MARCH 2021

## **RCSLT REPORT**

## Speech and language therapy during and beyond COVID-19: building back better with people who have communication and swallowing needs



## Speech and language therapy during and beyond COVID-19: building back better with people who have communication and swallowing needs

Dr Judy Clegg, Head of the Division of Human Communication Sciences, University of Sheffield

Padraigin O'Flynn, External affairs assistant, Royal College of Speech and Language Therapists

Peter Just, Head of external affairs, Royal College of Speech and Language Therapists

March 2021

#### #BuildBackBetterSLT

### Contents

Contents	2
Introduction	3
Executive Summary – people aged 18 and over surveys	5
Executive Summary – 0-18 surveys	9
Policy implications for people with communication and swallowing needs	12
Wider policy context	16
Design and analysis of the survey	18
18 years and over survey: descriptive data and analysis of the survey findings	22
0-18 years survey: descriptive data and analysis of the survey findings	47
Accessible (Easy Read) 18 years and over survey: descriptive data and analysis of	of the
survey findings	74
Accessible (Easy Read) 0-18 years survey: descriptive data and analysis of the su	irvey
findings	90
Aphasia-accessible survey: descriptive data and analysis of the survey findings	103
APPENDIX	117

### Introduction

COVID-19 has changed all our lives. For some, though, it will have repercussions that last for years to come, affecting their education, work, family life and mental health.

The UK-wide lockdown between March and June 2020 had a significant impact on the lives of people with communication and swallowing needs. It also had an impact on speech and language therapists' ability to support their clients, either because services were stopped or because speech and language therapists (SLTs) were redeployed to other roles.

The Royal College of Speech and Language Therapists (RCSLT) salutes how SLTs across the United Kingdom have adapted and continue to adapt the delivery of services in response to lockdown measures so they can meet the needs of their clients. These adaptations have included the greater use of telehealth, the training of other staff to support their work and changing usual working styles.

While this enabled some people with communication and swallowing needs to continue to receive the speech and language therapy they and their loved ones needed during lockdown, not everyone has been so lucky.

As lockdown went on, the RCSLT became increasingly concerned about the ability of people with communication and swallowing needs to access the speech and language therapy they require. Our members told us about their worries about not being able to provide speech and language therapy to their clients. Charities representing people with communication and swallowing needs shared their concerns with us too and we also heard directly from people with such needs themselves.

To understand the impact of lockdown on access to speech and language therapy and to inform its response, the RCSLT decided to undertake a survey of service users' experiences. It wanted to hear what people with communication and swallowing needs thought about their access to speech and language therapy in lockdown, any new ways their speech and language therapy was delivered, the impact of this on their lives and on the lives of their families and carers, and what they thought about the future.

The RCSLT is very pleased that despite the pandemic and the barriers to full participation that some people with communication and swallowing needs have faced and continue to face, so many people were still able to share their experiences with us.

To give just one example of a participation barrier, local support groups have often not been meeting.

Given these known barriers to participation, the survey findings represent, potentially, just the tip of the iceberg of the challenges facing people with communication and swallowing needs.

This report tells the stories of over 500 people and their families and carers. It also provides us all with a blueprint with which together we can build back better with people who have communication and swallowing needs.

The RCSLT is deeply grateful to everyone who took the time and trouble to fill out the survey. To you, we say, 'Thank you very much for sharing your experiences with us. We hope that these will help to make everyone's lives better.'

## Executive summary – people aged 18 and over surveys

The key findings of the main survey of people aged 18 and over are as follows.

#### Number of respondents

- The surveys for people aged 18 and over received a total of 100 responses.
- 77 responses were received to the main 18 and over survey; 7 for the accessible (Easy Read) 18 and over survey; and 16 for the aphasia-accessible survey.

#### Profile of respondents completing the main 18 and over survey

- More than half of survey respondents (51%) were adults who were having or had had speech and language therapy at the start of lockdown. 43% of respondents were family members/carers.
- The majority of respondents (81%) lived in England. 9% lived in Scotland, 5% in Wales and 5% in Northern Ireland. This matches the breakdown of populations across the United Kingdom.
- 50% of respondents were aged 50 and over. 17% were aged between 18 and 25. The remaining 33% were aged between 25 and 50.

#### **Respondents' conditions**

 A range of conditions were identified by respondents. Some identified more than one condition indicating complex comorbidities. Neurological conditions included Parkinson's Disease, stroke, brain injury, motor neurone disease, multiple sclerosis and dementia. Other conditions included learning disability, autism, hearing loss/deafness, stammer, mental health difficulties and persisting developmental language disorders.

#### Respondents' speech and language therapy

- More than two-thirds of the respondents (68%) were having or had received speech and language therapy before March 2020.
- Prior to the lockdown, the majority of these people were having or had received speech and language therapy for speech, language and communication; 10% for eating and drinking; and 14% for both.
- Before lockdown, 85% received speech and language therapy in person across a range of settings and 15% received speech and language therapy online or by telephone.

#### What happened during lockdown (March–June 2020)?

- After lockdown started in March 2020, there was more than a 50% reduction in access to speech and language therapy for survey respondents. Pre-lockdown, 68% were having speech and language therapy. After March 2020, only 33% did.
- During lockdown, only 16% of the respondents received the same amount of speech and language therapy as before lockdown. More than half of the respondents (52%) received less speech and language therapy, with 44% not receiving any speech and language therapy during this time.
- A range of reasons were given for the reduced speech and language therapy received during lockdown, including cancellations by speech and language therapy services and service users cancelling appointments. Nearly two-thirds of the cancellations reported (62%) were initiated by speech and language therapy services.
- People who received speech and language therapy during lockdown did so in a variety of ways, including in person, via telephone and online/telehealth. There was no clear consensus as to the perceived effectiveness of telephone and online/telehealth delivery. Respondents reported on the difficulties of telephone and online/telehealth delivery.

#### What was the impact of less speech and language therapy during lockdown?

- Overall, lockdown had a negative impact on adults' communication and eating/drinking. Nearly half of the respondents (43%) reported their communication and eating/drinking stayed the same and 28% reported it was worse.
- A decline in mental health was the area of impact highlighted most by the respondents (56%). This was followed by social life and friendships (54%), and home and domestic life (51%).

#### What happened after lockdown ended?

• From the end of lockdown (June 2020), 76% of the respondents were not receiving any in-person speech and language therapy provision.

#### What happened in the most and least deprived areas of England?

- Responses reveal a difference between the most deprived areas and the least deprived areas in terms of access to speech and language therapy in England for adults over the age of 18.
- A higher percentage of respondents from the most deprived areas received less speech and language therapy during lockdown than people from the least deprived areas 50% and 42% respectively.

- A lower percentage of respondents from most deprived areas received in-person speech and language therapy during lockdown than people from the least deprived areas 17% and 27% respectively.
- 58% of respondents from the most deprived areas reported receiving no inperson speech and language therapy during lockdown. The figure in the least deprived areas was 32%.
- 17% of respondents in the most deprived areas received face-to-face speech and language therapy after lockdown in the least deprived areas the figure was 30%.
- 83% of people in the most deprived areas reported not having face-to-face speech and language therapy after lockdown. In the least deprived areas, the figure was 70%.

#### What do people think about the future?

- Almost half of the respondents (49%) are concerned about being able to receive speech and language therapy in the future.
- They were concerned that a lack of access to speech and language therapy would make their lives worse.
- 65% highlighted the impact this would have on their social life and friendships.
  61% highlighted their mental health. 37% highlighted their home and domestic life.

#### What do people think about speech and language therapy?

- Speech and language therapy improves the lives of people with communication and eating and drinking difficulties. It also improves the lives of their family members and carers. Respondents were clear about this.
- 76% said speech and language therapy makes their life better.
- 29% said it makes their carer's life better.

#### What do people who filled out the accessible surveys say?

- While the small numbers of accessible survey responses make it difficult to identify trends as clear as those from the main survey, they do mirror the findings highlighted above.
- More detail is given in the descriptive data and analysis of the accessible 18 and over survey and aphasia-accessible survey below.
- Specifically, on the aphasia-accessible survey, it highlighted interesting, if slight, differences to the other 18 and over surveys:
  - There is some indication that people with aphasia received more in-person speech and language therapy than in the other surveys.

- People receiving speech and language therapy online or via video call were more positive about this than in the other surveys.
- There is some indication that more of these respondents reported that their communication got better during the lockdown.

### **Executive summary – 0–18 surveys**

The key findings of the main 0–18 survey are as follows.

#### Number of respondents

- The surveys for people aged 0–18 received a total of 425 responses.
- 414 responses were received to the main 0–18 survey and 9 to the accessible (Easy Read) survey.

#### Profile of respondents completing the main 0–18 survey

- The majority of the respondents (83%) were family members/unpaid carers of children and young people with speech, language and communication difficulties. These respondents completed the survey on behalf of their children and young people.
- The remaining respondents included children and young people with speech, language and communication difficulties, paid carers, and education and health professionals.
- The majority of the respondents (74%) lived in England. 17% lived in Scotland, 6% lived in Wales and 3% lived in Northern Ireland. 1 (0.2%) lived on the Isle of Man. Scotland is over-represented and England under-represented in relation to their populations.
- Approximately half of the responses (51%) were about people aged 5 to 11 years and 31% aged 0 to 4 years. 16% were aged 12 to 18 years.

#### **Respondents' conditions**

 A range of conditions were reported for these children and young people. Conditions included developmental delay, learning disability, developmental language disorder, autism, hearing loss or deafness, speech sound disorder, brain injury, stammer, ADHD, cleft lip and palate and selective mutism. Most respondents reported more than one condition.

#### Respondents' speech and language therapy

- The majority of respondents (88%) were in direct receipt of or had received speech and language therapy before March 2020, with fewer (only 12%) from March 2020 onwards.
- Before the start of lockdown, the majority (98%) received speech and language therapy for speech, language and communication. Prior to the start of lockdown in March 2020, all respondents received speech and language therapy in person at schools, colleges, homes and other locations.

#### What happened during lockdown (March–June 2020)?

- All respondents reported changes to their receipt of speech and language therapy. Only 10% received the same amount of speech and language therapy before and during lockdown. The majority (81%) received less speech and language therapy, with a very small proportion (2%) receiving more. More than half of the respondents (62%) did not receive any speech and language therapy during lockdown.
- A range of reasons was given for the reduced speech and language therapy received during lockdown. speech and language therapy services cancelling appointments was the most common reason due to the closure of schools and colleges, and the redeployment of speech and language therapy services.
- Experiences of the delivery of speech and language therapy during lockdown included in-person, telephone and online/telehealth. Experiences of phone and online/telehealth delivery were mixed, but did indicate some satisfaction with this mode of delivery.

#### What was the impact of less speech and language therapy during lockdown?

- Overall, lockdown had a negative impact on children and young people's speech, language and communication.
- Nearly half the respondents (47%) reported their communication stayed the same and 24% reported it was worse.
- A negative impact on education (67%), social life and friendships (59%) and mental health (45%) were the most cited ways in which people said their lives had got worse.
- For family members and carers, the areas most impacted were their home and domestic life (64%).

#### What happened after lockdown ended?

• From the end of lockdown (June 2020), 73% of respondents were not receiving any in-person speech and language therapy provision.

#### What happened in the most and least deprived areas of England?

- Responses reveal a difference between the most deprived areas and the least deprived areas in access to speech and language therapy in England for children and young people.
- Respondents from the most deprived areas received less speech and language therapy during lockdown than people from the leastst deprived areas 82% and 80% respectively.
- Interestingly, a higher percentage of respondents from the most deprived areas

reported receiving more speech and language therapy during lockdown than people in the least deprived areas – 4% and 1% respectively.

- A lower percentage of respondents from the most deprived areas also received in-person speech and language therapy during lockdown than people from the least deprived areas 7% and 13% respectively.
- 71% of respondents from the most deprived areas reported receiving no inperson speech and language therapy during lockdown. The figure in the least deprived areas was 58%.
- 22% of respondents in the most deprived areas received face-to-face speech and language therapy after lockdown. In the least deprived areas the figure was 39%.
- 78% of respondents in the most deprived areas reported not having face-to-face speech and language therapy after lockdown. In the least deprived areas the figure was 64%.

#### What do people think about the future?

- 79% of respondents were concerned about being able to access speech and language therapy in the future.
- They were concerned that a lack of access to speech and language therapy would make their lives worse.
- 82% highlighted the impact on education. 74% highlighted the impact on social life and friendships. 60% highlighted the impact on mental health.

#### What do people think about speech and language therapy?

- There was a clear consensus that speech and language therapy improves the lives of children and young people with speech, language and communication difficulties and the lives of their family members/carers.
- 76% said that speech and language therapy makes their life better.
- 29% said that it makes their carer's life better.

#### What do people who filled out the accessible surveys say?

- While the small number of the accessible 0-18 survey responses makes it difficult to identify trends as clear as those from the main survey, they do mirror the findings highlighted above.
- More detail is given in the descriptive data and analysis of the accessible 0-18 survey below.

## Policy implications for people with communication and swallowing needs

#### Introduction

The ability to communicate and eat and drink safely are basic human rights.

Communication is central to who we are and how we interact. It is key to our families, friendships, education, physical and mental health and wellbeing, jobs, leisure activities, and our role in society. Being able to eat and drink safely is central to enjoyable mealtimes, socialising and communal activities.

As we build back better, it is essential that people of all ages have their communication and swallowing needs identified and appropriately supported, including through the provision of speech and language therapy where required.

This is not only a matter of basic human rights. It also makes sound economic sense. Investing in speech and language therapy services now can reduce the risk of wasted public resources down the line. It can also help to prevent the development and escalation of mental health problems.

#### What happened during the first UK-wide lockdown?

We know that some people with communication and swallowing needs continued to receive the speech and language therapy they required during lockdown (March-June 2020). Some survey respondents reported positive experiences. We are proud of those speech and language therapy services that were able to continue supporting people, including through new ways of working and delivering therapy in different ways.

But, sadly, these positive experiences were not shared by all. Far from it.

We know that before the pandemic many people did not have their needs identified and did not receive the speech and language therapy they require. We know that many of those who did receive speech and language therapy before COVID-19 had it stopped during lockdown or delivered in ways that were difficult for them to access. With services being suspended, many people did not have their needs identified, let alone met, and they have gone too long without the support they require. We know that many people will now be in the process of having their needs identified, but will face significant waiting lists for the therapy they need.

We also know that health inequalities have widened, significantly exacerbating existing speech, language and communication inequalities that have existed for too long, particularly in areas of social disadvantage and among certain ethnic groups.

The survey findings are clear: a higher percentage of people of all ages in the most deprived areas in England received less speech and language therapy during lockdown than in the least deprived areas. In addition, a higher percentage of respondents in the least deprived areas than the most deprived areas received in-person speech and language therapy during lockdown. Similarly, after lockdown ended, a higher percentage of people in the least deprived areas than the most deprived areas than access to face-to-face speech and language therapy.

So, as we build back better with people who have communication and swallowing needs, we must also finally level up and tackle the significant communication inequalities that exist across the United Kingdom.

#### What are the implications for speech and language therapy services?

The challenge facing us is huge, both for people with communication and swallowing needs and their families, and for the speech and language therapy services so keen to work with them to achieve better outcomes so they can live the lives they wish to live.

The identification and intervention backlog facing speech and language therapy services is significant. This includes the need to provide therapy to people with long COVID, a brand-new clinical area, and increasing recognition of the links between communication and swallowing in mental health services.

The RCSLT will be sharing the important findings from this survey with its members to support their plans fully to restart their services. The RCSLT will also be using the findings to inform its own practice, including in its policy and influencing work, and in its work with service user organisations and service users themselves.

#### Turning challenge into opportunity

While huge, the challenge we face is also an opportunity – an opportunity to build back better. If we are to do that successfully, we must also level up.

Now is the time to ensure an equality of access to speech and language therapy. Access must be based on a person's individual needs, not on factors such as their postcode or ethnicity. It must be based on the only thing that matters, what they and their families and carers actually need. Some of this building back better and levelling up can be achieved by new ways of working. The survey responses showed that for some people, online therapy worked and we know of and are very proud of some outstanding speech and language therapy services that are delivered via telehealth.

But telehealth is not the solution in every situation. That is not just a question of digital poverty and a lack of digital literacy, it is also a question of an individual's personal preferences; and, as some survey responses showed, it may also be due to the particular condition they have or the age of the person with a communication or swallowing need, at both ends of the age range. People who are deaf highlighted the particular challenges they face with online therapy. It is also important to note that some of the people who filled out the survey reported that some NHS services themselves were unable to deliver online therapy.

#### What needs to happen

If we are really to seize on the opportunity that presents itself to us, the following action needs to be taken by the UK Government now:

- **National and local recovery policies** must identify and provide appropriate response to an individual's needs and specifically:
  - support for children and young people's communication and language development should be central to education recovery plans;
  - support for adults' communication and swallowing should be integral to the restart of rehabilitation services; and
  - given the clear links between communication and swallowing needs and mental health, speech and language therapy should be recognised as an integral part of the recovery plan for mental health services.
- **Speech and language therapy services** must be appropriately resourced to ensure that:
  - the increase in demand, among people of all ages, for speech and language therapy services as a result of the pandemic (including those with long COVID) can be addressed;
  - those who have developed a higher level of need due to delays in identification and reduced support during the pandemic can be supported;
  - staff who have been redeployed to other parts of the NHS are able to return to their substantive posts as soon as possible; and
  - SLTs are able to play their vital role in protecting and promoting the general mental health and wellbeing of people with communication and swallowing needs, and their family and carers – this could potentially reduce the risk of people then needing to access mental health services.

#### The future

If the UK Government delivers in these areas, speech and language therapy services will be in a much better position to work with people who have communication and swallowing needs to build back better and to level up.

Let 2021 be the year when we finally successfully tackle all the forms of unwarranted variation facing people with communication and swallowing needs. They and their families and carers deserve nothing less. As a country, we must not fail them. If we do, we will be failing all our futures.

### Wider policy context

The stories people have told us about their access to speech and language therapy during lockdown echo what other surveys have found since the beginning of the COVID-19 pandemic, including those by charities and other organisations.

Crucially, they also corroborate what SLTs have reported – the data from the users of speech and language therapy services have told us the same stories as the data from speech and language therapy services have told us.

#### Other organisations' surveys

Surveys undertaken by various charities and other organisations of the experiences of their beneficiaries and/or the professionals who work with them since the start of COVID-19 have found similar themes to those reported by respondents to the RCSLT survey.

Details from these surveys are included in the APPENDIX and include findings from Stamma, the Northern Ireland Assembly's All Party Group on Learning Disability, MENCAP, Parkinson's UK, the Neurological Alliance, the Alzheimer's Society, the MS Society, the Stroke Association, Cerebral Palsy Scotland, The Swallows, The Family Fund, the Disabled Children's Partnership, Ulster University and Ofsted.

Many of the themes people identified to us from lockdown persist with services not being back to their pre-pandemic levels. Recent surveys from the Disabled Children's Partnership and Special Needs Jungle, also detailed in the Appendix, highlight this.

On the postcode lottery of access to speech and language therapy for children and young people in England, this was the subject of a major report from the Children's Commissioner for England in June 2019.

#### **RCSLT** member surveys

What people have told us about their experiences of accessing speech and language therapy during lockdown has also been echoed by surveys of its members that the RCSLT has undertaken. Responses from SLTs to a survey conducted between August and September 2020 found the following:

#### Children and young people

For children and young people:

- Referrals were down by 50% in April–May compared to 2019.
- There was improvement by June–July, but they were still down by about a third.

- 90% said there were children on their caseload who had not received intervention (but would usually have done so) since the start of the pandemic.
- Common reasons for this were that the venue where intervention would normally be provided was closed; that delivering the intervention remotely was either inappropriate or not accessible to the child; or because of staff availability – many services were working with reduced capacity due to a combination of staff sickness, shielding and redeployment.
- Nearly a third of respondents reported that they had observed or been informed about a deterioration in the speech, language and communication of the children they support.
- Almost half reported the same about an increase in challenging behaviours.

#### Adults

For adults:

- Referrals were down by 28% in April–May compared to 2019.
- 72% said there were adults on their caseload who had not received intervention since the start of the pandemic.
- 44% reported a deterioration in speech, language and communication skills for many or some of the adults that they support.
- 43% reported a deterioration in swallowing function for many or some of the adults that they support.
- 36% reported an increase in challenging behaviours for many or some of the adults that they support.

#### **Overall conclusions**

Overall, our members have told us:

- Referrals to speech and language therapy services during the acute COVID-19 period in the UK were substantially less than in the same period in 2019.
- A number of service changes were common, including adopting more flexible approaches to provision (such as teletherapy) and being unable to provide services to some patients.
- Fewer patients have accessed speech and language therapy since the pandemic began, including a reduction in neurorehabilitation patients.
- For those who received speech and language therapy, the outcomes did not change.
- SLTs supported a range of needs of COVID-19 patients.
- Treatment outcomes for COVID-19 patients with dysphagia were positive.<sup>1</sup>

<sup>&</sup>lt;sup>1</sup><u>https://bit.ly/2O2ZRPC</u>

### Design and analysis of the survey

The survey was launched at the start of November 2020 and ran until the start of February 2021. It was designed over the summer of 2020.

#### **Consultation on survey questions**

Consultation on the questions to be included was undertaken with service user organisations over the summer of 2020. The RCSLT is very grateful for the feedback it received from:

- Action for Stammering Children
- Afasic
- Autistica/Embracing Complexity Coalition
- CICS (Children's Cochlear Implant Support Group)
- CLAPA (Cleft Lip and Palate Association)
- Communication Matters
- I CAN
- Motor Neurone Disease Association
- MS Society
- NDCS (National Deaf Children's Society)
- Stamma
- The Stroke Association

We also received feedback on the questions from service users.

We are also grateful to speech and language therapists Najma Timms and Sian Critchett for their advice.

#### Accessibility of the surveys

From the start, the RCSLT wished to remove any potential communication barriers to people telling us about their experiences.

We wanted to ensure that the survey would enable people with communication and swallowing needs to tell us their stories in whatever communication style suited them. The RCSLT was also clear: where people were not themselves able to tell us about their experiences, their loved ones and carers could do so on their behalf. We also wished to hear about their experiences too, because access to speech and language therapy does not affect only people with communication and swallowing needs. It also affects their families and carers.

Therefore, between September and November 2020 the RCSLT worked with speech and language therapists and others to make the survey both accessible to everyone, no matter how they communicate, and available in a range of inclusive formats, including Easy Read, aphasia-accessible and Talking Mats.

The speech and language therapists included:

- Viki Baker
- Lois Cameron
- Natalie Elliott
- Catherine Harris
- Dr Caroline Haw
- Laura Holmes

Others who helped with accessibility included:

- Lucy Westcott, the learning disability participation lead at the Sussex Partnership NHS Foundation Trust
- Melanie Derbyshire and Caitlin Longman (a speech and language therapist) from the Stroke Association

The RCSLT also received further advice and support on accessibility from speech and language therapists, Dr Abi Roper and Martina Curtin.

The RCSLT is deeply grateful to Viki, Lois, Natalie, Catherine, Caroline, Laura, Lucy, Melanie, Caitlin, Abi and Martina for all their help, advice and support with the survey and its promotion.

We are pleased to have extended the deadline of the Talking Mats survey until 30 June 2021 so we can also hear from people about their experiences of the current lockdown.

#### **Survey formats**

All versions of the survey were available in electronic format, via Google Forms. They were also downloadable from the RCSLT website in Word and PDF. A QR code was made available linking to the survey web page. The survey was also available in Welsh.

Recognising that not everyone has the same level of digital access, paper versions of all the surveys were available on request.

#### Testing of the surveys

The surveys were tested with service users, both parents of children and young people aged 0–18 and people who were having or had had SLT.

The RCSLT is very grateful to:

- Dave Harford and Steve Hermon, two parents who tested the survey.
- Toby Hewson and Helen Hewson (nee Quiller) who both use augmentative and alternative communication (AAC) for their input and help in testing accessibility on screen readers.
- The Stroke Association, which tested the aphasia-friendly survey with people with aphasia. We owe particular thanks to Janet Rockliffe and Heidi Matthews, both of whom have aphasia. Janet and Heidi took part in two sessions, each 90-minutes long, as well as a third session to review the final survey.

#### Promotion of the surveys

The survey was promoted to RCSLT members in a direct, personal email, through social media and in its e-newsletter. There was extensive promotion on Twitter via @RCSLTpolicy and @GivingVoiceUK.

Service user organisations disseminated the survey to their beneficiaries through a variety of means, including Twitter, Facebook, online fora, and in newsletters and magazines.

#### Analysis of survey findings

The survey findings were analysed and this report has been put together by Peter Just, Padraigin O'Flynn and Dr Judy Clegg BSc, PhD, FRCSLT.

Judy is a speech and language therapist by background and now works at the University of Sheffield where she is Head of the Division of Human Communication Sciences. She leads research into the speech, language and communication needs of vulnerable children and young people and teaches the next generation of SLTs. Judy is a Fellow of the RCSLT and a Trustee of ICAN, the children's communication charity.

The RCSLT owes a massive debt of gratitude to Judy for her tireless support of this project and for giving so generously of her time and advice in the design of the survey, the analysis of the survey findings and in the writing of this report.

Judy was supported in analysing the findings by Padraigin O'Flynn, the RCSLT's external affairs assistant. With a background in research methods from the fields of politics and economics, Padraigin designed the format of the surveys and led the data

collection process. Padraigin also led on the data analysis by identifying, extracting and collating the key data from the survey for the descriptive analysis.

Peter is the RCSLT's head of external affairs and led on engagement with charities and service users in the development, design and promotion of the survey. Along with Judy and Padraigin, he authored this report.

## 18 years and over survey: descriptive data and analysis of the survey findings

There were 77 responses to the adult 18 years and older survey. For some questions, responses were received from all 77 respondents. For other questions, responses from a smaller sample of the 77 respondents were received. The number of respondents completing each question is given in the description of the results. The design of the survey meant for some questions respondents were able to select more than one option, often selecting 2 or 3 responses. The descriptive results are described in detail for each question.

The questions and the results are grouped into five sections and the questions addressed in each section are given.

- Section 1 gives the demographic data about the respondents who completed the survey.
- Section 2 describes the respondents' background history of receiving speech and language therapy.
- Section 3 describes the respondents' experiences of speech and language therapy during lockdown (March to June 2021).
- Section 4 describes the delivery of speech and language therapy during lockdown (March to June 2020) and the respondents' experiences of this.
- Section 5 details the respondents' experiences of speech and language therapy during and after the end of lockdown.

The quantitative descriptive data is given along with the qualitative data. Qualitative data originates from the free text comments for some of the questions. These comments have been grouped into categories for ease of reference.

#### Section 1: Demographic data of the respondents

The demographic data is presented first. This data was obtained from the following questions:

Question 1: What is your postcode?

Question 2: Which country do you live in?

Question 3: Please tell us who you are.

Question 30: How old are you?

Question 31: How would you describe your gender?

Question 32: What is your ethnicity?

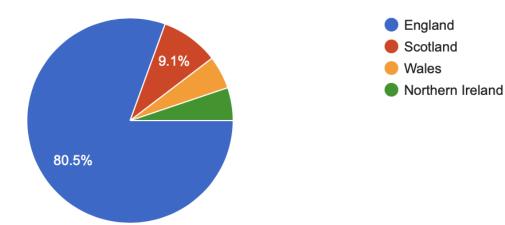
#### Who were the respondents?

77 people completed the survey.

- More than half were adults who were receiving or had received speech and language therapy at the time of the survey (n=41) (51%).
- Of the 36 remaining respondents:
  - 33 (43%) were family members or unpaid carers.
  - $\circ$  3 (4%) were paid carers.
  - 2 (3%) were healthcare providers.
  - $\circ$  1 (1%) was an adult trying to access speech and language therapy.

#### Country

- The majority of respondents lived in England (n=62) (81%).
- 7 (9%) lived in Scotland.
- 4 (5%) in Wales.
- 4 (5%) in Northern Ireland.



#### Postcode

Of the 77 responses, there were 48 with valid postcode entries. The other 29 postcode entries were either incorrect or from Scotland and Wales. The English indices of deprivation (Ministry of Housing, Communities and Local Government 2019) were used to obtain data about the level of deprivation of each postcode. The indices use categories of income, living environments, employment, education, skills and barriers to housing and services. The English Indices of Multiple Deprivation (IMD) were used to identify the IMD decile for the postcodes for these 48 respondents. The IMD decile range from 1 (10% most deprived) to 10 (10% least deprived). The following table shows the decile rankings of the postcodes of the 48 respondents.

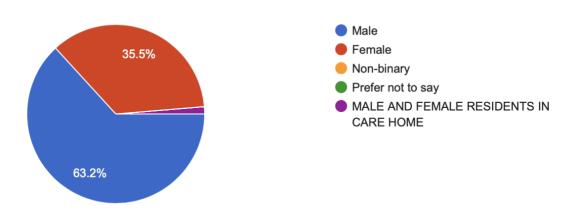
IMD Decile	Number of respondents (n=48)	Percentage of respondents
1 Most deprived	1	1.3
2	3	3.9
3	4	5.2
4	3	3.9
5	1	1.3
6	10	13.0
7	10	13.0
8	5	6.5
9	6	7.8
10 Least deprived	5	7.8
Total	48	100%

#### Gender

76 of the 77 respondents identified their gender.

- More than half of the respondents (n=48) (63%) identified as male.
- 27 respondents (36%) identified as as female.

The remaining response was unclear citing his/her residence as a care home for both male and female residents.

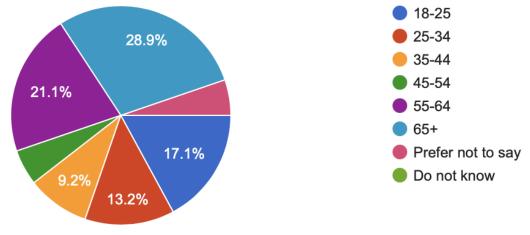


#### Age

76 of the 77 respondents reported their age.

- Most respondents (n=22) (29%) were 65 years and over.
- 16 (21%) were aged 55-64 years.
- 13 (17%) were aged 18-25 years.
- 10 (13%) were aged 25-34 years.
- 7 (9%) were aged 35-44 years.

4 respondents (5%) reported not knowing their age and 4 (5%) preferred not to say.

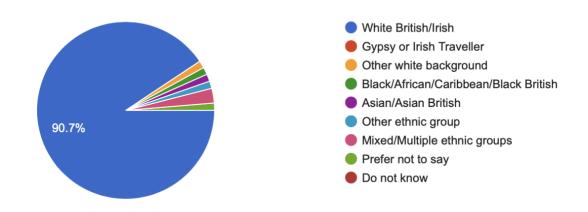


#### Ethnicity

75 of the 77 respondents reported their ethnicity.

- The majority of respondents identified as White British/Irish (n=68) (91%).
- 2 (3%) identified as mixed or multiple ethnic group.
- 1 (1%) from another white background.
- 1 (1%) as Black/African/Caribbean/Black British.
- 1 (1%) as Asian/Asian British,
- 1 (1%) as another ethnic group.

One respondent (1%) prefered not to say.



## Section 2: Background history of receiving speech and language therapy

In this section, the reasons why people were having speech and language therapy and when therapy started are presented. This covers the following survey questions: Question 7: Why are you having speech and language therapy? Question 6: What does speech and language therapy help you with? Question 5: When did you start having speech and language therapy? Question 24: How does your speech and language therapy help you? Question 11: How did you have your speech and language therapy before the virus lockdown (March to June 2020)?

#### Condition

The survey asked respondents to identify the condition for which they were receiving speech and language therapy.

77 responses were received with many respondents selecting more than one condition indicating complex comorbidities. Conditions selected included:

- Parkinson's Disease (n= 24) (31%) the condition with the most responses
- Learning disability (n=11) (14%)
- Stroke (n=11) (14%)
- Brain injury (n=10) (13%)
- Autism (n=9) (12%)
- Hearing loss and deafness (n= 6) (8%)
- Language disorder (n=6) (8%)
- Stammer (n=6) (8%)
- Developmental delay (n=4) (5%)
- Motor neurone disease (n=3) (4%)
- Dementia (n=3) (4%)
- Mental health diagnoses (n=2) (3%)
- Selective mutism (n=1) (1%)

The only condition not selected was head and neck cancer. Two respondents (3%) were waiting for a diagnosis.

13 respondents selected the other category and cited the following conditions:

- Suspected COVID-19 (n=2) (3%)
- Multiple system atrophy (n=2) (3%)

- Multiple sclerosis (n=1) (1%)
- Voice rehabilitation (n=1) (1%)
- Muscular dystrophy (n=1) (1%)
- Non-Hodgkin's lymphona (n=1) (1%)
- Angelman syndrome (n=1) (1%)
- Aphasia (n=1) (1%)
- Complications from laryngitis (n=1) (1%)

#### Reason for having speech and language therapy

All 77 respondents confirmed the reasons for having speech and language therapy.

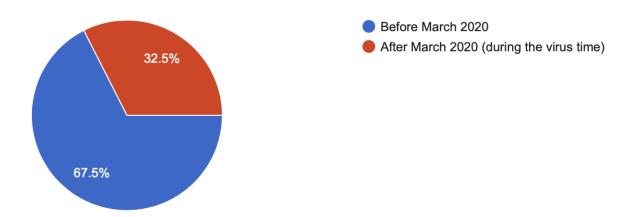
- Almost all the respondents (n=69) (90%) received speech and language therapy for their speech, language and communication.
- 26 (34%) respondents reported receipt of speech and language therapy for their eating and drinking.

5 respondents selected other citing the following reasons:

- For all sorts (n=1) (1%)
- Tube feeding (n=1) (1%)
- Visual support (n=1) (1%)
- Staff training (n=1) (1%)
- Involvement in the initial diagnosis of MND (n=1) (1%)

#### When speech and language therapy started

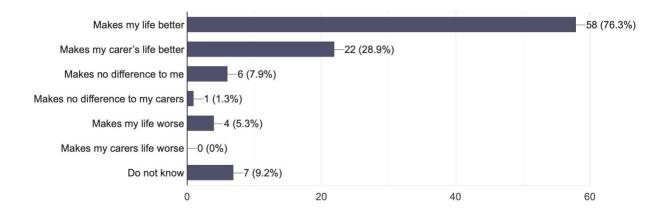
Of the 77 respondents, more than two-thirds of the respondents (n=52) (68%) were in receipt of speech and language therapy before March 2020 and 25 (33%) after March 2020.



#### How speech and language therapy helps

76 of the 77 respondents described how speech and language therapy helps them.

- For the majority (n=58) (76%), speech and language therapy makes their life better.
- 22 respondents (29%) said it makes their carer's life better.
- 4 (5%) respondents explained it makes their life worse.
- 7 respondents (9%) reported it makes no difference to their lives or the lives of their carers.
- 7 respondents (9%) did not know.



#### How speech and language was delivered before lockdown

73 of the 77 respondents reported how their speech and language therapy was delivered before lockdown in March 2020.

- 41% (n=30) received speech and language therapy outside of the home in health care settings.
- 29% (n-22) received it in person either at home, or
- 14% (n=10) in school or college.
- 15% (n=11) respondents reported receiving SLT online and 1% (n=1) by phone.

7 respondents were not receiving speech and language therapy before lockdown.

## Section 3: Experiences of speech and language therapy during lockdown (March to June 2020)

In this section, the experiences of receiving speech and language therapy during lockdown are presented. This covers the survey questions of:

Question 8: Did your speech and language therapy change during lockdown (March to June 2020)?

Question 9: What happened to your appointments?

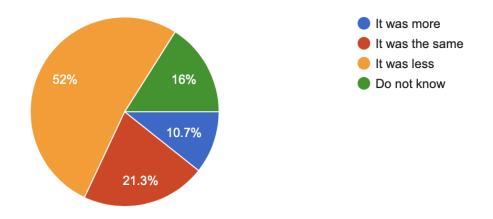
Question 10: Why were your appointments cancelled?

#### Changes to speech and language therapy

75 of the 77 respondents reported changes in their receipt of speech and language therapy.

- Only 16 respondents (21%) reported they received the same amount of speech and language therapy before and during lockdown.
- More than half of the respondents (n=39) (52%) received less speech and language therapy.
- 8 (11%) received more.

12 respondents (16%) were unable to confirm.



#### Changes to speech and language therapy by postcode area

Responses were broken down using the English Indices of Multiple Deprivation (IMD). IMD decile 1 to 5 was collapsed into Group 1/Most deprived and IMD decile 6 to 10 was

collapsed into Group 2/Least deprived. There were 12 respondents in Group 1 (most deprived) and 36 respondents in Group 2 (least deprived).

This has revealed that:

- Of those who saw an increase in their speech and language therapy during lockdown, a higher percentage lived in the most deprived areas than the least deprived areas.
- A higher percentage of people living in the least deprived areas had the same amount of speech and language therapy than people living in the most deprived areas.
- A higher percentage of people living in the most deprived areas received less speech and language therapy during lockdown than people living in the least deprived areas.

	Group 1 Most deprived	Group 2 Least deprived
It was more	2 (16.7%)	5 (13.8%)
It was the same	2 (16.7%)	11 (30.5%)
It was less	6 (50%)	15 (41.6%)
l don't know	2 (16.7%)	5 (13.8%)
Total	12 (100%)	36 (100%)

#### What happened to speech and language therapy appointments

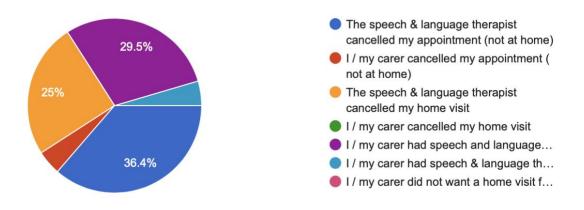
44 of the 77 respondents were able to report what happened to the speech and language therapy appointments.

- For 16 of the 44 respondents (35%), the SLT cancelled the appointment.
- 13 respondents (30%) received their speech and language therapy appointment online.
- 2 respondents (5%) received a phone appointment.
- For 11 of the 44 respondents (25%), the SLT cancelled the home visit appointment.

- 2 respondents (5%) cancelled their own speech and language therapy appointments.
- 31 respondents reported reasons for the cancellations. These ranged across:
  - Shielding (n=5) (16%).
  - Closure of health centres (n=3) (10%).
  - Feeling unsafe to attend appointment (n=2) (7%).
  - Closure of community/work centre (n=2) (7%).

19 respondents reported other reasons including:

- SLTs being redeployed.
- Cancellation of group speech and language therapy sessions.
- SLTs unable to make visits to care homes.
- SLTs having COVID-19,
- Closure of colleges.
- No contact received from speech and language therapy services.



## What people told us about why their appointments were cancelled during lockdown

Some respondents were not contacted at all, while others were contacted only to say that appointments were cancelled due to lockdown. In a few cases, face-to-face appointments were not able to happen, particularly in care homes.

# Section 4: Delivery of speech and language therapy and experiences of delivery during lockdown (March to June 2020)

In this section, how speech and language therapy was delivered during lockdown is presented. This covers the survey questions of:

Question 12: Did you get speech and language therapy in person during the virus lockdown (March to June 2020)?

Question 13: Did you get your speech and language therapy over the phone during the first virus lockdown (March to June 2020)?

Question 14: How was your speech and language therapy over the phone? Question 15: Did you get your speech and language therapy by video during the virus lockdown (March to June 2020)?

Question 16: How was your speech and language therapy help on video (online)? Question 17: How easy was it to use the computer/laptop/tablet/smartphone? Question 18: Did you get your speech and language therapy through other support, for example social media or printed materials, during the virus lockdown (March to June 2020)?

Question 19: Did you get help updating things on your communication support tools (for example communication pictures, communication books, electronic aids)?

Question 21: What has it been like if you have to wear a mask during your speech and language therapy?

Question 22: What has it been like if your SLT has to wear a mask during your speech and language therapy?

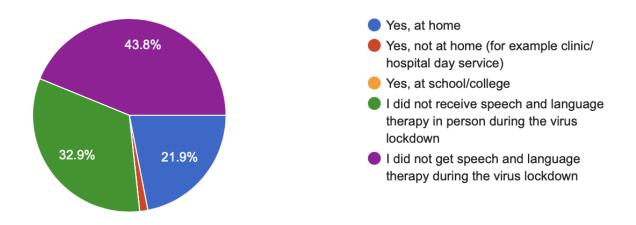
#### The delivery of speech and language therapy

73 of the 77 respondents reported on the delivery of speech and language therapy.

- Nearly half of the respondents (n=32) (44%) did not receive any speech and language therapy during lockdown.
- 24 respondents (33%) did not receive speech and language therapy in person.

Of the remaining 17 respondents who did receive speech and language therapy in person:

- 16 (22%) received speech and language therapy at home.
- 1 (1%) received speech and language therapy outside of the home.



#### Speech and language therapy in person by postcode area during lockdown

In relation to whether people had in-person speech and language therapy during lockdown:

- A lower percentage of respondents from the most deprived areas received inperson speech and language therapy during lockdown than people from the least deprived areas - 17% and 27% respectively.
- A higher percentage of people living in the most deprived areas received no inperson speech and language therapy than people living in the least deprived areas.
- A higher percentage of people living in the least deprived areas reported not having any speech and language therapy at all than people living in the most deprived areas.

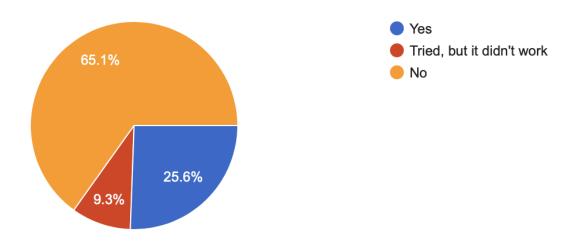
	Group 1 Most deprived	Group 2 Least deprived
Yes	2 (16.7%)	10 (27%)
I did not receive speech and language therapy in person during the virus lockdown	7 (58.3%)	12 (32.4%)
I did not get any speech and language therapy	3 (25%)	13 (35.1%)

during the virus lockdown		
Missing	0	2 (6.4%)
Total	12 (100%)	37 (100%)

#### Speech and language therapy over the phone

43 of the 77 respondents reported on the delivery of speech and language therapy over the phone.

- 11 of the 43 respondents (26%) received speech and language therapy via the phone.
- 28 of the 43 respondents (65%) did not.
- 4 respondents (9%) attempted to receive speech and language therapy via the phone but this proved unsuccessful.

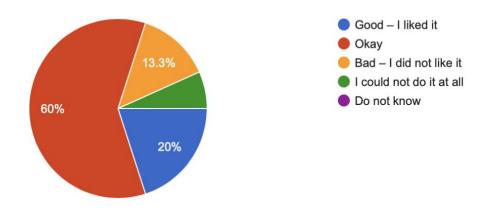


#### Experiences of speech and language therapy over the phone

15 respondents reported on their experiences of receipt of speech and language therapy over the phone.

- 9 of the 15 respondents (60%) found the phone delivery 'OK'.
- 3 (20%) liked the phone delivery.
- 2 (13%) did not like the phone delivery.

1 respondent (7%) reported not being able to engage in speech and language therapy over the phone.



### What people liked about speech and language therapy over the phone

Those who accessed speech and language therapy over the phone were grateful to have some form of contact with a speech and language therapist, because it helped them to feel supported. Additionally, phone-based check-ins helped them to consistently engage with resources.

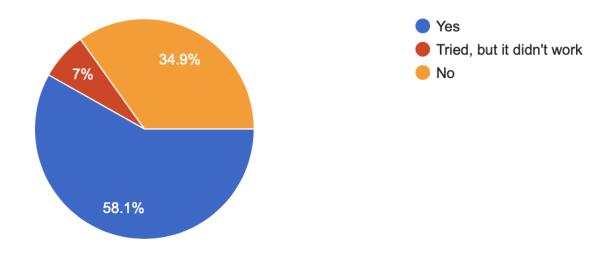
# What people did not like about speech and language therapy over the phone

The primary difficulty that respondents noted was that phone appointments were no replacement for face-to-face appointments, and it was more difficult to assess via phone. Additionally, some found it difficult to access therapy over the phone. They also mentioned that it was hard to lose the peer support that they had found via in-person appointments or group sessions.

### Speech and language therapy by video

43 of the 77 respondents reported on the delivery of speech and language therapy by video (online).

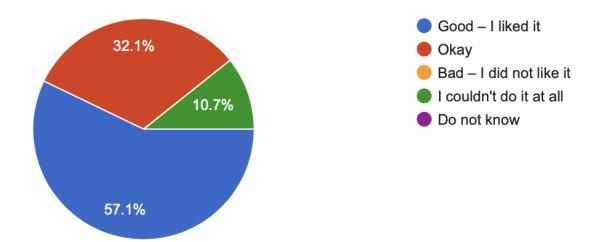
- 25 (58%) of the 43 respondents reported receipt of speech and language therapy delivery by video (online).
- 15 (35%) did not receive speech and language therapy in this mode of delivery.
- 3 respondents (7%) attempted to secure speech and language therapy by video, but this proved unsuccessful.



### Experiences of online speech and language therapy

28 respondents reported on their experiences of video (online) delivery.

- 16 of the 28 (57%) respondents liked this delivery.
- 9 (32%) found this delivery 'OK'.
- 3 (11%) were not able to engage in this delivery.

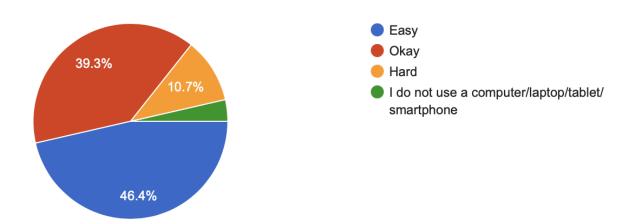


### Ease of using technology

In terms of the ease of use of the technology:

- 13 of the 28 (46%) respondents found it easy to use computers and phones for speech and language therapy.
- 11 (39%) found it OK.
- 3 (11%) found it hard

• 1 (4%) reported not being able to use this technology.



### **Difficulties using technology**

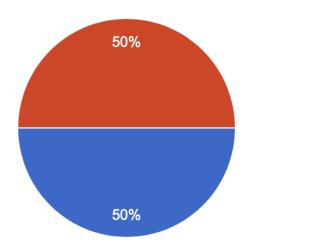
8 respondents explained why it was hard to engage with this technology.

- 3 respondents (38%) reported unreliable internet connections.
- 3 (38%) cited a lack of experience with the technology.
- 2 (25%) reported general difficulties.
- 1 (12%) cited security issues as a barrier.

### Other speech and language therapy support

28 of the 77 respondents responded to the question about receiving speech and language therapy for other support, such as printed materials or social media.

- 14 respondents (50%) did receive this support.
- 14 (50%) did not.



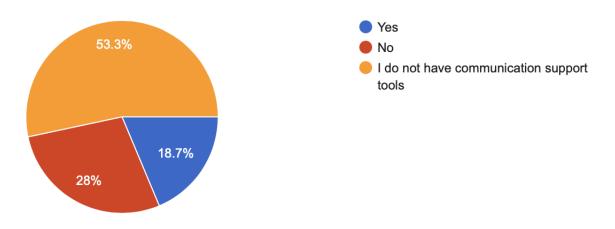


### **Communication tools**

75 of the 77 respondents responded to the question asking if they had received help in updating their communication support tools. 40 (53%) reported not having any communication support tools.

Of the 47% who did have communication support tools:

- 21 (28%) did not receive any help.
- 14 (19%) did receive help.



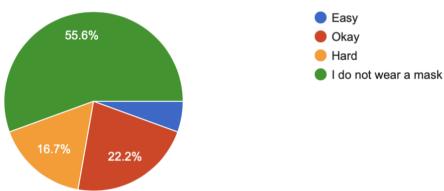
### Face masks

Respondents were asked if they or their SLT had worn a mask during their appointments and their experiences of this. 18 responses were received.

- 10 of the 18 (56%) respondents reported not wearing a mask.
- 8 (44%) did.

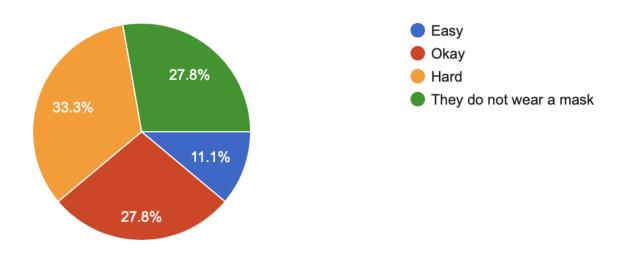
Of the 8 who did wear a mask:

- 4 (22%) reported this was 'OK'
- 3 (17%) found it hard
- 1 (6%) found it easy



13 of the same 18 respondents reported their SLT wore a mask. Of these 13 respondents, 6 (33%) found it hard.

- 5 (28%) found it OK.
- 2 (11%) found it easy.



#### What people told us about their communication support during lockdown

Many people lost support completely and found it difficult to access online resources. However, online resources were helpful for some and they were grateful to still have that link to their SLT. Those who received phone check-ins from their SLT found them helpful and motivating. Those who accessed speech and language therapy via video found it useful, but most did not see it as a replacement for face-to-face appointments. For some, a majority of their communication support came from family members and carers, a few of whom benefitted from liaising with a SLT.

#### What people told us about their speech and language therapy

Many accessed speech and language therapy to support their speech, language and communication. Some received support on their eating and drinking and were grateful for the SLT's input in this area. speech and language therapy allowed them to feel more confident in expressing themselves. A few accessed speech and language therapy in a group setting. Family members and carers brought up that they were the primary contact for the SLT and were grateful to have this contact and guidance. A few had not yet received speech and language therapy due to waiting lists or difficulty accessing support.

# Section 5: Experiences of speech and language therapy during and after the end of lockdown

In this section, data on people's experiences of speech and language therapy during and after lockdown is presented. This covers the survey questions of:

Question 23: Has your communication or swallowing become worse during COVID-19?

Question 15: If you had less speech and language therapy help during lockdown (March to June 2020) tick the things it made worse.

Question 26: If you are a family member or carer of someone who had less speech and language therapy during lockdown (March to June 2020) tick the things it made worse for you.

Question 20: Have your received speech and language therapy face to face since the end lockdown (June 2020)?

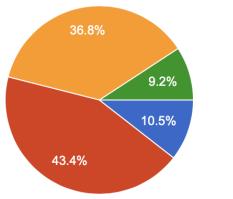
Question 27: Are you worried about getting your speech and language therapy help in the future?

Question 28: What are you worried about (if you don't have speech and language therapy help)?

### Impact on communication and swallowing

76 of the 77 respondents reported if their communication or swallowing became worse during lockdown.

- Only 8 respondents (11%) felt their communication or swallowing was better.
- 28 (37%) reported it was worse.
- 33 respondents (43%) reported their communication or swallowing stayed the same.
- 7 (9%) did not know.





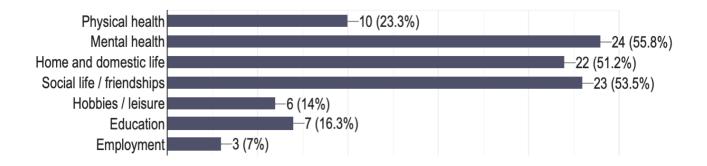
### Impact on people's lives of having less speech and language therapy

43 of the 77 respondents confirmed they had less speech and language therapy during lockdown. These 43 respondents identified things that were now worse for them because of having less speech and language therapy. Respondents selected more than one option.

The thing that people said had most got worse as a result of having less speech and language therapy was their mental health. 56% (n=24) said their mental health had deteriorated.

People identified other areas of their lives that had also got worse because of having less speech and language therapy:

- Social life and friendships identified by 54% (n=23) of respondents
- Home and domestic life reported by 51% (n=22)
- Physical health 23% (n=10)
- Education 16% (n=7)
- Hobbies and leisure 14% (n=6)
- Employment 7% (n=3)



Other aspects reported were speech deterioration, lack of access to physical and social activities, and loss of skills. One respondent reported an improvement in their self-reliance.

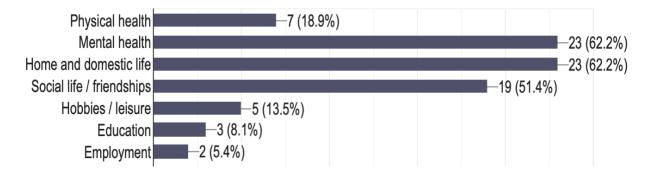
#### Impact on families and carers of having less speech and language therapy

Family members and carers were also asked to describe the impact of less speech and language therapy on their own lives. 37 of the 77 respondents described this impact on their own lives with respect to the things that were now worse for them because of having less speech and language therapy.

Again, the thing that people said had most deteriorated by their loved ones or the people they care for having less speech and language therapy was their mental health (n=23) (62%) and their home and domestic life (n=23) (62%).

Families and carers lives said their lives got worse in other ways too because of having less speech and language therapy:

- Social life and friendships (n=19) (51%)
- Physical health (n=7) (18%)
- Hobbies and leisure (n=5) (14%)
- Education (n=3) (8%)
- Employment (n=2) (5%)

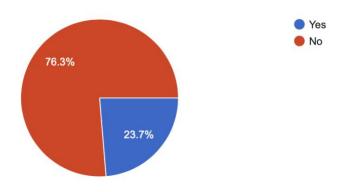


Other aspects reported were an increased need for support, lack of respite care and therefore increased caring responsibilities, social isolation and increased concerns about the future.

### Face-to-face speech and language therapy after lockdown ended

76 of the 77 respondents confirmed if they had received speech and language therapy face to face since the end of lockdown (June 2020).

- 58 (76%) had not received any face-to-face speech and language therapy since June 2020.
- 18 (24%) had.



### Face-to-face speech and language therapy since the end of the first UK wide lockdown (June 2020) by postcode area

In relation to whether people had in-person speech and language therapy after lockdown ended:

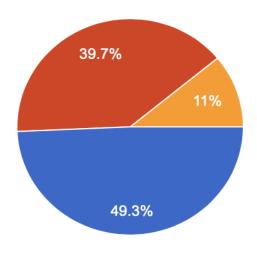
- Of the people who did have face-to-face speech and language therapy after lockdown, a considerably higher percentage did so in the least deprived areas rather than the most deprived areas.
- A considerably higher percentage of people living in the most deprived areas also had less in-person speech and language therapy after lockdown ended than people living in the least deprived areas.

	Group 1 Most deprived	Group 2 Least deprived
Yes	2 (16.7%)	11 (29.7%)
No	10 (83.3%)	26 (70.3%)
Total	12 (100%)	37 100%

### Access to speech and language therapy in the future

73 of the 77 respondents described if they were concerned about receiving speech and language therapy in the future. There was a fairly even split:

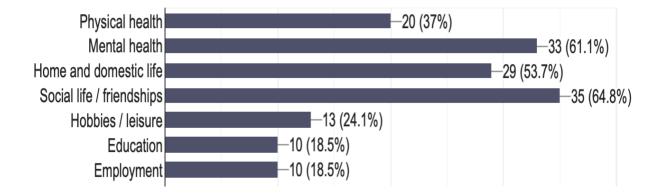
- 36 (49%) respondents were concerned.
- 29 (40%) were not concerned.
- 8 (11%) did not know.





54 of these 73 respondents went on to describe their concerns. Respondents selected more than one response. Concerns people identified if they had less speech and language therapy in the future were:

- Social life and friendships (n=35) (65%)
- Mental health (n=33) (61%)
- Home and domestic life (n=29) (37%)
- Physical health (n=20) (37%)
- Hobbies and leisure (n=13) (24%)
- Education (n=10) (19%)
- Employment (n=10) (19%)



Other aspects of concern were decreased self-esteem, trouble holding a conversation, going out in public, basic communication skills, implications on future care due to diminishing communication, lack of support for the service, monitoring, access to services if speech and language therapy remains scaled down, and the long-term impact of access to resources.

### Other things people told us about their speech and language therapy

Some respondents discussed how grateful they were for speech and language therapy, both in person and online, particularly noting how supportive their SLT had been throughout lockdown. Many found access to speech and language therapy particularly difficult during lockdown. For some, this was because online and video resources were not accessible due to service users' conditions, while for others it was because the service lacked resources or transitions led to complications in access at the new location. Even where online alternatives were provided, a few recognised a substantial difference without face-to-face appointments, which they preferred. When printed resources were provided respondents found them useful. Some needed speech and

language therapy to improve their communication but struggled to access it in the first instance due to these communication difficulties.

### Considerations for the descriptive analysis

Response rates varied across the 29 questions in the survey with some questions receiving a complete response rate of 77 responses and others a minimum of 28 responses. This variation in responses did limit the extent of the descriptive analysis completed. Some of the questions in the survey overlapped in content, which meant there was not always a consistent response rate across these questions. This means there were some differences in the responses received to questions asking the same content.

### 0–18 years survey: descriptive data and analysis of the survey findings

There were 414 responses to the 0–18 years survey. For some questions, responses were received from all 414 respondents. For other questions, responses from a smaller sample of the 414 respondents were received. The number of respondents completing each question is given in the description of the results. The design of the survey meant for some questions respondents were able to select more than one option, often selecting 2 or 3 responses. The descriptive results are described in detail for each question.

The questions and the results are grouped into five sections and the questions addressed in each section are given.

- Section 1 gives the demographic data about the respondents who completed the survey.
- Section 2 describes the respondents' background history of receiving speech and language therapy.
- Section 3 describes the respondents' experiences of speech and language therapy during lockdown (March to June 2021).
- Section 4 describes the delivery of speech and language therapy during lockdown (March to June 2020) and the respondents' experiences of this.
- Section 5 details the respondents' experiences of speech and language therapy during and after the end of lockdown.

The quantitative descriptive data is given along with the qualitative data. Qualitative data originates from the free text comments for some of the questions. These comments have been grouped into categories for ease of reference.

### Section 1: Demographic data of the respondents

The demographic data is presented first. This data was obtained from the following questions:

Question 1: What is your postcode?

Question 2: Which country do you live in?

Question 3: Please tell us who you are.

Question 30: How old are you?

Question 31: How would you describe your gender?

Question 32: What is your ethnicity?

### Who were the respondents?

414 people completed the 0–18 years survey.

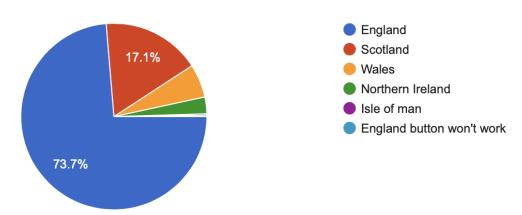
The majority of the respondents (n=345) (83.3%) were family members/unpaid carers of people with speech, language and communication difficulties.

This was followed by:

- Individuals who receive speech and language therapy (n=51) (12%)
- Paid carers (n=6) (2%)
- Special Educational Needs Co-ordinators (SENCOs)/other support staff (n=4) (1%)
- Individuals trying to access speech and language therapy (n=3) (0.7%)

### Country

- The majority of the respondents lived in England (n=306) (74%)
- 71 (17%) lived in Scotland
- 24 (6%) lived in Wales
- 12 (3%) lived in Northern Ireland
- 1 (0.2%) lived on the Isle of Man



### Postcodes

Of the 414 responses, there were 234 valid postcode entries. The other 180 postcode entries were either incorrect or from Scotland and Wales. The English indices of deprivation (Ministry of Housing, Communities and Local Government 2019) were used to obtain data about the level of deprivation of each postcode. The indices use categories of income, living environments, employment, education, skills and barriers to housing and services. The English Indices of Multiple Deprivation (IMD) were used to identify the IMD decile for the postcodes for these 235 respondents. The IMD decile range from 1 (10% most deprived) to 10 (10% least deprived). The following table shows the decile rankings of the postcodes of the 234 respondents.

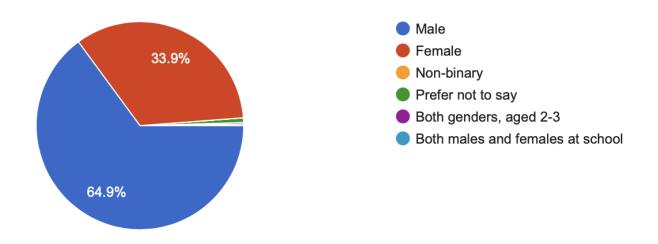
IMD Decile	Number of respondents (n=49)	Percentage of respondents
1 Most deprived	9	2.2
2	13	3.1
3	17	4.1
4	20	4.8
5	33	8.0
6	20	4.8
7	22	5.3
8	27	6.5
9	36	8.7
10 Least deprived	37	9.2
Total	234	100%

### Gender

With respect to gender, 413/414 responses were received.

- More than half of the respondents (n=268) (65%) identified as male.
- 140 (34%) identified as female.

3 (0.7%) respondents preferred not to say, and the remaining response was unclear, because the individuals reported being from a school for male and female students.

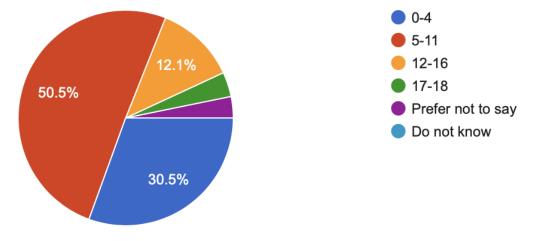


### Age

In terms of age, 406/414 responses were received.

- Approximately half of the respondents (n=205) (51%) were aged 5 to 11 years.
- The remaining half of the respondents was split across the age categories of:
  - 0 to 4 years (n=124) (31%).
  - 12 to 16 years (n=49) (12%).
  - 17 to 18 years (n=15) (4%).

13 (3%) respondents preferred not to say.

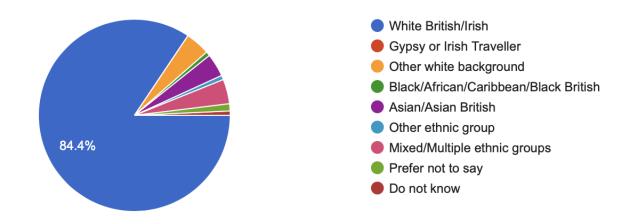


### Ethnicity

Almost all the respondents (411/414) reported their ethnicity.

- The majority of the respondents (n=347) (84%) were White British/Irish.
- 17 (4%) were mixed or multiple ethnic groups.
- 17 (4%) were another white background.
- 16 (4%) were Asian/Asian British.
- 3 (0.7%) were Black/African/Caribbean/Black British,
- 3 (0.7%) were another ethnic group.

5 (1.2%) preferred not to say and 3 (0.7%) did not know.



# Section 2: Background history of receiving speech and language therapy

In this section, the reasons for having speech and language therapy and when therapy started are presented. This covers the following survey questions: Question 6: Why are you having speech and language therapy? Question 5: What does speech and language therapy help you with? Question 4: When did you start having speech and language therapy? Question 24: How does your speech and language therapy help you? Question 11: How did you have your speech and language therapy before the virus lockdown (March to June 2020)?

### Condition

All respondents identified the condition for which they in receipt/ever in receipt of speech and language therapy. Many respondents selected more than one condition. Conditions selected included:

- Developmental delay (n=148) (35%) the condition with the most responses
- Learning disability (n=128) (31%)
- Developmental language disorder or another language disorder (n=106) (26%)
- Autism (n=100) (24%)
- Hearing loss or deafness (n=61) (15%)
- Speech sound disorder (n=52) (13%)
- Brain injury (n=25) (6%)
- Down's syndrome (n=23) (6%)
- Stammer (n=22) (5%)
- Attention deficit hyperactivity disorder (ADHD) (n=17) (4%)
- Cleft lip and palate (n=15) (4%)
- Selective mutism (n=15) (4%)

38 (9%) respondents were waiting for a diagnosis and 6 (1%) respondents did not know.

47 respondents selected the other category and cited the following conditions:

- Genetic condition (n=11) (3%)
- Verbal dyspraxia (n=9) (2%)
- Speech delay (n=9) (2%)
- Dysphagia (n=5) (1%)
- Cerebral palsy (n=2) (0.5%)

- Support with articulation (n=2) (0.5%)
- Craniosynostosis (n=2) (0.5%)
- Tourette's syndrome (n=1) (0.2%)
- Parkinson's (n=1) (0.2%)
- Rett syndrome (n=1) (0.2%)
- Aphasia due to stroke (n=1) (0.2%)
- Oropharyngeal cancer (n=1) (0.2%)

### Reason for having speech and language therapy

All 414 respondents confirmed the reasons for receipt of speech and language therapy.

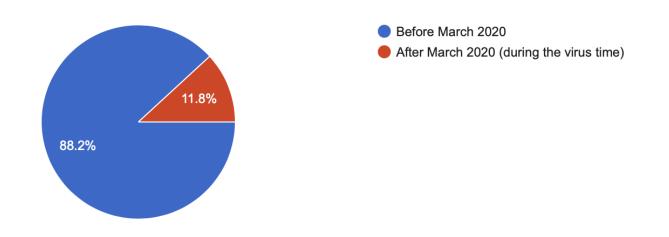
- The majority of the respondents (n=406) (98%) received speech and language therapy for their speech, language and communication.
- 57 (14%) received it for their eating and drinking.

Five respondents selected other citing the following reasons:

- Behaviour
- Social communication
- Language understanding

### When speech and language therapy started

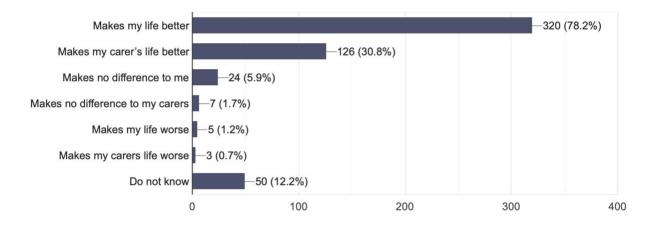
Of the 414 respondents, the majority (n=365) (88%) were in receipt of speech and language therapy before March 2020 and 49 (12%) after March 2020.



### How speech and language therapy helps

409 of the 414 respondents described how speech and language therapy helps them.

- For the majority (n=320) (78%), speech and language therapy makes their life better.
- 126 (31%) said it makes their carer's life better.
- 8 people (1.7%) explained it makes their lives and/or their carer's lives worse.
- 31 people (8%) explained it makes no difference to their lives or the lives of their carers.
- 50 respondents (12%) did not know.



### How speech and language therapy was delivered before lockdown

408 respondents reported how their speech and language therapy was delivered before lockdown in March 2020. Respondents selected more than one option.

- The majority, 57% (n=234) received speech and language therapy in person either at school or college.
- 14% (n=56) received speech and language therapy in person at home.
- 29% (n=118) received speech and language therapy in another location.

Some respondents were receiving speech and language therapy in other ways before lockdown:

- 3% (n=14) reported also receiving speech and language therapy by phone.
- 3% (n=12) online.
- 2% (n=8) through other means.

32 respondents (8%) were not receiving speech and language therapy before lockdown.

# Section 3: Experiences of speech and language therapy during lockdown (March to June 2020)

In this section, the experiences of receiving speech and language therapy during lockdown are presented. This covers the survey questions of:

Question 7: Did your speech and language therapy change during lockdown (March to June 2020)?

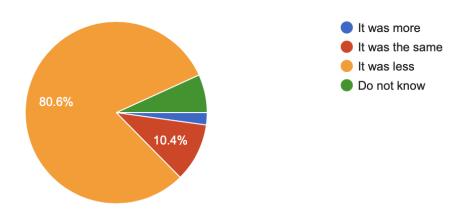
Question 8: What happened to your speech and language therapy appointments? Question 9: Why were your speech and language therapy appointments cancelled?

### Changes to speech and language therapy

Nearly all the 414 respondents reported changes in their receipt of speech and language therapy.

- Only 43 respondents (10%) reported they received the same amount of speech and language therapy before and during lockdown.
- The majority (n=333) (81%) received less speech and language therapy.
- 9 respondents (2%) received more.

28 respondents (7%) were unable to confirm.



### Changes to speech and language therapy by postcode area

Responses were broken down using the English Indices of Multiple Deprivation (IMD). IMD decile 1 to 5 was collapsed into Group 1/More deprived and IMD decile 6 to 10 was collapsed into Group 2/Least deprived. There were 92 respondents in Group 1 (most deprived) and 142 respondents in Group 2 (least deprived). Group 1 and Group 2 were then compared.

This has revealed that:

- A higher percentage of respondents in the most deprived areas had less speech and language therapy than the least deprived areas.
- A higher percentage of people living in the least deprived areas had the same amount of speech and language therapy than people living in the most deprived areas.
- Where people received more speech and language therapy during lockdown, a higher percentage lived in the most deprived areas of England than in the least deprived areas.

	Group 1 Most deprived	Group 2 Least deprived
It was more	4 (4.3%)	2 (1.4%)
It was the same	6 (6.5%)	20 (14.1%)
It was less	75 (81.5%)	114 (80.3%)
l don't know	7 (7.6%)	6 (4.2%)
Total	92 (100%)	142 (100%)

### What happened to speech and language therapy appointments

335 of the 414 respondents were able to report what happened to their appointments.

- For 226 of the 335 respondents (67%), the SLT cancelled their appointment.
- 67 respondents (20%) received their speech and language therapy appointments online.
- 37 respondents (11%) received phone appointments.
- 5 respondents (1%) cancelled their own appointments.

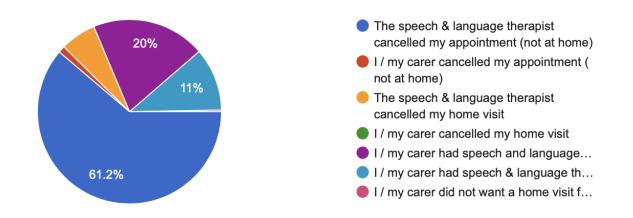
235 respondents reported reasons for cancellations. These ranged across:

- Their school/college being closed (n=76) (32%).
- Closure of health centres (n=43) (18%).
- Redeployment of speech and language therapy services (n=19) (8%).

- Being unable to get to the appointment (n=7) (3%).
- Shielding or carer shielding (n=8) (3.8%),

Other reasons cited were:

- The SLT was unable to come into school (n=11) (5%).
- Feeling unsafe and/or carers feeling unsafe to attend appointments (n=6) (3%).
- The SLT was shielding (n=1) (0.4%).
- For 13 respondents (6.4%), no contact was received from the speech and language therapy service.
- 68 respondents (29%) reported not knowing the reasons for cancellations of appointments and/or suspension of speech and language therapy services.



# What people told us about why their appointments were cancelled during lockdown

Those whose school or college was closed had difficulty accessing speech and language therapy, even when this was part of an Education Health and Care Plan. When schools reopened, external visitors were limited, so for many speech and language therapy did not restart. In cases where SLTs were redeployed within the NHS, some respondents lost all contact and were not given alternative appointment options, while others were discharged completely. In cases where the service was not running face-to-face appointments, some were offered online appointments (although this did not always work), while others were not offered any other option.

In certain cases, service users could not access speech and language therapy due to adjustments in the SLT's caseload prioritisation and changing risk assessments. Some could not access any appointments due to short staffing in their local services, while others were not offered online alternatives due to inadequate technology resources at

the service. The only reason some were given for cancelled appointments was "due to the pandemic" or "due to lockdown". Families were not given further details as to why appointments were cancelled or when they would restart. While some respondents had been contacted with a vague reason for cancellation, others were not contacted at all or offered a next appointment.

# Section 4: Delivery of speech and language therapy and experiences of delivery during lockdown (March to June 2020)

In this section, how speech and language therapy was delivered during lockdown is presented. This covers the survey questions of:

Question 11: Did you get speech and language therapy in person during the virus lockdown (March to June 2020)?

Question 12: Did you get your speech and language therapy over the phone during the first virus lockdown (March to June 2020)?

Question 13: How was your speech and language therapy over the phone?

Question 14: Did you get your speech and language therapy by video during the virus lockdown (March to June 2020)?

Question 15: How was your speech and language therapy help on video (online)?

Question 16: How easy was it to use the computer/laptop/tablet/smartphone? Question 17: If you found it hard, why was this?

Question 18: Did you get your speech and language therapy through other support, for example social media or printed materials during the virus lockdown (March to June 2020)?

Question 19: Did you get help updating things on your communication support tools (for example communication pictures, communication books, electronic aids)?

Question 21: What has it been like if you have to wear a mask during your speech and language therapy?

Question 22: What has it been like if your SLT has to wear a mask during your speech and language therapy?

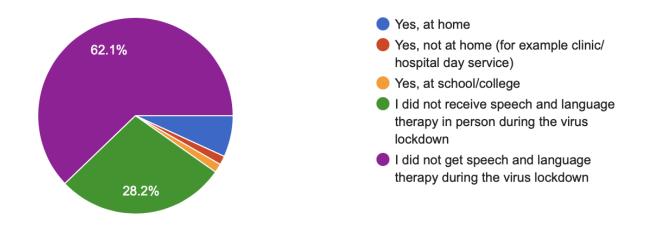
### The delivery of speech and language therapy

412 of the 414 respondents reported on the delivery of speech and language therapy.

- Nearly two-thirds of respondents (n=256) (62%) did not receive any speech and language therapy during lockdown.
- 28% (n=116) did not receive speech and language therapy in person.

Of the remaining 30 respondents (11%) who did receive speech and language therapy in person:

- 28 (7%) received speech and language therapy at home
- 6 (2%) at school or college
- 6 (2%) in other contexts



### Speech and language therapy in person by postcode area during lockdown

In relation to whether people had in-person speech and language therapy during lockdown:

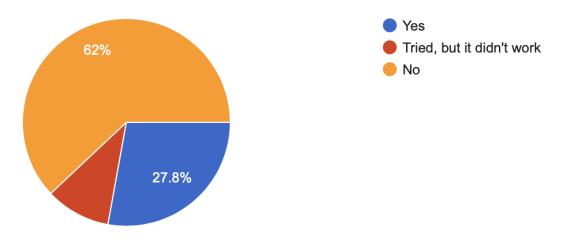
- A higher percentage of people living in the least deprived areas received inperson speech and language therapy than those living in the most deprived areas.
- A higher percentage of people living in the least deprived areas received no inperson speech and language therapy.
- A higher percentage of people living in the most deprived areas had no speech and language therapy at all.

	Group 1 Most deprived	Group 2 Least deprived
Yes	6 (6.5%)	19 (13.4%)
I did not receive speech and language therapy in person during the virus lockdown	20 (21.7%)	41 (28.9%)
I did not get any speech and language therapy during the virus lockdown	65 (70.7%)	82 (57.7%)
Missing	1	0
Total	92 (100%)	142 (100%)

### Speech and language therapy over the phone

158 of the 414 respondents reported on the delivery of speech and language therapy over the phone.

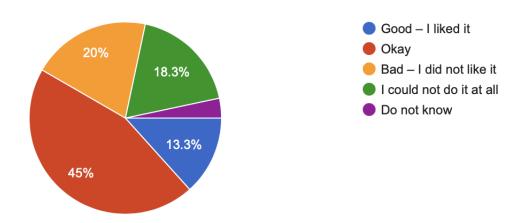
- 44 (28%) of the 158 respondents received speech and language therapy over the phone.
- 98 of the 158 respondents (62%) did not.
- 16 respondents (10%) attempted to receive speech and language therapy via the phone but this proved unsuccessful.



### Experiences of having speech and language therapy over the phone

60 respondents reported on their experiences of receipt of speech and language therapy over the phone.

- 8 respondents (13%) liked the phone delivery
- 27 (45%) found the phone delivery 'OK'
- 12 (20%) did not like it
- 11 (18%) could not do it
- 2 (3%) did not know



### What people liked about speech and language therapy over the phone

Those who accessed speech and language therapy on the phone were glad to have some way to contact their therapist, particularly in an otherwise isolating time. Parents and carers primarily used it to ask for advice, guidance and new ideas from the SLT. Some appreciated phone contact as it was easier to fit the appointments into their day and provided a way to ask questions in the short term without having to wait until the next appointment. These aspects improved the accessibility of speech and language therapy.

# What people did not like about speech and language therapy over the phone

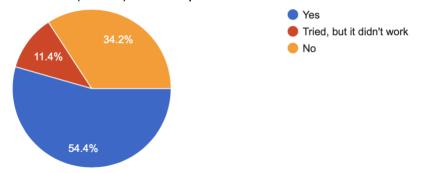
Some parents and carers did not feel that assessment over the phone gave an accurate or complete picture of their child's difficulties. In some cases, particularly with regard to swallowing issues, they felt virtual assessment was not only ineffective but also unsafe. Without in person access, some felt unsupported or that they were lacking guidance.

Many found that limitations of technology such as poor sound quality and connection issues had a large impact on the SLT's understanding of their needs and thus the efficacy of speech and language therapy. Others, particularly parents/carers working with young children, found it difficult to get their child to focus and engage on virtual platforms. In some cases, accessing speech and language therapy by phone was not possible for the service user, which led to the parent or carer being the only connection with the SLT.

### Speech and language therapy by video

158 respondents from the total 414 respondents reported on the delivery of speech and language therapy by video (online).

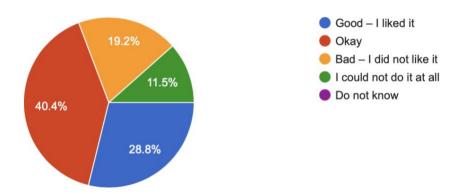
- 86 (54%) of the 158 respondents reported receipt of speech and language therapy delivery by video (online).
- 54 (34%) did not receive speech and language therapy in this mode of delivery.
- 18 respondents (11%) attempted to secure speech and language therapy by video (online) but this proved unsuccessful.



### Experiences of speech and language therapy online

104 respondents reported on their experiences of video (online) delivery:

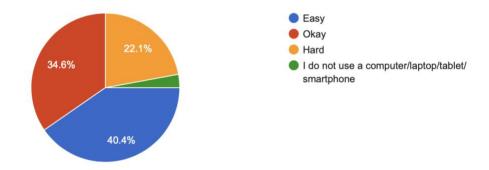
- 30 of the 104 respondents (29%) liked this delivery
- 42 (40%) found this delivery 'OK'
- 20 (19%) did not like it
- 12 (12%) were not able to engage in this delivery



### Ease of using technology

In terms of the ease of the use of the technology:

- 42 of the 104 (40%) respondents found it easy to use
- 36 (35%) found it 'OK'
- 23 (22%) found it hard
- 3 (3%) did not use any of this technology



### **Difficulties using technology**

47 respondents were able to give reasons as to why it was hard to engage with this technology.

- 17 respondents (36%) reported unreliable internet connections.
- 7 (15%) cited a lack of experience with the technology.

The remaining 23 respondents (47%) cited reasons across:

- Children finding it challenging to engage with an SLT online.
- Poor sound quality.
- Difficulties understanding the SLT due to a lack of visual aids.
- Reduced non-verbal communication.
- Reliance on parents to aid translation for deaf service users.

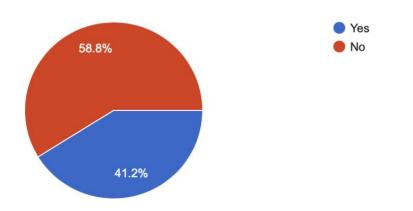
### What people told us about why they found speech and language therapy by video hard

Bad connection and technological lags made it difficult for some to capture non-verbal communication, as well as verbal communication in some cases where sound was distorted. Deaf service users and young children in particular found it difficult to access speech and language therapy on video. Deaf service users in some cases found it hard to follow the SLT and struggled with poor sound and image quality, while parents and carers of young children found it difficult to keep them engaged and concentrated within range of the screen. Some could not interact at all virtually. This made many extremely reliant on parents and carers to support and interpret.

### Other speech and language therapy support

102 of the 414 respondents responded to the question about receiving speech and language therapy for other support, such as printed materials or social media.

- 42 respondents (41%) received this support.
- 60 (59%) did not.

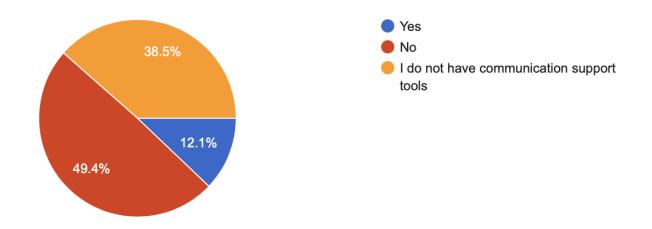


### **Communication tools**

Almost all of the complete respondents (n=413) responded to the question asking if they had received help in updating their communication supporting tools. 159 (39%) reported not having any communication support tools.

Of the 254 (61%) who did have communication support tools:

- 50 (12%) did receive help
- 204 (49%) did not receive help



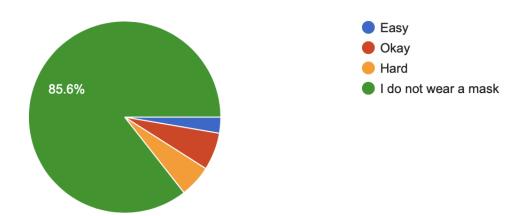
### Face masks

Respondents were asked if they or their SLT had worn a mask during their appointments and their experiences of this. 111 responses were received.

- 95 of the 111 (86%) respondents reported not wearing a mask.
- 16 (14%) did.

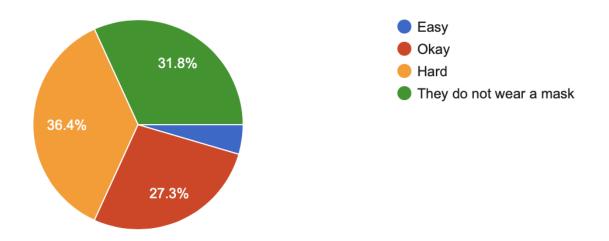
Of the 16 who did wear a mask:

- 3 (3%) found it easy
- 7 (6%) found it OK
- 6 (5%) found it hard



76 of the same 111 respondents reported their SLT wore a mask. Of these 76 respondents:

- 5 (5%) found it easy
- 30 (27%) found it OK
- 41 (36%) found it hard



What people told us about their communication support during lockdown

A significant number of respondents received limited or no support during lockdown. Some received a check-in at the very start via phone or had options for phone support, but many had no contact. Some were offered online support, but this was not always accessible, either because the service user did not have a pre-existing relationship with the SLT or because focus and engagement on a video call were difficult to achieve. Where phone or Zoom appointments were utilised, in many cases they were primarily communication with the parent or carer to provide advice and support rather than direct intervention with the service user. Some received support through printable or online resources. For some, families provided the primary communication support, with a few receiving at-home resources from the SLT. For those who received speech and language therapy primarily through their school, all speech and language therapy was suspended even once schools reopened. Some received online support and others received support via teachers, but some lost support completely.

### What people told us about their speech and language therapy

Many mentioned how vital speech and language therapy is in their daily lives. Respondents discussed how speech and language therapy has supported effective communication, helped them understand the world and the world understand them, improved their confidence, reduced frustration, supported safe eating and drinking, and provided advice and support to parents and carers. In particular, parents and carers felt supported in goal setting, future progression, and with at-home resources. A lack of speech and language therapy during lockdown has led to significant concerns about delayed diagnosis and treatment. While some had little support before lockdown which only got sparser during it, others had very strong support prior that completely disappeared when lockdown began. Many mentioned that this has made it difficult to progress. For some, lack of therapy during lockdown or lack of continuity led to slower progression, or in some cases regression. Some have not yet received speech and language therapy help from the NHS, as lack of resources in the NHS have led families to either still be on waiting lists or seek private speech and language therapy.

# Section 5: Experiences of speech and language therapy during and after the end of lockdown

In this section, data on people's experiences of speech and language therapy during and after lockdown is presented. This covers the survey questions of:

Question 23: Has your communication or swallowing become worse during COVID-19?

Question 25: If you had less speech and language therapy help during lockdown (March to June 2020) tick the things it made worse.

Question 26: If you are a family member or carer of someone who had less speech and language therapy during lockdown (March to June 2020) tick the things it made worse for you.

Question 20: Have you received speech and language therapy face to face since the end of lockdown (June 2020)?

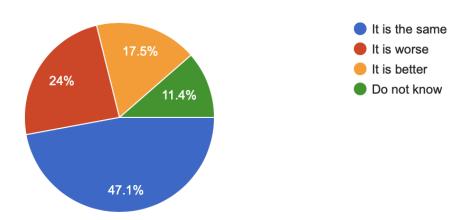
Question 27: Are you worried about getting your speech and language therapy help in the future?

Question 28: What are you worried about (if you don't have speech and language therapy help)?

### Impact on communication and swallowing

Nearly all respondents (412 of the 414) reported if their communication or swallowing became worse during lockdown.

- Most respondents reported their communication and swallowing was the same (n=194) (47%).
- Only 72 (18%) felt their communication or swallowing was better.
- 99 (24%) considered it was worse.
- The remaining 47 (11%) respondents did not know.



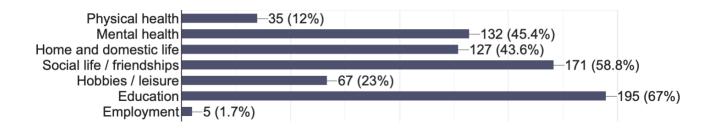
### Impact on people's lives of having less speech and language therapy

291 of the 414 respondents confirmed they had less speech and language therapy during lockdown (March to June 2020). These 291 respondents identified things that were now worse for them because of having less speech and language therapy. Respondents selected more than one option.

The thing that people most identified as getting worse was a negative impact on education (n=195) (67%).

People identified other areas of their lives that had also got worse because of having less speech and language therapy:

- Social life and friendships identified by 59% (n=171).
- Mental health reported by 45% (n=132).
- Home and domestic life identified by 44% (n=127).
- Hobbies and leisure reported by 23% (n=67).
- Physical health (n=35) (12%).
- Employment (n=5) (2%).



Other aspects reported were:

- A lack of progress or regression in speech, language and communication (n=14) (5%).
- Difficulties managing routines (n=2) (0.7%).
- A deterioration in eating and drinking (n=6) (2%).

6 respondents (2%) reported nothing got worse and they actually improved.

# What people told us about what got worse for them due to less speech and language therapy in lockdown

In addition to the options provided, respondents mentioned that a decrease in access to speech and language therapy led to worsening of eating and drinking and speech and communication development, as well as stunted or delayed progression.

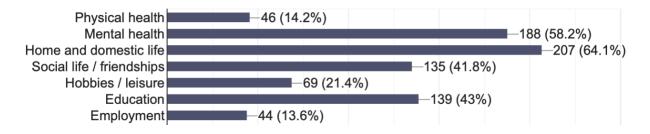
### Impact on families and carers of having less speech and language therapy

Family members and carers were also asked to describe the impact of less speech and language therapy on their own lives with respect to things that were now worse for them. Of the total 414 respondents, 323 described this impact on their own lives. Respondents selected more than one option.

The area which people most said had got worse due to having less speech and language therapy was home and domestic life. This was identified by 64% of respondents (n=207).

Families and carers said their lives got worse in other ways too because of having less speech and language therapy:

- Mental health (n=188) (58%).
- Education (n=139) (43%).
- Social life and friendships (n=135) (42%).
- Hobbies and leisure (n=69) (21%).
- Physical health (n=46) (14%).
- Employment (n=44) (14%).



Other aspects reported were:

- Not knowing how to support their child effectively (n=4) (1%).
- A deterioration in their relationships and communication with their child (n=3) (0.9%).

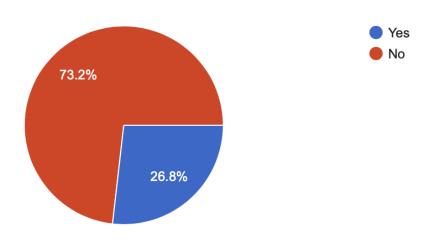
# What parents and carers told us about what got worse for them due to less speech and language therapy in lockdown

Parents and carers primarily mentioned feeling unsure and concerned about the support they were providing. In some cases, a lack of access to speech and language therapy increased pressure and responsibility on carers.

### Face-to-face speech and language therapy after lockdown ended

All respondents confirmed if they had received speech and language therapy face to face since the end of lockdown.

- The majority (n=303) (73%) had not received any face-to-face speech and language therapy since June 2020.
- 111 (27%) had.



# Face-to-face speech and language therapy after lockdown ended by postcode area

In relation to whether people had in-person speech and language therapy after lockdown ended:

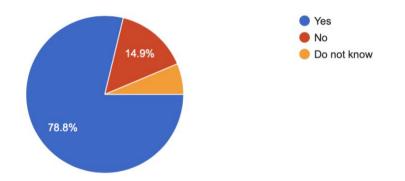
- Of the people who had face-to-face speech and language therapy after lockdown, a considerably higher percentage did so in the least deprived areas.
- A lower percentage of people living in the more deprived areas had access to face-to-face speech and language therapy after lockdown ended than those living in least deprived areas.

	Group 1 Most deprived	Group 2 Least deprived
Yes	20 (21.7%)	52 (36.8%)
No	72 (78.3%)	90 (63.4%)
Total	92 (100%)	142 (100%)

### Access to speech and language therapy in the future

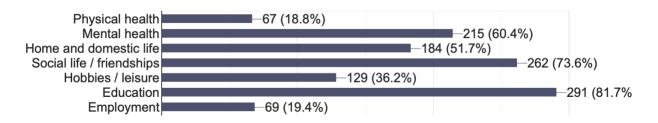
410 respondents described if they were concerned about receiving speech and language therapy in the future.

- The majority of respondents (n=323) (79%) was concerned.
- 61 (15%) were not concerned.
- 26 respondents (6%) did not know.



356 respondents from the initial 410 respondents went on to describe their concerns. Respondents were able to select more than one response. Concerns people identified if they had less speech and language therapy in the future were:

- Education (n=291) (82%).
- Social life and friendships (n=262) (74%).
- Mental health (n=215) (60%).
- Home and domestic life (n=184) (52%).
- Hobbies and leisure (n=129) (36%).
- Employment (n=69) (19%).
- Physical health (n=67) (19%).



Other aspects of concern were:

- Access and availability of speech and language therapy services after the first lockdown (n=13) (4%).
- Progress with speech, language and communication (n=7) (2%).
- The holistic impact on health and wellbeing (n=4) (1%).

## What people told us about the future if they had less speech and language therapy

Due to prior experiences with the length of waiting lists, some were concerned that services would run into issues of expanded waiting lists and may not restart. Many worried that the combination of lack of access to speech and language therapy during lockdown and the high pressures on services which they predicted following lockdown would lead to service users being lost in the system and unable to progress or access care as they had before (or at all, if they had not had previous access).

### Other things people told us about their speech and language therapy

Many brought up the value of speech and language therapy and how important it is to their communication. Respondents mentioned how grateful they are for the support they have received from their therapists, discussing both the value of support throughout lockdown as well as the difficulties they have faced if they lost this support during lockdown. Many respondents mentioned that a lack of resources played a large role in difficulty accessing speech and language therapy. They discussed a shortage of SLTs and general underfunding, which led to lower levels of pre-lockdown provision, and these issues were compounded by the pressures of lockdown. Some brought up that despite the importance of speech and language therapy, services are under resourced which makes them difficult to access consistently. Others struggled particularly in lockdown being unable to access face-to-face appointments. Some were glad to have online/video call appointments, although they see them as a substitute for face-to-face appointments, while others could not access online appointments at all. In particular, those who received speech and language therapy through school were concerned that the suspension of services during lockdown delayed or stunted progress. Some mentioned feeling abandoned or like they did not know how to help their child without contact from a SLT.

### Considerations for the descriptive analysis

Response rates varied across the 29 questions in the survey with some questions receiving a complete response rate of 414 responses and others a minimum of 158 responses. This variation in responses did limit the extent of the descriptive analysis completed. Some of the questions in the survey overlapped in content, which meant there was not always a consistent response rate across these questions. This means there were some differences in the responses received to questions asking the same content.

### Accessible (Easy Read) 18 years and over survey: descriptive data and analysis of the survey findings

There were 7 responses to the adult (18 years and older) accessible survey (Easy Read). For some questions, responses were received from all 7 respondents. For other questions, responses from a smaller sample of less than 7. The number of respondents completing each question is given in the description of the results. The design of the survey meant for some questions respondents were able to select more than one option, often selecting 2 or 3 responses. The descriptive results are described in detail for each question.

The questions and the results are grouped into five sections and the questions addressed in each section are given.

- Section 1 gives the demographic data about the respondents who completed the survey.
- Section 2 describes the respondents' background history of receiving speech and language therapy.
- Section 3 describes the respondents' experiences of speech and language therapy during lockdown (March to June 2021).
- Section 4 describes the delivery of speech and language therapy during lockdown (March to June 2020) and the respondents' experiences of this.
- Section 5 details the respondents' experiences of speech and language therapy during and after the end of lockdown.

The quantitative descriptive data is given along with the qualitative data. Qualitative data originates from the free text comments for some of the questions. These comments have been grouped into categories for ease of reference.

### Section 1: Demographic data of the respondents

The demographic data is presented first. This data was obtained from the following questions:

Question 1: What is your postcode?

Question 2: Which country do you live in?

Question 3: Please tell us who you are.

Question 30: How old are you?

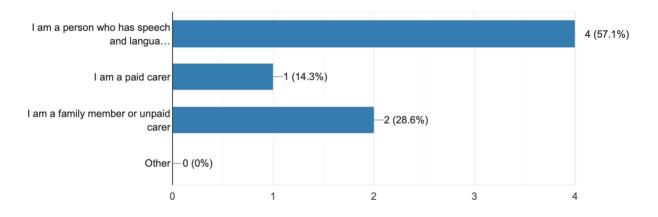
Question 31: How would you describe your gender?

Question 32: What is your ethnicity?

#### Who were the respondents?

7 people completed the Easy Read survey:

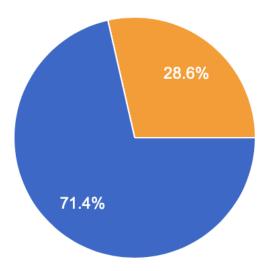
- 4 respondents (57%) were people who have speech and language therapy
- 2 respondents (29%) were family members or unpaid carers
- 1 (14%) was a paid carer



6 respondents (86%) were receiving or had received speech and language therapy at the time of the survey and 1 respondent (14%) after March 2020.

### Country

- 5 of the 7 respondents (71%) were living in England
- 2 (29%) were living in Wales

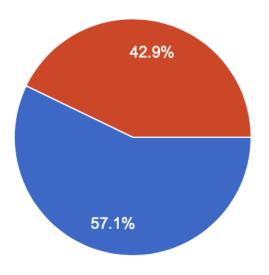




### Gender

With respect to gender:

- 4 (57%) identified as male
- 3 (43%) identified as female

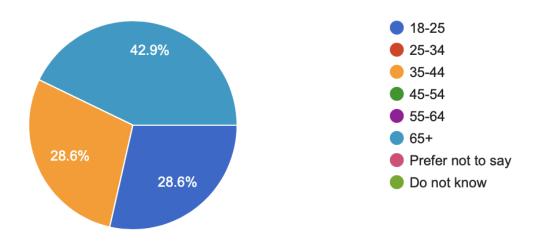




### Age

With respect to age:

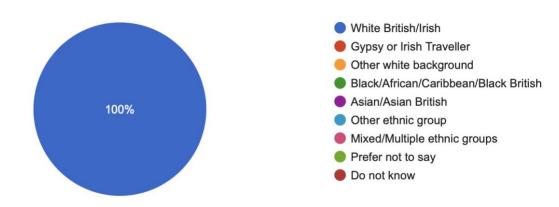
- 3 respondents (43%) were aged over 65 years
- 2 (29%) were between 35 and 44 years
- 2 (29%) were aged 18 to 25 years



The 2 respondents (25%) aged between 18 and 25 years were receiving speech and language therapy support for further education or training.

### Ethnicity

All 7 respondents identified as White British.



# Section 2: Background history of receiving speech and language therapy

In this section, the reasons for receiving speech and language therapy and when therapy started are presented. This covers the following survey questions: Question 7: Why are you having speech and language therapy? Question 6: What does speech and language therapy help you with? Question 5: When did you start having speech and language therapy? Question 24: How does your speech and language therapy help you? Question 11: How did you have your speech and language therapy before the virus lockdown (March to June 2020).

### Condition

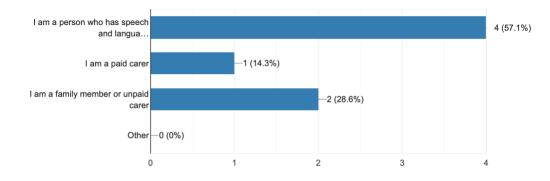
The survey asked respondents to identify the condition for which they were receiving speech and language therapy. All 7 respondents identified their condition(s) with several respondents selecting more than one condition indicating complex comorbidities.

- 2 respondents (29%) identified with autism
- 2 (29%) with Parkinson's Disease
- 2 (29%) with a stroke
- 1 (14%) with cerebral palsy
- 1 (14%) with a mental health difficulty
- 1 (14%) with a learning disability
- 1 (14%) with a stammer
- 1 (14%) with developmental language disorder

### Reason for having speech and language therapy

All 7 respondents confirmed the reasons for receipt of speech and language therapy.

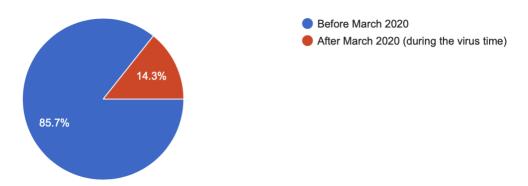
- All 7 respondents confirmed receipt of speech and language therapy for speech, language and communication.
- 3 respondents (43%) also received speech and language therapy for eating and drinking.



### When speech and language therapy started

Of the 7 respondents:

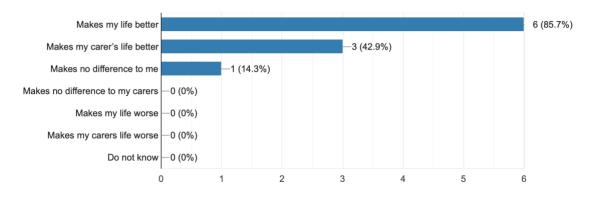
- 6 (86%) were in receipt of speech and language therapy before March 2020.
- 1 (14%) after March 2020.



### How speech and language helps

All 7 respondents described how speech and language therapy helps them.

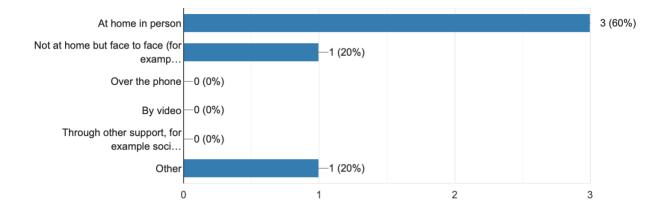
- For most of the respondents (n=6) (65%), speech and language therapy makes their life better.
- For 3 of these 6 respondents (43%) it also makes their carer's life better.
- 1 respondent (14%) reported speech and language therapy makes no difference to them.



### How speech and language therapy was delivered before lockdown

5 of the 7 respondents reported how their speech and language therapy was delivered before lockdown in March 2020.

- 4 of the 5 respondents (80%) received speech and language therapy in person.
- 1 respondent (20%) not in person.



# Section 3: Experiences of speech and language therapy during lockdown (March-June 2020)

In this section, the experiences of receiving speech and language therapy during lockdown are presented. This covers the survey questions of:

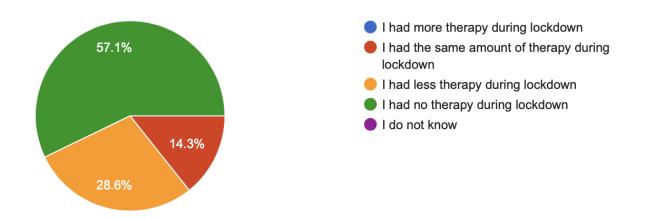
Question 8: Did your speech and language therapy change during lockdown (March to June 2020)?

Question 9: What happened to your speech and language therapy appointments?

### Changes to speech and language therapy

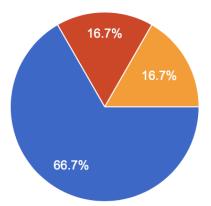
All 7 respondents reported changes in their receipt of speech and language therapy.

- Only 1 respondent (14%) received the same amount of speech and language therapy before and during lockdown.
- 4 respondents (57%) had no speech and language therapy.
- 2 (29%) received less speech and language therapy.



6 of these 7 respondents reported what happened to the speech and language therapy appointments.

- For 4 of the 7 respondents (67%), the speech and language therapy cancelled the appointment.
- 1 (27%) received an speech and language therapy appointment online.
- 1 respondent (17%) cancelled his/her appointment.



- The speech & language therapist cancelled my appointment
- l / my carer cancelled my appointment
- I had my speech and language therapy appointment using video
- I had speech and language therapy help over the phone

# Section 4: Delivery of speech and language therapy and experiences of delivery during lockdown (March–June 2020)

In this section, how speech and language therapy was delivered during lockdown is presented. This covers the survey questions of:

Question 12: Did you get speech and language therapy in person during the virus lockdown (March to June 2020)?

Question 13: Did you get your speech and language therapy over the phone during the first virus lockdown (March to June 2020)?

Question 14: How was your speech and language therapy over the phone?

Question 15: Did you get your speech and language therapy by video during the virus lockdown (March to June 2020)?

Question 16: How was your speech and language therapy help on video (online)?

Question 17: How easy was it to use the computer/laptop/tablet/smartphone?

Question 18: Did you get your speech and language therapy through other support, for example social media or printed materials during the virus lockdown (March to June 2020)?

Question 19: Did you get help updating things on your communication support tools (for example communication pictures, communication books, electronic aids)?

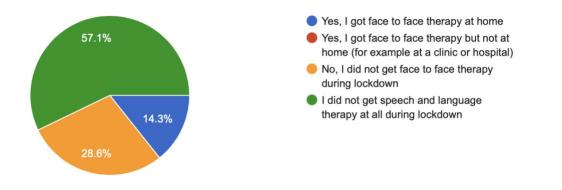
Question 21: What has it been like if you have to wear a mask during your speech and language therapy?

Question 22: What has it been like if your SLT has to wear a mask during your speech and language therapy?

### The delivery of speech and language therapy

All 7 respondents reported on the delivery of speech and language therapy.

- 4 respondents (57%) did not receive any speech and language therapy during lockdown.
- 2 (29%) did not receive speech and language therapy in person, but did receive speech and language therapy online and both respondents reported they liked this online delivery and found it easy.
- 1 respondent (14%) received speech and language therapy at home on the phone and he/she liked this delivery.

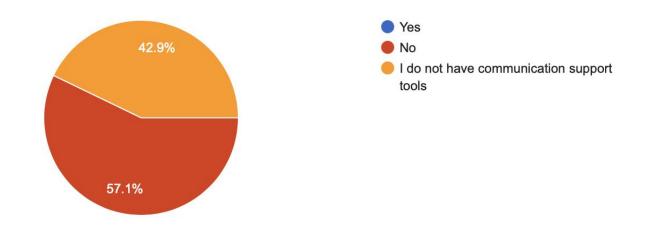


### Other speech and language therapy support

3 of the 7 respondents responded to the question about receiving speech and language therapy for other support, such as printed materials or social media. All 3 confirmed they did not receive this support.

### **Communication tools**

All 7 people responded to the question asking if they had received help in updating their communication support tools. 3 respondents (43%) reported not having any communication support tools. Of the 4 respondents (57%) who did have communication support tools, none of them received any help to update these.



### Face masks

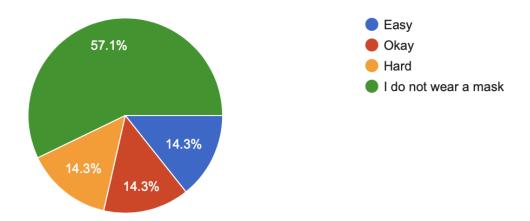
Respondents were asked if they or their SLT had worn a mask during their appointments and their experiences of this.

Of the 7 respondents:

- 4 (57%) reported not wearing a mask
- 3 (43%) did

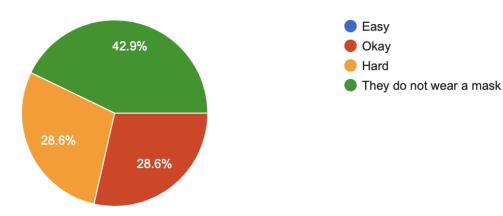
Of the 3 who did wear a mask:

- 1 (14%) reported this was 'OK'
- 1 (14%) found it hard
- 1 (14%) found it easy



Four of the 7 respondents reported their SLT wore a mask. Of these 4 respondents:

- 2 (29%) found it hard.
- 2 (29%) found it OK.
- None found it easy.



## Section 5: Experiences of speech and language therapy during and after the end of lockdown

In this section, data on people's experiences of speech and language therapy during and after lockdown is presented. This covers the survey questions of:

Question 23: Has your communication or swallowing become worse during COVID-19?

Question 15: If you had less speech and language therapy help during lockdown (March to June 2020) tick the things it made worse.

Question 26: If you are a family member or carer of someone who had less speech and language therapy during lockdown (March to June 2020) tick the things it made worse for you.

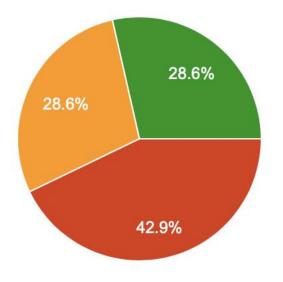
Question 27: Are you worried about getting your speech and language therapy help in the future?

Question 28: What are you worried about (if you don't have speech and language therapy help)?

### Impact on communication and swallowing

All 7 respondents reported if their communication or swallowing became worse during lockdown.

- None of the 7 respondents felt their communication or swallowing was better.
- 2 (29%) reported it was worse.
- 2 respondents (29%) did not know.





### Impact on people's lives of having less speech and language therapy

All 7 respondents confirmed they had less speech and language therapy during lockdown (March to June 2020).

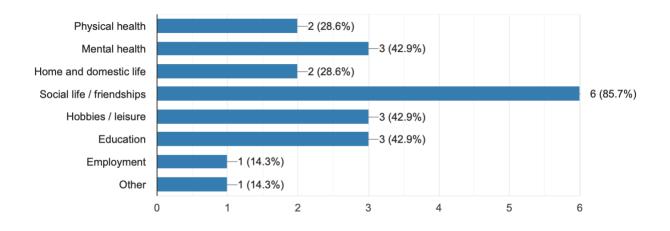
These 7 respondents identified aspects that were now worse for them because of having less speech and language therapy. Respondents were able to select more than one option.

The aspect with the most responses was social life and friendships (n=6) (86%).

This was followed by:

- Education (n=3) (43%).
- Hobbies/leisure (n=3) (43%).
- Mental health (n=3) (43%).
- Home and domestic life (n=2) (29%).
- Physical health (n=2) (29%).
- Employment (n=1) (14%).

1 respondent (14%) reported it made other aspects of their life worse.



### Impact on families and carers of having less speech and language therapy of having less speech and language therapy

Family members and carers were also asked to describe the impact of less speech and language therapy on their own lives. 5 of the 7 respondents described this impact on

their own lives because of having less speech and language therapy. Respondents were able to select more than one option.

The aspect with the most responses was social life and friendships (n=3) (60%).

This was followed by:

- Mental health (n=2) (40%).
- Home and domestic life (n=2) (40%).
- Employment (n=2) (40%).
- Education (n=1) (20%).
- Hobbies/leisure (n=1) (20%).

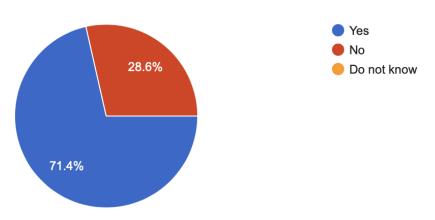
Physical health 0 (0%) Mental health -2 (40%) Home and domestic life 2 (40%) 3 (60%) Social life / friendships Hobbies / leisure 1 (20%) Education 1 (20%) Employment 1 (20%) —2 (40%) Other 1 2 0 3

2 respondents (40%) reported it made other aspects of their lives worse.

### Access to speech and language therapy in the future

All 7 respondents described if they were concerned about receiving speech and language therapy in the future.

- 5 respondents (71%) were concerned.
- 2 (29%) were not concerned.



### Considerations for the descriptive analysis

Response rates varied across the 28 questions in the survey with some questions receiving a complete response rate of 7 responses and others a minimum of 2 responses. This variation in responses did limit the extent of the descriptive analysis completed. Some of the questions in the survey overlapped in content, which meant there was not always a consistent response rate across these questions. This means there were some differences in the responses received to questions asking the same content.

### Accessible (Easy Read) 0–18 years survey: descriptive data and analysis of the survey findings

There were 9 responses to the children, 18 years and under, accessible survey (Easy Read). For some questions, responses were received from all 9 respondents. For other questions, responses from a smaller sample of less than 9. The number of respondents completing each question is given in the description of the results. The design of the survey meant for some questions respondents were able to select more than one option, often selecting 2 or 3 responses. The descriptive results are described in detail for each question.

The questions and the results are grouped into 5 sections and the questions addressed in each section are given.

- Section 1 gives the demographic data about the respondents who completed the survey.
- Section 2 describes the respondents' background history of receiving speech and language therapy.
- Section 3 describes the respondents' experiences of speech and language therapy during lockdown (March to June 2021).
- Section 4 describes the delivery of speech and language therapy during lockdown (March to June 2020) and the respondents' experiences of this.
- Section 5 details the respondents' experiences of speech and language therapy during and after the end of lockdown.

The quantitative descriptive data is given along with the qualitative data. Qualitative data originates from the free text comments for some of the questions. These comments have been grouped into categories for ease of reference.

### Section 1: Demographic data of the respondents

The demographic data is presented first. This data was obtained from the following questions:

Question 1: What is your postcode?

Question 2: Which country do you live in?

Question 3: Please tell us who you are.

Question 30: How old are you?

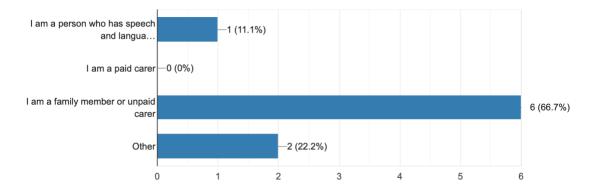
Question 31: How would you describe your gender?

Question 32: What is your ethnicity?

#### Who were the respondents?

Of the 9 people who completed the 0–18 years easy read survey:

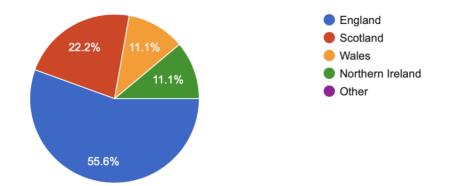
- 6 respondents (67%) were family members or unpaid carers of children and young people receiving speech and language therapy.
- 1 (11%) was a person receiving speech and language therapy.
- 2 (22%) identified as other.



All 9 respondents were receiving or had received speech and language therapy at the time of the survey.

### Country

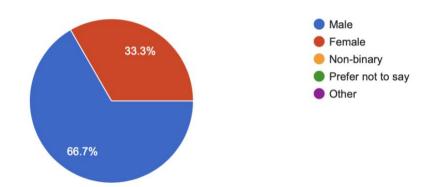
- 5 of the 9 respondents 5(6%) were living in England.
- 2 (22%) in Scotland.
- 1 (11%) in Wales.
- 1 (11%) in Northern Ireland.



#### Gender

With respect to gender:

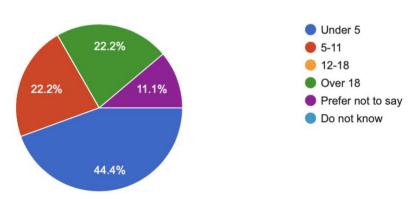
- 6 (67%) identified as male.
- 3 (33%) identified as female.



### Age

With respect to age:

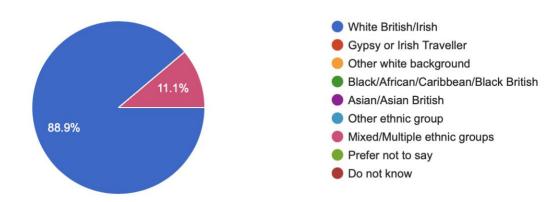
- 4 respondents (44%) were under 5 years of age.
- 2 (22%) were aged between 5 and 11 years.
- 2 (22%) were aged 18 years.
- 1 (11%) preferred not to say.



### Ethnicity

With respect to ethnicity:

- 8 of the 9 respondents (89%) identified as White British.
- 1 (11%) as mixed/multiple ethnic groups.



# Section 2: Background history of receiving speech and language therapy

In this section, the reasons for receiving speech and language therapy ever and when speech and language therapy started are presented. This covers the following survey questions:

Question 7: Why are you having speech and language therapy?

Question 6: What does speech and language therapy help you with?

Question 5: When did you start having speech and language therapy?

Question 24: How does your speech and language therapy help you?

Question 11: How did you have your speech and language therapy before the virus lockdown (March to June 2020)?

### Condition

The survey asked respondents to identify the condition for which they were receiving speech and language therapy. All 9 respondents identified their condition(s) with several respondents selecting more than one condition indicating complex comorbidities.

- 4 respondents (44%) identified with autism.
- 2 (22%) with hearing loss/deafness.
- 2 (22%) with a stammer.
- 2 (22%) with a learning disability.
- 1 (11%) with a brain injury.
- 1 (11%) with a developmental delay.
- 1 (11%) with selective mutism.
- 1 (11%) with a speech sound disorder.

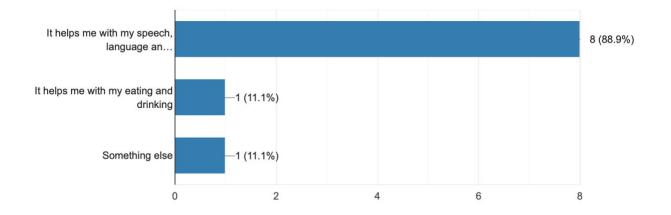
2 respondents (22%) were waiting for a diagnosis.

### Reason for having speech and language therapy

All 9 respondents confirmed the reasons for receipt of speech and language therapy.

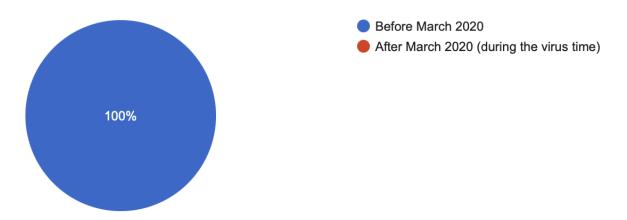
- 8 of the 9 respondents (89%) confirmed receipt of speech and language therapy for speech, language and communication.
- 1 (11%) for eating and drinking.

1 respondent (11%) reported needing support for something else.



#### When speech and language therapy started

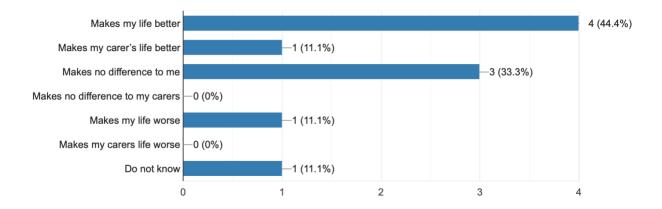
All 9 respondents were in receipt for speech and language therapy before March 2020.



### How speech and language therapy helps

All 9 respondents described how speech and language therapy helps them.

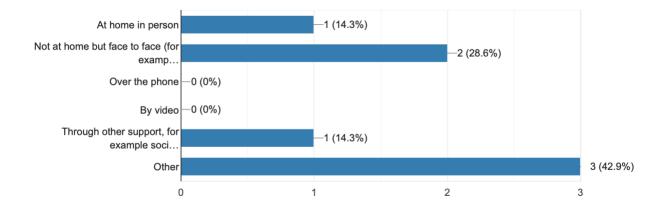
- 5 of the 9 respondents (55%) considered speech and language therapy makes their life better or the lives of their carers better.
- 3 respondents (33%) reported speech and language therapy makes no difference to them.
- 1 respondent (11%) reported speech and language therapy makes his/her life worse.
- 1 respondent (11%) did not know.



### How speech and language therapy was delivered before lockdown

Six of the 9 respondents reported how their speech and language therapy was delivered before lockdown.

- 3 of the 6 respondents (50%) received speech and language therapy in person either at home or in another location.
- 3 respondents (50%) received speech and language therapy another way.



# Section 3: Experiences of speech and language therapy during lockdown (March to June 2020)

In this section, the experiences of receiving speech and language therapy during lockdown are presented. This covers the survey questions of:

Question 8: Did your speech and language therapy change during lockdown (March to June 2020)?

Question 9: What happened to your speech and language therapy appointments?

### Changes to speech and language therapy

All 9 respondents reported changes in their receipt of speech and language therapy.

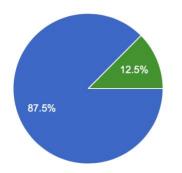
- 8 of the 9 respondents (89%) received no speech and language therapy during lockdown.
- 1 respondent (11%) did not know.



### What happened to speech and language therapy appointments

8 of the 9 respondents were able to report what happened to their speech and language therapy appointments.

- For 7 respondents (88%), the speech and language therapy service cancelled their appointments.
- 1 respondent (12%) received speech and language therapy over the phone.



- The speech & language therapist cancelled my appointment
  - I / my carer cancelled my appointment
  - I had speech and language therapy appointment using video
- I had speech & language therapy help over the phone

### Section 4: Delivery of speech and language therapy and experiences of speech and language therapy delivery during lockdown (March to June 2020)

In this section, how speech and language therapy was delivered during lockdown is presented. This covers the survey questions of:

Question 12: Did you get speech and language therapy in person during the virus lockdown (March to June 2020)?

Question 13: Did you get your speech and language therapy over the phone during the first virus lockdown (March to June 2020)?

Question 14: How was your speech and language therapy over the phone? Question 15: Did you get your speech and language therapy by video during the virus lockdown (March to June 2020)?

Question 16: How was your speech and language therapy help on video (online)? Question 17: How easy was it to use the computer/laptop/tablet/smartphone? Question 18: Did you get your speech and language therapy through other support, for example social media or printed materials during the virus lockdown (March to June 2020)?

Question 19: Did you get help updating things on your communication support tools (for example communication pictures, communication books, electronic aids)?

Question 21: What has it been like if you have to wear a mask during your speech and language therapy?

Question 22: What has it been like if your SLT has to wear a mask during your speech and language therapy?

### Delivery of speech and language therapy

All 9 respondents reported on the delivery of speech and language therapy during lockdown,

- None received speech and language therapy in person during lockdown.
- None received speech and language therapy by phone or online during lockdown.
- None received speech and language therapy for other support such as printed materials or social media.

### **Communication tools**

All 9 respondents reported if they received help to update things on their communication support tools.

6 respondents (67%) reported not having any communication support tools. Of the remaining 3 respondents:

- 2 (22%) did not receive any help.
- 1 (11%) did receive help.

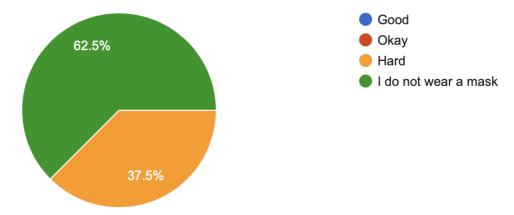
#### Face masks

Respondents were asked if they or their SLT had worn a mask during their appointments and their experiences of this.

Of the 8 respondents:

- 5 (63%) reported not wearing a mask.
- 3 (38%) did.

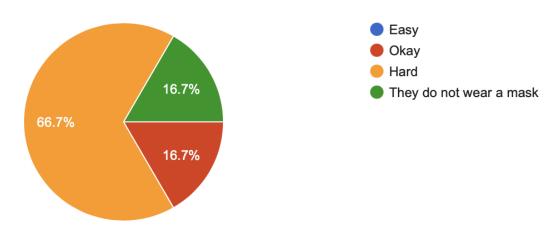
Of the 3 who did wear a mask, all found it hard.



Five respondents reported their SLT wore a mask. Of these 5 respondents:

- 4 (67%) found it hard.
- 1 (17%) found it 'OK'.

None found it easy.



## Section 5: Experiences of speech and language therapy during and after the end of lockdown (March–June 2020)

In this section, data on people's experiences of speech and language therapy during and after lockdown is presented. This covers the survey questions of:

Question 23: Has your communication or swallowing become worse during COVID-19?

Question 15: If you had less speech and language therapy help during lockdown (March to June 2020) tick the things it made worse.

Question 26: If you are a family member or carer of someone who had less speech and language therapy during lockdown (March to June 2020) tick the things it made worse for you.

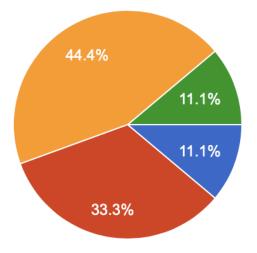
Question 27: Are you worried about getting your speech and language therapy help in the future?

Question 28: What are you worried about (if you don't have speech and language therapy help)?

### Impact on communication and swallowing

All 9 respondents reported if their communication or swallowing became worse during the lockdown.

- 1 respondent (11%) felt their communication or swallowing was better.
- 3 (33%) reported it was the same.
- 4 (44%) reported it was worse.
- 1 respondent (11%) did not know.





### Impact on people's lives of having less speech and language therapy

All 9 respondents confirmed they had less speech and language therapy during lockdown (March to June 2020).

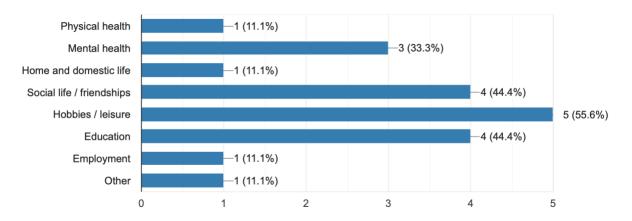
These 9 respondents identified aspects that were now worse for them because of having less speech and language therapy. Respondents were able to select more than one option.

The aspect with the most responses was hobbies/leisure (n=5) (56%).

This was followed by:

- Education (n=4) (44%)
- Mental health (n=3) (33%)
- Home and domestic life (n=1) (11%)
- Physical health (n=1) (11%)
- Employment (n=1) (11%)

1 respondent (11%) reported it made other aspects of their life worse.



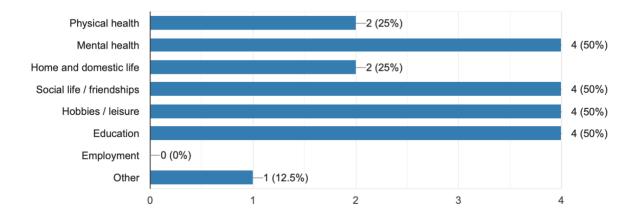
### Impact on families and carers of having less speech and language therapy

Family members and carers were also asked to describe the impact of less speech and language therapy on their own lives. 8 of the 9 respondents described this impact on their own lives. Respondents were able to select more than one option.

The aspects that families and carers said had got worse for them were:

- Social life and friendships (n=4) (50%)
- Mental health (n=4) (50%)
- Hobbies and leisure (n=4) (50%)
- Education (n=4) (50%)
- Home and domestic life (n=2) (25%)
- Physical health (n=2) (25%)

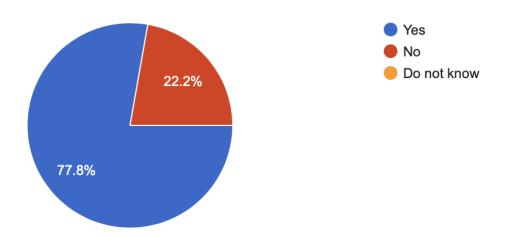
1 respondent (13%) reported it made other aspects of their life worse.



### Access to speech and language therapy in the future

All 9 respondents described if they were concerned about receiving speech and language therapy in the future.

- 7 respondents (78%) were concerned.
- 2 (22%) were not concerned.



### Considerations for the descriptive analysis

Response rates varied across the 28 questions in the survey with some questions receiving a complete response rate of 9 responses and others a minimum of 4 responses. This variation in responses did limit the extent of the descriptive analysis completed. Some of the questions in the survey overlapped in content, which meant there was not always a consistent response rate across these questions. This means there were some differences in the responses received to questions asking the same content.

### Aphasia-accessible survey: descriptive data and analysis of the survey findings

There were 16 responses to the aphasia survey. There were 23 questions across the 4 sections of the aphasia survey. For some questions, responses were received from all 16 respondents. For other questions, responses from a smaller sample of less than 16. The number of respondents completing each question is given in the description of the results. The design of the survey meant for some questions respondents were able to select more than one option, often selecting 2 or 3 responses. The descriptive results are described in detail for each question.

The questions and the results are grouped into five sections and the questions addressed in each section are given.

- Section 1 gives the demographic data about the respondents who completed the survey.
- Section 2 describes the respondents' background history of receiving speech and language therapy.
- Section 3 describes the respondents' experiences of speech and language therapy during lockdown (March to June 2021).
- Section 4 describes the delivery of speech and language therapy during lockdown (March to June 2020) and the respondents' experiences of this.
- Section 5 details the respondents' experiences of speech and language therapy during and after the end of lockdown.

The quantitative descriptive data is given along with the qualitative data. Qualitative data originates from the free text comments for some of the questions. These comments have been grouped into categories for ease of reference.

### Section 1: Demographic data of the respondents

The demographic data is presented first. This data was obtained from the following questions:

Question 1: My postcode is.

Question 2: Look at the map. Where do you live?

Question 21: How old are you?

Question 22: How would you describe your gender?

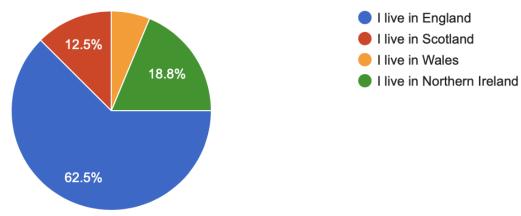
Question 32: What is your ethnicity?

#### Who were the respondents?

All 16 respondents were individuals with aphasia.

#### Country

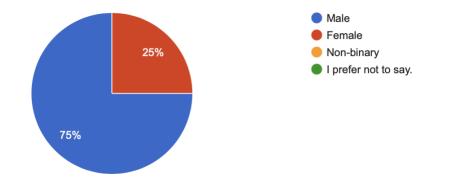
- 10 of the 16 respondents (63%) were living in England.
- 3 (19%) in Northern Ireland.
- 2 (13%) in Scotland.
- 1 (6%) in Wales.



### Gender

With respect to gender:

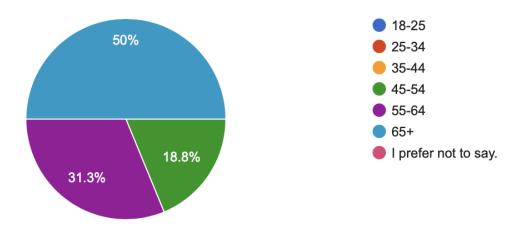
- 12 (75%) identified as male.
- 4 (25%) identified as female.



### Age

With respect to age:

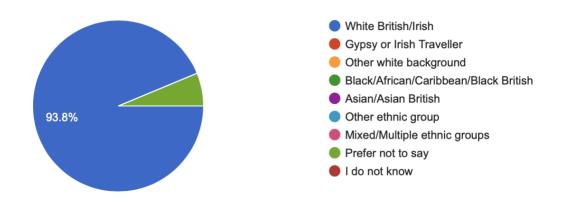
- 8 respondents (50%) were aged 65 years or over.
- 5 (31%) were between 55 and 64 years.
- 3 (19%) were aged 45 to 54 years.



### Ethnicity

With respect to ethnicity:

- 15 of the 16 respondents (94%) identified as white British.
- 1 (8%) preferred not to say.



# Section 2: Background history of receiving speech and language therapy

In this section, the reasons for having speech and language therapy and when speech and language therapy started are presented. This covers the following survey questions:

Question 7: Why did you need to have speech and language therapy?

Question 17: Does speech and language therapy help you?

Question 4: What does speech and language therapy help you with?

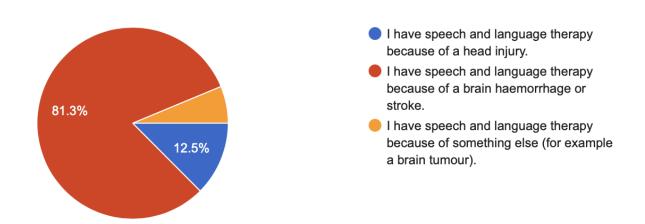
Question 3: When did you start having speech and language therapy?

Question 6: Think about your speech and language therapy before lockdown.

### Condition

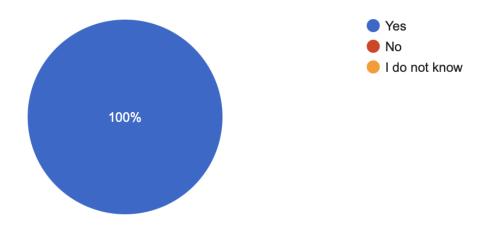
The survey asked respondents to identify the condition for which they were receiving speech and language therapy. All 16 respondents identified one condition.

- 13 respondents (81%) identified with a brain hemorrhage or stroke.
- 2 (13%) with a head injury.
- 1 (6%) due to another condition.



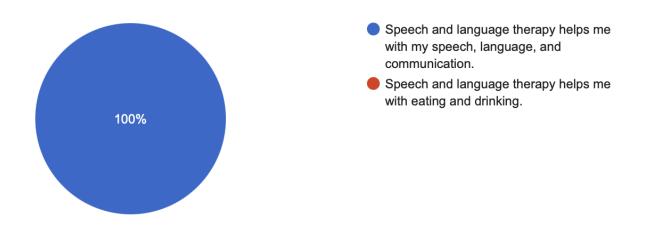
### Does speech and language therapy help?

14 of the 16 respondents said that speech and language therapy makes their life better. The remaining 2 respondents did not complete this question.



### What speech and language therapy helps with

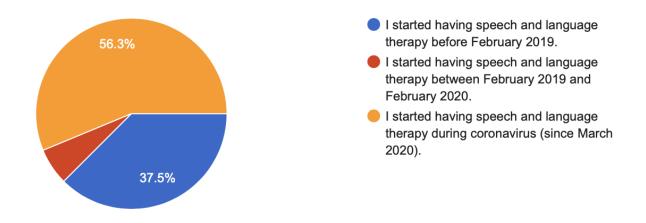
All 16 respondents confirmed they received speech and language therapy for help with speech, language and communication.



### When people started having speech and language therapy

Of the 16 respondents:

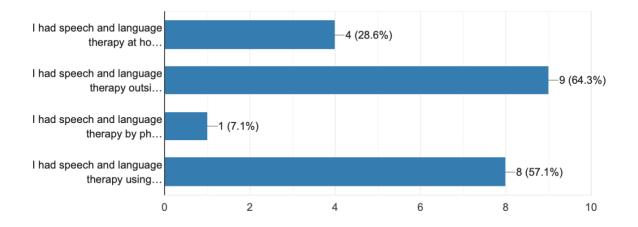
- 6 (38%) were in receipt of speech and language therapy before February 2019.
- 9 (56%) started receiving speech and language therapy from the start of lockdown (March 2020 onwards).
- 1 respondent (6%) received speech and language therapy between February 2019 and February 2020.



#### Experience of speech and language therapy before lockdown

14 of the 16 respondents reported on the delivery of their speech and language therapy before lockdown (March 2020). Respondents selected more than one response.

- 9 of these 14 respondents (64%) received speech and language therapy in person outside of the home.
- 8 (57%) by video call.
- 4 (29%) in person at home.
- 1 (7%) by phone.



# Section 3: Experiences of speech and language therapy during lockdown (March–ßJune 2020)

In this section, the experiences of receiving speech and language therapy during lockdown are presented. This covers the survey questions of:

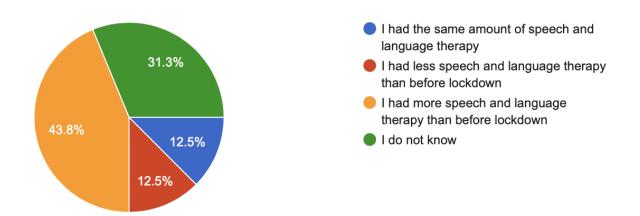
Question 7: Tell us how much speech and language therapy you had during lockdown?

Question 8: Did your speech and language therapy change during lockdown? Question 9: Think about your speech and language therapy during the lockdown.

#### Speech and language therapy during lockdown

All 16 respondents completed this question and respondents were able to select more than one response.

- Nearly half of the respondents (44%) had more speech and language therapy during lockdown.
- 2 (13%) had the same amount.
- 2 (13%) had less.
- 5 respondents (31%) were not sure.

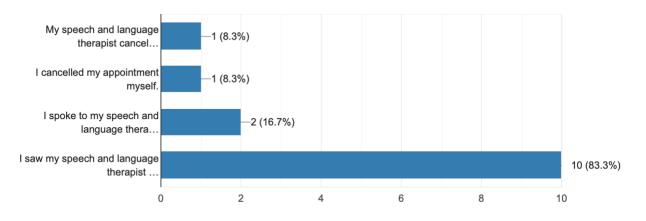


#### What happened to speech and language therapy appointments

12 of the 16 respondents reported what happened to the speech and language therapy appointments. Respondents were able to select more than one response.

• speech and language therapy appointments were only cancelled for 2 respondents (16%).

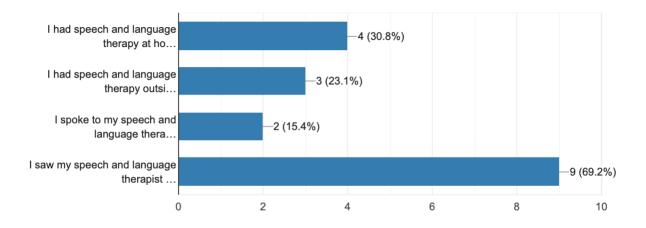
- 10 respondents (83%) said they received speech and language therapy online/video calls.
- 2 respondents (17%) said speech and language therapy was received over the phone.



#### Reflections on speech and language therapy during lockdown

13 of the 16 respondents reflected on the speech and language therapy they received during lockdown. Respondents were able to select more than one response.

- 9 respondents (69%) received speech and language therapy via video call.
- 7 (54%) received speech and language therapy in person either at home or outside of the home.
- 2 (15%) received speech and language therapy by phone.



# Section 4: Delivery of speech and language therapy and experiences of delivery during the lockdown (March to June 2020)

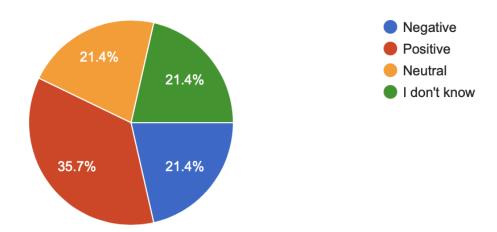
In this section, how speech and language therapy was delivered during lockdown is presented. This covers the survey questions of:

Question 10: How do you feel about speech and language therapy on the phone? Question 11: How do you feel about speech and language therapy using a video call? Question 12: Is speech and language therapy on a video call hard or easy? Question 13: What do you think about wearing a mask during your speech and language therapy? Question 14: What do you think about your SLT wearing a mask during your speech and language therapy?

### Speech and language therapy over the phone

14 of the 16 respondents described their experiences of receiving speech and language therapy by phone. Of these 14 respondents:

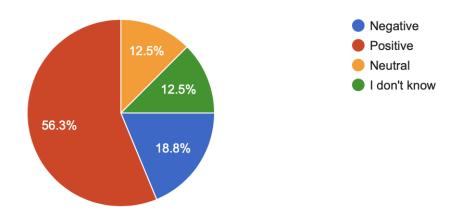
- 5 (36%) were positive.
- 3 (21%) were negative.
- 3 (21%) were neutral.
- 3 (21%) did not know.



#### Speech and language therapy by video

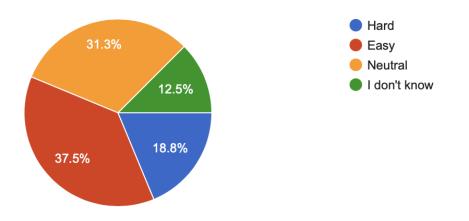
All 16 respondents reported on their experiences of receiving speech and language therapy by video call.

- The majority (n=9) (56%) were positive.
- 3 (19%) were negative.
- 2 (13%) were neutral.
- 2 (13%) did not know.



Of these 16 respondents:

- 6 (38%) found video calls easy.
- 3 (19%) found them hard.
- 5 (31%) were neutral.
- 1 (13%) did not know.

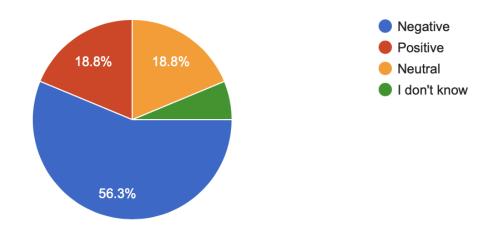


#### Face masks

All 16 respondents described their experiences of wearing a mask during speech and language therapy.

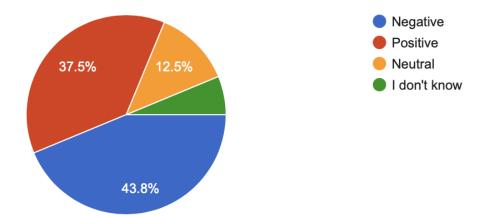
• More than half (n=9) (56%) of respondents were negative about mask wearing.

- 3 (19%) were positive.
- 3 (19%) were neutral.
- 1 (6%) did not know.



All 16 respondents described their experiences of their SLT wearing a mask during speech and language therapy.

- Nearly half of the respondents (44%) described their experiences as negative.
- 6 (38%) were positive.
- 2 (13%) were neutral.
- 1 (6%) did not know.



## Section 5: Experiences of speech and language therapy during and after the end of lockdown

In this section, data on people's experiences of speech and language therapy during and after lockdown is presented. This covers the survey questions of:

Question 15: Tell us about your communication during lockdown.

Question 16: Tell us about your swallowing during lockdown.

Question 18: This question is for people who had less speech and language therapy during lockdown.

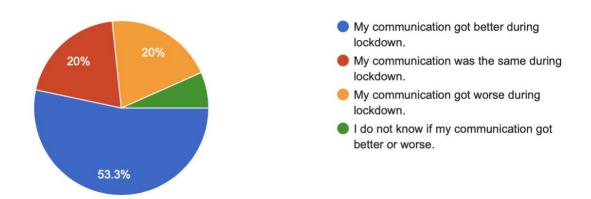
Question 19: Look at the different options.

Question 20: Look at the different options.

#### Impact on communication and swallowing

15 of the 16 respondents described their communication during lockdown.

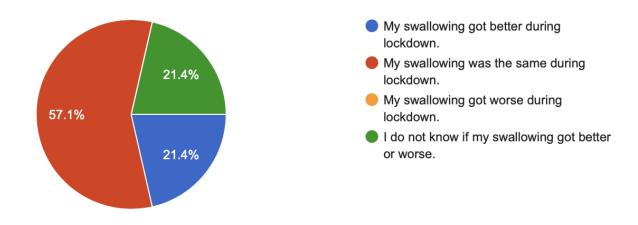
- More than half the 15 respondents (53%) described their communication as better.
- Only 3 (20%) described it as worse.
- 3 respondents (20%) found their communication the same.
- 1 (7%) did not know.



14 of these 15 respondents described their swallowing during lockdown.

- Only 3 respondents (21%) described their swallowing was better.
- More than half of the respondents (n=8) (57%) described their swallowing as the same.
- For 3 respondents (20%), their swallowing was worse.

1 respondent (7%) did not know.



#### Impact on people's lives of having less speech and language therapy

6 of the 16 respondents completed the question about the impact on them of having less speech and language therapy during lockdown. Respondents selected more than one option.

In terms of the impact of less speech and language therapy, the areas with the most responses were physical health (n=3) (50%) and mental health (n=3) (50%).

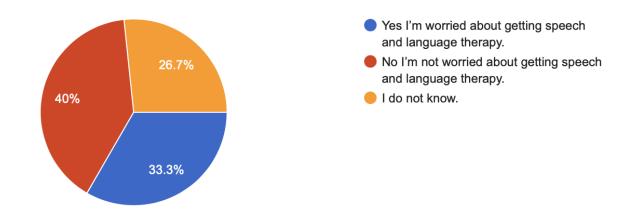
These were followed by:

- Home life (n=2) (33%).
- Hobbies (n=2) (33%).
- Work (n=2) (33%).
- Education (n=1) (17%).
- Social life (n=1) (17%).

#### Access to speech and language therapy in the future

15 of the 16 respondents reported their concerns about receiving speech and language therapy in the future.

- 5 (33%) were worried about receiving speech and language therapy.
- 6 (40%) were not.
- 4 (27%) did not know.



Of the 15 respondents, 11 reported on the potential impact of not receiving speech and language therapy in the future. Respondents were able to select more than one response.

The areas with the most responses were physical health (n=7) (64%) and social life (n=7) (64%).

These were followed by:

- Mental health (n=3) (27%).
- Hobbies (n=3) (27%).
- Work (n=2) (18%).
- Home life (n=1) (9%),
- Education (n=1) (9%).

#### Considerations for the descriptive analysis

Response rates varied across the 23 questions in the survey with some questions receiving a complete response rate of 16 responses and others a minimum of 11 responses. This variation in responses did limit the extent of the descriptive analysis completed. Some of the questions in the survey overlapped in content, which meant there was not always a consistent response rate across these questions. This means there were some differences in the responses received to questions asking the same content.

## APPENDIX

This is a selection of surveys by other organisations that have reported similar themes to the RCSLT survey.

#### Cerebral palsy

**Cerebral Palsy Scotland** also published a report in September 2020. *Understanding the Impact of COVID-19 Restrictions for people with Cerebral Palsy* found that:

- The largest issue for people was access to support for their physical health (physiotherapy, occupational therapy and speech and language therapy).
- 58% of people reported difficulty in accessing support from these services.
- 47% said that appointments with the health professionals they normally see about their CP have still not resumed.<sup>2</sup>

#### Dementia

In July 2020, the **Alzheimer's Society** published **the impact of COVID-19 on people affected by dementia**. Based on almost 2,000 respondents affected by dementia, this found that:

- Since being forced to stay isolated and inside their homes, more than 4 in 5 (82%) reported a deterioration in people with dementia's symptoms.
- Of those who had seen a decline, around half reported increased memory loss (50%) and difficulty concentrating (48%). More than 1 in 4 (27%) said reading and writing has become more difficult, and 1 in 3 said the same for speaking and understanding speech (33%). Worryingly, more than a quarter had seen a loss in the ability to do daily tasks, like cooking or dressing (28%).<sup>3</sup>

In September 2020, the **Alzheimer's Society** published **Worst hit: dementia during coronavirus**. This stated:

 National UK governments needs to set out a clear strategy to enable people affected by dementia to recover from the effects of the pandemic, including rehabilitation to counteract effects on cognitive or physical functioning, support for mental and physical health, and speech and language therapy.<sup>4</sup>

<sup>&</sup>lt;sup>2</sup> <u>https://cerebralpalsyscotland.org.uk/life-after-lockdown-survey-results/</u>

<sup>&</sup>lt;sup>3</sup> <u>https://www.alzheimers.org.uk/news/2020-07-30/lockdown-isolation-causes-shocking-levels-decline-people-dementia-who-are-rapidly</u>

<sup>&</sup>lt;sup>4</sup> <u>https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf</u>

#### Head and neck cancer

In January 2021, The Swallows revealed that:

- A decline in urgent referrals for cancer (70% decrease) during the initial lockdown.
- A decline in chemotherapy attendances (40% decrease) during the initial lockdown.
- For certain cancers, these declines had only partially recovered.<sup>5</sup>

#### Learning disability

In June 2020, the Northern Ireland Assembly's All Party Group on Learning **Disability** published **briefing paper on the impact of Covid-19**. This found that:

• 82% of parents reported a decrease in speech and language therapy support.<sup>6</sup>

In November 2020, **MENCAP** published a survey to mark 8 months since the start of lockdown. This found:

- Nearly 9 in 10 people with a learning disability have still not have all their social care support reinstated
- Almost three-quarters of family carers surveyed are worried that there are more cuts to care packages to come.<sup>7</sup>

#### Multiple sclerosis

In September 2020, the **MS Society** published findings from a survey of allied health professionals delivering rehabilitation to people with progressive neurological conditions in the UK. This found that:

• 76% of respondents said they were aware of a deterioration in the mental or physical health of their patients due to not accessing rehabilitation therapies during lockdown.

<sup>&</sup>lt;sup>5</sup> https://www.theswallows.org.uk/the-forgotten-cancer-in-the-fight-against-covid-19/

<sup>&</sup>lt;sup>6</sup> <u>https://northernireland.mencap.org.uk/sites/default/files/2020-</u>

<sup>10/</sup>APGLD%20Briefing%20Paper%20on%20Impact%20of%20Covid-19%20June%202020.pdf

<sup>&</sup>lt;sup>7</sup> <u>https://www.mencap.org.uk/press-release/i-am-only-human-and-if-i-cannot-get-break-then-i-will-break-myself-eight-months-first</u>

- 44% said their service had cancelled more than half of their appointments for people with progressive neurological conditions.
- 34% said the phone or video appointments they had provided in place of inperson appointments during the pandemic were 'not quite as good' for the patient as in-person appointments and 33% said they were 'much less useful'.
- Half of respondents said they had been able to see less than 25% of their patients with progressive neuro conditions in person during the pandemic.
- When asked to estimate the severity of the deterioration they were aware of in their patients, 49% of respondents reported they had seen severe deterioration in some of their patients.<sup>8</sup>

#### Neurological conditions

In July 2020, the **Neurological Alliance** published a report on **Restarting services** for people with neurological conditions after the COVID-19 pandemic and planning for the longer term. This argued:

- Swallow assessments carried out virtually by SLTs might not be accurate and therefore pose a potential risk to clients.
- Some people with neurodevelopment conditions (NDCs), such as autism, can struggle to engage and communicate effectively about their symptoms during virtual as opposed to face-to-face consultations.<sup>9</sup>

#### Parkinson's

In July 2020, **Parkinson's UK** published a report with **Lancaster University** on the impact of Coronavirus restrictions on people affected by Parkinson's. This found that:

- 57% of speech and language therapy appointments were cancelled this ranged from 56.2% in England, 60.9% in Scotland to 76.5% in Wales.
- Reduced frequency of appointments was reported by 12.4% in England, 4.3% in Scotland and 5.9% in Wales; 11.4% for the UK overall.
- Four people in Northern Ireland reported having these appointments and 1 said they were cancelled and one reduced in frequency.

<sup>&</sup>lt;sup>8</sup> <u>https://www.mssociety.org.uk/sites/default/files/2020-10/MS-Society-Survey-of-AHP-rehabilitation-professionals-September-2020-%281%29.pdf</u>

<sup>9</sup> https://www.neural.org.uk/news-07-07-2020/

 Online or telephone appointments were also not frequently offered for physiotherapy, occupational therapy or speech and language appointments (70.9% UK overall).<sup>10</sup>

#### Stammering

In April 2020, a survey of SLTs undertaken by **Stamma** found that:

- Although many SLTs (78%) are still working with people who stammer, a big proportion of NHS Trusts (43%) were providing only a very limited service which may not stretch to any contact for new referrals.
- 10% of SLTs have been redeployed to frontline NHS roles on hospital wards and in the community.<sup>11</sup>

#### Stroke

In September 2020, the **Stroke Associatio**n published **Stroke recoveries at risk**, a survey of almost 2,000 stroke survivors and their carers. This found that:

- 39% of stroke survivors who had a stroke this year said they had not received enough rehabilitation therapies, including physiotherapy, occupational therapy and speech and language therapy. This figure is even higher (56%) for those who had their stroke just before the pandemic (in January or February).
- 53% of all stroke survivors who responded to the survey also had therapy (including physiotherapy, occupational therapy and speech and language therapy) cancelled or postponed, and nearly half (49%) have also had some or all home care visits cancelled or postponed.
- 28% have had therapy (including physiotherapy, occupational therapy and speech and language therapy) online or over the phone.<sup>12</sup>

#### Children and young people

In May 2020, a survey of families of disabled or seriously ill children undertaken by **Family Fund** found found:

<sup>&</sup>lt;sup>10</sup> <u>https://www.parkinsons.org.uk/news/how-have-coronavirus-covid-19-restrictions-impacted-people-affected-parkinsons</u>

<sup>&</sup>lt;sup>11</sup> <u>https://stamma.org/news-features/impact-covid-19-stammering-services</u>

<sup>&</sup>lt;sup>12</sup> <u>https://www.stroke.org.uk/stroke-recoveries-at-risk-report</u>

 77% of families had lost speech and language therapy support following the COVID-19 outbreak.<sup>13</sup>

Also in May 2020, the **Disabled Children's Partnership** published **Left In Lockdown**. Based on the responses over 4,000 families of disabled children this found that:

- 66% of families reported their child had speech language and communication difficulties.
- Parents reporting an increased caring load, both for themselves and for their disabled children's siblings. Parents feel exhausted, stressed, anxious and abandoned by society. In many cases, the support families previously received has now stopped. Many families are seeing declines in both mental and physical health. Parents are particularly concerned about the pressure of children's behaviour and mental wellbeing; managing home-schooling; and what will happen to their children if they contract Covid19. The little support that had previously been provided for families has often stopped altogether. Children's friendships; learning and communications; mental and physical health; and emotions and behaviour have all been negatively impacted.<sup>14</sup>

In July 2020, **Ulster University** published **Understanding Parents' experiences of home-schooling in Northern Ireland** found that:

- 58% of parents reported that their children receive speech and language therapy in class.
- Only 3% of parents felt most confident supervising speech and communication.
- 6% of parents felt least confident supervising speech and communication.<sup>15</sup>

In a *COVID-19 series: briefing on early years* in October 2020, based on interviews with leaders in early years settings, **Ofsted** found that:

- Almost all providers said that the pandemic had significantly impacted the learning and development of children who had left and subsequently returned.
- Many children needed more support to make friends and mix with others outside of their home including with communication skills like turn taking.
- Some providers said they needed to focus on language and communication, because they had identified that children were now less likely to start a conversation or comment on things during play.

<sup>&</sup>lt;sup>13</sup> <u>https://www.familyfund.org.uk/news/health-and-wellbeing-of-disabled-children-at-risk-under-pandemic-as-government-announces-extra-10-million-funding-for-children-with-complex-needs</u>

<sup>&</sup>lt;sup>14</sup> <u>https://disabledchildrenspartnership.org.uk/left-in-lockdown/</u>

<sup>&</sup>lt;sup>15</sup> <u>https://www.ulster.ac.uk/coronavirus/research/impact/understanding-parents-experiences-of-home-schooling-in-northern-ireland</u>

- Concerns that the pandemic may widen inequalities 29% of leaders reporting that communication and language had fallen behind, but 21% saying it had actually improved due to parents having more time for interactions with their child in some households.
- Increasing delays in accessing support for speech and language therapy.
  These were often for existing diagnoses but also for new referrals.<sup>16</sup>

In February 2021, the **Disabled Children's Partnership** published **The Longest** Lockdown – The experiences of disabled children and their families during lockdown 3. This found that:

- 70% or more children could not access therapies such as occupational therapy, physical or physiotherapy, play therapy, speech and language therapy or music therapy.
- 72% of families reported that their EHCP or SEN plan had been negatively affected during the pandemic, with 67% stating that they were getting some or none of the support detailed.
- The most common reported disabilities were autism spectrum disorder (69.1%), learning (66.1%), speech, language and communication difficulties (59.4%).
- 16% of children receiving speech and language therapy at school continued to access this service during the first lockdown. 30% have received speech and language therapy during lockdown 3. Therefore, 70% of families are still not experiencing pre-pandemic levels of support.<sup>17</sup>

Also in February 2021, **Special Needs Jungle** published the findings of a survey of over a thousand parents of children and young people with special educational needs and disabilities. This found that:

- Nearly two-thirds of parents/carers of learners with EHCPs reported that their child's legally binding provision had not been fully restored.
- Fewer than 1 in 5 parents explicitly confirmed that all provision in their child's EHCP had been fully restored most of the rest weren't sure.
- NHS-delivered therapies such as speech and language therapy, occupational therapy, and hydrotherapy were all areas where parents were most likely to report that no legally binding provision had been restored.
- 16

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/93383 6/COVID-19\_series\_briefing\_on\_early\_years\_October\_2020.pdf

<sup>&</sup>lt;sup>17</sup> https://disabledchildrenspartnership.org.uk/the-longest-lockdown/

 For those children on SEN Support, without an EHCP, just 8% of parents/carers confirmed all the special educational needs support their child had prior to the spring lockdown in 2020 was now back in place. Almost threequarters of these said some or all of their child's SEND support had been withdrawn – not just therapies, but also large quantities of teaching assistant support.<sup>18</sup>

In June 2019, the **Children's Commissioner for England**, Anne Longfield, published a major report on access to speech and language therapy. **We Need To Talk** revealed a postcode lottery of support:

- The top 25% of areas spent at least £16.35 per child, while the bottom 25% of areas spent 58p or less per child. Among children with an identified speech and language need, the top 25% of local authorities spent at least £291.65 per child, with the bottom 25% of local authorities spending £30.94 or less.
- Local authority spend per child is highest in London at £7.29, and high in the South East of England (£5.73) and East of England (£4.83). It is lowest in the East Midlands (£0.34), the West Midlands (£0.90) and Yorkshire and Humber (£1.18).
- The North of England has the highest CCG spend per child (£17.61) followed by London (£17.14). The lowest CCG spend per child is in the Midlands & East NHS region (£10.20) followed by the South of England (£13.54).

The report also showed that spending on speech and language therapy services is actually falling in many parts of the country:

- Only 1 in 4 areas (23%) saw a real-terms increase in spend per child between 2016/17 and 2018/19. Nearly 3 in 5 areas (57%) saw a real-terms fall in spend per child.
- Almost two-thirds (63%) of areas saw local authority spend per child decline in real terms while over three-quarters (77%) of areas experienced a decline in CCG spend per child in real terms.<sup>19</sup>

In February 2021, the **Children's Commissioner for England** called for the levelling up on spending on speech and language therapy in her report, **Still Not Safe**.<sup>20</sup>

<sup>&</sup>lt;sup>18</sup> <u>https://www.specialneedsjungle.com/provision-denied-disabled-children-report/</u>

<sup>&</sup>lt;sup>19</sup> https://bit.ly/3en6976

<sup>&</sup>lt;sup>20</sup> https://bit.ly/3cfaCWX