



## **#BuildBackBetterSLT – Down’s syndrome: what people with Down’s syndrome told us**

### **Summary**

- There were 23 responses to the aged 0-18 survey from people with Down’s syndrome.
- This represents 5% of the 0-18 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](https://bit.ly/BuildBackBetterSLT)
- Contact: [peter.just@rcslt.org](mailto:peter.just@rcslt.org) and [padraigin.oflynn@rcslt.org](mailto: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

23 people completed the survey.

- Most were family members or unpaid carers (n=20) (87%).
- The remaining respondents (n=3) (13%) were people who have speech and language therapy.

### Country

Of the 23 respondents, 12 (52%) lived in Scotland, 8 (35%) lived in England, and 3 (13%) lived in Wales.

### Gender

With respect to gender, all 23 respondents identified their gender.

- Most of the respondents (n=14) (61%) identified as male.
- 9 respondents (39%) identified as female.

### Age

All 23 respondents reported their age.

- 8 respondents (35%) were aged 0-4.
- 13 (57%) were aged 5-11 years.
- 2 (9%) were aged 12-16 years.

### Ethnicity

All 23 respondents reported their ethnicity.

- The majority of respondents identified as White British/Irish (n=16) (70%).
- 4 (17%) identified as from another white background.
- 3 (13%) identified as from mixed/multiple ethnic groups or another ethnic group.

## 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 Down's syndrome, respondents also selected comorbid conditions, including:

- Learning disability (n=14) (61%)
- Developmental delay (n=8) (35%)
- Hearing loss / deafness (n=2) (9%)

Other conditions selected included speech sound disorder, verbal dyspraxia, mental health, developmental language disorder or language disorder, and autism.

### Reason for having speech and language therapy

All 23 respondents confirmed the reasons for having SLT.

- Most respondents (n=21) (91%) received SLT for their speech, language and communication.
- 4 respondents (17%) received SLT for their eating and drinking.

### When speech and language therapy started

Of the 23 respondents, nearly all (n=22) (96%) were in receipt of SLT before March 2020.

### How speech and language therapy helps

All 23 respondents described how SLT helps them.

- For the majority (n=22) (96%), SLT makes their life better.
- 12 respondents (52%) said it makes their carer's life better.

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

All 23 respondents reported how their SLT was delivered before lockdown in March 2020.

- 70% (n=16) received it in person at school/college.
- 26% (n=6) received SLT in person at home.
- 17% (n=4) received it in person but not at home.

## **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**

22 of 23 respondents reported changes in their receipt of SLT.

- 19 respondents (86%) received less SLT.
- 3 respondents (14%) reported they received either more or the same amount of SLT before and during lockdown.

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

18 of the 23 respondents were able to report what happened to the SLT appointments.

- For 14 respondents (78%), the speech and language therapist cancelled the appointment.
- 4 respondents (22%) received their SLT appointment online or on the phone.

Sixteen respondents reported reasons for the cancellations. These included inability to get to the appointment, shielding, not feeling safe going to appointments, closure of health centres, closure of schools and colleges, lack of video equipment, and redeployment.

## **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**

All 23 respondents reported on the delivery of SLT.

- 16 respondents (70%) did not receive any SLT during lockdown.
- 5 respondents (22%) did not receive SLT in person.

The remaining 2 respondents (9%) who did receive SLT in person received SLT at home.

### **Speech and language therapy over the phone**

7 of 23 respondents reported on the delivery of SLT over the phone. All 7 (100%) did not receive SLT in this mode of delivery or tried but it didn't work.

### **Speech and language therapy by video**

7 of 23 respondents reported on the delivery of SLT by video (online).

- 5 (71%) respondents reported receipt of SLT delivery by video (online).
- 2 (29%) did not receive SLT in this mode of delivery.

### **Other speech and language therapy support**

5 of the 31 respondents 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.

### **Communication tools**

All 23 respondents reported if they had received help in updating their communication support tools. 8 (35%) reported not having any communication support tools.

Of the 65% who did have communication support tools:

- 13 (57%) did not receive any help.
- 2 (9%) did receive help.

## 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

All 23 respondents reported if their communication or swallowing became worse during lockdown.

- 7 respondents (30%) felt their communication or swallowing was better.
- 10 (43%) reported it stayed the same.
- 4 (17%) reported it was worse.
- 2 (9%) did not know.

### Impact on people's lives of having less SLT

18 of 23 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 78% (n=14)
- Education 78% (n=14).
- Home and domestic life 33% (n=6).
- Mental health 22% (n=4).
- Hobbies and leisure 11% (n=2).
- Physical health 11% (n=2).



## **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. 17 of the 23 respondents 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 the following ways because of having less SLT:

- Education (n=10) (59%).
- Home and domestic life (n=9) (53%).
- Mental health (n=9) (53%).
- Social life and friendships (n=5) (29%).
- Physical health (n=2) (12%).
- Hobbies and leisure (n=2) (12%).

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

All 23 respondents confirmed if they had received SLT face to face since the end of lockdown (June 2020).

- 18 (78%) had not received any face to face SLT since June 2020.
- 5 (22%) had.

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

All 23 respondents described if they were concerned about receiving SLT in the future.

- 20 (87%) respondents were concerned.
- 3 (13%) were not concerned or did not know.

21 of these 23 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=17) (81%).
- Education (n=17) (81%).
- Home and domestic life (n=12) (57%).
- Mental health (n=11) (52%).
- Hobbies and leisure (n=8) (38%).
- Employment (n=5) (24%).
- Physical health (n=3) (14%).