



#BuildBackBetterSLT – learning disability: what people with learning disability told us

Summary

- There were 12 responses from or on behalf of people with learning disability to the survey for people aged 18 and over. This represented 12% of the total 18 and over responses.
- There were 130 responses to the 0-18 survey from or on behalf of people with learning disability. This represented 31% of the total 0-18 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 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

For 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

18+

Twelve people aged 18+ completed the survey.

- Most were family members or unpaid carers (n=6) (50%).
- The 6 remaining respondents were made up of people having speech and language therapy (SLT) and paid carers.

0-18

130 people aged 0-18 completed the survey.

- Most were family members or unpaid carers (n=111) (85%).
- Of the 19 remaining respondents, 18 (14%) were people having SLT.

Country

18+

All 12 respondents aged 18+ lived in England.

0-18

Of the 130 respondents ages 0-18:

- 83 (64%) lived in England.
- 38 (29%) lived in Scotland.

- 9 (7%) lived either in Wales or Northern Ireland.

Gender

18+

With respect to gender, all 12 respondents aged 18+ identified their gender.

- Most of the respondents (n=10) (83%) identified as male.
- 2 respondents (17%) identified as female.

0-18

With respect to gender, 126 of the 130 respondents aged 0-18 identified their gender.

- Most of the respondents (n=72) (57%) identified as male.
- 53 respondents (42%) identified as female.

Age

18+

11 of 12 respondents aged 18+ reported their age.

- 4 respondents (33%) were ages 18-25.
- 3 (25%) were aged 25-34 years.
- 2 (17%) were aged 35-54 years.
- 2 (17%) were aged 55-64 years.

0-18

126 of 130 respondents aged 0-18 reported their age.

- 68 respondents (54%) were aged 5-11 years.
- 29 (23%) were aged 0-4 years.
- 22 (17%) were aged 12-16 years.
- 7 (6%) were aged 17-18 years.

Ethnicity

18+

11 of the 12 respondents aged 18+ reported their ethnicity. The majority of respondents identified as White British/Irish (n=10) (91%).

0-18

125 of 130 respondents aged 0-18 reported their ethnicity.

- The majority of respondents identified as White British/Irish (n=103) (82%).
- 8 (6%) identified from mixed/multiple ethnic groups.
- 6 (5%) identified from another white background.
- 4 (3%) identified as Asian/Asian British.
- 2 (2%) identified as Black/African/Caribbean/Black British.

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.

18+

In addition to learning disability, respondents aged 18+ also selected comorbid conditions, including developmental language disorder or language disorder, developmental delay, autism, hearing loss / deafness, stammer, dementia and muscular dystrophy.

0-18

In addition to learning disability, respondents aged 0-18 also selected comorbid conditions, including:

- Developmental delay (n=82) (63%).
- Autism (n=35) (27%).
- Developmental language disorder or language disorder (n=34) (26%).
- Hearing loss / deafness (n=21) (16%).
- Down's syndrome (n=14) (11%).

- Speech sound disorder (n=12) (9%).
- ADHD (n=9) (7%).
- Brain injury (n=7) (5%).
- Genetic condition (n=5) (4%).
- Cleft lip and palate (n=5) (4%).

Other comorbid conditions identified included selective mutism, stammer, mental health, cerebral palsy, visual impairment and verbal dyspraxia.

Reason for having speech and language therapy

18+

All 12 respondents aged 18+ confirmed the reasons for having SLT.

- Almost all the respondents (n=9) (75%) received SLT for their speech, language and communication.
- 2 (17%) respondents reported receipt of SLT for their eating and drinking.

Three respondents listed other reasons, including support for the future and tube feedings.

0-18

129 of 130 respondents aged 0-18 confirmed the reasons for having SLT.

- All the respondents (n=129) (100%) received SLT for their speech, language and communication.
- 27 (21%) respondents also reported receipt of SLT for their eating and drinking.

When speech and language therapy started

18+

Of the 12 respondents aged 18+, most of the respondents (n=10) (83%) were in receipt of SLT before March 2020 and 2 (17%) after March 2020.

0-18

Of the 130 respondents aged 0-18, most of the respondents (n=123) (95%) were in receipt of SLT before March 2020 and 7 (5%) after March 2020.

How speech and language therapy helps

18+

All 12 respondents aged 18+ described how SLT helps them.

- For the majority (n=10) (83%), SLT makes their life better.
- 5 respondents (42%) said it makes their carer's life better.
- 2 respondents (16%) reported it makes no difference to their lives or the lives of their carers or did not know.

0-18

129 of 130 respondents aged 0-18 described how SLT helps them.

- For the majority (n=116) (90%), SLT makes their life better.
- 55 respondents (43%) said it makes their carer's life better.
- 9 respondents (7%) reported it makes no difference to their lives.
- 5 respondents (4%) reported it makes no difference to the lives of their carers.
- 5 respondents (4%) did not know.

How speech and language was delivered before lockdown

18+

All 12 respondents aged 18+ reported how their SLT was delivered before lockdown in March 2020.

- 50% (n=6) received SLT in person at home.
- 42% (n=5) in school or college.
- 17% (n=2) received it in person but not at home.

0-18

127 of 130 respondents aged 0-18 reported how their SLT was delivered before lockdown in March 2020.

- 69% (n=87) in school or college.
- 20% (n=26) received it in person but not at home.
- 17% (n=21) received SLT in person at home.
- 6% (n=7) respondents reported receiving SLT by video/online.
- 5% (n=6) respondents reported receiving SLT by phone.
- 4% (n=5) respondents reported receiving SLT through other support such as social media or printed materials.

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

18+

All 12 respondents aged 18+ reported changes in their receipt of SLT.

- Most of the respondents (n=8) (67%) received less SLT.
- Only 2 respondents (17%) reported they received the same amount of SLT before and during lockdown.

The remaining respondents received no SLT or received more.

0-18

All 130 respondents aged 0-18 reported changes in their receipt of SLT.

- Most of the respondents (n=108) (83%) received less SLT.
- 14 respondents (11%) reported they received the same amount of SLT before and during lockdown.

Two respondents (2%) received no therapy during lockdown, and 6 (5%) did not know.

What happened to speech and language therapy appointments

18+

Nine of the 12 respondents aged 18+ were able to report what happened to the SLT appointments.

- For 4 respondents (44%), the speech and language therapist cancelled the appointment.
- For 3 respondents (33%), the speech and language therapist cancelled the home visit appointment.
- 2 respondents (22%) received their SLT appointment online or via a phone appointment.

Six respondents aged 18+ reported reasons for the cancellations. These ranged across closure of health centres, closure of schools and colleges, closure of community/work centre, SLT had the virus or was redeployed, and shielding.

0-18

109 of the 130 respondents aged 0-18 were able to report what happened to the SLT appointments.

- For 74 respondents (68%), the speech and language therapist cancelled the appointment.
- 19 respondents (17%) received their SLT appointment online.
- 8 respondents (7%) received a phone appointment.
- For 4 respondents (4%), the speech and language therapist cancelled the home visit appointment.
- 3 respondents (3%) cancelled their own appointment.

80 respondents aged 0-18 reported reasons for the cancellations. These ranged across:

- Closure of schools and colleges (n=38) (48%).
- SLT was redeployed (n=10) (13%).
- Closure of health centres (n=9) (11%).
- Shielding (n=4) (5%).

- Could not get to the appointment (n=4) (5%).
- Closure of community/work centre (n=3) (4%).

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

18+

All 12 respondents aged 18+ reported on the delivery of SLT.

- Half of the respondents (n=6) (50%) did not receive any SLT during lockdown.
- 4 respondents (33%) did not receive SLT in person.

The remaining 2 respondents (17%) who did receive SLT in person received SLT at home.

0-18

128 of 130 respondents aged 0-18 reported on the delivery of SLT.

- Most of the respondents (n=89) (70%) did not receive any SLT during lockdown.
- 30 respondents (23%) did not receive SLT in person.

Of the remaining 8 respondents (6%) who did receive SLT in person, 5 (4%) received SLT at home, 2 (2%) received SLT at school/college, and 1 (0.8%) received SLT not at home.

Speech and language therapy over the phone

18+

Six of the 12 respondents aged 18+ reported on the delivery of SLT over the phone.

- 4 of the 6 respondents (67%) did not.
- The remaining respondents (34%) had SLT on the phone or attempted to receive SLT via the phone but this proved unsuccessful.

0-18

41 of the 130 respondents aged 0-18 reported on the delivery of SLT over the phone.

- 10 respondents (24%) received SLT via the phone.
- 29 respondents (71%) did not.
- 2 respondents (5%) attempted to receive SLT via the phone but this proved unsuccessful.

Experiences of SLT over the phone

18+

Two respondents aged 18+ reported on their experiences of receipt of SLT over the phone. They said was OK or were unable to engage in SLT over the phone.

0-18

12 respondents aged 0-18 reported on their experiences of receipt of SLT over the phone.

- 7 respondents (58%) found the phone delivery 'OK'.
- 2 respondents (17%) liked delivery over the phone.
- 2 respondents (17%) did not like delivery over the phone.

Speech and language therapy by video

18+

Six respondents aged 18+ reported on the delivery of SLT by video (online).

- 3 (50%) respondents reported receipt of SLT delivery by video (online).
- 2 respondents (33%) attempted to secure SLT by video but this proved unsuccessful.

0-18

41 respondents aged 0-18 reported on the delivery of SLT by video (online).

- 27 (66%) respondents reported receipt of SLT delivery by video (online).
- 13 (32%) did not receive SLT in this mode of delivery.

Experiences of online SLT

18+

Five respondents aged 18+ reported on their experiences of video (online) delivery.

- 2 (40%) respondents liked this delivery.
- 2 (40%) could not do it at all.

0-18

28 respondents aged 0-18 reported on their experiences of video (online) delivery.

- 13 (46%) respondents liked this delivery.
- 7 (25%) found this delivery OK.
- 7 (25%) respondents did not like this delivery.

Ease of using technology

18+

In terms of the ease of use of the technology for respondents aged 18+, 3 of the 5 respondents (60%) found it OK. The remainder found it hard or did not use a computer/laptop/tablet/smartphone.

0-18

In terms of the ease of use of the technology for respondents aged 0-18:

- 10 of the 28 respondents (36%) found it easy.
- 14 (50%) found it OK.
- 4 (14%) found it hard.

Difficulties using technology

0-18

14 respondents aged 0-18 explained why they found it difficult to use this technology, including:

- 6 respondents (43%) had difficulty getting children to engage.
- 4 respondents (29%) had a bad internet connection.
- 4 respondents (29%) had a lack of experience with technology.
- 3 respondents (21%) said they missed vital aspects of face to face interaction.

Other speech and language therapy support

18+

Five of the 12 respondents aged 18+ responded to the question about receiving SLT for other support such as printed materials or social media.

- 3 respondents (60%) did not receive this support.
- 2 (40%) did.

0-18

28 of the 130 respondents aged 0-18 responded to the question about receiving SLT for other support such as printed materials or social media.

- 15 respondents (54%) did not receive this support.
- 13 (46%) did.

Communication tools

18+

All 12 respondents aged 18+ responded to the question asking if they had received help in updating their communication support tools. 6 (50%) reported not having any communication support tools.

Of the 50% who did have communication support tools, 5 (42%) did not receive any help.

0-18

All 130 respondents aged 0-18 responded to the question asking if they had received help in updating their communication support tools. 40 (31%) reported not having any communication support tools.

Of the 69% who did have communication support tools:

- 78 (60%) did not receive any help.
- 12 (9%) did receive help.

Face masks

18+

Respondents aged 18+ were asked if they or their speech and language therapist had worn a mask during their appointments and their experiences of this. Six responses were received.

- 4 of the 6 (67%) respondents reported not wearing a mask.
- 2 (33%) did.

The two who did wear a mask found it OK or hard.

Five of the same 6 respondents reported their speech and language therapist wore a mask. Of these 5 respondents, 4 (80%) found it hard.

0-18

Respondents aged 0-18 were also asked if they or their speech and language therapist had worn a mask during their appointments and their experiences of this. 37 responses were received.

- 33 (89%) respondents reported not wearing a mask.
- 4 (11%) did.

Of the 4 who did wear a mask, 3 (75%) reported this was OK.

27 of the same 37 respondents reported their speech and language therapist wore a mask. Of these 27 respondents, 16 (59%) found it hard, 9 (33%) found it okay, and 2 (7%) found it easy.

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

18+

All 12 respondents aged 18+ reported if their communication or swallowing became worse during lockdown.

- 8 (67%) reported it stayed the same.
- 3 respondents (25%) reported it was worse.

0-18

129 of the 130 respondents aged 0-18 reported if their communication or swallowing became worse during lockdown.

- 20 respondents (16%) felt their communication or swallowing was better.
- 61 (47%) reported it stayed the same.
- 34 respondents (26%) reported it was worse.

- 14 respondents (11%) did not know.

Impact on people's lives of having less SLT

18+

Eight of the 12 respondents aged 18+ confirmed they had less SLT during lockdown. Seven of these 8 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:

- Social life and friendships 57% (n=4)
- Home and domestic life 57% (n=4).
- Mental health 57% (n=4).
- Education 29% (n=2).
- Hobbies and leisure 29% (n=2).

Other aspects reported were social skills, independence, and physical health.

0-18

108 of the 130 respondents aged 0-18 confirmed they had less SLT during lockdown. Ninety seven of these 108 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:

- Social life and friendships 56% (n=61).
- Education 56% (n=61).
- Home and domestic life 48% (n=52).
- Mental health 41% (n=44).
- Hobbies and leisure 19% (n=20).

Other aspects reported were speed of progression, lack of access to professional guidance, social and education communication, and general regression.

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. Seven of the 12 respondents aged 18+ described this impact on their own lives with respect to the things that were now worse for them because of having less SLT.

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

- Mental health (n=6) (86%).
- Home and domestic life (n=5) (71%).
- Social life and friendships (n=4) (57%).
- Physical health (n=3) (43%).
- Employment (n=2) (29%).
- Hobbies and leisure (n=1) (14%).

Other aspects reported were an increase in caring responsibilities and lack of access to resources.

0-18

104 of the 130 respondents aged 0-18 described this impact on their own lives with respect to the things that were now worse for them because of having less SLT.

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

- Home and domestic life (n=75) (72%).
- Mental health (n=62) (60%).
- Social life and friendships (n=50) (48%).
- Education (n=48) (46%).
- Hobbies and leisure (n=29) (28%).
- Physical health (n=20) (19%).
- Employment (n=14) (13%).

Other aspects reported were an increase in caring responsibilities and lack of access to professional guidance.

Face to face speech and language therapy after lockdown ended

18+

Eleven of the 12 respondents aged 18+ confirmed if they had received SLT face to face since the end of lockdown (June 2020).

- 6 (55%) had not received any face to face SLT since June 2020.
- 5 (45%) had.

0-18

128 of the 130 respondents aged 0-18 confirmed if they had received SLT face to face since the end of lockdown (June 2020).

- 92 (72%) had not received any face to face SLT since June 2020.
- 36 (28%) had.

Access to speech and language therapy in the future

18+

Ten of the 12 respondents aged 18+ described if they were concerned about receiving SLT in the future.

- 9 (90%) respondents were concerned.

Nine of these 10 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:

- Social life and friendships (n=7) (78%).
- Physical health (n=5) (56%).
- Education (n=4) (44%).
- Mental health (n=4) (44%).
- Home and domestic life (n=4) (44%).
- Hobbies and leisure (n=4) (44%).

- Employment (n=2) (22%).

Another aspect of concern was the long-term impact of lack of resources.

0-18

All 130 respondents aged 0-18 described if they were concerned about receiving SLT in the future.

- 102 (78%) respondents were concerned.
- 21 (16%) were not concerned.
- 7 (5%) did not know.

106 of these 130 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=85) (80%).
- Social life and friendships (n=76) (72%).
- Mental health (n=63) (59%).
- Home and domestic life (n=60) (57%).
- Hobbies and leisure (n=39) (37%).
- Physical health (n=29) (27%).
- Employment (n=22) (21%).

Other aspects of concern were general access, future communication and independence, no restarting of services, no contact with professionals, and worsening of already inadequate access to SLT.