# Our Lives, Our Journey

## Young People (16-21 years old)

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# Executive summary

**We are proud to launch Our Lives, Our Journey. This study is the first qualitative longitudinal study we know of that follows the lives of disabled people and their families in the UK.**

Disabled people tell us that there are key moments of change in their lives which have a big impact on their experiences as a disabled person. We call these transition points.

At these transition points, the kind of support that’s available, the interventions that take place, and the decisions disabled people and their families take – or are taken for them – can make a significant impact on what happens next.

This study is designed to understand these points better. Too often we only see disabled people’s lives as a snapshot or single moment in time, but disabled people’s lives change.

Becoming an adult, moving into work, growing up, adjusting to new health and support needs. These experiences are all part of a journey, a story of progress and setbacks, action and inaction that is rarely told in disability research. We aim, over five years, to tell this story.

This report looks at the different experiences of 18 disabled young people between the ages of 16 and 21 years old as they transition into adulthood. The focus of this study is to explore areas where young people are adapting to adult life and becoming - and hoping to become - more independent.

We will be following their progress over the next five years, looking at the positive and negative experiences they have, and the barriers and opportunities that help and hinder their journey to adulthood.

Positive experiences of equality lead to more independence and confidence. Overall, participants shared lots of examples in different areas of their lives where they felt they were being treated equally with non-disabled people. These areas included education, friendships, and certain social situations. But inequality was still common, and most participants felt that more awareness and education about disability would lead to more equality for disabled people.

The disabled young people in this study told us their everyday lives were full of barriers that non-disabled people didn’t have to face. They felt they often had to adapt to the world around them. Young people had less choice of where to go, what to do in their leisure time, and where they could socialise. There was a lack of choice of where to study, and a lack of formal support when trying to make that choice.

Young people often experienced negative attitudes from the public, who they felt have a limited awareness of disability and the challenges faced by young disabled people. This was particularly the case for young people in the study with less visible impairments.

Through following our participants experiences, young disabled people highlighted the key areas and the issues they faced:

### Similar aspirations to all young people

The disabled young people in this study all had short and long-term aspirations that could be considered typical this age group. They include completing their studies, pursuing their career goals and eventually having a family and owning their own home.

Another common aspiration was to become more independent. The young people felt independence was necessary to achieve many of their other aspirations. While they did not necessarily aspire to follow the path of ‘role models’, they were inspired by certain disabled and non-disabled people.

### Independence across their lives

The disabled young people in this study all wanted to become more independent as they moved into adulthood. They wanted to do more at home, as well as moving out of home and into university accommodation.

Moving on to higher or further education was a key factor in achieving more independence. This might be through moving out of home into student accommodation, making new friends and finding different sources of support, or even through the equality experienced during their studies.

Yet despite wanting to become more independent, the participants were worried about the future. The biggest causes for concern were the increased costs of being an adult and uncertainty surrounding their impairment and the future.

### Limited choices – with positive experiences being a significant enabler

Everyday life involved a mixture of positive and negative experiences. In public places, or in leisure activities, the participants frequently needed to research accessible options first, or change what they wanted to do. This meant that choice was often limited, for example, when shopping at their local grocery store, visiting the theatre in or arranging transport.

When public places were accessible, or when staff or organisers were helpful, this had a very positive impact.

### ‘Faking’ disability

Participants talked about the negative attitude of the public towards disability, including a lack of awareness, especially of less visible impairments. The young people gave examples of the public suggesting they are ‘exaggerating’ or ‘faking’ disability. These attitudes damaged confidence and sense of independence.

### Relationships and friendships as a positive enabler of confidence and independence

Most of the young people in this study had strong support from their families, friends or both. Establishing and maintaining friendships, was often seen as hard but worthwhile, as it enabled participants to feel more confident and independent.

### Further and higher education means opportunities and equality

Education, particularly further or higher education, was an important and positive area in the lives of the young people we talked to. Receiving the proper adjustments and support when studying meant that they felt they had the same opportunities as their non-disabled peers. Equally the availability of opportunities were particularly apparent to disabled young people when their learning was flexible and utilised online technologies.

### School experiences of bullying

Experiences in higher and further education were very different to experiences in school, where many participants were bullied and there was less disability awareness among students and staff. Where there were examples of career advice, it was mostly unhelpful and rarely tailored for disabled young people.

### Extra costs

The disabled young people in this study frequently mentioned money worries. They faced extra costs as a disabled person. These included equipment (such as wheelchairs), transport (such as taxis), medical-related (such as medication), home-related (such as laundry), clothing (such as needing to buy extra thermals), food (such as buying ready-meals as opposed to cooking) and holidays (such as travel insurance). Some of the extra costs were covered by participants parents or by their disability benefit (such as Personal Independence Payment (PIP), but even so, these costs still caused financial worry.

### Money worries due to inexperience and benefit claim difficulties

A lot of the young people in this study didn’t consider themselves financially stable, regardless of their financial literacy or who managed their money (such as themselves or their family). They discussed not being able to do the things they wanted to do because of financial reasons (for example, chances to do things with friends). The process of applying for PIP, or of moving from Disability Living Allowance (DLA) to PIP, was challenging and frustrating, leaving participants feeling that the PIP assessment process didn’t consider how they lived their everyday lives.

Many of these negative day-to-day experiences had a major impact on individual levels of confidence and wellbeing. Participants often felt they needed to prove themselves – either as genuinely disabled, or as determined to reach goals they felt other people didn’t think they could.

Disabled young people need the opportunities and support within society to enable them to fulfil their aspirations, become more independent, experience equality and remove the barriers of living the life they are beginning to define and choose for themselves.

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## Introduction

Sponsored by the Esmée Fairbairn Foundation, ‘Our Lives, Our Journey’ is a pioneering qualitative longitudinal research study, following the lives of disabled people over five years. The research aims to provide a qualitative evidence base of the life experiences of disabled people. It will focus on important transition points in disabled people’s lives and explore what prevents or supports them and their families living the life they choose.

The study focuses on four specific groups of disabled people:

* parents of an early years disabled child
* disabled people entering adulthood (aged 16 to 21)
* disabled people who have recently started a new job
* disabled people who have recently acquired an impairment

Data was gathered through in-depth semi-structured interviews with each participant. We discussed their life journey, their aspirations, and their experiences of disability and everyday equality. We examined in detail how they negotiated key transition points in their lives (for further details of the methodology and sampling used please see the appendix).

The interviews from year one of the study were thematically analysed and the main themes across all participants where then explored in further detail, looking in particular for common barriers and useful and positive solutions. In this study, we explore experiences of young disabled people’s transition to adulthood, followed by their experience in everyday life in the following areas:

* experiences of public places, leisure activities, public attitudes, transport and home
* sources of support in everyday life (including family support, digital support and social support)
* experience in education (including higher education, further education, school and career advice)
* experiences of financial security (including extra costs faced, experiences with PIP, DLA and Disabled Students’ Allowances (DSA), and budget management)
* experience of equality and their aspirations for the future

## Our participants

‘A’ is 20, a part-time student studying History at university and lives in shared accommodation. A has physical and mental health conditions.

Adam is 20, a full-time student studying Travel and Tourism at university. He’s employed part-time at a supermarket and lives in their family home. Adam has an Autism spectrum condition.

Avery is 17, a full-time student studying A-levels at college, employed part-time at a supermarket and lives in their family home. Avery has a physical condition.

Catherine is 18, a full-time student studying performance arts at college and lives in their family home. Catherine Mariah has physical and mental health conditions.

Chloe is 18, a full-time student studying Biology, Maths and Psychology at A-level and lives in their family home. Chloe has physical and mental health conditions.

Daniel is 21, a full-time student studying business at university and lives in their family home. Daniel has a physical condition and vision impairment.

Elise is 18, a full-time student studying Biology, Psychology and English at A-level and lives in their family home. Elise has a physical condition.

Fraser is 18, a full-time student studying film studies, business studies and law at A-level. Fraser lives in their family home and has an Autism spectrum condition.

Georgia is 19, a full-time student studying Medical Sciences at university and employed part-time. Georgia lives in their family home and has a physical condition.

Jack is 17, a full-time student studying Computing, Product Design and Geography at A-level and lives in their family home. Jack has an Autism spectrum condition.

Jennifer is 18, a full-time student studying Psychology, Sociology and English literature at A-level. Jennifer lives in their family home and has a learning impairment, a physical impairment and a mental health condition.

Jess L is 22, a full-time student studying Languages at university and lives in student accommodation. Jess has physical and mental health conditions.

Jess P is 16, a full-time student studying Physics, Maths and German at A-level and lives in their family home. Jess has an Autism spectrum condition and hearing impairment.

Kashif is 20, a full-time student studying accounting at university and lives in student accommodation. Kashif has an Autism spectrum condition and vision impairment.

Katie is 16, a full-time student studying English GCSE and lives in their family home. Katie has a physical impairment.

Martha is 20, employed part-time working as a liaison officer and lives in shared accommodation. Martha has a vision impairment.

Melissa is 18, a full-time student studying a supported learning course at college and lives in their family home. Melissa has a learning impairment,
a physical impairment, and a mental health condition.

Selvie is 20, a full-time student studying Education and Sociology at university, employed part-time and lives in their family home. Selvie has a hearing impairment.

## Transition to adulthood

### Independence

A key period of change in any person’s life is their transition from child to adult. We asked disabled young people how they were adapting to adult life and becoming more independent.

Independence was mostly related to moving out of their family home and away from parental support. Some young people felt this could lead to more independence in everyday life and moving towards independent living.

**“I want to be able to prepare for a day independently, so be able to remember to wash, dress and so on. I want to be able to plan and cook a meal, and deal with and understand finance... Essentially, I want to be able to live on my own with minimal outside support.”**

Jess P

**“I think it’s important to me that I can live independently. I think it’s a part of growing up as well, that you’re able to look after yourself now. I think that’s quite important to me, to be providing for myself. Self‑sustainability, I guess.”**

Fraser

Those disabled young people who moved away from home (and its associated support) found this a positive and enabling experience.

**“I think one of the best high points for me is just starting university, the freedom associated with it, becoming so independent. I guess that’s just one of the best things that’s ever happened. Obviously, not to say that I haven’t had any high points before, but I just enjoy my freedom a lot here.”**

Kashif

### Transition through education

Higher and further education formed a major part of moving to adulthood and becoming more independent. This was due to increased opportunities, moving away from home and positive experiences of living in a new setting (such as student accommodation), socialising, and experiences of equality.

**“I was applying to college and that, I was going through…a state of transition in my mind. I was, kind of, feeling more adult about myself.”**

Jack

**“Getting into college for me was like regaining the opportunity to have a social life and a ‘normal’ life, like others of my age group.”**

Elise

### Uncertainty of independence and changing support structures

The largest worries for young people were the cost of living independently as an adult, not knowing how their condition will affect them in the future, and living in an uncertain world. Jess P shared this anxiety, **“I feel like knowing what I’m up against has helped me to arm myself for the future as I know what affects me, but it’s also scary because I don’t know how I’m going to cope as an adult in the ‘real world.”**

Elise echoed this uncertainty, **“I think at my age anyway there is lots of uncertainty about the future, but, with my particular illness and it being one of a kind – having not recovered in the same way as any others I honestly have no idea. I guess I will always carry on planning two different timelines.”**

Young people also talked about changing support networks. This could be moving away from home, or from child services to adult services for the first time. Many young people reported significant gaps in their transition, sharing concerns over the lack of service provision to support their transfer.

**“The only thing that has been difficult has been transitioning between paediatric services to adult. There’s a complete lack of adult services for anything really. So, it’s mostly like making sure that all my consultants and things that are paediatric get transferred over to adult care in the next six months.”**

Chloe

However, when handled well, the move to adult services made some young people more confident in taking on responsibilities and coping with any anxiety that came with any subsequent decision making. Some young people felt it was important to be involved in decision-making during this transition.

**“I get a lot of anxiety with people I don’t know... One of my personal goals...has been to find more self‑confidence and to speak up. I want small steps at a time, and it will help, to be able to do stuff like that on my own.”**

Anonymous

**“I think it’s quite important to know that I’m happy and comfortable with it all. Actually, I don’t like people making decisions about me… I just like being involved in my decisions and knowing what’s going on and stuff.”**

Katie

## Experience of daily life

### Societal barriers and enablers to everyday equality

#### Leisure time experiences and places

Disabled young people had wide experience of using public spaces or leisure facilities. In their spare time they took part in a broad range of leisure activities, including:

* creative arts (such as drama, singing, art)
* sports (such as swimming)
* volunteering
* travelling (both in the UK and abroad)

All the young people recalled a mixture of positive and negative experiences in a range of public places. The most common public places used were food and retail shops, as well as theatre and concert venues. Accessibility had the largest impact on their experience of a venue, followed by the attitudes of staff.

There were positive experiences when public places or leisure activities were accessible. For example, flexible spaces at the theatre or at concerts. There were positive experiences when public places or leisure activities were accessible. For example, flexible spaces at the theatre or at concerts.

**“Arenas are excellent, they really are… you can either just sit in your wheelchair and have a carer either side of you, or the first full row of seating of standard seating is for disabled [people] as well – so you can either go in your wheelchair or not, but still sit in accessible seating.”**

Chloe

The participants felt more equal and confident after positive experiences in public places or using leisure activities.

Unsurprisingly, negative experiences of coming up against barriers due to inequality, made disabled young people feel their options were limited and that they were potentially missing out (for example, being left out of a social activity) because of inaccessibility.

Young people also discussed having to conduct their own independent research into accessible options when seeking out activities and places to visit, or the need to adapt their lifestyle and behaviour to match the choices available to them.

**“If I want to go on a day out, it’s fine. I always just check the [website] page. Sometimes it’s not easy to find, but I’ll just search for disabled access.”**

Elise

**“I just will try to figure out how to get into places, and if I can’t I will just go somewhere else.”**

Daniel

It was common for shops to be inaccessible. There were frequent reports of ‘difficulties’ when grocery shopping. This was mainly due to the accessibility of shops or the attitudes of staff.

Where there were friendly, welcoming staff, who were happy to help, this made a real difference to the shopping experience.

**“I feel like getting support is a major thing, especially in shops and that. You get some staff members that don’t really want to help you, but then you get those ones that do actually help you and it makes a big difference in the way you see things.”**

Melissa

### Attitudes

Young people felt that the public attitudes towards disabled people were mostly negative. Frequently, there was a lack of awareness or understanding of disability. This was particularly true for those with less visible impairments.

**“With the stuff that’s not so obvious – I’ve got Asperger’s and that – people don’t really know that just by looking at me. People need to be, in a way, more educated about the fact that there are all different kinds of disabilities.”**

Melissa

Many young people felt it was common for other people to imply they were making up or exaggerating disability. Selvie explained, **“When we were waiting in the queue [for the accessible toilet], a man was trying to pick an argument with me and my mum about the fact that I wasn’t deaf… he thought we’d made it up, so I had to, sort of, show him my hearing aid.”**

**“The worst thing that I worry about all the time is people thinking that I’m putting it on. I will always have that in the back of my head, even if people aren’t thinking that.”**

Georgia

**“…there’s a proper lack of awareness on hidden disabilities – things that aren’t obvious.”**

Chloe

**“I think there needs to be change and just more awareness of the fact that, yes, you don’t know what somebody else might be experiencing that you can’t see. It’s the same argument really as mental health problems, that they’re not obvious.”**

Jess

Young people experienced unwanted questions, comments or staring. As well as feeling patronised, they were often ignored or spoken over when with someone else.

**“People will talk to my Mam and not me. They’d assume I can’t speak or I don’t have a clue.”**

Chloe

**“Obviously, when you’re disabled, people love to talk down to you, yeah? Also, being a young disabled person, people love to tell you, and kind of, patronise you a lot… it always felt like I was either being patronised because I’m disabled, or patronised because I’m young and disabled.”**

Martha

These negative attitudes had different effects. For some disabled young people, their feeling of independence and their confidence to go out and do things was damaged, making them feel stressed and frustrated.

Disabled young people discussed a lack of awareness and understanding about disability and that people would often make assumptions or stereotype them. Many wanted to see a change in the negative attitudes of the public across society.

**“I think people’s attitudes go a long way, particularly when you’re first starting to gain your independence. It can be really upsetting and demoralising if everywhere you go people patronise you, or talk slowly to you. It’s not a nice feeling and I think that’s one thing where I’d really like to see change: people’s attitudes, and seeing disabled people as valued members of society to be celebrated, rather than, you know, the poor cripple that needs a cure.”**

Martha

### Transport

Disabled young people’s use and experience of transport was varied.

Some of them weren’t able to use public transport because there were accessibility barriers to people with a physical impairment. For others, public transport was their only means of transport. They discussed their experiences on different types of transport, such as buses, trains, in taxis, driving or being driven in a private car.

The main issues were poor attitudes and the limited choice of accessible transport. Several young people said they felt uncomfortable asking for assistance or a seat. Those with less visible conditions often reported poor attitudes from other people.

**“It can be helpful, but it also makes me feel less independent… When I’m asking for help, justifying
a seat sounds quite, in my opinion, a little bit silly in
terms of, it’s such a simple thing to do, and I’m having
to ask for help to do it.”**

Catherine

**“I think things like public transport can definitely be places where people don’t realise [your needs]. If you sit in a priority seat or whatever, they think you’re being rude.”**

Jess

Young people often felt they had limited options to travel. For some, learning to drive was not an option. Others were unable to use certain types of transport because they weren’t accessible. Some were not able to use public transport. Travelling by car was their only option. Each scenario resulted in extra costs and this left disabled young people feeling worried about the future.

**“[Due to the barrier of cost] There is no way, really, that I’ll be able to drive… I don’t get any [free] bus pass, train pass, anything like that... so transport’s really expensive. The moment you turn 16 it’s adult prices… If I had the choice I would get the train, but I don’t have that choice because the bus is cheaper.”**

Jennifer

**“My chair is so big and heavy. Public transport like trains and buses can only take certain weights of wheelchairs and certain sizes.”**

Katie

**“[Not being able to drive] takes away a whole level of independence away from you. I’m dependent on someone if I want to go more than a half hour away from here. Like, you can’t pay for taxis and you can’t do buses your whole life.”**

Kashif

As with other areas of their lives, positive experiences on public transport gave young people greater feelings of independence and equality.

### Home

Most of the disabled young people interviewed lived at home with their family. Of those living with their parents, many were soon moving out to study. Of those living independently (not with family), most had moved out to attend college or university.

Young people who lived away from home felt they had gained more independence and a different level of family support. Those who had not yet moved out of home wanted more independence and to live away from home.

Young people’s living arrangements (such as university accommodation) was often closely linked to feelings of independence. Some young people worried about the future, sharing concerns about their ongoing independence and continuing the life they wished to live.

Some young people’s experiences illustrated the practical frustrations of trying to live independently. Support networks and accessibility, such as home adaptations and the ability to get out and about, were crucial in creating equality.

**“There are times when I wonder what I will do when I live by myself sometimes. I think for the most part, hopefully I’ll be able to get to the life I choose and hopefully at some point, I’ll get married or whatever and then my husband can fill in the role of my friends.”**

Anonymous

**“I did try independent living, but the care company that we tried, it didn’t work out, so I just came back… but then maybe in a couple of years I’ll get moving out, but just… a job first, and do it bit by bit.”**

Daniel

**“I have to think about things more now. So, for example when I was choosing where to live this year, I had to think about the position of my room, the stairs where I was going to be in relation to the kitchen and the shower and stuff and try and make sure that I was on the same floor as much as possible. Like, the things I needed at home.”**

Jess

## **Experience of daily life**

### Support structures

### Sources of support

Everyday support came from family, friends and socialising, either in person or online.

#### Family support

For many young disabled people, their parents or family members were their main source of support. They rely on them for care, emotional and practical support. This includes cooking, travel to medical appointments, help with benefits applications and emotional support for personal issues.

Where parents were a main source of support, the young person often had a very strong and close relationship with them. Their parents provided practical support, with their friends providing more emotional support. For others, their parents provided both practical and emotional support.

**“I’m always reliant on my parents, to be honest. My parents sort out most things for me when it comes to finance and whatnot... and for emotional support, I’ve usually relied on my parents anyway.”**

Jack

**“My mum’s absolutely amazing. She’s my full-time carer and she’s incredibly supportive.”**

Katie

A couple of young people told us that although their parents were a source of support, they were reluctant to see them as disabled.

**“I don’t even know if they would necessarily class me as a disabled person. I’ve never asked them because I don’t want to know the answer.”**

Jess

**“I feel bad for saying this but I kind of wish that my parents were more supportive in allowing me to say that I had a disability… I think it was very hard for them to accept that they’ve got a child who is going to have a difficult life.”**

Avery

The disabled young people who relied on their parents wanted to gain more independence but worried about how they would cope with less support. Those who relied on their friends also worried about what they would do without that day-to-day support.

#### Online support

Disabled young disabled people spent most of their time online, accessing support and information. They found support groups for people with similar experiences to share their experiences or to help others.

**“I’m in a Facebook group for people with fibromyalgia. I’m in a Facebook group for people with invisible illnesses. So, there’s lots of things on there with other people my age going through the same thing. Different types of troubles with university or discrimination in their everyday life, which is nice to talk to other people about.”**

Georgia

**“I’m very active on Twitter. I’m part of a big community of chronically ill and disabled people on Twitter, and I’m in a lot of Facebook groups for [peer] support and advice.”**

‘A’

**“I’m on a couple of Facebook pages dedicated to hypermobility, and some people will ask for opinions and things on what their experience and I’ll give them my experience of what I’ve gone through. Sometimes, I’ve even done some more research into my own condition, to help someone else.”**

Catherine

Disabled young people found it far easier to socialise and keep up with friends online. This was even more important when young people sometimes found it difficult to keep up physical contact with friends.

**“I think it’s because I don’t manage to get out of the house a lot and think it’s just a really good way to still be able to interact with people and still be able to talk to my friends and keep up to date with what’s going on.”**

Katie

The overlap between online support and socialising varied, with some mixing the two worlds and others preferring to keep them separate, having different sites and groups for different uses.

**“That’s a good part about being in that network online...
I tend to have one [social media account] that I use more to follow that kind of stuff and one that I use just to see my friends, a normal one so to speak. So, if I want I can kind of cut off being surrounded by illness-related stuff and just be whatever normal is.”**

Elise

Even though being part of online groups had a positive impact on their feelings of equality, some young people mentioned they still wouldn’t feel comfortable disclosing they are disabled.

**“Being on the online world, living, leisure, attitudes, advice and support, shopping and services, I feel on the same level, due to the fact that it doesn’t really require any, emotion or thought to it… Personally, on Facebook I rarely post anything, so I don’t have to display either all my joys or wallows to the world.”**

Jack

**“I think definitely in terms of online, you always have the same equality as other people… I think the online world is very much a place where I’m not really different from anybody else. I have completely equal access to online facilities and the whole online world as any average person in the world.”**

Jess

Although specifically mentioned by a few, this may suggest disabled young people experience equality differently online than offline, based on whether they choose to say they are disabled.

#### Support from friends

Social experiences were a recurring and important theme. There was a wide range of positive and negative experiences. Social support, access to social life and talking about disability were important.

Making and maintaining friendships was both challenging and rewarding. It was harder to maintain friendships for people who weren’t always able to be there. Daniel talked about making friends, **“I don’t do it as much as I would like to, but because of where I live, it’s just a bit difficult to get out with uni and all that.”**

Socialising and friendships had a very positive impact on confidence, independence and feelings of equality. When asked what the best experience of equality has been, Jess answered, **“definitely my friends, they’ve definitely made the most difference in terms of everyday life… there’d have definitely been things I couldn’t have done without help from them.”**

Feeling equal when socialising was often described as a balance between experiences being accessible and adaptable, such as researching accessible places to meet or keeping in touch via social media, and not being treated differently.

**“My friends aren’t allowed to ask me if I’m okay because hearing that every day, 20 times a day, gets a bit exhausting. So, no one is allowed to ask me if I’m okay because it’s not always a positive thing… because I wouldn’t want to be friends with someone who constantly went on about something that’s dreary in their life.”**

Avery

The young disabled people we interviewed had mixed experiences of talking about and explaining their condition to new friends. Some told us that being upfront about their impairment was an important part of making new friends.

**“Generally, the first thing I tell [new friends] now when I meet them, is that I have autism and they’re all really cool about it.”**

Fraser

Others felt it was difficult for a friend to understand their experience. For young people who had less visible, pain-related conditions, this was especially true.

**“For the most part they can sympathise, but they can’t empathise, if that makes sense. They are very helpful and they’re very sympathetic and they’re always willing to do what they need to do, but there are only probably two of them I would say that have really taken the time to understand where I’m coming from.”**

Jess

This was very different to friendships with people with a similar or the same condition. Katie explained the difference between the support she had with a friend with the same condition.

**“She just understands it because she has it as well. Obviously, people can understand but I don’t think you ever truly understand unless you’re going through it yourself. If there’s someone you can relate to and you know, like, you’re not alone with it, I suppose.”**

Katie

Katie also welcomed a different kind of support from her other closest friend, who was non-disabled person.

**“Oh, she’s amazing. So, she comes and sees me when I’m in hospital and she just treats me like I’m normal.... We do a lot of things together and, yes, she just treats me like I’m normal really.”**

Katie

There were some young people who found it hard to socialise, yet still felt that putting effort in would have a positive impact on their independence and confidence.

**“Anything that involves other humans that requires a level of focus, I find to be so difficult… and that I struggle to maintain the level of energy required to get through it. If this could change so I can save my energy, I could be more independent.”**

Jess

## Education

### Further and higher education

All bar one of the disabled young people involved with ‘Our Lives, Our Journey’ were studying at college or university. Experiences of college and university were very similar, so the findings have been combined. Since most were students, education was an important topic and part of life.

#### The search and application process

The disabled young people discussed how they chose where to study.
 This included deciding on a course, attending open days, choosing and applying to institutions. Individuals did this independently with varying degrees of support.

Most chose courses or career paths based on their interests and their future aspirations, although some disabled young people had to adapt career path.

**“I originally wanted to go into nursing because of everything that I had been through medically… but as time went on it was clear that physically I wasn’t going to be capable of doing that. So, going into occupational therapy, I was still able to help people in a medical sense and be able to empathise with not having complete independence with the body.”**

Avery

After choosing a course, there were limitations on where they could study. Choosing an accessible institution was important. The most common factors were practical, such as:

* being close to the family home or in an accessible area
* the suitability of student accommodation if they were moving away to study
* the availability of support or flexible learning

These factors commonly affected their choice. These were more important than which institution was considered best for the individual’s career aspirations, or which had the best reputation. Many young people went to open days to judge the location and availability of support for themselves.

**“When I go to university open days I also visit the student support people, and when I’m looking around
the university, I’m thinking, ‘is everything accessible?
Are there lifts? What’s the accommodation like?”**

Avery

Most participants felt applying to their chosen institution gave them a positive experience of equality. As Kashif explained, “applying to college, there’s nothing about that that’s hard… it’s all done through UCAS, and UCAS is pretty user-friendly. You’ve just got to put some work into it and it’s done.”. While career advice was limited in some respects, several young people mentioned that they had assistance with their application, such as writing their personal statement.

#### Adjustments, accessibility and available support

Experiences of adjustments, flexibility and support were mainly positive. This was mostly because young people chose institutions that met their access needs. However there were a few who stopped studying or changed institutions because of inflexibility or poor student support.

There were adjustments and a wide range of support options available to disabled students, including flexible attendance, assessments, study support, non-study support and online learning. Many students talked positively about the support they received and how the adjustments helped to support their study as well as their overall wellbeing.

**“I don’t know when I’ll graduate, because I don’t know how long it’s going to take me to do this, but I can take up to sixteen years... It’s just like a normal bachelors [degree], but I can take a long time to do it, which is good.”**

‘A’

**“I think if my teachers weren’t as supportive as they were, I would have dropped out and gone into part-time education, maybe [academic institute] which is more vocational. So, I would have done one BTEC and just worked at that one BTEC for two years. So, their support has meant that I can still do A-levels.”**

Avery

**“Being able to get a bit longer to do assignments really took the pressure right off… it just makes me less stressed because I’m not working to such a tight deadline.”**

Daniel

Online learning also helped the disabled young people complete their studies. It made studying more flexible and meant they could study more from home. However, many young people noted the potential to miss out on social experiences, as they weren’t physically around as much.

**“The thing is, it was quite hard not going back to school, mostly because of that socialising side of things, but I do find the online school really, really good. I’ve done really well there and it’s very flexible.”**

Katie

Non-study related support and access to having disability support workers also greatly benefited disabled young people. Adam outlined the support he received to help him with socialising at his institution, **“The support that I had, so, basically… if you were trying to strike a conversation, what things you would say, how to get a conversation going… and stuff like that”.**

These levels of support and adjustments had a positive impact on the young peoples’ feelings of equality.

**“[The right support and flexibility] gives me the same opportunity to learn as everyone else. The same opportunity to get my GCSEs and to be happy.”**

Katie

**“...the best are the places where I go to do the same thing as everybody else - so, everybody goes to the library to sit down and work, and I can go to the library and sit down and work. That’s not something where I need to think twice about it or do anything differently to anybody else… there’s nothing to make you stand out or make you look different in any way.”**

Jess

#### Attitudes and social experiences

The attitudes of other students in further and higher education were mostly positive and often described as inclusive. There was more awareness of disability and of diversity in general, than people in other contexts.

Disabled young people felt equal with other students, with extra support received treated positively by all. Universities or colleges were seen as a unique environment that was often associated as a key place for socialising and experiencing the inclusive attitudes of other student peers.

**“I can immediately say attitudes of other students [were positive]. I don’t hide the help I get, and no one’s ever begrudged me for it… It’s not a big deal for me and it’s not a big deal for anyone else.”**

Kashif

**“I think, especially if you’re going to uni, there are so many different people that go to uni that actually, me being hearing impaired is not anything shocking or weird… The fact that someone is disabled is not actually, that much of a factor.”**

Selvie

**“I feel like it’s more to do with the mindset of people that go to university nowadays than anything else, but everybody’s a bit more open, so you can say these things and people will listen rather than automatically jumping to an assumption.”**

Georgia

Despite this, some young people did still experience some negative attitudes from other students, including stereotyping or a lack of awareness.

**“[Sometimes I experience negative] attitudes from other students around me. It’s like I said before, there are a lot of people that still have those stereotypes and stigmas with autism, which can feel a bit hurtful.”**

Fraser

Attitudes of staff such as tutors and learning support staff were mixed. Some were supportive and attentive to the young person’s needs, were as other staff had negative attitudes towards the individual, their accessibility requirements and what they could attain in their studies and career.

**“I love my tutors, they’re really supportive. They’ll give me longer on my work and they’re like, ‘You can do it’ but, some of them had the attitude like, ‘Oh, you are not going to get your degree, you’re not going to work,’ just because I’m in a wheelchair.”**

Daniel

Unfortunately, some staff attitudes were patronising and lacking awareness of disability. This was often the experience of young people with less visible conditions.

**“Some of them…talk to you like you’re a toddler or something… Just because I’ve got problems doesn’t mean I’m still a kid, I just need a bit of extra help.”**

Melissa

**“Unfortunately there are cases, like when I use the lift in college. Some students - and I’ve heard staff - use comments towards me like, ‘that’s for disabled people’. I’m like, ‘I know!’”**

Avery

Disabled young people reported that education was a major social experience, especially compared to their experiences of school. Many of them were looking forward to, or had already experienced, the ‘student environment’. They spoke about being able to get out of their comfort zone and socialise more with other young people, as well as giving other people the opportunity to get to know them.

**“I talk to new people every day. I’ve enjoyed the social side and trips quite a lot. I mean, I’ve got the chance to go out, go to parties, and on the trips, I’ve had the chance to socialise with a lot of people I never thought to, and I’ve established links with them.”**

Jack

Elise looked forward to going to university. **“Uni, I feel in a sense it will be quite cool to regain the whole ‘social environment’… I find it therefore harder to just gain friends, unless they are friends with my friends and see me interacting to know that I am able to socialise. So, in a uni environment people would be put into the situation where they almost have to give that little bit of time to realise I’m not some ‘alien form’ and that they don’t need to feel awkward about socialising.”**

The young people also discussed how proud they were of the progress they had made with socialising.

**“I felt like I fitted in much better at Hereford, made a lot more friends… It really opened my eyes to autism, in a way, so I understood myself better, and understood the people around me better.”**

Fraser

However, Georgia’s experience was more negative:

**“Maintaining friendships, I think, has been really quite difficult for me. Also, once I am friends with somebody, I lose contact with people very easily because I’m not in their lecture and I’m not attending that specific day, and then there’s only so many times that you can text somebody saying, ‘I’m not going to be in today’. So, I have lost a majority of my friends through that network.”**

Georgia

Reflecting on experiences of school

In contrast to further and higher education, disabled young people were much less positive about their school experiences. Most of them were bullied at school and some spoke about school as being a particularly negative time in their life.

**“Probably quite a low point, high school, at times.
I wasn’t very happy there, I don’t think. I definitely struggled more with making friends at high school,
it’s a lot harder.”**

Fraser

**“My social life from year five upwards was just constantly being bullied, with, like, occasional talking to someone and having a nice conversation and thinking, ‘Wow, that’s amazing, is this what life is supposed to be like?”**

Adam

The young people told us they felt schools had a poor awareness of disability and did not make the necessary adjustments.

**“The school was not good with [supporting] my ADHD at all, as in really, really not good. They didn’t make any reasonable adjustments for me and I was just constantly in trouble for not doing anything.”**

‘A’

Where schools made positive adjustments, these included extra time to complete an exam and giving students technology to help them with their studies, such as tablets and assistive software.

Overall, the experience of school and the attitudes of teachers were more negative than in higher levels of education. Schools were described as being unsupportive, with teachers and the school environment unable or unwilling to personalise support or adapt to the needs of the individual student.

**“I was seen as a health and safety risk, I was no longer a person or a student… - for a while they said that I could no longer come to the secondary school until they had sorted something out. And as soon as I got the tiniest bit worse it was in a wheelchair, in a taxi, sent home for a week.”**

Avery

#### Careers advice

Disabled young people did receive some career advice, but it varied greatly depending on the individual and level of education. Adam described how he didn’t think he would attend university, but with support and advice from a careers adviser, he started a foundational degree and is progressing into an undergraduate degree.

**“When I went to college it did change, because they knew I had Asperger’s and they just thought that he’s got potential, that he’s quite knowledgeable, he knows quite a lot… I did really well in the first year and that’s how I progressed onto university.”**

Adam

There were also examples of poor or limited career advice, including a lack of disability specific advice, advice that was too general, irrelevant or unhelpful. This led to the young people feeling as if their career opportunities were limited because they were disabled. Many felt advice received and support offered focused too much on high achieving students or those that wanted to go to university.

**“The people that weren’t too academic were just shoved to one side, because they didn’t really care. All they cared about was the top 10% who were getting the highest grades.”**

Adam

There were very few examples of helpful career advice. Advisers often did not know how to find suitable institutions or how to access disability support.

## Financial security and extra costs

### Extra costs

All disabled young people discussed a wide range of extra costs as a direct result of their condition. Examples of extra costs frequently experienced included:

* specialist equipment such as wheelchairs, headphones, large print, weighted blankets
* transport, such as taxis or running a private vehicle
* medication, medical appointments, physiotherapy
* extra laundry, bedding, home adaptations
* essential specialist clothing or extra thermals
* ready meals for those unable to cook
* more expensive travel and insurance

These categories included costs incurred (or were expected to be), in addition to costs covered by someone else due to personal circumstances (such as a parent or other relative paying).

**“I would have done without a mobility scooter, but
I got given one when a relative died, so without that
we would have had to buy something similar.”**

Elise

Most young people told us their extra costs were being covered by their parents or by the benefits they were receiving. This led to worries about future costs and their family’s ability to financially support them.

**“My mum doesn’t like me to know a lot of their finances, but the extra cost that is needed to keep me warm and to buy those things, I worry that it affects her, but I’m not sure to what extent it does.”**

Georgia

### Financial management

Disabled young people received money either from a disability benefit payment (for example DLA or PIP), from their parents, from part-time or full-time employment, or from a combination of these. Many felt confident in managing their money independently and were careful with their budgets and benefits.

**“I manage [my money] quite good. Whenever I get paid, you know, I don’t spend a lot of it but I just, sort of, save it – I save up quite a lot of money, so it’s like for the future.”**

Adam

Parents were responsible for teaching the young people how to be careful with money. Georgia reflected on her approach to the management of her finances, “‘I think it’s definitely come from my parents and my upbringing, just that being very conscientious of where my pocket money has gone.”. Being good with money also led to a better sense of independence, as young people were less reliant on their parents. Avery explained, **“I don’t like asking my parents for money. I like to be a bit more independent.”**

Some young people thought they had poor money management skills. This had led to money problems and parents taking control of financial situations, such as limiting the money available in accounts, using cash instead of debit cards, or paying bills in advance. Those who felt they couldn’t manage money relied on their parents or family to help with budget management.

**“I stay away from money management as much as possible. It’s something I find very hard. I essentially set up a pocket money account for myself and occasionally I put some money in to buy video games and other stuff, but I can’t handle big stuff.”**

Jess P

**“I’ve never been very good with money. My dad’s my appointee, so he handles my bills for me, but then, he gives me an allowance every month, so I can get what I want, like little snacks or ready meals or something for throughout the week.”**

Melissa

However they felt about their financial skills, most disabled young people did not consider themselves financially stable. Many said they worried about money frequently, including extra costs and upcoming expenses, such as university accommodation and rent. Money problems had a major impact
on young people’s lives, with some of them going into debt.

**“I have cut back on a lot and I’m still in debt and getting in more debt as time goes on.”**

‘A’

Some families of disabled young people also had financial troubles, with some unable to get together as a family, or take part in socialising. The future costs of being an adult were also cause for concern.

**“One of the things I’m really nervous about university is, like, being able to cope and manage my finances... I’m a bit more worried because I know I’m not very good with my money. So, it’s about trying to manage those as well as university being quite expensive to live in, but I feel like I’m a bit more worried because I feel like I have more additional needs.”**

Fraser

**“When you’re older you’ve got a house, you’ve got a car, you’ve got big bills, you’ve got tax, you’ve got kids, you’ve got to pay to look after them. There’s so much stuff that you have to pay for and for me sometimes I do worry about, financially, where I’m going to be. Like am I going to be able to survive on my own? Am I going to be able to live independently? Am I going to be financially secure?”**

Adam

### Personal Independence Payment (PIP) and Disability Living Allowance (DLA)

Most of the young people were either receiving or applying for the Personal Independence Payment (PIP) or Disability Living Allowance (DLA)[[1]](#footnote-2). They were at different stages in the process, with some people already receiving benefits. Others had applied for PIP and were waiting on a decision, were planning on re-applying for PIP soon, or had previously applied (or even appealed) and been rejected.

Disabled young people had a mix of positive and negative experiences when moving from DLA to PIP. DLA was felt to have a more general application when compared to PIP. As Martha explained, **“DLA seemed very much all‑encompassing, whereas PIP is what you can and can’t do.”**

Selvie, whose PIP application was rejected when she moved from DLA, agreed. **“I think DLA was definitely more human because they recognised, yes, you’ve got a disability and then they would calculate your funding according to how disabled you were. At least they recognised that you had a different ability. Where I failed the PIP, they are not, sort of like, if you can live your life with your disability then that means you’re not disabled. That was, sort of, the vibe that they gave off.”**

There was more negativity about PIP, particularly the length of application and assessment process. The disabled young people were asked a long and wide range of questions about their impairment, as well as many questions that were not applicable. Young people felt that their PIP application did not take their experiences into account, for example, they felt the process didn’t consider the unpredictability or fluctuating nature of their impairment. Catherine, who has a physical pain-related condition, explained the difference it makes being assessed on a “good day”:

**“When you do the [PIP] assessment for whether you can have [PIP payments] or not, they might not necessarily see me on a day where my disability is having a full effect on me - when it’s really limiting me... [Not assessing me then] might affect the actual overall outcome.”**

Catherine

Selvie, who has a hearing impairment and was rejected for PIP, felt it was unfair to be assessed in an environment where she could hear quite well, rather than one she couldn’t.

**“What we were trying to ask them to do was meet me in a challenging environment for me, to understand my needs and they refused to do that. I feel like they weren’t accommodating in that regard.”**

Selvie

Several young people felt the PIP assessors lacked awareness and understanding of their condition. As Martha explained, **“[The assessor] didn’t really have much understanding about vision impairment. She didn’t understand many of the aids that I use, that kind of thing.”**

Some young people were particularly concerned that the system was trying to ‘catch them out’. They felt they had to prove themselves at the assessment, especially when their condition was less visible or they didn’t have a formal diagnosis.

**“I think at that time, I couldn’t walk further than 60 metres without any mobility aids. Now it’s I generally can’t go anywhere without mobility aids. They were just, ‘Ah, okay,’ and then they told me that I was faking, because I didn’t have a diagnosis of anything and they also were not very good about the mental health stuff… I have a feeling that they were just trying to find out if I was just faking being ill or something, but I think also they may have been trying to find out how serious my mental health problems were.”**

‘A’

**“It’s that reoccurring thought of, ‘They think I’m making
it up’. You’re made to feel like you’re worthless.”**

Georgia

PIP caused several participants anxiety and stress. The experience was better for those who didn’t need to go through a PIP assessment.

**“A lot of people that have claimed PIP have to go for a consultation with a PIP assessor. I didn’t have to do any of that. It was mainly they sent you a booklet and my mum filled it out for me… I don’t understand how I wasn’t seen, like physically assessed by somebody.”**

Adam

Although good for individuals in some cases, examples like these suggests a lack of consistency in the assessment process.

### Disabled Students’ Allowance (DSA)

Experiences obtaining and managing Disabled Students’ Allowances (DSA) were much more positive than Personal Independence Payments (PIP). DSA was used to cover some of the extra costs disabled students have to pay for. This included funding adjustments they needed to study, such as laptops or devices to record lectures, as well as covering the cost of travelling to classes (such as paying for taxis).

Most DSA assessors had a good knowledge of what students might need, as Chloe explained, **“He [was] really knowledgeable to be fair… he was asking us questions about my needs at uni that I hadn’t really considered.”**

Some felt this process was different their experience of a PIP assessment. It was a lot more informal and they ‘didn’t feel pressured to answer correctly’.

Some felt their DSA assessors could have made more suggestions for adjustments.

**“They could suggest stuff more, because as a disabled individual, we may have not experienced a type of support and we are not aware of it. I definitely think they should bring it up at the assessment meeting and say, ‘Would you think you might benefit from this?’, rather than us having to try and research everything, to see what we might need.”**

Selvie

## Aspirations

### Role models

Many of the young people didn’t have specific role models – people they aspired to be like or who inspired them. Avery stated, **“To be perfectly honest I don’t strive to be someone else. I don’t look up to celebrities. Well I’ve got the example in my parents, but I wouldn’t want to be someone else”.** Jack echoed this sentiment reflecting on his own role within decision-making in his life, **“If I was going to say who my role model is, I’d, kind of say nobody. I think the only reason why I follow the path I choose, is the opportunities that were given to me and the possibilities I explored with decisions, or, if they happen by chance.”.**

When the young people did mention role models or inspirational people, parents were most commonly named, especially in terms of being hard-working and compassionate. When famous people or celebrities were mentioned as role models, they included both disabled and non-disabled people. Other role models identified were people known on a personal or professional level, for example, a friend, teacher or work colleague who was a positive influence.

### Aspirations for the future

The most common aspirations for disabled young people were focused on careers, study or education goals, starting a family, and becoming more independent. In the short-term, the young people were working towards their career goals through studying and achieving the right qualifications.

Career aspirations were often linked to past experiences, for example wanting to work in health or mental health, due to their own experiences of health professionals and the system. Longer-term, they hoped for a family and to buy their own home.

Most young people had an idea of where they wanted to be in the future and were working on goals to get them there. However, their own perceptions of what was and wasn’t possible or achievable limited their aspirations. And some were told their career aspirations were not possible.

**“I’m just thinking about, you know, my future, and I’m going to pick jobs that should be okay to do and not get too tired.”**

Selvie

**“So before secondary school, I was, like, ‘Yes, I’m going to be the Prime Minister,’… Then secondary school happened, and I was like, ‘Ah, everyone is telling me that I’m useless, so maybe I will just not do that”.**

A

**“I was told I wouldn’t be able to be a doctor.”**

Kashif

Most disabled young people were highly motivated and were working towards life goals. For some, being disabled was itself a motivating force.
For others, it had affected their plans for the future.

**“I think, in a way, being disabled has given me this unrelenting determination and if I want something, to go and get it. I don’t think I would be political if I wasn’t disabled. The reason I’m political is because, you know, I’ve had to challenge – even as a teenager in school, challenge people when they didn’t provide adjustments. I, kind of, feel like I’ve got this voice and I should use it – try to use it to do something.”**

Martha

**“I’ve got this thing inside of me that says I’ve got to prove to someone that I’m actually a really useful accountant and that I can do something... [even though] sometimes I can’t do this [and] I can’t do that. So, I need to do something substantial to prove to myself that I’m actually not someone... who can’t all the time. I can achieve stuff, which is, I think, a good goal for myself.”**

Kashif

## Appendices

### Appendix A: Research objectives, methodology and sampling

#### Research objectives

The aim for this research is to explore common issues of equality that disabled young people in transition experience. The foundation year report covers objectives to:

* map disabled young people’s aspirations
* track journeys of disabled young people in transition
* understand the emotional resilience challenges they face
identify opportunities to improve support for disabled young people in transition
* explore the barriers and enablers to getting the best start in life and moving into adulthood
* identify the extra disability-related costs for young people experience

#### Year 1 interview journey

The first year interviews were split into three parts. Firstly, participants prepared timelines for themselves as homework. Timelines covered key life journey high and lows and aspirations for the future. Secondly, participants described their timelines in an in-depth phone interview.

For part three, participants took part in a home in-depth interview. Participants covered Scope policy topics on ‘getting the best start in life’, ‘financial security’ and ‘living the life I choose’. Participants covered topics answering semi-structured questions. Stimulus material was also introduced to ask participants:

* to evaluate their equality and inequality experiences on ‘getting the best start in life’ issues
* to recall unprompted and prompted all the extra disability-related costs they and their family pay for
* to draw an overall satisfaction past, present and future timeline on their most important equality issue

### Appendix B: Sample breakdown

Eighteen young disabled people were interviewed about their experiences of transitioning to adulthood, in a range of areas in their life. This included future aspirations, experience in everyday life, experience in education and work[[2]](#footnote-3) and financial security.

**Total participants 18**

**Age** (at report)

16 to 177

18 to 195

20 to 216

**Gender**

Female11

Male7

**Location**

North5

Central6

South7

Wales1

**Ethnicity**

White British16

Ethnic minorities2

**Disability (participants could be in more than one category)**

Physical impairment9

Autism spectrum8

Mental health condition6

Vision impairment3

Hearing impairment2

Learning impairment1

Other impairment2

**Contract**

Student16

Full-time employment1

Part-time employment4

### Appendix C: Coronavirus context

For information, we include a section from the original report, which discusses the negative and positive effects of the coronavirus pandemic on young disabled people and our research participants.

In releasing this report following an unprecedented global event, the impact of coronavirus pandemic on the lives of disabled young people (and their families) has been significant. As the disabled young people transition towards independence, evidence of the pandemic’s effect is still widespread – within employment, education and throughout their social lives and at home.

The research presented in this report is based data collected via interviews conducted prior to the pandemic, and we have since conducted our second round of ‘Our lives, our journey’ interviews with disabled young people during the pandemic. In the following section, we pull together some of the early findings from the second wave of the study to provide some current context of young people’s lives.

#### Changing job market and employment uncertainty

The job market for disabled young people is frequently a difficult one to negotiate. Disabled young people often face unnecessary hurdles, with many employers and recruitment agencies still not providing appropriate support and adjustments for disabled employees and prospective employees.

Access to this market became more difficult following the pandemic; limiting the number of jobs available and increasing levels of unemployment. This employment is adversely affecting 16 to 24 year olds, with levels of youth unemployment at their highest since 2016 (at 14.5% between August and October 2020).

There were early indications from young people participating in the Our lives, our journey project of restricted access to the job market. Some reported that they are in ‘limbo’ searching for employment and that their job searching has been put on hold.

Their pre-existing concerns of finding a job as a disabled person were heightened following the pandemic and current economic climate. This has been particularly stressful as leaving education, navigating the recruitment journey and entering the world of work for the first time is already daunting and challenging.

#### Future of education and attainment concerns

As students return to academic settings, there were many concerns and uncertainty about the kind of education they will receive, their potential attainment levels, and what the future may hold for them.

Government guidelines state that education providers must maintain the quality and standards of their tuition – and registration online – if teaching moves towards an increase in online learning activities. It is anticipated that courses would therefore ‘provide a high-quality academic experience, students are supported, and achieve good outcomes, and standards are protected’.

Although the Office of Students wished to ensure that quality of teaching remains high, they cite a number of examples of issues relating to adjustments which disabled students faced following impact of coronavirus on the education institutions.[[3]](#footnote-4)

* Study support – for example, the assistance some students receive from note-takers and sign-language interpreters – may be less readily available.
* Hearing or visually impaired students may struggle to access lectures and webinars as teaching and learning move online, in addition to those digitally isolated by lack of accessibility for people with learning or behavioural conditions, or even physical access to IT equipment or the internet.
* Some students may be self-isolating because of underlying health conditions and be unsure how to access the support they need.
* Students with mental health conditions may find their impairments exacerbated by lockdowns.

Furthermore, some disabled students are worried that their attainment will be affected by modified assessment processes that may not take full account of their needs; a concern raised by disabled young people participating in the research study. The majority are in education and have shared their aspirations to either move into further education, take a gap year, or start their career. The young people are uncertain whether their plans will still be on track. For example, Katie is in her final year of A-levels and is unsure if she will complete her qualifications in time.

#### Impact on home-life and independent living

This uncertainty is exacerbated by extending its reach into young people’s living arrangements.

Following the news that the coronavirus began predominantly in the young for the second wave of virus, mass migration of students back to their education localities across the UK and their subsequent living arrangements became a issue for some students. Amid concerns about students bringing the virus into student and wider communities, many disabled students had to self‑isolate from commencement of the new academic year.

Clarity of responses from some universities about classroom, campus and living arrangements may have caused some worry to some disabled young people. They were concerned about their ability to achieve safe social distancing, particularly within their term-time accommodation, and negotiating shared areas with other students, such as kitchens or bathrooms. And indeed, ‘some universities have moved students who are shielding into self-contained flats to avoid this problem’.

In addition, young people beginning to transition into independent living beyond the family home encountered difficulties due to circumstances of coronavirus pandemic. Disabled young people may have their hand forced further by needing to self-isolate, and if homeworking is not available and people jobs are put on hold or worse, previously secure accommodation arrangements can become destabilised.

**Selvie is just a few months into her working career, after graduating from university. She is adjusting her life from education and becoming more independent to being employed. This meant moving away from
her family home and finding the right accommodation near work. She faced challenges finding accessible accommodation that she felt comfortable in, but finally found a place she is satisfied with and signed a six‑month contract.**

**Unfortunately, due to the coronavirus situation, her job has been paused and she must completely self-isolate because she falls into the Government’s clinically vulnerable category. She now needs to leave her accommodation that she has only been in for two months and move back to her family home, so support needs can be met during her self-isolation. She now sees herself living in her family home for the foreseeable future. This situation has had a great effect on her independence, socialised and the new life that she only just began to build.**

#### Reasonable adjustments and a changing approach

A number of disabled young people have also reflected on positive changes resulting from the coronavirus pandemic, such as more employers adopting working from home as standard and education institutions streaming lessons and lectures remotely. Martha highlights that being able to attend her lectures from the comfort of her home has had a hugely positive impact on her studies (and mental well-being). She feels a lot less anxious and is able to better focus on her education.

Although these changes are obviously very much welcome, many young people reported frustration around the lack of inclusiveness for disabled people before the pandemic and how quickly changes frequently requested in the past, can be implemented when the majority of the population are affected. Adjustments such as working from home (in both a professional and education setting) should be adopted as standard quickly for disabled people and others who need it.

Many young people pondered on how this new way of working may change the future of inclusiveness for the better. Some said it gives people insight into the impact of isolation and ongoing challenges which disabled people face on a daily basis (as outlined in the section above). However, for some young people in the study, this practice came frustratingly too late, despite frequently raising these issues with organisations and individual gatekeepers (such as tutors).

**Avery was unable to complete their degree after
two years of university because they didn’t have the right support or adjustments put in place. Their fluctuating condition means that some days they are unable to physically attend university. Avery would have greatly benefited from the online access that is now offered since the Covid-19 pandemic.**

**“I’ve always found it really hard to go into lectures because I’m autistic and now I can just sit in the kitchen and watch the lectures. It’s great. It’s wonderful. I haven’t got to worry about getting up and being anxious. It’s great. It’s really wonderful. It’s quite frustrating that it’s only just happened now because I’ve asked for online access to lectures before and they said it’s not possible.”**

Martha

Due to years of campaigning by disabled people for better accessibility with remote learning and online education, the schools, colleges and universities which were the best at enabling accessible courses, were more capable of managing a smooth transition and delivery of the switch to online learning during the pandemic.

The adaptations following coronavirus pandemic highlights that, by initially considering accessibility of disabled people when designing products and services, organisations and the services they provide become more accessible for everybody. Non-disabled people are, on the one hand, reaping the benefits of years of work by disabled people and universities to make higher education more accessible, and on the other hand are now beginning to see how much there is left to do in this area.

**We’re Scope, the disability equality charity. We won’t stop until we achieve a society where all disabled people enjoy equality and fairness. At home.
At school. At work. In our communities.**

We provide practical advice and emotional support to disabled people and their families whenever they need it most.

We use our collective power to change attitudes and end injustice. And we campaign relentlessly to create a fairer society.

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1. During the period of data collection for Wave 1 of ‘Our lives, our journey’, Disability Living Allowance (DLA) payments were being phased and being replaced with Personal Independence Payments (PIP), a benefit intended to support extra costs of disability. [↑](#footnote-ref-2)
2. Given that most of the young people in this study were involved in education, as opposed to full-time work, work and employment was not focused on as a key topic. Please see the Scope website for the ‘Our Lives, Our Journey’ report covering details of disabled people’s experience in employment. [↑](#footnote-ref-3)
3. Office for Students (2020) Briefing note. Note 8, 25 June 2020, https://www.officeforstudents.org.uk/media/8f61cef7-4cf7-480a-8f73-3e6c51b05e54/coronavirus-briefing-note-disabled-students.pdf) [↑](#footnote-ref-4)