Speech, Language and Communication needs of CYP and families in Suffolk: results of engagement with parents, carers and families

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Introduction

Speech, language and communication (SLC) difficulties can have a significant impact on a child’s health, social and educational needs, as well as outcomes\(^1\). While some speech and language difficulties are evident from birth, others become apparent later on in a child’s life\(^2\). Early identification of a SLC need can ensure that effective support is put in at an earlier stage, reducing the effects on a child’s progress and development.

Recognising this, Suffolk County Council (SCC) together with its partners have mapped universal, targeted and specialist provision, and reviewed services across the providers with a view to developing a new integrated service with clear pathways. The aim of this work is to enhance the universal offer to support the development of speech, language and communication skills of all children, and to ensure that those with identified speech, language and communication needs (SLCN) have their needs met through an effective, efficient and sustainable integrated offer.

This report aims to present the findings from a series of engagement activities undertaken between June – August 2016 with parents, carers and families of children and young people (CYP) in Suffolk. By understanding the experiences and views of families supporting CYP, we can ensure the development of integrated services with clear pathways of support which are appropriate to the needs of the people of Suffolk.

Purpose of Engagement

The purpose of the engagement work was to gain an understanding of the experiences of families in Suffolk in relation to speech, language and communication development (SLC) of their children. In particular, we wanted to know about:

- Level of understanding of SLC development in children among parents/carers
- Views and perceptions of parents/carers about importance of SLC for their children’s development
- Day to day practice that parents/carers do at home to support SLC development
- Views and wishes of parents about available resources in this area
- Experiences of those parents who used local SLC services

Outline of Engagement Activities

Data was collected from parents/carers using an online survey undertaken between June and August 2016. In order to engage parents from different geographical areas different approaches and channels have been used – survey requests were sent to all SCC staff, advertised on parents and carers network websites, sent to all schools via the Suffolk Headlines newsletter, and all children’s centres were contacted both in East and West Suffolk. Despite our effort, the uptake of the participants in each geographical area were not equal, meaning responses were skewed more to East.

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More detailed information was elicited from 29 parents via face-to-face interviews at local children’s centres and libraries across Suffolk and within opportunity groups with parents of children with special educational needs (SEN).

Specifically, interviews were gathered from parents attending children’s centres in Bury St. Edmunds, Leiston, Stanton and Sudbury and a toddler’s session at Ipswich library. Also, parents and carers responded during opportunity groups in Ipswich, Stowmarket and Eye. This has allowed us to reach out to a larger number of parent/carers and understand their views and experiences in a relaxed environment.

It is important to note that interviews were mainly conducted with parents who could be reached in children’s centres, and the group who were interviewed had predominantly never received support from SLC services. This meant that we were unable to follow up views and opinions on SLC services specifically. Participants, did however provide more in-depth information in the ‘comments’ section of the questionnaires, which have been fed back in part 3 of this report. Our observation shows that those who want to share their views are often the ones who have something to say about services or who have children who already experience problems. These limitations should be borne in mind when reading the results.

Results

Part 1: Characteristics of Respondent

In total, 225 people responded to the survey, with the large majority of respondents being parents.

Table 1. Relationship of respondents to the children in their care

<table>
<thead>
<tr>
<th></th>
<th>Parent</th>
<th>Carer</th>
<th>Legal Guardian</th>
<th>Foster Parent</th>
<th>Relative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of respondents</td>
<td>216 (96%)</td>
<td>3 (1.3%)</td>
<td>1 (0.4%)</td>
<td>1 (0.4%)</td>
<td>4 (1.8%)</td>
</tr>
</tbody>
</table>

Almost 40% of all respondents were aged between 30-39, followed by those aged 40-49 (29%) and 21-29 (24%). Just 7 people reported being less than 20 years of age.

Figure 1. Number of responses by Age (percentages rounded to nearest decimal)
Around half of all respondents reported having just one child in their care and around a third of them having 2, with the remaining with more than 3 children.

Figure 2. Number of Respondents by the Number of Children in their care

![Bar chart showing distribution of children by number of respondents.

Although data on the ages of the children of the parents who responded is not available, figure 3 shows that the children attended a range of educational settings. Primary school and day nursery were the most common educational settings amongst the children of respondents with there being fewer parents of older children from secondary schools and academies.

Figure 3. Number of respondents by the number of children in their care

Most people completing the survey reported living in or around Ipswich, however responses were obtained from people living across the different localities in the county. Below is a map showing the number of responses plotted by postcode.
Out of 225 respondents, 90% reported English was their child/ren’s first language and 8% of children spoke English as an Additional Language (EAL).

30% of all respondents reported to have children with disability, and 27% of respondents said their children were receiving (or had previously received) support with speech, language and/or communication. Relatively small numbers of respondents reported having their children as attending special needs schools. Characteristics of children requiring SLC support show that 66% of them were described as having a disability. Recognising that the knowledge and understanding of parents/carers whose children have received support with SLC may be different from those who have children who have never received extra support, the responses from these parents and carers are presented separately in part 3.
Part 2: Knowledge and Understanding of Parents/ Carers

The questions in this part of the survey were aimed at all respondents, and were intended to build a picture of what parents/carers know, what matters to them, what they are doing to support SLC development of their children and what they feel they need support with.

The large majority (80.9%) of 225 respondents believed that speech, language and communication are very important for the development of their children. Approximately one third indicated that they had at some point been concerned about the SLC development of their children.

40% of respondents felt that they knew “quite a lot” about SLC development, 25.6% reported a good understanding, and the remaining (34%) were either unsure or felt they had a limited understanding in this area.

When looking at knowledge in relation to the age of respondents, older age groups reported to have a good understanding and to know quite a lot. In those who felt they had a good understanding, there was a larger proportion of those between the ages of 40-49, despite the fact that the majority of respondents overall were aged between 30-39.

Figure 4. Perceived knowledge of SLC development by age of respondent *proportion of responses from each age group is not accounted for

Over 60% of those reporting having a good understanding about SLC development, indicated that they had previously received information in this area.
Among those who received information previously in this regard, over a third of respondents reported receiving it from a health visitor, another third from either early year’s providers or an education setting, and 20% from Children’s centres and speech therapists.

Midwives, social workers and family support workers were reported as a less likely source of information, however this is expected as not all families have a family support/social worker, and midwives will typically cease their work with parents shortly after birth and the responsibility for discussion about child development will move over to the health visitor. However, although most families will see a GP at some point during their child’s development,
only 5% reported receiving information from their GP on SLC development. This shows families are receiving support from appropriate provisions before contacting their GPs.

Half of all respondents said they had never received any information about SLC development. When asked about where they would go for information and advice about SLC, health visitor, early years/education provider and internet were reported to be favoured sources, followed by Children’s Centre and GPs.

*Figure 7. Number of respondents and where they would go for information on SLC development where respondents could select more than one answer*

When asked about the most useful channels to provide information to parents and carers, over half preferred online methods such as websites and email, followed by face to face communication which was preferred by a quarter of respondents.

*Figure 8. Respondents’ perceptions of the most useful way to provide information where each respondent could only select one option*
We also wanted to understand what parents/carers were doing at home to support the SLC development of their children. Figure 10 provides an overview of the types and frequency of activities.

The responses to this answer provided an indication of general family routines, with the majority of respondents talking and listening to their children more than once a day; sharing play activities at least daily; reading books together daily; attending activity groups weekly; and although less respondents reported attending the library, those who did reported attending once a month or every two weeks. However, there is recognition that because the respondent group was homogenous, this may not account for the routines of families from different backgrounds, geographical areas and community groups.

*Figure 9. no. of respondents indicating type and frequency of activities they undertake with CYP at home*

![Graph showing frequency of activities](image)

**Part 3: Experience of Service Users**

In order to understand the experiences of the services received, specific questions were asked about the effectiveness of contacts with different parts of the system supporting SLC development.

**Education and Early Years Settings**

Overall, almost all 225 respondents reported having good contact and easy communication with their education or early year’s settings. This was supported by parents/carers who were interviewed who highlighted the qualities of good communication with the education and early year’s settings:

**Availability of staff**

Parents/ carers valued staff availability, and reported being happy with the willingness of school staff to provide their time and attention to keeping them informed. This was reflected in comments such as:
“Always happy to give advice and talk about any issues”

“Availability of the teachers is excellent”

“Nursery picked up there was a need…and highlighted it to me”

**Involving parents in the support their child is receiving**

Respondents reported being happy when they felt involved in the support their child was receiving. Further conversations revealed that this involved the staff being approachable, supportive and helpful. On several occasions parents/carers stressed the importance of approachability:

“The pre-school makes a point of being really open and supportive so I feel I could approach them with any concerns”.

“They are approachable and always have time”

“They are very approachable and listen to any concerns you may have”

“the school is really supportive and helpful”

“They work on her speech in the classroom…and have suggested ways we can help at home”

**Use of effective communication tools**

Respondents were positive about the types of tools that were used to communicate in education and learning settings. The use of regular meetings and a two-way diary system were highlighted as effective communication tools:

“My child attends [a] mainstream and special needs school and the communication is amazing. They use a communication book which goes from both schools to home”

“The schools use a two-way diary system which works well, every three or four months we have a catch up meeting which the SLC therapist attends”

“They keep us informed in what the children do at school”

Although more than one parent mentioned the usefulness of the diary system, there was a stress on the need to make sure it is completed, as in some cases this was not the experience the respondents had.

“I fill in the home-school book, but it doesn’t get filled in from the other side”

**Experiences of parents/ carers with children requiring SLC support**

The key themes arising from the survey were largely centred on the capacity of the services, which in turn affected the frequency of communication from the service to parents/carers. We have presented quotes of survey participants below. These quotes represent the views and comments of small number of parents, and may not be a true representation of all parents whose children received services in relation to their SLC needs. This needs to be considered when reading these results.

26.7% of survey respondents (60/225 people) reported that their children had received extra support with their speech, language and/or communication needs. It would have been ideal to follow up this group of parents for more insight understanding, however it wasn’t possible due
to confidentiality and anonymity and none of 29 parents interviewed had any experience with services.

When looking specifically at the SLC needs of these children, the most common difficulties were reported as being social communication difficulties and speech difficulties.

*Figure 10. Main SLC needs of children as reported by respondents *based on responses of 53 out of 60 respondents*

<table>
<thead>
<tr>
<th>Main SLC need</th>
<th>No. of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social</td>
<td>20</td>
</tr>
<tr>
<td>Speech</td>
<td>15</td>
</tr>
<tr>
<td>Other</td>
<td>10</td>
</tr>
<tr>
<td>Under</td>
<td>5</td>
</tr>
<tr>
<td>Slvm</td>
<td>3</td>
</tr>
<tr>
<td>Taking</td>
<td>1</td>
</tr>
</tbody>
</table>

Therapy Service

When asked about communication with the speech and language therapy services, just over half of the 60 respondents who had accessed services (55%) felt that they could contact the therapy service about their children’s needs and felt it was effective (54%). It is important to note that parents referred to Speech and Language Therapy services in general, and didn’t specify which service they had received i.e. NHS or other. In depth comments were provided on the survey questionnaires, and from these some key themes emerged.

Delay in receiving services

Parents expressed concerns about the amount of time it had taken to been seen by the speech and language service. It was clear that some parents were not aware about standard waiting time for some provision. For some parents this led to disengagement and a lack of confidence in the services:

“We held off referrals to speech and language therapists as we knew there would be a significant wait before we were seen”

“We have been waiting for an appointment to see a therapist for about a month”

“I was told my daughter needed speech and language help when she was 2 and a half…But she didn’t see a therapist until a year and a half later. That is too long to wait. I know several mums who have paid to go privately at £70 an hour because of the delay”
Communication
Parents/carers expressed concerns about the lack of communication they received from the therapy services. Phrases such as “little communication”, “I never hear anything” and “No response” were used on more than one occasion.

“I emailed my SALT regarding a report and had no reply, then I tried again and received the report but had no response. I don’t really feel supported or confident”

Respondents reported wishing for an update, but receiving little communication and feeling like they didn’t know who to contact. This left some parent/carers feeling unvalued:

“I don’t know who to contact. [I feel] parental concerns are played down and not treated sensitively”.

“It was extremely hard to communicate…I often end up leaving messages with people in the office which never got answered”

“More contact information is needed”

Capacity of Services
There was a recognition among parents that the SLC services were stretched, and phrases such as “overwhelmed system” were used to describe their perceptions of the support available. They also highlighted the effects this had on the support their children were receiving:

“There have been major cutbacks in speech and language therapy over the last 12-18 months which has meant my son has gone from having weekly sessions with a therapist, to quarterly, and now he has been signed off despite still having SLC delay”

“I think the main problem with the service is the lack of speech therapists that are available, so my child only gets to one very occasionally even though he is at special school”

Expanding on this, some parents/carers offered acceptance that this was the reality of services, and stressed the important role earlier intervention and use of universal services could play in improving support:

“We have been lucky that our son’s nursery has taken a keen interest in supporting his early year’s development, and are probably best placed to meet his needs as they see him regularly. Please support nurseries to do this”

“I know resources for SALT is very limited…it would be really useful to have a tool for nurseries to assess your child, with resources to then work on with support of a SALT”

“It is important to train teachers in identifying SLC problems”

“Information on speech and language could be incorporated into the 2 year check to provide more information and ask more questions about speech and language development”

In general, the majority of parents indicated that once they had a received a service that communicated regularly, their experience was very good.

“Once we got the support it was great”

“Found the services to be spot on”
Local Authority

Just over half of these 60 survey participants who’s children received some extra support for their SLC needs reported that contacting the local authority was problematic. 61% stated that they don’t know who to contact within the local authority.

When asked whether there was anything more the current services could do for parents/carers and their children, 44 people responded to this question. Approximately 20% of these 44 respondents indicated that better communication would help to improve services and another 20% suggested that they would like the service to provide workshops or training opportunities for parents and families.

Figure 11. % of participants indicating areas for service improvement

Dissemination of Information on SLC Development

We were also interested in where else respondents would go to discuss the speech, language and/or communication needs of their children, in order for us to capture some of the wider system of support. Over half (54.9%) of all 225 survey respondents reported that they would go to health professionals. Around 20% of respondents also reported that they would use other support such as other parents and carers, opportunity groups, children’s centres, private therapists and school nurses.
What can we do better?
Responses from survey and conversations with parents at different settings highlighted a number of areas to be considered to ensure they are responding to families in an effective and more supportive way.

Parents and Carers voices are valued
One theme which emerged is the need to place parents and carers in the driving seat for their children’s care. This involves allowing their opinions to be valued and providing opportunities for them to voice their views. A number of parent’s expressed their concerns that this was not always the case:

“To make communication even better, it is important to allow the parents to remain in the driving seat and to be fully involved in conversations and plans for their child’s development. As an older mum, I have taken a career break and pay cut to fully embrace the role as a mother so would actually like to own that role”

“It would be good to have more engagement and more opportunities to share our views to shape services”

“Parents are not given a choice to voice concerns”

“She [therapist] doesn’t listen to us as parents”

Information is provided at an earlier stage
Many parents/carers felt there would be a benefit in providing information earlier, to ensure they felt confident in understanding what their children should be doing at certain ages to develop good speech and language skills.

“It would be useful to be given information on interesting ways to improve their speech, in fun creative ways. For a first parent it’s a learning curve and this could be helpful”

“I feel I need extra information as I can only compare him to other children his age”

“I could have benefited from extra information and support as a mum. This would have been good face to face to tell me what I could be doing to support him at home”
Some of the respondents felt that if they didn’t have any concerns, then they wouldn’t really identify a need for further information. However, the majority of parents/carers felt they would welcome extra information and that this in turn would help them feel more informed.

Some parents went on to talk about the best ways to provide this information, and many felt that children’s centres were ideally placed to do so:

“Make sure more parents know about children’s centres as they are easily accessible, and have a relaxed atmosphere in which you can get support for both yourself and your child”

“have leaflets available in children’s centres to provide information because people don’t always like to ask for help and advice”

“I feel well informed as it [SLC] has been brought up in classes and groups and on posters and leaflets in children’s centres”

These reflections highlight the fact that more can be done in universal services, prior to the identification of a specific SLC need.

Conclusion

It is important to bear in mind the limitations of this engagement exercise when looking at the results. The sample of parents that responded are likely to be those who have engaged with the services already or have concerns about the SLC needs of their children. Indeed, the survey showed that one third of the respondents stated SLC was a concern for them. Although concerted effort was made to engaging participants from across Suffolk, respondents were disproportionately from East Suffolk. In terms of educational settings, children of respondents were mainly from non-specialist schools and in the younger age groups. This is to be expected as it is the younger ages where SLC needs are becoming apparent. Comments in the report come from face to face interviews as well as from the online survey. They are useful in providing depth and context to the answers but do only come from a minority of respondents that have been in touch with the services thus responded to this exercise.

Overall, the engagement activities highlighted some areas of strength in terms of service provision in Suffolk. Namely, the effective communication from education and early year’s settings, the quality of support once speech and language services are received, and the useful role that children’s centres can play in disseminating information and supporting parents/carers with the SLC needs of their children. However, it also brought to light some key areas of improvement including more efficient and effective communication with parents about the care of their children, involving parents/carers in process of supporting their children and providing opportunities for them to share their views, and improving the ability of services to respond more quickly to concerns to ensure support is put in at an earlier stage. Early prevention and identification of issues relating to SLC was very important to parents, they suggested both online and face to face information and education on developmental milestones, the ways parents can support their children and who to go to (with contact details) when issues arise.