# Our Lives, Our Journey

## Young People:

## Life Journeys

Sally Field

Rebecca Mobbs

Purple text on a black background

Description automatically generated with medium confidenceCraig Moss

# Executive summary

We are proud to launch the second round of research from the ‘Our lives, our journey’ longitudinal study, following the lives of disabled people and their families in the UK.

For the disabled young people participating in the study, becoming an adult, moving into work, growing up, adjusting to new health and support needs are important life transitions. These experiences are all part of a journey; a story of progress and setbacks, action and inaction that is rarely told in disability research.

Two years on from our first interviews, this report covers the second time that we met our participants and looks at the different lives of 18 disabled young people. These young people tell us about their experiences as they transition into adulthood.

Previously, disabled young people faced several issues in their lives. Assumptions that they were faking their condition or that there are disabled, limitations of their life choices when compared to non-disabled young people, and their ambition to achieve equality in society through opportunities afforded by their education. The young people also experienced bullying (particularly in secondary school) and stigma due to limited awareness of disability amongst students and staff, as well as experiencing money worries due to extra costs and inexperience of managing finances.

This report catches up with the same individuals to see if there have been any changes in the main points that they raised in the first interviews. 2 years on and these young people have gained more independence in their lives.

Central to the second wave of the research report are 10 life journeys of disabled young people, collated around 3 important areas: home life, education, employment and careers. Within these themes, we explored where people are currently in their life, revisiting aspects of living previously raised the last time we contacted them.

We covered aspects of each young person’s life, such as their home and relationships, support networks, education or working experiences, and their financial security. We were interested how their experiences in the different aspects of their journey interconnected. Their insight providing us with understanding about the barriers they had to overcome and support available to them, in their progress of navigating their journey of transition to adulthood.

## New findings

To illustrate our findings across 3 important areas, we outline the life journeys of 10 young people. They highlight common experiences among this group and their reflections on life as a disabled young person.

### Home

Participants either lived at home with their parents, with housemates or alone. Whoever they lived with, these people were a big source of emotional, and sometimes physical support. This was an important theme for disabled young people because home life has a huge effect on their mental and physical wellbeing.

#### Main findings:

* **Choice limitation:** restricted to finding accessible accommodation, in certain locations, near public transport or shops.
* **Financial security**: some are having to live with others as rent is cheaper, or at home to save money. The emotional burden of budgeting their finances is tough for this age group.
* **Accessibility:** leading to independence of movement, in and outside their home.
* **Independence:** the young people felt independent, regardless of living situation whether they choose to live with others or by themselves.
* **Relationships:** those relying on benefits felt they had to make a hard decision between sharing accommodation with their partners and losing their benefits.

### Education

Most participants were in higher education in mainstream institutions. There were a variety of experiences in the group, but important themes emerged around choice, support and accessibility.

**Main findings:**

* **Choice limitation:** some universities do not have facilities for disabled students or have restrictions on what support they provide. Some disabled students need to live near their families and/or healthcare providers for support.
* **Positive support:** advice centres were helpful, as were academic tutors and note takers.
* **Lack of support:** being accused of laziness by lecturers if they struggle to attend lectures or need the lecture materials before the classes.
* **Accessibility of the campus:** a focal area where participants felt unequal to their peers.
* **Friendships:** friends they could trust and confide in about their conditions were an excellent emotional support.

### Employment and careers

Some participants were in permanent employment or working towards a career. Others were in part-time work while they studied or looked for more permanent positions.

#### Main findings:

* **Independence:** earning their own money or working towards a career made our participants feel independent.
* **Support:** feeling supported at work was incredibly important, this included being given responsibilities, feeling part of the team and being able to work flexibly.
* **Choice limitation:** those struggling to find work felt that they did not have the right qualifications, skills or experience to secure the job of their choice.
* **Discrimination:** Some felt that they did not get offered job interviews, or the job, if they disclosed their disability at any time during the hiring process.

These 3 themes interconnect through each of our participant’s experiences. This gives us a true perspective of the barriers and enablers that they face.

Disabled young people that strive for financial independence experience barriers of extra disability costs across these 3 themes. This includes being unable to afford to move homes, living in inaccessible accommodation, or travel costs to education or work locations.

Societal structures and support needs which enable an independent life are different for everyone. From parental support and housemates or friends, to more formal networks such as the structure of lectures, course materials and exams, as well as approach of education staff and disability support officers. Or the inclusive, proactive attitudes of managers and colleagues in the workplace.

These connected structures allow these young people to live the life they choose, in their own unique way, reinforcing that interdependence is crucial to leading their own independent lives.

## Contents

Executive summary 2

New Findings 4

Introduction 9

Our participants 11

1. **Living arrangements**  **14**

**Living in shared accommodation** **14**

‘A’s life journey 15

Selvie’slife journey  18

**Living with family** **21**

Adam’s life journey  22

Katie’s life journey  24

**Living alone** **26**

Martha’slife journey  27

Jessica’slife journey  30

1. **Experiences in education** **33**

**Choice and support in Education** **33**

Melissa’slife journey  34

Georgia’s life journey  36

**Unmet needs in education** **39**

Kashif’slife journey  40

Avery’slife journey  42

1. **Moving into employment** **45**

Jennifer’s life journey  46

Adam’s life journey  48

Conclusion 50

Appendices 56

**Appendix A**: Research objectives,

methodology and sampling 56

**Appendix B**: Sample breakdown 57

**Appendix C**: Summary of themes from Wave 1 56

**Appendix D**: Contextual research 60

The coronavirus pandemic  63

## Introduction

‘Our lives, our journey’ (OLOJ) is a pioneering qualitative longitudinal research study, following the journey of disabled people over five years. This research report aims to provide a rich evidence base documenting the life experiences of disabled young people in the second wave of the OLOJ study. It focuses on important transition points in the young people’s lives and explores what prevents or supports them and their families living the life they choose.

In the first wave of OLOJ, data was gathered through in-depth, semi-structured interviews. We discussed their life journey, aspirations, and their experiences of disability and everyday equality. The main themes from the first wave were:

* Choice, control & independence for social & home life
* Confidence and independence gained from relationships & support networks
* Equality and opportunities in further and higher education
* Aspirations and experiences in career and employment journeys
* Financial security

See appendix C for further detail of these themes.

From these themes and related research on disabled young people (See appendix D), this report further explores 3 main areas: home life, education and employment.

We revisited the lives of 15 disabled young people 2 years on from the beginning of the study and interviewed them again. The interviews were in-depth, semi-structured interviews as before, but we met with the participants online. The world had just entered the coronavirus pandemic and the first lockdown had started soon after.

Within the 3 main areas of home life, education, and employment there are some reoccurring themes from the first report:

* Limitation of choice and accessible environments
* Financial security
* Attitudes
* Support
* Independence

Disabled young people are already adjusting to the changes and responsibilities of adult life, but they also face barriers in society as a disabled person.

This report gives you a closer look at disabled young people in ‘Our lives, our journey’. We share some insightful quotes and details of their individual experiences.

## Our participants

**Adam** is now 22, he was studying Travel and Tourism at university, and employed part-time in a supermarket. He has now finished university and is working full-time in the hospitality industry. He currently still lives in his family home but is planning to move out. Adam has an Autism spectrum condition.

**‘A’** is now 22, they were a part-time student studying History at university. A is currently not in employment or education due to lack of support, and still lives in shared accommodation. ‘A’ has physical and mental health conditions.[[1]](#footnote-2)

**Catherine** is now 20 and is still a full-time student, studying performance arts at college. Since we first met her, she has moved out of the family home into student accommodation. Catherine has physical and mental health conditions.

**Avery** is now 19, they were a full-time student studying Biology, Maths and Psychology at A-level and lived in their family home. They are no longer in education due to lack of support and is now employed part-time at a supermarket. Avery lives in shared accommodation and has a physical condition.

**Daniel** is now 23, he’s still a full-time student studying business at university, and lives with his family. Daniel has a physical condition and vision impairment.

**Georgia** is now 21 and is still a full-time student studying Medical Sciences at university. Since we last met her, Georgia has moved out of the family home, and now lives in shared accommodation. Georgia has a physical condition.

**Jack** is now 19, he was studying Computing, Product Design and Geography at A-level and living in his family home. Now, Jack is a full-time student studying Geography at university and lives in shared accommodation. Jack has an Autism spectrum condition.

**Jennifer** is now 20, she was a full-time student studying Psychology, Sociology and English literature at A-level. She is no longer in education due to lack of support and is looking for employment. Jennifer lives in her family home. Jennifer has a learning impairment, a physical impairment, and a mental health condition.

**Jess L** is now 24, she was a full-time student studying Languages at university and living in student accommodation. She has now finished university, is working full-time, and lives by herself. Jess has physical and mental health conditions.

**Jess P** is now 18, she was a full-time A-level student studying Physics, Maths and German. Now Jess is just about to start university and, as before, lives in her family home. Jess has an Autism spectrum condition and hearing impairment.

**Kashif** is now 22, he is still a full-time student studying accounting at university and lives in student accommodation. Kashif has an Autism spectrum condition and vision impairment.

**Katie** is now 18, not much has changed since we first met her; she is a part-time student studying English GCSE and lives in her family home. Katie has a physical impairment.

**Martha** is now 22, she was previously employed part-time as a liaison officer and lived in shared accommodation. Now she has just started university and lives alone. Martha has a vision impairment and an Autism spectrum condition.

**Melissa** is now 20, is still a full-time student studying a supported learning course at college and lives in her family home. Melissa has a learning impairment, a physical impairment, and a mental health condition.

**Selvie** is now 24. She has finished university and is now a supply teaching assistant for SEN children and lives in shared accommodation. She has a hearing impairment and wears a cochlear implant and a hearing aid.

## Living arrangements

This section highlights the real-life experiences of disabled young people gaining their independence. For disabled young people, independence has different meanings for each person, and one is not seen to be better than the other [[2]](#footnote-3). This does not necessarily mean living outside of the family home; many of the young people we spoke to live at home but enjoy independence afforded by income from their jobs, owning a car or the ability to move around an accessible house.

### Living in shared accommodation

Our participants told us that:

* **Accessible housing** was important for their independence.
* **They felt equality in society**, such as the freedom to come and go as they choose, freedom of choice in what they did and when.
* **Rent** is cheaper when living in shared accommodation and there are extra costs associated with living alone. This can be a barrier for disabled people who benefit from living alone.
* **Support** was appreciated from housemates when it is on their terms (disabled people often feel they have to reiterate their support needs).
* **Financial security** was a concern for many, compounded by parents which were not available to support them. One participant had the support of their parents financially as they had lost their job, while the other one was relying on benefits as they couldn’t find work. The pressure of this means that they felt ‘stuck’ in shared accommodation or living with their parents with no option of changing their living situation.

#### ‘A’s’ journey with living arrangements

‘A’ is a wheelchair user who has recently moved to a larger city. Their new location has much more accessible transport and housing, than the small city they were living in before. In the new city ‘A’ feels much more equal to those around them. Their social life has improved because there are more opportunities for them to socialise since being able to travel more easily (they have a tram stop right outside their house!).

Although ‘A’ feels that moving to a new city has significantly improved their life and independence, their financial situation remains challenging. ‘A’ is unable to find suitable employment and relies on benefits with no way to currently improve their standard of living. ‘A’ also feels that they cannot find complete equality as they aren’t able to live with a partner due to the risk of losing benefits.

‘A’ enjoys the freedom and independence, both in and away from home:

**“Well, now I live in a more accessible house where everything is level access [sic]. Moving has made an impact on what I can do around the house, how much I can leave, in that I can, sort of, do stuff in the house now. If I have the energy, I can just pop out if I feel like it. It's just like, roll in, roll out.”**

‘A’s social life has benefitted from the move as they can now travel alone on public transport more freely than before, living close to good public transport links. Some of ‘A’s friends who are disabled also have accessible housing which means that they can all meet more easily. ‘A’ enjoys visiting them at their homes:

**“Yes. I've done a lot more visiting friends and stuff, I think, partly because some of my friends here… have wheelchair-accessible houses, which is great. Also, the public transport here is more accessible, yes.”**

Moving has also had a financial benefit for ‘A’ as rent is less and they can also rely on public transport to get around, they save money previously spent on taxis. However, ‘A’ is still struggling with finances due to relying on benefits to survive:

**“Well, my rent is less, and I have PIP now, but before, I was surviving by borrowing a lot of money, so I'm still in quite a lot of debt. I'm still struggling to get by.”**

Due to this, ‘A’ feels that they can never hope to improve their quality of life and live in more comfortable accommodation:

**“The fact that when you're on benefits and that's the only way that you're living, you can never get more than a certain amount. You can never hope to, like, earn more money, ever. I'll say money... is, like, a barrier.”**

**“There are barriers towards disabled people [increasing their income], [with difficulty finding] work, the accessibility of workplaces (physical or otherwise) and whether people are even going to employ us.”**

‘A’ also feels that the rules imposed by the benefit system prevent them from being able to move romantic relationships to the next level and move in together. This has detrimentally affected control of their personal life and their future planning with potential partners. Financial stability and a lack of equality in relationships is a serious concern for ‘A’ as it has caused relationship breakdowns in their past:

**“I would suggest campaigning for people on benefits to be able to live with partners, and to be able to get married without losing their benefits. That's horrible, because it's either you are signing yourself up to an equal relationship [living apart], or there's no money [living together].”**

‘A’ is wary that their independence would be lost if they lived with, or married a partner, became their dependent without sufficient income to support themself. ‘A’ reflects that on the surface the have equality of choice, but in reality, they feel no control over life choices due to financial pressure from relying on benefits:

**“We have the ghost of equality; if you don't look deeply, it looks like we have equality.”**

#### Selvie’s journey with living arrangements

Selvie feels that she has lost some of her independence due to the pandemic as she is no longer able to earn money from her SEN substitute teaching assistant role. She’s lost her income and now has to move back home. Selvie will be financially supported by her parents. She enjoys helping other disabled people and used to volunteer when she was at university as a peer mentor. This year she intends to live at home and go back to university to undertake a postgraduate degree. In the future she wants to take advantage of the disability scholarship schemes which help disabled graduates to find work.

She only just moved into her current place and is very happy with her new house mates. Unfortunately, the pandemic has meant that she is not earning due to her jobs being on hold during the lockdown. Now she can no longer afford to live in the shared house and faces financial implications to dissolve the six-month rental contract which she is tied into:

**“Both my jobs are stopped... I can no longer even afford to live here... [and now] we're in the process of just discussing how much it might cost me to get out of the contract.”**

She intends to move back in with her parents for the duration of the lockdown due to her current financial situation and the issues with her accommodation. Although she was always planning to move back to the family home when she starts her master's degree, she is frustrated at having no freedom of choice and losing the independent living that she was looking forward to over the next 6 months. Knowing that there is an end date to her moving home makes it easier for her to cope with.

However, she is very happy to be moving back in with her parents for mutual support. Although she seems relatively unconcerned about getting ill herself, she is worried about her parent's wellbeing and support needs. Despite initially being frustrated by the change in her living plans, Selvie would rather be there to support her parents.

**“Every time I move back in for a bit, I love being around family and everything, but in my head it's also, sort of, a backwards step. It's like, I should have moved out, and I should be in a job and staying there [living independently].”**

Selvie believes with appropriate adaptations to her accommodation she is well equipped to live independently. She enjoys the freedom of being able to come and go as she pleases and through owning a car, she has a safer transport option to visit friends and family during the pandemic.

**“In terms of moving to a new house, as long as I have my specialist fire alarm, which you can get installed for deaf people, so, it, like, vibrates under the pillow just like my alarm clock. As long as I have that, and I've got my car, I can feel very independent here.”**

Selvie doesn’t aspire to live alone but is clear this is because she thrives off the company of other people rather than her being disabled. Her housemates have had to return home due to the pandemic, which means that Selvie is temporarily living on her own:

**“I never want to live alone, and that's just something to do with feeling lonely, rather than my disability.”**

Selvie’s parents are her major supporters and contribute to her financial security. This has allowed her to effectively plan her career without the stress of not being able to make ends meet. She currently has no income due to her employment stopping in lockdown and believes she isn’t entitled to be furloughed or to claim statutory sick pay.

**“I've got enough money to pay the bills for now, because I saved. That's going to run out soon.”**

However, she is appreciative of support from her parents if she continues to be without work. She foresees that her outgoings will be minimal during the pandemic which potentially gives her an opportunity to save while living in the family home.

### Living in the family home

Our participants told us that:

* **Young people felt well supported** both physically and emotionally.
* **Parental support** enabled them to build the confidence to live by themselves in the future.
* **Experienced more independence** as they are able to pursue lives outside of the home, such as being in employment or education.
* **Extra effort** was still required to establish the support needed in work or education settings.

#### Adam’s journey with living arrangements

Adam has a full time job where he feels very supported. This has allowed him to gain confidence and independence to consider moving out of the family home in future. His parents are important support for him both emotionally and financially. He aspires to stay in the hospitality industry and live by himself.

Adam lived at home throughout university and has recently completed his degree. He now works full-time in the events and hospitality industry which provides him with a steady income, it offers him long-term stability and more security than he had in his part-time job in retail. He feels supported at work, meaning that he has become more confident in his ability to be independent.

Adam’s aim in the future is to be independent and have his own space. He is excited about the idea and has considered what this might look like:

**“I've thought about it for quite a while, it's just, I want to have that independence, where you can go into your own flat, or house and just shut the door and go, 'This is my place.”**

However, he is concerned that he won’t be able to look after himself when he lives alone, :

**“Then, I worry, like, how am I going to look after myself, being on my own?”**

As Adam now has a stable job, he feels financially secure enough to consider moving out of the family home. His job provides him with the basis for a long-term career which has helped him with feeling more independent.

Although Adam’s job provides him with the skills to live independently, he has fears regarding his ability to live on his own. These skills include the knowledge and confidence to complete practical tasks which improve his self-confidence for running a household in the future.

**“The skills that I've learnt from work I can now implement at home, which is good.”**

#### Katie’s journey with living arrangements

Katie lives with her mum, who is her most important source of emotional and physical support. Her mum recently had their new home adapted to be fully accessible for Katie including the installation of accessible bathrooms and widening of doorways to allow access for wheelchair. She seems excited about the independence that these home improvements bring and loves that the is garden accessible to her.

The wet rooms and adaptations in their last house were paid for by Katie’s Disability Living Allowance (DLA), however, they did not think that they were entitled to the same financial aid again in their new home. Katie and her mum appear to have accepted these circumstances as it was their choice to move house, and have absorbed the financial costs themselves.

The intention with refurbishing the house was to make it suitable for Katie to live in independently in the future. She has an agreement that she will pay rent to her mum for the house, when her mum does move out. Her mum has supported the setup of this agreement to ensure that Katie is financially independent in the future, and allows her to plan for her independent living:

**“I don't have any plans to move out… I'll stay here, and then I'll pay her rent for staying here so she can afford to live somewhere else.”**

If she was to apply to university, she would also be restricted to attending education institutions close to hospitals that currently provide her care needs.

So, instead of moving away to university, she intends to live at home and study either through the open university or part-time at a local university.

Katie seems to accept that there are barriers to her having equality due to lack of funding from universities to make campuses accessible and provide the support she needs.

### Living alone

Our participants told us that:

* **Independent space** away from the world is important; it’s space where they don’t have to manage other people’s expectations.
* **Accessible housing** is important for independence but the expense makes it difficult to save money.
* **External support** is important for those who lived alone to avoid feeling isolated; support systems included friends, family, colleagues, and carers.

#### Martha’s journey with living arrangements

Martha loves living by herself because it gives her control over her environment, whereas living in a shared house exhausts her. She gets financial aid from her university and her benefits, however, she is having to compromise financially by living in an accessible apartment, meaning that she has less disposable income and cannot save money. This affects her mental health as she doesn’t feel like she has opportunities to unwind. Security is important to her.

Martha is at university and is happy to live by herself as it gives her control over her life and surroundings, which she believes better supports her condition. She feels that she does not have the same choice and control when living in shared accommodation. Martha enjoys living alone as she can relax more easily without having to manage the expectations of those she lives with, and she likes having her own space:

**“I think being visually impaired, [it helps for me to have] complete control over where everything is, which is very important. So, I know that if I trip over something, it's because of me, because I've left something out. It's not because one of my housemates has done it.”**

Living alone means that Martha doesn’t feel as self-conscious for needing the extra support her condition requires, such as a personal assistant:

**“Another positive thing as well, I don't feel as embarrassed about being supported by a personal assistant when I'm living at home, living on my own.”**

Martha highlights the importance of having an accessible home for her, such as easy access living and accessible security so she is comfortable and safe living alone. She has felt concerned in the past when answering the door, so having a secure home with accessible technology is important to her. Other aspects of her flat are also more accessible than previous accommodation, such as good lighting and an accessible kitchen:

**“[I] feel a lot safer, [as] there's an intercom. So, one thing that always worried me was opening the door because I couldn't see who was there, whereas now I can have a conversation with them and say, 'Who are you?' Which is really useful.”**

Financially she is better off since attending university as she has accessed financial aid as a student, and from her disability benefits. Her university has been helpful in arranging the support that she is entitled too.

**“I do a lot better financially, quite significantly better. I get my PIP which is really useful. As a disabled student I get a higher rate of maintenance loan, and I also get a significant bursary from the university and because I'm a disabled student I get a housing benefit. So, I do great. Being a student is wonderful.”**

She manages her own budget but struggles with infrequent lump sum benefit payments. She feels that with the excellent dedicated support she has received frrom the university, she is able to relax and enjoy being a student.

Although Martha is getting more income, her cost of living has increased substantially as she is having to live in accessible accommodation and is unable to save. She is having to compromise; either she lives somewhere accessible and comfortable, or that she has disposable income.

Martha also feels that her physical and mental health may be compromised as she is unable to afford to take holidays and unwind. She recognises that these extra costs prevent her from being able to live the life that she would be able to have if she wasn’t disabled:

**“Finding somewhere [to live] that was accessible costs more. Yes. I can afford it, but if I wasn't paying this much on rent, I could go on holiday more.”**

Martha’s financial security is important for her future planning as she is aware that finding a job after university can be difficult for all students, regardless of whether they are a disabled young person or not. She recognises that she has intersectional barriers imposed on her due to her sexuality and impairments, being aware of these barriers she feels pressured to save money and plan ahead. She is worried about the instability of her financial situation as she is reliant on Personal Independence Payments (PIP):

**“I don't have savings and that is one thing that I would really like to be able to do, because the fact is a lot of people find it hard out of university to find a job... and it would be nice to have something saved for when I finish uni and that's not possible.”**

#### Jessica’s journey with living arrangements

Jessica moved to a new area for work which meant that she left behind some of her support network. Although she is overall happy with the move and loves living by herself, the hassle of switching to a different NHS trust was enough to make her feel as if she should not have moved. She has faced discrimination from people who have said that she is too young to be disabled and had to go without her much needed medication for months. She values her independence but has support in place in case her fluctuating condition worsens.

Jessica lives alone in a remote area of the United Kingdom. Previously she had lived in London where she studied for her postgraduate degree. She moved as she had found a job in a local government. Moving caused Jessica to lose some of her support network from where she used to live. She also struggled with adapting to full-time work alongside moving house and starting a new job, initially she had doubts about whether this was the right choice for her:

**“That was like a massive change from anything that I had planned for or envisaged and involved moving a long way away from everybody I knew. And then also the transition into a full-time 9 to 5 job is huge for everybody, whether you consider yourself to be disabled or not, it's still exhausting and stressful for [anyone].”**

In addition, moving caused a huge upheaval for Jessica in terms of her medical care as she was required to change consultants. This was a very challenging and frustrating time for Jessica. There was an extra level of consideration that she wasn’t aware of when moving to a new area as a disabled person:

**“I would say probably apart from starting a job the biggest impact has been that I tried to change consultants and my whole medical set up; it just was a disaster. [It] was just really frustrating and soul destroying. I think [it] kind of comes down to the age thing and assumptions people make about you. So, there was an element of, 'You're 24, you must be fine.'”**

The process of changing consultants took 5 months which she attributes to NHS staff making assumptions about her conditions due to her age. She was left without the medication that she needs during this time as her medical records were not transferred within the NHS. She also had no guidance as to how transitions are handled. Jessica suggests that this experience may stop her from wanting to move outside her current area of the UK in the future.

Future choices about living accommodation may be affected by the extra effort she experienced around moving her healthcare. The situation made her feel down sometimes, so she was regretting the move.

She is otherwise very happy with her move. The new geographical area (such as climate; natural beauty; relaxed atmosphere) helps her to keep in good physical health and supports her mental health and well-being. Jessica also likes that the locals are friendly and she can afford to live by herself without the complications of having to share with others, like managing the household and her condition.

**“The people are really kind, really nice people. I also live by myself which is another thing that I've never done before but actually I think having full independence is quite good. It's worked out a lot better than I had anticipated.”**

One of the consequences of living alone does mean that if Jessica’s fluctuating condition worsens, it can be more difficult for her to function by herself, both physically and mentally, like trying to manage pain with her mood and wellbeing.

**“…One time when I was in a flare [sic] and I was in bed trying to go to sleep not knowing if I'd be able to move when I woke up, that is scary when you're by yourself, and there's nothing you can do about it.”**

**“…I think predominantly for me it's been a good thing and I've enjoyed [living on my own], but there are just those times when you're a bit like, 'What am I going to do in the morning if I'm still like this?”**

As a contingency, Jessica has a supportive friend who has access to her property if she needs help. However, Jessica believes if her condition deteriorates and puts her at risk in the future, she would be willing to live with other people to ensure access to support when she needs it.

## Experiences in education

The choice and support section of this report highlights the real-life experiences of disabled young people in educational settings. Experience of education varied depending on where the individuals were studying and how much support they were offered by the institutions. These experiences have been broadly grouped into two sections: choice and support in education, and unmet needs in education.

An individual’s experience of education has the capacity to make or break their careers, increase confidence in their abilities and either hinder or help them achieving their potential. With young people’s career paths increasingly including higher or further education, these institutions need to meet the needs of all their students regardless of disability.

### Choice and adjustments supporting education

* **University disability support** received from advice centres was mostly positive
* **Lack of awareness** from teachers regarding disability, disabled young people suggested that appropriate training would help
* **Limited choice** of education institutions with sufficient disability support

#### Melissa’s journey with education

Melissa felt that her choices were limited when she went to apply for colleges as only a limited number had the facilities that she required. She also felt that there was a general lack of awareness from staff regarding disabilities but she is required to study in mainstream institutions to gain the qualifications that she needs. However, she had a positive experience with support from her college to help her with her studies.

Melissa was left with a limited choice of colleges when her condition was taken into consideration. This had a negative effect on her self-esteem and left her feeling excluded.

**“I was given a list of the colleges that I could attend, and that made me feel, kind of, rubbish because I was like, 'Well, so many places don't want me.'”**

Melissa is at college studying health and social care. She started her course in the supported learning department, where she has additional support with her Autism spectrum condition. She has since began transitioning into education with reduced supported learning. In Melissa’s experience, some teachers in the mainstream setting haven’t been able to adapt to different ways of teaching and show a lack of support for disabled students.

**“…it's all well and good going to a mainstream college, but if you've got disabilities, you're just going to be stuck in with people who don't have disabilities, so then-, everyone learns in a different way.”**

Melissa plans to move back into supported learning where she feels better supported. However, in the future she’d like to study midwifery and needs to finish her studies outside of supported learning in order to achieve sufficient qualifications.

Melissa has experienced a lack of support from some teachers in a mainstream education setting and believes this comes from a lack of understanding and training on disability.

**“I think even mainstream teachers should have to go through some training to try and understand how people react differently to things.”**

#### Georgia’s journey with education

Georgia had an extended break between leaving her previous university and joining her current one. This time away from her established relationships at university highlighted the importance of friends and social life, and being able to build and develop her support network.

**“…I lost a lot of friends when I changed university, because I had two years out. I was at home with my mum and not in the circles of the eighteen year olds that I should have been.”**

Time away from her support network at university made Georgia realise how important these connections are. So, when she started her new university, she made sure to make some strong connections. She feels that she can speak openly to her peers about her condition and has received excellent support from her the accessibility team at her university.

Georgia values her support network at her current university as it is a significant part of feeling well supported, building her own resilience and confidence to succeed in her education.

**“I found a very close support network of some amazing people that I opened up to gradually over the first term of the first year, and they are all absolutely amazing. I say to this day that without them I don't think I would be able to do university. They are the reason that keeps me here on bad days.”**

The student support network Georgia has at university gives her the confidence to talk openly about her condition. In turn, she is keen to give similar support to other disabled students so they can also grow in confidence as they begin their university life.

**“I've started, recently, to become quite happy with telling people about my pain, because I talk to people within the university. I talk to younger students that have a similar thing, and try and support them in knowing that it's okay to come to university, and there is support out there. I think that process of me talking to people has given me more confidence to say it to other people.”**

Georgia receives lecture materials (notes and slides) ahead of her lectures to help her prepare, an adjustment which supports her condition and enables her to focus on the content in lectures. Although this adjustment is met, she still experiences negative attitudes from staff who assume she won’t attend lectures. This is frustrating for Georgia as she’s explained how this would benefit her and others accessibility needs.

**“You don't understand how much different a lecture is for me, it's so much more helpful and so much more educational if I can have my notes done beforehand… [but] it's always… going back to, 'But people are going to use it as a chance to skive off.”**

Georgia has had a positive experience with the accessibility team at her university. They have ensured she has the right adjustments which means she receives the right support in her lectures and they give her the confidence that she has equal opportunities to other students.

**“The accessibility team have provided things which mean that in lectures, you can't tell that I have a disability. I'm definitely not disadvantaged in lectures.”**

Georgia is worried she won’t have as much support when she moves into work. Although the accessibility team have been reassuring and given her the right information about her entitlement for support at work.

**“I am absolutely terrified at the idea of coming out of uni and all of these people who are so supportive. Part of me just feels like I shouldn't be asking for a flexible working policy and the things that are possibly out there. Because I feel like I'm not entitled to it...'”**

Georgia was not receiving enough support from her tutor and requested to change tutor. Since then, she receives one-to-one support and now feels she has equality.

Georgia aspires to work within the neuroscience field and hopes to continue into postgraduate studies to achieve her career goal. The accessibility team have given her career advice and helped her secure a work placement. She starts her work placement next year doing research for Parkinson's disease which is a step towards her career goal.

### Unmet support needs in education

* **Lack of education support needs** provided by university, either from lecturers or education staff, as well as poor university culture
* **Negative attitudes and behaviours** demonstrated by educational staff, such as assumptions of student laziness when requesting flexible lecture adjustments
* **Lack of empathy from staff** was experienced by disabled young people requiring support
* **Education and career goals negatively impacted** by unmet support, resulting in delayed exams, quitting education all together, and missing out on graduate employment opportunities

#### Kashif’s journey with education

Kashif has not had the support that he needs from his university, he feels that they very reluctantly offer to print off the slides he needs for lectures and expect him to walk across campus to pick them up.

Kashif is in his 3rd year of university studying business and accounting. He recently completed a 14-month work placement as part of his course and had a positive experience of work. Returning for his final year of university, Kashif explains that he has not had the correct adjustments or support from staff to feel equal at university.

He lives in student accommodation and needs the library on campus to do his work. However, his campus has inaccessible lighting and walkways which means it is not safe for him to use the library after dark. Kashif has a vision impairment, so the poor lighting and uneven footpaths mean he does not feel safe or equal to others getting around the campus.

**“…Right now if I walk across campus, I'm having to make sure I wear white trainers, put my torch on and just keep to the path that I know otherwise I'll walk into a concrete bollard, for example.”**

Kashif’s experiences of inaccessibility also extends to the teaching at university.

**“I can't see the lecture screens, so the university prints them out but they print them out for me to collect at [an alternative campus]... I'm like, 'This is a twenty to thirty minute walk away from me, and you want me to come and just pick up 3 lecture slides?”**

Kashif has not received the correct adjustments for learning, although the resources are there. Kashif has a notetaker for his lectures which allows him to feel more present and less stressed. However, Kashif was let down when he needed those notes for an upcoming exam. There were no notes or recordings of the lecture needed for revision which left Kashif feeling anxious and stressed.

The university was able to mitigate the exam but it delayed Kashif's graduation by six months, again causing strain on his mental health, particularly with a graduate job lined up after university. Kashif is left feeling penalised and unsettled about the situation without any acknowledgement or apology for the stress it has caused.

Kashif says he couldn’t have done so well at university or even got onto his placement without his university career advisor who has given him continuous support and is still in contact with him now. Kashif is looking forward to full-time work after university, he wants to save up for his own house and develop his career as a finance analyst.

#### Avery’s journey with education

Avery feels that lecturers and other support staff at their university assumed that they are lazy because they wanted them to be more flexible with them due to the demands of their condition. They also feel that they missed out with social opportunities as all extracurricular activities tend to be inaccessible for them and offer no online options. Avery’s negative experience at university led them to drop out after 2 years.

Avery studied Sociology and Applied Criminology at university but left after 2 years due to a lack of support and adjustments. The university staff were keen to keep their physical attendance high and were not accommodating when they needed adjustments if their condition flared up so they had to leave university.

Avery’s experience of inequality to other students included non-inclusive extracurricular events, rigid lecture times, accessibility on campus and attitudes from staff.

Extracurricular events were not accessible. With no online access, Avery was unable to benefit from these events like other students.

**“…any of these additional seminars, or these careers fairs, or where they'd get, like, relevant people to come in and give talks, that was all based on if you could physically be there and that was so difficult for me that it just wasn't possible. So, I just missed out on that entirely.”**

Lecture times were not flexible, and Avery faces assumptions as a young person that being young means being healthy but choosing to be lazy.

**“I would either sound like a lazy student or they would just assume that I'd been on a really heavy night and I just wasn't able to get in because I was hungover or something. Because people think of young people, oh can't get up early in the morning.”**

Avery was restricted by campus accessibility at university.

**“…you'd enter at the top and they'd be sloped down with stairs. So, the only wheelchair or stair-free access was the top row but as soon as you sat down, you couldn't see over the row in front of you, so there was no point in me even attending for that lecture because I couldn’t see anything.”**

Without the correct adjustments to access lectures or appropriate exam conditions, Avery was left with no choice but to miss their exams and wait to resit them. They had the right adjustments (e.g. their own room) at the resits, but at the cost of their grades. Resitting an exam means you can only get a pass grade.

**“…it was capped at a very basic pass level. So, that hindered my overall mark, which was a great shame.”**

Staff such as lecturers, tutors and disability support staff can often be encouraging and essential support for some of the disabled young people in this study. However, Avery had the opposite experience with one senior staff member suggesting that leaving university was a good solution for them.

**“…I had them say to me, 'If you're struggling to attend, I think you should drop out and attend Open University where, you know, your attendance isn't necessary.”**

**“They had really stigmatised this whole, 'If you don't attend physically, then you're a bad student.”**

The pandemic has pushed education settings to adapt to online learning quickly. This made Avery reflect on the adjustments they could have had to continue their education and highlights the lack of support they were given.

**“I'm… no longer at uni because I was having such issues attending, which is incredibly frustrating now everything's suddenly gone online for Covid and, quite obviously, they could have gone online before.”**

Ultimately, Avery chose to leave university but the inequalities they experienced left them with little choice.

Avery currently works part-time at a supermarket, feeling well respected and valued by their employer. In contrast to the inequality they experienced at university, Avery is positively supported in their role and flexible adjustments are made in response to their fluctuating condition. Avery also has opportunities to develop a career in their workplace.

**“Work was a really good supportive environment and I can get a career out of it as well. You know, it's an environment where I'm respected and valued… compared to being in education where I just seem to get lost in the system”**

**“I can do something that's more office-based or… have a sit down in the office for five minutes and do some work in there to do with something.”**

## Moving into employment

Employment was a very important theme for our participants as it is their path to independence in multiple ways other than just financial; they gain skills that are useful for their personal lives, make friends, and gain confidence in their abilities. However, employment is often harder for disabled people to access due to workplace discrimination,

* **Support from employment and career services** were positive experiences from those provided by the Job Centre and university career advice services.
* **Difficulty getting interviews** **and jobs** for appropriately skilled roles which fit career ambitions and support needs
* **Important support needs** were flexible working hours and being able to work from home
* **Openness at work** about being disabled and impairments or conditions led to increased support and adjustments in the workplace
* **Social groups with work colleagues** were a positive aspect of employment for disabled young people

#### Jennifer’s journey with employment

Jennifer is struggling to find suitable employment as she feels too overqualified for low skilled entry level jobs but not skilled enough for higher level jobs. She has received support from the job centre to find work but feels that she is not confident in interviews as she has not been able to experience one. Her plan is to go back to university and get work experience while she is there to help her find employment afterwards.

Jennifer recently left her university, after 2 years of her degree

course. She currently feels stuck in the job market; too skilled for low entry jobs and not applying for higher level jobs, as she does not meet requirements of work experience or have a completed degree.

The Job Centre have been supportive and understanding of Jennifer’s condition. Her job centre support worker has lived experience of disability and Jennifer feels they are more understanding than others, listening to her needs and filtering out job vacancies that were not appropriate to her.

Jennifer would like some legal advice about her disability rights and what employers are allowed to do when recruiting. This would give her confidence in job applications and interviews.

**“One thing I've never really quite been able to deal with, the law says you can't ask a disabled applicant what adjustments they need for the job, but employers still do and I would like someone to tell me how to respond to that.”**

Jennifer has little experience with job interviews because she often doesn’t receive a response from employers. Therefore, she has been unable to build interview skills and her confidence.

**“I was like, 'No one's responded to me, I've had nothing.' I didn't want it to feel like I wasn't trying because I was. It was just, I never had experience.”**

Jennifer plans to go back to university nearer to home, where she can commute. She wants to continue studying politics but she is probably going to have to repeat the second year to have sufficient grades to progress. After her recent experience of job searching, she’d like to gain some work experience while at university to better prepare her for a career.

**“I don't think I've learned much, more that just what the job world was like and it wasn't what I expected.”**

#### Adam’s journey with employment

Adam has had a positive experience at his workplace; he feels supported and valued and has friends on the team who he sees outside of work. He is open with his colleagues about his condition and feels that the majority are understanding. His job has allowed him to gain the skills and confidence he needs to become independent in the future. He feels very satisfied with his job.

Adam spoke openly about his condition at his interview which encouraged his employer to also have an open discussion with him right from the beginning.

By simply asking Adam about his condition, his manager was able to get a better understanding of how to best support Adam at work. Adam felt reassured and positive about his new employer, manager and colleagues.

**“…I'd got the position but [my new manager]… asked me to just explain how [Asperger’s] affects you in your day-to-day life, just so that he can make adjustments and, as an employer [understand] what can they to do support?”**

The support Adam receives from his manager and colleagues is an important part of his positive work environment. He feels they understand his condition and he has plenty of people to seek support from, should he need it.

**“All the staff that I work with…really support and understand [my] condition. They're always, you know, ‘if you need support, there is always someone there.”**

**“Some people really understand it and some people don't so understand it. What I usually tend to do is just not, not obviously work with them but just not-, if they're not-, if I support them and they don't support me, it has to work both ways, which sometimes it doesn't, but you just have to get on with it.”**

Adam says he feels 100% satisfied with his employer and is well looked after.As he is well supported and has learnt valuable skills, Adam gives his loyalty to the company and intends to stay with them for a long time.

**“I really do enjoy working for them and they've given me so much skills and confidence and they make you really independent.”**

## Conclusion

Independence looks different across disabled young people’s home lives, education and employment journeys. We discovered numerous barriers and enablers that affected young disabled people’s experiences of transitioning towards adulthood. Those barriers and enablers also impacted their feelings of independence and equality.

### Limitation of choice and accessible environments

Restricted choices across home life, education, and employment were a common barrier for disabled young people. Some had a strong sense of freedom and independence when they moved away from their family home. Accessible living costs more and it can be challenging for disabled people to find facilities that fully support their needs. This can lead to a restricted life, limiting their personal and professional lives and aspirations. Appropriate support, accessible accommodation and infrastructure enables disabled young people to experience equal opportunities and live the life they choose.

Disabled young people reflected on their equality and opportunities in an education setting. Due to a lack of disability related support and facilities, some left education or decided not to go. Those young people who had limited choice in their place of education felt ‘unwanted’ or ‘not good enough’ for most colleges and universities. This negatively impacts their confidence and future aspirations.

Disabled young students who were well supported in an accessible institution, had a positive experience of education. They were optimistic about fulfilling their academic potential and achieving their future career goals. The response to the needs of the disabled student is crucial. Attitudes of staff and culture of the education institution, flexible ways of learning and examination, accessibility of the campus and disability support provided were all important for an equal experience.

Disabled young people moving into employment have often had their confidence knocked previously from education. They have difficulty getting interviews and jobs for appropriately skilled roles that fit their career ambitions and support needs. Provision of appropriate support and flexible working from employers is crucial for disabled people to find and stay in work. We found that openness and support around disability led disabled young people to feel secure and satisfied in their jobs.

### Financial security

Besides taking on the extra financial responsibilities of adult life, disabled young people face extra costs as a disabled person. Accessible living costs more, and often means leisurely activities are scarified as a result.

Higher costs to live alone compromises living arrangements for disabled young people, particularly when they can better manage their condition living alone.

**“I think being visually impaired, it has complete control over where everything is which is very important. So I know that if I trip over something, it's because of me because I've left something out. It's not because one of my housemates has done it.”**

Martha

Some disabled young people have had to adapt to shared accommodation when it isn’t suitable to their needs. This can create extra efforts such as repeatedly explaining a condition to housemates or engaging with household chores at unsuitable times for fluctuating conditions. Disabled young people can be left feeling misunderstood and uncomfortable in their own home which can negatively impact their overall wellbeing. Some have stayed at their family home despite wanting to find a place of their own. The extra costs of being disabled puts an extra strain on affording to move out, let alone the added cost for accessible facilities. Although it costs more, our research tells us that moving to a more accessible home results in a better quality of life for young disabled people.

This group of disabled young people are mindful of working harder to build job security and a successful career to feel financial security. There is added caution when considering fluctuating conditions and unpredictable circumstances that often come with disability. Creating equal opportunities

### Attitudes

Many disabled young people experienced negative public attitudes that were specific to their age group. They believe there is a general lack of awareness and understanding about disability. They report experiences of the public making assumptions and stereotypes about disabled young people faking their condition or being lazy.

These attitudes can extend to education staff lacking trust in young people and assume laziness if a disabled student would request lectures online or materials in advance. There is a general culture in some education settings for upkeep of physical attendance and reluctance to embrace more flexible ways of learning. These negative attitudes prevent students from progressing and fully engaging with their studies and student life. Limited expectations of educational attainment and career prospects from educational staff discourages disabled students and led some students to leave education.

By the time disabled young people are moving into employment, they have often already had their confidence knocked by negative attitudes in education. They then face a limited job market and sometimes experience negative attitudes and lack of awareness around disability employment.

Improved understanding of disability facilitates better support for disabled people from a young age. Empowering and encouraging staff nurtures the needs of disabled students and supports their aspirations. There are indications of cultural shifts since the coronavirus pandemic, which has had a positive affect on accessibility. Better support means disabled young people are more likely to have equal opportunities in education and employment and go on to achieve their goals.

### Support

Disabled young people rely on informal structures such as friends and family who understand their condition and support needs. For some disabled young people, it is important for them to live with friends and family to feel supported day to day. More formal structures of support can also be important for independent living. This includes medical professionals, support workers and disability staff in education. These overlapping support structures work together to create an interconnected network of support. Having the right support enables disabled young people to feel more independent and live the life they choose.

Disability staff teams were not offered at all colleges or universities for our disabled young people. When there was access to disability staff, some staff did not have the right knowledge to help and some lacked empathy. Education and career goals were negatively impacted by this unmet support. This became apparent with delayed exams and some disabled young people even leaving education.

Disabled young people reported that a positive aspect of education and employment is being a part of social groups with colleagues. When colleagues and employers were open to understanding conditions and encouraging of flexible working, disabled young people felt positive about their place of work. Those who felt supported at their workplace reported a sense of loyalty.

### Independence

Home life was directly related to themes of independence and moving into adulthood, regardless of each individual’s living arrangements. For some young people, this meant having parental support (both emotionally and financially) while they develop the self-confidence and knowledge to live independently. This enables them to work full-time and enjoy leisurely activities without having the practicalities of running a home.

For those young people who have moved away from their family home, they felt that having their own space suited their needs and allowed them to live more independently. For those who need accessible living, this is often a more expensive option. This creates a barrier for many disabled young people finding independence in their own home.

Societal structures and support needs which enable an independent life come in many forms. From parental support and housemates or friends, to more formal networks such as the structure of lectures, course materials and exams, as well as approach of education staff and disability support officers. Or the inclusive, proactive attitudes of managers and colleagues in the workplace.

Networks and relationships frequently work both ways with individuals and organisations supporting and depending on each other to create a fairer and more equal society. These connected structures allow individuals to live the life they choose, in their own unique way, reinforcing that interdependence is crucial to leading their own independent lives.

This group of disabled young people show remarkable resilience and ambition, despite the barriers they face. They have become fiercely independent despite their lives frequently requiring extra effort and cost to navigate societal barriers. We’ll continue to follow their life journeys as they transition into adulthood and find their own sense of independence.

**“You can make something of yourself. You can prove that you can do something, regardless of your disability and stuff, because that's the thing that work taught me, like, despite some aspects that were difficult during work, I proved to myself I can achieve something for my-, regardless of my disability.”**

Kashif

**“I was forced to become independent incredibly quickly and it helped prove to myself my capability of being able to be independent despite having disabilities and, you know, despite having to get through all these, like, extra obstacles. They've shown me that I can still do it on my own”**

Avery

**“[My job has] given me a lot of confidence because it's made me become more skilled. Like, when we make food, I can make food at home. Where we do cleaning and that, like, deep cleans of the kitchen and all surface areas, like toilets and that, I can do that now.**

**That, for me, has given me a lot more confidence in thinking that I can live independently, because the skills that I've learnt from work I can now implement at home, which is good.”**Adam

## 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 second 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

#### Wave 2 interview journey

All participants took part in an online in-depth interview with our Scope researcher, Sally Field. In the interviews, we 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, work, and financial security.

**Total participants 18**

**Age** (at wave 1)

16 to 177

18 to 195

20 to 216

**Gender**

Female12

Male6

**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: Summary of themes from Wave 1

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.

The main themes from the interviews were explored, looking for common barriers and useful or positive solutions.

#### Choice, control, and independence for social and home life

* Participants talked about lack of choice and control over their social lives; such as venues they could meet at, and home life; where they can live and with whom.

#### Confidence and independence gained from friendships and relationships

* Our young people highlighted the importance of support from their close friends and family. These included work colleagues that had supported them with gaining skills and responsibilities in their work.

#### Equality and opportunities in further and higher education

* Equality was not felt by our participants regarding opportunities in education as they were limited to a small number of institutions which could give them the support that they require.

#### Aspirations and experiences in career and employment journeys

* Our participants are ambitious and have aspirations for their future which they are working towards. These are important on their journey to independence.

#### Financial security

* Being financially secure and having confidence to handle finances responsibly plays a big role in feeling independent. Parents were a big financial support as were any benefits they received, however, extra costs for some were considerable such as needing accessible accommodation

### Appendix D: Contextual research

### The disability price tag

Existing Scope research shows that disabled young people are more likely to come from disadvantaged backgrounds and tend to lag behind non-disabled people in educational, occupational, and social outcomes in adulthood[[3]](#footnote-4). Disabled young people are more likely to have left education before the end of year 13. They are more likely to end up unemployed once they leave school and are less likely to attend university. Disabled young people are less likely to be in managerial or professional roles at the age 25 and are more likely to be doing semi-routine and routine occupations.

Government led research into the disability employment gap has shown that there is a clear divide in the employment levels of disabled and non-disabled individuals, with disabled individuals more likely to be unemployed. Young disabled people are more likely than non-disabled to not be in education, employment, or training often because their needs are not being met by employers or educational institutions. This gap widens with age going from a gap of 20% for those aged 18- to 24-years-old, to 33% with 50 to 64 years-old meaning that as our participants age they potentially face even more barriers to getting into work[[4]](#footnote-5).

Disabled people want to be seen as more than their impairment. Attitudes and assumptions can be barriers or enablers to disabled people being able to live the life they choose. Negative attitudes from others negatively impacts disabled people’s feelings of self-worth and confidence1.

Finance was a barrier to independence for these young people, more so than usual for their age group. We know that disabled people experience extra costs which for young people mean that they often can’t afford to move out of their parents’ home and have barriers which prevent them from living with their partners.

Scope research shows that being able to get into and stay in work is a significant enabler for disabled people achieving independence. It is not just about the money, respondents who are in work said that they felt confident, liked contributing to society, and maintaining social connections[[5]](#footnote-6).  
Making connections[[6]](#footnote-7)

Scope wanted to better understand disabled young people’s lives and what’s important to them. It helps to understand how to support disabled young people and what to do next.

Scope asked researchers and disabled young people from iHuman at the University of Sheffield to find out what support disabled young people need to live their lives in ways that meet their hopes and aspirations [[7]](#footnote-8).

This research allows us to:

* Understand how disabled young people can best live in the world.
* Explore disabled young people’s resources and relationships.
* Understand the whole of a disabled young person’s life in an interconnected way.
* Recognise that disabled young people’s lives continuously evolve and change.
* Highlight those resources and relationships that might have been ignored in the past.

The main issues that emerged for disabled young people:

* Emotions and Identities
* Digital Lives and Mental Health
* Education and Expectations
* Work and Aspirations
* Human and Animal Relations
* Belonging and Mobility

The data focuses on the importance of interdependency. Interdependency represents us all connected within a web of relationships, groups and communities. The data shows that autonomy was closely related to the support of others and independence is tied to human interconnections including friends and family. Living life as independently as possible is an essential ambition for young people, but it doesn’t mean doing everything alone.

### The coronavirus pandemic

The coronavirus pandemic began just as we started our second interviews with disabled young people. As such, we have little understanding of how the pandemic has affected our participants. Although there are some insights presented here, our next report will be able to highlight the effects of the pandemic in much more detail.

Research conducted during the pandemic by the Council for Disabled Children[[8]](#footnote-9) has highlighted the effect that lockdowns have had on disabled children and young people. They felt they had missed out on practising their social skills or felt lonely and isolated, however, many on the participants appreciated the time at home with their family and the opportunity to learn how to connect with their friends and relatives online. Those with social anxiety welcomed the time away from other people, with video calling being easier than face to face meetings for some. Pets were valuable for helping the young people through the lockdowns.

During lockdowns there was not enough support for families of disabled children at a time when it was most needed, essential appointments were cancelled or delayed, and announcements about Covid rules were often confusing for disabled young people. Online education was challenging as lessons were often not adapted to those with SEND and others found that it wasn’t engaging.

The pandemic has disrupted education and career goals for many young people. A change in assessments and grading systems meant that many students were not achieving the qualifications they had hoped for or needed to progress. Finding a job also became more difficult as there were fewer opportunities during the pandemic. Some participants told us how their employment or job search had been paused whilst things were so uncertain with the pandemic.

Disabled young people have had a particularly tough time during the pandemic. Some participants recently moved back to their family home because they needed support whilst isolating during lockdown. Some have described this as a step backwards from independence and adulthood.

It's not yet certain how permanent these changes will be, but we will consider the effects of coronavirus for disabled people in the coming waves.

'Our lives, our journey' has been able to continue throughout the pandemic with online interviews.

**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.

For more information please contact:

ourlives.research@scope.org.uk

020 7619 7376

Research

Scope

Here East Press Centre

14 East Bay Lane London, E15 2GW

@scope

scope.org.uk

SC0903 Scope is a registered charity, number 208231 and is a company limited by guarantee number 520866 (England).

Registered office: Here East Press Centre, 14 East Bay Lane, London E15 2GW. Copyright Scope February 2023.

1. Some individuals want to stay anonymous. We have replaced these individuals with a letter to protect their identity. [↑](#footnote-ref-2)
2. Scope (2021) ‘Making connections’ <https://www.scope.org.uk/campaigns/research-policy/making-connections-disabled-young-people/> [↑](#footnote-ref-3)
3. Scope (2019) ‘Disability price tag’ https://www.scope.org.uk/campaigns/extra-costs/disability-price-tag/ [↑](#footnote-ref-4)
4. UK Government (2021) ‘The employment of disabled people 2021’ <https://www.gov.uk/government/statistics/the-employment-of-disabled-people-2021/the-employment-of-disabled-people-2021> [↑](#footnote-ref-5)
5. Scope (2018) ‘Independent, Confident, Connected’ https://www.scope.org.uk/campaigns/independent-confident-connected/ [↑](#footnote-ref-6)
6. Scope (2021) ‘Making connections’ <https://www.scope.org.uk/campaigns/research-policy/making-connections-disabled-young-people/> [↑](#footnote-ref-7)
7. We spoke to 39 disabled young people, aged 18 to 36, in online interviews and focus groups. They told us what they thought they have needed while growing up to live a full life. [↑](#footnote-ref-8)
8. Council for disabled children (2021) ‘Lessons Learnt From Lockdown: The highs and lows of the pandemic's impact on disabled children and young people’ https://councilfordisabledchildren.org.uk/resources/all-resources/filter/inclusion-send/lessons-learnt-lockdown-highs-and-lows-pandemics [↑](#footnote-ref-9)