TOGETHER TRUST charity
Disability, care and education

National Star
Realising the aspirations of people with disabilities

What comes after education?

Transitions to adulthood for disabled young people







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Executive summary

Too many young people with disabilities face a difficult – and often bleak – future once they leave education. That step into adulthood, which marks years of preparation and development, should be a time of celebration and optimism. Sadly, for many young people and their families and carers it is a time of crisis and anxiety.

This report, based on research by charities National Star and the Together Trust, reveals the incredible obstacles young people and their families and carers face. It involved hundreds of parents, carers and young people to better understand their experiences, emotions and needs.

Young people with disabilities have the same aspirations as their peers. They want to choose where they live, what they do and how they fill their days. This report shows that instead they are not living where they want, experience loneliness and isolation and wait too long for the right support.

The adult social care system is so broken that it is having an incredibly detrimental effect on young people with disabilities, especially those who access specialist education.

Lack of appropriate services, housing and opportunities results in these young people being stuck at home with little or no community access and causing incredible stress and anxiety for the young person and their loved ones.

Young people with disabilities have so much to give to society. By excluding them we not only waste their talents and sentence them to unhappy and meaningless lives, but we, as a society, are all the poorer without their contribution.

Key findings



More than half of young people are not living where they would like to be, though the majority are happy where they live.

4 in 5 parents did not know what was supposed to happen when their son or daughter left education.





2 in 3 parents and carers said that their son or daughter didn't get the outcome they wanted.

3 in 4 parents and carers said that all organisations did not work well together.





Almost half of young people didn't have a plan for leaving school or college.



More than half of young people felt worried about leaving school or college.

More than half of parents and carers were not kept up to date if plans changed about their son or daughter's transition from education.





Less than half of parents and carers said they felt partially or fully listened to.

2 in 5 young people didn't feel listened to when preparing to leave school or college.







Recommendations

Young people have the right to lead a fulfilling life. They require appropriate support and activities to be available to them within their community. Our recommendations cut across the areas young people and their parents told us were important to them, and which require our immediate attention.

Ensure choice through flexible and sustainable funding – Central government, local authorities and providers must work together to create flexible long-term services. Young people with disabilities and their families need to be at the heart of this process to ensure that services deliver meaningful outcomes and focus on what matters most to people. Young people experience a lack of choice over where they live and who they live with and how they lead their lives. Young people should be able to choose to live in their local area or 'out of county' depending on what best meets their needs. Where young people are unable to lead on these decisions, families and carers should be encouraged to proactively advocate on their behalf and be heard.

Put young people at the heart – All services need to be shaped by the voices of those with lived experience. Young adults with disabilities must at the heart of all planning. That will result in us delivering outcomes that matter to young people and their families and carers. The young person needs to be at the centre of planning transition into adulthood. That process should be consistent across England and transparent for young people and their parents/carers to navigate. This will reduce young people's fear of the future, develop a clear pathway for their continued success, and provide information on their rights and needs to those who will support them in the future.

Access to work and reforming the benefits system – Employment brings many benefits to young people with disabilities, their families and the economy. The current benefits system penalises people with disabilities who want to work. For many, getting paid work will make them poorer and places them in an untenable position of choosing between work and state support. The benefit system needs reform to support young adults with disabilities into the workplace including those who will require a job mentor/support and reasonable adjustments. Access to work is underutilised and not understood by employers or by working age adults with disabilities. Reform is needed to create an easily accessible process to support employers and those seeking work. Those with life-long diagnosis and disability must be recognised, they will not get better or be cured. The immense pressure and fear that continual reassessment places on people with disabilities cannot be underestimated. The guarantee of legacy benefits needs to be re-enforced and communicated to ensure that disabled adults who want to work can do so and those who are unable to work are not labelled as 'scroungers' off the state.

Ensure regular access to meaningful activities – Paid or voluntary work is often unsuitable for some young adults with disabilities. Those young adults need access to regular social and community activities to live meaningful, fulfilled lives. There is a huge demand for activities and community services which is unmet. Meaningful services that are regulated and funded appropriately should be enabled, providing community inclusion and engagement. Services need to be driven by the users themselves and their families. Providing regular activities will promote physical and mental wellbeing for disabled adults and can allow family members who have become full-time carers to potentially return to work themselves.

Find innovative solutions to challenges – Local authorities should proactively seek collaborative and innovative housing solutions that involve young people, parents and the community in the design. Partners and commissioners need to be brave and not so risk adverse. Innovative and creative approaches for all services, not just housing, will help us find solutions that matter.

Start planning early – Transition planning should start early, with children's services working in partnership with adult services several years before transition to enable the development of appropriate adult provision and ensure future budget planning both locally and from central government.

Support to access university – Further Education SEND experts should collaborate with universities to support seamless transition from further education to higher education for those with disabilities and complex needs. Systems and funding need to be made available to promote collaborative partnerships to ensure young people have equality to access higher education and successfully achieve their aspirations.

Follow the law – Statutory guidance (such as the SEND Code of Practice 2015) must be followed to enable all young people to contribute to their own transition plans. Local authority processes should be reviewed to make sure that the young person remains at the centre. This should not just be a case of listening to the young person and their family but allowing them to influence their future, which is their right, as it would be for any other young person.

Access to advocacy – We recommend introducing an "active offer" of independent advocacy for children, young people with disabilities, and their families. Access to independent advocacy should be extended to support children and young people with disabilities through key transition points (e.g., starting or leaving school), post–16 pathways, and supported internships). Advocacy should also include referrals to services such as SENDIASS and therapy, ensuring support for those without an Education Health and Care (EHC) plan. Additionally, the government should collaborate across departments to improve employment and training opportunities for young people with SEND.

Keep young people safe – Ensure that no young people with disabilities live in unregistered accommodation without proper oversight from regulators. Implement the recommendations of the Child Safeguarding Practice Review Panel for children living in residential settings (Hesley report) and ensure high quality joint inspection by Ofsted and Care Quality Commission (CQC).

Outcomes

All partners have a part to play in making the UK the best place for young adults with disabilities to live and work.

We want to see a society which provides equity and opportunity for all young people with disabilities. We believe our recommendations will:

1. Hold local authorities and statutory partners to account by requiring them to follow the law (such as the Children and Families Act, 2014), and adhere to timelines.

2. Ensure every young person has a person–centred transition plan, started early, which is driven by their needs and choices, rather than by costs.

3. Put all partners around the table to collaboratively plan with a young person what they want their future to look like, with shared responsibility.

4. Generate capacity within the voluntary sector through realistic funding streams and lower the risk of high quality providers quitting the sector.

5. Ensure continuity in relationships for young people as they leave education and enter adulthood.

6. Prioritise post–16 support and put it back on the agenda for government reform.

Forward ⟆ one family's journey

We were so very proud of our daughter Daisy when she left education at age 21. She had attended a specialist further education college as a residential student. During her time at college, she was transformed from a teenager into an independent and confident young woman. Daisy moved into residential care after college, but we had to remove her due to serious concerns about the care and support she was receiving. She remains at home though she still dreams of being able to *"live in a house with friends, but still see mum and dad"*.

Daisy happily attended a group based in the community, but that closed due to funding and the pandemic. She moved on to a different group which was part of a college. Then, without warning, it also closed due to funding. There is a severe lack of alternatives where we live. The local authority provides just two day centres. Daisy has tried both, but neither are suitable for her. Why should day centres, with a very broad mix of ages, be the only alternative for her after education?

Daisy needs structure and routine. While we have some private groups in our community, they all struggle with funding. Some don't accept wheelchair users. Others don't provide personal care. We have become more and more responsible for Daisy's care and activities. We could not get respite. Daisy was unhappy. We were exhausted. It came to the point where, in my darkest moments, I thought of taking Daisy to social services and saying *"here she is, you look after her 24 / 7. I can't do this anymore"*.

We love her so much and we would do anything for her, but you can feel alone and that no one is listening. All those independence skills Daisy learned at college slowly ebbed away. It was heartbreaking to watch. There have been some glimmers of hope. Daisy can now access respite, where they understand her, and she feels she can be herself. It provides us with the rest we desperately need. She also attends activities two days a week, but that has been a difficult fight.



Daisy deserves more.

She has so much to give but society doesn't see her potential.

They only see her as an expense, what it costs to provide her care and support. I constantly worry about Daisy's future. Why shouldn't she be able to live where she wants, meet her friends and do the activities that bring her joy?

This report tells the stories of parents like us and young people like Daisy. It highlights how the system is letting down our young people and what needs to be done to ensure adulthood is meaningful and happy, not one crisis after another. Isn't that what every parent wants for their child?

Sharon and Carl,
Daisy's parents

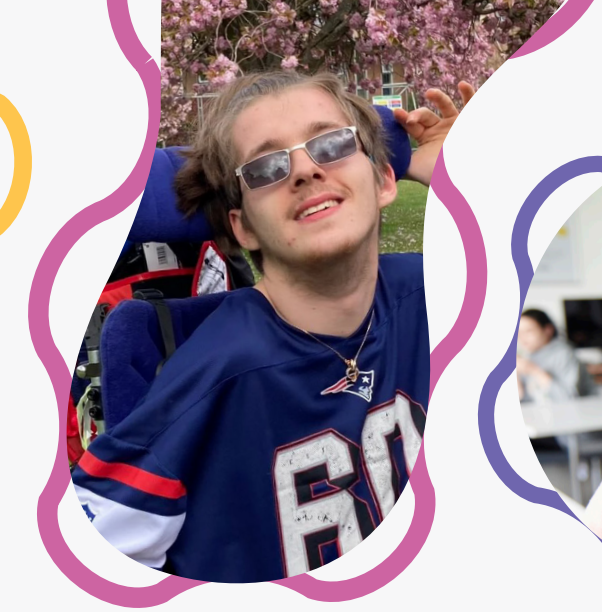




Introduction

A crucial milestone of adulthood is leaving education. **This report offers a glimpse into some of the obstacles young people with disabilities face as they leave education and transition into adulthood.** It draws on insights from surveys conducted with young people and parents and carers, with the aim of better understanding their experiences, emotions, and needs as they embark on the next phase of their lives.

Our charities, the Together Trust and National Star collaborated on this research project, which was started in 2023, to better understand the obstacles that exist and prevent young people with disabilities from having meaningful adult lives. We were motivated by our experiences as specialist education providers and practitioners, and our observation of detrimental patterns which leave young people and their families without the support they need.







We know from existing research that the things young people generally say they value include high–quality education, good career opportunities, mental health support, access to social relationships and community involvement, the opportunity to express themselves creatively, the opportunity to learn about and advocate on social justice issues and climate change, digital connectivity, and their own independence.

Our research shows that disabled young people broadly want access to the same opportunities, and care about similar issues as their peers. But it also shows that they face many more obstacles, and that many young people with disabilities are not living where they want to, experience loneliness and social isolation, and wait far too long for the right support.

While the need to get transitions right is obvious, what needs to be done to improve the experience remains unclear. In the past few years, we've had the SEND Green Paper, the Disability Action Plan, countless consultations, pilots and working groups.

This report is an attempt to re–orientate the policy landscape towards what young people and their families say is important to them, providing recommendations that we believe directly address what we've been told.

With that as a starting point, **we've come up with a transition roadmap geared towards government, local authorities, education and social health providers.** Within this report, there are practical actions every professional could take to ensure they are listening to and responsive to the needs of the young people they support.

Finding 1

Young people do not feel listened to

"I just feel frustrated, unsupported and like I am forgotten." – Young person, 21

"We just needed someone to help us with the transition. We were left to sort out everything, and we still don't know what's available in our area." – Parent

Before we can consider how to improve the process, we must first know how young people feel about their transition to adulthood, and how fulfilled their adult lives are.

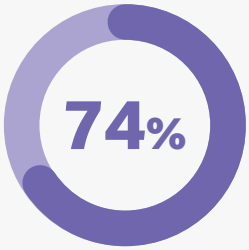
Too often young people don't feel listened to as they plan to leave education (39%). This is despite statutory guidance (the SEND Code of Practice 2015) explicitly stating that *"as young people develop, and increasingly form their own views, they should be involved more and more closely in decisions about their own future".* Most of the young people we spoke to had already left school (72%), and some said that they were leaving school in Summer 2024 (7%). The rest were in college, further education, or had finished education completely. The cohort of young people we spoke to should have been actively involved in discussions about their adult life, and yet many of them weren't.

Participation of young people in decisions that affect their lives promotes autonomy, empowerment, and self–determination. Research has shown that where young people are actively involved in decisions about their future, they are more motivated and have better outcomes. The UK has ratified two international treaties which advocate for this – the United Nations Convention on the Rights of Persons with Disabilities, and the Convention on the Rights of the Child. It is unacceptable that so many young people with disabilities feel that they are not being listened to over their next steps into adulthood.

Guidance is clear that from year 9, 'preparing for adulthood must be a focus of education, health and care plan reviews', and that 'for teenagers, preparation for adult life needs to be a more explicit element of their planning and support'. Yet a startling number of young people told us that they didn't have a plan in place for leaving education (45%). There are two possible explanations for such a figure – that there is no transition plan for some young people with SEND, or that young people themselves are not aware of what is being planned for them. The full picture likely includes both scenarios. Both explanations are unsatisfactory. Statutory guidance is clear. For every young person there should be a plan, and that plan should be built around the views of the young person.

One finding from our survey was that young people who said they had a transition plan were more likely to report being listened to than those who did not.





Young people with a transition plan



Young people without a transition plan

There are a range of negative outcomes associated with not routinely being listened to. There is the risk that where young people's views are not properly considered, the services they receive may not align with their needs. Not being listened to can result in feelings of worthlessness and low self–esteem, confidence issues, anxiety and depression. Lastly, for young people with disabilities, a recent Icelandic study has shown that exclusion from decision–making intensifies feelings of isolation and loneliness.

It is also true that parents and carers play a crucial role in supporting young people to make decisions about their future and should be consulted as part of transition planning. Yet less than half of parents and carers who responded to our survey (46%), said they felt partially or fully listened to. Often, parents could point to one professional who had gone above and beyond to try and support their family and described a system where obtaining a successful transition was largely down to luck.

Shockingly, parents and carers told us that they were worried that their child would end up living somewhere unsafe or without proper support unless they became full–time advocates. **One person we spoke to said:**

"I suffered a career breakdown and later my husband had a heart attack. The first specialist placement we had broke down in three months after being found guilty of neglect during a S.42 investigation. The other specialist placement was a 3.5–hour drive away. Our daughter wants to be with family but there is nowhere suitable."





All parents and carers wanted to see their son or daughter in an environment where they were thriving, but the absence of support, respite care, and appropriate provision meant they were often left to juggle it all, sometimes with negative effects to their own physical and mental health, jobs and relationships.

What was also clear from our findings was that the impact of institutional abuse and neglect, and the fear of it happening, is creating distrust within the system. As one carer said, *"there are no clear paths for young people with SEND, and the horror stories we see in the press about the abuse of young people in care homes is frightening".* Regulators, government, and providers must ensure that young people are kept safe from harm, and the concerns of parents and carers must be routinely listened to and acted upon.

Recommendations:

Follow the law – Statutory guidance (such as the SEND Code of Practice 2015) must be followed to enable all young people to contribute to their own transition plans. Local authority processes should be reviewed to make sure that the young person remains at the centre. This should not just be a case of listening to the young person and their family but allowing them to influence their future, which is their right, as it would be for any other young person.

Keep young people safe – Ensure that no young people with disabilities live in unregistered accommodation without proper oversight from regulators. Implement the recommendations of the Child Safeguarding Practice Review Panel for children living in residential settings (Hesley report) and ensure high quality joint inspection by Ofsted and Care Quality Commission (CQC).

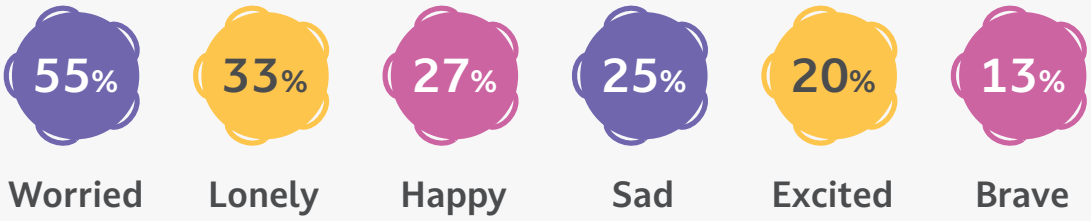


Finding 2

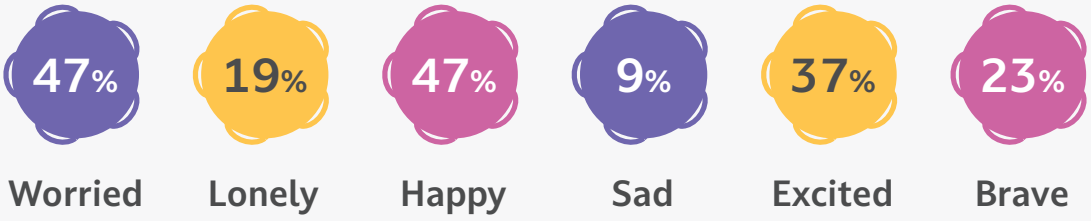
Young people feel worried about leaving education

Our survey findings show that young people feel worried about the transition process (55%). One in three said that they felt lonely (33%). While it is normal for young people to feel nervous about significant transitions, such as leaving education and stepping into adulthood, the high percentage of young people reporting feelings of loneliness during this transition is concerning.

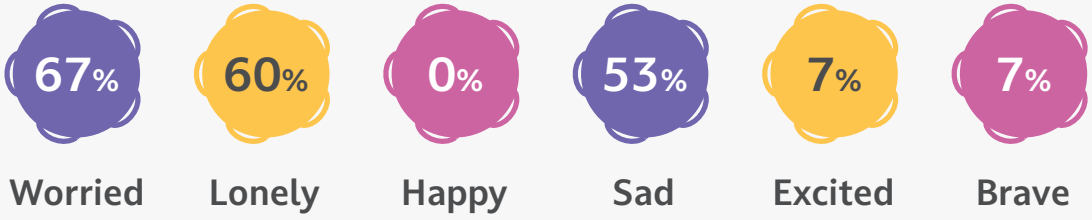
Total responses:



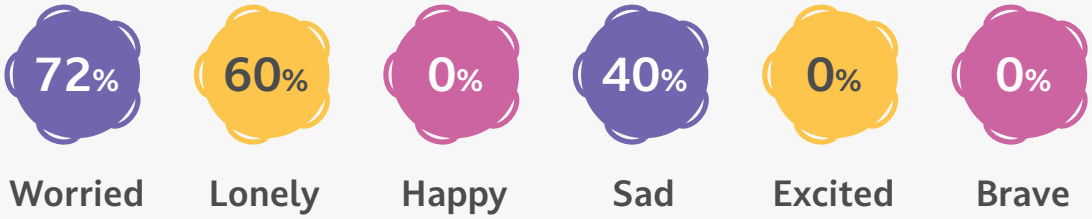
Young people who had a transition plan and felt listened to:



Young people who had a transition plan but did not feel listened to:



Young people who did not have a transition plan and did not feel listened to:



While young people with a transition plan experienced a lower prevalence of negative emotions overall, our findings clearly indicate that **the most important factor is whether young people feel that they have been listened to.** Where young people feel listened to, they are more likely to feel excited or brave about leaving education.

Some young people told us that they experienced other emotions related to leaving education. In order of occurrence, these were: **scared, frustrated, apprehensive, frightened, that they were not important, and suicidal.** We believe that every young person leaving education should feel excited about the future that lies ahead.

“I am scared that I won’t be able to cope with life anymore.”

Preparation for transition to adult life should be taking place both in school and at home, yet data from our survey shows that the vast majority of parents and carers don't know what to expect as their son or daughter leaves education. Often, there is a significant gap in communication and parents and carers are turning to each other to fill in the blanks and offer support.

Because of the uncertainty, it is hard for parents to accurately communicate with their son or daughter about the future when so much is subject to change. One parent working as a professional SEND Advisor told us that *"professionals were generally quite knowledgeable, but only about their own area, which inevitably leads to gaps. Other parents ahead of me filled those gaps in."* It is unsurprising then, that 3 in 4 parents and carers (76%) said that all organisations did not work well together.

The gap in communication exists between professionals too, with many parents explaining that services do not routinely talk to each other, meaning that every time they interact with a new professional, they must explain their son or daughter's history again, as part of a merry–go–round between relevant professionals.

It doesn't have to be this way. **More transitions should look like this:**

"The key to it all for her transition from college into supported living was the collaboration between all parties involved. College was especially supportive and attended all our (online) meetings with social care, the housing provider and the care provider. There also weren't any barriers to our parent commissioning the young people's home. Everyone was on board, supportive and for the most part did their part in a timely manner." – Parent

By closing the communication gap, planning early and getting all partners around the table to plan a transition properly (including young people and their families), young people's fear of the future will be mitigated, and parents and carers will feel more confident.

Recommendations:

Put young people at the heart – All services need to be shaped by the voices of those with lived experience. Young adults with disabilities must at the heart of all planning. That will result in us delivering outcomes that matter to young people and their families and carers. The young person needs to be at the centre of planning transition into adulthood. That process should be consistent across England and transparent for young people and their parents/carers to navigate. This will reduce young people's fear of the future, develop a clear pathway for their continued success, and provide information on their rights and needs to those who will support them in the future.

Start planning early – Transition planning should start early, with children's services working in partnership with adult services several years before transition to enable the development of appropriate adult provision and ensure future budget planning both locally and from central government.



Finding 3

Young people need access to meaningful activities

One of the main things we aimed to capture with our survey was what activities young people themselves saw as worthwhile after leaving education. The responses were extremely varied, but broadly fell into three categories: quality of life, employment, education and training, and hobbies.

Quality of life included seeing friends, living in the right place and travelling. Under employment, education and training young people listed access to work, further study, university and apprenticeships. Hobbies listed included a wide range of activities from singing and reading to campaigning and advocating for people with disabilities. Every individual, regardless of their needs, has activities which give them a sense of enjoyment and satisfaction and are crucial for their mental and physical wellbeing. Seeing and spending time with close friends ranked consistently high.

In the UK 'disabled adults report having little choice over their free time compared with non–disabled adults'. Some of the reasons for this include inaccessible public spaces, transport systems, and recreational facilities, social exclusion, stigma and economic disparities which can restrict options for leisure. Ultimately, it is essential that wherever young people live, they are provided with the opportunity and support to continue to do the activities that they find meaningful into adulthood.

Article 30 of the United Nations Convention on the Rights of Persons with Disabilities promotes the right of disabled people to take part on an equal basis with others in cultural life, and to participate on an equal basis with others in recreational, leisure and sporting activities.

"I want to learn how to drive, get a camper and then travel the country on my own. My mum says it's probably to escape people as I'm selective mute and autistic."

Some parents and carers who responded to our survey told us that meaningful activities were especially important, as their son or daughter experienced anxiety and pressure related to working. The role of the charity sector and the value of the community services they offered was also a common theme – one parent said that opportunities for participation in a *"forum by Mencap and the opportunity for my son to attend a local Learning Disability Forum was useful".* It is vital that local authorities' "Local Offer", which summarises activities available for young people in their local area, is accurate and easy to access in language and layout, and that opportunities for in–person connection exist following a decline during COVID–19.

Recommendation:

Ensure regular access to meaningful activities – Paid or voluntary work is often unsuitable for some young adults with disabilities. Those young adults need access to regular social and community activities to live meaningful, fulfilled lives. There is a huge demand for activities and community services which is unmet. Meaningful services that are regulated and funded appropriately should be enabled, providing community inclusion and engagement. Services need to be driven by the users themselves and their families. Providing regular activities will promote physical and mental wellbeing for disabled adults and can allow family members who have become full-time carers to potentially return to work themselves.

"My favourite thing to do is to walk my dog, read books with my screen reader's help, watch TV, and write my own poems."

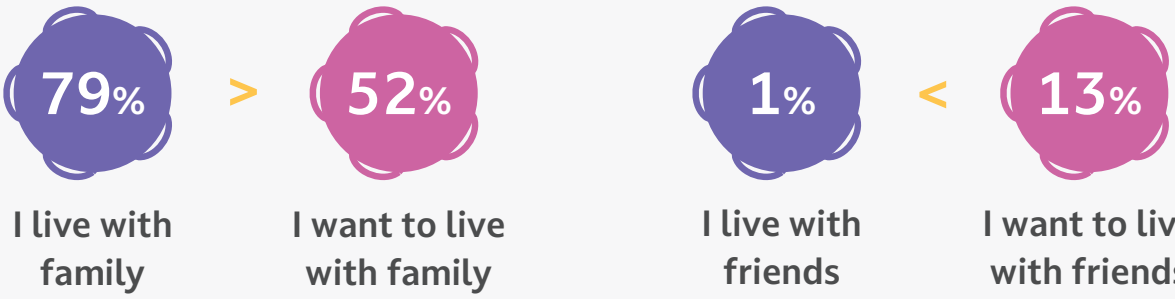
Finding 4

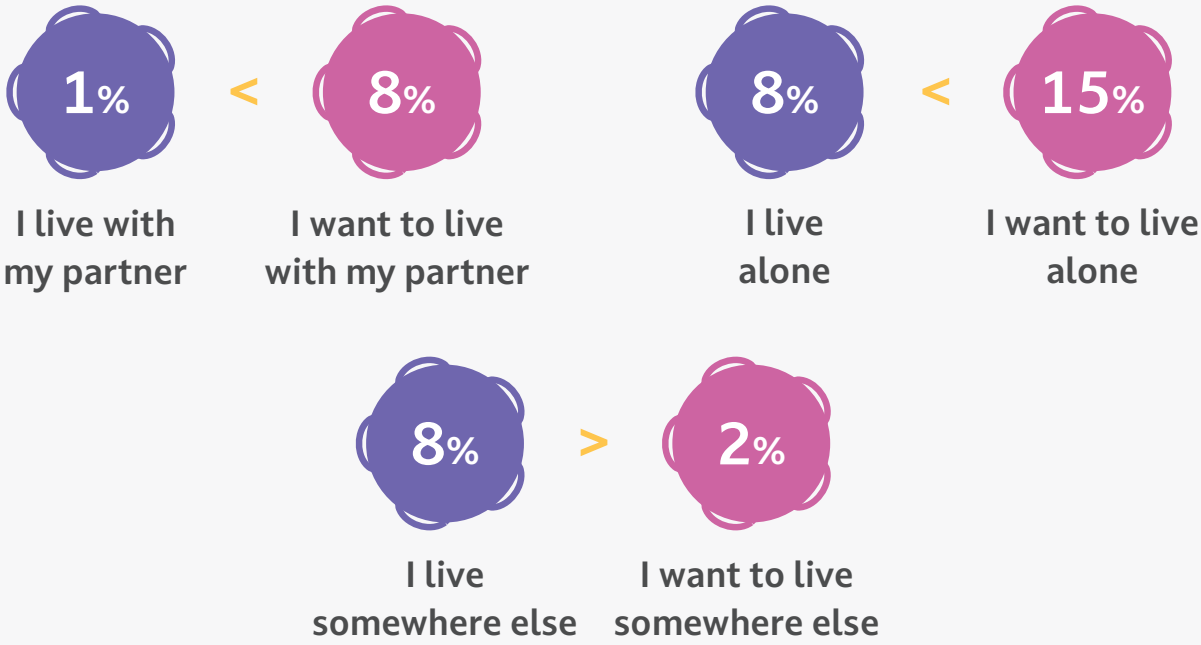
Young people want to choose where they live and who they live with

Living arrangements play a critical role in overall life satisfaction, as they directly impact a young person's sense of independence, security, and control over their daily life. Findings from our survey highlighted that many young people want a greater level of autonomy in their living arrangements, as well as the opportunity to explore creative or flexible living arrangements, such as living with their friends or their partner.

What is clear is that there can be no "one–size–fits–all" approach, and that the decision of where a young person lives should be driven by consideration of their needs, views and feelings about the matter.

Of the young people who responded to our survey, 4 in 5 (79%) currently live with family. The rest live in supported living (8%), somewhere else such as university halls or residential homes (8%), with their partner (3%), alone (1%), or with friends (1%). We then asked young people where they wanted to live (giving them the option to choose multiple arrangements) from the same list. Just over half (52%) said that one of their preferences would be to live with family, however, there was a substantial number of young people who wanted access to different living arrangements.





Looking closer at young people's individual responses, we were able to see that more than half of young people (51%) are not living in any of the places they would like to live.

However, some young people we spoke to expressed worry about the idea of living outside of their family home, as one young person put it *"I need someone who knows me and my disabilities. I need prompting to eat, shower, take medication and learn new skills."*

The range of responses we got to this question shows how necessary it is to ensure the correct balance between supporting independent life skills and meeting young people's needs. One young person who said they were happy with their current living arrangements said *"I enjoy living with my family. I have my own living space which my parents created for me, so I have independence, that means I don't have to sit with them in the lounge and can just be in my bedroom."*

Right now, there are limited housing solutions for young people with disabilities. Some of the known issues include long waiting lists, insufficient supply, inconsistent quality, and a "one–size–fits–all" approach to supporting young people. With this, there is a risk that young people's individual needs will not be met, and that there will not be enough opportunities for meaningful activities and interaction with peers.

We believe that the best providers focus on:

- **Person–centred care:** Providing tailored support that meets the needs of young people.
- **Community links:** Support to ensure young people engage in meaningful activities and maintain their friendships.
- **Diversity in provision:** Offering a range of high–quality living arrangements.
- **Knowledge:** Ensuring their staff have a high degree of knowledge about the people they support, and who their accommodation is suitable for.
- **Co–production:** Involving young people in shaping the services and support they receive.
- **Accessible:** Set up properly for the people who live there, including any young people with physical disabilities.
- **Promote independence:** Support young people to develop life skills and provide the right technology to encourage their independence.



We know that there is a significant shortage of high–quality accessible homes in some areas of the country. In rural parts, finding suitable accommodation can be extremely difficult (as the results of our parents' and carers' survey demonstrates). This can lead to young people being placed in accommodation far from their families and support networks, even when it is not in their best interest.

Over half of parents and carers (66%) said that their son or daughter didn't get the overall outcome they wanted – and housing is a crucial part of this. Worry about where their son or daughter will live was expressed by many parents.

When our daughter's EHCP ends, we don't know where, with whom, or how she'll live. She's non-verbal with severe learning disabilities, she can't read, write, or use social media and relies entirely on carers—or strangers' kindness when she leaves home. Her vulnerability, coupled with housing and carer shortages, deeply concerns us.

Recommendations:

Find innovative solutions to challenges – Local authorities should proactively seek collaborative and innovative housing solutions that involve young people, parents and the community in the design. Partners and commissioners need to be brave and not so risk adverse. Innovative and creative approaches for all services, not just housing, will help us find solutions that matter.

Ensure choice through flexible and sustainable funding – Central government, local authorities and providers must work together to create flexible long-term services. Young people with disabilities and their families need to be at the heart of this process to ensure that services deliver meaningful outcomes and focus on what matters most to people. Young people experience a lack of choice over where they live and who they live with and how they lead their lives. Young people should be able to choose to live in their local area or 'out of county' depending on what best meets their needs. Where young people are unable to lead on these decisions, families and carers should be encouraged to proactively advocate on their behalf and be heard.

Case Study: Linden Farm



The Lawrence family, like many families across the UK, faced a shortage of local housing options for their son, Simon, who has complex needs and is deaf. Surrey County Council, despite their efforts, could only find placements far from home, and therefore Simon lived outside of his family's local area, before being transferred to a young people's centre on the same site. However, he could only stay there until he was 26.

"We used to say that school was like the honeymoon period for people with severely disabled children, because after that there is nothing." – Sally Lawrence, Simon's mother

Fuelled by a desire to have Simon live closer to them, the family refused the council's offer of a placement in either Yorkshire or Cornwall, due to a shortage of provision, and along with other local parents, set up the Simon Trust.

Working in partnership with Surrey County Council, The Simon Trust established Linden Farm, a 10–bed home that offers specialised care, activities, and accommodation for autistic adults with complex needs. The Trust took a creative fundraising approach, raising £300,000 to contribute to the project and ensure features like bespoke kitchens and sensory rooms were included. The council provided land, funded construction, and sourced and trained care staff. Residents live as tenants, with the autonomy and rights that come with a rental agreement, ensuring stability and independence.

By collaborating with the local authority and community, the project has saved public funds while creating a sustainable, high–quality living solution. Linden Farm serves as a blueprint for other local authorities. This model shows that partnerships between families, communities, and councils can provide innovative housing solutions that benefit young people with disabilities, their families, and local government.

Finding 5

Young people want to be able to work

For this research project, we deliberately chose to focus on what meaningful activities young people with disabilities would like access to, rather than homing in specifically on employment.

However, **it is important to recognise that the UK has a large disability employment gap.** The gap measures the difference in the employment rate of adults with disabilities and people who are not disabled. At the end of 2023, it stood at 27.9 per cent. Over the past few years, the former government published a raft of strategies designed to lower this gap – for example, the National Disability Strategy (2021 – updated 2022), the Transforming Support White Paper (2023), and the Disability Action Plan (2024). While the disability employment gap has decreased slightly from 30.1% in 2018, more needs to be done to improve access to employment for people with disabilities.

Findings from 'Disability and Youth Transitions', a project exploring the experiences of disabled young people in Glasgow and the North East, highlights that some of the major barriers that young people with disabilities experience as they transition to work include "one–size–fits–all" employment initiatives, a lack of or insufficient reasonable adjustments, employers misunderstanding neurodivergent behaviours, and a sense of tokenism on the part of employers (with disabled young people often feeling that they are making up the numbers).

Yet many young people we spoke to said that they want to have the experience of working. Some wanted to gain specific experience in industries such as TV, gaming, or working with people with disabilities. Others had maintained voluntary jobs for a long period of time and the sense of self–worth that it brings. For some, supported internships had offered a real opportunity to gain experience.



With this in mind, we welcome the government's commitment to review the Disability Action Plan, as we believe there is an opportunity to strengthen the approach taken to supporting people with disabilities in the workplace. But it is vital that legislative developments, strategies or targets, build upon a foundation of support for young people with disabilities, and that they recognise the importance of meaningful activities beyond employment, including the role of volunteering.

"Commitments made in the Disability Action Plan will be reviewed and considered as part of the Government's approach to improving the lives of deaf and disabled people." Baroness Sherlock, 5 August 2024

Recommendation:

Access to work and reforming the benefits system – Employment brings many benefits to young people with disabilities, their families and the economy. The current benefits system penalises people with disabilities who want to work. For many, getting paid work will make them poorer and places them in an untenable position of choosing between work and state support. The benefit system needs reform to support young adults with disabilities into the workplace including those who will require a job mentor / support and reasonable adjustments. Access to work is underutilised and not understood by employers or by working age adults with disabilities. Reform is needed to create an easily accessible process to support employers and those seeking work. Those with life-long diagnosis and disability must be recognised, they will not get better or be cured. The immense pressure and fear that continual reassessment places on people with disabilities cannot be underestimated. The guarantee of legacy benefits needs to be re-enforced and communicated to ensure that disabled adults who want to work can do so and those who are unable to work are not labelled as 'scroungers' off the state.

Finding 6

Young people want meaningful relationships

We believe that how young people feel about leaving education is intricately connected with their experience of education, especially the strength of relationships they have developed with their peers. Yet after education ends, there is no duty for young people to continue to see friends. If they don't go through other life phases like "university", they are less likely to have close friendships and more likely to experience loneliness.

The issue around isolation and social exclusion can only be addressed by reforming the benefit system to support people with disabilities into the workforce and a full review of provision for working age adults whose disability prevents them from entering paid or voluntary employment. Parents and carers frequently told us that they wished that there was a single point of contact for their son or daughter to help navigate further education, training and work. One parent said *"there should be a named person to support them, and a better supported internship experience which leads to employment".* The Law Commission's 2024 Disabled Children's Social Care Consultation Paper emphasises advocacy as essential for independent living and full citizenship for disabled people, proposing an "opt–out" advocacy model.

This is an approach that the previous government had accepted in its response to the independent review of children's social care in the context of children involved in the care system. Access to independent advocacy is especially crucial during key transitions, such as the shift into adulthood, to support families in understanding the available options for their children.

We believe that the term 'active offer' instead of 'opt–out advocacy' makes it clearer to professionals that there is a responsibility to routinely communicate the offer and that the offer of advocacy is always there should they need it in future.

An additional theme that emerged from our research was that young people were concerned about the burdens placed upon their parents and carers as a result of a broken SEND system. **One young person expressed frustration, stating:** *"My mum tried to help and got a solicitor involved... but those in authority refused to listen or help."*

Concerns about the future were prevalent in our research findings, with one individual saying: *"I'm worried I won't have anyone when my parents die, I might be really lonely and sad".*

Recommendations:

Access to work and reforming the benefits system – Employment brings many benefits to young people with disabilities, their families and the economy. The current benefits system penalises people with disabilities who want to work. For many, getting paid work will make them poorer and places them in an untenable position of choosing between work and state support. The benefit system needs reform to support young adults with disabilities into the workplace including those who will require a job mentor / support and reasonable adjustments. Access to work is underutilised and not understood by employers or by working age adults with disabilities. Reform is needed to create an easily accessible process to support employers and those seeking work. Those with life-long diagnosis and disability must be recognised, they will not get better or be cured. The immense pressure and fear that continual reassessment places on people with disabilities cannot be underestimated. The guarantee of legacy benefits needs to be re-enforced and communicated to ensure that disabled adults who want to work can do so and those who are unable to work are not labelled as 'scroungers' off the state.

Access to advocacy – We recommend introducing an 'active offer' of independent advocacy for children, young people with disabilities, and their families. Access to independent advocacy should be extended to support children and young people with disabilities through key transition points (e.g., starting or leaving school), post–16 pathways, and supported internships. Advocacy should also include referrals to services such as SENDIASS and therapy, ensuring support for those without an EHC plan. Additionally, the government should collaborate across departments to improve employment and training opportunities for young people with SEND.

Finding 7

Young people need reasonable adjustments to attend university

Of those at university, some told us that they were forced to delay attending because of failures to make reasonable adjustments, or that they were struggling because of the lack of disability support available. Research by UCAS in 2022 highlighted that young people with disabilities are *"up to 28% more likely to defer than their counterparts"*, a figure which has worsened since the pandemic. The likelihood of deferral was particularly high for autistic young people, although the reasons for this are not explored in greater detail.

Under the Equality Act 2010, universities are required to make reasonable adjustments to make sure that disabled students are not disadvantaged. This includes making sure that facilities, bathrooms and accommodation meet the needs of those with physical disabilities.

"I left school last year to go to university, but I had to take a gap year at the last minute because of inaccessible university accommodation."

Recommendation:

Support to access university – Further Education SEND experts should collaborate with universities to support seamless transition from further education to higher education for those with disabilities and complex needs. Systems and funding need to be made available to promote collaborative partnerships to ensure young people have equality to access higher education and successfully achieve their aspirations.

Finding 8

Transition plans must be proactive and involve the young person and their family

Often, when young people come to providers such as the Together Trust and National Star, they have high levels of need and either have not been in education recently or have been in education settings which are inappropriate (oftentimes because there is a lack of suitable education facilities available). School waiting lists are extremely long. Parents often must fight for their son or daughter to be admitted to specialist schools / colleges or are in active disagreement with their local authority about the right course of action for their education. Once they have been accepted, the young person becomes settled with us, makes new friends and starts to develop a routine.

A transition plan (involving the key partners) is made with the young person and their family to outline what should happen after they leave education. There are few options in the community for activities, and it is presumed that the young person will want to continue to live with their parents (or occasionally in supported living). **There is an absence of creative housing solutions which would allow young people to live with their friends or partners.** There is a focus on getting young people into work, but not on sourcing meaningful activities and facilitating them to maintain relationships with their peers.

At some point, the young person's transition plan often breaks down, either because their funding runs out or because there aren't enough trained staff to fulfil their transition plan. In that situation, professionals are left scrambling to find an alternative placement. The question of what the young person wants for their own life becomes less important and is superseded by the question of what is available.

The young person experiences disruption, as they have no certainty about where they are going to live or what their life is going to look like. The result of the disruption is detrimental to the young person and their family. Parents who are in a solid financial position might look to find and pay for a solution, for example, choosing to rent a house and pay for a team of carers privately – but they still face uncertainty about long–term arrangements. Those without financial means have few options.

Often, the waiting goes on longer than anybody can anticipate, and parents resort to getting an outcome through the SEND Tribunal (where they are overwhelmingly likely to win against the local authority).

Recommendations:

Put young people at the heart – All services need to be shaped by the voices of those with lived experience. Young adults with disabilities must at the heart of all planning. That will result in us delivering outcomes that matter to young people and their families and carers. The young person needs to be at the centre of planning transition into adulthood. That process should be consistent across England and transparent for young people and their parents/carers to navigate. This will reduce young people's fear of the future, develop a clear pathway for their continued success, and provide information on their rights and needs to those who will support them in the future.

Start planning early – Transition planning should commence early, with children's services working in partnership with adult services several years prior to transition to enable the development of appropriate adult provision and ensure future budget planning both locally and from central government.

Find innovative solutions to challenges – Local authorities should proactively seek collaborative and innovative housing solutions that involve young people, parents and the community in the design. Partners and commissioners need to be brave and not so risk adverse. Innovative and creative approaches for all services, not just housing, will help us find solutions that matter.

Methodology

This research project and dissemination of its findings was undertaken primarily by Lucy Pettinella and Styliana Pasiardi (the Together Trust) and Marianne Sweet (National Star) and was not subject to external funding. The Together Trust and National Star ran two surveys, one for young people with special educational needs and disabilities, and the other for parents, between November 2023 and February 2024.

Our young people's survey

We used a platform called VideoAsk for our young people's survey. We chose this platform as it allowed young people to respond verbally (with the audio being recorded), which we know is preferential for some of the young people we work with. Each question was displayed in a written and video form, with the video questions being asked by young people with disabilities. Subtitles were included to accompany video questions.

The survey asked a range of quality of life and wellbeing questions, as well as specific questions about their experiences of leaving education. Our target age demographic was 14–25. We received 202 responses. Almost 70 of those came from respondents over the age of 31, which we removed from our sample to ensure that our findings reflected the experiences of our intended cohort. In total, we received 134 valid responses from young people, with the average respondent age being 21.

Our parents' and carers' survey

We used Typeform for our parents' and carers' survey. Each question was available in a written and video format, with the video questions being asked by real parents of young people with disabilities. Subtitles were included to accompany video questions.

In total we received responses from 304 parents and carers. Parents and carers who responded to survey #2 are not necessarily those of the young people who completed survey #1.

Help us drive change

This report is just the beginning. We know that changes are urgently needed. Sadly everyone, including commissioners, providers and central government, have contributed to a system that is failing young adults with disabilities.

For us to move forward we need to put an end to the blame culture and stop working in silos. If we collaborate, we can create sustainable, innovative and flexible services. Most importantly we need to ensure those with lived experience are at the centre of all services.

By having young adults with disabilities and their families and carers at the heart of services we can create services that have real value. We have an opportunity to create sustainable long-term services that would transform lives.

While this report has many recommendations these are the actions that are most urgently needed for us to move forward:

Preparation – For every young disabled person, early preparation is critical for successful transition. Young people should have the opportunity to make choices about their future and receive support to prepare them for adulthood.

Planning – Focus on the long-term, not the short term. Planning must create sustainable services that provide wonderfully ordinary lives for young disabled adults. What matters most to the person at the centre: Their journey, their way!

Progressive – Transition together, collaboration with the young person at the centre. Families, commissioners and providers need to execute the plan, through a system which is navigable and enabling, not daunting and formidable.

We can all play a role in driving this change. Let us ensure that young people with disabilities can lead fulfilling lives after they finish education.

Moving forward

In the time we have spent researching this report we have benefitted from many valuable conversations with professionals inside of our organisations, external professionals, academics and providers of all natures, charities and businesses.

We have particularly benefited from organisations who have shared our surveys with young people and the parents and carers they support to help us gain a much greater understanding of where the system requires change. This includes VODG (Voluntary Organisation Disability Group), DCP (Disabled Children's Partnership) and many other individual organisations. Thank you.

We believe that we're much stronger together, even if our perspective is different. That's why we want to listen to the experiences of those who have picked up this report, and who have an insight that they want to share about the transition of young people with disabilities into adulthood.

Help us drive change

By scanning this QR code you'll be able to:

- Register your support for this report's recommendations.
- Leave a comment about your own experience as a professional or as a person with lived experience of the system.

In compliance with GDPR, you are free to withdraw your contribution at any time

Explore the report and support our work at whatcomesaftereducation.com

TOGETHER TRUST charity

Disability, care and education

The Together Trust

The Together Trust is a charity based in the North West. For over 150 years, we've been championing and caring for people with disabilities, autism and complex health needs, as well as providing life–changing support for care–experienced people. We support around 3,000 people aged 5 to 25+ each year across 40 different services. Our vision is a society where people thrive because they are valued within their communities.

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supporttogethertrust · together_trust

together–trust · togethertrust

togethertrust.org.uk

Registered charity number 209782

National Star

Realising the aspirations
of people with disabilities

National Star

National Star is a national charity, based in Cheltenham, providing education, care and support to young adults with complex needs and disabilities. It has a residential and day college in Cheltenham as well as providing specialist education and therapy in Hereford, Mamhilad and Worcester. Young people from across England, Scotland and Wales attend the specialist college. The charity also runs four long–term accommodations.

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