

Parents' experiences of Infant Emotional Health Services

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Involve North East

Hawthorn Terrace
Newcastle upon Tyne
NE4 6RH
Tel: 0191 226 3450
www.involvene.org.uk

Deaflink

Key House
11 Tankerville Place
Jesmond
Newcastle upon Tyne
NE2 3AT
Tel: 0191 281 2314
www.deaflink.org.uk

Health and Race Equality Forum

Carnegie Building
Atkinson Road
Benwell
Newcastle upon Tyne
NE4 8XS
Tel: 0191 226 1221
www.haref.org.uk

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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

Section 1: Introduction

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).

1.1 NHS Newcastle Involvement Forum

1.1.1 Involve North East

Involve North East is an independent charity working across Newcastle and the North East. We are experts in innovative and practical involvement, working with patients, communities and harder to reach groups to gain the insight needed to design the best, most responsive and cost-effective health and social care services.

1.1.2 Health and Race Equality Forum (HAREF)

HAREF is a network focused on reducing inequalities. The network keeps the voices of people across black and minority ethnic communities heard in settings where decisions are made about health service developments. Positive relationships, consistency and quality are at the heart of the work of the Health and Race Equality Forum.

1.1.3 Deaflink

Deaflink is an open, inclusive and supportive organisation working to empower and improve the quality of life of D/deaf, hard-of-hearing and deafblind people in Newcastle. We aim to improve access to employment, education, health, leisure and social opportunities and to raise awareness of the needs of these excluded groups to organisations and agencies through training, support and advocacy.

1.2 Context

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 at 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.

As part of Big Lottery Fund's 'A Better Start' investment programme which aims to improve the life chances of babies and children, research was carried out by The Social Research Unit at Dartington in 2011/12 to provide evidence of the need for such a programme in Newcastle. The table below shows the prevalence of poor social and emotional development in Newcastle with one quarter of children having poor development in this area. The research also focused on the target wards of

Benwell and Scotswood, Byker, Elswick and Walker which showed the prevalence in these areas was higher than the average for Newcastle.

Prevalence of children not meeting Key Developmental Outcome

	Newcastle	Target Wards
Poor social and emotional development	25.6%	34.1%
*Good level of development (EYFS)	60.6%	n/a

Source of data: Area Wellbeing Survey (0-8): Ages and Stages Questionnaire (SE.) six months – five years.

*Early Years Foundation Stage (EYFS) is a teacher assessment of children’s development at age 5 across communication, physical development, social and emotional development, literacy, maths, expressive arts, designing and making.

The above table shows that one quarter of children within Newcastle have a poor social and emotional development whilst approximately 40% do not have a good level of development as designed by the EYFS.

1.2.1 Definitions

The Common Assessment Framework (CAF) was introduced by the Government Green Paper ‘Every Child Matters’ (2004) and is described as:

“an easy-to-use assessment of all the child’s individual, family and community needs, which can be built up over time and, with consent, shared between practitioners.”

In Newcastle, the tool can be used by a wide range of practitioners such as a Health Visitors or Sure Start worker and is particularly relevant to this research with parents who require additional support. The aim is to identify problems that the parent or child may be having either through a home visit or simply through attending an open group where the nursery nurse recognises that the family might need additional support.

The family is closely involved in the CAF process which includes an assessment by a range of practitioners and the development of a delivery plan. Once the CAF is complete, a team of support for the family is put together, usually consisting of a Health Visitor, a Sure Start worker and the parent(s). The CAF would also be given to the weekly Supporting Families panel consisting of a wider range of professionals who would suggest and offer resources to the team working directly with the family. This could include Sure Start groups and wider services, for example, for a mother with post natal depression, they may be referred to Tyneside Women’s Health for support. The Supporting Families panel and the team working directly with the family aim to create a personalised package of support for each individual.

Families that require extra support must consent to being part of the CAF process from which a CAF action plan is developed so the family are aware of the extra support available to them and what is involved. The support is usually short term and focused to allow for early and brief interventions to resolve issues as soon as

possible. Discussions between the team and the family will help families to ensure that issues are resolved and, with the consent of the parents, the CAF would be closed.

1.2.2 Infant Emotional Health Support

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:

1) Sure Start Children's Centres

Sure Start Children's Centres offers a wide range of services for children under five years old and their families. The goal of Sure Start is to try to contact every family with a new baby to engage them in the Sure Start services and make them aware of the groups available to access. Sure Start provide a whole host of services for all parents to access including Baby Massage, Baby Social, Sing and Sign Course, Toddle Time, Stay and Play Sessions and many more.

Within Sure Start's remit, they provide more specialised support for parents identified with specific issues to support infant emotional health. The parent and child can be referred for extra support through a number of routes with one of the main tools to identifying parents being the CAF. As part of the CAF, Sure Start groups and courses could be part of the action plan and Sure Start resources could also be suggested by the Supporting Families panel.

For families that require additional support, Sure Start offer a range of courses that parents can attend as well as providing family support with one-to-one home visits, help with play and the Early Education Additional Support Team for children who have special educational needs.

In addition, Incredible Years is another service for parents who need extra support. It is delivered by Newcastle City Council in conjunction with Sure Start and it is a 14 week, evidence-based programme which runs for two hours each week. It focuses on play, praise, effective limit setting, using ignoring strategies and using time out.

Due to cuts in funding, provision of Sure Start services has now been reduced to cover areas within the top 30% of the Index of Multiple Deprivation.

2) Health visitors

Health visitors, provided by Newcastle upon Tyne Hospitals NHS Foundation Trust (NUTH), deliver the Healthy Child Programme working with families to support children's development and to signpost and provide additional support when it is needed. Health visitors provide a professional public health service based on evidence of what works for individuals, families, groups and communities; enhancing health and reducing health inequalities through a proactive, universal service for all pre-school children and for vulnerable populations targeted according to need.

Most health visitors work with parents who have new babies, offering support and informed advice from the ante-natal period until the child starts school. Health

visitors visit parents at home and invite them to join groups, clinics and networks run by the health visitors or colleagues who work with them, such as nursery nurses or community mothers. Health visitors use the widely recognised Solihull approach. It promotes emotional health and wellbeing in children and families and the model supports practitioners and parents to understand their child. It gives professionals a framework for thinking about and working with the relationship between the parent and child and it is a recognised early/brief intervention approach for use with families experiencing mild-moderate difficulties, for example, with behaviour, sleep, feeding and toileting.

All new parents are entitled to a health visiting service (called the universal 'family offer'), regardless of their situation and number of children, but a more intensive service is provided to families who need more support. However, families from all walks of life may need support for specific issues that affect their children's health and development. Therefore, the actual services provided to each particular family will vary according to a personalised assessment of their own needs and evidence of what will work for them.

Families that need extra support are supported by the health visiting team and may also be referred on to other agencies. Health visitors are also trained to support women experiencing mild to moderate post natal depression by providing a low intensity psychological intervention. They also provide universal screening/case finding for all women.

3) Northumberland, Tyne and Wear NHS Foundation Trust (NTW)

NTW are one of the largest mental health and disability Trusts in England and provide Urgent Care Services, Planned Care Services and Specialist Services. Planned Care Services include community based specialist mental health assessment, care, rehabilitation and treatment for adults, older people and people with learning disabilities. Urgent care services include Adult Mental Health/Stepped Care Services and Older People's and Learning Disabilities Inpatient Services whilst specialist services focus on Specialist Adult Services and Children and Young People's Services.

NTW Children and Young Peoples Service offers assessment and interventions for under 5 year olds and their parents or carers when the family requires a specialist mental health provision. The referral into NTW services is usually made by the GP or health visitor or by the social worker if the child is Looked After by the Local Authority.

A team of clinicians specialising in 'Under Fives' review the referrals. In cases where there is not enough information, or the clinicians are unsure whether NTW is the most appropriate service, the referrer is contacted by one of the team to gain more information and possibly signpost to other services.

Where the referral is appropriate the parent and/or their health visitor/other professional may be invited to a consultation meeting. This is an opportunity for the parent or carer and/or relevant professionals such as health visitor, speech and language therapist or social worker to discuss the concerns about the child with an NTW clinician and plan a course of action. Alternatively the parent or carer may be

invited to bring their child to the first appointment. Further sessions may be offered at this point. On average the length of intervention is five sessions.

The members of the 'Under Five' group all work into Clinical Networks, each which deal with emotional and enduring disorders in children under 5 such as Attention Deficit Hyperactivity Disorder (ADHD), autism and learning disabilities. If there is a clear indication of, for example, a learning disability, the clinical representative from that network will get involved from this early stage. If a particular need or presentation emerges during the early sessions the case will be discussed with the relevant clinical network and if appropriate a referral will be made to another clinician with a particular specialism. Each clinical network carry out their own assessment and/or treatment process depending on the condition.

NTW services are delivered during the day from Benton House with parents/carers and children attending the clinic. In some cases it may be more appropriate for the clinicians to liaise with health visitors and nursery teachers to carry out observations elsewhere.

1.3 The project

1.3.1 Aim

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.

1.3.2 Objectives

The key objectives of the project were to:

- Explore parents' experience of current infant emotional health services
- Explore parents' experience about early access to the services
- Explore parents' outcomes from using the services
- Identify gaps in current service provision
- Identify additional services or support parents would like
- Explore parents preferences around access to the services

Section 2: Methodology

2.0 Methodology

In order to meet the objectives of the project, a number of distinct and complementary qualitative techniques were used. A qualitative methodological approach was deemed to be the most appropriate as it is concerned with gaining a depth of understanding of how people feel, their beliefs, reasoning and motivations and therefore fitted with the objectives of the project.

2.1 One-to-one interviews

Involve North East and HAREF carried out one-to-one interviews that took place with patients either by telephone or face-to-face. Interviews allowed us to explore issues arising from the questions we ask, and to prompt interviewees to elicit richer and more detailed responses.

2.2 Self-administered questionnaires

Deaflink invited feedback through an online questionnaire which was accessible to those who are D/deaf and others with sensory issues such as deafblind, Hard of Hearing and visual impairments. The questions were the same as those used in the interviews to enable consistent data collection and analysis.

See Appendix 1 for questions.

2.3 Participants

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.

In order to recruit and engage participants the three organisations used the following methods:

- Involve North East:
 - Parents within the infant emotional health pathway were recruited by the Health Visitor services, NTW, Sure Start Children's Centres and Incredible Years who identified relevant parents and gained consent

- for Involve North East to contact them to conduct follow up engagement
 - NTW used their members database to try to identify relevant people who expressed an interest in taking part in research
 - Involve North East's and Healthwatch Newcastle's e-news recipients
- HAREF:
 - Involve North East determined numbers of black and minority ethnic parents from service providers and details of those parents were given to HAREF to contact for the follow up engagement
- Deaflink recruited and engaged patients who were D/deaf patients (Deaf with a capital 'D' refers to those who identify with the Deaf community and culture and deaf with a lower case 'd', to those who are deaf and do not identify with the Deaf community) and others with sensory issues such as deafblind, Hard of Hearing and visual impairments via:
 - their contacts and networks
 - an online questionnaire

Overall we engaged with 60 people, of which:

- 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.

NTW were unable to recruit as many parents as other services. A total of 51 letters were sent to parents/carers who had accessed the service and seven replies to take part were received. Upon contacting the parents, Involve North East were unable to speak to three parents. Despite the low numbers of parents taking part from the service, the information received still indicates patient experiences of the service.

2.4 Report structure

Involve North East spoke with 47 people and HAREF spoke to 5 people and the findings of these interviews will be as follows:

- Section 3: Findings – Sure Start
- Section 4: Findings – Health Visiting
- Section 5: Findings – NTW
- Section 6: Finding – Overall (this includes further support and a findings summary)

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 the findings of these interviews will be as follows:

- Section 7: 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.

The recommendations will be detailed in Section 8.

2.4 Limitations

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:

- R001 – “Services unable to collect parents’ consent from enough parents”
All services were unable to recruit the target number of parents and alternative recruitment methods were explored to mitigate this, however, the number of participants was still reduced significantly.
- R002 – “Parents change their mind about taking part in the research after giving consent”
In some cases, after parents gave consent to take part in the research, when Involve North East contacted them, they had changed their mind and did not complete a questionnaire. This reduced the number of participants and this cohort are not included in the final respondent numbers.
- R003 – “One service is overrepresented when contacting parents”
The project aim was to have equal representation from all services, however, NTW were only able to recruit four parents despite trying alternative recruitment methods. Sure Start services were able to recruit more parents than the Health Visiting service. To prevent findings being skewed the analysis of each service will be carried out separately.
- R004 – “Information governance issues at the services would delay recruitment”
The Health Visiting service was required to submit a Caldicott application which delayed recruitment taking place within the service. This reduced the number of participants recruited.

These limitations should be recognised when considering the information contained in the report.

Section 3: Findings - Sure Start

3.0 Findings from 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.

For a participant profile of parents who accessed Sure Start services, see Appendix 3.

3.1 Access to Sure Start

More specifically, of the 37 parents, 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, parents provided a range of responses and could give more than one response. Fifteen (40.5%) parents were told about the services via a Sure Start worker, usually when attending a universal play group.

"I accessed the Early Educational Additional Support Team via a Sure Start worker who put a referral in for me, and from that I have been able to access SALT and Physiotherapy support."

"I was going along to the play groups and one of the workers suggested that the family support would be good for me and referred me in."

Six (16.2%) parents found out about the service from friends or family who had attended the specialised groups and enquired about taking part in the courses and six (16.2%) parents were recommended the service by their CAF worker.

"I was told about Teen Mums by my friends."

"I was told about it from my CAF worker. They mentioned it and I said I would be interested - I wasn't a very experienced mother."

A further five (13.5%) were put in touch with the service because they or their child had additional needs and required further support. Another five (13.5%) parents were told about the services by their Health Visitor. Four (10.8%) parents were struggling

with their child's behaviour and felt the service would be beneficial and three (8.1%) parents were recommended the service by their Social Worker. A further two (5.4%) were referred by a consultant at the RVI and two (5.4%) parents felt that as a family they were struggling and needed help.

"I have an older son with additional needs who is under a paediatrician at the RVI, they suggested that as a family we were struggling and needed some help."

"My daughter has a brain condition and my Health Visitor told Sure Start that I could do with some support."

"The Health Visitor put me in touch with Sure Start, she told me about it straight after my baby was born."

"Social services put us in touch with them. We've had children taken off us before so they put us straight in touch."

One (2.7%) parent was in an abusive relationship and was recommended the service by Women's Aid and one (2.7%) parent was recommended the service by their child's nursery.

Some parents only access support services just before their child starts school and may benefit from the support sooner, so all parents were then asked if they felt they had accessed the services at the right time. Twenty-four (64.9%) parents felt it was the right time, however, 13 (35.1%) felt they would have liked the support sooner.

Of those 13 parents who would have liked access to the support sooner, ten provided reasons why. Six parents said that a health professional did not recognise their need for further support until they reached breaking point.

"A few years ago a Health Visitor came to the house for my older son. I asked for help - I had never heard of Incredible Years but the Health Visitor gave me the impression that the support available wasn't for me."

"I would like to have known about the services sooner. I didn't think to go to my GP or anything either. I did go to Sure Start before the nursery put me in touch with them but I was just told that I was doing a good job. It wasn't until I reached breaking point that I was put in touch with people. I was struggling for a while before I reached breaking point and my little girl was 4 by the time we got any help."

"I think I would have liked it a bit earlier, the consultant took a while to let me know what was available."

Two parents said they would have benefited from support sooner but also recognised that they would not have been ready to seek help.

“Sooner would have been good but I had that feeling about being a failure and not wanting anyone to help. So it was at the right time in a way.”

“I would have liked support earlier but because I was blocking it out a bit and not seeking help or I didn't want to admit it, I don't think it could have happened any earlier. That's maybe why it took the Health Visitor to recognise it.”

One parent said it was difficult to know about services and how to access them and another parent said the services were too far away to attend any earlier.

All parents were asked how easy the Sure Start services were to get to and access:

Access	No. of Responses	% of participants
Very easy	15	40.5
Easy	15	40.5
Average	4	10.8
Difficult	3	8.2
Very difficult	0	0.0
Total	37	100.0

Of those three parents who said access and getting to services was difficult, all parents had attended Incredible Years and provided their reasons:

“I didn't know about the services and professionals didn't know about it either.”

“It was a poor location with limited public transport.”

“It's a poor location. I had a long way to go and had to rely on taxis that didn't always turn up. If it was closer, I could have gone myself.”

We also asked parents when the best days and times were for them to attend Sure Start services and 35 parents provided a response. Thirteen (37.1%) parents said they require a flexible service with the majority reporting the service is currently flexible enough.

“[Sure Start worker] always made sure she fitted around my other appointments. She was always very flexible with the day and appointment length.”

“The worker would arrange to see me and fit around my schedule.”

A further nine (25.7%) said anytime would be good for them to access support, however, eight (22.9%) said the best time was when their children were in school or nursery.

Four (11.4%) parents said that the support would be best if it could fit around work or college hours and one parent (2.9%) said some courses were too early in the morning and would prefer courses to begin a little later in the day.

3.2 Sure Start information and communication

Parents were asked what information they were given about Sure Start services:

Information	No. of Responses*	% of responses	% of participants
Explanation by a Sure Start worker	17	37.0	45.9
Leaflet	10	21.7	27.0
Explanation via a home visit	8	17.4	21.6
Information pack	4	8.7	10.8
Explanation via a phone call	2	4.3	5.4
Explanation by a Health Visitor	1	2.2	2.7
Explanation by a CAF worker	1	2.2	2.7
Other	3	6.5	8.1
Total	46	100.0	

*Participants could give more than one response

Almost half of parents were given an explanation of the service by a Sure Start worker and just under one third were given a leaflet.

“I was told about the activities and a drop in group. The workers at Sure Start explained it to me.”

“I received a leaflet with information about the courses available. It was a very gentle introduction because I didn't want to go at first.”

Eight parents stated that they had a home visit, of which six attended Incredible Years. A further four had a phone call to explain the service, all of which attended Incredible Years.

“My Sure Start worker asked if I would be interested in the course [Incredible Years], she briefly explained what it was – helping me to look at my child's behaviour. The worker then came out and explained it to me in more detail.”

“I was given a flyer about the support before I was referred so I could think about it. When I decided to go ahead with the referral the Sure Start worker (who I knew and referred me) and a representative from the team (Early Educational Additional Support Team) came out to see me.”

Thirty-two (86.5%) parents felt the information they received was enough, four (10.8%) parents would have liked more and one (2.7%) was not sure. Of those that would have liked more, they gave the following responses:

“I would have liked more, I was assessed not my child which was strange - perhaps I misunderstood what the course was about and had a different impression. I would have liked a more information.” [Incredible Years]

“I would have liked more beforehand just to know what it was about.” [Incredible Years]

“The information was quite brief. I would have liked more information on how many weeks it would run for and what was happening each week. An outline of the programme would have been good and a leaflet so I could know what was happening in each session.” [Incredible Years]

“I would have liked more. I was only told (verbally by the Health Visitor) that it would support me and my child.” [Sure Start]

All 37 parents felt their communication needs were met. In particular, two parents of five from black and minority ethnic communities said their experience was particularly good.

“Yes, the language was easy to understand but the information was just too brief.”

“Yes, the Sure Start worker is Bengali so if we are talking and I don't understand something in English she will say it in Bengali. It helps, she understands my culture.”

Three (8.1%) parents did feel communication could have been improved.

“The Health Visitor didn't explain things very well to me.”

“It's always been alright but sometimes I wouldn't get called back when I put my name down for courses.”

Parents were then asked if they were aware of any other services in Newcastle that were available to support them. Twenty-eight (75.5%) parents said they did not know of any other services that could help them other than the Sure Start services they were attending. Nine (24.3%) parents were aware of other services 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.

3.3 Sure Start support

All parents were asked what kind of support they have received from Sure Start services. Seventeen (45.9%) parents said they received one-to-one support at home and at groups and had a Sure Start worker to provide support.

“I have one-to-one support for anything really. They teach you baby massage, play time - just a bit of everything really.”

“I have a one to one support worker. They help me get my children into a routine and support me through home improvements.”

A further seventeen (45.9%) parents had attended a variety of courses to help them learn new skills and provide further parenting support, this included Incredible Years.

“I go to Incredible Years. We watch films and discuss how the film shows how to deal with things - it's all about how to deal with different situations like time outs and that kind of thing.”

Fourteen (37.8%) parents said they valued the extra support and signposting they had received from Sure Start about other issues including housing and debt.

“At Teen Mums, it's everything. It doesn't just have to be about my daughter, it has helped me with my CV, looking for a job, family issues when my grandmother passed away and housing.”

“At the time, my housing situation wasn't good. My daughter's behaviour got better through the advice and I felt more confident but the support continued to help me with the housing situation.”

Ten (27.0%) parents said they had constant support from Sure Start and this was invaluable as their worker was there for them as and when needed. Ten (27.0%) parents also said that attending the groups and courses provided them with a support group of other parents which allowed them to feel that they are not alone.

“You have someone to talk to, rant at, and cry at. I can call her up about anything in work time and talk to her.”

“You know someone is there for you.”

Ten (27.0%) parents specifically stated they had learnt coping techniques for how to deal with their child and their child's challenging behaviour and a further seven (18.9%) said they received support that allowed them to gain confidence in dealing with their child and confidence that they are a good parent.

“I got support on how to deal with behaviour. During the course I had a problem with my grandson and [Incredible Years worker] spoke to and chatted through what I could try. Basically, how to handle behaviour, play and do all the natural things.”

“It reminds you that you are a good parent and you can learn new skills.”

A further six (16.2%) parents said that sharing experiences with their peers at groups and courses was beneficial; four (10.8%) parents said the courses and teachers were helpful; and four (10.8%) said they had specifically received support around play.

“It’s learning for my little boy, you get to meet new people and children can interact. They help you make new friends and you can share stories.”

“It’s all about support from your peers and knowing that everyone is in the same situation.”

Two (5.4%) parents said they had developed new skills in relation to parenting; one (2.7%) parent said there was a buddy system to enable peer-to-peer support and one (2.7%) person said they had better knowledge of challenging behaviour and how to deal with it.

All 37 parents said that the support they have received was useful because it improves their parenting skills, it means they have someone to talk to and it allows them to make friends and socialise. Parents also said the support was useful in giving them confidence as parents and that the support is always non-judgemental.

“I have learned a million and one things. I wish I had been on this course when I had my first child (I have 3 now).”

“The support meant that I could watch them [the workers] with my children and it gave me the confidence to be able to do that with them as well.”

“I did feel isolated. I was new to the area and they helped and encouraged me to go to groups and make friends. I now have a couple of good friends.”

3.4 Accessing the support

All parents were asked how long it took to access the additional support from Sure Start.

Length of time	No. of Responses	% of participants
Within two weeks	25	67.6
Within six weeks	7	18.9
A few months	2	5.4
Not sure	3	8.1
Total	37	100.0

Of those that accessed the support within two weeks, five of the 11 parents who attended Incredible Years fell into this category.

“It was very quick because the CAF went in one week and the course started the next. Someone at the meeting suggested it would be good for me to go to Incredible Years so I got onto the course straight away.”

“I got straight onto the next course (within a couple of weeks) and it happened to fit around my work”

The remaining 20 parents had accessed a variety of Sure Start support and courses within two weeks.

“I got support straight away. The meeting with Social Services was one day and the next day we were put in touch with Sure Start.”

“From the Health Visitor referring me to see the Sure Start worker it was about a week or two.”

Those that waited longer for the support were usually attending a specific course and had to wait for the next course to begin before accessing the support fully.

“We had some basic support over the summer holidays and I started Incredible Years the first week of term.”

“The course started in September. I think I had to wait over the summer holidays which was quite a long time.”

Thirty-four (91.9%) parents were happy with the length of time they waited to access the support. Three (8.1%) parents said they would have liked the support sooner but understood that, at the time, there were no courses running.

“I would have liked it to be a bit shorter time but I appreciate that it was the summer holidays. I’m not sure they run the courses then and they had to wait until more people were available to start the course.”

“It should have happened quicker.”

“It just wasn't possible to start any sooner because there were no courses running which was fine.”

3.5 Sure Start experiences

All parents were asked whether they felt the Sure Start services had worked for them and all 37 parents said that it had. Parents were asked why they felt the services had worked and what worked well, 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

Sixteen (43.2%) parents said that the constant support from the workers was invaluable and knowing they were there as and when they were needed was a comfort.

“The support, the signposting and learning new skills. When I came back to the UK they helped me with everything and I was amazed at what was available. I don't think I would have coped as well with it.”

“The ability to talk to someone when I need too.”

A further 12 (32.4%) parents said the support has given them confidence as a parent to know they are doing a good job and to know how to deal with different situations.

“I'm very happy and much more confident now. The help has been great. I can't even explain - I feel so much more confident and happy, 150 times better than I was.”

“It's increased my confidence; I am now less soft with my son. I feel less self-conscious when he is behaving badly in public as I know I am doing the right thing. In the past I would feel I was being a bad parent if he was screaming or shouting or crying in public - I didn't like to see him upset but now I realise that by reacting to him he just keeps on doing it.”

Nine (24.3%) parents said they could see a noticeable change from the support they have received and the techniques they had learnt.

“Well it takes a lot of time and it's a slow process but I can definitely see changes and improvements. We're getting there slowly.”

“The fact that it worked - my daughter has calmed down.”

Eight (21.6%) parents said the support offered personalised solutions and recognised that what works for one parent and child, might not work for another. A further eight (21.6%) parents said that the course or group they attended had good, supportive workers and course material.

“They give you lots of tools to be able to use and it's good because what works for one child, doesn't work for the other.”

“It was good being able to discuss things, having homework and stuff you can try out at home. You also get hand outs which you can take home and you can go back to stuff to try out at a later date.”

Eight (21.6%) parents said they had learnt new skills and coping techniques; eight parents (21.6%) said they benefited from sharing experiences with the wider groups; and five (13.5%) parents said the support had helped them to feel less isolated and make new friends.

“The openness of the course is good, there is also an environment of respect and everyone gets involved. The facilitator is excellent.”

“I am quite isolated, just me and my son at home. Incredible Years has helped improve my life.”

In addition five (13.5%) parents said the extra support and signposting they received was valuable for issues including housing and debt. Five (13.5%) parents said that the support workers talked them through everything from basics, which they felt was important and four (10.8%) parents found the groups and courses to be a supportive environment with other parents facing similar situations.

“I didn't know they could help you beyond you child. They have helped me with housing.”

“I think it's all about baby steps - being talked through every aspect from the very beginning. They also start from the very basics no matter what your level of knowledge is, right from play up to other stuff.”

“It's such a friendly environment, a very positive environment with the people and refreshments - tea and biscuits - and I had never seen an environment like that before. I feel more relaxed now.”

Three (8.1%) parents found the support helpful as it addressed the issues of the parent and parents' behaviour as well as focusing on their child and a further three (8.1%) thought all parents would benefit from the extra support. Two (5.4%) parents said that the timing and length of the courses were good and encouraged their attendance and two (5.4%) said everything about the support they received was excellent.

“It's also helped me to look at myself as well and that's difficult but it's part of the problem too.”

“It's something I would recommend. Think it's brilliant - everyone should do it, a lot of people could benefit.”

“The two hour session; it’s long enough for you to learn but not too long that it impacts on your week.”

3.6 Sure Start improvements

Parents were asked what they thought did not work well about the support they received and over two third of parents (25 parents, 67.6%) said nothing and that they were happy with the support.

Of those that did provide reasons, five (13.5%) parents said that using the new techniques at home when faced with challenged situations and behaviour was difficult. However, they did recognise that it was a learning curve and part of a longer process.

“For me personally, it can be hard to do you "homework" but I appreciate that you only get out what you put in.”

“The time out - I found this really challenging. Both me and my son found it hard.”

Two (5.4%) parents said the referral process could be improved as they felt like other health professionals should have recognised their difficulties and referred them to the support services sooner.

“The doctors don't know about the support. I went to see them and they did nothing because they didn't know what was out there.”

“The Health Visitor and GP were reluctant to refer me as my daughter was only 11 months and they don't classify late development until 18 months.”

Two (5.4%) parents said the course or support they received was too short and would have preferred it to continue longer and two (5.4%) parents said the location of the courses was difficult to access.

“Just more time there really. I don't think some of the courses and the time you spend there are long enough.”

“The only thing I don't like is the location - it's the other side of Newcastle to where I live and it's hard to get there and back in time to pick up my kids. They do provide transport but it's just a bit too far away.”

One (2.7%) parent did not like the lack of follow up after courses had finished; one (2.7%) parent felt the groups were predominantly female and this led to negative discussion about males; and one (2.7%) parent said that there was a translator in their group and, although she recognised this is necessary, they were quite noisy and made it difficult to hear the course leader.

As well as asking parents what worked well and what did not work well about the support they received, they were also asked if there was anything that would have made the experience of Sure Start services better for them. Again, the majority of parents (23, 62.2%) felt that nothing would make the experience better.

Seven (18.9%) parents would like more access to and time with services and four (10.8%) parents would like more follow up and one-to-one support away from the main courses and groups which continue beyond the course duration.

“The cuts have meant that access to classes has reduced.”

“I think the Teen Mums group should be advertised more, I only heard about it through a friend.”

“I would just like more time at the groups and courses.”

“You get support in the session which is good but outside the session there isn't the support - you need more. Also group work is good but an opportunity for one to one work would be good. It would also be good to have follow up support.”

Two (5.4%) parents from Incredible Years felt the DVDs used in the programme were unrealistic; one (2.7%) parent felt the class size was too large; and one (2.7%) parent would like more signposting to other services that could further support them.

“The children on the DVD they use are very compliant though, it's not that realistic.”

“Reduce the class size – the large classes reduce the ability to actively learn. Smaller groups would mean you could do more activities.”

Two (5.4%) parents had other suggestions for ways the support could be improved:

“I think going out on trips would be good.”

“Perhaps there should be more opportunities for older children – mine range up to 12.”

Section 4: Findings - Health Visiting

4.0 Findings from 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.

For a participant profile of parents who accessed Health Visiting services, see Appendix 4.

4.1 Access to Health Visiting

All 14 parents were asked how it came about that they were put in touch with the specialised Health Visiting service. For the majority of parents, they 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 because they were struggling more generally with the pressures of being a parent.

More specifically, six (42.9%) parents had been referred automatically and four (28.6%) parents had an early visit by a Health Visitor during their pregnancy.

“It was through the normal route. I was seeing a midwife during pregnancy then moved to a Health Visitor.”

“As part of my pregnancy, she [Health Visitor] came out to see me. It was good to have those early conversations.”

A further three (21.4%) parents said the Health Visitor simply contacted them after they had their baby and one (7.1%) parent was referred by their GP.

“They made contact as soon as I got my son (foster child) from the hospital.”

“I went to my doctor after giving birth and he recommended the Health visiting service.”

Parents were asked if they felt like they had accessed and had extra support at the right time or if they feel they would have liked support sooner. Thirteen (92.9%) parents said it was the right time to access the support and one (7.1%) parent would have liked support earlier.

“Looking back, I could have done with support a bit earlier but I don't suppose I had realised or recognised I needed help.”

All parents were asked how frequent the Health Visitor would visit them and all 14 parents said it would depend on the situation. For most parents, monthly appointments were the norm unless more frequent appointments had been arranged, however, all

parents said they could request to see their Health Visitor more often if they felt they needed it and all valued this approach. All 14 parents were happy with the timing of the visits.

“They are as and when I need it. I've seen her every couple of weeks recently but before that it was a little less unless I needed her.”

“When she comes round she sees how I am and depending on that it can be 2 weeks maybe a month.”

“I used to see her 2 to 3 days a month and it's less frequent now. She's on holiday at the moment and I'll see her again this month. I know I can get in touch with her if I need to. She sees me if I need that.”

All parents were asked what the best days and times were for the Health Visitor to visit them and 12 parents provided a response.

Access	No. of Responses	% of participants
Arranged around other commitments (work etc.)	8	66.7
Weekends	1	8.3
Anytime	3	25.0
Total	12	100.0

Parents were also asked how long their Health Visiting appointments were and whether they thought this was too long, too short or sufficient. Seven (50.0%) parents said it depends on the situation and that the appointments are flexible depending on their needs. The remaining seven (50.0%) parents said appointments were usually around 30-45 minutes. All parents were happy with the length of their appointments.

4.2 Health Visiting information and communication

Parents were asked what information they were given about Health Visiting services:

Information	No. of Responses*	% of responses	% of participants
Explanation by a Health Visitor	9	50.0	64.3
Leaflet	5	27.7	35.7
Information pack	2	11.1	14.3
Other	1	5.6	7.1
Not sure	1	5.6	7.1
Total	18	100.0	

*Participants could give more than one response

Most parents were given an explanation of the service by their Health Visitor during their first contact.

“The Health Visitor came out before I gave birth and explained the service and what it did.”

“They came out to see me and check him over. They introduced themselves and their service.”

A further five parents were given a leaflet and two were given an information pack.

“I was given some information when they came out to see me - a leaflet.”

“I got a booklet and lots of information, including information about others services.”

All 14 parents felt the information they received was enough and all 14 parents felt their communication needs were met and did not require anything else to support them.

Parents were then asked if they were aware of any other services in Newcastle that were available to support them. Seven (50.0%) parents said they did not know of any other services that could help them other than the Health Visiting service. A further seven (50.0%) parents were aware of other services all of which named Sure Start as being able to offer further support. One parent also specifically named Incredible Years.

4.3 Health Visiting support

All parents were asked what kind of support they have received from Health Visiting services. Overarching all responses was the value parents placed on the Health Visitor being there for them, as a parent, as well as for their child, and treating them as individuals. In addition to this, nine (64.3%) parents said they received support as and when they need it and found this invaluable to know they always had someone to talk to.

“She's just there if I need her. I can just ring but she's not breathing down my neck and there all the time because I like to be able to get on with stuff myself.”

“It's been good, having someone to talk too, to unload on. They have provided me with advice on things and have been a really good support.”

A further nine (64.3%) parents said they valued the extra support and signposting they had received from Health Visitors about other issues including housing and debt and eight (57.1%) parents said they had received regular home visits.

“Helped with housing, helped get me move, very supportive not just for children

“I've had 3 Health Visitors. The first one, when I had my first baby, was amazing. We had some behaviour difficulties just around school age and I got good support and practical tips. The Health Visitor used to say "I'll just pop in and see you", because I have a history of depression and I had really bad anxiety and she knew that and she was always amazing. She changed jobs and she came to let me know that she was leaving. The Health Visitor I have now is caring, understanding and kind and she listens. She's there for me one hundred per cent. She's there if I'm feeling low or upset or frustrated.”

Three (21.4%) parents said they valued the one-to-one support; two (14.3%) parents said they had been given coping techniques of how to deal with difficult behaviour; and one (7.1%) parents said their Health Visitor had helped refer to other services.

“I got one to one support, quite intensive. They would come whenever I needed them and would come over quickly. I would ask them to come in between the normal check-up dates. They took me as an individual.”

“I was given new parenting techniques which help with my son's behaviour such as how to calm him down and how to use wall charts. It's very individual and she will take me through it as well as my son when she's here.”

All 14 parents said that the support they received was useful.

4.4 Health Visiting experiences

All parents were asked whether they felt the Health Visiting service had worked for them and all 14 parents said that it had. Parents were asked why they felt the services had worked and what worked well, 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

Thirteen (92.9%) parents said that the constant support from the workers was invaluable and knowing they were there as and when they are needed is a comfort.

“Having someone to talk too is great and someone who you can ask questions. I like to get on with things but it's good to know she's there if I need her.”

“It’s knowing that she’s there for support when I need her. Also that she’s there to talk about my son’s needs and understands.”

Four (28.6%) parents said the family approach taken by the Health Visitors works well and is a positive approach.

“It’s the supportive, whole family approach. In general I have had a good experience of the Health Visiting service. My Health Visitor has been very supportive and understanding.”

Three (21.4%) parents said everything about the service has worked for them and a further three (21.4%) parents said the Health Visitor had provided support in relation to their mental health.

“The practical and emotional support, helping me with my mental health issues and helping me develop my support network.”

“She helped me with my depression.”

Two (14.3%) parents said the Health Visiting service was non-judgemental; two (14.3%) parents said they felt like the service treats you as an individual; one (7.1%) parent said they had been given support to get equipment; and one (7.1%) parent said the signposting to other groups and services has worked well.

“She can help with whatever I need and listens and doesn’t judge you.”

“It’s the one to one support. The Health visitors took me as an individual, they didn’t frown upon my situation. I had my first baby at 17 and have different children to different fathers and they are non-judgemental which helps you open up.”

4.5 Health Visiting improvements

Parents were asked what they thought did not work well about the support they received, ten (71.4%) parents said nothing and that they were happy with the support. Four (28.6%) parents did provide issues that did not work well about the service:

“I would have liked more support around bathing, maybe it’s something that would have been covered in hospital but I obviously missed that.”

“I would have liked more information about autism covering diagnosis and how to access support.”

“It’s not always the same Health Visitor. One Health Visitor came twice to see my son and she said he seems normal and said we should wait.”

“I have had a Health Visitor in between the first and the one I have now and I didn't really get on with her. One night I couldn't sleep and I didn't want to put the baby down because I was frightened and she was a bit insensitive because she said "You can get leaflets about cot death" and I didn't want to hear those words and she didn't seem to know me, or my history, or my family. She was saying the wrong things and she came in and talked too much like "Oh, I've had such a busy day" and she didn't listen.”

As well as asking parents what worked well and what did not work well about the support they received, they were also asked if there was anything that would have made the experience of Health Visiting services better for them. Again, ten (71.4%) parents felt that nothing would make the experience better.

Four (28.6%) parents provided the following suggestions:

“Maybe more support around things that might have been covered in hospital.”

“Due to service cuts I had 3 different Health Visitors. With my previous child I had 1. If it had been the other way round I am not sure I would have engaged so well.”

“You do feel obliged to follow their rules. You speak to other parents who say this worked for me but feel you should follow their rules such as when to start weaning.”

Section 5: Findings - NTW

5.0 Findings from NTW

This section provides a summary of the findings of Involve North East's research with 4 parents who accessed NTW services. A total of 51 letters were sent to parents/carers who had accessed the service and, despite the low numbers of parents, the information received still indicates patient experiences of the service.

For a participant profile of parents who accessed NTW services, see Appendix 5.

5.1 Access to NTW

All four parents were referred to NTW by their GP because they were concerned about their child's behaviour or development. Parents were asked if they felt like they had accessed and had extra support at the right time or if they feel they would have liked support sooner. All parents felt like they accessed the support at the right time and felt they were seen as soon as possible.

Parents were asked how long it took to be referred to the service after the GP referral. For all parents it took at least two months but one parent (25.0%) waited nine months. Three parents (75.0%) were happy with the length of the referral time and the remaining parent (25.0%) was unhappy with the time waited.

"It took three months."

"It took 6-7 months for a referral."

"It took about two months."

"I was referred in April and only accessed the service in December. In April I was told my child was too young so the GP wrote another letter in August and I got an appointment in December."

Whilst numbers are too small to make a fully informed conclusion, 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.

All four parents felt the NTW clinic was easy to access at Benton House. Two parents (50.0%) could attend the service at any time, one (25.0%) would like appointments to be after 4pm and for one parent (25.0%), if attending without her daughter, would like to attend during school hours. All parents said there was a small waiting time for their appointment when they arrived at the service and they were all satisfied with this.

"They are as and when I need it. I've seen her every couple of weeks recently"

5.2 NTW information and communication

Two parents (50.0%) said they received information about the service and did not feel as though they required any more information. However, two parents (50.0%) said they were not given enough information, with one parent only receiving a referral letter:

“No information just a letter through the post. I didn't know what to expect at the initial consultation.”

All four parents felt their communication needs were met and did not require anything else to support them.

Parents were then asked if they were aware of any other services in Newcastle that were available to support them. Three parents (75.0%) were not aware of any other services and one (25.0%) was aware of other services but did not state an example.

5.3 NTW support

All parents were asked what kind of support they have received from NTW services. One parent (25.0%) felt they had not received any help or support from the service. The remaining three parents (75.0%) had received different support tailored to their needs.

“We received a diagnosis for my child and we're waiting for speech and language therapy for more support.”

“The Children and Young Peoples Service stuff is ongoing but I am getting guidance about ADHD and attachment.”

“We were told about coping groups for us and the child.”

For all three parents that detailed the support they received, they felt it was useful.

5.4 NTW experiences

Three parents (75.0%), who detailed the support they received, felt the service had worked well. One parent (25.0%) was grateful to be receiving support after a diagnosis and one parent felt the service had helped with anxiety. One parent (25.0%) felt everything had worked well about the service.

“It has helped us to deal with the anxiety issues and meltdowns and we feel we are coping better.”

All three parents (75.0%) felt the service had worked for them and would continue to do so and they explained why:

“We are getting a diagnosis for my child but in the meantime they want to medicate to see if they can control the ADHD to see what part of the autism spectrum my daughter is on.”

“She explained everything connected to my son’s needs and made it understandable and easier for me to deal with situation.”

“We have coping strategies now.”

5.5 NTW improvements

Parents were asked what they thought did not work well about the support they received, two parents (50.0%) said nothing and that they were happy with the support. One parent (25.0%) felt the waiting time for an appointment and the length of time it took for a diagnosis was too long.

“Waiting for an appointment and waiting for a diagnosis was too long. It’s a long process and I have to pester them for the next appointment.”

One parent (25.0%), who felt the service had not supported them at all, said they had not received any support, information or guidance.

As well as asking parents what worked well and what did not work well about the support they received, they were also asked if there was anything that would have made the experience of NTW services better for them. Two parents (50.0%) felt there was nothing that would make the experience better. Two parents (50.0%) explained issues that could be improved:

“The process should be quicker to access.”

“I don’t find the service helpful, they just ask questions but I don’t feel like they’re doing anything.”

Section 6: Findings - Further support

6.0 Findings regarding 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.

6.1 Further support

All parents who used Sure Start, Health Visiting and NTW services were asked what other support or services might help parents. Thirty-two (61.5%) parents were not sure what else might help parents.

Of the remaining 20 (38.5%) parents, five (9.6%) parents said that they think there are lots of services and support out there but access to information could be improved to allow more people to access the services early.

“It's more about knowing where to look for the services.”

“I think when you're pregnant you should get some more information. You get a pack from the midwife but it didn't include any information about other support like Sure Start. I found out about a breastfeeding support group but it was too late as I'd already stopped breastfeeding. There should be more information given to you when you're pregnant.”

Three (5.8%) parents would like more support in general and three (5.8%) parents would like more services and support for children with additional needs.

“I think that more support would be better but I am happy with what is available.”

“Because I have another child with additional needs I am more aware of other networks in Newcastle so more signposting and awareness of other organisations that can help would be good. Things like the Family Information Service but with a lean towards additional needs would be helpful.”

There were a range of other, more specific suggestions from nine (17.3%) parents including:

“I am aware of Dyslexia due to my husband having it but it would be worth having a child psychologist look at children who learn in a different way.”

“More support about dealing with the future as the child gets older.”

“I think there needs to be more help on the parents own behaviour, how to cope in situations and how your behaviour effects children's behaviour. I would also like something to help with my self-confidence.”

“Maybe more support for older parents – they don't get as much support.”

“Maybe more father groups. They seem to be mainly attended by mams.”

“Maybe more peer lead courses would be good.”

“I would like to know about other places to go like Sure Start but that aren't in this area. It's the same people that go to all the groups. It's always the same people that are in my area.”

“Maybe coffee mornings that offer not only a chance to play with your child but also a bit of adult interaction. You spend all day with your child so it's good to interact with other adults. Maybe they could have a health visitor there to answer questions. I know there are pop in sessions where you can pop in a speak to a health visitor but that's only an hour long so maybe something longer.”

“A course would be good on how to think like my child thinks and how to control her behaviour.”

Parents were then asked if there were any particular issues that parents struggle with that it would be useful to have further support for. Twenty-two (42.3%) parents said they weren't sure or could not think of anything.

Of the remaining 30 (57.5%) parents, ten (19.2%) parents suggested behavioural issues as something they would like further support for.

“More support for when your children kick off, especially in public, so maybe something to help you understand and cope with it. You get judged by other people so someone to explain in detail how to deal with it.”

“More support and behaviour advice, especially when a new baby arrives, and how to deal with a toddler in this situation and how to help them cope.”

Six (11.5%) parents felt that issues within the family could be a problems and further support as a whole family would be beneficial.

“Perhaps a whole family approach would be good. Offering you advice, helping parents improve their relationships and come together over parenting styles. Some current groups often just turn into man bashing.”

“It would be good to have some sort of family team building. My children don't play well together; they just fight all the time so some team building would be good.”

Five (9.6%) parents said wider issues such as housing, debt and relationships can have an impact and a further five (9.6%) parents said that accessing information about groups and support can be an issue.

“It would be good to have someone to speak too, like counselling. If you’re not in a good place you can snap at your child, so you need to look at wellbeing more generally. Maybe cover debt and housing - anything that causes stress as it has a knock on effect.”

“Handling money and budgets would be useful. Having a child is a big change in circumstances, so something on how to manage your money better.”

“There's enough support out there but it's knowing where to go.”

In addition, three (5.8%) parents specifically said that support with marriage or relationship issues would be important; three (5.8%) parents felt that helping parents to integrate into their area was needed; and three (5.8%) parents would like more support around mental health issues.

“Support with relationship or marriage counselling would be good. For a new parent it's a very difficult time and people can learn bad habits. If you can improve relationships and look at a family orientated approach that would help.”

“More support for people who are new to the area to help them integrate better.”

“For lone parents who have mental health issues they could offer support as sometimes these issues can result in physical conditions making it hard to look after your children.”

One (1.9%) parent felt there were not enough play groups for children and five (9.6%) parents provided other specific suggestions:

“I think it would be good to probably know everything about a child, if they needed it, not just behaviour.”

“Education - how to help parents educate their children. Courses for new or expecting parents would be helpful.”

“What to expect at developmental stages such as sitting up etc. You end up just checking the internet.”

“For me, as a first time parent with a child who was suffering from reflux and colic, I found it hard to understand and cope. I think you need more support to help you understand what it is. You worry as they are upset but you can't help and you don't get enough information.”

“There is no support until the child is diagnosed. My child goes to year 1 next year and there is no one-to-one for her. She won't cope on a table with other children.”

Overall, parents suggested:

- 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

6.2 Summary of findings

6.2.1 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. It was also highlighted

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.

6.2.2 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.

6.2.4 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.

6.2.5 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.

6.2.6 NTW access and information

Whilst numbers are too small to make a fully informed conclusion, 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.

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.

6.2.7 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.

6.2.8 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 a further 22 (42.3%) parents suggested issues that parents may struggle with that 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 regarding 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 children can play and socialise and the parents are able to 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 healthy
- Budgeting support
- Support for mental health issues
- Support for children before their official diagnosis

Section 7: Findings - Deaflink

7.0 Findings from Deaflink

This section provides a summary of the findings of Deaflink's research with 8 parents:

- 4 parents accessed Sure Start services
- 8 parents accessed Health Visiting services

For the full Deaflink report, see Appendix 6.

7.1 Summary of findings

This section details the findings from Deaflink with eight parents:

- 3 D/deaf parents
- 1 hard of hearing parent
- 4 hearing parents

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 gave communication barriers to several answers and describe having to persistently request interpreters.

“Yes, I requested a BSL interpreter with health visitor, however with the sure start, I received a letter last Friday and they stated that they have booked me a place for weaning class. However, I have requested a BSL interpreter to the named contact but never heard back and also they know me from the previous weaning class that I attended with a BSL interpreter with my first child.”

“I didn't really get support. Health Visitor told me they were there for me but didn't do anything.”

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.

“She was very good and understood my needs, by providing a BSL interpreter, however it would be nice if there was a deaf health visitor to

enable us to express more concerns, or information sharing, etc. with my first child, I struggled to understand the weaning process, other things, etc. it would be good to have a group to enable us to share information in relation to baby.”

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.

None of the Health Visitors or Sure Start staff could sign but only one parent had access to an interpreter so how did those people assess the needs of the deaf parent and baby?

“Need interpreter. My partner hearing and health visitor hearing so I was not involved or don’t know what being said it was hard for my partner to sign and talk time was wasted

“Lack of deaf awareness information about early years foundation that baby need to meet.”

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

“Not very good - worker was talking about her family and it didn't really help. Asked me how I was - I explained problems and then she told me that other families have same experiences!”

The lack of knowledge about services and what is available to support new parents was significant. The question to identify issues that they needed more support with was telling in the fact that most of the replies – the support requested should be delivered by one of the 3 agencies we have been asking about.

“Information about early years foundation, weaning, healthy eating, etc. and social interaction, these are imperative for the babies to receive a better start in their life.”

“Need support more by health visitor, they need deaf awareness course to understand deaf people's needed”

“Parenting support after birth of child. Breastfeeding support.”

“Children Sleeping, Very active children and sibling jealousy and how to deal with it. Would have liked them to observe [my child] in action and advise me what to do - maybe film him and they watch and tell me what to do differently.”

Section 8: Recommendations

8.0 Recommendations

It is suggested that NHS Newcastle Gateshead CCG and Newcastle City Council take time to analyse the findings of this research to inform the decision on the future service delivery model for infant emotional health services. However, from the findings, some recommendations can be made.

It should 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 within the parameters of the resources available. For example, due to cuts in funding, provision of Sure Start services has now been reduced to cover areas within the top 30% of the Index of Multiple Deprivation.

8.1 Sure Start

8.1.1 Information

Four (10.8%) parents would have liked more information about Sure Start services. Of those four parents, three had attended Incredible Years and felt they would have liked more specific information about the course, including an outline of what each week entails. In addition, one parent who attended other Sure Start support felt the Health Visitor did not explain the services.

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

The majority of parents referred or recommended a course within the Sure Start service were able to access it within two weeks, mainly because the course was due to start soon after the referral. However, nine (24.3%) parents accessed the support within six weeks or waited a few months because the support was not available during holidays.

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

Thirteen (35.1%) parents who accessed Sure Start services would have liked to receive support sooner. Two (5.4%) parents said the referral process could be improved as they felt other health professionals should have recognised their difficulties and felt health professionals were not aware of the support available. One parent from Sure Start also would have liked support sooner but recognised they were not ready to seek help or did not realise they would benefit from further 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

Of 37 parents who accessed Sure Start services, 28 (75.5%) parents did not know of any other services that could support them

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

In relation to Incredible Years, two (5.4%) parents did not like the location of the course. A further three (8.2%) also stated they found the location difficult to access as it was too far away with limited public transport.

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

A small number of parents said they would like more specific information about illnesses and issues they may face with their child and felt the service currently does not provide that.

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

Seven (50.0%) of the 14 parents who accessed Health Visiting also did not know of any other services that could support them and those that did report services, only knew of Sure Start services. One parent from Sure Start felt the Health Visitor who signposted them to the service did not explain the support fully.

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

Of the four parents, one parent waited two months, one parent waited three, one waited seven and one waited nine months for an appointment from being referred. One parent in particular was unhappy with this length of time.

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

Of the four parents, two said they were not given any information about the service prior to their first appointment and would have liked more to know what to expect. In addition, one parent did not feel that the service had helped them and felt they asked questions but were not doing anything else.

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

Three of the four parents were not aware of any other support or services that could help them or their child.

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

NTW were able to recruit seven parents to take part in the research, four of which chose to take part.

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

Nineteen (39.6%) parents suggested other services that may help parents and a further 29 (60.4%) parents suggested issues that parents may struggle with that 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

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

8.5.1 Communication needs and interpreter access

The overwhelming issue for the D/deaf respondents was the lack of access to interpreters – the one client where interpreters had been arranged led to that family having longer appointments with a much higher satisfaction and understanding of what was happening.

D/deaf people find it difficult to complain and will very often 'make do' with writing notes or trying to lip read however it is their right to have an interpreter to enable communication and better understanding. It is important for Health Visitors and Sure Start workers to be able to communicate fully with parents in order to deliver their service.

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

Many people assume that D/deaf people can understand the written word yet research has shown that most BSL users have an average reading age of 8 ¾ years old when they leave school. When providing information about services or courses special consideration needs to be made for how will the information be distributed and how deaf friendly is it. Is it in Plain English and with visual support? 86.5% of hearing respondents said that they had enough information fewer than 40% of Deaflink respondents felt they had enough information.

It is recommended that:

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

8.5.3 Delivering services

There was a distinct lack of knowledge and awareness of what services were being offered or were available. A number of respondents also reported a lack of D/deaf awareness in staff.

It is recommended that:

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

8.5.4 Courses

Training and group learning are incredibly important and the respondents to INE and HAREF stated that they were 'invaluable' or 'improved their parenting skills'.

It is recommended that:

- A review is undertaken of the course 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

D/deaf people experience isolation, they cannot access the everyday options available to hearing communities. The number of BSL users accessing the Health Visitor or Sure Start make it economically unviable to provide interpreters at every venue or event and this excludes the D/deaf community from an important part of parenting and developing parent skills.

It is recommended that:

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

Appendices

Appendix 1 - One-to-one interview/questionnaire questions

Infant Emotional Health Questions

Your GP, along with others in Newcastle is looking to improve services provided for new parents, including health visiting services, Northumberland, Tyne and Wear NHS Foundation Trust (NTW) services and Sure Start Children's Centres services. In order to be able to improve this service for you and others we need to understand your experiences for each of the services you have used.

Services accessed

1. What services have you accessed to support you and your child/children?
(Prompt: looking for health visiting services, NTW services and Sure Start services)
2. How did it come about that you were put in touch those services?
3. What information were you given about the different services when you were referred?
 - a. Did you feel that was enough or would you have liked anything else?
4. Do you know of any other services that would be able to support you?
 - a. *(Prompt: For example, if they've only accessed 1 service, do they know of the other 2)*
5. Do you feel that your communications needs were met?
(Prompt: interpreters, BSL etc)
Yes/No
 - a. Is there anything that would have made communication better for you?
6. When would have been the best time for you to have accessed NTW/Health Visiting/ Sure Start services?
(Prompt: some parents have accessed NTW, Sure Start or Health Visiting specialist services just before their child started school because they identified, for example, their child may not cope and may have benefited from accessing the support sooner)

Health Visitor – experiences

7. What kind of support have you received from the health visitor?
 - a. Is that support useful?
8. What do you think worked well about the health visitor and the support you receive?
9. What do you think didn't work well about the health visitor and the support you receive?
10. Do you feel the health visitor service worked for you?
Yes/No
 - a. Why?
11. Is there anything that would have made the experience of the health visitor better for you?

Health Visitor – details, place, time etc.

12. How frequent are the health visitor visits?
 - a. Would you like visits more or less often?
13. What are the best days and times for the health visitor to visit you? (Can't offer weekends)
14. When the health visitor visits, how long are the appointments?
 - a. Do you feel this is sufficient or would you like longer or shorter appointments?

NTW – experiences

15. How long did it take for you to be referred and access the NTW?
 - a. Were you happy with this length of time?
16. What kind of support have you received from NTW?
 - a. Is that support useful?
17. What do you think worked well about NTW and the support you receive?
18. What do you think didn't work well about NTW and the support you receive?
19. Do you feel the NTW services worked for you?
 - Yes/No
 - a. Why?
20. Is there anything that would have made the experience of the NTW services better for you?

NTW – details, place, time etc.

21. How easy was the clinic to access:
 - Very easy
 - Easy
 - Average
 - Difficult
 - Very difficult
22. If ease of access was difficult, why was this?
 - Poor location
 - Limited public transport
 - Limited parking
 - Opening hours
 - Other
23. What days and times are best for you to attend appointments?
24. When attending appointments, how long did you wait to see the health professional?
 - a. Were you satisfied with this wait?

Sure Start – experiences

25. What kind of support have you received from Sure Start?

a. Is that support useful?

26. How long did it take for you to be access additional support from Sure Start since an assessment was made of your needs (a CAF)?

a. Were you happy with this length of time?

27. What do you think worked well about Sure Start and the support you receive?

28. What do you think didn't work well about Sure Start and the support you receive?

29. Do you feel the Sure Start services worked for you?

Yes/No

a. Why?

30. Is there anything that would have made the experience of Sure Start services better for you?

Sure Start – details, place, time etc.

31. How easy was the Sure Start services to access:

Very easy

Easy

Average

Difficult

Very difficult

32. If ease of access was difficult, why was this?

Poor location

Limited public transport

Limited parking

Opening hours

Other

33. What days and times are best for you to attend Sure Start services?

Further support

34. Apart from the services and support you know about, is there any other support or services you think might help parents? If yes, what?

35. Are there any particular issues that parents struggle with that it would be useful to have further support for?

36. Any other comments?

Monitoring

29. Gender

Male

Female

30. Age

- Under 18 55 – 64
 18 – 24 65 – 74
 25 – 34 75 – 84
 35 – 44 85 and over
 45 – 54

31. How do you describe your sexuality?

- Lesbian Bisexual
 Gay Prefer not to answer
 Heterosexual

32. Please indicate your ethnic background:

White	✓	Asian or Asian British	✓
British		Indian	
Irish		Pakistani	
Central/Eastern European		Bangladeshi	
Any other White background		Any other Asian background	
Mixed		Black or Black British	
White and Black Caribbean		Caribbean	
White and Black African		African	
White and Asian		Any other Black background	
Any other mixed background			
Other ethnic groups			
Chinese			
Any other ethnic group (<i>write in</i>)			

33. Do you consider yourself to have a disability?

- Yes No

34. What is the first part your postcode?

Appendix 2 – Full participant profile

Gender

	No. of participants	% of participants
Male	6	10.0
Female	54	90.0
Total	60	100.0

Age

	No. of participants	% of participants
18-24	13	21.7
25-34	25	41.7
35-44	21	35.0
45-54	1	1.6
55-64	0	0.0
65-74	0	0.0
75-84	0	0.0
85 and over	0	0.0
Total	60	100.0

Location – first part of postcode

	No. of participants	% of participants
NE3	16	26.6
NE4	5	8.2
NE5	6	10.0
NE6	20	33.3
NE7	1	1.7
NE12	1	1.7
NE13	1	1.7
NE15	6	10.0
NE27	1	1.7
NE37	1	1.7
NE39	1	1.7
DL3	1	1.7
Total	60	100.0

Ethnic background

	No. of participants	% of participants
White British	53	88.2
White Irish	0	0.0
Central/Eastern European	0	0.0
Any other White background	1	1.7
Mixed White and Black Caribbean	0	0.0
Mixed White and Black African	0	0.0
Mixed White and Asian	0	0.0
Any other Mixed background	0	0.0
Asian or Asian British - Indian	3	5.0
Asian or Asian British - Pakistani	1	1.7
Asian or Asian British - Bangladeshi	1	1.7
Any other Asian background	0	0.0
Black or Black British – Caribbean	0	0.0
Black or Black British - African	1	1.7
Any other Black background	0	0.0
Chinese	0	0.0
Any other ethnic group	0	0.0
Total	60	100.0

Sexuality

	No. of participants	% of participants
Bisexual	0	0.0
Gay	0	0.0
Heterosexual	58	96.7
Lesbian	0	0.0
Prefer not to say	2	3.3
Total	60	100.0

Do you consider yourself to have a disability?

	No. of participants	% of participants
Yes	10	16.7
No	49	81.6
Prefer not to answer	1	1.7
Total	60	100.0

Appendix 3 – Sure Start participant profile

Gender

	No. of participants	% of participants
Male	4	10.8
Female	33	89.2
Total	37	100.0

Age

	No. of participants	% of participants
18-24	8	21.6
25-34	17	45.9
35-44	11	29.8
45-54	1	2.7
55-64	0	0.0
65-74	0	0.0
74-84	0	0.0
85 and over	0	0.0
Total	37	100.0

Location – first part of postcode

	No. of participants	% of participants
NE3	7	18.9
NE4	4	10.8
NE5	3	8.1
NE6	15	40.5
NE7	1	2.7
NE12	1	2.7
NE13	1	2.7
NE15	5	13.6
Total	37	100.0

Ethnic background

	No. of participants	% of participants
White British	32	86.5
White Irish	0	0.0
Central/Eastern European	0	0.0
Any other White background	1	2.7
Mixed White and Black Caribbean	0	0.0
Mixed White and Black African	0	0.0
Mixed White and Asian	0	0.0
Any other Mixed background	0	0.0
Asian or Asian British - Indian	1	2.7
Asian or Asian British - Pakistani	1	2.7
Asian or Asian British - Bangladeshi	1	2.7
Any other Asian background	0	0.0
Black or Black British – Caribbean	0	0.0
Black or Black British - African	1	2.7
Any other Black background	0	0.0
Chinese	0	0.0
Any other ethnic group	0	0.0
Total	37	100.0

Sexuality

	No. of participants	% of participants
Bisexual	0	0.0
Gay	0	0.0
Heterosexual	35	94.6
Lesbian	0	0.0
Prefer not to answer	2	5.4
Total	37	100.0

Do you consider yourself to have a disability?

	No. of participants	% of participants
Yes	5	13.5
No	31	83.8
Prefer not to answer	1	2.7
Total	37	100.0

Appendix 4 – Health Visiting participant profile

Gender

	No. of participants	% of participants
Male	1	7.1
Female	13	92.9
Total	14	

Age

	No. of participants	% of participants
18-24	3	21.4
25-34	8	57.2
35-44	3	21.4
45-54	0	0.0
55-64	0	0.0
65-74	0	0.0
75-84	0	0.0
85 and over	0	0.0
Total	14	100.0

Location – first part of postcode

	No. of participants	% of participants
NE3	7	50.0
NE4	1	7.1
NE5	2	14.3
NE6	4	28.6
Total	14	100.0

Ethnic background

	No. of participants	% of participants
White British	10	71.4
White Irish	0	0.0
Central/Eastern European	0	0.0
Any other White background	1	7.1
Mixed White and Black Caribbean	0	0.0
Mixed White and Black African	0	0.0
Mixed White and Asian	0	0.0
Any other Mixed background	0	0.0
Asian or Asian British - Indian	2	14.4
Asian or Asian British - Pakistani	0	0.0
Asian or Asian British - Bangladeshi	0	0.0
Any other Asian background	0	0.0
Black or Black British – Caribbean	0	0.0
Black or Black British - African	1	7.1
Any other Black background	0	0.0
Chinese	0	0.0
Any other ethnic group	0	0.0
Total	14	100.0

Sexuality

	No. of participants	% of participants
Bisexual	0	0.0
Gay	0	0.0
Heterosexual	14	100.0
Lesbian	0	0.0
Prefer not to say	0	0.0
Total	14	100.0

Do you consider yourself to have a disability?

	No. of participants	% of participants
Yes	2	14.3
No	12	85.7
Total	14	100.0

Appendix 5 – NTW participant profile

Gender

	No. of participants	% of participants
Male	1	25.0
Female	3	75.0
Total	4	

Age

	No. of participants	% of participants
18-24	0	0.0
25-34	2	50.0
35-44	2	50.0
45-54	0	0.0
55-64	0	0.0
65-74	0	0.0
75-84	0	0.0
85 and over	0	0.0
Total	4	100.0

Location – first part of postcode

	No. of participants	% of participants
NE3	1	25.0
NE5	1	25.0
NE6	1	25.0
NE15	1	25.0
Total	4	100.0

Ethnic background

	No. of participants	% of participants
White British	3	75.0
White Irish	0	0.0
Central/Eastern European	0	0.0
Any other White background	0	0.0
Mixed White and Black Caribbean	0	0.0
Mixed White and Black African	0	0.0
Mixed White and Asian	0	0.0
Any other Mixed background	0	0.0
Asian or Asian British - Indian	1	25.0
Asian or Asian British - Pakistani	0	0.0
Asian or Asian British - Bangladeshi	0	0.0
Any other Asian background	0	0.0
Black or Black British – Caribbean	0	0.0
Black or Black British - African	0	0.0
Any other Black background	0	0.0
Chinese	0	0.0
Any other ethnic group	0	0.0
Total	4	100.0

Sexuality

	No. of participants	% of participants
Bisexual	0	0.0
Gay	0	0.0
Heterosexual	4	100.0
Lesbian	0	0.0
Prefer not to say	0	0.0
Total	4	100.0

Do you consider yourself to have a disability?

	No. of participants	% of participants
Yes	0	0.0
No	4	100.0
Total	4	100.0



INFANT EMOTIONAL HEALTH

Deaflink Responses

Heidi Jobling
heidi@deaflink.org.uk

Deaflink Diabetes Education summary

May 2015

Methodology

Deaflink invited feedback from our members 4 weeks through November & December 2014. We offered one to one interviews however all responses were through our questionnaires available through our website.

We had 8 responses (3 D/deaf, 1 hard of hearing and 4 hearing). 4 respondents were living in Newcastle (of which 2 were Deaf) and 4 were from other parts of the North East of which 1 was deaf and one was the partner of a deaf person.

Summary of Findings

Whilst not a significant 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 gave communication barriers to several answers and describe having to persistently request interpreters.

The one Deaf parent from outside of Newcastle had a different experience, 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 numbers of people participating however it is safe to assume 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 not enough time given to them.

None of the Health Visitors or Sure Start staff could sign but only one parent had access to an interpreter so how did those people assess the needs of the deaf parent and baby?

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

The lack of knowledge about services and what is available to support new parents was significant. The question to identify issues that they needed more support with was telling in the fact that most of the replies – the support requested should be delivered by one of the 3 agencies we have been asking about.

RESPONSES

The replies from the 3 Deaf people are in red.

The replies from 5 hearing people in black.

Replies from Newcastle residents have a blue background and 'others' do not.

Have you (or your child) had help from any of these services - tick the one you have used?

A Health Visitor	8	100%
Sure Start	4	50%
NTW Service	0	0%

All respondents had used a Health Visitor. Half had used a Sure Start service, 1 of those were deaf but not a Newcastle resident.

Why did you use that service?

Most stated that they felt that the Health Visitor referral was automatic however one Deaf respondent from Newcastle stated that they asked for a Health Visitor and they never came.

“Was advised by the health visitor to access information with regards to services for children who is under five, and I have requested for further information with regards to deafness and hearing child to see what, how they can support us.”

“We did asked for health visitor and never came, It's was a poor service and we had do our self. For example Health visitor never came we had go to medical centre ask GP etc. for weight and information for nursery for our child etc.”

“For advice related to health. I made the decision to contact the health visitor directly.”

“No choice with health visitor. Sure Start - wanted help with son, aged 18 months - his sleep and behaviour problems.”

“Health visitor has do routine visits and extra visits due to son being poorly and needing emergency care at the RVI hospital 4 weeks old. “

What information were you given about other services that could help you?

6 out of 8 replies said 'nothing' or 'not much'. One Newcastle Deaf parent said they were given phone numbers to contact. 2 stated they were given information about Sure Start and one was told to contact the GP is they were concerned.

“Activities for children and signpost to other relevant agencies. Not much really, as it would be useful for deaf parents to know other deaf parents within the borough to enable us to share information and communicate effectively with professionals to raise awareness about deaf, the barrier that we faced with agencies, in either education, social settings, etc.”

“One or two leaflets about local Sure Start Mum and baby groups.”

Were you given enough information? Would you have liked anything else?

Two people said that they were given enough information. 3 deaf people felt that they needed more information one person feeling that the visits were 'pointless'. One person specifically requested a BSL interpreter at Sure Start but was still waiting to hear. Two others felt more practical support was needed.

"No, I was not given enough information. The visits were all pretty pointless and I only really wanted my baby weighed."

"Yes, I requested a BSL interpreter with health visitor, however with the sure start, I received a letter last Friday and they stated that they have booked me a place for weaning class. However, I have requested a BSL interpreter to the named contact but never heard back and also they know me from the previous weaning class that I attended with a BSL interpreter with my first child."

"Not enough information."

"No, I said I was not coping and they said that I would get used to it, seemed more bothered about whether house was clean. I would have liked some real help where I could have had someone look after my son and give me a rest or let me spend quality time with my new daughter. "

"Would have liked a little more support and advice about my son's illness and his lactose intolerance "

Do you know of any other service who would have helped you?

There was no reply in 3 submissions, said they didn't know of any other service and one deaf person thought CAMHS might help.

"I knew CAMHS but our baby is hearing! not sure if CAMHS is aim only for deaf or both!"

Were your communication needs met?

The 2 deaf Newcastle parents both stated they needed an interpreter and one felt that they were 'signposted' to other services. The hearing people were all happy that their communication needs had been met.

"They didn't explain what their service was - just where to go. "

"I didn't really get support. Health Visitor told me they were there for me but didn't do anything."

When best time for you to access NTW/Health Visiting/ Sure Start services?

No response to this question.

HEALTH VISITOR

Did you use a Health Visitor?

100% yes

What kind of help or support did you get from your Health Visitor?

The deaf person who replied to this who lived out of the Newcastle area was clear about the support received from the Health Visitor, the 2 deaf parents from Newcastle were more negative in what they felt they received in terms of support.

“Baby development, nursery and weaning, feeding, etc.”

“None”

“Not much, not support enough”

“Advice”

“She told me how to do the bottles, what to expect when they are born and remind me when they need their needles.”

“Health visitor very helpful but I think big caseload and very busy meant unable to extend visit for further advice.”

“Monthly progress advice”

“She weighed my baby, did an assessment to ensure she was meeting her milestones, asked me about breastfeeding and food weaning.”

Was it useful?

A mixed bag of replies to this question. 2 did not bother to reply. 2 thought yes it was useful, 2 didn't agree and a further 2 thought 50/50 or to some extent. These replies were consistent in spread across the areas.

What was good about the help from your health visitor?

The statements below highlight the clear issue of communication. The deaf parent from outside of the area had on average a 45 minute appointment and an interpreter was arranged. Their response shows an understanding and clarity of purpose of a Health Visitor and more importantly of issues in the development of their child. The 2 deaf parents from the Newcastle area felt that it 'wasn't good enough' and the other 'needed interpreter'.

“She was very good and understood my needs, by providing a BSL interpreter, however it would be nice if there was a deaf health visitor to enable us to express more concerns, or information sharing, etc. with my first child, I struggled to understand the weaning process, other things, etc. it would be good to have a group to enable us to share information in relation to baby.”

“needed interpreter!”

“Not good enough”

“Information, didn't really know a lot about the sterilising and bottles.”

“She is a very good listener and gives a range of possible solutions to the problem.”

“Weekly weighing of baby”

What was not good about your health visitor?

There is a consensus about lack of support or understanding. One Deaf parent felt isolated from the conversation with the Health Visitor and their partner put in the position of either listening to Health Visitor or Interpreting!

“Just that they don't have enough time to meet regularly due to government.”

“Need interpreter. My partner hearing and health visitor hearing so I was not involved or don't know what being said it was hard for my partner to sign and talk time was wasted

“Need support more and give information more as possible.”

“Checked house but didn't explain why. Referred to Sure Start - said they could help me”

“Made suggestions that didn't relate to my child and didn't fully understand the issue.”

“She appeared under trained, disinterested, clinical and ‘ticking it off her list”

Were you generally happy with Health Visitor service?

The 2 deaf parents from Newcastle were not ‘generally happy’ with the service, however the 2 deaf people outside of Newcastle said they were happy.

No = 3 (2 from Newcastle both Deaf)

Yes = 5

Why?

The reasons for dissatisfaction for deaf are focussed on accessibility of communication support – ‘no deaf access’ ‘Need interpreter’ but also a feeling of not enough time. Happy parents stressed the Health Visitor was never hurried and knowledgeable and tries to help.

“No deaf access”

“Been explained see above Also never come my house at right time or day always delays”

“Did what she could and tried to help”

“She is always there to offer advice, never any waiting times. Pick up the phone and I always get an answer.”

“Conversations are never hurried.”

“Very experienced and knowledgeable and she diagnosed his lactose intolerance”

“She offered no support, gave me minimal information and spent about 5 minutes with me.”

Is there anything that could have improved your experience with Health Visitor?

More time; More support; Deaf Aware and Book interpreter please.

“None that I can think of”

“They needed be deaf awareness and they should provide interpreter”

“Make it better for me or everyone, Provide BSL interpreter Give enough information
Come to house on time or day Need Support more”

“Should come round more often when you're struggling. Couldn't get a message to them
- phoned a few times and message not passed on to them.”

“No”

“Bit more time and advice”

“I would have liked longer with her, more time spent talking about things that had
happened, where my daughter was at now, what is next for her. Genuine interest shown,
more information about local groups and at a more convenient time.”

HEALTH VISITOR - CONTACTS, MEETINGS

How often were your Health Visitor appointments?

Every week 3

Once a month 5

Would you have liked more or less visits?

One person said they wanted less visits, one was ‘fine’ and 5 wanted more.

What were the best days and times for your visits?

No consensus.

“Anytime really due to being a maternity leave,”

“Arrange which date when suitable”

“None in particular”

“Late afternoon during the week.”

“Any time as I was on maternity leave at the time.”

“Morning”

How long were the visits?

This varied, the Newcastle HV were 20-30 minutes. Outside of Newcastle it was again 20-30 minutes however one person stated 45mins to an hour. This was a deaf person whose HV had arranged an interpreter and therefore the meeting was lengthier – this is the recommended when using an interpreter double the appointment time. This parent was consistently more positive in their assessment of services.

Were you happy with this?

“Too short” 30m “It's alright” 30 min

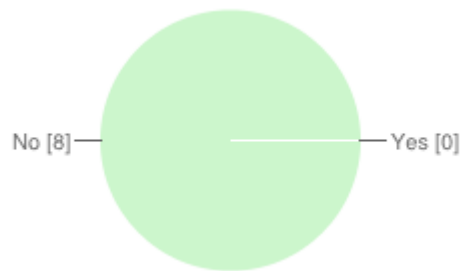
“Too short - always 'running late' checking her watch” 15 m “yes” 20/30 min

“Health Visitor disinterested” 15 min “Happy” 45 min

“Health visitor in a rush” 20min “Yes” 20 min

NTW - EXPERIENCES

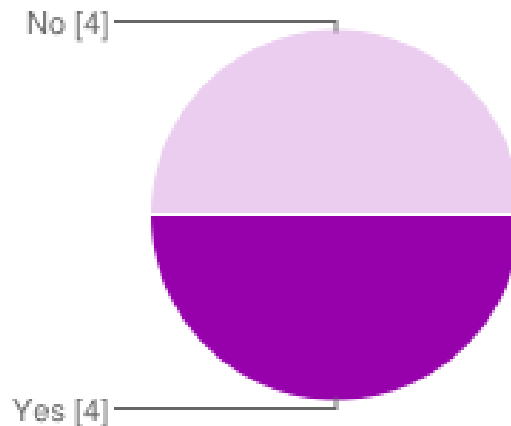
Have you used a NTW Service?



None of our participants had used NTW services or were aware of any services.

SURE START - EXPERIENCES

Have you used Sure Start?



50 % of our respondents had used Sure Start and one of these were deaf, however they did live outside of Newcastle. 1 hearing person had used the Newcastle Sure Start. One Newcastle deaf person wrote “Know nothing about Sure Start”.

How long before you met Sure Start worker?

Two person answered:

“About 6-8 weeks”

“Went along to baby groups and met the workers”

Happy with waiting time?

2 people replied to this and yes, they were happy.

What help or support did you get from Sure Start?

A deaf parent from Newcastle wrote “Baby massage, weaning and activities, but was not able to attend due to communication difficulties”.

Of the people who did use Sure Start their responses varied:

“nothing!”

“Course info and baby social groups”

“Weaning advice, sleep advice”

Was this useful?

Yes 3 0%

No 1 0%

Did you get assessed for additional support from Sure Start?

No-one was assessed for additional support.

Were you happy with the waiting time?

No responses for this question.

Were you happy with the time it took to do this CAF?

No responses for this question.

What was good about the support and help you received from Sure Start?

Another mixed bag of replies.

“Nothing!”

“Hmmm, not sure about this questions.”

“Friendly advice”

What was not good about support and help from Sure Start?

The response from the Newcastle parent was a negative experience not feeling supported or listened to. The Deaf person out of Newcastle area felt that was a lack of accessible information

“Not very good - worker was talking about her family and it didn't really help. Asked me how I was - I explained problems and then she told me that other families have same experiences!”

“Lack of deaf awareness information about early years foundation that baby need to meet.”

Do you feel that the Sure Start services worked for or helped you?

75% of respondents did not feel that Sure Start had helped them.



Is there anything that would have made the experience of using Sure Start better for you?

Better communication skills and Deaf Awareness.

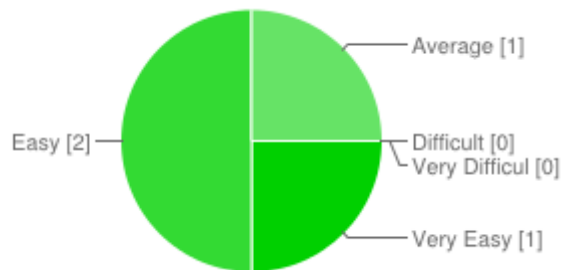
“Increase deaf awareness, set up a group that have deaf parents with deaf or hearing children to enable us to share information,”

“If she had listened and actually acknowledged what I was saying to her.”

SURE START - CONTACT AND MEETINGS

How easy was it to access Sure Start?

The consensus here is that it was easy or very easy to contact Sure Start. However one of the parent who hadn't used Sure Start but wanted to said that this was because of communication difficulties and this is not reflected in this question.



If it wasn't easy - why?

No responses yet for this question.

What were or are the best days and times for you to use Sure Start?

“Anytime”

“Depends on what is happening.”

“Any time as I was on maternity leave”

MORE SUPPORT

Apart from the ones above do you know of other organisation who can help parents - who?

Every parent replied that they didn't know of any other organisation who could help them with the exception of one Newcastle resident who identified toddler groups.

“Local baby/toddler groups. Often, other parents are the best to speak to for advice and support. “

You know any issues that parents might need more support with?

However parents were good at identifying issues that they needed more support:

“Information about early years foundation, weaning, healthy eating, etc. and social interaction, these are imperative for the babies to receive a better start in their life.”

“Need support more by health visitor, they need deaf awareness course to understand deaf people's needed”

“Parenting support after birth of child. Breastfeeding support.”

“Children Sleeping, Very active children and sibling jealousy and how to deal with it. Would have liked them to observe Michael in action and advise me what to do - maybe film him and they watch and tell me what to do differently.”

“Weaning, sleep issues. Lactose intolerance”

Diversity Monitoring

Gender

Female 7 87%

Male 1 13%

Age:

18 - 24 2 25%

35 - 44 6 75%

How would you describe your sexuality?

Heterosexual 8 100%

Please tell us your ethnic background

White - British 8 100%

Do you have a Disability?

3 said yes, have disability and 5 said no disability

What is the first part of your postcode? e.g. NE2

NE3 ne39

NE6 DL3

NE3 Ne27

NE6 NE37