

Executive Summary

1.0 Introduction

NHS Newcastle Gateshead Clinical Commissioning Group (CCG) and Newcastle City Council are undertaking a review of infant emotional health services currently being provided by Sure Start, Health Visiting and Northumberland, Tyne and Wear NHS Foundation Trust (NTW).

Infant emotional health generally relates to the first three years of a child's life which are critical for the child in the long term. The baby's relationship with their mother or care giver(s) has a significant impact on the baby's social and emotional development. The care giver's ability to provide a nurturing relationship is also partly dependent on their own emotional wellbeing. When parents have issues with this stage, they can often struggle to form a bond with their child which can lead to further emotional, psychological or behavioural issues in childhood. For parents who find it difficult in the early stage of their child's development, there are a range of services to support the wellbeing of the parents and their child. In Newcastle there are three main services, for a detailed description of the services, see Section 1.

The project sought to engage with parents of children under five years old that have accessed infant emotional health services for the child/children within the last 12 months.

Although, in general, infant emotional health relates to the first three years of a child's life, from discussions with service providers, the age was extended to include children up to five years old. Discussions with service providers highlighted that some parents only access infant emotional health services when their child is four years old and they begin to realise their child may have problems when starting school. The extension to five years old allowed us to capture those experiences and to explore whether, in such situations, earlier access to infant emotional health services would have been better.

2.0 The project

The overall aim of this project was to understand parents' experience of the current infant emotional health services to identify gaps in current provision and what further support or services would be useful for parents.

The key objectives of the project can be seen below along with a summary of how the research has responded to each objective:

- Explore parents' experience of current infant emotional health services

Overall, parents' experience of current services was overwhelmingly positive except those from the D/deaf community where issues regarding communication were apparent. On the whole, parents felt that Sure Start, Health Visiting and NTW services were supportive and few issues were identified.

- Explore parents' experience about early access to the services

The majority of parents felt they had accessed infant emotional health services at the correct time. A small number of parents felt they would have liked the support sooner which shows the need for early identification, however, some parents recognised they had not recognised their own need for support.

- Explore parents' outcomes from using the services

Almost all parents felt the services had worked for them, reporting outcomes such as improved behaviour and increased confidence. As well as this, the wider support for housing, debt and other issues also showed positive outcomes from the support given to parents.

- Identify gaps in current service provision

The main gap in service provision was the lack of support for D/deaf parents. There was a range of issues, including poor information and communication as well as a lack of interpreting services, all of which prevent parents from being fully supported. In addition, parents from the NTW services had waited a number of months before receiving the support.

- Identify additional services or support parents would like

Parents provided a wide range of suggestions of further support including more signposting to other organisations, greater access to information, more support for older parents, more sensory activities and family team building. A full list of parents' suggestions can be found on page VII.

- Explore parents preferences around access to the services

Almost all parents were happy with the current access to services in terms of their location, timings and frequency of appointments. Parents felt that the flexibility of services was essential but that all services could already provide that.

Via telephone interviews or online questionnaires 60 parents gave their views:

- 41 parents had accessed Sure Start services
- 22 parents had accessed Health Visiting services
- 4 parents had accessed NTW services

Please note some parents had accessed both services. For a full participant profile, see Appendix 2.

Involve North East interviewed 47 people and HAREF interviewed 5 black and minority ethnic parents and a summary of these findings of these interviews will be as follows:

- 3.0 Findings – Sure Start
- 4.0 Findings – Health Visiting

- 5.0 Findings – NTW
- 6.0 Findings – Further support

In Newcastle in 2010, 88% of the population was white British and 12% comprised other ethnic groups (Newcastle City Council). In this research, HAREF interviewed 5 parents from black and minority ethnic communities which, overall, is 8% of the total participants.

Deaflink spoke to 8 people and a summary of these findings will be as follows:

- 7.0 Findings – Deaflink

The findings from Deaflink are detailed in a separate section as the Deaflink report was presented in a different format. The data collected from Deaflink compared participants who had used the Newcastle based services as well as services from other parts of the North East, therefore the findings could not be consistently amalgamated.

In the Project Initiation Document five risks were outlined and, at various stages in the project, four of those risks were realised which impacted on the number of participants recruited. Issues included services unable to collect consent from enough parents; parents changing their mind about taking part in the research and information governance issues which delayed recruitment.

3.0 Findings – Sure Start

This section provides a summary of the findings of Involve North East's and HAREF's research with 37 parents who accessed specialised Sure Start services.

3.1 Sure Start services access and information

Of the 37 parents who had accessed Sure Start services, 16 (43.2%) had one-to-one family support, 11 (29.7%) had specifically accessed Incredible Years and ten (27.1%) had attended various Sure Start course including Whoops Baby Course.

All 37 parents were asked how it came about that they were put in touch with Sure Start's specialised services. The majority were referred to the targeted services by a health or social care professional after they identified the parent was struggling with aspects of parenthood. For most parents, they were struggling with their child's behaviour and were unable to discipline their child effectively. This caused many parents to feel they were not in control and lose their confidence. For a smaller number of parents, they were specifically struggling with their or their child's additional needs and required further support.

More specifically, the majority of parents (15, 40.5%) were put in touch with the specialised groups and services via a Sure Start worker. Of the remaining parents, they accessed the support through their friends and family (6, 16.2%); their CAF worker (6, 16.2%); their social worker (3, 8.1%); their Health Visitor (5, 13.5%); or their consultant (2, 5.4%). For some parents it had been recognised the parent was having specific difficulties around behaviour or their own family situation which led to them accessing support (7, 18.9%).

Almost two thirds of parents (24, 64.9%) felt it was the right time to access the support. The remaining parents (13, 35.1%) felt they would have liked the support sooner, of which two parents said that they did recognise their own need for support and one parent said that they did not know there were support services available. A further six parents said that a health professional did not recognise their need for further support including two Health Visitors, two Sure Start workers, one physiotherapist and one consultant. The issue of parents stating they would have liked support sooner and that those health professionals did not recognise their need for support shows the need for service improvement to recognise that early access to support is vital.

All parents said they received information about the services with just under half of parents (45.9%) stating they received an explanation by a Sure Start worker. The remaining parents were given leaflets (10, 27.0%), information packs (4, 10.8%) or an explanation via a home visit (8, 21.6%), the majority of whom attended Incredible Years. Other parents received explanations by their Health Visitor, CAF worker or by a health professional over the phone. The vast majority of parents (32, 86.5%) felt they received enough information and all parents felt their communication needs were met. In particular, two of five parents from black and minority ethnic communities said their experience was particularly good with Sure Start and Incredible Years. For the small number of parents (4, 10.8%) who did feel they needed more information, they provided some suggestions that services could consider taking into account to further improve the information given to parents.

Three quarters of parents (28, 75.5%) did not know of any other services that could help them other than the Sure Start services they were attending which signals the needs for greater promotion of services to staff and parents. One quarter of parents (9, 24.3%) suggested other services they knew of including a freedom programme for domestic violence, Barnardo's, Health Visiting services and, for those specifically attending Incredible Years, they were aware of Sure Start support.

The majority of parents (30, 81%) found the support easy to access and those that found it more difficult to access were from Incredible Years and did not like the location.

Most parents would prefer the support to fit flexibly around their other commitments, of which the majority of parents reported that service currently is flexible. Parents also said they would prefer the support to fit around their work or college, or to be able to access groups and courses when their child is in school or nursery.

3.2 Sure Start experiences

All parents detailed a wide range of benefits that they felt the service had provided for them, including:

- One to one support
- The ability to speak with a worker whenever they felt they needed to
- Extra support relating to wider issues such as housing or debt
- The constant and continuous nature of the support
- Supportive workers and course leaders
- Being able to share experiences with other parents

- Having access to a group of parents that are able to support them
- Learning tools and techniques to cope with their child's behaviour
- Giving them confidence they are a good parent
- Confidence to be able to deal with their child's behaviour
- Improving their parenting skills
- Enabling parents to make friends, socialise and have someone to talk to
- Access to personalised support

Over two thirds of parents (25, 67.6%) accessed the support within two weeks. Those parents who waited longer recognised that it was because specific courses and groups were not available in school holidays. Almost all parents (34, 91.9%) were happy with the length of time they waited to access the support, but a small number (3, 8.1%) were not happy and would have liked the support to be available during holidays which could be something services consider.

All parents provided a range of responses as to what works well about the Sure Start services with just under half of parents (16, 43.2%) citing the constant support from workers as invaluable. Just under one third of parents (12, 32.4%) said the support had given them confidence as parents; one quarter of parents (9, 24.3%) had been able to see a noticeable change because of the support they had received; just over two fifths (8, 21.6%) said they were offered personalised solutions. Other responses detailing what works well about the support included supportive workers, good course material, being able to learn new skills and behavioural techniques, sharing experiences, reducing isolation, extra support around wider issues and a supportive environment.

Over two thirds (25, 67.6%) said they could not think of anything that did not work well about the support they received. The remaining parents (12, 32.4%) stated reasons including the referral process could be improved, the course was too short or the location of the course was difficult to access.

Just under two thirds of parents (23, 62.2%) felt there was nothing that would make the experience better. The remaining parents (14, 37.8%) had a range of suggestions as to ways their experience could be improved including, more access to and time with the services, more follow up and on-to-one support away from the main groups and courses, smaller class sizes and signposting to other services.

4.0 Findings – Health Visiting

This section provides a summary of the findings of Involve North East's and HAREF's research with 14 parents who accessed non-universal Health Visiting services.

4.1 Health Visiting access and information

Of the 14 parents who had accessed Health Visiting services, the majority of parents were referred automatically as part of the standard service but, upon realising there was an issue, the Health Visitor provided more support for issues the parent was struggling with. For the majority of parents, they were struggling with their child's behaviour or struggling more generally with the pressures of being a parent.

Most parents were referred automatically or received an early visit by the Health Visitor before their baby was born. Almost all parents (13, 92.9%) felt they had accessed the services at the right time and one (7.1%) parent felt they would have liked the support earlier but recognised she did not identify that she needed help.

Just under two thirds of parents (9, 64.3%) were given an explanation of the service by their Health Visitor during their first contact and half (7, 50.0%) were given a leaflet or information pack. All 14 parents felt the information they received was enough and also felt their communication needs had been met.

Half of parents (7, 50.0%) were not aware of any other services that could support them apart from the Health Visiting service which signals the needs for greater promotion of services to staff and parents. The remaining parents all identified Sure Start as a service they could access for support with one parent specifically identifying Incredible Years.

All 14 parents said the frequency of the Health Visiting appointments would depend on the situation. For most parents, the visits were arranged monthly unless more frequent appointments were required, however, all parents said they could request to see their Health Visitor more often or in between visits if they felt they needed the support. All parents valued the flexibility of this approach.

Most parents would prefer the support to fit flexibly around their other commitments, their work or college and all parents said they were happy with the length of their appointments.

4.2 Health Visiting experiences

All parents detailed a wide range of benefits that they felt the service had provided for them, including:

- The value of the Health Visitor being there as support whenever needed
- Treating them as an individual
- Being there to support them as a parent as well as support their child
- One to one support
- Extra support relating to wider issues such as housing or debt
- Parents found home visits particularly helpful
- Learning tools and techniques to cope with their child and their behaviour
- The whole family approach
- Referrals to other services that could provide further support
- Support regarding mental health issues
- The non-judgemental nature of the service

The majority of parents (10, 71.4%) said they could not think of anything that did not work well about the Health Visiting service. The remaining parents (4, 28.6%) suggested issues including the need for more support about bathing your child, more information about specific health conditions and the need for consistency in seeing the same Health Visitor.

Again, the majority (10, 71.4%) said that nothing would have made the experience

of Health Visiting better for them. The remaining parents (4, 28.6%) suggested the need for more support about issues that may have been covered during pregnancy or in hospital after the birth and the need for consistency in seeing the same Health Visitor.

5.0 Findings – NTW

Four parents took part in the research due to the difficulty in gaining consent from parents who had accessed the service. Although a small number, the findings can still be used to understand patient experience and the findings do indicate that some parents are waiting too long for an appointment.

There is a need to acknowledge that there are criticisms given by parents about not receiving the appropriate support in a timely way. Therefore, consideration is required around how to explore these comments further to understand how reflective they are of the service.

5.1 NTW access and information

All four parents who had accessed NTW services were referred by their GP because of concerns about their behaviour or development and all parents felt they had accessed the support at the right time. Two parents (50.0%) waited 2-3 months for the referral whilst one parent (25.0%) waited 6-7 months and one parent (25.0%) waited nine months. Three (75.0%) of four parents were satisfied with the length of time, however, this could point to a need to review referral timings. All four parents found the clinic at Benton House easy to access and were happy with their appointments times.

Two parents (50.0%) said they received information about the service and did not require anything else. Two parents (50.0%) did not receive information and would have liked to have known more about the service prior to attending suggesting the need for more information to be given to parents at an early stage in the referral process. All four parents felt their communication needs were met.

Three parents (75.0%) were unaware of any other services in Newcastle that could support them and their child suggesting the need for more signposting to further support.

5.2 NTW experiences

Three parents (75.0%) felt they had received support that was useful for them and their child, including a diagnosis of a condition, guidance about ADHD and information regarding support groups. One parent (25.0%) did not feel they had received any support from the service. They felt the service asked questions but did not feel they were doing anything.

Three parents (75.0%) felt the services worked well to ensure their child was diagnosed and received treatment as well as helping the parents to cope. Of the three parents (75.0%), two (50.0%) felt nothing could improve the process and one parent (25.0%) felt the waiting times for referrals could be improved.

6.0 Findings – further support

This section provides a summary of the findings of Involve North East's and HAREF's research with all 52 parents who accessed Sure Start, Health Visiting and NTW services and details the findings around the further support parents would like.

Twenty (38.5%) parents suggested other services that may help parents and parents suggested issues that parents may struggle with, where further support could help. These included:

- More signposting to organisations for support specifically for children with additional needs
- Greater access to the information about support services already in existence
- More information about services provided by child psychologists
- Support to deal with the future as the child gets older
- More promotion of the support services available to parents
- More information given to parents when they are pregnant including the services available after their baby is born
- More support and guidance for parents and their own behaviour and situation
- Support for parents to develop their self-confidence
- More support for older parents
- More support for fathers
- Have support that is peer led
- Coffee mornings where parents and children can socialise, with health and social care professionals available to answer questions
- More sensory activities
- Support for behavioural issues and discipline
- Family team building
- Relationship or marriage counselling
- Support around a child's diet and how to eat healthily
- Budgeting support
- Support for mental health issues
- Support for children before their official diagnosis

7.0 Findings – Deaflink

This section provides a summary of the findings of Deaflink's research with 8 parents who accessed specialised Sure Start and Health Visiting services.

Whilst there was not a large number of replies due to the small number of Deaf people giving birth in the area in the last year, there are some common themes. The experience of Deaf people outside of Newcastle allowed a good comparison of experiences.

One of the most significant findings is the lack of any communication support for Newcastle residents from either Health Visitors or Sure Start. The 2 Deaf Newcastle based parents noted communication barriers in response to several questions and described having to persistently request interpreters.

The one Deaf parent from outside of Newcastle had a different experience, including much longer appointments, access to interpreters and more clarity in their understanding and knowledge of what was happening. It is hard to draw conclusions based upon the small numbers of people participating in this study. It is safe to assume, however, that if someone receives information in a format that they can understand they will be clearer on the process.

The lack of interpreters left the Deaf parents feeling unsupported, and the standard length of appointments left them feeling as if they did not have enough time given to them.

All parents commented that no Health Visitors or Sure Start staff could sign and only one parent had access to an interpreter. One parent commented that this isolated them from the conversation as their partner found it hard to sign and talk at the same time. Others commented that they had no way of communicating effectively with their Health Visitor.

Hearing people also had mixed responses with many asking for more support or more time.

The Deaflink findings also show the lack of knowledge about services available to support new parents. Particular concern was around the lack of understanding and confusion about the services provided by Health Visitors and Sure Start.

8.0 Recommendations

It must be recognised that the vast majority of responses from parents within this research were overwhelmingly positive about Sure Start, Health Visiting and NTW services. The following recommendations are based on issues and suggestions raised by a small amount of parents, however, changes or improvements could still be made.

All recommendations should be considered within the context of the service stated, particularly during times of service reorganisation. Improvements and changes should be considered, but it is recognised that this needs to be within the parameters of the resources available.

8.1 Sure Start

8.1.1 Information

It is recommended that:

- Sure Start provides more written information to parents which outlines the support available and what that entails
- Incredible Years could provide an outline of the curriculum and provide an opportunity for parents to speak with a worker if necessary
- Sure Start liaises with the Health Visiting service to ensure staff are fully aware of the service and support available to parents

8.1.2 Accessing courses

It is recommended that:

- Sure Start provides support to parents throughout the year, including during school holidays
- Sure Start explore the need for courses to run during school holidays and, if this is not viable, alternative support is put in place ensuring parents do not wait to access additional support

8.1.3 Referral process and early access to support

It is recommended that:

- The extra support services offered by Sure Start are promoted to a range of health professionals to inform them of the service, how to refer parents to the service and the criteria for referrals
- Health professionals involved in the referral of parents to Sure Start services are able to recognise parents who require further support to ensure they receive the support early and do not reach breaking point

8.1.4 Signposting

It is recommended that:

- Sure Start services ensure workers are able to signpost to a variety of organisations that are able to provide further support to parents and encourage all staff to be aware of the support available

8.1.5 Location

It is recommended that:

- The locations are considered for Incredible Years to ensure they are the most appropriate for the service and ensuring parents are able to access the course location is vital during discussions with the parent about attendance

8.2 Health Visiting

8.2.1 Information

It is recommended that:

- Health Visiting provide more information about issues that parents many face and, where appropriate, be able to signpost to other sources of information about specific illnesses

8.2.2 Signposting

It is recommended that:

- Health Visiting services ensure workers are able to signpost to a variety of organisations that are able to provide further support to parents
- Health Visitors are aware of the support available and are able to provide detailed information to parents about other services
- Existing online information resources, such as the Families Information Service, are promoted to all staff and, in turn, all parents to ensure parents can access information at all times

8.3 NTW

8.3.1 Referral process

It is recommended that:

- NTW consider the referral process for the Children and Young People's Service to ensure parents and children can be seen in a more appropriate time frame, given the important stage of infant development

8.3.2 Information

It is recommended that:

- NTW services provide information to all parents referred to the service explaining what the service is, what they do and how they can support the parent and child
- NTW services provide information for parents about what they can expect from the service to manage expectations and ensure parents are clear about the support
- NTW work with the parents to ensure they understand the support, what the process is and how it can help them and their child

8.3.3 Signposting

It is recommended that:

- NTW services ensure workers are able to signpost to a variety of organisations that are able to provide further support to parents
- Existing online information resources, such as the Families Information Service, are promoted to all staff and, in turn, all parents to ensure parents can access information at all times

8.3.4 Patient engagement

It is recommended that:

- NTW consider how their approach to patient involvement could be improved to allow engagement with their service users to gather patient experience data

8.4 Further support

It is recommended that:

- The services included in this research consider the above suggestions made by parents to potentially provide further support for parents or to signpost to relevant organisations
- If the services included in this research already provide some of the above suggestions, greater promotion to parents should be considered

8.5 Recommendations from Deaflink to all services

8.5.1 Communication needs and interpreter access

It is recommended that:

- Every visit or contact with a British Sign Language (BSL) user must be done with an interpreter present (preferably one that they chose)
- The communication needs of all clients are clearly identified and met
- Each appointment with a D/deaf person should be extended to allow enough time for an appropriate communication process
- Consideration is given to the early adoption of the NHS England Accessible Information Standards

8.5.2 Information

It is recommended that:

- A review of all literature is undertaken with specific reference to BSL accessibility
- Consideration is given to producing of BSL accessible signed information about services and general issues or topics

8.5.3 Delivering services

It is recommended that:

- A full review is undertaken of D/deaf service users, including a review of services offered and how D/deaf people can access them, to inform future service delivery
- Deaf Awareness training is given to all staff and volunteers

8.5.4 Courses

It is recommended that:

- A review is undertaken of the courses offered in terms of accessibility to D/deaf parents to include how many D/deaf parents have attended courses, whether interpreters been provided, and how the offer of interpreters has been communicated

8.5.5 Support

It is recommended that:

- Services explore the possibility of setting up D/deaf parent support groups at a regional level

