

Family Action *Health Champions Service*: Evaluation Report Executive Summary, May 2018

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.

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

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.
- **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.

Challenges facing the service

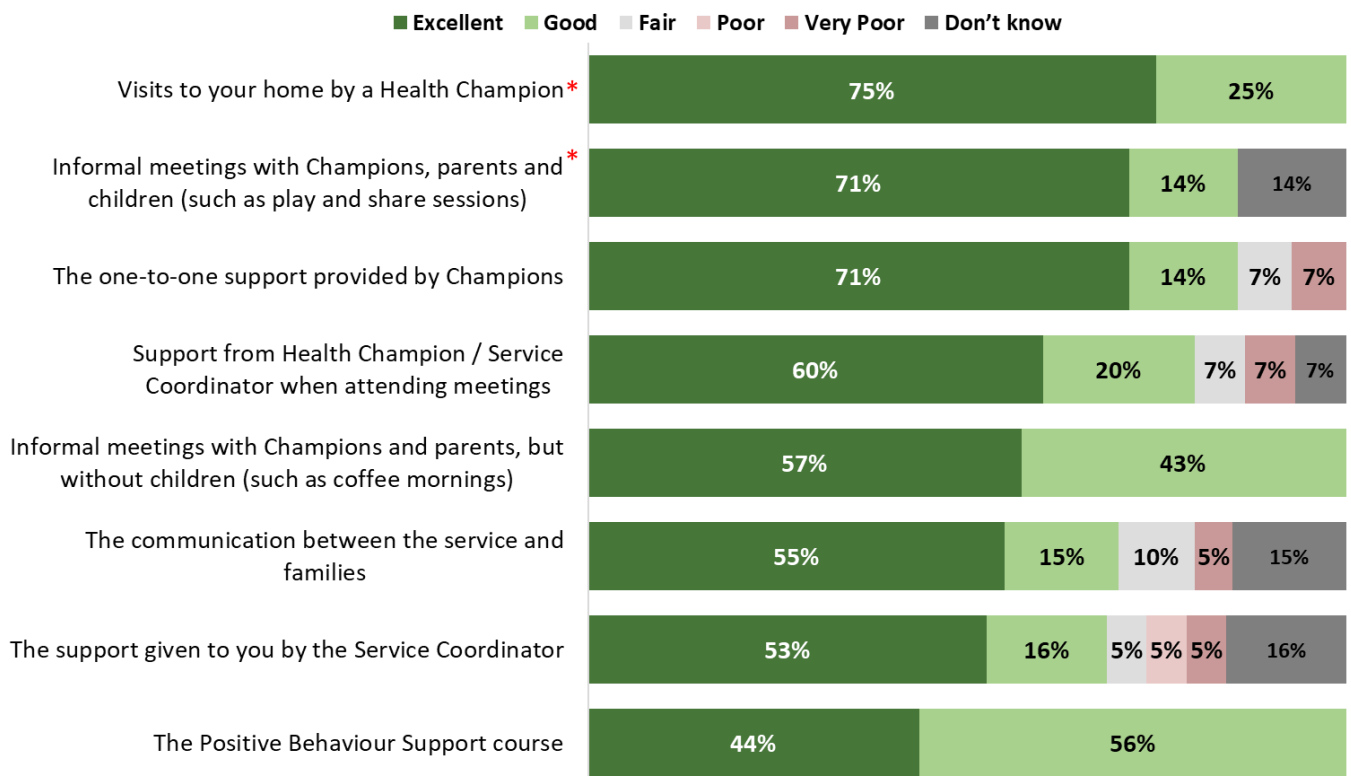
The evaluation also highlighted a number of challenges facing the service. The report discusses both those challenges which had been addressed by the time the evaluation commenced (or during the evaluation), and those that are still ongoing. This is so that the report can inform future service delivery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

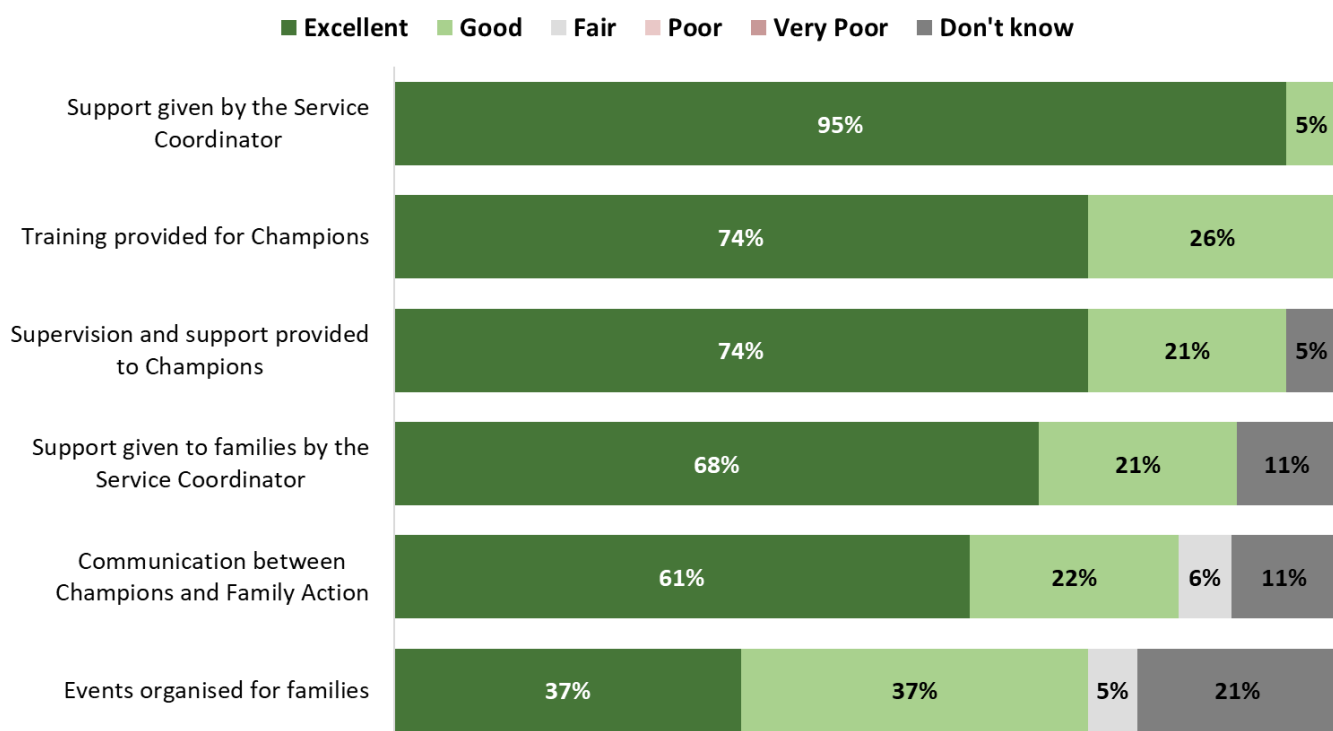
Figure 1: Parents' views on the effectiveness of different aspects of the service²



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

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% |

³ Source: Health Champions' survey

⁴ Source: Parents' survey, n=39

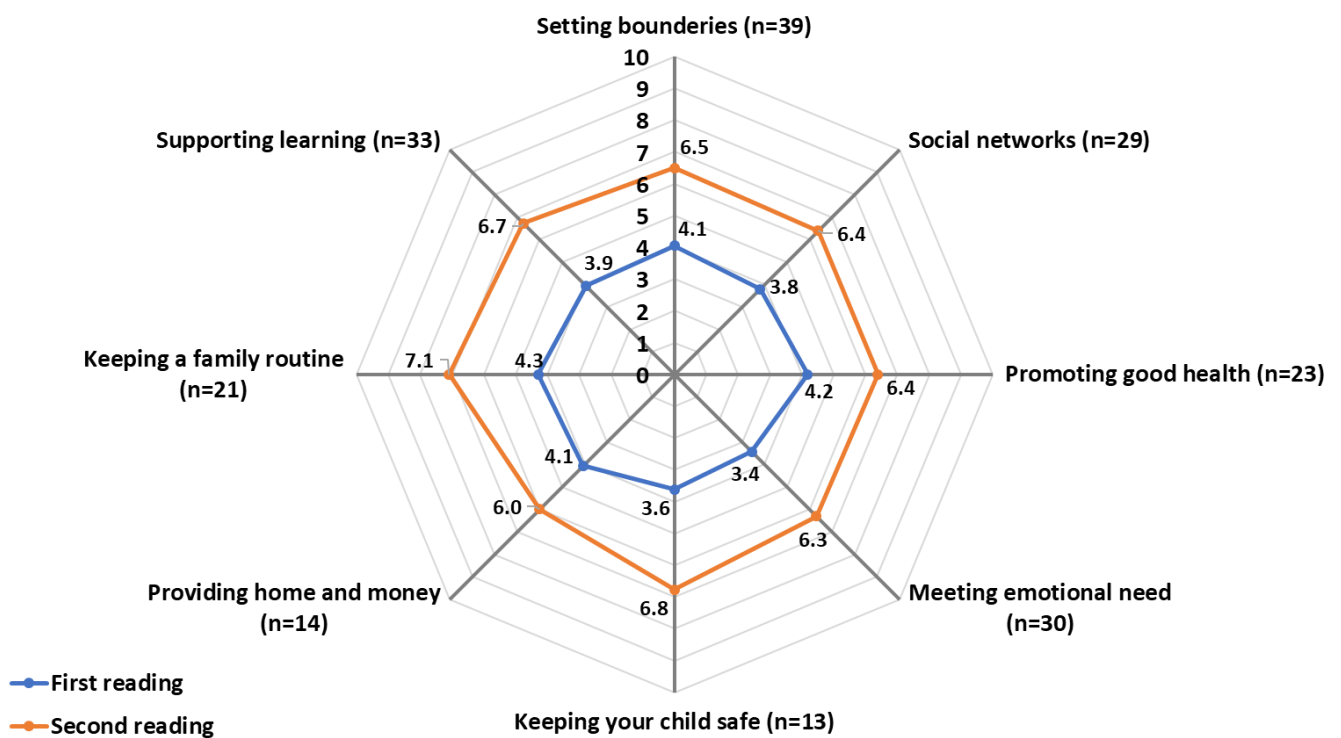
“It’s a million times better than it was.” [Parent]

“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’.

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.

⁵ Family Action uses the Family Star developed by Triangle Consulting to support parents and families to plan and measure benefits to be achieved. Details of how the Family Star scores are calculated can be found in the main report.

⁶ Source: Family Action data

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% |

“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]

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 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]

⁷ Source: Parents’ survey, n=25-28

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.

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.

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.