

**Family Action
Health Champions Service
Evaluation Report**

May 2018

Executive Summary

Family Action's *Family Health Champions Service* is a pilot service designed to support families where children or young people in the family are diagnosed with, or are suspected of being affected by, Autistic Spectrum Disorder (ASD) and/or Attention Deficit Hyperactivity Disorder (ADHD). The service was established in 2016, and is currently running in Peterborough, Sandwell and Swaffham. It is funded by the Department for Health's *Health and Social Care Volunteering Fund*.

Envoy Partnership were commissioned by Family Action to evaluate the Health Champions Service in 2017. The evaluation sought to understand the impact of the service on stakeholders, to provide an evidence base around the model's effectiveness, to contribute to the *Theory of Change* for the service, and to inform future developments of the project.

About the service

A key characteristic of the service is the use of volunteers (known as 'Health Champions' or 'Champions') who work with the Service Coordinator to support families to better understand their child's behaviours, to help improve attainment and to improve the wellbeing of the family.

The main types of activities provided by the service are one-to-one meetings with Health Champions, informal group meetings such as 'coffee mornings', activities for children and families and support for families when accessing other services. The service also delivers training courses, such as the Positive Behaviour Support (PBS) Course, Incredible Years Courses and one-off workshops. By February 2018, 177 families had received one-to-one support and by March 2018 there had been 2,090 attendances at group activities and training sessions in total.¹

As of January 2018, 57 Champions had been recruited, with 28 active at that moment in time. The gap between volunteers and service users is narrower than in many volunteering services: around two-thirds of the volunteer Champions have children with ASD, ADHD or similar conditions and many of these Champions gain support from the service for their own family situations. Many families who use the service want to support other families; so far six service users have gone on to become volunteers themselves, with a further five expected to start soon.

Most families access the service before they have a diagnosis for their child and, for some, support in seeking a diagnosis was part of the motivation for accessing the service. Regardless of whether or not they have a diagnosis, most parents/carers and Champions felt that the support available for families affected by ASD and/or ADHD in their area was severely lacking, and that the service therefore filled a significant gap.

Strengths of the service

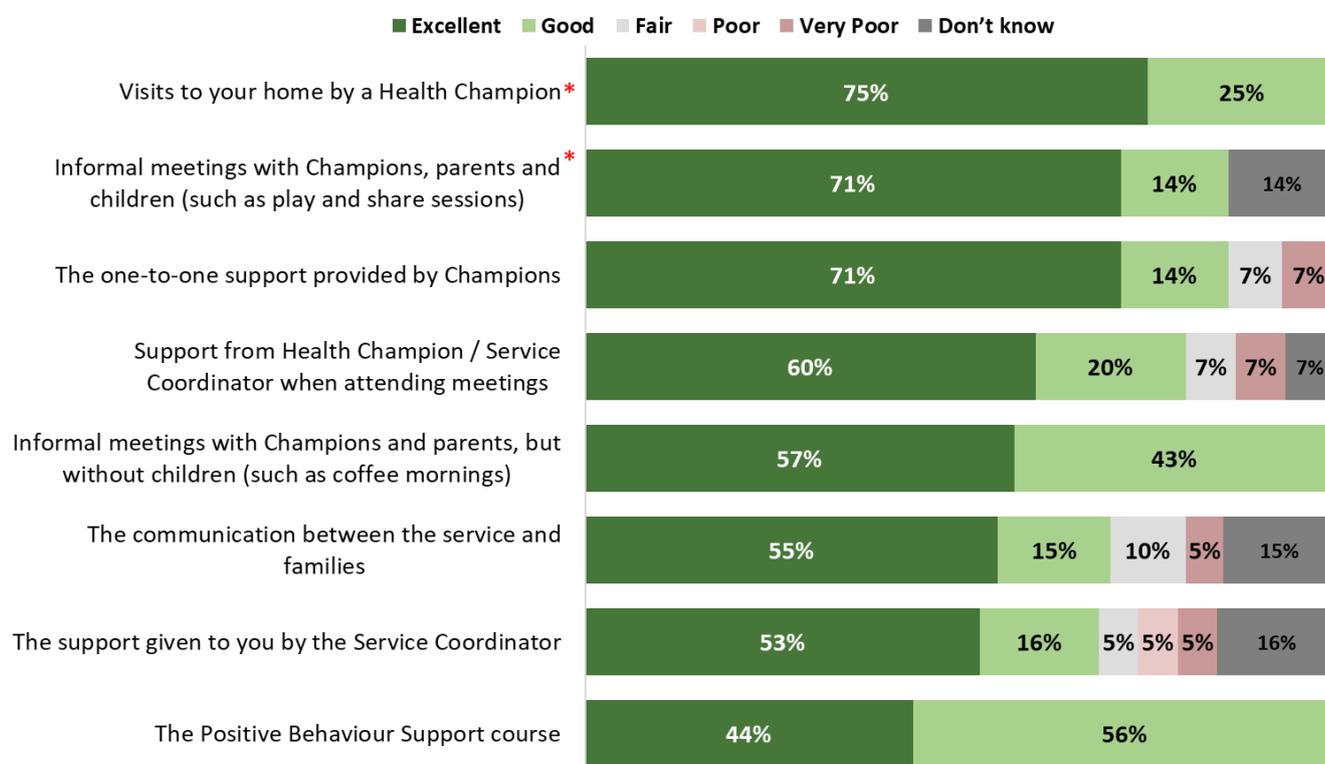
The evaluation identified a number of strengths of the service. In particular:

- **The positioning of the service** as independent from other statutory services. The Health Champions Service is seen as supportive, accessible, and non-judgemental, and Family Action is perceived as professional and impartial. In contrast, many families felt that other services were less likely to be 'on their side' and to be more judgemental. There was particular anxiety about potential intervention from social services.

¹ The number of people attending will be below 2,090 as many people will have attended more than one session.

- **Recruiting the right people**, for both the Health Champions and the Service Coordinators:
 - Many families spoke very highly of the support provided by Health Champions. Champions' empathy and understanding are seen as their most important characteristics, and the knowledge and experience they had built up (including through the training they are provided) are also important. Champions are supportive of each other, and in many cases have formed their own groups and networks that have some independence from the service and the Service Coordinator.
 - Likewise, the Service Coordinators are seen as empathetic, knowledgeable, and able to support families effectively. The Service Coordinators play an important role in advocating for families; many families were particularly grateful for Service Coordinators' support at meetings with school and healthcare providers, and several credited them with an improved level of support from their child's school.
- **The combination of informal support and formal training** provided by the service works well. The 'befriending' element (the informal support provided by Champions) gives many parents/carers the opportunity to feel listened to for the first time, and a sense that they are not on their own. Meanwhile, information and advice are provided through both formal channels (such as training courses) and informal channels (such as sharing of behaviour strategies at coffee mornings).
- **The availability and adaptability of provision** made the service easier to access than many other services and the frequency with which service users could meet with Champions was important.
- **The word of mouth communication about the service** was important: both parents/carers and professionals who have had positive experiences of the service can be powerful advocates for the service.

Figure 1: Parents' views on the effectiveness of different aspects of the service²

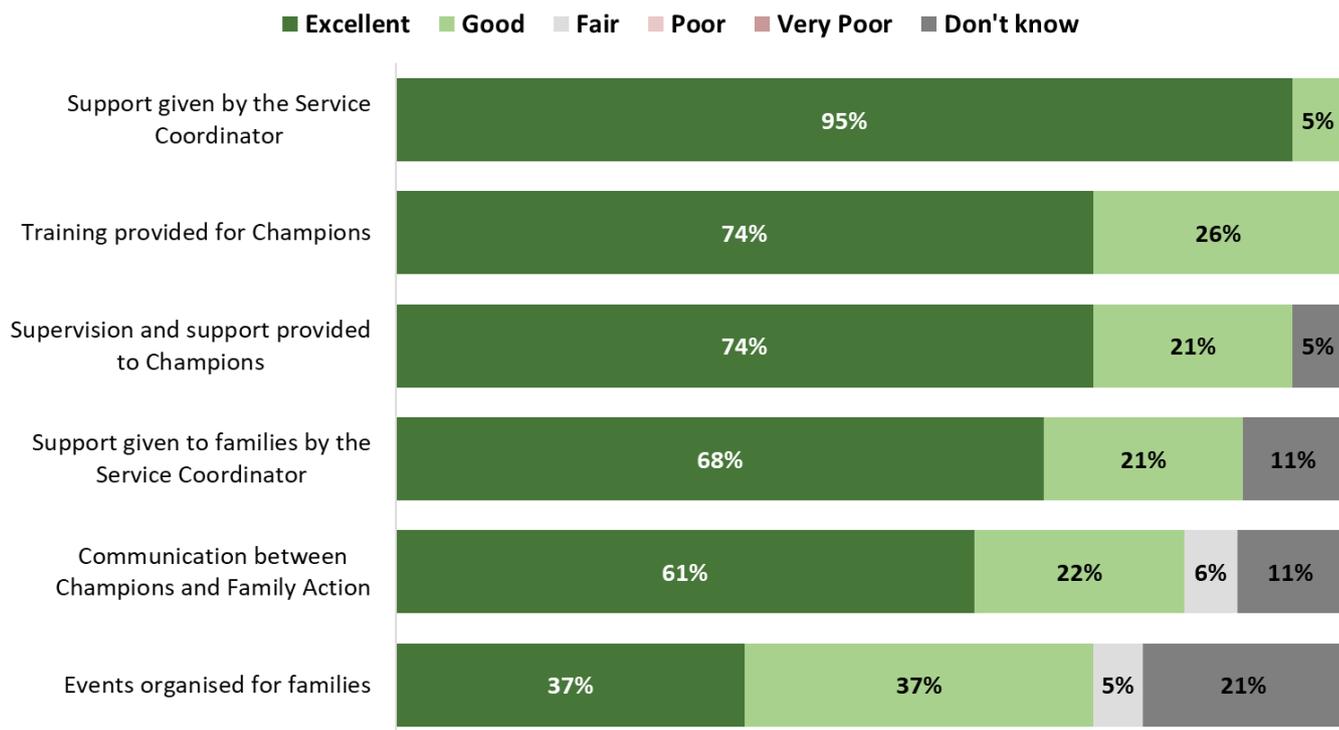


Q12. "Thinking about your experience of the Health Champions service, how would you rate the following aspects of the service?" n=8, 7, 14, 15, 14, 20, 19, 16 [Base size for each statement in turn]

* Fewer than 10 responses

² Source: Parents' survey

Figure 2: Champions' views on the effectiveness of different aspects of the service³



Q. "Thinking about your experience as a Health Champion how would you rate the following aspects of the service?" n=19

Challenges facing the service

The evaluation also highlighted a number of challenges facing the service. The report discusses both those challenges which had been addressed by the time the evaluation commenced (or during the evaluation), and those that are still ongoing. This is so that the report can inform future service delivery in other areas beyond Peterborough, Sandwell and Swaffham.

- **The mix of Health Champions** was discussed by some stakeholders. In particular, whether the service would benefit from more male Champions, more Champions with experience of ADHD (rather than autism), and more Champions with older (secondary school age) children. Our view is that, while this may benefit the service, it is desirable rather than necessary.
- **Vulnerability to change:** Strong partnership working appears to have made the services relatively resilient to external changes, such as changes in the availability of other support services or in school structure. Nonetheless, there was some concern that the service is vulnerable both to changes in personnel at the service, as well as external changes.
- **Communication** is seen as strong overall, but with some areas for improvement. Referrals to the service often do not include a phone number, meaning it can be hard for Service Coordinators to contact potential service users. The Service Coordinators were also aware of, and actively managing, the danger of service users doing so much research that they become 'self-made professionals', who may give other service users incorrect or misleading information.
- **Number of families supported:** The service originally aimed to support 750 families, but this was ultimately not practical for the service as originally designed, and local populations affected by ASD or ADHD appear to be lower. Nonetheless, there have been improvements in the efficacy of the service: in the earlier days of the service, a significant amount of Service Coordinator time was taken

³ Source: Health Champions' survey

up by supporting families with very high levels of need; clearer referral thresholds have reduced this over time.

- **Practicalities of meetings:** Parents/carers had a few suggestions about how meetings might be improved, some of which may not be realistic. One area that Service Coordinators have needed to balance is the need for parents/carers to be unable to ‘unwind’ and share their experiences at meetings, while ensuring that the most vocal do not take over and dominate a meeting.

Outcomes of the service

The evaluation outlines a range of outcomes for Champions, parents/carers, children and other stakeholders, in the short, medium and long-term. The biggest impact of the service is on parents/carers and Table 1 shows parents’ feedback on the outcomes that they experience from the service.

Table 1: Outcomes for parents⁴

Outcome	% parents who ‘strongly agree’	% parents who ‘strongly agree’ or ‘somewhat agree’
I am better at understanding needs & behaviours linked to ASD/ADHD	67%	82%
I feel more confident when speaking up for my child	58%	82%
I am better able to manage the behaviour of my child/children	54%	72%
I have more of a network of people who I can go to for support	46%	74%
I feel more confident about my parenting ability	44%	72%
I am more aware of my child’s rights	41%	77%
I feel better able to communicate about my child’s condition	41%	69%
I feel less isolated	41%	67%
I feel more positive about myself	41%	64%
I feel more able to help my child do well in the future	38%	85%
My own mental health and/or well-being has improved	38%	59%
The support that I get from my child’s school has improved	37%	54%
I am more aware of local provision for families affected by ASD/ADHD	34%	63%

“It’s a million times better than it was.” [Parent]

“I’ve definitely seen relationships between parents and children improve and stabilise, and also seen the parent’s relationship and attitude with the school develop more positively.” [Champion]

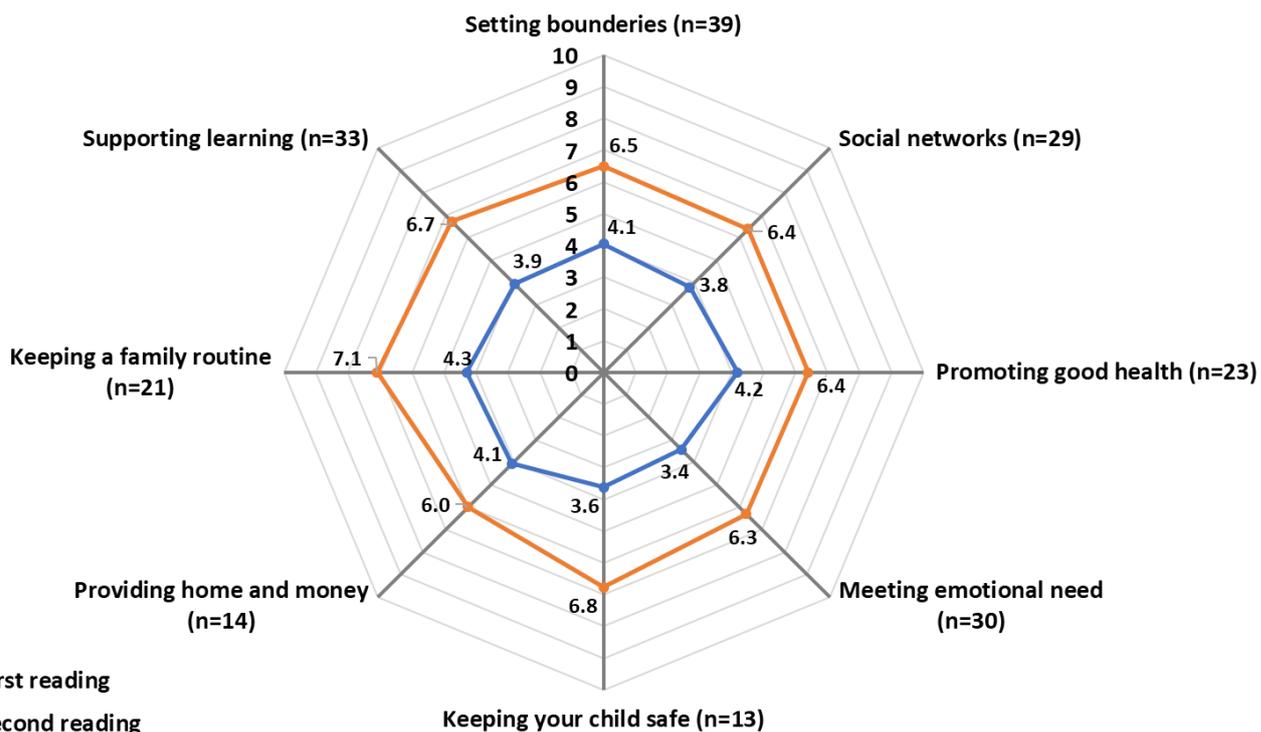
In addition, data from the Family Star shows the impact on parents.⁵ The Star covers eight areas of parenting: physical health, emotional wellbeing, keeping your children safe, social networks, education and learning, boundaries and behaviour, family routine, and home and money.

Figure 3 shows the results of the Family Star for service users where there are least two readings, and where the first reading is five or lower; this is intended to show the impact on outcomes where the starting point was particularly low, and hence need for support in these areas is highest. It shows that the Health Champions service has a particularly significant impact when the parent is starting from a lower point. The chart demonstrates particularly large increases in ‘keeping your child safe’ and ‘meeting emotional need’.

⁴ Source: Parents’ survey, n=39

⁵ Family Action uses the Family Star developed by Triangle Consulting to support parents and families to plan and measure benefits to be achieved. See page 47 for more details.

Figure 3: Family Star: Results when first reading is five or lower⁶



Data from Family Star. Clients where at least two Outcome Star readings are available, and the first reading is 5 or lower. n=13-39

There were also important outcomes for children from the service. The service’s focus however is on supporting parents; when there is an impact on children, this is often because the service’s support to parents/carers enables them to support their children more effectively. Table 2 shows parents’ feedback on the outcomes for their children.

Champions’ reasons for volunteering are largely around their desire to support other families, rather than any potential benefits for themselves. However, there are a number of benefits to Champions themselves, as shown in Table 3. As many of the Champions are themselves parents/carers of children with ASD and/or ADHD, many of the benefits to parents/carers also applied to Champions.

Table 2: Outcomes for children⁷

Outcome	% parents who ‘strongly agree’	% parents who ‘strongly agree’ or ‘somewhat agree’
They enjoy joining in the activities with other children and adults	22%	56%
They are more trusting of other people	19%	52%
They have built new friendships with other children	19%	31%
They are better able to manage their own feelings	14%	50%
They are calmer and less anxious	14%	43%
They are coping better at school	12%	44%
They are better able to manage their behaviour	11%	61%
They are more relaxed	11%	44%

⁶ Source: Family Action data

⁷ Source: Parents’ survey, n=25-28

“I wouldn’t have the confidence to know how to express my concerns, I feel more empowered and proactive rather than passive and not knowledgeable. That would have had a negative outcome for my daughter, as she would have had to cope with me being angry, panicky, anxious and not calming. I have skills to calm things down now as well.” [Parent]

There were some outcomes for other services, in particular improved knowledge about ASD and ADHD, and improved practice in some schools. The evaluation also explored potential financial or resource savings for these services. While such savings may be made in some instances (for example, if the health of a parent or carer improves meaning they need less support from the NHS), the research showed that in many cases families were not getting the support that they were entitled to from schools and health services in the first place, and the work of the service can lead to the family getting this support. Therefore, Local Authorities and schools may experience increased costs in the short term, although this is in relation to services that they are duty bound to supply. It may be that, in the longer term, there are resource savings created by families getting the right support in the short term; however, this is beyond the timeframe of this research.

Table 3: Outcomes for Champions⁸

Outcome	% Champions who ‘strongly agree’	% Champions who ‘strongly agree’ or ‘somewhat agree’
I valued the opportunity to give something back	95%	100%
I gained experience and skills that will be useful to me	68%	84%
It affected my well-being (positively or negatively) ⁹	53%	84%
I gained knowledge about autism and/or ADHD	37%	63%
I made new friends	32%	84%
It made me more attractive to potential employers	32%	53%
It contributed towards my professional development	28%	67%
It supported with issues or challenges in my own life	26%	63%

“Now it feels like I have more of a voice and we [Champions and parents] are being listened to and action is happening. Peer group/peer support is a big part of why it helps. It helps everyone stop sweeping things under the carpet.” [Champion]

Conclusions

The Family Action Health Champions Service offers a creative and effective response to the needs of families affected by ASD and/or ADHD. The evaluation shows that the service model works well, the right people are in place to deliver positive outcomes for families, the service has been delivered effectively in Peterborough, Sandwell and Swaffham, and the outcomes for different stakeholders are significant.

In our view, the need for services that support families affected by ASD and/or ADHD is not likely to recede in the short-term. While one single service cannot address all the different needs presented by these families, it is our view that the Health Champions model is an effective way to deliver significantly increased levels of support, and to greatly improve the lives of those affected.

⁸ Source: Champions’ survey. n=18-19

⁹ While this question asked about positive or negative changes, the follow-up question showed that all of those indicating a change experienced a positive change.

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Introduction

Family Action's *Family Health Champions Service* (referred to in this report as the 'Health Champions Service') is designed to support families where children or young people in the family are diagnosed with, or are suspected of being affected by, Autistic Spectrum Disorder (ASD) and/or Attention Deficit Hyperactivity Disorder (ADHD). The service particularly seeks to support families at difficult transitions (for example, pre-diagnosis, or moving between nursery, primary, and secondary schools). The service is a pilot, funded by the Department of Health from 2016 to 2018, with the original aim of supporting 750 families in that time.

The service draws on existing Family Action models which have been evaluated and shown to be effective. These service models include Perinatal Support, WellFamily and Social Prescribing. The service is currently running in three locations: Peterborough, Sandwell, and Swaffham; these are referred to as 'the service(s)' throughout this report.

A key characteristic of the service is the use of volunteers (known as 'Health Champions' or 'Champions') to support families affected by ASD and/or ADHD to better understand their child's behaviours, to help improve attainment and to improve the wellbeing of the family. The service was designed to provide three main components of support to families:

- Befriending – Champions offering practical and emotional help, information and advice
- Peer-to-Peer Support Groups – a network of parents who are provided with informal advice, emotional support, and practical support by the Champions, Service Coordinator and other parents/carers
- Social Prescribing – increasing families access to existing support such as Special Educational Needs and Disabilities Information and Advice Services (SENDIAS) or Young Carers services, as opposed to relying on GP support or inappropriate use of A&E Departments

Over time the new areas of the service were introduced. These are described in more detail on page 19.

The service largely works with families before they get a diagnosis of ASD and/or ADHD. It aims to help fill the gap in support that families experience when they are waiting for a diagnosis (see page 12 for a discussion of the service context, including the challenges of obtaining a diagnosis). In practice, the nature of the service varies a little from one location to the next. The variations are driven by factors such as:

- The geography of the region. For example, the Swaffham service operates in a much more rural area than the Peterborough service
- The makeup of existing family services in the area. This includes statutory services such as healthcare services, schools, Local Authority support, other Family Action services, and services provided by other voluntary organisations
- The involvement of local stakeholders. In Sandwell, for example, parents who were already involved in services, such as Autism West Midlands, were involved in coproducing the service locally and deciding how the overarching model would be adapted and delivered in Sandwell

The services provide activities that include children, as well as activities that focus just on the parent or carer. By carers, we are referring to informal carers, such as grandparents or step parents, as well as formal carers such as adoptive parents. When this report discusses 'parents', it is referring to the informal and formal carers, and the biological parents, that use the service. They are also defined as the main 'service users' in this report.

Evaluation of the Health Champions Service

Envoy Partnership was commissioned by Family Action to evaluate the Health Champions Service. The aims of the evaluation were as follows:

- To contribute to an evidence base around the model’s effectiveness
- To examine the impact of the service on families’ emotional and mental wellbeing
- To examine the impact of the service on parents’ understanding of their child’s condition and how they can support development
- To examine the impact of the service on families’ ability to access other local services and reduce their isolation
- To examine the impact of the service on other health and social care agencies and professionals
- To consider indicative financial savings and value for money of the service to commissioners
- To inform future developments of the project, and practice-sharing resources
- To develop a robust Theory of Change for the programme in conjunction with Family Action

Evaluation methodology

Envoy Partnership designed a nine-stage evaluation methodology at the beginning of the evaluation, as outlined in Table 4.

Table 4: Evaluation methodology

Stage	Objectives
1. Inception meeting and project setup	Review evaluation objectives, research plan, and key deliverables.
2. Literature Review	Understand the evaluation tools and existing evidence used by other organisations, their strengths and weaknesses, and how they might be used in this evaluation.
3. Family Action workshop and Theory of Change development	Gather input of key Family Action staff, discuss evaluation options, develop draft Theory of Change. Establish key topic areas for qualitative research.
4. Qualitative Interviews Phase 1	Test the first draft Theory of Change. Begin the Process Evaluation by exploring how the project creates change. Begin development of quantitative tools.
5. Qualitative Interviews Phase 2	Test and refine the new data collection tools.
6. New quantitative research, conducted by Envoy Partnership	Gather additional quantitative data beyond that currently being collected by Family Action. In particular, the perceptions of parents and Champions, and drivers of effectiveness of the programme.
7. Additional data collection by Family Action	Gather quantitative data that is not currently being collected by Family Action. In particular, to consider observational measures of outcomes.
8. Qualitative Interviews: Round 3	Review the initial data and findings, test interpretation with key stakeholders.
9. Analysis and Report Writing	Analyse the qualitative and quantitative data, and prepare a report for Family Action.

As the evaluation proceeded, a few changes were made to the methodology to reflect the needs of the services and the level of access to stakeholders. In particular it was decided that Stage 7, *Additional data collection by Family Action*, would not be undertaken. This was because the existing data collection requirements of the services were proving challenging to meet, and a decision was made by Family Action and Envoy Partnership to keep the research focus on meeting the existing data collection requirements, rather than introducing additional requirements.

Partly as a result, the Qualitative Interviews at Phases 1 and 2 were effectively treated as one stage, and conducted between May and July 2017. The decision not to develop additional data collection tools meant that the testing of these tools was no longer required during these interviews. Instead the qualitative interviews focused on achieving a greater understanding of the effectiveness of the service, the factors affecting the success of the service, and the outcomes created by the service.

In addition, one of the aims of the evaluation was *“to consider indicative financial savings and value for money of the service to commissioners.”* Resource savings may be made in some instances (for example, if the health of a parent improves, meaning they need less support from the NHS). However, the research showed that in many cases families were not getting the support that they were entitled to from schools and health services in the first place, and the work of the service can lead to the family getting this support. It may be that, in the longer term, there are resource savings created by families getting this support in the short term; however, this is beyond the timeframe of this research, and this report does not attempt to calculate any financial savings.

Table 5 shows the planned sample sizes the Qualitative Research and the actual research achieved. The research team spoke to fewer Family Action staff than originally envisaged, but this is because there are fewer staff directly involved in each service than had been anticipated.

Table 5: Sample Sizes for Phases 1 and 2 of the Qualitative Research

	Phase 1		Phase 2		Phase 3		Total	
	Planned	Actual	Planned	Actual	Planned	Actual	Planned	Actual
Family Action Staff	6	4	6	4	6	5	18	13
Champions	9	13	6	4	12	9	27	28
Partners	6	6	-	1	3	3	9	10
Parents	12	10	9	6	12	13	33	32
Children	-	-	15	9	12	0	27	9
Total	33	33	36	24	45	30	114	92

The biggest gap between planned and actual research was for children with autism and/or ADHD. Engaging children proved more challenging than anticipated in Phases 1 and 2 of the research. A decision was made by Family Action and Envoy Partnership at the beginning of Phase 3 *not* to focus on children in the final phase of the research. This was because:

- Most of the work of the service does not involve children directly
- When children were involved with the service, they were generally younger children who were less able to understand and describe the impact of autism and/or ADHD
- Interviews with children would require home visits or specially arranged events, with the potential for negative impacts on the children’s routines, and potentially on their emotional wellbeing and behaviour

As the focus of the service is on the parents, and the outcomes created are largely for parents, it was believed that conducting high-quality research with children would take a disproportionate amount of research resource and would put unnecessary demands on the families of those children.

For Stage 6, *New quantitative research, conducted by Envoy Partnership*, an online survey was developed for Health Champions, and a paper and online survey was developed for service users (as some service users had not given the Health Champions Service their email address). An incentive of a £5 Costa Coffee e-voucher was offered to service users who completed the survey. The surveys were completed in December 2017.

Purpose of this report

This report describes the service's outcomes for different stakeholders, the Theory of Change, the service's strengths and challenges facing the service.

Context for the Health Champions Service: Support for ASD and ADHD in the UK

There has been increased media coverage recently of the shortfalls in support for families affected by ASD and ADHD, and the impact that this can have on families. Government cuts to funding for statutory and voluntary services, and increasing demand on public services, has created a challenging environment for the Health Champions Service.

The Equality Act 2010¹⁰ sets out the legal obligations that schools and other organisations have towards disabled children and young people. These include the following:

*"They [schools and other organisations] must make reasonable adjustments, including the provision of auxiliary aids and services, to ensure that disabled children and young people are not at a substantial disadvantage compared with their peers. This duty is anticipatory – it requires thought to be given in advance to what disabled children and young people might require and what adjustments might need to be made to prevent that disadvantage."*¹¹

The Children and Families Act (2014)¹² introduced a new system for children and young people with Special Educational Needs and Disabilities (SEND). The National Autistic Society summarises the ambitions of the new system:

*"The Government has said that the new system will be simpler to navigate and will give families a greater say over the support a child or young person with SEN receives.¹³ New Education, Health and Care (EHC) plans are replacing statements and aim to better join up support from different agencies. EHC plans will be for children and young people from 0 to 25, and are intended to focus much more on life outcomes, including employment and independence. Importantly, for those without a statement or EHC plan, under the new system councils must also publish a 'Local Offer', which gives families clear information on the support available for all children and young people with SEND in the area."*¹⁴

¹⁰ <https://www.legislation.gov.uk/ukpga/2010/15/contents>

¹¹ Equalities Act 2010, cited in "Special educational needs and disability code of practice: 0 to 25 years", Department for Education and Department for Health, 2015, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf

¹² <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

¹³ Department for Education and Department of Health (2015) Special educational needs and disability code of practice: 0 to 25 years. London: Department for Education and Department of Health. Cited in: School Report 2015, the National Autistic Society, <http://www.autism.org.uk/~media/nas/documents/news-and-events/news%20story/sen-report-branded-280815.ashx?la=en-gb>

¹⁴ School Report 2015, the National Autistic Society

Support from Health and Social Care

The National Institute for Health and Care Excellence sets out extensive guidance on the support and management of ASD in under 19s. In particular, it outlines recommended interventions for 'behaviour that challenges'.¹⁵ This was recently highlighted in a BBC report that summarised the services that families can expect as follows:

- Assessment of the problems that may provoke challenging behaviour
- A care plan outlining steps needed to manage it
- Help to increase structure and minimise unpredictability
- If all else fails, anti-psychotic medication can be considered¹⁶

However, the same report highlights the plight of some of the families who do not get the help they need. It cites Tim Nicholls, from the National Autistic Society, who argues that parents and families need more support *"to help them avoid or de-escalate challenging behaviour"*.¹⁷

The Local Government Association says that while *"councils are working hard to make sure children with autism and other special needs get access to the support they need... they have been put in an impossible situation due to increasing demand and historic underfunding"*.¹⁸

Meanwhile, a report by *Born to Be ADHD*, published in October 2017, highlights some of the impacts of ADHD.¹⁹ It notes that *'around a third of people with ADHD are thought to have to wait over two years before they are formally diagnosed'* and that *'children with untreated or poorly controlled ADHD are more than five times as likely to participate in fights, more than twice as likely to feel frustrated at school, [and] three times as likely to have a reading disability'*.²⁰

Medical professionals have also highlighted issues with the ADHD support available. For example, Dr Matthew McConkey, consultant paediatrician at Lisburn Hospital, Northern Ireland, said *"ADHD remains chronically under-diagnosed, and access to services and treatment in the UK is woefully inconsistent"*.²¹

The three geographical areas of focus for the Health Champions Service experience many of these problems. The challenges are particularly acute in Swaffham, where the waiting time for diagnosis is currently around three years. According to families and Champions, even when a diagnosis is received, there is little follow-up support provided by the Local Authority for many families, especially when the ASD or ADHD is not accompanied by learning difficulties. Child and Adolescent Mental Health Services (CAMHS) can help some families, but may not be able to help all of the families supported by the Health Champions Service, as a family needs to meet a specific set of criteria to receive support. In the research, stakeholders described how there is a large gap in targeted support for families with children with ADHD and ASD – with the local ASD service in one location 'in a pickle' and a waiting list of up to three years.

¹⁵ <https://www.nice.org.uk/guidance/cg170/chapter/1-Recommendations#interventions-for-behaviour-that-challenges>

¹⁶ <http://www.bbc.co.uk/news/education-41597815>

¹⁷ Ibid.

¹⁸ Ibid.

¹⁹ A Lifetime Lost, or A Lifetime Saved Report, <https://www.borntobeadhd.co.uk/wp-content/uploads/2017/09/A-Lifetime-Lost-or-a-Lifetime-Saved.pdf>

²⁰ Ibid., p. 2

²¹ <http://www.bbc.co.uk/news/health-41847026>

In Peterborough, the referral waiting list for support was 'closed' for over eight months, to deal with the backlog of referrals. The City Council has worked with Family Action on the Health Champions Service, partly in the hope that the service would lead to some families on the waiting list no longer needing support, therefore reducing the waiting list for other families.

Finally, some parents expect diagnosis of ASD and/or ADHD to have a significant impact on them and their child, and therefore their primary focus is to achieve this diagnosis, rather than seek support for the behaviour their child displays. Often, the reality of diagnosis does not match their expectations; it does not lead to the extra services and support that they had expected. This is discussed further on page 25.

Support provided by schools

Data from the National Autistic Society shows that 42% of parents and carers of children and young people with autism thought that education provision for children with autism had got worse in the three years to June/July 2015, while only 13% said it had got better.²² It is a similar story for ADHD; *Born to Be ADHD's* report, *A Lifetime Lost, or A Lifetime Saved*, argues that 'data suggests around half of children with ADHD in the UK do not feel supported by their school'.²³

In recent years there appears to be a decreased likelihood of families getting approved for further support. In order to access funding for further support, a child needs an Education, Health and Care (EHC) plan. Local Authorities have discretion over whether to provide an assessment for an EHC plan, and may turn down requests for assessments if they believe that the request does not demonstrate sufficient need. According to Department for Education figures cited in the Guardian,

'There was a 35% increase between 2015 and 2016 in the number of local authority refusals to carry out EHC needs assessments on children. And for those who did get an assessment, in just over 40% of cases, the family had to wait longer than the 20 weeks cut-off date by which a decision whether to approve an EHC plan should be made, as councils struggle to do their job with the funding they have'.²⁴

These findings are borne out by primary research with stakeholders of the Health Champions service. There are some examples of good working relationships with schools, and schools that are providing effective support for families affected by ADHD and/or ASD. Schools are also a significant source of referrals to the services (see Figure 6). However, Champions, parents, and other local partners pointed to a number of problems with school provision overall. In particular they highlight that:

- There is a perception among many parents and Champions spoken to during the research that schools do not take the issues affecting children with ASD and/or ADHD seriously. This is particularly true when children's behaviour at school is good, but then deteriorates outside of the school; such children are seen as relatively easy for schools to ignore. The schools would likely disagree that they are 'not taking the issues seriously', but the different theoretical and/or professional perspective on ASD/ADHD and behaviour management that some school staff will have is leading some parents and Champions to draw this conclusion.

²² School Report 2015, the National Autistic Society, p. 5. Survey completed in June and July 2015, by 1,431 parents and carers of children and young people with autism

²³ *A Lifetime Lost, or A Lifetime Saved* Report, Ibid., p. 2

²⁴ The Guardian (2017), <https://www.theguardian.com/education/2017/sep/05/crisis-in-support-for-sen-children-ehc-plans>. Citing Department for Education: <https://www.gov.uk/government/statistics/statements-of-sen-and-ehc-plans-england-2017>

- There is a lack of acceptance among some schools that outside support could help their pupils. A ‘power struggle’ was referred to by one stakeholder.
- Money from Local Authorities to support children with special educational needs is very low, and in some cases exhausted, meaning schools do not get the additional funds that they need.
- There was one discussion during the research about how schools were giving out ‘incorrect information’. No concrete evidence came up during the research to show that schools are indeed giving out incorrect information, but it is clear from parental feedback that many have a misunderstanding about the requirements for diagnosis and support (see page 25).
- One parent who is supported by the Health Champions Service has a son who is in a special school. The parent described how the school does not have the capacity to look after him, so instead he is ‘locked’ in a classroom for his own safety. He is isolated from his peers and his needs are not met.

Quotes from stakeholders illustrate some of the frustrations with the support provided by schools:

“Don’t talk to me about schools though! It’s a battle – I don’t know if it’ll ever be solved. Not many are progressive or willing to be equipped and to change to adapt how they deal with ASD or ADHD with parents and multi-agency approach. [However] one school is really good... they always go over and above to help.” [Champion]

“The Head teacher changed in one school – it went from really good to terrible really quickly.” [Parent]

“Schools are a battle – it’s like banging your head against a brick wall. They don’t have the understanding... Teachers are under so much pressure.” [Parent]

“Schools are a big problem- if they can’t meet children’s needs then they need to accept this.” [Focus Group discussion]

“The schools needed constant persuading though!!! School readiness is a big outcome for them, so they ought to be more engaged.” [Partner]

“There is a lack of understanding in schools regarding ADHD and therefore they cannot offer support.” [Focus Group discussion]

“I have a really good relationship with the teachers. The previous school were horrendous, but at the current school, the Headteacher even picked her [child affected by ASD/ADHD] up from their house and drove her to class. They [school staff like that] are worth their weight in gold.” [Champion]²⁵

Support provided by other programmes

The literature review explores the approaches that other programmes are taking, how they are engaging with families, and in particular how befriending is being used. The literature review is available as a separate document, but the findings are summarised below.

Approach of other programmes targeting ASD and ADHD

There are a wide variety of programmes designed to support families affected by ASD and ADHD both nationally and internationally; these are mainly targeted at those who have received a diagnosis. For ASD the

²⁵ Family Action have responded to this quote and highlighted that they are aware that this does not necessarily represent best practice on behalf of the headteacher, and that this approach is not endorsed by the Family Health Champions Service.

main components of programmes include practical advice, workbooks and resources, and one-to-one sessions. ADHD is targeted similarly but also includes features such as counselling.

These programmes draw on a set of recognised ways of treating and intervening with ASD and ADHD. ASD is often targeted via educational programmes, service-based interventions and medical treatment, whilst ADHD heavily relies on medical treatment as the main intervention method. Whilst other methods include psychosocial and behavioural treatment it is suggested that pharmacological treatment is still the most effective way of supporting someone with ADHD.

ASD interventions include the SCERTS model of intervention,²⁶ the Early Start Denver Model,²⁷ the TEACCH programme,²⁸ and in the UK, THOMAS training.²⁹ There are fewer family-targeted ADHD models but the Incredible Years Parent Training model³⁰ is used globally in interventions to give parents the abilities to support their child with ADHD.

The literature review also suggests that services designed to support families recognise that ASD and ADHD can have a significant impact on families, such as a negative impact on family cohesion and marital happiness, and a high rate of divorce.

Use of befriending in ASD and ADHD support programmes

'Befriending' is an increasingly common approach in charitable services that support individuals and families. There is more evidence of the use of befriending in ASD services than in ADHD services. Befrienders are mostly used to support families, with befrienders seen as useful in reducing the effects of marital stress and lack of free time. There have been independent evaluations of befriending programmes for ASD with projects having positive effects on parents' mental wellbeing and parenting style, as well as on their children's behaviour.³¹ With ADHD, there is limited, if any, research of interventions that support the family via befriending. General befriending programmes often allow those with ADHD on to them, but specific programmes are very hard to find.

The Theory of Change for the Health Champions Service

A **Theory of Change** is a representation of the change created by an organisation, project or intervention for its stakeholders. A Theory of Change can show the different outcomes that are experienced by stakeholders, how the outcomes are brought about, the factors that can enable or prevent these outcomes, and the assumptions that are made.

The Theory of Change for the Health Champions Service has been developed jointly by Envoy Partnership and Family Action. It draws on the research outlined in this report, but not every outcome discussed in the research is shown in the Theory of Change. This is because some outcomes, such as outcomes for siblings, are outside the scope of the service, and are therefore outside of the scope of this Theory of Change. As the

²⁶ See: <http://www.scerts.com/>

²⁷ See: <https://www.autismspeaks.org/what-autism/treatment/early-start-denver-model-esdm>

²⁸ See: <https://www.teacch.com/>

²⁹ See: <http://www3.hants.gov.uk/childrens-services/childcare/providers/childcaretraining/short-term-cpd/sen-courses/thomas-training.htm>

³⁰ See: <http://www.incredibleyears.com/programs/parent/>

³¹ See, for example: 1) Marden, R, Rabindrakumar, S and Laws, S (2013): *Family Lives 'Instructions Not Included' befriending pilot. Final evaluation report*. Evaluation commissioned by Coram. 2) Mavropoulou, S (2006). *'Befrienders to persons in the autistic spectrum in Greece: what support do they offer and what challenges they face?'* (Looks at the implications of a befriending service as a means of social support for families with persons with ASD).

Theory of Change represents the pure service model, it is not created just from the research conducted for this evaluation. It is meant to be a working tool for Family Action, to be updated and developed more in the future as required.

The Theory of Change for the Health Champions service, set out in Figure 4, represents the journeys of the stakeholders that engage with the service. It shows:

- The **long-term goal** that the service is aiming to achieve.
- The **activities** that take place as part of the service.
- The different **outcomes** that stakeholders experience.
- The **enabling factors** that allow or 'enable' the change. The more that the enabling factors are present, the greater the change for stakeholders.
- The **barriers** that prevent change. The more the barriers can be avoided or overcome, the greater the change for stakeholders.
- The **assumptions** that are being made. There may be different levels of evidence for the assumptions; for some there will be some evidence that the assumption is likely to be true; for others there will currently be much less evidence.
- The **line of accountability**. This shows:
 - Which outcomes are directly within the remit and focus of the service, and which the service can therefore be 'accountable' for, and,
 - Which outcomes are beyond the remit and focus of the service, either because they are too long-term, are more affected by external factors, or are not in an area that the service is focusing on, and which the service is not therefore 'accountable' for.

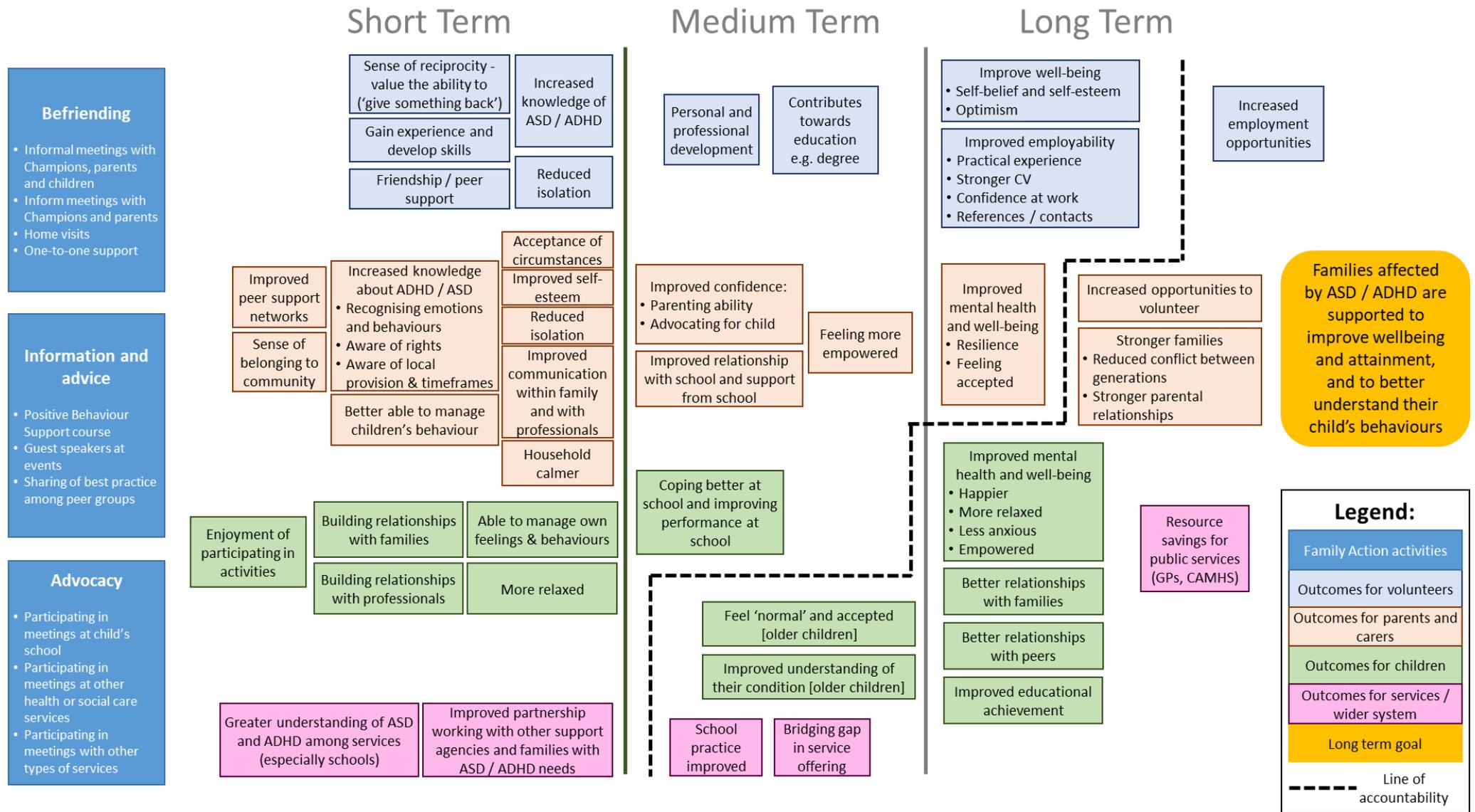
The placement of an outcome within Figure 4 indicates approximately when that change might occur: the further to the left a box is, the earlier in a stakeholder's journey it is likely to occur. The outcomes have also been divided into short-term, medium-term and long-term outcomes:

- **Short-term outcomes** are those that can happen very quickly during and after engaging with the Health Champions Service.
- **Medium-term outcomes** are those that happen while engaged with the Health Champions Service, but that usually take longer to arise.
- **Long-term outcomes** are those that are expected to arise totally or partially because of the Health Champions Service, but take longer to occur. As the Health Champions Service is a relatively young service, these outcomes have usually not occurred yet, and have therefore not always been observed directly.

Ultimately, the outcomes in the Theory of Change are expected to contribute to the **Long-term Goal** of the service, which is that *"Families affected by ASD / ADHD are supported to improve wellbeing and attainment, and to help understand their child's behaviours"*.

The long-term outcomes are largely beyond the timeframe of the service, and evidence for them has not been collected directly from parents (beyond the occasional anecdote). Instead, the expectation that these outcomes will be achieved draws on two main sources. Firstly, evidence is drawn from the literature review (discussed below). Secondly, the Champions themselves have often gone through the kind of journey that parents are describing (even though most did not access the Health Champions Service), and both the improved mental health and wellbeing, and the stronger families, are outcomes that Champions are able to point to as a result of support that they received in the past.

Figure 4: Theory of Change



The literature review provides some insight which contributes to the Theory of Change alongside the qualitative research conducted for this evaluation. Much of the literature points to the impact on family life of having a child with ASD or ADHD, rather than the benefits to family life of interventions. For example, a study in the journal *Paediatrics*³² states that mothers of children with ASD often rated their status of mental health as fair or poor. Compared with the general population, their stress level was much higher. A study in the *Journal of Family Psychology* also states that parents of autistic children had a 9.7 percent higher chance of getting divorced than their peers did.³³

However, there is evidence that interventions can influence these areas; for example, Behavioural Parent Training (BPT) has been found to result in benefits such as reducing parenting stress.³⁴ This Theory of Change therefore assumes that the Health Champions service has the *potential* to replicate these benefits, although it doesn't predict the *extent* to which these benefits will be replicated in practice.

Inevitably the journey towards the long-term goal is not straightforward. Each child, family member and Champion is unique, and outcomes do not occur at the same time or in the same sequence for each person. Nor do we expect every stakeholder to experience every outcome; most stakeholders will benefit from many, but not necessarily all of the outcomes identified. Some of the outcomes might occur beyond the timeframe of the service. The three Health Champions Services are set in different locations where there are varying levels of external support and expertise. Outcomes might temporarily get worse for stakeholders, sometimes for identifiable reasons (the summer holidays and the associated lack of routine) and sometimes for no identifiable reason. The Theory of Change therefore aims to represent the aggregate change for stakeholders affected by the service.

The outcomes shown in the Theory of Change are discussed later in this report. The other components of the Theory of Change are outlined below.

Activities for families

The service offers a number of different activities for families, including one-to-one meetings with the volunteer Health Champions, informal group meetings such as 'coffee mornings', activities for children and families together, and support when dealing with other services. Most of the services are provided by the Champions, or by the Service Coordinator and Champions together.

The range of activities has expanded since the service was designed. For example, parental behaviour courses such as the Positive Behaviour Support (PBS) Courses have also been developed, as an 'added value' element, and the Service Coordinator or Champions sometimes act as advocates for the families with other services.

There is some variation in activities provided between the three locations, reflecting the different local needs (as outlined earlier in the report). Feedback from stakeholders suggests however that there are three elements of the provision that are common across the services:

³² Psychological Functioning and Coping Among Mothers of Children With Autism: A Population-Based Study Guillermo Montes, Jill S. Halterman

³³ *Journal of Family Psychology* - <https://psychcentral.com/blog/archives/2015/02/25/4-ways-a-child-with-autism-affects-family-life/>

³⁴ Chronis et al (2004)

- The role of the volunteer Health Champions in **befriending** the families is key. This includes one-to-one befriending, and support groups involving Champions, families, and the Service Coordinator. This is set out in the service design and is reflected in feedback from families.
- Provision of **information and advice** is valued by families. This can be from the more formal training sessions, but it also includes tips and advice from the Champions, the Family Action Service Coordinator, and other parents.
- Both the Champions and the Family Action Service Coordinator are effective **advocates** for families. They can help with meetings with health professionals, schools, and council services.

While these are described as three different types of activity, in practice the activities overlap. So, for example, a coffee morning may both involve befriending (as Champions work one-to-one with individual parents), and information and advice (from a guest speaker or the Service Coordinator).

Enabling Factors

The research highlighted several **enabling factors** that allow or 'enable' the change. The more that the enabling factors are present, the greater the change for stakeholders. They are:

- **Sufficient funding** for the service to run for long enough to make a significant difference
- **Clarity of message and purpose** for the service
- The **adaption of the national model to meet local needs**. This means that the services in the three locations are slightly different, reflecting factors such as the different local services that are available for families, and the geography of the area
- That the **service is in the right place geographically to access those in need**
- **Frequency and accessibility of meetings**; the services meet frequently enough and are accessible enough (in terms of location, timing, day of the week) to make a difference
- That the Family Action Service Coordinator and Champions can spend **sufficient time with families**
- That the different strands of the service work together; in particular the **combination of support groups, training/advice, and advocacy/referrals**
- Sufficient **engagement of stakeholders, especially families, Champions, partners**
- Suitable Champions volunteering. In particular, the **availability and retention of Champions with appropriate skills and knowledge, and who are non-judgemental, understanding and caring**
- That the **training** provided as part of the service is **well regarded by stakeholders**
- That the service is supported by a **professional advocate (a member of Family Action staff)** who is listened to and respected by professionals in other services.

Barriers

The research also highlighted several potential **barriers** that can prevent change. The more the barriers can be avoided or overcome, the greater the change for stakeholders. They are

- **Insular communities** that do not want to engage with external practitioners. This was particularly the case for a religious community in Swaffham
- **Poor school practice and social service practice**. Several schools and social service practitioners were not providing a high-quality service to families. This might be due to insufficient awareness, knowledge, skills or focus on the issue, plus a lack of financial support

- The **time required to build trust**, and a lack of engagement and openness until that trust has developed
- With a small number of families, **harmful family relationships** within the families that the service is supporting. This can range from lack of support between partners, to domestic abuse
- **Length of waiting lists** for access to other services, particularly diagnosis
- **Lack of other autism specific services** available for families, and a reliance on more generic services to support alongside the Health Champions Service that might not have the same level of expertise
- **Lack of shorter term training or support groups for other relatives to raise their own awareness** e.g. uncles, aunts, grandparents, who often don't remember or understand the techniques or practices and therefore work inadvertently against the parents
- **Low engagement levels from fathers**, who are frequently less prepared to engage, or able to engage (e.g. because of work commitments) than mothers
- **A lack of male staff and volunteers:** in Swaffham parents explained how having a male voice caused their partners to listen to advice, which was not taken as readily from female practitioners or the mother

Assumptions

The logic of the Theory of Change is based on several assumptions that are being made. If something is labelled as an assumption it does not mean that there is no evidence for it or that it is likely to be untrue. Instead, labelling the assumptions helps us to be clear about how the Theory of Change works and helps us to ensure that important factors and potential risks are identified. The assumptions are:

- That there is **sufficient capacity at Family Action** to run and manage the service well
- That **other agencies will work with and refer to** the Health Champions Service appropriately
- That the families who access the services are those with **the appropriate type and level of need**
- That **families want to, and are able to access** the support
- That **families are ready to benefit from support** (e.g. they are not in denial about the condition of their family member)
- That **parents share learnings with their children**, so that children's knowledge improves as well as parents' knowledge.
- That **families' progress is not overly hindered by complicating factors**, e.g. family breakup, domestic abuse, or factors such as job loss

The Health Champions

As of January 2018, a total of 57 volunteers had been recruited and trained to be Health Champions, with 28 of those volunteers volunteering as Health Champions at that moment in time. In total, just under 2,300 hours of volunteering had been logged by the Health Champions.

The Health Champions have a range of backgrounds and experiences before starting to volunteer. From a survey conducted in December 2017, it was found that many have been affected by ASD or ADHD themselves:

- Around two-thirds (63%) have children with ASD, ADHD or similar conditions

- Nearly four-in-five (79%) have other friends or family with either ASD, ADHD or similar conditions themselves, or who have children who have one of these conditions (see Figure 5).

Others have professional experience working with families and children in general (37%) and/or have professional experience of working with people with ASD, ADHD, or similar conditions (32%). A smaller proportion (11%) say that volunteering as a Health Champion is helping or has helped by contributing towards a qualification.

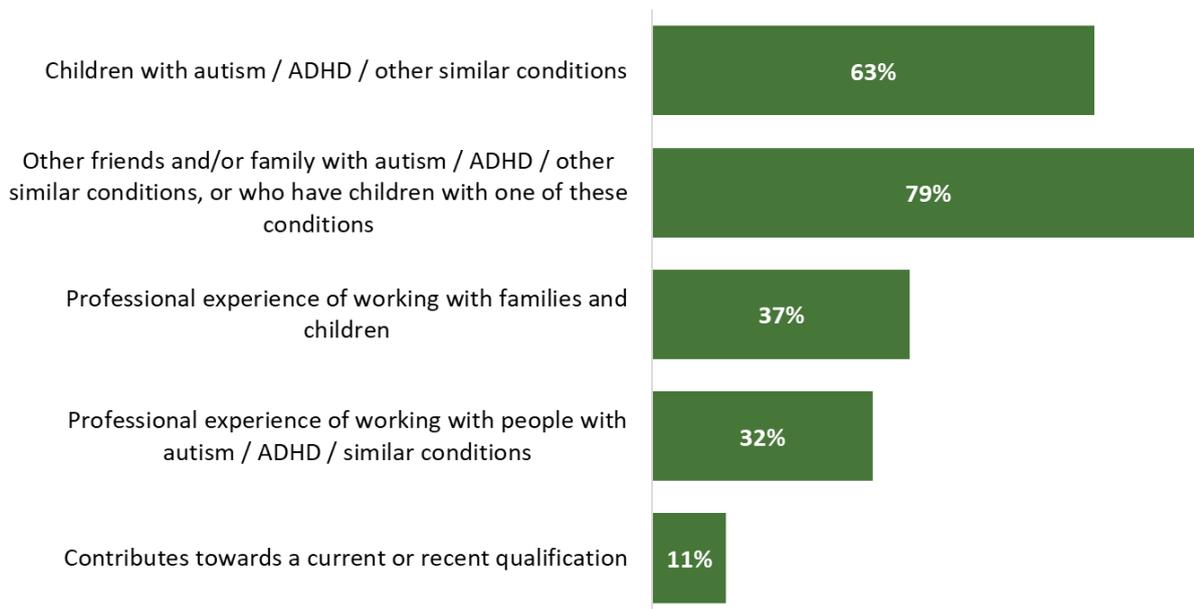
There is a relatively even age spread for the Champions. Nearly a third (32%) are in the 35-44 bracket; this may be because at this age the volunteers' own children are old enough that the volunteers have sufficient free time to volunteer, but in many cases have also received support themselves relatively recently.

Data from the survey of Champions suggests that:

- 26% are between 25-34 years old
- 32% are between 35-44 years old
- 26% are between 45-54 years old
- 16% are 55 or older

In addition, 17 of the 19 Champions who completed the survey are female.

Figure 5: Experience of the Health Champions³⁵



Q. "Do any of the following apply to you? Please select all that apply." n=18

NB, the base sizes shown in the charts (for example where it says "n=18" above) vary. This is because questions in the survey were not compulsory, and participants occasionally skipped a question.

Health Champions' motivations for volunteering vary, but the biggest driver is a desire to 'give back'. This is particularly true of those who have been affected by ASD and ADHD themselves; many recognise from their personal experience how hard it can be for parents to manage, and want to make a difference for those who are struggling at the moment. Several of the Champions are former service-users themselves.

³⁵ Source: Health Champions' survey

“I chose to become a Health Champion volunteer after I attended a pop-up coffee morning where I met [the Service Coordinator] and we had a conversation about becoming a volunteer, and I felt that it would be a fantastic opportunity to help others that have children either with ASD or on the pathway, as my son has ADHD and when he was diagnosed eight years ago and it was a very frightening and confusing time. I also felt very alone during that time in my life and it would have really helped me knowing that other people were feeling the same.” [Champion]

“I am a parent-carer of a child with ADHD and wanted to give something back to other families as I knew how much I relied on support. I also have a psychology degree and was looking for relevant work experience to enhance my own career prospects within a field I'm passionate about.” [Champion]

“I wanted to support families who are just starting on a diagnosis pathway, as I was left with no help when my child was younger, so I feel that my knowledge is used best further helping other families.” [Champion]

“I have experienced friends struggling when a SEN diagnosis is upcoming and during that process. I wanted and still want to help parents in that situation.” [Champion]

“Life as a parent of ASD children is extremely difficult. My first experience of dealing with this was 15 years ago. I was supported myself through Family Action and went on to become a face-to-face volunteer back in 2008. I have seen how Family Action has grown in their knowledge training and being part of a bigger network of people all making the service we offer so much stronger. The amount of parents needing this service has grown so much. May we continue to be there to help the families, which improves life for them on a very big scale.” [Champion]

Many Champions are also very grateful for the opportunity to volunteer with Family Action:

“I love volunteering for Family Action. They support me at all levels, including not doing too much to the detriment of my own wellbeing.”

“Thank you for giving us this opportunity to volunteer as a Health Champion.”

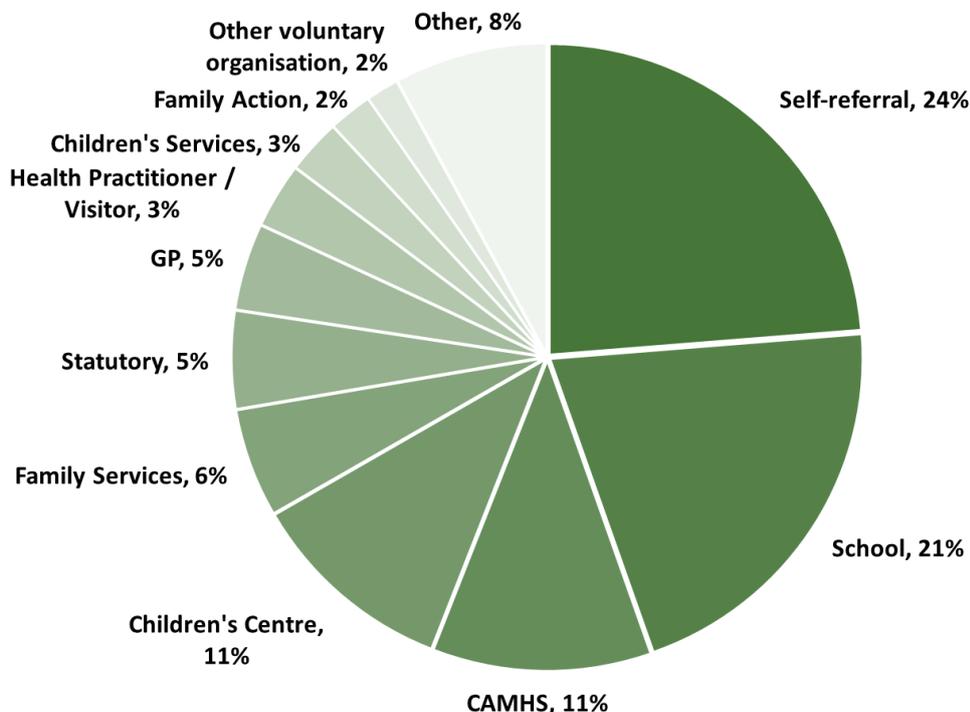
Users of the Health Champions Service

The Health Champions service began work in April 2016. By the beginning of February 2018, 177 users of the Health Champions service have been recorded by Family Action. 43 of these service users were from the Peterborough service, 61 from Sandwell and 73 from Swaffham.

The informal nature of the support and the ‘drop-in’ nature of many of the sessions means that getting a more precise number is harder than for some other services as case files are not created for every attendance. Data for the group sessions run by the Health Champions Service show that between April 2016 and March 2018 there have been 2,090 attendances at group sessions in total (although the number of people attending will be below 2,090 as many people will have attended more than one session). 781 of these attendances were from people who have a case file open with Family Action, while 1,309 were for people who do not have a case file with Family Action and just attended the group session. This suggests that the actual number of users of the Health Champions Service is significantly above the 177 for whom case files are open with Family Action.

Families are referred to the service by a variety of people and organisations. The largest groups are those who self-refer, and those who are referred by a school. The self-referrals reflect the spread of information about the service by word-of-mouth; during the qualitative research a number of parents spoke about how they had heard about the service through other parents who were already using the service.

Figure 6: Source of referrals to the Health Champions Service.³⁶



Results from Family Action records. n=177

Families become involved with the Health Champions service because they need more help; in the research some spoke about how they are desperate for more support. They also want to get support in an environment where they feel believed and not judged. In some cases, the recommendations of other service users, or meeting the Service Coordinator were also important.

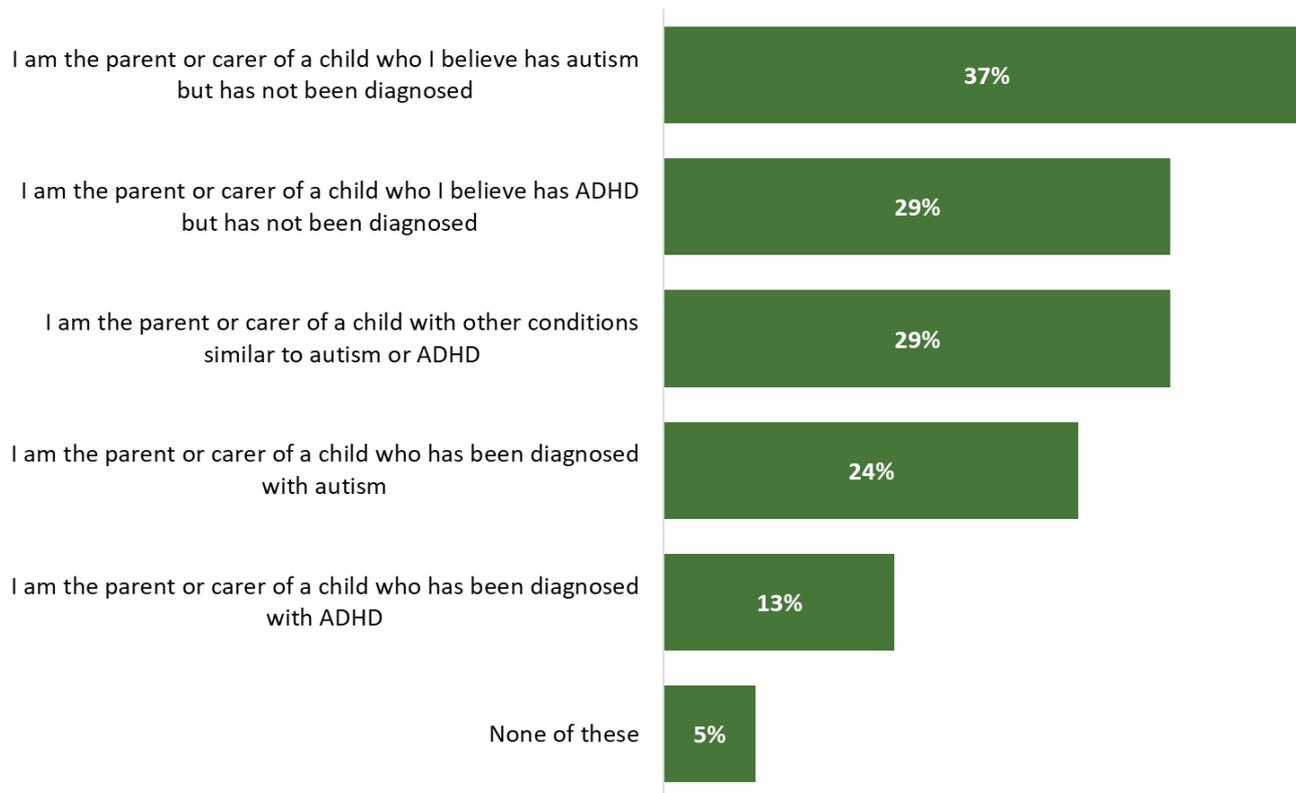
“The reason I wanted to attend – I met [the Service Coordinator]!” [Parent]

“I had an email about the service, and the school had suggested it too. My son has ADHD and ASD. We had been starved of help for a long time, so it was great to get some help and support and not feel so alone.” [Parent]

Results from the survey of parents, together with feedback from Champions and Family Action staff, show that most families accessing the service do not yet have a diagnosis for their child. Of the 39 parents who completed the survey, 37% said they were the parent of a child with undiagnosed autism, 29% said they were the parent of a child with undiagnosed ADHD, and 29% said they were the parent of a child with a similar condition that was undiagnosed (see Figure 7). 24% said they had a diagnosis of autism, and 13% said they had a diagnosis of ADHD. The lower levels of diagnosis reflect the challenges in accessing the diagnosis service, rather than parents misunderstanding their children’s condition.

³⁶ Source: Health Champions’ survey

Figure 7: Condition and diagnosis³⁷



Q. "Do any of the following apply to you? Please select all that apply." n=39

Motivations for accessing the Health Champions Service

Parents were asked about their motivations for using the Health Champions service. The results are shown in Table 6. Ten parents answered by referencing their referral, but there were also several mentions of needing support, and about wanting information and advice.

Diagnosis

Most families do not yet have a diagnosis for their child (see Figure 7). Those who do now have a diagnosis for their child often did not have a diagnosis when they first accessed the Health Champions service. As described above, the delays to diagnosis cause frustration and can prevent access to some sources of help, particularly at school where a diagnosis can help persuade a school that they need to provide specialist support. Parents also seek a diagnosis as it can provide reassurance that their child’s condition is real rather than imagined, and that their child’s behaviour is due to the condition, rather than to poor parenting.

“I have no diagnosis on my daughter and it's frustrating as you got so many blocks and people make you feel like it's all in your head.” [Parent]

When asked about their reasons for starting to use the Health Champions service, six parents mentioned that it was helpful, or required, as part of their pathway to a diagnosis. In some instances, there is a misunderstanding about the role of the Health Champions service; despite what some parents think (as

³⁷ Source: Parents’ survey

shown in the comments below), using the Health Champions service does not contribute towards the assessment pathway.

“My school told me it was a compulsory measure set by the government to enable me to proceed to get a neuro-developmental assessment/referral for my son, so he can have a diagnosis to aid him in future in the school setting.” [Parent]

“My son has not been diagnosed with anything yet... I need to complete this course in order for my son to be seen.” [Parent]

There is some concern among staff and Champions that families’ expectations of the impact of getting a diagnosis do not always match with reality. For most families, getting a diagnosis will not fundamentally change their situation; the diagnosis will not unlock much in the way of additional services and support, and parents will still have to deal with behavioural challenges that ASD and ADHD can create. There are benefits of a diagnosis: it can make the difference in persuading a school to take action, and in the case of ADHD, medication can be prescribed. But for some parents, gaining a diagnosis does not help them as significantly as they had hoped. For the Health Champions service, managing parents’ expectation of both the timeframe for diagnosis, and the impact of diagnosis when it finally comes, is important.

Table 6: Motivations for accessing the service³⁸

Q. Please think back to when you first started using the Health Champions Service. Why did you decide to start using the service?

Area	Number responses	Example responses
Referral	10	<i>“I was referred by my daughter’s Inclusion Worker and because my daughter has ADHD they thought as a parent I would benefit talking with other parents in similar situations.”</i> <i>“I was referred under MAGS [Multi-agency groups] panel.”</i>
Need for support	8	<i>“Because I needed extra support to make sure the children get the right support they need long term.”</i> <i>“I was feeling isolated with my feelings over my daughter and felt I didn't know what to do or where to turn to.”</i>
Information and Advice	7	<i>“Useful workshops/seminars being held in the local vicinity.”</i> <i>“I wanted to find out more about my child's autism.”</i>
Required as part of diagnosis	6	<i>“It is needed to progress to a diagnosis.”</i> Further responses on this area are discussed below. It is not the case that engagement with the Health Champions Service is needed to achieve a diagnosis.
Challenging Behaviour	4	<i>“Difficulties with daughter's behaviour at school, at home and in public. Aggressive behaviour.”</i>

³⁸ Source: Parents’ survey

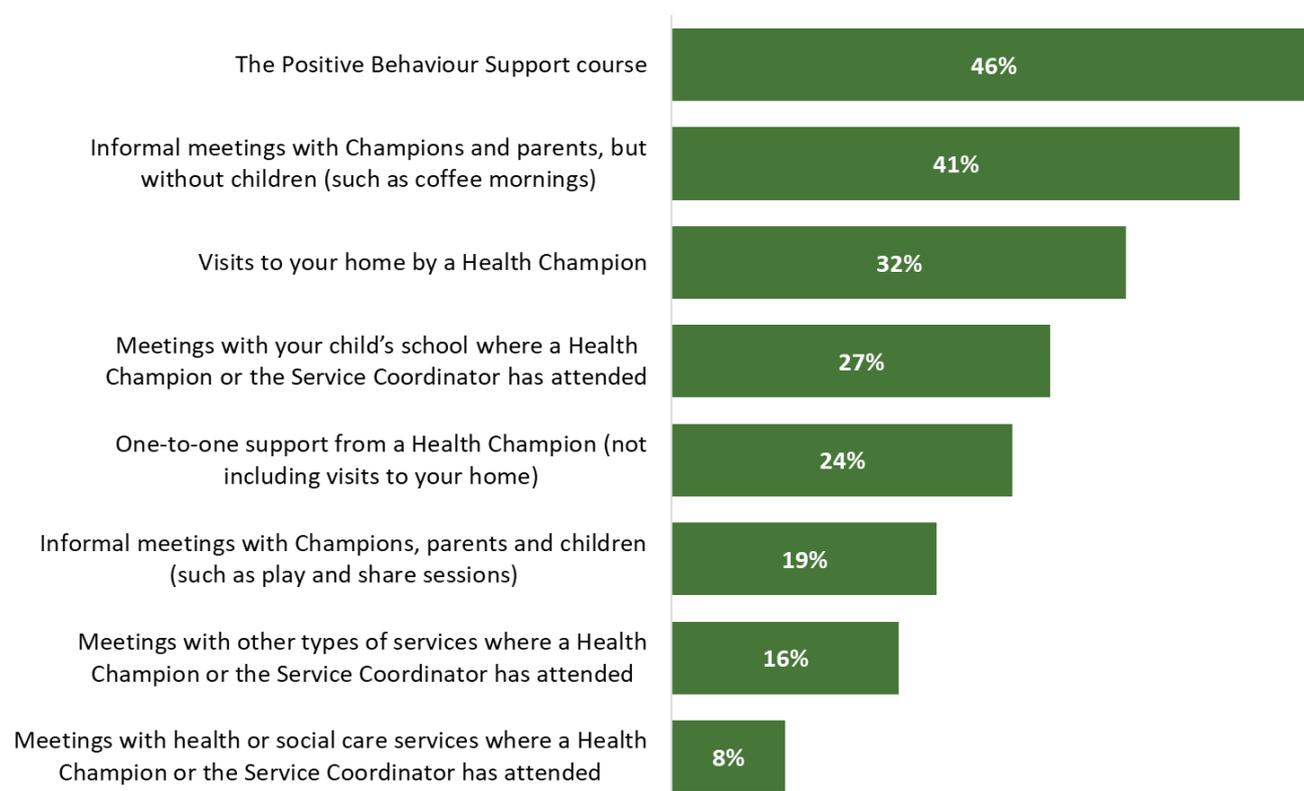
The effectiveness of the Health Champions Service

This section of the report analyses the effectiveness of the Health Champions Service and the factors that contribute to the outcomes. It draws on feedback from parents, Champions, partners, and Family Action staff.

Figure 8 shows the different activities that parents have taken part in. The most commonly used area of the service is the Positive Behaviour Support (PBS) course,³⁹ followed by informal meetings with Champions and parents, and home visits by Champions. It might be, however, that those who have attended parental behaviour courses are more likely to have completed a survey than those who only attend informal meetings.

Figure 9 shows parents' views on the effectiveness of the different activities of the service, and of operational aspects of the service, such as communication. Parents are only asked their view of an activity if they have used that activity, meaning that the base sizes are relatively low.

Figure 8: Activities taken up by parents⁴⁰

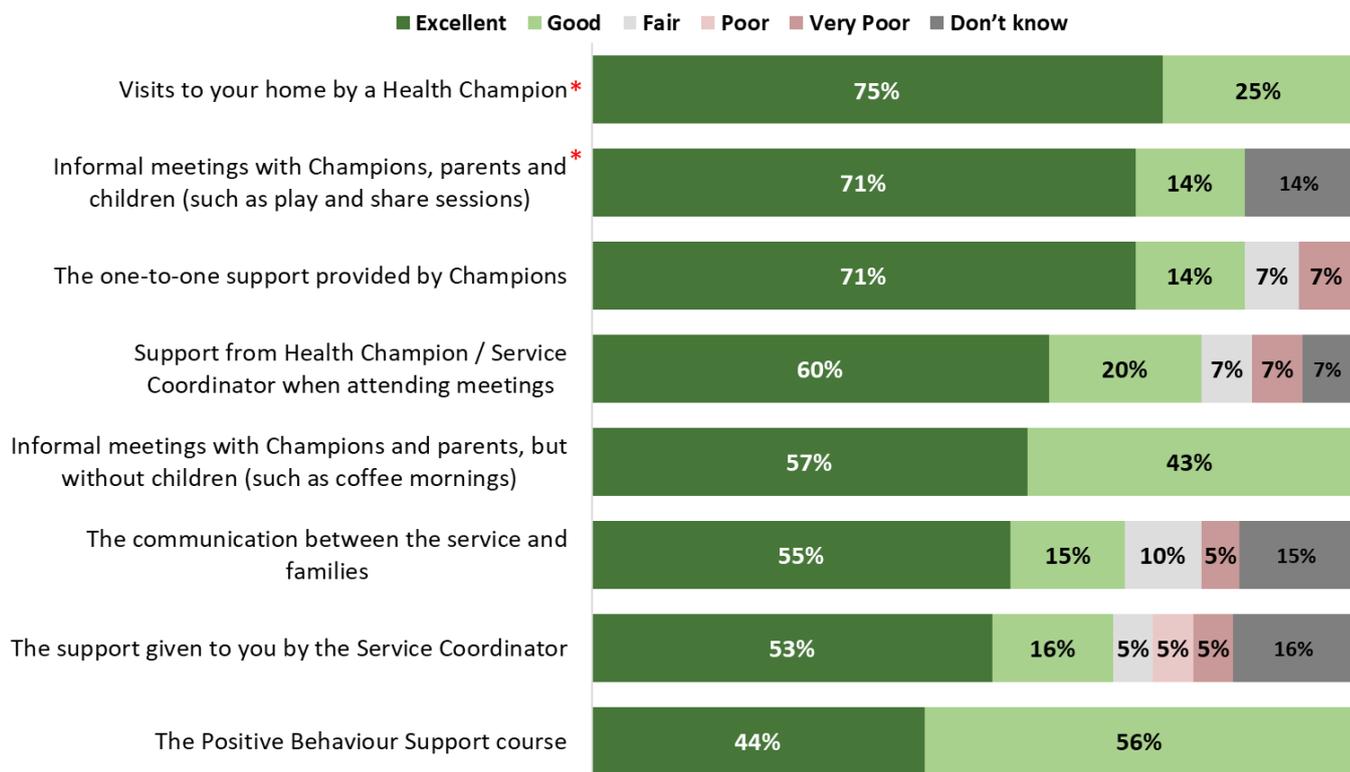


Q. "Which of the following activities of the Health Champions Service have you taken part in? Please select all that apply."
n=37

³⁹ The survey was conducted on the basis of feedback that indicated that the PBS course was the only course undertaken. However, it later emerged that the course in Peterborough was *similar* to the PBS course, but not the *actual* PBS course. A large proportion of survey participants from the Peterborough service indicated that they have taken the PBS course, and it therefore seems that parents are equating the course that they actually took with the PBS course in this research. We are confident therefore that the results can be applied to the parental behaviour courses that were actually taken, but the data should be treated with some caution.

⁴⁰ Source: Parents' survey

Figure 9: Parents' views on the effectiveness of different aspects of the service⁴¹



Q12. "Thinking about your experience of the Health Champions service, how would you rate the following aspects of the service?" n=8, 7, 14, 15, 14, 20, 19, 16 [Base size for each statement in turn] * Fewer than 10 responses

Feedback from parents and carers

The two activities rated most highly by parents were ‘visits to your home by a Health Champion’, and ‘informal meetings with Champions, parents and children’. These were both rated by fewer than ten parents. However, these activities were thought of highly, as is the ‘one-to-one support provided by Champions’.

The PBS course is rated ‘excellent’ or ‘good’ by all the parents who took part in the survey, but fewer rate it as ‘excellent’ than they do other activities. Our interpretation of this is that parents usually see the one-to-one support as the most important and valuable part of the service, and while the training is useful, it does not provide the same level of emotional support. While it is still valued by parents, it therefore receives a slightly lower rating.

“The training is better than other training I’ve been on. I’ve been on training courses [from another charity] and training at work. You learn useful things [about autism], it helps that [the person delivering the course] has a child with autism too.” [Parent]

“The PBS training was very informative.” [Parent]

“Children on the spectrum have processing issues/sensory issues [and] do not respond the same to common disciplines/methods and can in fact suffer if parenting methods are not adapted. This course has enabled me to parent my child more effectively (though it is clear he has underlying issues still).” [Parent]

⁴¹ Source: Parents’ survey

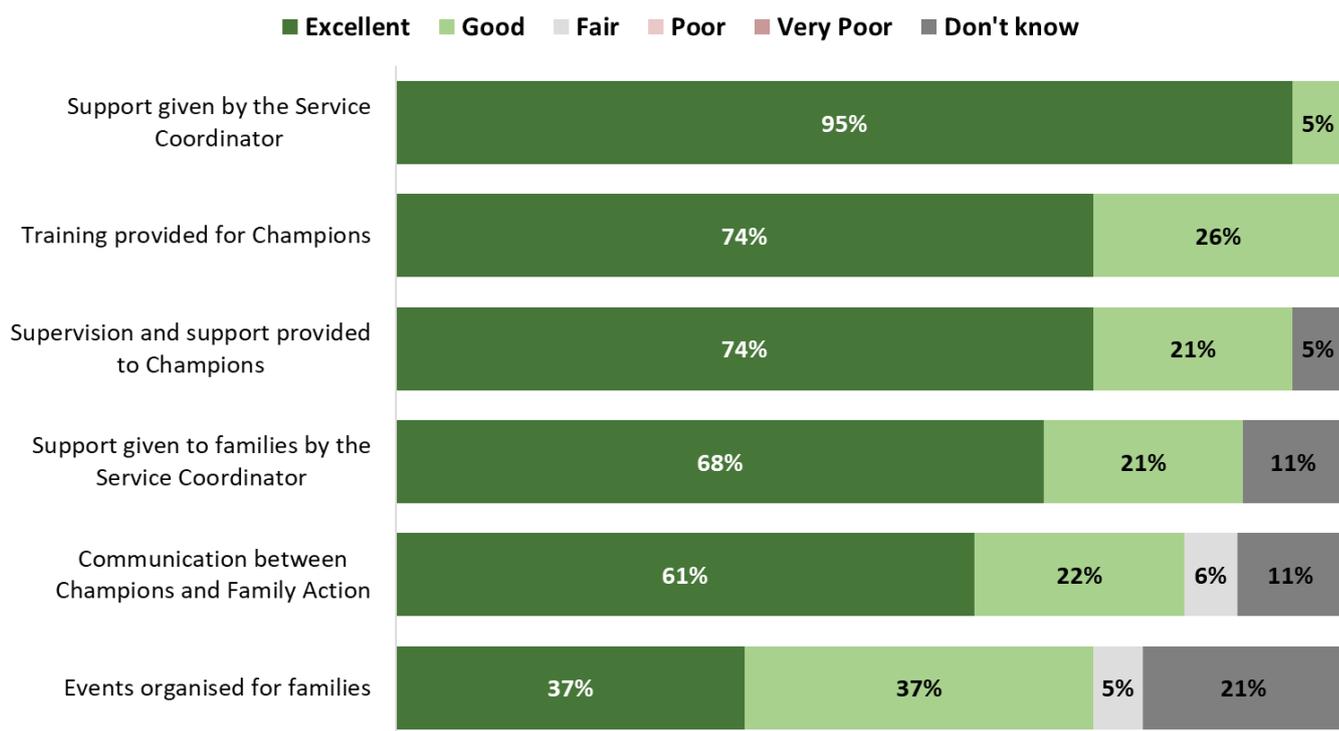
During a focus group with parents in Peterborough, some parents were very negative about the parental behaviour course they had attended. However, it turned out that they had taken the course through their child’s school, rather than through Family Action, and the course was a more generic course than the one delivered as part of the Health Champions Service (which is more focused on autism and ADHD). Anecdotal feedback suggests it was not delivered as well as the Family Action course. While this does not seem to have affected the service responses (no parents taking the survey rated the PBS course as less than ‘good’), it shows both that the Family Action course is received better by parents than the other courses, and that parents are not necessarily clear which organisation is providing the course they have taken.

There is some negative feedback shown in Figure 9, but this represents very small numbers of people: It is clear that one individual from the survey had a negative experience of the service and rated several aspects as ‘very poor’. This is discussed further below, but it is not representative of wider families. A further one person (5%) rated the support given by the Service Coordinator as ‘poor’. Part of this negative feedback is due to communication issues, which are explored on page 37.

Feedback from Health Champions

Figure 10 shows the Champions’ views on the effectiveness of the different activities of the service, and operational aspects of the service, such as communication.

Figure 10: Champions' views on the effectiveness of different aspects of the service⁴²



Q. "Thinking about your experience as a Health Champion how would you rate the following aspects of the service?" n=19

Champions believe that the support they are given by the service to Champions is very strong: 95% felt that the support given by the Service Coordinator is excellent, while 74% felt that the training provided to Champions is excellent, and that the supervision and support provided to Champions is excellent.

⁴² Source: Health Champions’ survey

A much smaller proportion (37%) of the Champions felt that the events organised for families are ‘excellent’, compared with other aspects of the service. However, only 5% said it was ‘fair’ and nobody said it was ‘poor’ or ‘very poor’. 21% of Champions said they ‘don’t know’ about the quality of events, suggesting that many Champions don’t feel confident judging the events for families or that they have not engaged in them themselves and therefore cannot comment.

Success factors for the Health Champions Service

Parents were asked what, if anything, they felt was particularly good about the service. Most of the responses described the emotional support they received, the information and advice they received, and/or their increased ability to manage their children’s behaviour. The responses are categorised in Table 7.

As well as exploring the strengths of the service, the research was designed to show the factors that are most important for the service’s success. The qualitative interviews highlighted various factors of the Health Champions service that Champions and parents felt were important. These different factors were grouped together into a list of ‘success factors’. Both parents and Champions were asked their views on these success factors in the surveys, and asked to choose up to six that they felt were most important.⁴³

Figure 11 shows the parents’ views on the most important success factors, and Figure 12 shows the Champions’ views. The analysis of this feedback points to a set of factors that are crucial to the delivery of the service, which are explored below.

Table 7: Best things about the Health Champions service⁴⁴

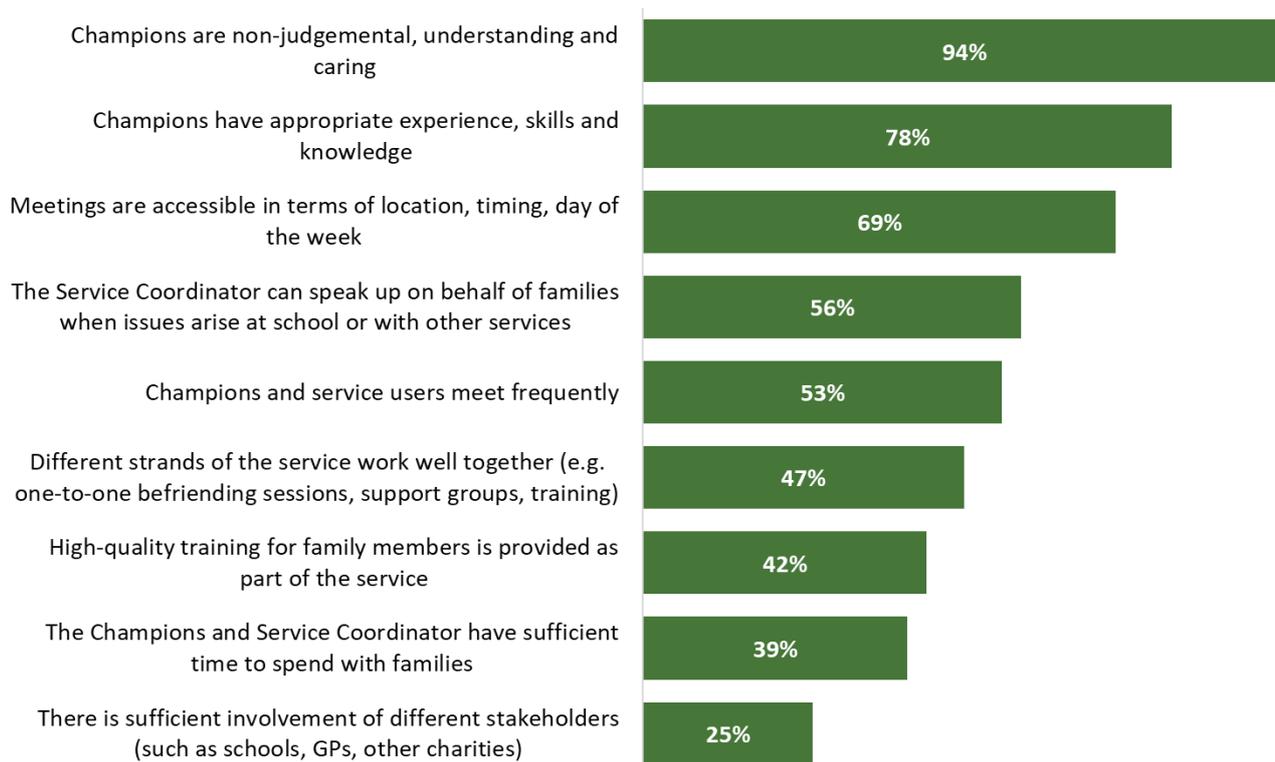
Q. What, if anything, do you think is particularly good about the Health Champions service?

Area	Number responses	Example responses
New tools and techniques to manage difficult behaviour	12	<p><i>“They provided a ‘feelings chart’ so my daughter was able to communicate feelings. Also ‘Golden Hour’ to help relax before bedtime.”</i></p> <p><i>“The service and programme has helped me to realise that I can manage the behaviour in a more consistent way which has worked: example-reward charts.”</i></p> <p><i>“It has helped in providing suggestions for sensory items and other ideas in helping manage behaviour.”</i></p>
Better communication and understanding of child’s needs	5	<p><i>“Understand more about my son’s diagnosis and how best to handle him and his behaviour using time outs and rewards.”</i></p> <p><i>“Understanding best practices what work for me and my child on the autism spectrum, and understanding more re sensory needs etc.”</i></p>
Increased confidence	2	<p><i>“They help with my confidence with my parenting.”</i></p>

⁴³ Not all of the factors were put to parents. For example, ‘High quality training for Champions’ was not asked of parents

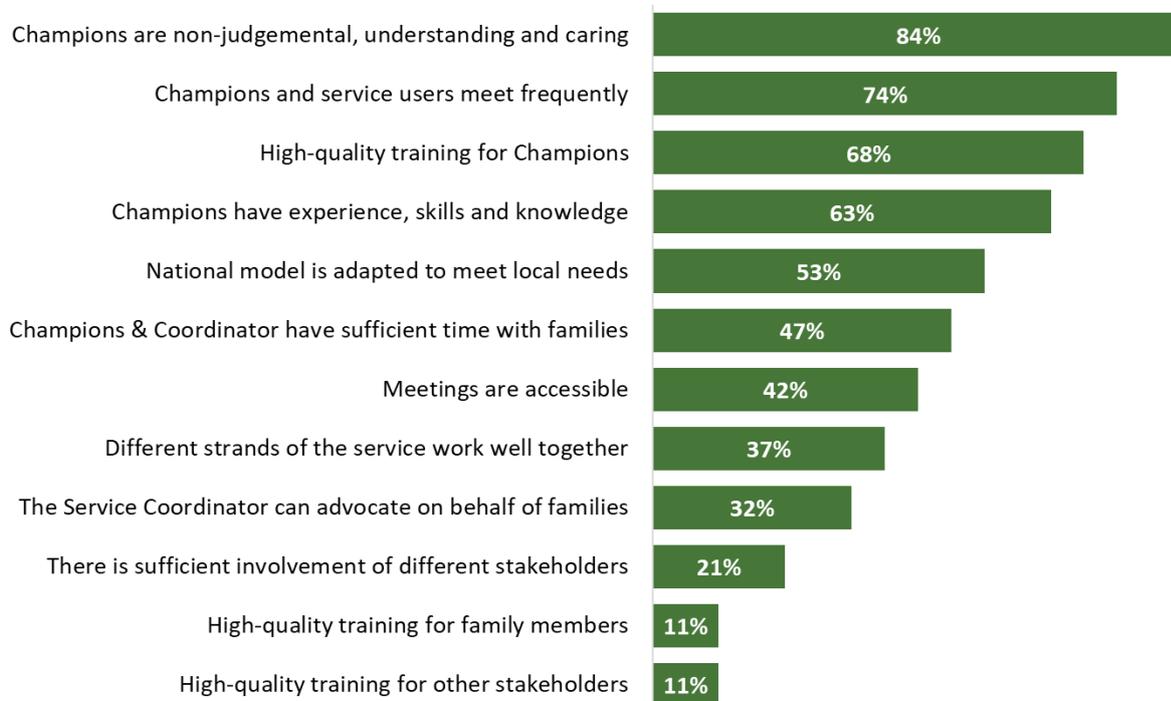
⁴⁴ Source: Parents’ survey

Figure 11: Parents' perspectives on the most important success factors for the service⁴⁵



Q. "What do you think are the most important things about the Health Champions service? Please look at the list of statements below, and select up to six that you think are most important." n=36

Figure 12: Champions' perspectives on the most important success factors for the service⁴⁶



Q. "Please think about the factors that can help make the Health Champions service a success. Please look at the list of statements below, and select up to six that you think are most important in ensuring that the service is a success." n=19

⁴⁵ Source: Parents' survey

⁴⁶ Source: Health Champions' survey

The positioning of the service

It is important to stakeholders that the Health Champions service is separate from schools, healthcare services, and other statutory services. Families' perceive those other services to be more official and part of the 'authority'. This means that they feel they are more likely to be judged, particularly on their parenting ability and family life. There is also a sense for some of having been let down by these services in the past.

For some, there is a fear of intervention from social services, potentially even of having their child taken into care. Schools are not necessarily seen as 'on their side' and some feel that if they admit their concerns and worries to their child's school, then this may be held against them by social services. This research does not explore whether parents had strong grounds to fear this, but it was a very real concern for some.

In contrast, the Health Champions service is seen as supportive, accessible, and non-judgemental. Families feel more comfortable opening up and sharing issues with Health Champions, and at events run by the service, than they do with other services. This is helped by the location of meetings: Children's Centres and community centres are seen as less 'scary' than schools or Local Authority offices.

As well as benefitting from not being a statutory service, the Health Champions service also benefits from the Family Action brand. Family Action is seen as professional and impartial, as well as non-threatening. This means that they are more credible to parents when delivering information and advice and when supporting parents in meetings (for example with school staff), and it also means that partners feel secure in referring to the service.

"When they [are speaking to] someone else who is in authority, whether it's the charity coordinator or a support worker, there's a power thing going on. As in they [parents] feel judged, or fear action could be taken against them if they say something and it's taken out of context."
[Champion]

"Without Health Champions [the support] becomes more formal, or it is then forcing the issue to be addressed at a formal/institutional setting, and so [parents] are less likely to be as open. For example, if they are arranging to go and speak to teachers, or arrange appointments with health visitors." [Partner]

Getting the right people: The Health Champions

Parents and Champions believe that, for Champions, being non-judgemental, understanding and caring (94% of parents, 84% of Champions) is more important than having experience, skill and knowledge (78% of parents, 63% of Champions). As one Champion put it:

"Skills, knowledge and experience are important but with good training and understanding this can be overcome." [Champion]

This is supported by the high-quality training that is provided to Champions; 74% of Champions believe the training to be excellent, and 68% thought this was one of the most important success factors.

"The training which is offered throughout my time, has been greatly received. Additionally, the support and guidance from both [Family Action staff members] has been fantastic. Finally, the team meetings and thank-you tea... was lovely 😊." [Champion]

The real-life experience of many of the Champions also assists in many cases. When Champions can refer to their own experiences and the difficulties that they themselves faced, it makes them a more credible messenger. This is further supported by the Champions being locally based and rooted in the area.

It is also important that the Champions are not seen to be patronising, or giving instruction on how to be a 'better parent'. There is a sensitivity around parenting practice, and anything that suggests that parents are doing a poor job can alienate parents quickly. In many cases this is heightened by the sense that other family members and other services do not really believe that their child has a condition and that their behaviour cannot just be 'fixed' by better parenting.

"Honesty and respect, they have for us, they are caring, calming, it's a fantastic service, they act and provide action appropriately, it's all spot on. I feel I can trust them completely, I can open up about where I'm struggling, and what I can be coached on. They really listen, they don't butt in. I've never been treated so well in my life by any profession. They coach you on the right practices and behaviours. I've accessed lots of support online, doctors, I'm in need in a bit of support, not masses, but Family Action, they go extra mile to make sure I'm really OK. It's great to have someone there by you, not judging." [Parent]

"The way they communicate with families, and engage with them, and their team give them a high level of understanding and empathy and experience – parents don't feel mistrust and they don't feel judged and they really feel heard." [Partner]

"It's a friendly non-judgemental service with amazing support." [Parent]

"I can't thank [the Service Coordinator] and [the Health Champion] enough. Their help and advice has been spot-on and amazing – our family is so much better off for knowing them even though we have a long journey ahead I know we will do it a lot better thanks to them." [Parent]

The Health Champions are also supportive of each other, and in many cases have formed their own groups and networks that have some independence from the service and the Service Coordinator. This is the case regardless of whether or not the Health Champions knew each other before they joined the service (for example, through Autism West Midlands). This independence of the Champions and lack of dependency on the service (and particularly the Service Coordinator) is a source of resilience for the service, as Champions are showing they feel empowered and confident to use their own initiative.

"I go to a training event, and I see that some of the Health Champions are also attending as a group. They've arranged to go independently of me." [Service Coordinator]

Getting the right people: Service Coordinators

A lot of responsibility lies with the Service Coordinators. 95% of Champions think that they are doing an excellent job, and there are a number of reasons for this. Like the Health Champions, the Service Coordinators are able to relate to and empathise with parents, children and Champions. Several Champions and parents have expressed how well supported they feel:

"[The Service Coordinator] went above and beyond. I went to see her for six weeks, and prior to that I was at the lowest point, I had a complete breakdown, and an overdose, and having someone to talk to once a week was something I needed to turn things around. I don't speak with family and I had nobody to turn to... I felt straight away that [the Service Coordinator] cared, that I could say anything to her, she didn't judge me, she was someone I could open up to, and she said to me "you can ring me any time you want"." [Parent]

“[The Service Coordinator] is a ‘diamond’- she cares about things. She took the time out to come to school meetings and I can call her for advice. I felt like I had a professional in my pocket – to bounce ideas, to get information and know where to go and for practical support.” [Champion]

The Service Coordinators are also able to support families by advocating on their behalf to other services. This includes schools and healthcare providers. 56% of parents believe that “the Service Coordinator can speak up on behalf of families when issues arise at school or with other services”, and that this is one of the most important factors of the service. Parents believe that the Service Coordinator’s professionalism and knowledge is important, and that they are able to advocate effectively because they are less emotionally attached and can be more objective.

“We can get extra support – I have got meetings now with health professionals. [The Service Coordinator] is a professional – she makes them pay attention. Sometimes you speak to them and nothing happens. But as soon as a professional rocks up, they do something.” [Parent]

“The first meeting I went to at school I was crying. They made me feel awful. It was like they were telling me that everything I had been doing was wrong, and that it was all my fault. Then [the Service Coordinator] came along with me and for the first time they listened to me. It was the first meeting with school when I didn’t leave crying – I felt listened to.” [Parent]

Part of the problem for parents is the level of professionalism that is expected in navigating assessment processes. This was particularly felt to be the case in the EHC plan process. Parents would describe how during the meeting they would forget what they had planned to say, due to the pressure of the meeting situation and the feeling that other people were not on their side.

Feedback about the Service Coordinators is positive from the partners who took part in the research too.

“My experience of the service is all positive – the communication I’ve had from the service has been excellent, [the Service Coordinator’s] team even sent me a home visits schedule, I’ve not had that before from any other service, and feedback from them was all proactive, and I even received notification of any forward activity and progress.” [Partner]

“We’ve never had a family who have said they’ve had a bad experience, which is great.” [Partner]

The combination of informal support and formal training

The Health Champions service combines both a ‘befriending’ element (the informal support provided by Champions), other group meetings that offer peer-support, support from the Service Coordinator and Champions, and formal training opportunities.

This combination of activities seems to work. The ‘befriending’ element in particular can help build trust, and the group meetings allow reflection and sharing what works. Parents get information, advice, and knowledge in a number of ways:

- Champions offer tips, behaviour techniques and advice
- The peer-support allows parents to share best practice and ideas
- Guest speakers (for example, at coffee mornings) provide a more specialist level of insight and expertise. They are considered by parents to be ‘fantastic’ in terms of accessing accurate information from the services/ organisations most closely connected to the pathway and statutory provision. This knowledge could then also be shared by the champions through their work, continuing to add to the quality of the service. It is unlikely that families would hear from the guest speakers if they were based in a more formal setting.

- In Swaffham, the local crisis team developed a PBS course to offer to local families that is now co-delivered by Family Action. This course was adapted from the evidence base around supporting those with autism by a clinical psychologist from the crisis team. The course is delivered to six people at a time for two hours a week for three weeks. It comprises of information and activities to help with the identification and understanding the reasons for challenging behaviour and helps parents to “put themselves in their child’s shoes”.

“Many families are isolated or have little knowledge of autism and/or ADHD, and to know they have someone who will listen and understand their concerns helps.” [Champion]

“Parent volunteers are better... than medical teams, doctors, other professionals, when it comes to experience and knowledge about what to do and how to cope – because [peer volunteers / parents] understand, they’re not gobsmacked by anything, and so [parents] can feel a bit “oh thank goodness” and not embarrassed by it, and [parents] feel the volunteers are not judging... in the same way as other professionals. Even family members judge, but the volunteer has usually been through it and we trust it.” [Champion (who also has children with ASD and/or ADHD)]

Availability and adaptability of provision

Families find the support of the Health Champions relatively easy to access (at least in Peterborough and Sandwell). The frequency and location of the services make it much more useful for families than some other services. A comparison was made with another service which, while helpful, is less frequent and so doesn’t provide the level of community and support that is needed for some families.

Over two-thirds of parents believed that one of the most important factors of the service is that ‘meetings are accessible in terms of location, timing, day of the week’, and around half believe the same for ‘Champions and service users meet frequently’. Likewise, around three-quarters of Champions believe that one of the most important factors is that ‘Champions and service users meet frequently’. When parents had suggestions for how the service could be improved, a large proportion of these suggestions revolved around the practicalities of the meetings, e.g. location and timings. This is explored further on page 39.

“I love the fact the coffee mornings are arranged for the whole year, so can ensure I put it in the diary in Jan, so able to make each of the mornings throughout the year, therefore building up a vast amount of knowledge, pertinent to me and my child (& their sibling).” [Parent]

The size of the geographical area covered by the Swaffham service presents additional accessibility challenges. Most services (including the Health Champions Service group meetings) are located in the urban centres, which requires parents to travel across the county. Home visits were originally planned as part of the service in Swaffham, but some Champions do not feel comfortable with this. In particular, a number of those who participated in the research came from a professional background and did not feel that as a volunteer it was appropriate to go into the house.

Word of mouth communication about the service

In the latter stages of the research, the importance of ‘word of mouth’ communication about the service became apparent on more than one level:

- Parents listen to other parents who are facing similar challenges. Parents who have benefited from the service can therefore be powerful advocates for the service. When asked how the service could reach more people, many parents felt that word of mouth - including through an online forum such as a Facebook groups – would be an effective way of reaching more families.

- Professionals working directly with service users also get information on valuable support options through word of mouth, particularly from other professionals working directly with service users. It was felt by at least one partner that this was the most effective way to reach new referral partners.

“If somebody else working on the front line tells you that this service is something that can help, you’re much more likely to listen than if you get a leaflet or your Service Coordinator tells you about it.” [Partner]

In some cases, the coffee mornings present an opportunity for professionals working in the field to meet other parents and network with each other.

Challenges facing the Health Champions Service

The three Health Champions services covered by this research are piloting the Health Champions model. Further Health Champions services might be developed in other areas, and the findings from this research may contribute towards how the model is applied in those locations. This section of the report therefore discusses *both* the challenges facing the Health Champions service that have already been addressed in Peterborough, Sandwell, and Swaffham, *and* those which still need to be considered. This is so that these issues can be considered in other areas, as well as in Peterborough, Sandwell and Swaffham.

Mix of Health Champions

Health Champions are very well regarded by the parents and are fundamental in creating the outcomes identified in the Theory of Change. One area for consideration, however, is whether the mix of different types of Champions is ideal.

One service partner suggested that a priority is that volunteers are impartial when they are giving information, and they wondered ‘does the lived experience of Champions [those with their own children with ASD and/or ADHD] affect their delivery?’, while acknowledging the empathy that such Champions bring. Parents tended to disagree, feeling that it was helpful to have Champions that understood (from personal experience) what they were going through. The view of Family Action and the evaluators is that there are a broad range of experiences that can help a Champion be understanding and empathetic: this includes being the parent of a child with autism and/or ADHD, but also having a relative who has ASD and/or ADHD (i.e. not their own child) or professional experience in the field.

As well as the consideration of the benefits of personal experience compared with professional experience, there are three further considerations for the mix of Champions:

- There are more female Champions than male Champions. This is to be expected in a volunteering service, and the service is working well with fathers (and other male relatives). However, it might be that more male Champions would help ensure fathers engaged with the service
- In at least one service there are significantly more Champions with experience of autism than experience of ADHD
- In at least one service, Champions felt that it would be helpful to have more Champions with children at secondary school, as most Champions had children at primary school. The issues faced within the two age groups are quite different and they felt they might not be able to support parents

with children at secondary school quite so effectively. Of course, if those Champions continue to volunteer for the service, then in a few years they will fulfil the criteria of 'Champions with children at secondary school' themselves

Our view is that in this case it is highly unlikely that the set of volunteers will be totally representative of the people they support, and the mix of Champions overall is good. A greater mix of experience is desirable, rather than necessary, and is something to consider for any future Health Champions Service.

Vulnerability to change

The service may be vulnerable to changes to personnel in either the service itself or in partner services, and to other external changes.

In Sandwell, a recent change in Children's Centre provider made service delivery more challenging initially, and it was believed that the new provider may start their own service targeting the same families. The relationship between the service and the Children's Centre provider now appears to be working well. This is due to the collaborative work of the Service Coordinator, and the perception among staff working for the new Children's Centre provider and other services that the Health Champions service is valuable.

However, there is no guarantee that further changes of this nature would work out as positively for the service. Further changes could include a change in service provider in the area, a change in the nature of provision, or school structures changing (such as becoming an academy) which may prompt new approaches to partnership working.

It appears that the strong partnership working ethos of the services has helped to increase the perceived value of the Health Champions Services to partners, and this should make the services more resilient and joined-up if future changes do occur.

Finally, the three Service Coordinators who established the services are still in post. If one of the Coordinators was to leave, it would definitely have some effect on the service, especially given the low staffing levels within the services. This is the case with many services and is not unique to the Health Champions Service. However, it is worth considering how such a change would be managed in any new services that are established. The commitment of the Champions to the service and their networking with each other would probably help reduce the impact of a change in Service Coordinator.

Communication

Communication between Champions and Family Action is seen as very strong (61% say it is excellent – see Figure 10) but this is an area where there may be some room for improvement. One Champion mentioned that communication with the multi-disciplinary teams could be developed, while another said that *"I think at times, better communication between everyone [would help]"*.

Communication is also an area that shows potential for improvement on the parents' feedback. This was explored in more detail in the final round of qualitative research, and a range of communication issues have arisen.

- When Family Action receives referrals to the Health Champions Service, the referrals often do not include a phone number, and frequently only have a postal address. Sometimes the Service Coordinator writes to the family several times before they respond, and it may be that the parent only responds when they receive a letter telling them that their case is about to be closed. Many parents also admit to not checking their emails. Calls or texts to mobile phones are seen by parents as the best way of communicating.
- There have been some IT issues with Family Action emails recently, meaning that some people have not been able to receive emails from Family Action. This occurred after the survey was completed and so will not have affected the results of the quantitative research. However, it was highlighted as an issue with communications in the final round of qualitative research.
- One group of parents spoke about a meeting being cancelled at the last minute, with the message not getting through to parents in time.
- The person who scored aspects of the service as ‘very poor’ was most concerned with communication and lack of follow-up after training courses. When parents gave lower scores for ‘the support given to you by the Service Coordinator’, this tended to also be for communication reasons:

“After finishing the Positive Behaviour course, we broke up for 6 weeks holiday, my son has started at secondary school and I have not received any phone calls, not even just to see if I'm ok.”

[Parent]

“Well I haven't been invited to any training or courses. Others have been going... [I ask] can I get involved, they say it's not for you. I've been left out.”⁴⁷ [Parent]

The Service Coordinators were also aware of the danger of parents doing so much research that they become ‘self-made professionals’, who may give other parents incorrect or misleading information. While it is a strength of the service that parents can learn from each other (for example, on effective tools to use with children) and that parents and Champions do not feel significantly different from each other, the distinction between the Champions (who have received training and supervision) and parents (who have not) is important. This is something that the services are actively managing, but future services should also be aware of.

Number of families supported

The service is some way below its original target of families supported, although these targets have since been revised with the funders, as the original targets of 750 families was higher than the population of families in the areas who had children with ASD or ADHD who did not have complex needs. Many of the volunteers also commented that that they would like to support more families. This is partly due to the time taken to build relationships with partners and get referrals, and partly due to the challenges that are placed on a single Service Coordinator in expanding to more geographic areas. It is worth exploring whether some Champions can be empowered to take on more of the service delivery in some situations, giving the coordinator more capacity to further expand the reach of the service.

⁴⁷ The Service Coordinators have responded to this quote, and highlighted that they felt that it would be unlikely that the service didn't follow up with any of the service users, because the Family Action case management system would show this. It was the view of the Service Coordinators that this feedback may have been partly a reflection of the other issues that this parent was also facing at the same time.

“[How could the programme be improved?] More volunteers to expand the programme.”
[Champion]

“[How could the programme be improved?] Finding a way to reach more families.” [Champion]

“[One] family is getting more complex for other reasons, but the Mum says she doesn’t want to let me go, she said “I still need your support even more!”” [Champion]

“The only problem is because we have to go through [the Service Coordinator] for arranging visits etc, sometimes when she has a lot on her plate, sometimes she might get too stretched, and maybe communication gets lost or we get crossed wires and miss a visit. So [it would be helpful to have] either two [Service Coordinators], or let volunteers maybe arrange and get sign off from the parent to give to [the Service Coordinator]?” [Champion]

Some of the families that the service supports have a very high level of need, and are effectively in crisis. These families should be getting support from statutory bodies, but either social services are too stretched, or the families did not want to seek help or would not admit that they needed it. The services are now being stricter on the referrals they receive, and are only working with families with lower-level need, whilst rejecting referrals of those with higher levels of need because other support is most appropriate. However, if a family’s situation escalates during the referral and assessment process, Service Coordinators might explore what support they can offer to higher-level need families, although the coordinators are now limiting the amount of time spent on this. This can take up further Service Coordinator time, and it is important for any future Health Champions service that the referral threshold is established and adhered to effectively at the start of the service.

Practicalities of meetings

When parents were asked about potential improvements to the service, most suggestions were about the practicalities of meetings, as shown in Table 8. However, the most popular answer was that there was ‘nothing to improve’.

Suggestions for meetings were varied. The responses are as follows:

“Think it needs wider advertising as I only found out by chance. Possibly also maybe just now and then meeting in a neutral yet comfy setting like a coffee shop i.e. Costa.” [Parent]

“At times at the coffee mornings some parents have been very vocal and taken over and dominated the time together. Not giving others a chance to talk.” [Parent]

“The times of the coffee mornings and other events. Always in morning which is no good for me, due to my own health issues, afternoons are better.” [Parent]

“Possibly longer slots for certain speakers, i.e. at the last one, only one of the 2 speakers got to speak as ran out of time. Additionally, Family Voice (+1 other) very informative and struggled to fit everything into the two-hour slot, however was still extremely informative.” [Parent]

“More frequent meetings.” [Parent]

“I think the service is great, it’s a chance for parents to let go and unwind. To tell all their problems and have someone listen and to know you’re not alone. I wouldn’t change anything, but I guess it might be good to have professionals in to either give talks but not dictate or judge, and for them to have a better understanding themselves of how it is for us parents.” [Parent]

“Support groups held locally to any parents/carers that may need any type of support and information sharing i.e. signposting to any charities locally they can access.” [Parent]

“Meetings in our area, West Bromwich.” [Parent]

Table 8: Parents' perspectives on potential improvements to the service⁴⁸

Q. What, if anything, do you think could be improved about the Health Champions service?

Area	Number responses	Example responses
Practicalities of Meetings	8	Full responses given below
Elements of the one-to-one Support	3	<p><i>“To be more individual support, follow up calls to see how things are.”</i></p> <p><i>“More time with them, but I have telephone contact if needed.”</i></p> <p><i>“Signposting for different courses.”</i></p>
More events for Children	1	<i>“Maybe some more events as the kids really enjoyed them especially London trip & Ferry Meadows outing.”</i>
Nothing to improve	11	n/a
Don't know	2	n/a

The frequency, timings and location of the meetings are clearly significant to parents, and might be explored on a service-by-service basis. This report doesn't evaluate every suggestion given by parents, but there are two areas that are worth expanding on.

One of the comments is about some parents being very vocal and taking over. There is a balance here for the Service Coordinators: events such as coffee mornings are an opportunity for parents to unwind and share their problems. They need to have the opportunity to 'unload'. At the same time, it is easy for one or two more vocal parents to dominate the conversation – this was a challenge in one or two of the focus groups conducted for this evaluation.

“We come here to moan! And to get good advice.” [Parent]

In addition, there were some suggestions about increasing the variety of training courses. One suggestion in the qualitative research was shorter courses (e.g. two hours) for relatives that focus on issues around ASD and ADHD, potentially aimed at other family members, especially grandparents. It can be particularly challenging for families when relatives (perhaps grandparents in particular) perceive the issue to be one of 'bad behaviour' that primarily arises from poor parenting. The services are open to supporting wider family members, e.g. at drop ins, but further communication may be required for wider family members to engage with the service. Another parent asked for more training courses targeted at parents of children over the age of 13.

⁴⁸ Source: Parents' survey

Outcomes of the Health Champions Service

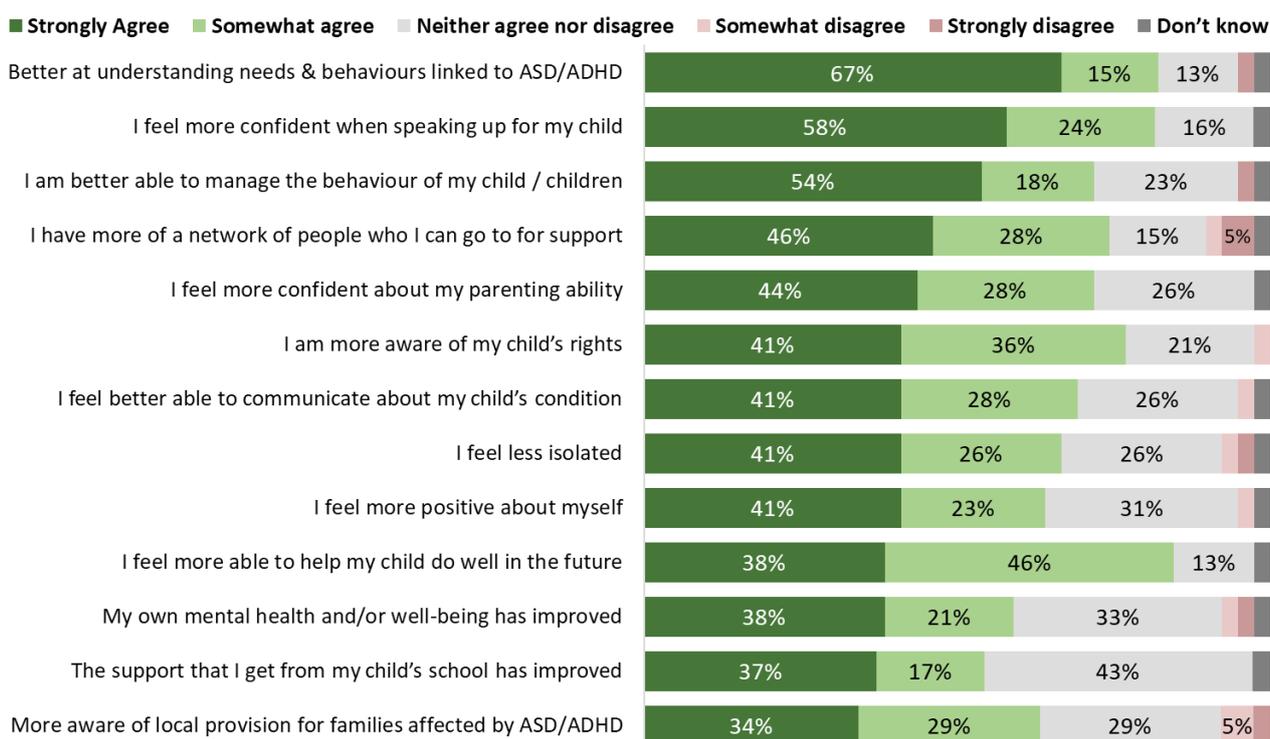
This section summarises the research findings on the outcomes that arise for the different stakeholders as a result of the Health Champions service. It draws on the qualitative research, the quantitative research with parents and Champions, discussions with Family Action staff, and on researchers' observations of group sessions. It refers back to some areas of the service practice in describing these outcomes, and also highlights in bold outcomes that are then referred to in the Theory of Change section earlier in the report.

Outcomes for parents and carers

Outcomes for parents and carers are divided into short, medium and long-term outcomes (as in the Theory of Change) and described below. Figure 13 shows parents' perspectives on outcomes for themselves that have resulted from the Health Champions service. Parents are asked how much they agree or disagree with a series of statements, and the statements are ranked by the percentage saying that they 'strongly agree' with each one. The data in Figure 10 is referred to throughout the section below.

In addition, the Family Star data is referred to in the discussion below. Family Star data is shown in Figure 15 and Figure 16 and an explanation of the Family Star is shown on page 47.

Figure 13: Parents' perspectives on outcomes for themselves⁴⁹



Q. "Please think about the impact of the Health Champions service on you. Please look at the statements below, and indicate how much you agree or disagree with each" n=39

Short-term outcomes for parents and carers

Parents and carers have a variety of different needs that led to them seeking support. However, common amongst the parents who used the service was a sense that they were not getting the support, help and

⁴⁹ Source: Parents' survey

advice that they needed from other local services, and that they often felt isolated and alone. Sometimes parents accessed other support networks, but this was infrequent and could be inaccessible because of inconvenient timing or location.

The most immediate benefit to parents is **improved peer support networks**: 46% of parents ‘strongly agree’ that they ‘have more of a network of people who [they] can go to for support’ (Figure 13), and the Family Star score for ‘Social networks’ increases from 3.8 to 6.4 (for those where the first reading is 5 or lower – see Figure 16). Parents can meet with someone (the Champion or Service Coordinator) who understands their child’s condition and its effects on the family, and to share concerns and worries. They can also get peer-support through meeting other parents who have similar experiences. This contributes to some of the later outcomes that are described below, such as reduced isolation.

“I think that parents end up feeling and knowing they are not alone and isolated. Otherwise, without any support, having to deal managing the conditions can cause problems with family life/marriages, lead to more severe mental health illnesses, feeling physically down. But with face-to-face volunteers, they feel supported, listened to, and that they can save everything up to offload onto a volunteer [rather] than their relatives.” [Champion]

“Feeling supported, feeling more positive about the situation... I had someone to confide in rather than nobody.” [Parent]

This increased support leads to parents gaining a **sense of belonging to a community**, in this instance a community of parents who share similar experiences and challenges. The support networks give parents the opportunities to share how they are feeling and to feel like they are listened to by someone who understands. They can also lead to sharing of ideas and tips for supporting their child and for engaging with other services.

“It’s nice to spend time with people who are in the same boat, have the same sort of need. You can talk about things, but not get judged.” [Parent]

“Now it feels like I have more of a voice and we [Champions and parents] are being listened to and action is happening. Peer group/peer support is a big part of why it helps. It helps everyone stop sweeping things under the carpet.” [Champion]

“Having the peer network of other Mums, of people who have been through it, leads to a sense of being better understood, feeling less like an outcast, and less alone or isolated with it.” [Champion]

Most parents’ **knowledge about ADHD and/or ASD** increases: 67% of parents ‘strongly agree’ that they are better at ‘understanding the needs and behaviours linked to ASD and/or ADHD’ (Figure 13). This increase comes through formal training for those who attend it, but also through the informal support networks that have been established. Parents gain a greater understanding of the conditions and what they mean, but in addition they become better at **recognising emotions and behaviours** of their children, why these emotions and behaviours are arising and what is triggering them. They also become better at recognising the triggers themselves, particularly where the child is unable to communicate their feelings and emotions.

“We also get... ideas for tools for helping calm them [children with ASD and/or ADHD] down.” [Parent]

“The Positive Behaviour Support [course]... was really interesting – it’s probably how I’ve helped [my child] with his different behaviours. It’s the same sort of thing that we’ve always done with him, but put down in paper nice and clear, so nice and easy for everyone to understand.” [Parent]

Parents become more **aware of their rights** as parents and the rights of their children (41% of parents 'strongly agree' that they are 'more aware of [their] child's rights' - Figure 13), particularly in what support they are entitled to from their children's school(s). They also become more **aware of local provision** for autism and ADHD and the likely **timeframes** involved. This is particularly important for those families awaiting a diagnosis.

“One thing parents feel is that there is very little out there to support them. When they get knowledge of the offer [the local offer for families that need support with ASD and/or ADHD] they realise how much [it] can support them. It's about empowering parents and then they can access support and services.” [Partner]

A lower proportion (34%) of parents 'strongly agree' that they are 'more aware of local provision for families affected by ASD / ADHD' (Figure 13). This likely reflects the low level of local provision available, rather than parents being unaware of existing provision that is available.

Around half of parents 'strongly agree' that they are **better able to manage the behaviour of [their] child / children**' (Figure 13). This can happen from a very early stage in the process as Champions share strategies and tools with parents, and can be as simple as using planning tools such as pictorial routine cards with their children. This can provide a 'quick win' to families, and help them get used to trying new things. In the Family Star score there are two indicators related to managing behaviour; the score for 'Keeping a family routine' increases from 4.3 to 7.1 and the score for 'Setting boundaries' increases from 4.1 to 6.5 (for those where the first reading is 5 or lower – see Figure 16).

Parents were asked *how* the service helped them improve their children's behaviour, and the results are shown in Table 9.

“I've got better at “owning” how I communicate in the appropriate way with my daughter, so it's helped her (me being brought out of my shell) that I'm open, and not scared or caring about what other people think. I've got to put those things into practice and I know what works now. So, for example, I'm happier to step back now, as I see they need to let something out, and my job is to let them do that safely and in their own time. I felt like I was being judged before.” [Parent]

These changes lead to some short-term *wellbeing* benefits to parents. For example, parents' **self-esteem can improve** (41% of parents 'strongly agree' that they 'feel more positive about [themselves]' - Figure 13), particularly as they feel listened to and valued by Champions and Family Action staff, and recognise that their child's behaviour is not their 'fault'.

“Webster Stratton: it has a massive impact on self-esteem, it helps to feel more like I wasn't doing a bad job as a parent.” [Champion]

Champions, parents and project partners all highlight how important this increase in self-esteem is. The existing Outcomes Star data (see explanation below) shows that 'Meeting emotional need' is one of the areas where parents score lowest on their initial reading (see Figure 15).

Table 9: Managing children's behaviour⁵⁰

*Q. You said that the support you have had from the Health Champions service has helped you to **manage the behaviour of your child(ren)**. Please explain how the service has helped you to manage their behaviour.*

Area	Number responses	Example responses
Emotional support	13	<p><i>“As a parent with a child with additional needs/challenging behaviour, you are always made to feel like you have done something wrong or it’s your fault. Going to the Health Champions Service has allowed me to express my feelings without being judged. I feel I’m listened to and I have the support from the health champions and other parents. It’s an invaluable service that I couldn’t be without now.”</i></p> <p><i>“Makes you feel less isolated and alone. You feel like someone else actually understands what you are going through, and it is such a big relief I can’t explain. It’s somewhere you can gain information on things you’ve never heard of beforehand but also know they are there to help support you.”</i></p> <p><i>“The continued support and friendliness. Nice to be listened to as a parent.”</i></p>
Increased understanding and awareness	12	<p><i>“Finding information about resources and services that are available for children with autism.”</i></p> <p><i>“Sharing ideas from other parents.”</i></p> <p><i>“Very supportive, informative service. Good to meet other mums in a similar situation. Provides equipment, ideas that may be useful to my son. Points to other useful services.”</i></p> <p><i>“It is important for parents to be able to support one another in all areas and signpost each other to any help and support that may be available.”</i></p>
Increased ability to support and manage child(ren)’s condition <i>(There is some overlap between these responses and the responses categorised as ‘Increased understanding and awareness’)</i>	8	<p><i>“They help with different strategies to manage a child’s behaviour.”</i></p> <p><i>“I feel it has given me emotional support. To give me tools to support my daughter. Got us a place on Webster Stratton.”</i></p> <p><i>“I have found these meetings very useful with giving me the tools I need to hopefully get my [son]’s behaviour back on track.”</i></p>
Quality Family Time	1	<p><i>“The trips out or cooking session to get the kids to try and eat healthier and the fact it’s included the whole family were really awesome – we really enjoyed it, all of us.”</i></p>

⁵⁰ Source: Parents’ survey

In addition, parents can become more realistic and **accepting of their circumstances**, recognising, for example, that a potential diagnosis of ASD or ADHD is unlikely to unlock significant extra help or lead to straightforward solutions. An important observation from the behavioural workshops that parents pointed out was the role of communicating emotions, and how many parents need support with this. Parents can also think about how they manage their own emotions which helps them to support their children.

“The home visits and one-to-one support really helps with the parent’s low self-esteem. Previously she had low self-esteem, she didn’t believe in herself or that she was doing a good job, and was quiet and insular. But now she’s more confident and stronger-voiced, so I think we help build that resilience, and now she’s getting her opinions across more often. For example, when she was doing a parenting course (with Family Action), at the start she was less confident, and at the end of the sessions, she was more vocal about putting her views across, more forthright. We’ve seen a massive change in her that way, and also, she doesn’t seem as stressed. And that’s really because she feels she has someone on her side that doesn’t judge her, but whilst we can understand and empathise because I’ve been there, I can be quite straightforward and blunt, I can tell her as it is, and get her to be more realistic that this is a long-term thing, not something that gets ‘cured’.”
[Champion]

“I come here even if it’s a bad day, I feel better. Sometimes even the adult “bucket”⁵¹ fills.”
[Parent]

Parents’ wellbeing is affected in other ways beyond self-esteem. The support networks lead to significantly **reduced isolation** among parents; 41% of parents ‘strongly agree’ that they ‘feel less isolated’ (Figure 13).

“You can feel alone, with nobody to turn to. I didn’t know who to turn to. You might not see your friends - your friends might think ‘I’m not going round there – she’s got a naughty kid’, or ‘their kid might hurt my kid’ or even ‘they [other child] might catch autism’.” [Parent]

Some parents see **improved communication within the family and with professionals** as they are supported when seeking support for their child, and equipped with the knowledge needed to advocate for their child more effectively. 41% of parents ‘strongly agree’ that they ‘feel better able to communicate about [their] child’s condition’ (Figure 13). Overall, many parents believe that their **household is calmer and less stressful** because of the support of the Health Champions service.

“If I’m feeling supported and my personal situation is better, I can be better with my children. I stick to routines more and stuff. And that helps my kids – it helps avoid meltdowns.” [Parent]

“I think they [parents] have become calmer, and once Mum is calmer there is a stabilising effect, when the parents are confident and assured, and calm, not anxious or panicking, the child picks up on that.” [Partner]

Medium-term outcomes for parents and carers

In the medium-term, parents’ **confidence improves**. This can be confidence in their **parenting ability** (44% of parents ‘strongly agree’ that they are ‘more confident about [their] parenting ability’ - Figure 13), recognising that, for example, if their child has a ‘melt down’ then this is not because of any poor parenting on their behalf. It can be confidence in **advocating for their child** (58% of parents ‘strongly agree’ that they are ‘more confident when speaking up for [their] child’) and in liaising with services such as GPs.

⁵¹ The “bucket” is a concept used in the workshops in Swaffham (and potentially elsewhere) to indicate the increasing levels of stress in a person’s life that eventually spill over.

Partly because of this improvement in confidence, parents' **relationship with their child's school** often improves, and the **support from school** improves significantly. The proportion of parents agreeing that 'the support that [they] get from [their] child's school has improved' is lower than for most other statements (Figure 13), reflecting the struggles that many parents still experience with schools.

When there are improvements in relationships with schools, this is sometimes driven by the intervention of the Service Coordinator, who intervenes on their behalf and is sometimes respected more by the school as they are seen as a fellow professional.

"There can be power struggles in schools. For example, teachers sticking with what they think will work [based on educational knowledge]. It's about working closely to help them. We need to promote positive relationships between parents and schools." [Champion]

"I've definitely seen relationships between parents and children improve and stabilise, and also seen the parent's relationship and attitude with the school develop more positively." [Champion]

This combination of factors often leads to parents **feeling more empowered**. In this context 'empowered' means feeling they have the right language, they know their rights and they have a deeper understanding of conditions, meaning that they are able to help their child do well in the future. It means they feel that they have the knowledge and skills to be able to make their best case, even if in the past they felt that the "professional" was more powerful. 38% of parents 'strongly agree' that they 'feel more able to help [their] child do well in the future' (Figure 13).

"I wouldn't have the confidence to know how to express my concerns, I feel more empowered and proactive rather than passive and not knowledgeable. That would have had a negative outcome for my daughter, as she would have had to cope with me being angry, panicky, anxious and not calming. I have skills to calm things down now as well." [Parent]

"Family Action has helped me fight my fight that I was fighting for seven years, but they helped me win it." [Parent]

Long-term outcomes for parents and carers

Long-term outcomes are those that largely arise outside of the timeframe of the Health Champions service; there is evidence to show that they will arise, but for the most part the Health Champions service has not been running for long enough to show direct evidence of them.

The exception to this is **improved mental health and wellbeing**,⁵² in many instances, the mental health and wellbeing of parents starts to improve in the short-term (and this is reflected in short-term outcomes such as improved self-esteem). 38% of parents 'strongly agree' that their 'own mental health and/or wellbeing has improved' (Figure 13). This is explored further in Figure 14, where the level of impact on parents' wellbeing is explored, using statements derived from the Warwick-Edinburgh Mental Wellbeing Scale.⁵³ In the Family Star score for 'Meeting emotional need' increases from 3.4 to 6.3 (for those where the first reading is 5 or lower – see Figure 16).

The long-term outcome here refers to the continuing improvement in mental health and wellbeing over and above that seen in the short-term, and the self-sustaining improvements that do not require the continuing

⁵² By 'mental health' we are referring to lower level mental health issues such as stress and anxiety, rather than issues such as psychosis, schizophrenia or personality disorder.

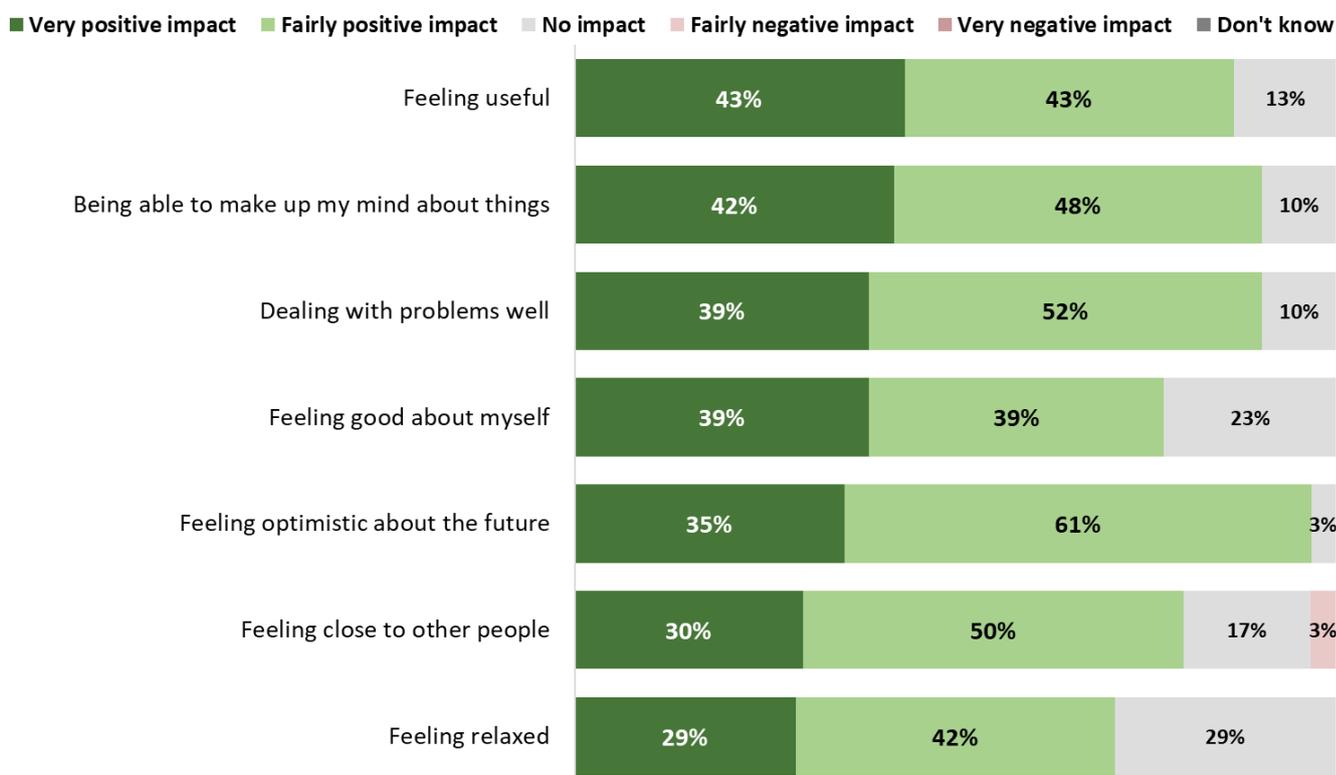
⁵³ For more details on the scale, see: www.healthscotland.com/documents/1467.aspx

input of the service. In particular, it refers to the increased **resilience** of parents, i.e. their ability to deal with challenges and problems, and **feeling accepted** in society (both themselves as a parent, and their child).

“I think a lot of it is also down to the practices and knowledge they learn through the service and parents’ groups they access with the service, to try those things with [their] children - and that gives them more resilience and coping strategies. The service also means they are attending groups more and building their networks more, and they feel they’re not alone with it all – so that peer support is a big deal.” [Partner]

“When I started to use the service, I was suffering depression anxiety and did not know where to turn. They believed in me, listened to me, helped me.” [Parent]

Figure 14: Parents' perspectives on their change in wellbeing⁵⁴



Q. "If you said that the support you have had from the Health Champions service has affected your mental health and/or your well-being, please indicate **what level of impact** has the Health Champions service had on the things below." n=30-31

There are also **increased opportunities to volunteer** for parents, sometimes as Health Champions themselves. There are currently six Health Champions who started off as users of the service, with a further five expected to start volunteering soon.

“Looking at what the service has done for my own self-esteem, I am thinking of now volunteering myself.” [Parent]

The service can also lead to **stronger families**. This is driven by factors such as **reduced conflict between generations** (partly due to the calmer and less stressful household), a sense that their children are seen in a positive light (rather than as a ‘problem’ that needs addressing), and in many cases **stronger parental relationships** (as the ASD or ADHD of their children takes less of a toll on the relationship of the parents).

⁵⁴ Source: Parents’ survey

“I feel a lot better informed about my son's condition and think I can look forward to a happier and better future for my family.” [Parent]

“Certainly, the service can impact on parent wellbeing, it empowers the parents, stops strains on parental relationships.” [Partner]

“Parents grow from being nervous wreck, some were on anti-depressants, to being brave enough to go out – and even volunteering themselves – which is really wonderful.” [Champion]

The conflict within families is not just between children with ASD or ADHD and their parents. It can also apply between parents and the parents' friends, siblings and parents. As one Champion explains:

“Otherwise they go around thinking my daughter behaves OK because when she's with them she's generally good, and grandparents or relatives end up saying “Oh she's not like that with me” like they're some guru and they don't believe me, and they need to stop kicking a girl [the mother] while she's down kind of thing.” [Champion]

The Family Star

Family Action uses the Family Star developed by Triangle Consulting to support parents and families to plan and measure benefits to be achieved. The tool covers eight areas of parenting: physical health, emotional wellbeing, keeping your children safe, social networks, education and learning, boundaries and behaviour, family routine, and home and money.

Family Star scores are out of 10 and relate to a series of steps. These steps and corresponding scores can be summarised as follows:⁵⁵

“(1-2) Stuck”: Parents are not yet aware of the children's needs and not doing anything yet to change the situation or acknowledge problems/behavioural challenges; parents are sometimes resisting others involvement and not seeking help; or other important things take parents' attention away from the issues. Stepping forward to a score of 2 reflects acknowledgement of the issues and starting to open up, but not yet taking enough action to make change possible.

“(3-4) Accepting help”: Children are not developing as well as they could or have behavioural problems, either at school or home. Parents can talk about the issue and are open to getting help if arranged or if they feel the need to co-operate, although they do not necessarily follow through with advice or actions on their own initiative. Stepping forward to 4 reflects going along with support more consistently, but only if the initiative is from support workers.

“(5-6) Trying”: Step 5 reflects parents recognising they are responsible for improving things for their children and for taking more initiative to try new ways to address challenges or needs. Parents may feel less confident or find it difficult trying new solutions. Children may at first feel unsettled or resistant to change, and the benefits are not immediately felt; it may be easy to give up. Stepping forward to 6 reflects parents sticking with new practices for longer and finding hope from some positive outcomes.

“(7-8) Finding what works”: Parents start learning from experience what works or works less well, and are finding consistency in how they manage children's needs. Children are more clearly benefitting. Things might still be hard to cope with during a time of crisis or when lots of demands happen at once. Stepping forward

⁵⁵ Triangle Consulting, *Family Star User Guide* (2013)

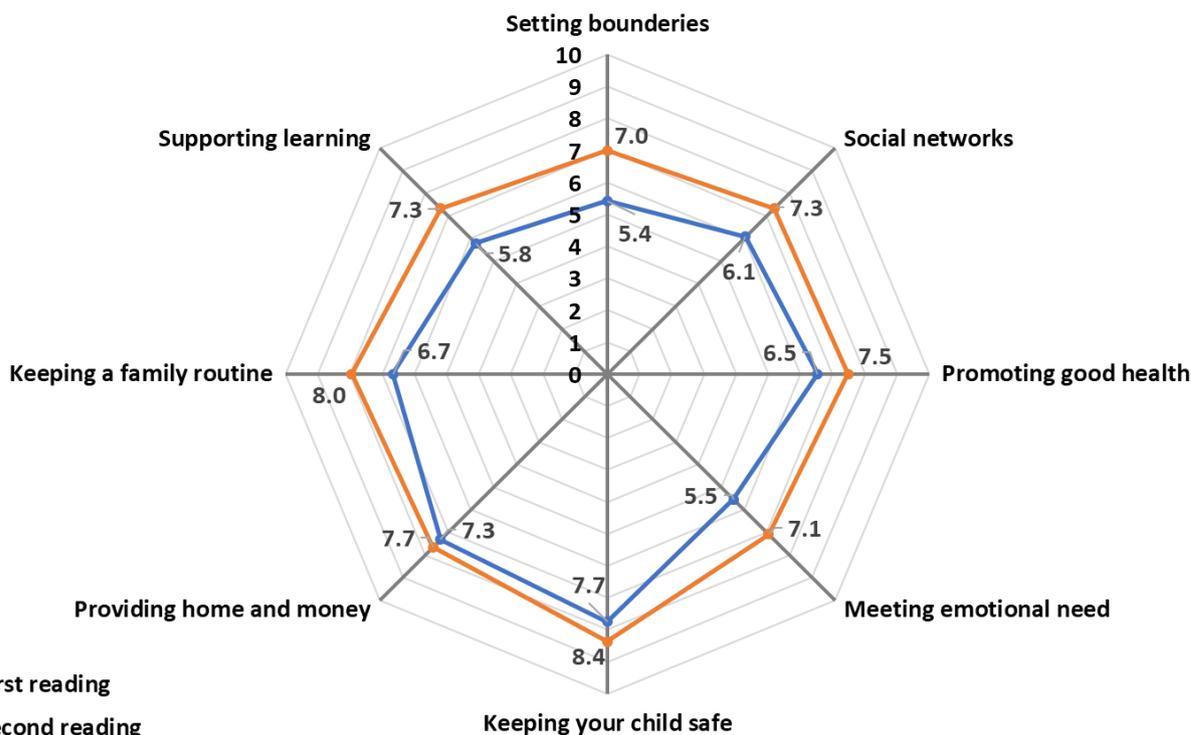
to 8 reflects parents doing well enough for their children, although recognising they still need to be proactive in their new practices and in finding other sources of support where needed.

"(9-10) Effective parenting": Children are doing well and starting to flourish. Parents are using practices and techniques to better balance their children’s needs with their own. Coping, resilience, and understanding improve for the whole family. Stepping forward to 10 means that parents are doing well with what they have learned to not need further support services.

Figure 15 shows the average first reading and average latest reading for all parents where there are at least two readings (66 parents in total). The difference between the first and latest Star indicates the change that parents have experienced since getting support with the service. This does not necessarily show the total benefit of the service, as parents may experience further benefits after the second reading of the Star is taken.

Figure 16 shows the results only where the first reading is five or lower; this is intended to show the impact on outcomes where the starting point was particularly low, and hence need for support in these areas is highest. It shows that the Health Champions service has a particularly significant impact when the parent is starting from a lower point. The base sizes in Figure 16 vary, but it the chart demonstrates particularly large increases in ‘keeping your child safe’ and ‘meeting emotional need’.

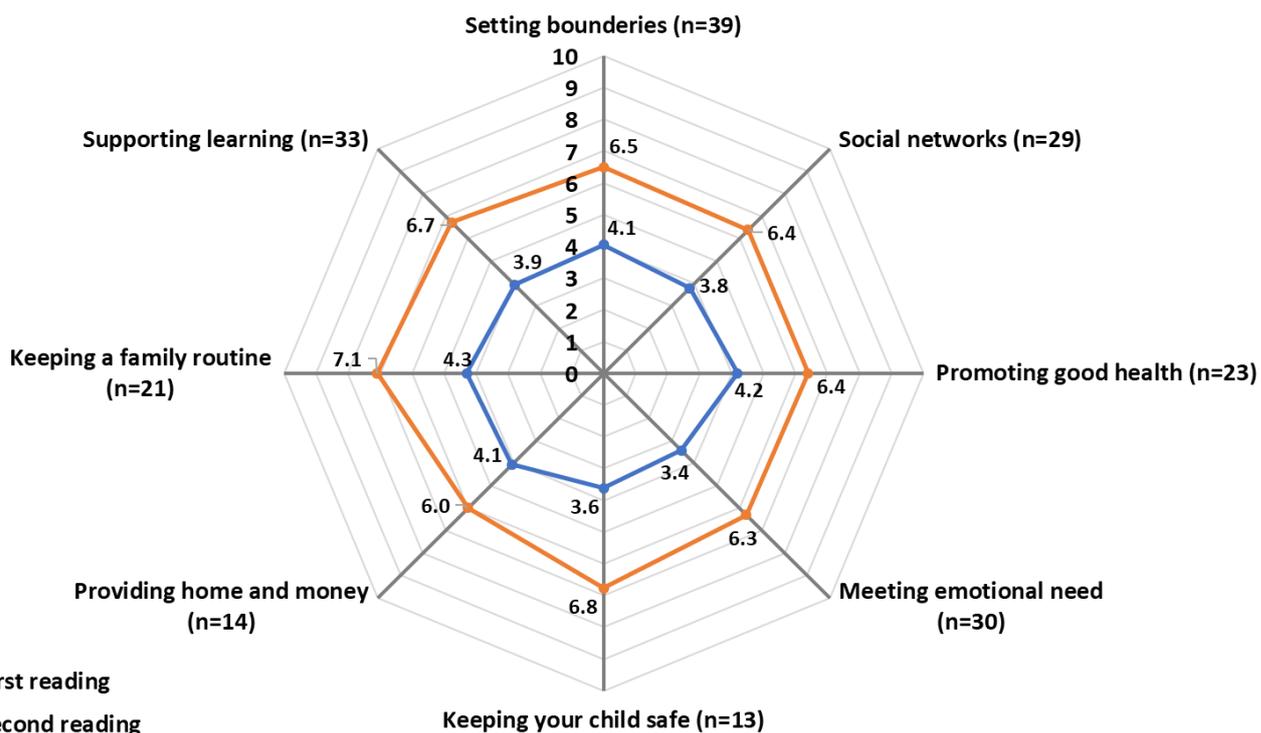
Figure 15: Family Star results⁵⁶



Data from Family Star. Clients where at least two Outcome Star readings are available. n=66

⁵⁶ Source: Family Action data

Figure 16: Family Star: Results when first reading is five or lower⁵⁷



Data from Family Star. Clients where at least two Outcome Star readings are available, and the first reading is 5 or lower. n=13-39

Outcomes for children

When asked about outcomes for children, parents often thought first about the events that included children. Those who attended events with children believe that their children have really good relationships with volunteers and staff, and that their children were more relaxed than at other events, and did well interacting with the other children at those events.

Other outcomes for children largely arise because of parents’ improved understanding and management of behaviour, or because of improved school Special Educational Needs provision. For some parents, the impact on children has been marginal.

“Children pick up on emotions of parents. So if you’re stressed, they get stressed.” [Parent]

“If I’m feeling supported and my situation is better, I can be better with my children, stick to routines more... And that helps my kids.” [Parent]

Children were not surveyed about their outcomes; however, Figure 17 shows parents’ perspectives on outcomes for their children. Additional qualitative research that took place since the survey was completed has highlighted two issues with the phrasing of outcomes in the survey:

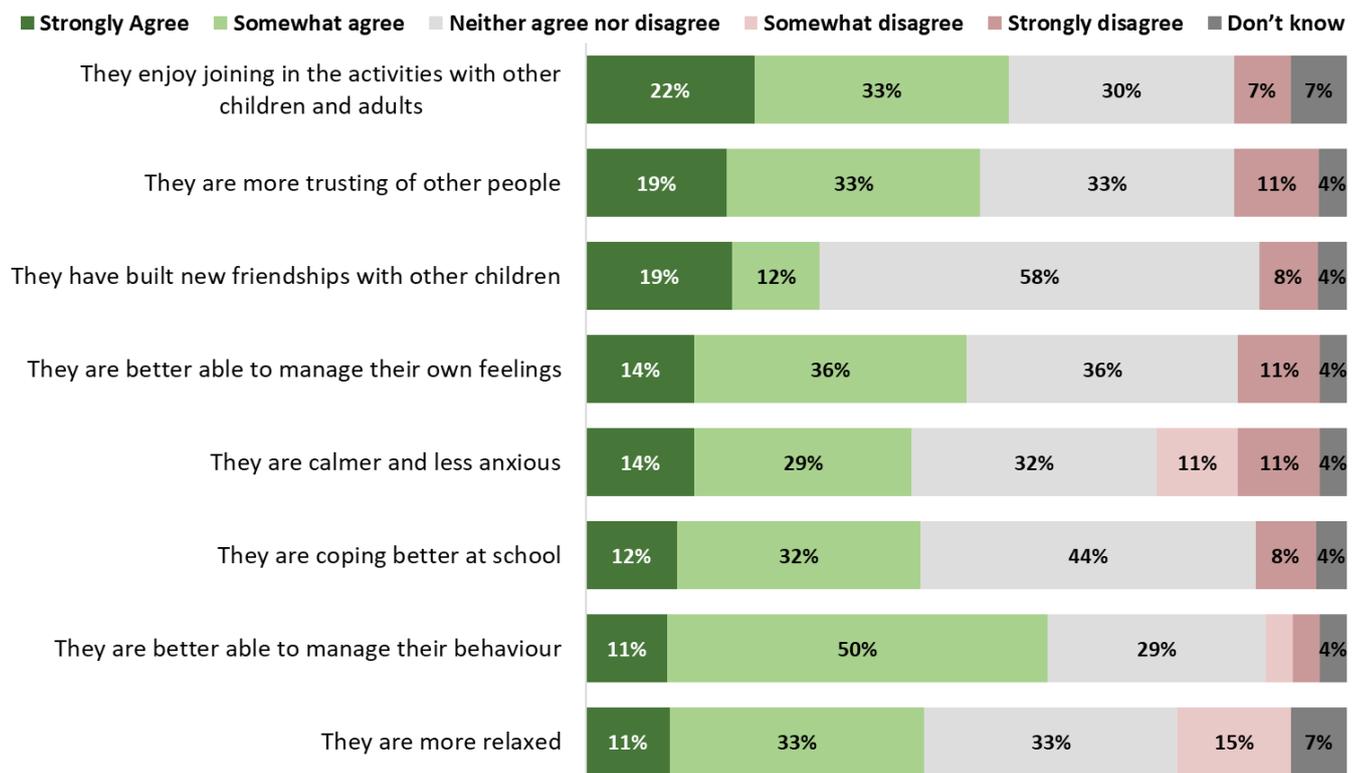
- The survey asks whether children are more trusting of other people. However, subsequent feedback suggested that children with autism in particular can be too trusting, and may not understand appropriate boundaries with strangers. So ‘more trusting’ may not actually be a good outcome in every case.

⁵⁷ Source: Family Action data

- The survey also asks about building friendships with other children. However, the concept of friendship is understood differently by some children with autism and/or ADHD. Parents described how their children defined friends as ‘everyone in my class’ or ‘someone whose name I know’.

The data for these two statements is included in Figure 13. However, the data is not directly drawn on as evidence for the outcomes that follows.

Figure 17: Parents' perspectives on outcomes for their children⁵⁸



Q. "Please think about **the impact of the Health Champions service on your child / children with autism and/or ADHD.** Please look at the statements below, and indicate how much you agree or disagree with each one." n=25-28

Short-term outcomes for children

The activities that involve children as well as parents result in children experiencing the **enjoyment of participating in activities**; 22% of parents strongly agreed that their children ‘enjoy joining in the activities with other children and adults’. One example was a ‘Come Dine with Me’ event in Peterborough, where children were encouraged to eat healthily, were involved in food preparation (for example, cutting fruit and vegetables), and could be physically active, through dancing.

“The events are good because you don’t feel that your kids are judged by other parents. In the park, 90% of children will be neurologically normal, and your kid will be different. But not here.”
[Parent]

Events like these could also lead to children **building relationships with families and professionals**; for example, the children felt trusted when they were able to help with food preparation, and appreciated that people were taking an interest in them. They also developed relationships with peers, many of whom had

⁵⁸ Source: Parents’ survey

similar conditions and were facing similar challenges. These events can also lead to children being more **relaxed** (although only 11% of parents 'strongly agreed' that their child is 'more relaxed'). For example, parents reported that activities held for parents and children in Sandwell would lead to children's mood improving significantly.

Some activities (such as group activities and individual support provided by Champions) also gave children tools to manage their own feelings that they could use outside of the sessions. Parents also gained strategies and tools for managing their children's behaviours from parent-only sessions, as discussed above, and often use these strategies and tools with their children at home.

In many cases the strategies and tools that children have gained mean that they are better able to **manage their own feelings and behaviours**, at home, at school, and when out-and-about. 14% of parents 'strongly agreed' that their child is better able to manage their *emotions*. 11% of parents 'strongly agreed', and a further 50% 'agreed', that their child is better able to manage their *behaviour* (Figure 14).

Medium-term outcomes for children

Children sometimes **cope better at school** and see an **improved performance at school**. 12% of parents 'strongly agree', and a further 32% 'agree', that their child is coping better at school. In this instance 'improved performance' refers to better attention, behaviours, interaction with other children and learning, rather than academic attainment. There are, however, many children who were performing well at school anyway; in these instances there may be little or no change at school.

There are a number of different reasons for improvements in performance at school, as shown in the quotes below and in Table 10.

"It has transformed some of the families' lives, in terms of major improvements in managing the child's condition and behaviours, and learning to be more positive about dealing with the condition effectively rather than feeling hopeless or negative about the whole pathway at the start. The children's behaviour changes and we can see the children get better at self-managing their emotions... Certainly, I've seen quotes and feedback where parents have said "I can't believe how good this has been for improving the relationship with my child!" So, there is improved emotional wellbeing on both sides [children and parents]. I even received an email saying, "Thank you so much" from one of the schools, and as an aside, two teachers approached one of the parents on separate occasions to enquire if something had been happening in the home, as the children were better fed, better behaved and more presentable, even reading at home together with the parent." [Partner]

"One son is now better at voicing his own needs and wants, and it's about working with school to come to a compromise." [Champion]

Table 10: Reasons for coping at school⁵⁹

Q. You said that your child / children are coping better at school. Please explain how they are coping better at school.

Area	Number responses	Example responses
New tools and techniques for child at school	3	<i>“Health Champions worked with me and school, daughter has reward charts at school for behaviour at toileting. Daughter participates in activities more frequently and shows less challenging behaviour whilst at school/more manageable.”</i>
Specialist support	3	<i>“My child has been placed in specialist education which helps a lot.”</i> <i>“Children now have a family worker seeing them weekly in school and have better support to voice their problems.”</i>
Other school intervention	2	<i>“Teachers he has this year seem to be able to control the class better than the previous school year which in turn has improved his behaviour.”</i> <i>“The school is brilliant and they have made changes.”</i>
Improved communication with school	1	<i>“The communication is better with school.”</i>

For older children, the gap between their own emotions and behaviours, and those of their peers without ASD and/or ADHD, can reduce. Furthermore, the way that they are treated by teachers and other adults can become more ‘normal’. This leads to them **feeling ‘normal’ and accepted**, as well as potentially reducing additional harm. Older children can also gain an **improved understanding of their own condition**, and the reasons why their emotions and behaviours might be different to those of other people.

Long-term outcomes for children

In the long-term, children are expected to see **improved mental health and wellbeing**. The short-term and medium-term outcomes discussed above, such as feeling ‘accepted’ and having strategies for managing their feelings can lead to children being:

- **Happier**, by which we mean their day-to-day mood is better and they have a greater proportion of positive feelings and a lower proportion of negative feelings,
- **More relaxed**,
- **Less anxious**, which is also a short-term outcome but is expected to continue in the long term
- **Empowered**, by which we mean better able to make decisions and enact decisions about how to live their lives.

In the short-term, children gained relationships with peers and built trust with families and professionals. In the long-term, as the children grow older, it is believed that these gains will lead to **better relationships with families and peers**, and **improved educational achievement**, in school and beyond.

⁵⁹ Source: Parents’ survey

Outcomes for other family members

In some families, the benefits to parents and to the child with ADHD or ASD can lead to benefits to siblings too. As behaviour is better managed, parents may be able to give more time and attention to siblings, leading to siblings feeling more supported by their family.

“For some the big knock on impact is on siblings, who don’t have the opportunity to go and play, or feel sad or not used to going out because the parents are keeping everything indoors as they’re too unconfident [sic] and scared about going out. So previously some siblings aren’t used to being out playing with other kids. But once parents feel confident, the siblings can go out, express themselves without feeling like their sibling with SEN is in a bad place, and they can discover their own voice. I’ve seen that in a sibling, she’s really come out of herself.” [Champion]

Outcomes for Champions

The outcomes for Champions are determined both by the qualitative research with Champions, and the online survey completed by Champions. The online survey asked about the extent to which Champions agreed that certain outcomes applied to them, and then explored the wellbeing and employability benefits in more depth. Data from the Rosenberg scale, which was completed by several Champions, is also used to give an indication of the extent that outcomes are achieved. Figure 18 shows the extent to which Champions agreed that certain outcomes applied to them.

Short-term outcomes for Champions

Champions gain opportunities for sharing their own experience and learning, whether that is experience of having a child with ASD or ADHD, having worked as a professional in the field, or just bringing their own life experience.

There are three key benefits that Champions then gain in the short-term, and these are often Champions’ motivations for becoming a volunteer in the first place. Firstly, there is a sense of **reciprocity, or ‘giving something back’**. This is particularly true for those Champions with children with ASD or ADHD who have received support in the past, who might feel that they are ‘through the worst of it’, and who feel they have something to give to other people as a result. This sense of giving something back is combined with a sense of pride in the progress made by the parents that they have supported.

“It is a wonderful feeling knowing you’ve helped someone.” [Champion]

Champions also **gain experience and develop skills**. This is particularly important for those who see potential professional benefits and career development from their volunteering. The champions have a range of things they can volunteer for through the service, and this allows them to choose how to develop their skills as they think would best benefit them.

“There has been sufficient and really good support, lots of training and courses, new opportunities for skills [development].” [Champion]

Thirdly, Champions get **friendship and peer support** themselves from other Champions and families that are supported; this is particularly true for those with their own children with ASD or ADHD.

“We had a great group [on the training], we still talk now, all still friends and in contact.” [Champion]

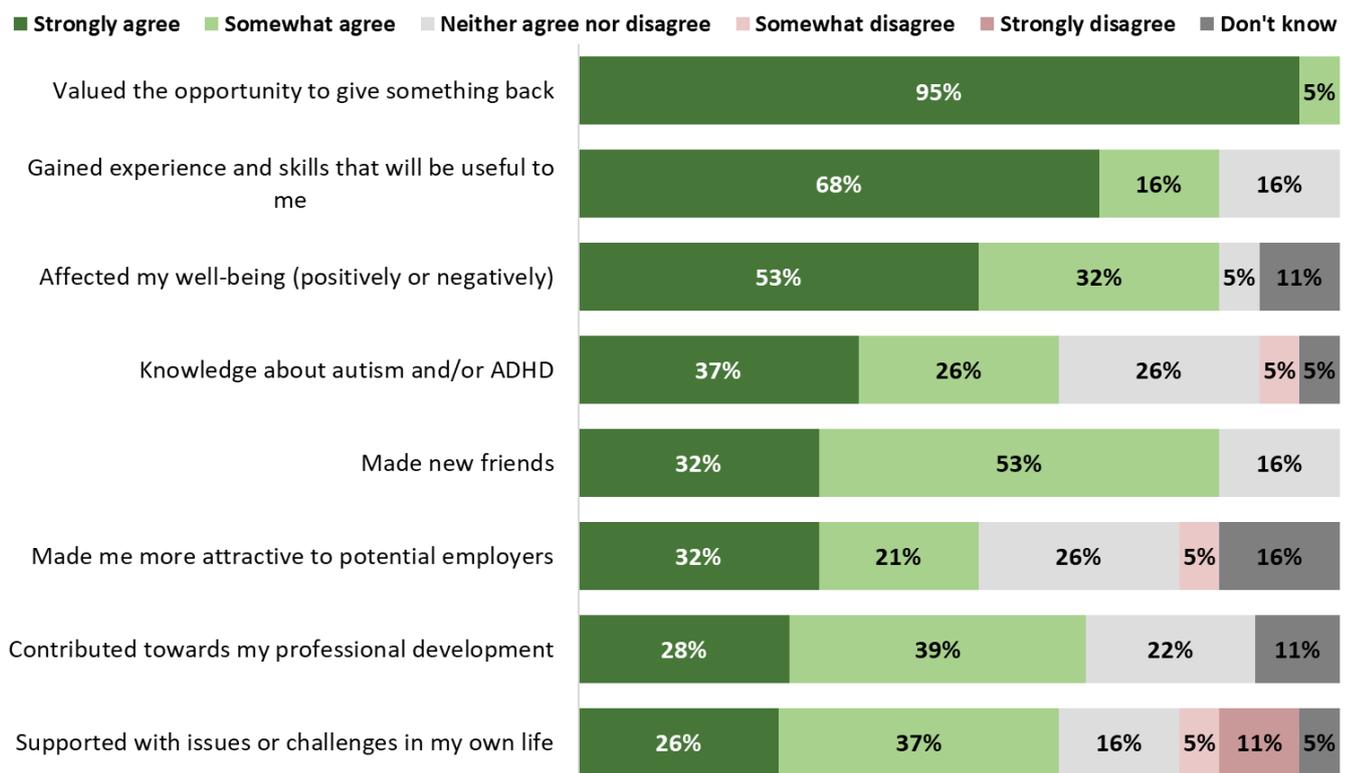
Champions gain **increased knowledge of ASD and ADHD**, around techniques for managing behaviour, and around supporting families in general. This increased knowledge can come about through the formal

training, through informal support provided by Champions and the Service Coordinator to other families, and through hearing about the experiences of families themselves. For those Champions with their own children with ASD or ADHD, the friendship and peer support can also lead to **reduced isolation**.

“Since coming to coffee mornings – we’ve seen guest speakers who have given great information. [He] was amazing – we found out so much information that we were able to go to school and question the education that families were receiving.” [Champion]

“Meeting other parents was empowering. [Previously] I genuinely thought I was on my own.” [Champion]

Figure 18: Outcomes for Champions⁶⁰



Q. "Now please think about the impact of being a Health Champion on you. Please look at the statements below, and indicate how much you agree or disagree with each one." n=18-19

Medium-term outcomes for Champions

For many Champions, the volunteering provides an opportunity for **personal and professional development** (28% strongly agree in Figure 18). This includes becoming better mentors or befrienders, and gaining extensive knowledge and experience. For some, it also **contributes towards their education**, for example if they are taking a degree and pursuing a career in a related field.⁶¹

“I would like to think that my role with Family Action will in time leader to greater [employment] prospects.” [Champion]

⁶⁰ Source: Health Champions’ survey

⁶¹ This applied to too few of the Champions taking the survey to quantify here

Long-term outcomes for Champions

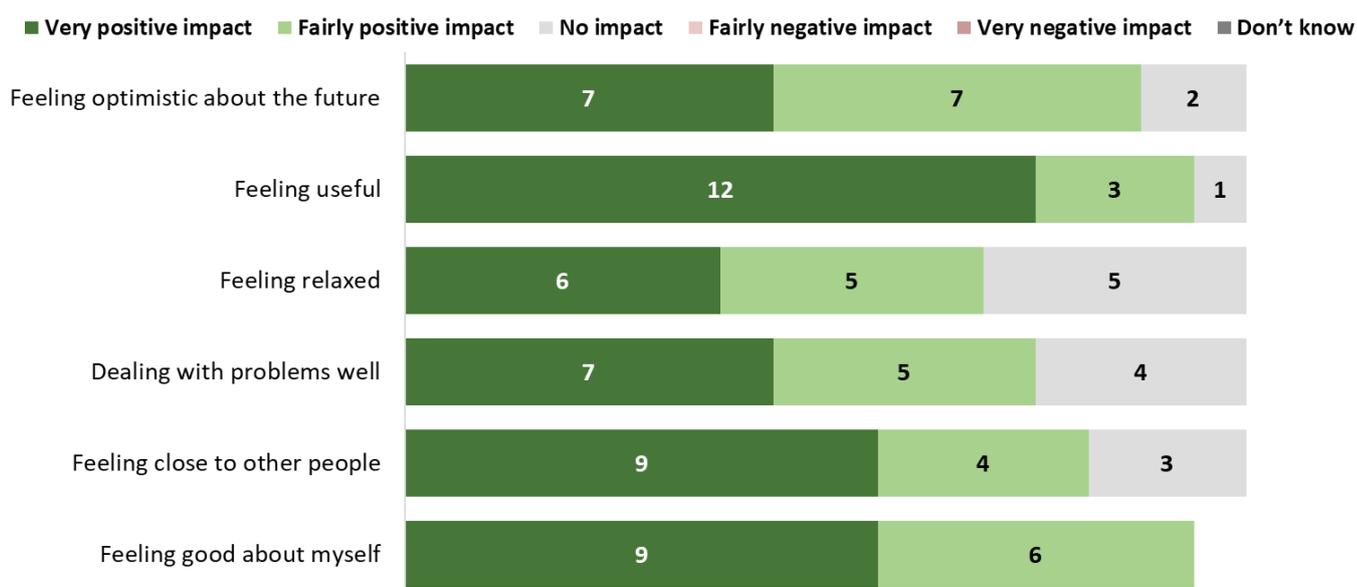
In the long-term some Champions gain through **improved wellbeing**. This particularly applies to those Champions who may have been more isolated because of their family situation, although it can also apply to those who benefit from the sense of ‘giving something back’, regardless of their own circumstances. In particular, Champions can gain a sense of **self-belief and self-esteem**, and an increase in **optimism** about the future.

“I was chuffed to be asked to deliver the [parental behaviour] course. I am talking to people who believe in my skills. I was made redundant and I felt that didn’t have skills. I am becoming proud and confident and feeling professional again.” [Champion]

“I can really not explain in words how much of a difference becoming a Health Champion has made in my life, I feel part of something, it is a fantastic feeling knowing that you may have helped someone or even listened when there was no one else there too. I feel that I have become a better person and I can’t thank the service enough for giving me this opportunity.” [Champion]

Figure 19 shows Champions’ survey feedback about their wellbeing outcomes, for those who believe that being a Health Champion has affected their wellbeing. The biggest impacts are on their ‘feeling useful’, and ‘feeling good about myself’.

Figure 19: Wellbeing outcomes for Champions⁶²

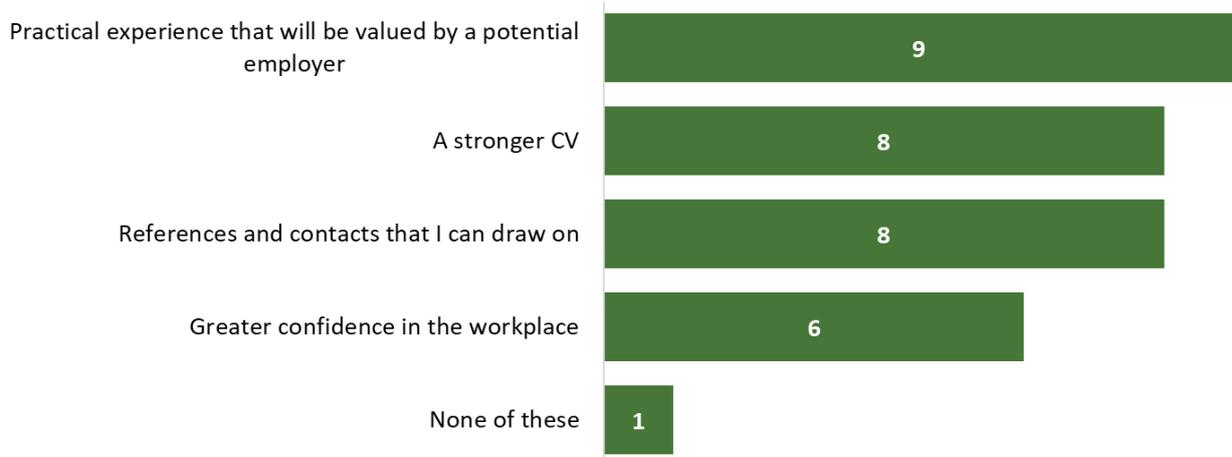


Q. "You said that your experience as a Champion has affected your well-being. What level of impact has being a Health Champion had on the following?" n=15-16

Some Champions also gain **improved employability**. This can be because they gain more **practical experience**, they develop a **stronger CV**, they gain more **confidence at work**, and they secure more potential **references** and professional **contacts**. 13 Health Champions have gained employment since becoming Champions, and in most cases the training they received made a contribution to their employment. Figure 20 shows Champions’ feedback about their employability outcomes, for those who believe that being a Champion has made them more employable.

⁶² Source: Health Champions’ survey. Numbers of respondents are shown rather than percentages, due to low base sizes

Figure 20: Employability benefits for Champions⁶³



Q. "You said that your experience as a Champion has made you more attractive to potential employers. Please indicate how being a Health Champion has made you more attractive to potential employers." n=10

Additional data was also collected for Health Champions using the Rosenberg Self-Esteem Scale. The service collects data before and after the training that Health Champions receive, and sometimes in the medium-term, once they have been volunteering for a while. Figure 21 shows the scores before and after the training that Health Champions receive (there was insufficient data collected in the medium-term, once Champions had been volunteering for a while, to be included).

Statements 1, 3, 4, 7 and 10 are framed as positive statements, meaning that a positive change would show improvement for the individual. Statements 2, 5, 6, 8 and 9 are framed as negative statements, meaning that a negative change would show improvement for the individual. Scores range from 1-4.

The results are mixed; there are some positive changes (for example, 'I am able to do things as well as others' increases from 2.1 to 3.1 out of 5). However, there are some negative changes too (for example, 'I definitely feel useless at times' increases from 2.6 to 3.0).

This suggests that changes to Champions' wellbeing don't happen immediately after the training; they happen later in the process, once the Champions have started supporting parents. Feedback from Family Action staff suggests that sometimes the Champions' training makes them feel less positive in some ways, as Champions become aware of all of the challenges that parents might face and the expectations that might be placed upon them.

⁶³ Source: Health Champions' survey. Numbers of respondents are shown rather than percentages, due to low base sizes

Figure 21: Rosenberg scores for Health Champions⁶⁴

Statement	Average: Start of training	Average: End of training	Change
1. I am quite satisfied with myself	2.7	2.9	+0.2
2. At times I think I am no good at all	3.0	3.1	+0.1
3. I feel I have a number of good qualities	2.5	3.1	+0.5
4. I am able to do things as well others	2.5	3.1	+0.6
5. I do not have much to be proud of	3.0	3.2	+0.2
6. I definitely feel useless at times	2.6	3.0	+0.4
7. I feel I'm a person of worth	2.7	2.7	+0.0
8. I wish I had more respect for myself	2.5	2.5	+0.0
9. I tend to think I'm a failure	2.7	2.9	+0.2
10. I take a positive attitude to myself	2.5	2.9	+0.4

n=11

Outcomes for partner organisations

The Health Champions Service has an influence on a range of informal partners, both directly (for example, if they support an organisation’s practice to improve), and indirectly (for example, if an individual’s health improves and health services do not need to commit as much resource to that individual). Partners include local health services (such as GPs or CAMHS), schools and other education organisations (such as those supporting children with special educational needs), and voluntary organisations supporting families affected by autism and/or ADHD (such as Autism West Midlands). The data in this section draws on the qualitative research with partners and other stakeholders, and the literature review.

As with outcomes for families, children and Champions, the extent to which the outcomes are achieved varies a little between the different locations: the partners themselves are different, the quality of their practice varies, and other external conditions (such as the local geography) are different. However, there are several outcomes that are common to all three locations.

The work of the Health Champions service often leads to a **greater understanding of ASD and ADHD among local services**, particularly among schools. This understanding might be about the conditions themselves, the support that is available, and how they can better support families affected.

This greater understanding also contributes to **improved partnership working with other support agencies and families with ASD and/or ADHD needs** as organisations often work better together, or at least can refer families on more effectively. For some partner organisations, the Health Champions service has given them a specialist support service to refer to which was previously lacking. Some partners are also able to use Health Champions events (particularly the coffee mornings) as an opportunity to speak to parents and to network with other professionals.

In some instances, **school practice improves** around ASD and ADHD; this can arise because the Service Coordinator works with them directly, and because families are more assertive about their child’s needs and

⁶⁴ Source: Family Action data

rights. The service can also help by **bridging the gap in service offering** for families with ASD and ADHD, providing support that in some instances is not available at all elsewhere.

“It’s enhancing what we deliver: it follows a similar framework to school groups, but is a halfway house between the community and professionals. The training and support for volunteers is better. It’s filling a niche.” [Partner]

The work of the Health Champions Service may lead to **resource savings for public services such as GPs or CAMHS**. This may happen because the health of children or parents improves, meaning they need less support from the NHS. The strengthening of the family also may make it less likely that they will reach crisis and need intervention from social care. It may also happen because families no longer book appointments with NHS or other services when looking for support, as they get this from the service instead. However, the work of the Champions may lead to more support being provided by schools or by health services. There isn’t clear evidence that the Health Champions service creates resource savings overall for other services.

“Families would get lost in the system without this service and things likely would feel worse, yet we all need to look after the parents’ wellbeing, if their welfare drops, the impact is very real on children and needing more social support/social services/safeguarding – it’s more and more difficult because these families don’t fit the narrowing criteria for support, across a lot of statutory services.” [Partner]

“Health care is fundamentally benefitting from this. Social services or social care potentially benefit also further down the line. This new pathway prevents escalation to a variety of specialist statutory services, and prevents escalation to referral and getting a diagnosis or not – the question is what’s the knock-on effect – and we’re so early in this.” [Partner]

Conclusions

The Family Action Health Champions Service offers a creative and effective response to the needs of families affected by ASD and/or ADHD. The service model works well, the service has been delivered effectively in Peterborough, Sandwell and Swaffham, and the outcomes are significant.

The service is underpinned by the caring, non-judgemental approach of the Service Coordinators and Champions, high quality training, and the creation of a space where parents and carers feel able to share their problems without fear of judgement. Challenges remain, especially around communication and vulnerability to change, but the services have grown, strengthened, and addressed many of the issues they were facing.

The Health Champions' service's biggest impact is on parents and carers of children with ASD and ADHD. Many of these parents and carers had very little other support. Many felt isolated and alone before accessing the service, feeling judged by others and at a loss about how to support their child. While parents and carers still face significant challenges, the service helps them feel listened to and understood, helps them understand their child's condition, and provides them with tools and strategies to manage the emotions and behaviour of their children. It also gives parents and carers confidence in speaking up for their child, and helps them access further support from schools and other services.

Health Champions also benefit from the service. Many Champions are parents of children with ASD and/or ADHD themselves, and they too get support and advice for their children. Champions receive high-quality training, gain useful skills, and some have gone on to employment. Delivering training courses such as Webster Stratton and the Positive Behaviour Support courses have given Champions skills beyond those which they might get from other volunteering opportunities. The Health Champions Service also offers more variety in terms of the tasks that Champions can become involved in than other services might.

The Health Champions service is delivering above and beyond the original vision for the service. For example, the parental behaviour courses were not originally part of the model, but the service adapted and worked in partnership to deliver the course, leading to significant benefits to both parents/carers and Champions. The Service Coordinators have acted as powerful advocates for families, supporting them in their relationships with schools and other services.

It has been a privilege to spend time with the Health Champions team, and meet and speak to Champions, families, and partners. Staff and volunteers have invested significant time, energy and enthusiasm into the service, and provided an invaluable service to families in very difficult circumstances.