



#BuildBackBetterSLT – autism: what autistic people told us

Summary

- There were 117 responses to the survey from autistic people.
- This represents 22% of the total survey responses.

Survey responses

Survey responses are grouped into five sections*:

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

* Percentages may not always add up to 100% as we have removed some responses with very small percentages.

More information

- Visit the dedicated #BuildBackBetterSLT webpage: bit.ly/BuildBackBetterSLT
- Contact: peter.just@rcslt.org and padraigin.oflynn@rcslt.org

Section 1: Demographic data of the respondents

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

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

117 people completed the survey.

- Most were family members or unpaid carers (n=94) (80%).
- 21 (18%) were people who had speech and language therapy.
- 2 (2%) were education professionals or paid carers.

Country

Of the 117 respondents, 93 (79%) lived in England, 13 (11%) lived in Scotland, 11 (10%) lived in Wales or Northern Ireland.

Gender

With respect to gender, 114 of 117 respondents identified their gender.

- Most of the respondents (n=84) (74%) identified as male.
- 30 respondents (26%) identified as female.

Age

112 of 117 respondents reported their age.

- 15 respondents (13%) were aged 0-4.
- 59 (51%) were aged 5-11 years.
- 18 (16%) were aged 12-16 years.
- 10 (9%) were aged 17-18.
- 5 (4%) were aged 18-25.
- 5 (4%) were aged 25-54.

Ethnicity

114 of 117 respondents reported their ethnicity.

- The majority of respondents identified as White British/Irish (n=100) (88%).
- 4 (4%) identified from another white background.

- 4 (4%) identified as Asian/Asian British or Black/African/Carribbean/Black British.
- 4 (4%) identified from mixed/multiple ethnic groups.
- 2 (2%) did not know or preferred not to say.

Section 2: Background history of receiving SLT

In this section, the reasons why people were having SLT and when SLT 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 SLT before the virus lockdown (March to June 2020)?

Condition

The survey asked respondents to identify the condition for which they were receiving SLT.

In addition to autism, respondents also selected comorbid conditions, including:

- Developmental language disorder or language disorder (n=40) (34%).
- Developmental delay (n=37) (32%).
- Learning disability (n=36) (31%).
- Speech sound disorder (n=17) (15%).
- ADHD (n=14) (12%).
- Hearing loss / deafness (n=8) (7%).
- Selective mutism (n=6) (5%).
- Cleft lip and palate (n=4) (3%).
- Stammer (n=4) (3%)

Other conditions listed included brain injury, mental health, Tourettes, OCD, genetic conditions, stroke, dysphagia, verbal dyspraxia, and Down Syndrome.

Three respondents (3%) were waiting for a diagnosis.

Reason for having speech and language therapy

All 117 respondents confirmed the reasons for having SLT.

- All of the respondents (n=117) (100%) received SLT for their speech, language and communication.
- 8 (7%) respondents also reported receipt of SLT for their eating and drinking.

When speech and language therapy started

Of the 117 respondents, most (n=106) (91%) were in receipt of SLT before March 2020. Nine (8%) after March 2020.

How speech and language therapy helps

116 of the 117 respondents described how SLT helps them.

- For the majority (n=90) (78%), SLT makes their life better.
- 51 respondents (44%) said it makes their carer's life better.
- 14 respondents (12%) did not know.
- 8 respondents (7%) reported it makes no difference to their lives.
- 3 respondents (3%) said it made no difference to their carer's life.

How speech and language was delivered before lockdown

111 of the 117 respondents reported how their SLT was delivered before lockdown in March 2020.

- 54% (n=62) received it at school or college in person.
- 19% (n=22) received it in person but not at home.
- 14% (n=16) received SLT in person at home.
- 6% (n=7) reported receiving SLT by video/online or by phone.
- 4% (n=4) reported receiving SLT through other support.

Eight respondents (7%) were not receiving SLT before lockdown.

Section 3: Experiences of SLT during lockdown (March to June 2020)

In this section, the experiences of receiving SLT during lockdown are presented. This covers the survey questions of:

Question 8: Did your SLT change during lockdown (March to June 2020)?

Question 9: What happened to your SLT appointments?

Question 10: Why were your SLT appointments cancelled?

Changes to speech and language therapy

116 of 117 respondents reported changes in their receipt of SLT.

- 91 respondents (78%) received less SLT.
- 15 respondents (13%) reported they received either more or the same amount of SLT.
- 5 respondents (4%) received no SLT.
- 4 respondents (3%) did not know.

What happened to speech and language therapy appointments

95 of the 117 respondents were able to report what happened to the SLT appointments.

- For 66 respondents (69%), the speech and language therapist cancelled the appointment.
- 14 respondents (15%) received their SLT appointment online.
- 7 respondents (7%) received their SLT appointment on the phone.
- For 6 respondents (6%), the speech and language therapist cancelled the home visit appointment.
- 2 respondents (2%) cancelled their own appointment.

70 respondents reported reasons for the cancellations. These included redeployment, closure of schools / colleges, shielding, closure of health and community centres, and inability to run home visits.

Section 4: Delivery of SLT and experiences of SLT delivery during lockdown (March to June 2020)

In this section, how SLT was delivered during lockdown is presented. This covers the survey questions of:

Question 12: Did you get SLT in person during the virus lockdown (March to June 2020)?

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

Question 14: How was your SLT over the phone?

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

Question 16: How was your SLT help on video (online)?

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

Question 18: Did you get your SLT 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 SLT?

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

The delivery of speech and language therapy

115 of 117 respondents reported on the delivery of SLT.

- 76 respondents (66%) did not receive any SLT during lockdown.
- 30 respondents (26%) did not receive SLT in person.

Of the remaining 9 respondents (8%) who did receive SLT in person, 6 (5%) received SLT at home and 3 (3%) received SLT not at home.

Speech and language therapy over the phone

40 of the 117 respondents reported on the delivery of SLT over the phone.

- 9 respondents (23%) received SLT via the phone.
- 28 respondents (70%) did not.
- 3 respondents (8%) tried but it did not work.

Experiences of SLT over the phone

12 respondents reported on their experiences of receipt of SLT over the phone.

- 9 respondents (75%) found the phone delivery good or 'OK'.

- 3 respondents (25%) did not like delivery over the phone.

Speech and language therapy by video

40 of 117 respondents reported on the delivery of SLT by video (online).

- 17 (43%) respondents reported receipt of SLT delivery by video (online).
- 18 (45%) did not receive SLT in this mode of delivery.
- 5 (13%) tried SLT in this mode of delivery but it didn't work.

Experiences of online SLT

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

- 8 (36%) respondents liked this delivery.
- 7 (32%) found this delivery OK.
- 4 (18%) did not like this delivery.
- 3 (14%) could not do it at all.

Ease of using technology

In terms of the ease of use of the technology:

- 8 of the 21 respondents (38%) found it easy.
- 8 (38%) found it okay.
- 5 (24%) found it hard.

Other speech and language therapy support

22 of the 117 respondents responded to the question about receiving SLT for other support such as printed materials or social media.

- 16 respondents (73%) did not receive this support.
- 6 (27%) did.

Communication tools

116 of 117 respondents reported if they had received help in updating their communication support tools. 41 (35%) reported not having any communication support tools.

Of the 65% who did have communication support tools:

- 60 (52%) did not receive any help.
- 15 (13%) did receive help.

Face masks

Respondents were asked if they or their speech and language therapist had worn a mask during their appointments and their experiences of this. 36 responses were received.

- 31 of the 36 (86%) respondents reported not wearing a mask.
- 5 (14%) did.

Of the 5 who did wear a mask:

- 2 (40%) reported this was OK.
- 3 (60%) found it easy.

22 of the same 36 respondents reported their speech and language therapist wore a mask. Of these 22 respondents, 11 (50%) found it hard, and 11 (50%) found it easy or okay.

Section 5: Experiences of SLT during and after the end of lockdown

In this section, data on people's experiences of SLT 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 SLT 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 SLT during lockdown (March to June 2020) tick the things it made worse for you.

Question 20: Have you received SLT face to face since the end lockdown (June 2020)?

Question 27: Are you worried about getting your SLT help in the future?

Question 28: What are you worried about (if you don't have SLT help?)

Impact on communication and swallowing

116 of 117 respondents reported if their communication or swallowing became worse during lockdown.

- 12 respondents (10%) felt their communication or swallowing was better.
- 42 (36%) reported it stayed the same.
- 48 respondents (41%) reported it was worse.

14 respondents (12%) did not know.

Impact on people's lives of having less SLT

88 of 117 respondents identified things that were now worse for them because of having less SLT. Respondents selected more than one option.

People identified areas of their lives that had got worse because of having less SLT:

- Education 69% (n=67).
- Social life and friendships 53% (n=59).
- Mental health 49% (n=50).
- Home and domestic life 49% (n=48).
- Hobbies and leisure 25% (n=31).
- Physical health 10% (n=14).

Other areas included behaviour, routines, and independence.

Impact on families and carers of having less SLT

Family members and carers were also asked to describe the impact of less SLT on their own lives. There were 95 responses to this question.

Families and carers said their lives got worse in the following ways because of their loved ones or the people they care for having less SLT:

- Home and domestic life (n=70) (74%).
- Mental health (n=62) (65%).
- Education (n=53) (56%).
- Social life and friendships (n=42) (44%).
- Hobbies and leisure (n=26) (27%).
- Physical health (n=18) (19%).
- Employment (n=12) (13%).

Face to face speech and language therapy after lockdown ended

110 of the 117 respondents confirmed if they had received SLT face to face since the end of lockdown (June 2020).

- 79 (72%) had not received any face to face SLT since June 2020.
- 31 (28%) had.

Access to speech and language therapy in the future

113 of 117 respondents described if they were concerned about receiving SLT in the future.

- 93 (82%) respondents were concerned.
- 16 (14%) were not concerned.
- 4 (4%) did not know.

101 of these 113 respondents went on to describe their concerns. Respondents selected more than one response. Concerns people identified if they had less SLT in the future were:

- Education (n=84) (83%).
- Social life and friendships (n=76) (75%).
- Mental health (n=70) (69%).
- Home and domestic life (n=58) (57%).
- Hobbies and leisure (n=43) (43%).
- Employment (n=24) (24%).
- Physical health (n=22) (22%).