

# "No one feels worse about my condition than me"



A research project exploring the experiences of 11-25 year olds with Special Educational Needs and Disabilities or Long Term Conditions in Educational settings.

## NHS Youth Forum 2021

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# Introduction

## What is the NHS Youth Forum?

The NHS Youth Forum is a national forum consisting of 25 young people from across England. Our members range in age from 14-25 and all joined the forum with a passion for improving health and social care services for children and young people.

The NHS Youth Forum was founded in 2013 and since then has had a massive impact, engaging with thousands of young people from across the country. Each year the forum's campaigns and agenda have been adapted to address crucial issues raised by members and young people. This year our focus includes Health Inequalities, Transgender and Non-Binary Access to Health Services and the Experience of Young People with Special Educational Needs and Disabilities (SEND) and Long Term Conditions (LTC).

## The Special Educational Needs and Disabled and Long Term Conditions Group

Members of the forum were asked to decide which group they would like to be a part of based on their own experiences and interests. The decision to focus on the experiences of young people with SEND and Long Term Conditions within education was partly due to our own experiences of being stigmatised for needing extra support in school and/or university. We also wanted to give young people the opportunity to share the issues they were facing with receiving support during lockdown due to the Covid-19 pandemic.

Members had a wide range of experience relating to Special Educational Needs and Disabilities and Long Term Conditions so knew what to ask and then who to send the feedback form to once it had been created. This means this project is truly designed by young people, answered by young people and then written up by young people with personal experience.

# Meet the Group members

## Within the NHS Youth Forum



Emma



Sonia



Aishah



Chelsea



Andy



Georgia



Melika



Aaron



Hannah



Clémence

You can meet the rest of the NHS Youth Forum members, [here](#)

# Aims of the SEND and LTC Project

## **Improve understanding**

Improve understanding of the experiences of young people with Special Educational Needs and Disabilities and Long Term Conditions in schools.

## **Educate teachers**

Teachers spend a lot of time with their students so it is vital they know how to support them the best they can. Through our survey we have been able to collect the experiences of young people which can then be used to educate the educators.

## **Reduce stigma**

Young people with additional needs are often stigmatised for needing extra support by both their teachers and peers. By sharing how this makes young people feel we hope to reduce this stigma and create discussion.

## **Give young people a platform to share their experiences**

Young people with SEND and Long Term Conditions often experience things being done to them rather than with them. By sharing their experiences, young people are given the opportunity to share what has happened to them (often a negative thing) in a safe way. Taking control of their story in this way can empower young people and increase their confidence.

# Who answered our feedback form?

We targeted our survey at 11-25 year olds. We shared the feedback form across the NHS Youth Forum Twitter and Instagram accounts where it was shared and engaged with by a number of charities and organisations working within the Special Educational Needs and Disabilities and Long Term Condition space.

Groups including RCPCH&us and The Luna Project shared the survey with their networks of young people.

We also shared the survey with the Learning Disabilities and Autism team within NHS England who shared it with their patient participation networks.

41.0%

Had a Special Educational Need

14.8%

Had a Learning Disability

9.8%

Had a Physical Disability

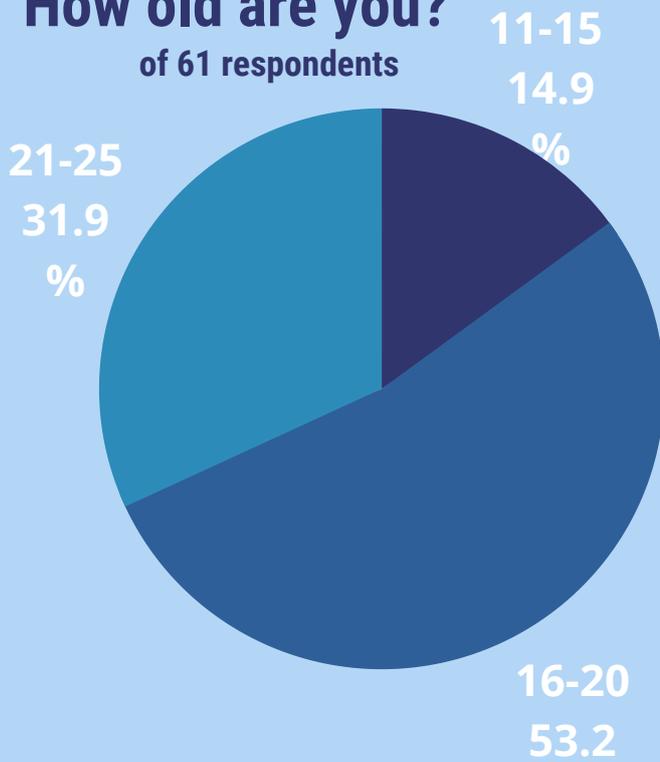
34.4%

Had a Long Term Condition

# Who answered our feedback form cont.

## How old are you?

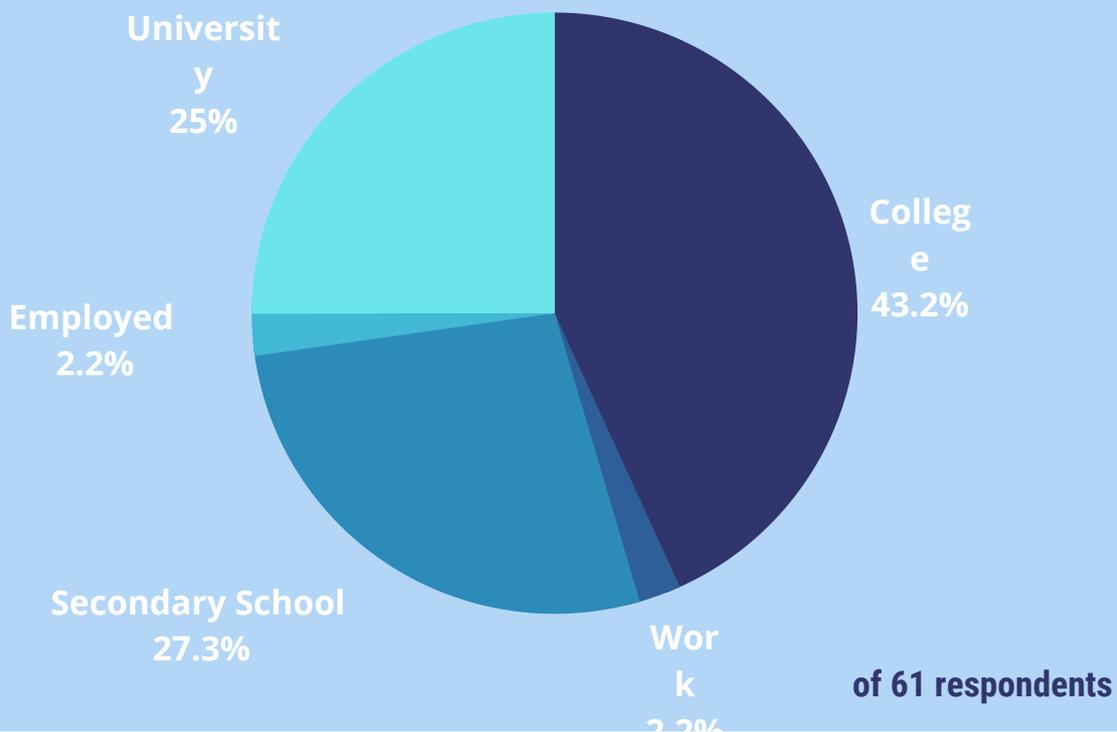
of 61 respondents



To understand who was answering our survey we asked our respondents how old they were and what stage of education they were attending.

You can see the results in the pie charts on this page.

## What stage of education are you currently attending?



# Question 1

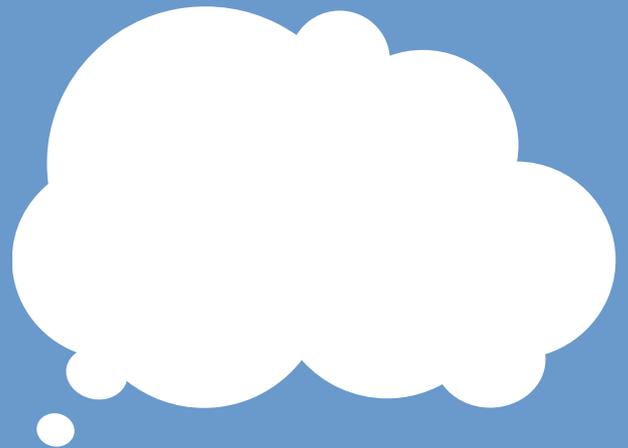
## When I attend my education setting I feel:



We wanted to give our respondents the chance to inform us how they feel when in education



By allowing our respondents to share their feelings we were able to understand the subjective experience of education as someone with an SEND or LTC



The page below explains our varied approach to this question to allow for each young person to answer in a way that was suitable for them

# When I attend my education setting I feel cont.

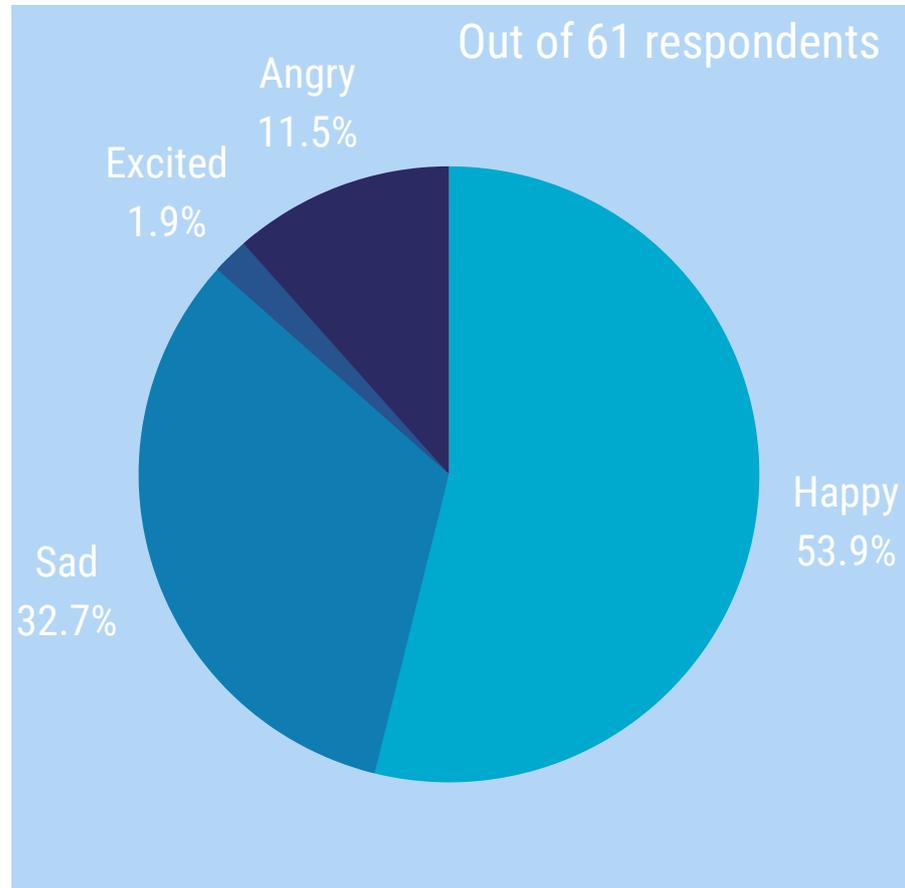
In order to find out the feelings of those who were answering our survey, we asked how they would like to respond to the statement, 'When I attend my education setting I feel:'

We gave the options of:

- Ticking a box from a list of emotions
- Typing how you feel
- Send us a creative response by uploading a file

The answers we received from those who chose to answer from ticking from the list of pre written emotions can be seen in the pie chart on this page.

Nearly half of those who chose to repond in this manner said they felt 'happy' when attending their education setting.



However, there is still a large amount of children and young people who experience negative emotions when attending education, with 35.2% saying they feel sad and 15.1% describing their feelings as angry.

The following pages display the answers we received from those who typed out how they feel in their education setting.

**Confident**  
**that I am meant**  
**to be there**



**When I was in  
education I felt  
supported in  
lessons**

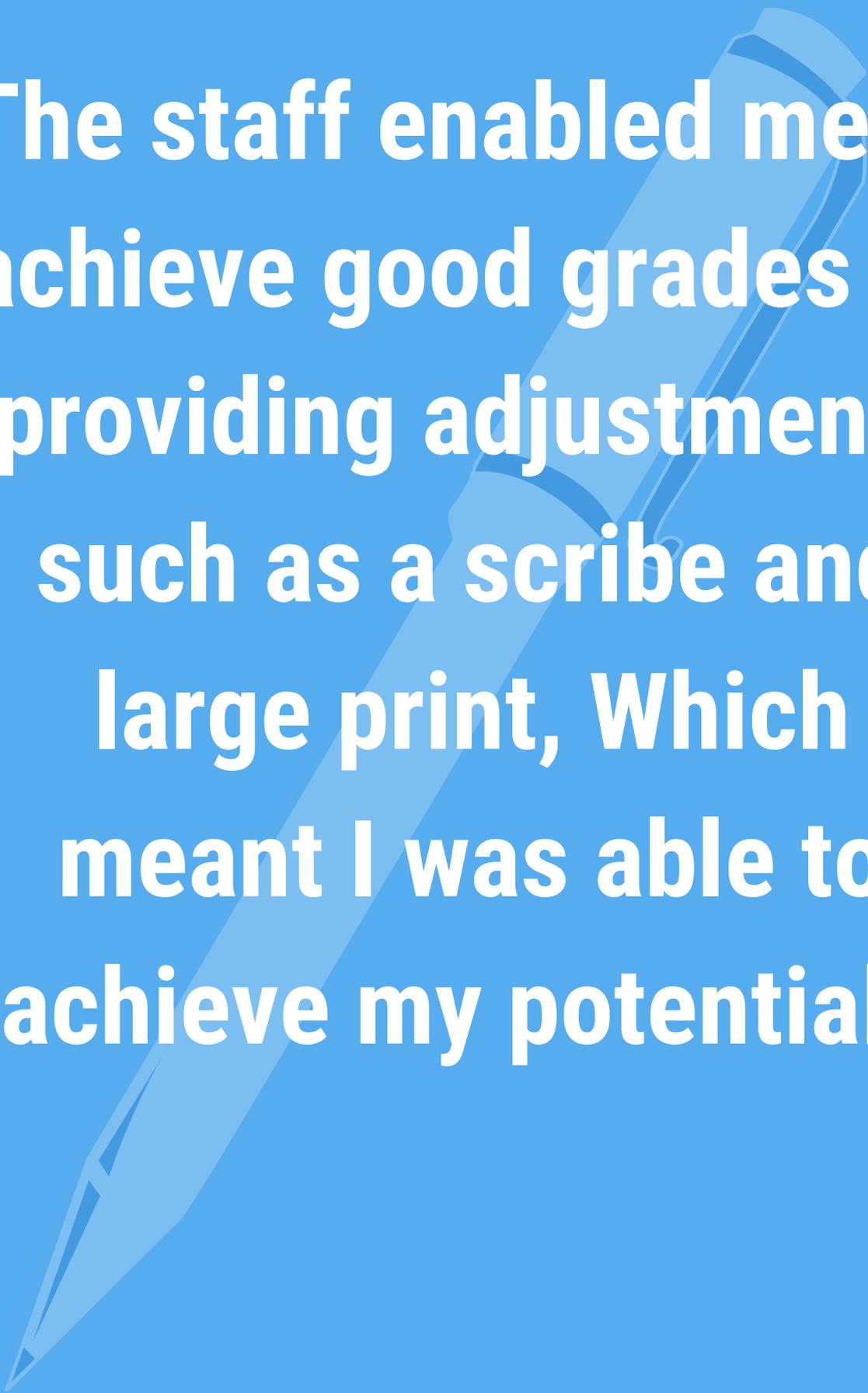


“Anxious to ask for help or an extension on a deadline because I feel like I don't deserve it or haven't tried hard enough.”

“Education can make me feel left out as though I'm not included or as important as other students because of my condition ...which isn't right”



“Nervous and worried, although I have started to feel more confident attending lately as I have been provided with more support.”



**The staff enabled me to achieve good grades by providing adjustments such as a scribe and large print, which meant I was able to achieve my potential.**

# I would like my teacher to know...



We asked the respondents to explain something that they would like their teacher to know.



The following pages of the report contain a series of answers and reflections from those who completed our survey.



We did not guide the answers we received and instead asked respondents to be open and honest about their experiences.

# **That my disability is not a**

**'One size  
fits all  
box'**

**I have ever-changing needs that  
need to be kept upto date with  
having someone who respects and  
understands this is vital for me  
and it is so important to have key  
members of staff who know about  
my needs and health**

**School is**

really hard for me

**I hate how some  
teachers make me  
feel.**

Some teachers tell me off

**for the smallest  
things**

**“I was very aware of the institutional attitudes when applying to universities and it sadly meant that I didn't apply to certain universities due to concerns about not being able to access support”**



**“The first sixth form college that I attended was not a positive experience. It was a constant battle to get the support that I needed”**

**“Support lacks,  
and  
understanding is  
not there;**

**except for certain  
teachers and  
professionals**”

**That I try really hard to attend school and engage, but it's not always simple or easy. I find school really uncomfortable- the noise, lights, that sometimes it's really cold, or too warm. These minor things can really throw me off and make me unsettled and cause me to disengage. I struggle to understand them sometimes, but feel silly asking them to repeat what they have already said. I would like the tasks and instructions written down to help me understand but I don't want to ask as I know they already have so many things to do. I know I get top grades but this doesn't mean that I don't find things really hard. I know I have come a long way but this doesn't mean that I don't struggle anymore- my condition isn't something that goes away.**

**Sometimes it's hard to admit you need help or are behind on work because it makes you feel bad about yourself**

**That I am valuable and that they are dismissing real human needs when they dismiss me**

**That I really am trying. Adhd means I just can't concentrate.**

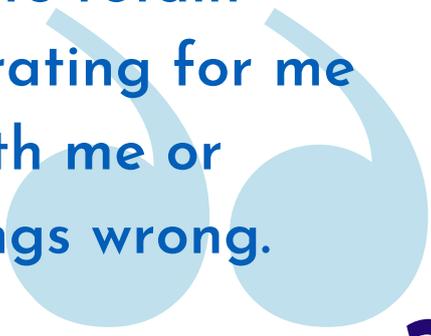
**I am happy  
with all the  
support I get  
from  
everyone**

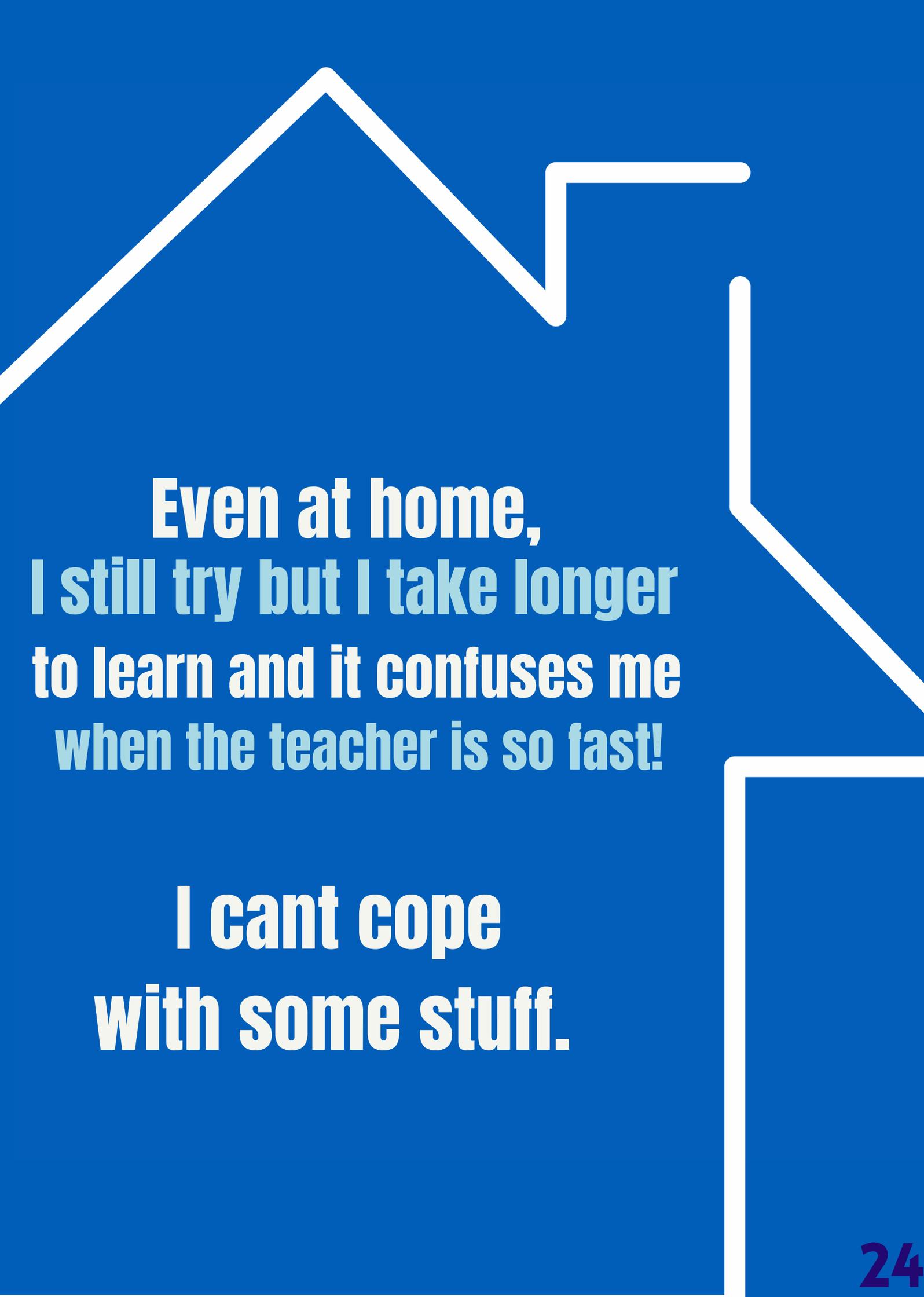
# Please don't assume.

You told me what I  
was not capable of  
and questioned if I  
could even do GCSEs.  
I proved you wrong.



I would like to be listened to more. When I say I can't do it, I mean I can't do it. I'm not just being lazy. My brain doesn't work in the same way that yours does. Sometimes it just doesn't work. Please research into Autism and Adhd and other conditions that I have. I need someone to try to understand me. I need alot of support which I don't always get. I learn in a certain way that is different from how you try to teach me. I can't learn the way that you teach. I can show you the best way to teach me. I do want to learn, I struggle to learn, even with support. I do my best, even when you think I'm not trying hard enough. Pushing me too hard has the opposite effect and makes me feel like I cannot cope. I have problems processing Information. I think everyone forgets that. Please give me time to process everything. I struggle to retain Information. It can be very frustrating for me so please don't get angry with me or frustrated with me if I get things wrong.





**Even at home,  
I still try but I take longer  
to learn and it confuses me  
when the teacher is so fast!**

**I cant cope  
with some stuff.**



**I feel anxious and  
worried, I don't  
want to be there  
I feel invisible**



**“I would like my teachers to know more about learning difficulties and mental health and how to deal with student's emotional well-being state properly”**

**I look normal**

Low level pain is a thing  
just because I get good  
grades doesn't mean it isn't a  
problem

When I'm absent or late  
to class it is due to my  
conditions

I shouldn't be scrutinised  
for it

I find it hard to communicate  
when i'm struggling and  
would sometimes like them to  
check in with me about how  
i'm feeling



**They  
are  
amazing**



**My conditions can and do affect how attentive I am in lectures. That if I am having a bad day for pain or for my mentality, I may not be able to attend, and just because I may not want to go into why I can't attend, it is not because I can't be bothered, or that I am lazy or don't want to achieve. And also, that I can achieve academically without attending every lecture, and support for those times when I can't attend lectures is important.**

**If I have been absent for a while without communicating why, I wouldn't mind a message or an email from them just to check in and see how I'm doing, because it isn't likely that I would reach out of my own accord for fear of being seen as a burden.**



# Teachers, to make our learning experience better we need you to:

Please listen to and trust us when we say we can or cannot do something

Give us the support we are entitled to

Remember that we are trying our best

Provide support outside of the classroom

Don't rush us with our work

Make us feel as valued as all the other students in the room

Know that we feel anxious to ask for help and notice when we're struggling

Want to learn more about our conditions, and about us individually

# What did we find?

We were thrilled to receive 61 amazing responses to our feedback form giving us a wide range of perspectives on being in education with Special Educational Needs and Disabilities and Long Term Conditions.

The feedback overwhelmingly shows that young people have negative experiences in education which is predominately linked to lack of resources and lack of understanding from teachers. These are key themes that arose across the answers we received. However, it's important to note that young people do understand how pressured their teachers are, this makes them reluctant to ask for help as they don't want to burden their teachers or support staff.

The answers we received show that with the correct support, young people with Special Educational Needs or Disabilities and Long Term Conditions are able to reach their goals and ambitions. As explained in one response: "***staff enabled me to achieve good grades by providing adjustments such as a scribe and large print, Which meant I was able to achieve my potential***".

Resource and understanding is therefore two of the key issues faced by SEND and LTC students.

Hopefully by sharing their experiences the young people that have been involved in this project have been able to turn a negative experience into a positive one by allowing their teachers, support staff, and wider educational institutions understand that individualised educational support for SEND and LTC young people will make for a better education experience.

# What can I do to support students with SENDs or LTCs?

We ask that if you have been struck by what you have learnt in this report to explore the hyperlinks below to continue improving how you support children with Special Educational Need or Disability and/or a Long Term Condition in your education setting

**National Association of Special Educational Needs:**

<https://www.nasen.org.uk>

**Five things you need to know about SEN in schools**

**Children's Commissioner report :**

<https://www.childrenscommissioner.gov.uk/report/five-things-you-need-to-know-about-sen-in-schools/>

**Council for Disabled Children:**

<https://councilfordisabledchildren.org.uk/resources-and-help/i-work-education>

**The Oliver McGowan Mandatory Training in Learning Disability and Autism:**

<https://www.hee.nhs.uk/our-work/learning-disability/oliver-mcgowan-mandatory-training-learning-disability-autism>

**Autism Education Trust School Programme:**

<https://www.autismeducationtrust.org.uk/training-programme/schools/>

# ACKNOWLEDGEMENTS

A huge thank you to:

All the young people who shared their experiences and enabled this report to be made.

Charities including The LUNA Project, RCPCH&us and Making Ourselves Heard who shared our form with their members and on social media.

The staff at the NHS Youth Forum, the NHS CYP Team and wider CYP programmes the NHS Public Participation Team for supporting us at every step.

To find out more about our report and the other projects carried out by the NHS Youth Forum, please visit: [LINK](#)

You can also visit the NHS Youth Forum:

 [Twitter](#)

 [Instagram](#)

**THANK YOU**  
**FOR READING OUR REPORT**