SEND Carers Discussion Group Summary Report

This focus group consisted of two parent SEND carers and one grandparent SEND carer who have all experienced the Health Visiting service. Not all participants answered every question, as it was covered earlier on. The below is an analysis of the responses given.

The questions in the focus group were intentionally phrased differently to the survey questions, but retained the same areas of focus so that they were accessible and enabled greater space for open dialogue and discussions. The focus group followed the same framework of questions as the online survey, but asked in an appropriate way so that participants could more easily understand the questions whilst keeping consistency. This focus group was delivered by representatives from the Local Authority’s commissioning team.

The session was recorded with the permission of participants so that notes could be cross checked after the session for accuracy. Any analysis below has all names and identifying information removed – some quotes may be modified to exclude any potentially identifiable information.

Key messages

- All participants agreed that a partnership between services would be beneficial if changes to the service were made.
- Health visitors with specialised training knowledge of additional needs would be very beneficial to parents of children with SEN.
- Better communication and consistency of service.
- Better links between services to support the child and parent.
- Building trusted working relationships and preference of face-to-face clinics.
- Service gaps for children from 2.5 years to starting school.
- Importance of having someone to touch base with.
- Need for clarity around the health visiting role.

Below is a summary of the responses provided for each question.

What do you like the most about the support you receive?

The discussion moved to experiences of the service and recommendations:

- One participant described their health visiting experience as not so great as it wasn’t supportive. Whilst waiting for diagnosis, “*the nursery and schools would keep referring parents to parenting courses and sleep training which makes the parent feel they are doing a rubbish job at parenting”.*
- Participants felt there was a lack of understanding around complex needs. Health visiting picked up on developmental delay but didn’t initiate EHC (plan) and didn’t understand what the EHC is.
- Participants raised the importance of their Health Visitor able to recognise and acknowledge the traits of complex needs whilst waiting for a diagnosis, noting this would have facilitated an easier journey for the parent.
- One participant shared they have seen a big difference in the level of service from prior to COVID-19 to the present.
- Participants felt that the gap between when the health visiting service support ends and school begins is too long. Children’s needs may be missed, and conditions may not be picked up early enough.

What is the best thing about having this support?

- One participant had a good health visitor experience. Their child has complex needs and they had two health visitors which were the central point of contact and good at contacting other professionals and hurrying things along in other services.

- Another participant explained their health visitor was able to recognise the traits of complex needs. They supported with a referral for a EHC assessment and chased the relevant services for incontinence support.
- Having a named Health visitor and their direct contact details.

How did you hear about Health Visiting? How easy is it to contact the support you need for you and your baby? How important is that to you?

- Participants advised they heard about the service through other professional teams (SALT, IDS, Portage) and from their own research.
- One participant said its "*hugely important" that accessing support is easy*. Prior to COVID, there were regular weigh in clinics. "*It's useful to have regular contact with someone, to have a soundboard and reassure you rather than just having someone to raise issues or concerns"*. A check in with parents sometimes done in an informal chatty way was seen as helpful.

One participant explained *"There should be a specialist health visitor that can understand the impact one child with SEND can have on the rest of the family".*

Have you used any other services/support for you and your child, during the first few years?

- One participant shared they had accessed 'By Your Side' a Mental Health Charity set up by a local mum who had post-natal depression. They noted how you don't have to be referred by a professional but can be. The parent found the do 121 peer support for both pre and postnatal helpful and felt this should be made more visible to new parents.
- One participant advised they know lots of services and charities to help support the different communities and their needs. These charities are picking up activity NHS are unable to do but questioned whether the Health Visiting service is aware of this local support.

Do you feel the right services are available to support you and your baby?

Participants agreed – no.

We asked if there was anything else. Participants added:

- To make the service more accessible. Participants felt the process to request support was arduous. Participants noted their experiences when contacting the service and signposted to online resources where they felt for the presenting need it was more aappropriate for the health visitor to come out and assess the child.
- Participants expressed they needed a greater understanding of what the health visitor role is, what issues can a health visitor support with and what they cannot. They felt that more self-promotion and communicating what the HV team does and who they are would be helpful.
- One participant felt that Health Visitors need to be made aware of the local children centres offer and whether or not there could be a SEND specialist health visitor role.

Participants were then asked to rate how important each of the proposed benefits of the proposal were to them.

How important are these to you? where 10 is very important, 1 is not very important at all.

Number 1. Knowing what services you can go to for support?

All participants said 10.

Number 2. Services who support you working together such as the Family Nurse Partnership, health visiting, mental health support or other support you may need?

All participants said 10.

Number 3. Being able to easily access support.

All participants said 10.

Number 4. Having a regular point of contact, and not having to have any disruption to the support you receive part way through?

All participants said 10.

Number 5. Having the right level of support for your needs, so when things are more difficult you feel you can access/ask for more support and you can have support in a more timely way, rather than a long-time waiting.

All participants said 10.

Number 6. If you have more than one person supporting you, knowing what each does and what to go to them for?

All participants said 10.

Number 7. If you have more than one person supporting you, they talk to each other to ensure you can have the best support available by sharing information and building a better picture of your needs?

All participants said 10.

Number 8. As your child grows, how important is it you can access in different ways support for you and your baby in such as home visits, clinics, online etc.

10/8. Participant added that virtual support is great but in certain areas they may not have the technology. There is a digital divide in some areas.

Number 9. Feeling understood and accessing the right service first time and that your voice is listened to.

All participants said 10.

Is there anything else not mentioned that you feel needs to be considered when trying to make support better for families?

- Better education for the Health Visitor in general on what an EHC is and the impact on the whole family/family bubble.
- Provision of information on what benefits you can apply for.
- One participant noted that if they could change one thing about early years, it would be helpful if they could acknowledge traits that are similar to complex needs. More openness about neurodiversity.

Thinking about what we have discussed so far, about the proposal and the potential benefits, to what extent do you agree that this will be a positive thing for you and your family?

Agree, not sure, Disagree.

- If all the above changes were to happen, participants agreed it would be positive.
- Concerns if a full service cannot be delivered in alignment with population it may create safeguarding issues.
- Participants noted they valued when the service was able to be clear about what can be provided by the service and if an areas, support need cannot, directed effectively to other support.

"Needs an honest admission of what the current state of the service is and what changes realistically can be done".

When we look at designing services and support for mothers and their babies is there anything else we need to consider or keep in mind to ensure you have the best experience and support available?

Nothing more to add.

Equalities Section: Finally, when we consider a proposal like this it is important for us to understand that it may impact different communities and people of different genders, faiths, ages, disabilities and ethnicities differently, as we all can have a different experience of things. Based on what you have heard today, and other information do you feel the proposal will impact well or badly for anyone in society?

- One participant recommended that the LA needs to do a deep data dive, so that areas where it is not initially possible to comment on effect, that wider data sources are utilised. Participants felt demographic and geographic data needs to be used to model the service.