ASD

Given the relatively small number of people who we were able to interview for this evaluation, and the fact that all of them had attended a PBS course, it is difficult to disaggregate the different service elements and the different outcomes or impacts that may be associated with each, for example the 1:1 support from the service co-ordinator, versus the knowledge gained through the PBS, versus the opportunities to interact with other parents. However, we were able to explore the different factors (through interviews and observation) that are likely to have contributed to the outcomes observed.

The most important factor that contributed to the positive outcomes experienced by parents related to a much improved understanding of why their child behaved the way they did in certain situations. This generated a shift away from parents blaming their child for being 'difficult', to a feeling that 'this is who my child is' and that they needed to manage those situations differently. And while parents understood that the strategies they learnt about during the PBS course, and through discussion with other parents, would not always work, this shift in mindset was fundamental to the lower levels of stress and improved confidence that parents reported and which we observed during the PBS sessions. Some of the parents we spoke to also noted that this had resulted in a much calmer and positive family environment, and that their children were showing greater engagement in learning and development, both within and outside school.

Linked to this very powerful shift in mindset was the value of the supporting resources and information that parents were able to access, all of which were either immediately relevant to their family situation, or which could be adapted easily to fit with the individual challenges they were facing as a family. The resources also gave them really practical ideas, tools, and advice that they could use to improve their understanding of their child's behaviour and to avoid or manage difficult situations with more confidence and with less stress.

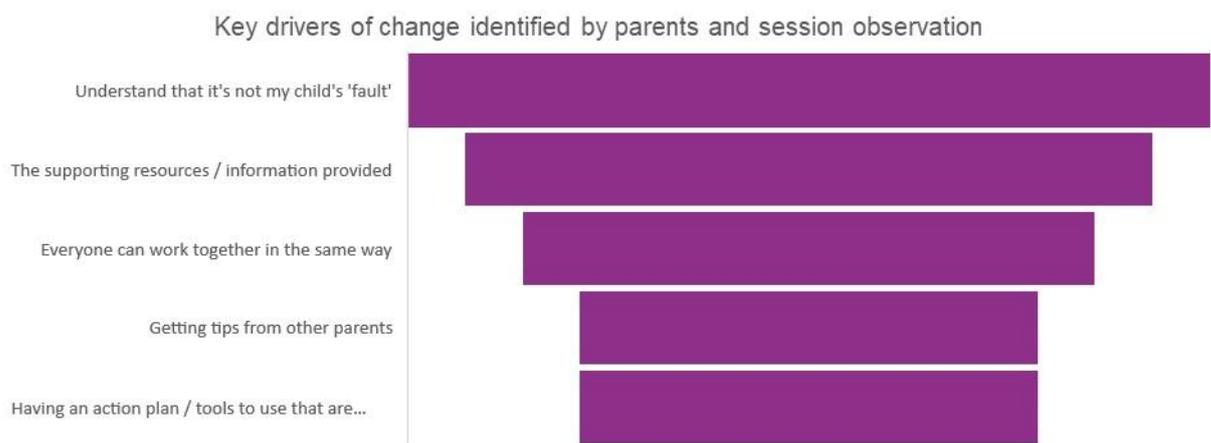


Figure 9: Key drivers of change

'Most of the time now, we look at things from a completely different angle. We think about why, and we feel better equipped to handle things because of that. It has really changed the way we think. And that has taken a lot of effort. So it's not thinking that the behaviour is a lack of respect. It is more about trying to understand why.' – Parent of a child with ASD

'Thank-you for providing families with so much brilliant information and resources they otherwise wouldn't know about. You're doing a fantastic job and it's been eye opening and interesting to take part in the sessions, I really appreciate the work you are doing and the help and knowledge you provide.'
- Parent

'The action plan has really helped a lot. We are able to use it at home, and give it to the school. And it means everyone is working in the same way.' – Parent of a child with a sensory processing disorder

Among the professionals we interviewed, there was a consistent view that the opportunity to develop knowledge and skills, and to create action plans relevant to their own family, were the key drivers of positive change for those attending the PBS course. This was also something that differentiated Helping Hands from other support that those professionals could either provide themselves or signpost families to.

'The key thing is that the PBS is focused on upskilling them [the parents]. They learn more about their own child's needs, and how to handle those needs.' – Family Support Worker

'The course gives them a better understanding of behaviours and an understanding that is specific to their own children. And different strategies to use so that they can deal with behaviours better. It goes well beyond what I can do for them.' – Family Support Worker

For three of the 10 families we interviewed, their experience of the support they received through Helping Hands was described as almost life changing. This highlights the potential the service has to transform the way parents think about and understand their child's behaviour, and to equip them with tools and techniques they can use to create a much calmer and more consistent environment, both at home and in other settings.

'I can't praise them [Helping Hands] enough. I wouldn't be here. I was constantly crying. Whereas now, it's totally amazing, totally different. I've put the work in to get where I am, but it has been worth it. The school also says that they can see the difference that the changes to my parenting have made.' – Parent of a child with a sensory processing disorder

'My only regret is that I didn't know about the course years before. I just wasn't aware of it and no-one else helped me in this way. My son goes to a SEN school now, they are much more supportive than his previous school, and things are so much better at home.' – Parent of a child with ADHD

Case example – Emily and Katie

All names have been changed to protect anonymity.

Emily, a mother of three school aged children, came into contact with Helping Hands following a referral from one of her daughter's Doctors. Katie, who is in primary school, had been diagnosed some years before with a condition that affects her sensory processing. This caused Katie to struggle with high levels of anxiety, and to demonstrate challenging behaviours including meltdowns that would sometimes last for up to three hours. Emily was struggling with Katie's behaviour and how best to manage her anxiety. She felt isolated and exhausted. She felt that Katie's school wasn't doing enough. She was frustrated and angry. And she had started to shut out the outside world.

The Helping Hands service gave Emily a new perspective on how to be a parent for Katie. She learnt about the different strategies she could use to better manage Katie's anxiety, and importantly, to understand why meltdowns happen and what she could do to prevent them. She also got help to talk to Katie's teachers about what they could do to better support Katie at school. Being able to talk to other parents in the sessions was a real lifeline for her too. To know that she wasn't the only one struggling with these behaviours, and to get ideas from the other parents about things to try was really helpful.

Emily feels that she is much calmer now. The whole family is. She feels that using the different strategies she learnt during the PBS course has made life much easier. She is able to make more time for Katie and to help her in a much more positive way. Although there are still difficult days, and while Emily recognises that she has had to put in a considerable amount of effort into changing the way she does things, her views on parenting, and the day to day routines that the family now follows, she is much more positive about the future.

'I can't praise them enough. I wouldn't be here. I was constantly crying. Whereas now, it's totally amazing, totally different. I've put the work in to get where I am, but it has been worth it and I've learnt so much.' - Emily

9 Benefits across the wider support system

9.1 Filling a gap in provision

In addition to the outcomes for parents and families that professionals observed in connection with the Helping Hands service, the greatest benefit for them by far was that the service fills a gap between more specialist mental health provision (such as through CAMHS) and universal support, such as early help services and more generic parenting support. And while children with ASD or ADHD (or other behavioural conditions) can vary considerably in terms of the types of behaviours they demonstrate, the severity and complexity of these in day to day life, and the longer term impact this may have on the child's learning and development, the Helping Hands service (and the content of the PBS course in particular), seems to be generic enough to suit a broad range of conditions, while at the same time being very specific to the challenges faced by the majority of these families. This, in turn, could have a potentially substantial impact on reducing demand for those other services (including more specialist mental health provision) over the longer term.

'For children who are displaying behaviours that are out of the norm, they won't respond to normal parenting strategies. And I think it's important for Helping Hands to be very specific about who they are there for. That is, the family must have a diagnosis or be on a pathway towards one.' – Family Support Worker

'There really is no other option for these families. Helping Hands is the stop gap between us and CAMHS. While there are general parenting courses out there, PBS is specific to the needs of these families.' – Family Support Worker

'The only other options for these families is inclusion support through the child's school, or a parenting course. But these are often not specific enough and not for children with disabilities.' – Family Support Worker

Professionals also recognised the pressures on schools and the variability they have seen in the capacity and capability that schools have to support children with additional needs. While they recognised the compassion and professionalism that teachers and other school staff routinely demonstrate, they believe that the wider school system often doesn't allow the necessary support to be provided for children with additional needs.

Schools are an important place in the lives of these children. Not only is school often a source of anxiety and sensory overload for children with ASD or ADHD, it must also be the place where these children can feel that they are understood, and which gives them consistency and routine so as to minimise the potential negative impacts and maximise their potential.

'There is very little help for these children at school. There is no doubt the teachers are very compassionate, but the system just doesn't allow the right support to be provided. There is no room for the grey areas. Also, they often won't do anything extra unless the child has a diagnosis.' – Family Support Worker

'Schools really are my nightmare. They are often the hardest people to get past. Not very understanding, and often not really trained in how best to support these children. They often just don't have that knowledge. There are certainly some good SENCOs around, but they're not always full-time, which makes things even harder.' – Family Support Worker

Through its work with schools, the service has observed some really positive progress in relation to strengthening SEND provision, such as setting up regular coffee mornings for parents with children with additional needs to improve social interaction and peer support, and to find ways to build and maintain stronger relationships between parents and teachers.

9.2 Opportunities for greater reach and impact

The Helping Hands service has made good progress since its launch in Sandwell to raise its profile and to build a greater understanding across the system about the help that families with a child with ASD or ADHD need. The service has also shown that positive changes, both at home and elsewhere, can come about if people better understand why children with these conditions behave the way they do. However, the level of need, both for directly supporting families, and for building capacity and capability across health, education, and more generic prevention and family support services, far outweighs the reach and impact that Helping Hands has been able to achieve within the time and resources it has had to date. This is certainly the case in Sandwell, and most likely elsewhere.

'I just wanted to ask you if you were aware of any services similar to Family Action in or around [this area]? It is such a great service you guys offer and I am wondering what I will do in terms of signposting families now that I no longer work in Sandwell. I have always said that you guys provide such a great service and it was one of the things I was really conscious about when making the move here, that there is not anything comparable to share with children, young people and families when I see them for assessments.' – Social Worker

'I found it shocking to hear the other parents' experiences of Early Help and Social Care, I will be feeding back to my manager that there needs to be some proper training regarding Autism and sensory needs, and highlight the lack of understanding some parents said many professionals had. I will be requesting all staff in children's services receive some specific training.' – Family Support Worker

'I think there is definitely room for expansion. They need to cast their net as widely as possible.' – Family Support Worker

However, service expansion will require funding, not only to deliver more PBS courses, but to train more people in how to deliver them and to provide the necessary administrative support to ensure the available capacity is used most effectively. It is also likely to require a greater complement of paid staff (as opposed to relying on volunteers to support the delivery of the sessions). While volunteers are an important and really valuable part of the service offer, the experience of the Helping Hands service is that their availability can change unexpectedly, which in turn will impact on the ability of the service to deliver the core elements in a timely and effective way. We would recommend that volunteers (particularly if those volunteers are themselves parents of children with additional needs) continue, where possible, to play a role in supporting families who have been referred to the Helping Hands service, but that this be seen as a 'value add' rather than part of the core offer.

There may also be opportunities to consider the timing of the PBS sessions so that they are held outside of work hours. This may open up access to those parents who work full-time. At the same time it should be considered if there is future potential for offering both virtual and face to face sessions. The experience of the service to date is that the virtual sessions worked well for some people, opening up access and removing barriers connected with travel time and cost.

'The only one thing I would change about PBS – make it outside of work times so my husband could attend. It would have been really valuable for him.' – Parent of a child with ASD

Building greater knowledge and capability across the system, especially in schools, through a more clearly defined consultancy and training offer, also needs to be properly resourced in future funding arrangements. And it needs buy-in from senior leaders and key decision makers across health and care, and education, so that the whole workforce sees the value in being better equipped to help families before things escalate. Understanding and dealing with conditions that affect sensory processing in children should no longer be seen as only the remit of specialists. Any professional working with these families should have a level of understanding that enables them to take early and effective action when problems start to become apparent.

Linked to this is the level of resource required to raise awareness of the service and to continue to educate professionals about referral pathways and suitability criteria. While this will in part require more evidence on the profile of families for whom the service delivers the greatest impacts, the level of staff turnover elsewhere in the health and care system means that this type of activity needs to be ongoing if the capacity available in the service is to be used most effectively. It also needs to be established as a more formal part of the care pathway for families that are at an early stage along the diagnostic pathway, given the amount of time this can typically take.

'I think within CAMHS and our partners there is now a pretty good awareness and understanding of the Helping Hands service. However, there is much less within schools, and given parents go online to find information and support, I'm surprised that Helping Hands doesn't come up more often. Maybe there could be more on social media to raise awareness, such as an open Facebook group, and also work with GPs and Paediatricians who are likely to come into contact with families that would benefit from this type of support.' – Clinical Lead

10 Potential for sustainable and longer term impacts

The evidence from this evaluation points to a clear potential for there to be sustainable and longer term positive impacts for those families who have been involved in the Helping Hands service. Not only have we seen that the service helps parents to tackle the specific challenges they are facing in day to day life, the PBS course in particular provides parents with the fundamental knowledge and skills that they can apply, not just in the short term, but as their child continues to grow and develop. This is likely to have a direct impact on wellbeing, and better longer term outcomes for children.

What this might mean for families over a longer time period we don't yet know, but we do know that many parents continue to use the knowledge and skills they have gained in their everyday life some months after completing the course. We also know that for many, they feel better able to communicate with school staff and other professionals, something which is likely to help them over the longer term. This is likely to be especially beneficial for those who are still be on a pathway to diagnosis.

'I'm still using all the strategies [that I learnt during the PBS]. It is hard sometimes, but using them has made life a lot easier. It has changed me as

a parent and I'm much more positive about my parenting, and about the future.' – Parent of a child with a sensory processing disorder

'I recently had a meeting with my child's new teacher. She didn't know about any of her problems. But I felt much more confident speaking to the teacher about how to do things, and what to put in place at school.' – Parent of a child with a sensory processing disorder

'My son has now been assessed for ASD. Doing the course has helped so much with that process, knowing what to say, what terms to use. I'm more confident explaining how he behaves and to speak to people using the right language.' – Parent of a child with ADHD

'I really feel part of a group. They give you extra tools, and it is great. My son was really difficult last week, so I got my notes out, and now this week is much better.' – Parent of a child with a sensory processing disorder

I feel more confident and I'm still using the strategies and am in a better place than before the course. It is really beneficial knowing that others are going through the same thing.' – Parent of a child with ASD

'Learning about the bucket model made the school wake up a little bit. I now get meetings with the school and they are getting better at supporting my daughter. We still have problems with her not wanting to go to school. But I wouldn't have had the help of the school without Helping Hands.' – Parent of a child with a sensory processing disorder

11 Strength of evidence for key outcomes

The following table sets out the key outcomes of the Helping Hands service for different stakeholder groups and the strength of evidence we have from this evaluation.

Overall, there is strong evidence that the service delivers a number of positive outcomes for parents, and some promising evidence that there are positive impacts on children and the whole family, including over the longer term. There is also promising evidence in relation to awareness and trust in the service among professionals. In terms of whole system impacts, we believe that there is some initial evidence from this evaluation of the potential to improve partnership working for children and families experiencing ASD/ADHD, and to potentially reduce demand elsewhere in the wider health and care system (including within schools), however, further research on this is needed.

Group	Outcome area	Outcomes	Strength of evidence ²⁴
Parents	Developing skills and knowledge	Parents are better prepared to manage behaviour	Strong
		Parents have better knowledge of the support available to them	Strong
		Parents feel more confident advocating for their child	Strong
	Feeling better	Parents more confident in their parenting ability	Strong
		Parents less anxious/worried	Strong
		Improved self-esteem	Promising
		Parents more optimistic about the future	Strong
	End results	Improved parent wellbeing	Promising

²⁴ The strength of evidence is categorised as follows: Strong – we can be confident that there is an impact for the stated group, and within the context of the service; Promising – we have some evidence of impact which needs to be investigated further; Initial – there may be an effect, but further investigation is needed.

Group	Outcome area	Outcomes	Strength of evidence ²⁵
Children and the whole family	Understanding and better meeting child's needs	More open and effective ways to communicate with each other and the whole family	Promising
	Behaviour awareness and management End results	Children more aware of their feelings and how this impacts on their behaviour	Initial
		Children better equipped to understand their feelings and behaviours	Initial
		Children better able to communicate their feelings with important people in their lives (parents/teachers)	Promising
		Better family relationships, including between siblings	Promising
Professionals	Awareness and trust	Professionals have trust in the service's ability to meet the needs of these families in a timely and effective way	Promising
		GPs have improved knowledge of ASD/ADHD and the support available	Not able to be determined due to the impact of the coronavirus pandemic on service delivery
Whole system	-	Improved partnership working for ASD/ADHD (pre- and post-diagnosis)	Initial
		Reduced need for escalation to higher level support services	Initial

Table 6: Key outcomes and the strength of evidence available from this evaluation

²⁵ The strength of evidence is categorised as follows: Strong – we can be confident that there is an impact for the stated group, and within the context of the service; Promising – we have some evidence of impact which needs to be investigated further; Initial – there may be an effect, but further investigation is needed.

12 Conclusions

This evaluation has shown that Helping Hands has the potential to transform the lives of families living with ASD or ADHD (or other sensory processing conditions), and to generate longer lasting benefits through knowledge and skills transfer, the development of action plans that are specific to each family context, and by supporting a calmer, more confident, and less stressful family environment. There is especially strong evidence that parents feel better equipped to manage behaviour, that they are more confident advocating for their child (especially within school and with healthcare professionals) and more confident in their parenting ability, and that they are less stressed and worried about the future. There is also some promising evidence of a positive impact on wellbeing and the potential for this to be sustainable over the longer term.

However, there are opportunities to use the emerging evidence from this evaluation to inform a more evidence based Theory of Change and set of assumptions around the intended and likely outcomes from the service. This would include better insights into which families are most likely to engage with and benefit from the service, whether that be in relation to the diagnosis of their child, the child's age and/or time since diagnosis, or different family situations. This would require more systematic capture of this type of information from families, and more robust data on engagement in different aspects of the service and the reasons why people do and don't engage. And while there is clearly some strong evidence from this evaluation about the positive impact the service has, there are opportunities to both strengthen the service offer around follow up support (following the PBS) and to build in measurement of longer term outcomes, such as school engagement and learning, and in relation to the creation of sustainable support networks. Both of these would require additional resources, however, we believe the evidence from this evaluation makes a strong case for that type of additional funding in the future.

There are also opportunities to extend the reach of the service across the wider health and care system, both from formal (as a recognised part of the care pathway) and less formal (such as awareness raising, education and training) perspectives. This includes, in particular, more work in schools and consideration of how Family Action could work in partnership with other condition specific charities. It would also be useful to raise awareness outside of the traditional support structures, so that more parents see the value in having a better understanding of sensory processing and the benefits this can bring. This could be aligned to the work being done as part of the UK Government's national strategy for autistic children, young people and adults.

Alongside this, we believe there is a strong case for Family Action to work with commissioners across Integrated Care Systems to establish the service as a more formal part of the care pathway for families that are at an early stage along the diagnostic pathway. This would help to better manage demand on more specialist care services and ensure that these families receive appropriate and meaningful support that can prevent problems escalating (including the potential for family and/or relationship breakdowns), and ensure that children are supported to maximise their engagement in learning and development at the earliest opportunity.

We also believe that the future funding model should rely less on volunteers to deliver the more specialist aspects of the service (the PBS course and TIM workshops) and look to use volunteers primarily as a 'value add' and as a key part of the wider support to parents that the service provides. Any service expansion will therefore be reliant on a funded programme of work to skill up and retain paid workers to deliver the PBS course and TIM workshops, and to be a point of contact for professionals working elsewhere in the system.

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