

Kids

Disabled children
say we can

On the cliff edge

Disabled young
people and their
journey to adulthood.



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Executive summary

For too many young people with special educational needs and disabilities (SEND), the transition from childhood to adulthood is like falling off a cliff edge.

They are often left without the support, skills and connections they need to live good adult lives. And the more complex the needs, the steeper the cliff edge.

In the report, we share research findings exploring the experiences of a diverse group of young people with SEND in England and their families, as they move into adulthood – known as ‘transition support’ – and what can be done to improve the support they receive.

Five signals that the current transition support system is broken

We found that the current system of transition support in England often leaves young people with SEND and their families unprepared and unsupported as they reach adulthood. It makes it harder to find information about options for the future, leaves young people with SEND waiting without the vital support they need, and too often fails to meaningfully include them in society.

Five key challenges faced by young people with SEND and their families:

1. The transition support system is complex, confusing and hard to navigate.
2. There are significant and widespread gaps in support and services as young people with SEND move into adulthood. This is especially true for young people with the most complex needs, where family involvement will remain particularly close and for whom independent living is not an option.
3. Young people with SEND lack meaningful support to live independently as adults, including a lack of opportunities to develop real life skills or find work.
4. Young people with SEND still face widespread discrimination and social exclusion.
5. A perfect storm where the current economic climate is driving services already struggling to meet people’s current needs towards financial breaking point.

Principles of good transition support

The report also sets out what good transition support looks like, sharing best practice case studies, and a set of principles of good transition support that were co-developed with young people with SEND, parents and practitioners.

Good transition support is:



Personalised:

Tailored support to the needs of the specific young person, recognising each young person will have different aspirations, abilities and needs.



Relationship-based:

Ongoing support provided by a trusted adult that knows the young person with SEND, in order to provide continuity and a familiar face throughout their journey into adulthood.



Timely:

Early planning to provide sufficient space and time for young people with SEND and their families to prepare for adulthood without feeling rushed.



Explorative and collaborative:

Exploring real and meaningful options and choices with the young people with SEND and their families, wherever possible, based on needs, aspirations and what is available locally.



Clear and honest:

Clearly communicate what young people with SEND and their families can expect, when, and from whom.

Executive summary (cont)

Five priorities for action

Working with young people with SEND, parents and stakeholders, we identified five key areas for action.

We recognise that others reading this may have a different 'top five', and so we share this as an invitation to others for a discussion about how we can work together to ensure young people with SEND are supported to live good adult lives.



- 1. Navigating the system:**
Advocacy and support to help young people with SEND and their families navigate the system.
- 2. Life skills:**
Supporting young people with SEND to develop real skills for life through practical and meaningful activities.
- 3. Employment support:**
Supporting young people with SEND to find and keep work, where this is an option and ambition.
- 4. Leaving no-one out:**
Increasing opportunities for young people with SEND to take part in social activities and connect with their peers.
- 5. Family support:**
Supporting families by facilitating connections with other parents for peer support and advice.

Our recommendations

With the views and experiences of young people with SEND and their families front and centre:

1. The Government should prioritise action to prevent young people with SEND from falling off the ‘cliff edge’ as they become adults by appointing a Minister for Special Educational Needs and Disabilities (SEND), who will take responsibility for fixing the disjointed transition support system for young people with SEND.
 - a. The minister for SEND should work with named leads from the Department for Education, the Department for Health and Social Care, the Department for Levelling Up, Housing and Communities, the Department for Work and Pensions and any other relevant departments to publish a national, cross-departmental plan.
 - b. Alongside the cross-departmental plan, the named departments should work with Kids and the wider sector to ensure the views and experiences of young people with SEND and their families are at the centre of any plan, by running a nationwide listening campaign with young people, parents, and practitioners to understand and prioritise key challenges and develop ideas for better transition.
 - c. The plan should outline how they will work together with the sector to address the current challenges and close the support gaps by the end of the next term of government, paying specific attention to the rights and needs of young people with the most complex needs.
 - d. The plan should set out national standards for transition support with appropriate support and funding for local authorities as well as meaningful compliance mechanisms, building on the DfE’s SEND & AP Improvement Plan, findings of the House of Lords Public Services Committee inquiry, and insights from Ofsted and the Care Quality Commission (CQC) thematic reviews of preparation for adulthood arrangements in local areas inspections.
 - e. The plan should provide funding to 10 areas to bring local partners together to develop and pilot new models of inclusive, joined up, and meaningful transition support.
 - f. Building on the work of the DfE’s post-16 stakeholder group, the Government should ensure their upcoming guidance is informed by the views of young people and parents and adopts a co-designed shared definition, using our principles of good transition support as a starting point for discussion.

2. Commissioners of local children services and adult services should ensure that every young person with SEND has access to timely, quality transition support by:
 - a. Establishing formal mechanisms for meaningful participation of young people with SEND and families to ensure all transition support is co-produced.
 - b. Establishing and publishing details about the elements that make a good transitions plan and measures that are taken to quality control the support in the plan.
 - c. Reviewing transition service arrangements to ensure they comply with the law and government guidance and identify actions for improvement, drawing on insights from this report and others such as the upcoming Ofsted and CQC report on SEND inspections, as well as local expertise and experience.
3. Led by young people’s and families’ expertise, public, voluntary and private providers of transition support should collaborate to raise awareness of the importance of fixing the broken transition support system by:
 - a. Using their networks to engage local and national policy stakeholders with the importance of transition support in the run-up to the upcoming General Election.
 - b. Registering their interest with Kids to connect and collaborate on how to transform transition support.
 - c. Convene as a new national cross-sector alliance.

Throughout, the strengths and needs of every young person, especially those with the most complex needs, and their families, who are often forgotten, must be recognised and resourced, so that a good transition into adulthood becomes a reality for all.

1. The Government must step up and demonstrate action on a national level to fix the disjointed transition support system.
2. Local Authority Commissioners must comply with the law and catalyse access to timely, quality transition support.
3. Led by young people’s and families’ expertise, a new national cross-sector alliance should convene and collaborate to achieve transformational change.



Foreword

Listening to the experiences of a disabled young person, parent or provider on the topic of the transition into adulthood, it is rare to hear a positive account of these pivotal journeys.

Instead, the term 'cliff edge' crops up again and again.

Whatever pathway they have been navigating through childhood, the cliff edge comes as they face a gap in a formal move from children's to adults' services.

This leaves so many families desperately struggling to fill the gap.

"I look at him and I kind of think, if I don't go out and find out stuff he'd just be kind of forgotten.

It feels like I have to do a lot of leg work to make it a successful transition, otherwise nothing will happen.

The last thing I want for my son is this kind of forgotten 18 year old.

It's not what he wants, he's got ambitions, he wants to do things in life, it feels very much that as a parent I'm the one that has to make it happen."

Parent

Unpacking people's experiences, it is clear the issues run deeper still.

The cliff edge comprehensively depicts an entirely broken system, which is leaving too many young people with SEND and their parents on the precipice.

The scale of the problem must not be underestimated, nor the impact it has on family relationships, finances, and mental health.

"There were nights when I would lay up and think 'what's next?'

I have to do things, I have to put things in place.

I was very scared, but oh it was very overwhelming."

Young person with SEND

Expertise in what works is plentiful – and especially powerful – when it comes from young people and families who have somehow found their way through.

There are excellent examples of provision, some highlighted in this report.

But mostly, disabled young people are being badly let down and denied the support that is right for them.

Fresh thinking and urgent action are needed to flatten the cliff edge.

A better system would open doors to different futures, reflecting individuals' strengths and needs.

As one parent said:

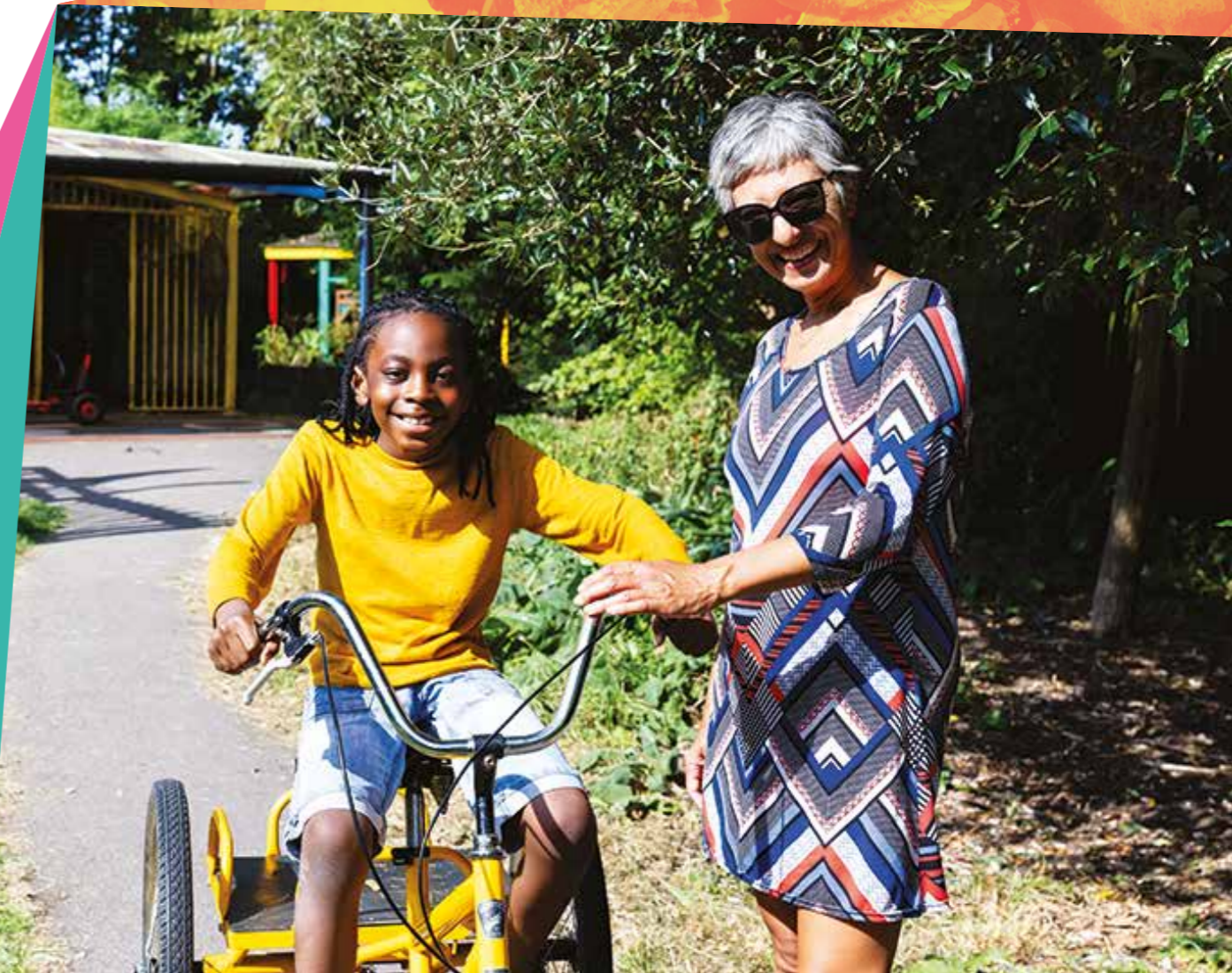
'Something better must be possible.'

Whether this report is used as a conversation-starter, or to work alongside brilliant collaborations and activity already happening at many levels, we want it to be a springboard for change.

We urge you to join us in transforming transitions into adulthood, once and for all.

Katie Ghose

Chief Executive



About the authors

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Will is an expert in qualitative and participatory research methods, conducting social and policy research for organisations including Australia's Prime Minister's Department, Citizens UK, Essex County Council, the National Lottery Community Fund, Nesta, and the University of Oxford.

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Anthill Collective is a collective of independent social researchers, policy people and service designers working with charities and local public services to create more people-led support.

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They generously shared their experiences of the transition from childhood to adulthood and took part in co-design sessions to shape research findings, tell us what good transition support should look like and develop ideas to tackle their key challenges.

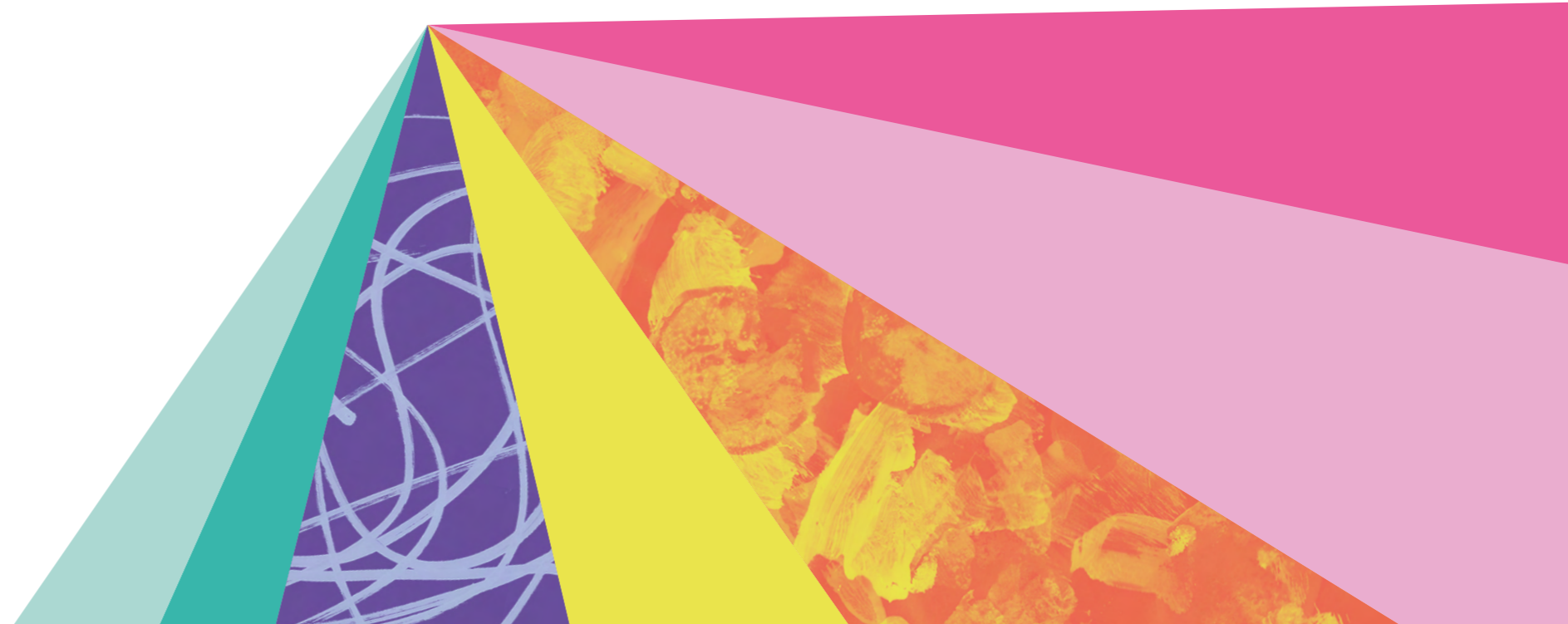
We'd also like to thank all the organisations who took part in this research for sharing their expertise and experiences.

These include:

David Lewis Centre
The Disabled Children's Partnership
Fair Shot Cafe
Islington Council, London
Sense
South Yorkshire Integrated Commissioning Board
Westside School
Team Domenica.

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This report was only made possible by the support of Frances Prens, Austin Erwin and Meriem Laouiti who share our ambition to unlock fresh thinking to help shape transition support that is fit for the future.



Chapter one

Introduction



“It was really really scary, I’m leaving school with the thought of what to do next. It’s really scary. People like me don’t get something to do, we don’t have something to do. We are expected to rely on someone for the rest of our lives. It was scary for me because I had to submit a lot of forms, write a lot of applications, it was very challenging.”

Young person with SEND

The transition from childhood to adulthood can be daunting at the best of times.

As the quote above shows, this is felt more acutely by young people with SEND.

We heard how this period can be a frightening and confusing time as the nature of the support, settings, and relationships they’ve relied on all change at once in various ways.

As this report details, these challenges are further exacerbated by a profoundly inadequate system of transition support in England, which makes it harder to find information about options for the future, leaves young people waiting without the vital support they need, and too often fails to meaningfully include them in society.

We heard about young people left without any support for two years before they could access adults’ services.

We heard cases of young people with SEND being evicted unlawfully or being dismissed from their job without being offered adequate support.

And we heard of young people, especially those with the most complex needs, who are excluded

from society, left out of social life or in settings with no-one their own age.

We spoke to parents who felt like they were caught up in a spider’s web of complexity and confusion.

We encountered parents who felt they had to do a law degree to support their child.

And we heard countless stories of parents who had to fight every day to ensure their children got the support they needed and were entitled to.

We heard from passionate professionals who described seeing the young people with SEND they had previously supported regress, as they didn’t have the support they needed in their new setting.

This was a frequent occurrence, which the professionals described as ‘soul-destroying’.

We heard from providers of support to young people with SEND who are at the brink of financial collapse. And we heard from commissioners trying to bring together a complex and disjointed system.

The transition to adulthood is increasingly being recognised as a key stumbling block for young people with SEND in England.

The Department for Education (DfE) recognised the need to improve transition support in their Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) Improvement Plan published last year (DfE 2023).

Ofsted and the Care Quality Commission have made preparation for adulthood their theme for SEND inspections this year (Ofsted & CQC 2024).

And the Public Services Committee has launched a new parliamentary inquiry investigating the transition from education to employment for young people with SEND (Public Services Committee 2023).

In this report, by transition support or preparation for adulthood, we mean: working with young people with SEND aged 14–30, and their families, to explore their aspirations

Types of transition support

We found three broad types of support that help young people with SEND and their families through the transition from childhood to adulthood:

Support delivered by statutory organisations such as information, advice and guidance services, as well as dedicated transition support teams;

Support provided by voluntary and community organisations, which included a wide range of specialist services that support young people with SEND move into adulthood;

and support and guidance for professionals.

for the future and provide the support they need to successfully find their path to a good life.

This can include supporting young people with SEND to move from school to further education, moving from education to work, moving from children’s to adults’ services, or support to help young people with SEND live more independently and take part in community life.

Recognising that disability can be conceptualised in a range of ways, in this report we adopt a broad and inclusive definition.

We spoke to young people (and their families) who self-identified as having a special educational need or disability, ranging from those with moderate to higher, more complex support needs for whom education, work or independent living may not be options.



A snapshot of transition support for young people with SEND moving into adulthood

Transition support delivered by statutory organisations

Every young person with SEND should receive transition support, and there are statutory entitlements depending on their need.

All local areas must provide accessible information about local SEND services through their SEND Information, Advice and Support Service (SENDIASS) and SEND Local Offer, though invariably quality is inconsistent.

Some local offers provide high-quality and easy-to-access information on a range of local support options. However, many local offers are hard to navigate, contain poor quality information, or do not include any information on transition support at all.

Some social care, health and education services also have dedicated transition support teams that focus on coordinating support, planning for adulthood, and helping young people with SEND and their families navigate their options. They typically work 1:1 with young people and their families, as well as other professionals, to provide information and advice, with a large focus on planning and support to smooth the transition from children's services into adults' services.

While the focus of transition support teams is usually on the transition from children's to adults' services, they will often also link young people with SEND and families up with other relevant support.

Transition support delivered by other organisations

There is a wide range of specialist services delivered by non-statutory organisations such as charities and social enterprises, that aim to support particular parts of children's transition into adulthood.

To provide a snapshot of this type of support, we spoke to some representatives and conducted desk research around the following organisations:

- Schools and colleges offering a specialist curriculum such as David Lewis School, Woodlands School, or Merrist Wood.
- Organisations supporting independent living through supported living services such as St Elizabeth's, Brandon Trust, or Affinity Trust.
- Organisations supporting access to work through supported internships, traineeships and apprenticeships or supported work experience opportunities like the Team Domenica, Fair Shot, David Lewis Centre and the Open Doors Café.
- National disability charities providing a range of helpful resources, typically focusing more on information, advice, tips and guides about the process of transitioning into adulthood, what to expect, and the rights young people with SEND and their families have.

Support & guidance for professionals

Finally, there are resources, guidance and support developed and tailored for professionals and practitioners working with disabled children and their families to support good transition.

One example is the Preparing for Adulthood programme, which developed resources, tools, and guides to help professionals and local SEND leads support young people with SEND into adulthood.

Delivered by the National Development Team for Inclusion (NDTi) and funded by the DfE, the Preparing for Adulthood programme created resources on paid employment, independent living and housing options, good health, and friendships, relationships and community inclusion.

The DfE has also published a SEND and AP Improvement Plan, where they commit to working with young people, families and professionals (for example through DfE's Post-16 SEND stakeholder group) to develop good practice guidance to support transitions by 2025 (DfE 2023). This guidance will be used to inform new National Standard and practice guides for local authorities and educational settings.



About the report

This report aims to raise the voice and perspectives of young people with SEND and their families by exploring and sharing their experiences of transition support in England.

It is a call to action for the Government to prioritise transition support for young people with SEND.

This means taking steps to address the challenges that we heard from young people with SEND and their parents and from providers and commissioners of transition support.

We hope the report will be of interest to anyone with a stake in the English transition support system, but particularly policymakers in central government, and from providers and commissioners of transition support for young people with SEND.

Specifically, we share this report as an invitation to kick-start fresh conversations and collaborations with other people and organisations who want to take action to improve the existing transition support system.

To inform the report, we undertook primary and secondary research to understand the experiences of young people with SEND, and their families, as they move from childhood to adulthood and explore what needs to be done to better support young people with SEND during this period.

We used a mix of research methods, which included:

- Undertaking a rapid desk-based review of existing transition support.
- Conducting 27 semi-structured 45-60-minute interviews with young people, parents and providers.
- Holding two 90-minute focus groups with young people with SEND and parents.

We also included a co-design phase, where we invited young people, parents and practitioners to take part in three 90-minute workshops to discuss the research findings and co-develop our definition of transition support, setting out what good transition support looks like, prioritising key areas for action, and developing ideas to address them.

In total, we spoke to:

- 20 young people with a mix of special educational needs and disabilities and a range of backgrounds.
- 18 parents of young people with a range of special educational needs and disabilities and backgrounds.
- 21 practitioners, providers or commissioners of transition support.



Chapter two

Five signals that the current transition support system is broken



1. The transition support system is complex and hard to navigate

Almost everyone we spoke to talked about how complex, disjointed or hard to navigate the current transition support system is - to the extent that there is one.

This presents challenges for young people with SEND and families, who have to navigate a confusing system, with huge variability across the country, too often by themselves. It also presents challenges for providers and local commissioners to try and bring the system to work together to support young people with SEND, as there are often multiple different service pathways that don't connect.

1.1. Local support is difficult to find, understand & access

We commonly heard how hard it was to find information about what support options were available, with one parent describing the situation as like having to complete a law degree to get support for her son.

"The [transition support] system is like a spider web. It's completely confusing.

I feel like I've had to do a law degree to support my son and find out about his condition to get medical support."

Parent

Young people with SEND and parents often didn't know where to go to find out about relevant support, and rarely did the families we spoke to get any help navigating or accessing this information.

"Transition is a really big jump for young people but there's very little support available or help to find out about it.

People often don't know where to go.

You don't know what you don't know regarding what's out there.

There's also not always a lot of choices out there in reality.

We used to have transition social workers, where from 19 onwards they'd be assigned to a family to help with the transition. But that's gone now."

Chief Executive of an education and supported employment provider

"One of the key challenges is finding the right support and where to look for it.

There is a lack of information, this becomes an issue. My friend told me about mentoring support.

I wouldn't have accessed any of this support without my friend."

Young person with SEND

"I'm always the one who's having go out and find the information."

Parent

The difficulty that is commonly experienced in finding information about support options not only makes it difficult to access locally available support, it can also lead to considerable stress and anxiety for young people with SEND and families.

This is because it creates uncertainty around what support will be available, and increases the burden of labour that needs to be expended to find, understand and secure appropriate support.

Almost all young people with SEND we spoke to reported profound fear, loneliness and feeling lost when leaving their educational setting and entering the adult world.

Many of them hadn't accessed any support from charities or the local council at all during this transitional period.

"There were nights when I would lay up and think 'what's next?'

I have to do things, I have to put things in place.

I was very scared, but oh it was very overwhelming, it's scary to get to the end of something and the uncertain next steps."

Young person with SEND

"When he was in his last year in college, we were incredibly worried about what would happen.

Nobody had a clear answer, the local authority didn't have a clear answer, no charitable support, that was a big transitional challenge."

Parent



1.2. Access to support is reliant on parental engagement

“I look at him and I kind of think, if I don’t go out and find out stuff he’d just be kind of forgotten. It feels like I have to do a lot of leg work to make it a successful transition, otherwise nothing will happen.”

The last thing I want for my son is this kind of forgotten 18 year old. It’s not what he wants, he’s got ambitions, he wants to do things in life, it feels very much that as a parent I’m the one that has to make it happen.”

Parent

“It was a case of involving the funders and providers, that’s what’s so exhausting, you have to chase all the time.”

Parent

“In terms of the transition, he had no support. It didn’t feel like there’s anybody out there to help without us.

The whole system for young people with SEND and adults relies on cultural capital. That’s the whole scandal.”

Parent



Parental and familial support is understandably a key and primary source of support for young people with SEND.

However, both parents and young people expressed significant concern regarding how much harder things would have been for them without familial support.

“My family [is] the main backbone of my support, without them I don’t know how life would have been.”

Young person with SEND

“I don’t want to think about it, I feel he would have found it difficult to survive.”

Parent

Multiple previous studies have made similar findings, pointing to how a lack of joint working and communication between services means that parents are left planning and coordinating transitional support and having to navigate a complex, disjointed and often poorly signposted system by themselves.

For example, Sense notes that a common challenge can be the lack of communication between services, and that families can find the process stressful, as the responsibility of coordination falls to them (Sense 2023).

The Local Government Association (LGA) reviewed data which highlighted how disabled young people were having to repeatedly provide the same information to different organisations due to a lack of coordination between child and adults’ services, reporting a significant amount of additional strain on families (Alma Economics 2023).

Similarly, researchers from the University of Surrey found a lack of publicity and lack of knowledge of support services available in local areas, finding that young people with SEND and their families are left to do the research themselves (Shanahan et al 2020).



1.3. Lack of awareness of rights & welfare entitlements

A related challenge that we found was that most of the young people with SEND or their parents had never received any information or advice on their rights or entitlements, such as protections from discrimination, including in the workplace or housing, or on their benefit eligibility.

For example, we spoke to a young person with SEND who was employed and hadn't heard of the Access to Work scheme. A number of parents and young people with SEND weren't aware of disability benefits that were relevant to them.

“Legal protections, understanding my rights and protection under the law, there are people who don't know how to treat people like me. They don't think we're normal humans, they look down at us. People like us need to be taught our rights in the community or wherever they are, and self advocacy, so people can selfadvocate in the workplace and education.”

Young person with SEND

“I've never claimed disability benefits [on behalf of my son], I don't know how to do it, I need someone who has actually claimed the benefit to help me.”

Parent

We heard repeatedly that access to this information would have been extremely helpful and several asked us to send them relevant information after the interview, including on the Access to Work scheme and signposting to welfare advice agencies for benefit advice.

Those who did access relevant information were largely signposted by incidental sources, such as word of mouth through informal parent or family networks, through friends, or by a private counsellor.

Only three of the 20 young people with SEND we spoke to learnt about their legal rights through school, with one receiving relevant information from a YMCA youth group and one from Mencap.

“Not as far as I know from school. I don't think he has actually. The only place where possibly conversations like that could happen... he attends a local youth club at the YMCA.

They're quite proactive actually at telling the young people they do have certain rights and I know they've talked about discrimination and how to make someone aware they've been made to feel bad about themselves.”

Parent

2. There are significant and widespread support gaps as young people move into adulthood

One reason why the transition period between childhood and adulthood can be so challenging for young people with SEND is because this is when many of the service and support gaps begin to appear, just at the time when they most need support and continuity.

This phenomenon is commonly referred to by young people, parents and providers as the 'cliff edge', with this 'cliff edge' getting steeper and steeper as a young person's need increases and becomes more complex.

2.1. A lack of specialist SEND support at college

The first transition area where there are important support gaps is when children move from school to further education (FE).

We heard that the ability to find appropriate further education provision for young people with SEND is becoming increasingly difficult, particularly within mainstream educational settings.

For example, a transition head at an alternative provision school told us that further and higher education settings increasingly lack the capacity or expertise to support pupils with SEND.

He described this as partly a funding issue and partly because many specialist schools are now supporting young people up to 18 years so post-16 education providers are re-evaluating - i.e. reducing - their SEND provision.

“The hardest thing has been trying to ascertain what level of support is next.

The ability to find appropriate provision that is willing to accommodate young people with SEND is becoming increasingly difficult as many further and higher education settings just don't have capacity or expertise anymore.”

Assistant Head of an AP secondary school



2.1. A lack of specialist SEND support at college (cont)

We also heard about delays in securing the appropriate placements or support, and while there is a requirement for children with an Education, Health and Care Plan (EHCP) to have a transition plan and provision organised by an established deadline, we heard this frequently doesn't happen.

This was a key barrier to a smooth transition for many young people with SEND and we heard multiple stories of placement breakdown as a result.

"It's harder to meet those needs because lots of FE settings don't have occupational therapists, or speech and language therapists or are using the borough's speech and language therapist, who is already very over-stretched."

Assistant Head of an AP secondary school

This challenge was echoed by a local SEND commissioner, who highlighted the lack of specialist or therapeutic support in mainstream colleges as a challenge as it limits the choice of post-16 education providers for young people with SEND and drives even more competition for the already limited special school places.



"There's no therapeutic support in mainstream colleges.

If a young person is receiving therapy of some sort, if they're in a special school and stay on for post-16, then they'll continue to receive specialist therapy.

But there's no therapeutic support within mainstream colleges, so the choice of post-16 providers is very limited and it drives further demand for special school places."

Local SEND commissioner

2.2. Lack of appropriate support for young people with SEND moving from education to adults' services

The second transition area where there are significant support gaps is the move from education to adult settings.

We heard from one provider that after leaving school or college, at least 50% of students don't have an appropriate placement when they leave and that this is where support falls down for the majority of their young people.

"Often the local authority's offer for the next step is not appropriate. This is where it falls down for the majority of our young people, even for students for whom work is an option but who need full time support to do the work and particularly for people with higher support needs..."

From college, at least 50% of our students don't have an appropriate placement when they leave."

Executive Director at a specialist college

This finding supports previous research, such as a study done by the Disabled Children's Partnership, which found that more than half of families with disabled children aged 16 or over did not have a transition plan in place (Lunt 2022).

This gap was partly attributed to a lack of understanding of an individual's specific needs and a lack of knowledge about how to support those needs.

Another issue that was commonly mentioned - by both providers and local authorities - was that the threshold for onward services (such as mental health services or supported living) are very high.

So, for many young people with complex or multiple needs, there isn't appropriate support available.

"It's almost soul destroying when there's nothing or they fail very quickly because then there's not a lot you can do.

And we do continue to support, but we can't send a staff member when we're no longer responsible but we do check up on students for up to three years."

Executive Director at a specialist college



2.2. Lack of appropriate support for young people with SEND moving from education to adults' services (cont)

“We had a young person who left college and went to a day service and it’s all 40 year olds or older and he was 23.

Adults’ services is the challenge as it moves to a less structured environment but a lot of young people need that structure and routine.”

Executive Director at a specialist college

There are such limited services to signpost people to and if they are signposted, it has to be a very high level of need and there’s always a waiting list and the support is only available for a limited time.

They have to be in crisis now to access support and it’s too late at that point.

We’ve had to become de facto social workers but we’re not skilled in that but we’ve had to do it because either there’s nowhere else or they’re waiting to be seen by someone.”

Chief Executive of an education and employment provider

There are also some common gaps in support for young people with less common or more complex disabilities, where provision can be extremely variable, akin to a postcode lottery that determines whether a young person with SEND will get the support they need.

“There’s a lack of specialist MSI [multi-sensory impairment] support.

Some local authorities do have specialists in MSI in place but lots of services don’t have that MSI support so communication can be lost during transition.”

Operations Director at a national disability charity

“I’ve never seen any [external] provision for non-verbal people.”

Executive Director at a specialist college

2.3. Major gaps between children’s & adults’ services

“Surely there’s an easier way. Why does such a big gap exist between 16 and 18?”

Parent

Finally, a related challenge is a gap in support for young people with SEND moving from children’s services into adults’ services.

At the most concerning end of the spectrum, we found major gaps in service provision between children’s and adults’ services.

This was especially true for young people with the most complex needs. For example, in one area there is a two year gap between children’s services, which finish at 16 years, and adults’ services, which start at 18 years.

As the local commissioner in the area describes the situation:

“Locally, there’s no real transition support in place currently.

The problem across all services is that children’s pathways only go up to age 16 and adults’ services start at 18.

Families talk about it like a cliff edge.

Some services will keep young people on until 18 if they are known to them and some adults’ services might take young people earlier.

However, that’s not across the board or if there’s a new diagnosis then they will fall through the gap.”

Local commissioner of SEND services



2.3. Major gaps between children’s & adults’ services (cont)

In another area, we heard similar gaps for young people needing to access adult health services but who are no longer eligible for paediatric care.

“For younger ones aged 17–18, they get discharged from the paediatric team and move to the adult health team.

But if they’re still in school, the adult health team won’t provide support so there are gaps for some people who turn 19 but they’re still in school.”

Head of service at a local authority

We also frequently heard how it can take a long time – up to nine months and sometimes longer – to be placed into adult provision.

This means for that period, the young person in question is not receiving any support.

One provider told us that while they appreciated the challenge local authorities faced, very few were able to support as successfully as they would like.

The consequence, according to them, was that the skills young people with SEND learned in their settings are lost and they felt like a lot of their work and progress was being undone.

“The gap between leaving education and going into the next provision is just too wide and too long that some of the skills to be independent are lost as they are not being reinforced; and the skills they’ve learned in our settings regress.

In the interim, the local authority should be thinking about arranging for someone to come into the home and taking them out on day trips etc. but it requires the staff to do it.

I know they’re doing their best but it can take weeks and weeks and weeks if something they put in place doesn’t work.”

Executive Director at a specialist college



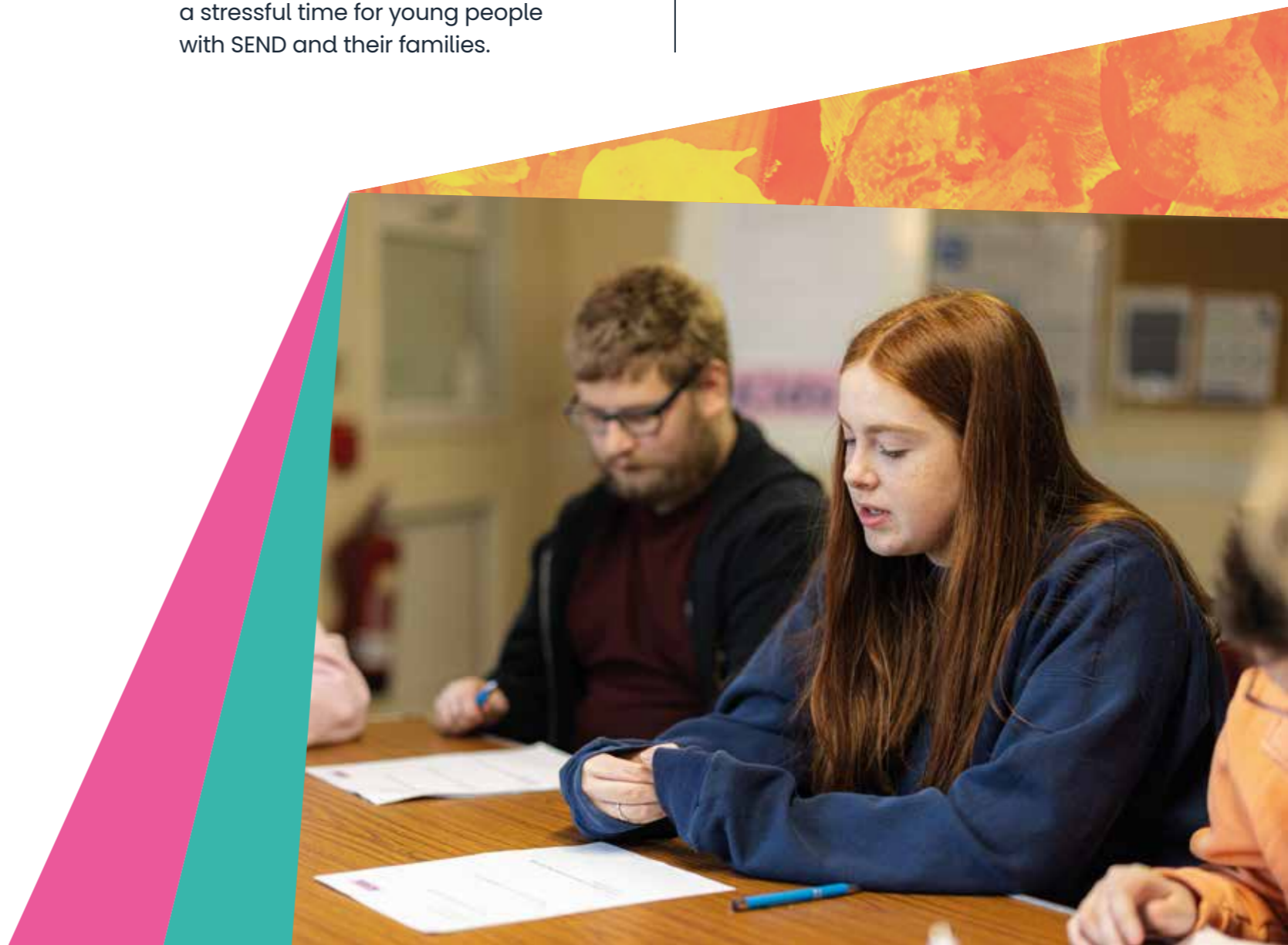
The ‘cliff edge’ phenomenon has also been reported in other research studies.

For example, a recent study on the experiences of transition from children’s to adult health services also concluded that NICE guidelines surrounding transition are frequently ignored.

Specifically, it found that flexibility around age thresholds for services is not practised (Shanahan et al 2020).

This often leaves people without care, resulting in transition being a stressful time for young people with SEND and their families.

The Disabled Children’s Partnership also found that parents reported delays accessing routine appointments for support, and numerous challenges accessing adult health and social care services – with over a third of families reported challenges accessing adult social care services (Lunt 2022).



3. Young people with SEND lack meaningful support to live independently as adults

We spoke to a wide range of young people with SEND with a range of disabilities and needs. It is important to recognise that living independently or finding employment isn't an option for everyone and that many young people with SEND will need and are entitled to ongoing support to help them live good lives.

But for young people with SEND for whom independent living was an option, this was typically a significant aspiration for them. Yet they faced three key barriers that often stopped or thwarted their ambitions in this area.

3.1. A lack of support to develop the practical living skills of young people with SEND

“Young people need to be supported to develop real skills and then have a mechanism to help them apply them and do real things so they are practising and using them in real life. Real skills that are applied in a real context.”

Youth participation lead at a national disability charity

Most young people with SEND we spoke to received some kind of basic information at school with key life skills, such as cooking, personal hygiene, financial management, or relationships. However, the majority reported that it was too basic or brief in nature.

Many young people with SEND had to rely on family for more comprehensive and tailored guidance on how to take care of themselves and their environment.

“Yes, cooking and hygiene and finances but only towards the end [of school].

It was there but they weren't really making sure it was actually working for us.”

Young person with SEND

“I learnt some personal hygiene at school, but I learnt more about that from my Dad...

How to do my laundry, how to clean my room, how to keep my things tidy and neat, how not to mess up the whole place and leave things after I'm done.

I learnt cooking from him because he likes to cook too. We didn't do anything like cooking at school.”

Young person with SEND

This finding was supported by several practitioners who work with young people with SEND who reported that young people were not learning the life skills they needed to be successful and independent as adults, arguing that where it does happen the quality is often poor and doesn't help young people learn and practice skills in a real life context.

“Young people are not learning real life skills. An example is a young person who went to a cooking club, which they absolutely should be helped to do this.

But they're not actually getting taught how to make a recipe, they're just chopping carrots or mixing ingredients in a bowl.

So the quality is not high. They're not being taught meaningful, usable skills.”

Young participation lead at national disability charity

3.2. Insufficient support to secure & maintain appropriate work

Many young people with SEND reported that they hadn't received any training or advice on finding employment.

The few who did have employment support at school stressed its limitations, such as lack of specificity, practicality, or inclusive access to the support provided.

“The school counsellors help us with different career choices but no one tells you how to write a CV or apply for a job.”

Young person with SEND

“I don't actually think any of the children did any work experience, because we couldn't find anywhere that would take them as placements.

It would have been nice to have the school's support there.

There is information but in terms of practically accessing it, it would be nice if the school could do a little bit more.”

Parent

3.2. Insufficient support to secure & maintain appropriate work (cont)

We also heard that familial support was often essential for finding work.

For example, a number of young people with SEND were reliant on family businesses for work experience and income, rather than universally available sources of support, such as school or government schemes.

This introduces the potential for further inequality and marginalisation for young people with SEND whose parents are not in a position to do this.

“My parents helped me find an office job where I don’t have to be mobile and avoid that day to day stress.”

Young person with SEND

“He needs to rely on family for that, he can work in the family business.”

Parent

We also heard cases from young people with SEND who had secured work experiencing at best a lack of support, and at worst discrimination in the workplace.

This resulted in considerable stress, diminished confidence, and in one case even being dismissed from their role.

“I haven’t had that kind of patience in the workplace, I have to adjust to their kind of way.”

No-one wants to adjust to your way, I have to speed up and it’s really stressful. There have been a lot of breakdowns.

I lost a job because of that. I was given a task and I couldn’t do it fast enough and I miscalculated and I was sacked.

No support from my employer, none.”

Young person with SEND

“I feel like people wouldn’t really want me to work in their organisation.”

Young person with SEND

3.3. Barriers to finding and maintaining suitable housing

Many young people with SEND in their 20s were struggling to move out of their parents’ home and several said transitioning into their own housing arrangement was a specific area where they felt that support was lacking.

“I haven’t lived on my own yet. I wouldn’t know where to go to get support with housing.”

Young person with SEND

Amongst those who did manage to access housing designated for disabled people, there were mixed experiences, with some young people being supported well, connecting with other people, and feeling integrated into the community.

However, we also heard reports of limited tailored options, as well as young people with SEND being placed in unsuitable housing for their needs.

“There’s a big difference between residential care and supported living.”

School and college was residential care. Now he’s in supported living he doesn’t have a communal kitchen, another classic example of support not being individually tailored. Supported living is more isolating.”

Parent

One local authority we spoke to also talked about a gap in support in this area, saying there were very few options locally to support young people with more moderate support needs.

“There’s definitely a support gap for young people with moderate needs to live independently.”

We get a lot of young people with more moderate needs who want housing and want to live independently but we’re not at the level of provision.

They don’t want to live in supportive living and it breaks down quite quickly if it’s something we have set up.”

Head of transition support at a local authority

Housing was also an area where a lack of rights education resulted in serious harm for young people with SEND, including discrimination leading to unlawful eviction.

“I don’t really know all the rights for someone with disabilities.”

I got unlawfully evicted when I was 21. My family friend brought (sic) me a lawyer.”

Young person with SEND



4. Young people with SEND still face widespread discrimination and social exclusion

4.1. Most young people with SEND faced bullying & discrimination

Most of the young people with SEND and parents we spoke to described bullying as a result of their disability at school, among their friends, and in the community, which was also reported to intersect with racism in many cases.

This had a significant impact on those affected, including considerable emotional distress and loss of self-confidence.

“People in my college were discriminating [against] me.

Most of the teachers, they try as much as possible to make sure that they questioned them and tell them not to do it again.

It’s something that can make me emotional.”

Young person with SEND

“A notorious bully was expelled, the school took proactive action, but kids will be kids. There will always be someone, but the school has an anti-bullying campaign, they tried their best.

Initially [it held him back] because he didn’t want to be looked upon as someone who is different, didn’t want to go outside.”

Parent

Some young people with SEND, especially young black people, felt that it wasn’t worth reporting as the school didn’t make any meaningful routes of intervention available.

“As a black person, I didn’t find myself in a place where I could file a report or anything, because you’re black it was justified. So I didn’t expect the school to do anything.”

Young person with SEND

“No, nothing about how to go about when you’ve been discriminated. It feels like normal and not like a crime at all.”

Young person with SEND

This is particularly important in the context of transition support as the fear of being discriminated against also stopped some young people with SEND from trying to access support.

Consequently, multiple young people and parents expressed a wish for some kind of awareness raising effort about disabilities in schools for pupils and training for the teachers.

“Just thinking that I can’t exactly get it, like when I’ve had the opportunity I think I’m going to get discriminated and I’m not going to get the help I need.

I sometimes can’t bring myself to go out there, but I just shut off and I didn’t know how to get help.”

Young person with SEND



4.2. Barriers to taking part in social activities & meeting other young people

A significant number of young people with SEND miss out on opportunities to socialise and meet other young people their age.

For example, we commonly heard from young people with SEND who wanted to be involved with extracurricular or community-based activities outside of school or work, but were unable to access them due to confidence and accessibility issues.

“Community, that usually has been a problem.

I do not know how to communicate better and get involved in the local community and I cannot contribute a lot in my community.

First of all, I would like to get involved in community projects that involve physical activities, something athletic.

I can’t take myself out of my fears.

I’m scared of being judged.”

Young person with SEND

4.2. Barriers to taking part in social activities & meeting other young people (cont)

A common refrain we heard was that even groups or activities that labelled themselves as ‘accessible’ or ‘inclusive’, were often found not to be in practice, or at least not for everyone, especially those with complex needs.

“I’ll be honest with you, [where we live] we have very few resources for kids, in terms of after school activities, I don’t know of any.

The ones who say ‘we’re all inclusive’, you turn up with your child and they turn out to be inclusive up to a point.”

Parent

“We’ve always struggled with inclusive activities outside of school.

There was nothing that was truly inclusive.”

Parent

We also heard stories of young people with learning disabilities being left in day services, supported living or residential care where there was no-one else their age.

Overall, a picture emerged of young people with SEND – often those with the greatest support needs – too often being left out of society, and experiencing a reduced quality of life.

“We had a young person who left college and went to a day service and it’s all 40-year-olds or older and he was 23.”

Executive Director of a specialist college

“The biggest things are around potential loneliness and isolation. You can very easily become isolated and lonely, even if you’re in supported living. Trying to keep people connected to the wider community and part of society... you can become very marginalised at the time and become invisible.”

Chief Executive of an education and employment

Another barrier to meeting and connecting with other young people that we heard was a lack of support and education around relationships and sex.

“Looking back, one thing I feel I didn’t get support for was my sexual life. Everyone was most interested in how I could do well with my condition. I didn’t get any support with my sexual life, no sex education.”

Young person with SEND

4.3. Lack of support for young people and families to understand their disabilities

The lived experience of disability within the current support context was often linked to profound psychological distress and loss of confidence, which affected young people’s ability to participate in social aspects of adult life.

There was a widespread feeling from young people with SEND and parents that there is a lack of support for understanding disability.

“What we have in place is not enough. For those with a disabled child there should be an orientation, training, checking from time to time. I spent all the time reading, checking things that could have been told to me in a few seminars.”

Parent

“Growing up, I didn’t really understand my condition, I remember always wondering why I was different from others.”

Young person with SEND

“I wasn’t told about my condition on time, or educated on my condition and had to find out about it myself. It was really depressing and I ran away from home. It took a lot before I could accept reality and face life as it comes.”

Young person with SEND

Some young people with SEND we spoke to also felt that their caregivers and other people in their lives could have had more support to understand their disability and experiences.

“Dad doesn’t understand what I’m going through as a disabled person. And other people are going through that out there.

It would have helped him support me if he came across knowledge and understanding. I’m special and I’m supposed to be treated special.”

Young person with SEND

“Family members don’t always know what you’re going through, they might be busy, they won’t understand you every time.”

Young person with SEND

“My parents gave up very easily on me... At that point I had only myself and myself alone. I think a little bit of training for parents, if they were enlightened to what we’re passing through... they would know we are passing through depression every day of their lives.”

Young person with SEND

4.3. Lack of support for young people and families to understand their disabilities (cont)

We also heard from parents who reflected on their experiences ‘as a journey’ and as well as parents who had benefited from support to understand their child’s disabilities and how to best meet their emotional needs.

“The Autistic Society has really been helpful for shaping my understanding of the autism spectrum and changes that come with education and trying to be more patient and flexible with my daughter.

It’s really impacted me and I think a whole lot of people need a lot of support and guidance.

It’s really so important that we have this awareness as parents.

It has changed me a whole lot, I’ve been able to be closer to my daughter, to my family generally, I’ve been able to understand complex needs.”

Parent



“We saw he was not so much interested in a lot of things.

He has gone through a lot of bullying and being told he can’t amount to something.

I take some responsibility myself, because I didn’t know how to navigate that barrier of being a parent with a disabled child.

I may have said some things that were hurtful but Mencap helped me, I’m grateful.”

Parent

“Training parents on children with disabilities, that would be helpful.

Parents have the responsibility for taking care of their kid but having the training is gonna be a plus.”

Parent

4.4. Late diagnosis and access to support make transition even more difficult

As well as outlining elements that made transitioning to adulthood challenging at the time, various young people with SEND also shared that they thought this period wouldn’t have been as difficult if they’d had support earlier, including an earlier diagnosis.

This sentiment was particularly prevalent amongst neurodivergent young people and those with mental health conditions.

“I still have trauma from that age.

It can be super hard when you don’t understand yourself, when people around you don’t understand you.

I’d be more advanced by now, I would have been in a better place.”

Young person with SEND

“They would have known which school to send me to earlier, my school didn’t have many people like me.

It affected my education and skills. If this problem was identified on time and I had gotten support and strategies it would maybe help me more now.”

Young person with SEND

“It would have been easier if she’d been diagnosed earlier.

Therapies would have been more impactful, she’d be on a better level.”

Parent

It was also stressed that whilst a diagnosis is helpful medically, the pathway to support shouldn’t be reliant on a diagnosis but should be needs-based and focused on what a young person with SEND actually requires.

One of the things we should be doing is going by need not diagnosis; instead of going that person’s got this or that.

It’s not useful in terms of what they need to have a good life. What that does is it dehumanises immediately.

I’ve got needs, [my child] has got needs, we’ve all got needs.

Parent



5. A perfect storm is driving services towards financial breaking point

A confluence of factors, such as increased complexity of demand, the current economic climate, and persistent under-funding are converging to push an already over-stretched sector to breaking point.

5.1. Demand for support is growing

Commissioners in different parts of the country and providers across a range of settings commonly reported that demand for support is growing, particularly the number of young people with complex and/or multiple needs.

A number of stakeholders attributed this to the knock-on impacts of the COVID-19 pandemic, saying they had noticed a distinct increase in the number of young people with multiple, complex needs, and in particular mental health issues presenting alongside SEND.

“The number of young people with additional needs who are transitioning is increasing.

Demand and complexity is going up. It’s a bigger and more complex cohort so meeting needs is more challenging.”

Local SEND commissioner

“The needs of young people have been changing since COVID. We’re seeing a lot more young people with complex needs. So the transition is harder because it needs more specific provision and support.”

Assistant Head of an AP secondary school

“The complexity of needs and the timeliness of support that is required is a challenge. Some young people need really intensive support for a period of time, they can’t just complete an assessment, get set up support and move on.

Often things are kicking off for the young person, so [we] need to be more involved.”

Chief Executive of a supported employment provider

“The nature of the young people we are seeing now is far more complex needs. And also multiple, co-existing needs since covid.”

Chief Executive of a supported employment provider

“This year has been particularly hard.

The needs young people have been presenting with, makes it harder to meet those needs because lots of FE settings don’t have occupational therapists, or speech & language therapists or are using the borough’s therapist, who is already very over-stretched.”

Assistant Head of an AP secondary school

This requires more resource-intensive support for already over-stretched and under-funded services.

It also makes planning for often unknown needs much harder for the new setting, who don’t always know who they will be supporting for the new academic year.

This can lead to delays in securing the appropriate support, which is itself a key barrier to a smooth transition and we heard multiple stories of placement breakdown as a result.



5.2. The current economic climate is exacerbating insufficient funding for services

Government funding was unsurprisingly another big concern across the sector and was acknowledged by both local and central government stakeholders.

The funding situation was already extremely difficult, but we heard how the current economic challenges have led to increased costs across the board.

These have been compounded by an increase in and growing complexity of demand, with no additional funding available to cover these costs.

This has led to services running at a loss, making services more difficult to commission and deliver, and creating significant gaps in support.

“Very few local authorities are able to support as successfully as we would like.

I completely appreciate they’re challenged by staffing and do recognise their issues as well. It’s almost a thankless task.”

Executive Director at a large charitable provider

“The current economic challenges have led to increased costs. Not just staff costs, where we’ve had two increases in staff wages and a National Living Wage increase as well, but costs of doing any activity, working with people, travelling.”

We’ve seen a build up of costs across the board that’s making commissioned services more difficult to deliver.”

Operations Director at a national charity

“There’s a big gap [between children’s and adults’ services] but it requires resources, money, and staff to fill it, which is a big challenge and none of the providers are willing to take it on without additional funding.

We want to commission something differently.”

Local SEND commissioner

“It’s bigger than that talking about education funding of course but schools are working in deficits and there’s less money available, which leads to schools being less effectively able to meet young people’s needs without it.”

Assistant Head of an AP secondary school

For example, we heard from one provider whose funding from the Government covers less than half of their operating costs to deliver their programme.

“We get high needs funding for our education programme as everyone has an EHCP.

But the funding is minimal. We get £12k a student per year, while our costs are £25k for each student per year and that gap’s got bigger since the cost-of-living crisis.

The Government is trialling a scheme where you don’t need an EHCP to do a supported internship.

But if you don’t have an EHCP, you get less than half the funding [from the Government], so we’d really have to cut down the offer quite drastically.

However, you need to put in the resources to get results.”

Chief Executive of an education and employment provider

We heard from another provider who recently had to decide to withdraw from operating a commissioned service because of the high costs of running it in the context of already very tight operating margins.



“It’s very difficult in the current climate.

We have very tight operating margins, which means that if any gaps in who we are supporting emerge and we can’t fill it, it makes the service run at a loss.

We’ve had to hand back some commissioned work due to the high costs and disparate nature of needs.”

Operations Director at a national charity

Chapter three

What does good transition support look like?



Good transition support can have a transformational impact on the experience of a young person with SEND becoming an adult.

When done well, it can give them, and their families, the skills, confidence, knowledge and support they need to live good lives as an adult, whatever that may look like for each person.

Despite the myriad challenges discussed in the previous chapter, the situation is not all bleak.

We heard many examples of great support provided to young people with SEND as they move into adulthood.

Young people with SEND spoke very positively about the support they received from teachers and health services and we spoke to numerous providers delivering critical support from passionate and highly-skilled professionals.

To define what good transition support looks like, we worked with young people, parents, and practitioners to co-develop a set of principles of good transition support, based on their experiences of transition support and what they valued most in the support they'd received.

In this chapter, we share these principles alongside key research findings identifying key factors of good support, showcasing a snapshot of good transition support through six good practice examples.

Co-designed principles of good transition support

Personalised:

Tailored support to the needs of the specific young person, recognising each young person will have different aspirations, abilities and needs.

Relationship-based:

Ongoing support provided by a trusted adult that knows the young person with SEND, in order to provide continuity and a familiar face throughout their journey into adulthood.

Timely:

Early planning to provide sufficient space and time for young people with SEND and their families to prepare for adulthood without feeling rushed.

Explorative and collaborative:

Exploring real and meaningful options and choices with the young people with SEND and their families, wherever possible, based on needs, aspirations and what is available locally.

Clear and honest:

Clearly communicate what young people with SEND and their families can expect, when, and from whom.

1. Personalised:

Tailored support around individuals' specific needs

Good transition support is personalised. It is based on a deep understanding of a young person's needs so that options and support can be tailored to their specific needs and aspirations.

We heard countless times from young people, parents and practitioners alike about how important this is, from highly tailored education support to personalised communication plans to job roles scoped around young people's skills and needs, or personalised support options for young people with the most complex needs.

"The daily consistent support from the school, it was tailored to everyone's specific need individually.

I needed attention. I get really emotional at times and the support they give us for social skills means I can approach a group of people without feeling less of myself."

Young person with SEND

"We provide individualised, personalised, and differentiated learning and teaching on a daily basis and plans for the future.

It's all about how we personalise our offer, to young people, to make sure it fits their needs because they won't be successful with us [without that] let alone planning to move into adult life."

Executive Director at a specialist college

"Different disabilities have different profiles.

Support should be shaped for these different groups. The needs of people with learning disabilities, especially severe ones, are very different from people with physical disabilities.

Support needed varies by socioeconomic, educational and cultural background."

Parent



Team Domenica: Tailoring training and job roles to match individuals' skills and needs

Team Domenica is a Brighton-based charity that provides personalised education, training and employment opportunities for young people with learning disabilities aged 19-25 through a Wrap Around Programme.

In the first year of their programme, young people take part in a mix of training, education and social activities four days a week, through a personalised and tailored curriculum, in-house training in cafes, as well as work experience tailored to the specific needs of each person.

In the second year, young people move into supported internships with more than 50 employers from a range of sectors.

Team Domenica works with each employer and young person to carve out a job role so they can fit in and flourish with an employer with a view to getting paid work. They are also supported with one day a week of classroom based learning to help develop skills for the workplace and life.

Team Domenica also provides ongoing 'wrap-around' support for young people once they've completed the programme, offering young people careers advice and guidance, social activities and events, pastoral support and signposting to other services.

Their programme has achieved an employment rate of 82% over 6 years.

It is in high demand locally, with many more people wanting a place than is available, but Team Domenica

is unable to meet the scale of the demand due to insufficient funding.

A key enabler of providing personalised and tailored support is having highly-skilled and sufficiently resourced services.

Highly-skilled staff who were passionate about their work was mentioned by nearly all provider stakeholders we interviewed as key to delivering good quality specialist and tailored support - whether this was in school, colleges, social care team, or employment support.

The importance of supporting a new setting to understand the specific needs of young people was stressed by multiple stakeholders.

For example, where a young person with SEND is moving to a new setting, such as from school to college, or from a children's service to an adults' service, we heard examples of good practice where the current provider would work with and alongside the new setting to help them understand the specific needs of the particular young person.

This often involved supporting a new setting through being available for regular visits and meetings for between a few months to up to a year or more.



2. Relationship-based:

Continuity through a relationship with a trusted adult

Good transition support is based on a relationship with a young person with SEND (and their family) and a trusted adult they can go to for advice and support.

Young people we spoke to frequently mentioned an adult in their life who they trusted and who helped them during their transition into adulthood.

They were often a professional who had an existing relationship with the young person, but were not always in a specific transition support role, taking on the role of an informal mentor.

Westside School: Maintaining relationships through an alumni programme

Westside School is an Outstanding-rated alternative provision secondary school in West London that supports young people who are disengaged in mainstream education.

They support young people with a wide range of special educational needs and disabilities, including autism and mild learning disabilities.

Westside School places a big emphasis on getting transitions right, having a dedicated senior transition lead leading a small transition team. As part of this effort, Westside wanted to take charge of transition post 16 and beyond so they developed an alumni programme to *“keep a layer of connection between past pupils and the school”*.

As part of their alumni support offer, when a young person leaves the school, Westside:

- Maintains contact and can go into post-16 settings if things are breaking down
- Invites young people back for academic or pastoral support
- Sends out letters to young people and parents to remind them that support is here if they need anything
- Holds an open slot every Friday afternoon at the school for anyone who wants to come back to get direct support from staff
- Supports some young people with UCAS applications or who have graduated from university and come back for support around finding employment
- Holds an alumni event each year to have a chat to keep that connection

For example, young people with SEND often reported having a close one-to-one relationship with a teacher, who mentored them and gave them ongoing support during and beyond this transitional time, with some still in touch well into adulthood.

These teachers advocated for them and helped them find appropriate support or workplace schemes, as well supporting young people to feel more confident interacting with their peers or other goals such as completing university courses after leaving school.

“I did get to be really close with my teacher.

She has been providing me with moral support, I found it difficult to integrate and have conversations with people [so] she’s been helping me to know how to interact with people.

She’s been really helpful in my journey. She encouraged me to do the research. We’re still in touch.”

Young person with SEND

“If I didn’t have the support [from my teacher], I probably wouldn’t have finished university. I wouldn’t have had the courage.

There was a point when I broke down, I was really depressed, I was locked inside. I’m still in touch with that teacher. He still calls me, he still chats to me.”

Young person with SEND.



2. Relationship-based: Continuity through a relationship with a trusted adult (cont)

While these arrangements tended to be informal and ad hoc in nature, several stakeholders spoke about the value of formalised roles that filled a similar function – providing consistent support, a familiar and trusted person to go to, and continuity between settings – such as mentors, a SEND navigator, or transition keyworker, that often used to exist but are now increasingly rare due to funding reductions.

“We can’t afford [to provide housing support] now so we depend on charities but many have closed so it’s difficult for everyone.

For example, Keyring used to support young people when leaving care or their family home to live independently with support from a keyworker who provided practical support around paying bills, tenancy, offering advice and guidance, counselling and nurturing.

It’s no longer there but it was really helpful when it was.”

Head of transition support
at a local authority

We also heard many examples of providers, in an attempt to prevent new placements from breaking down, offering young people ongoing, ‘wrap-around’ support, such as Team Domenica or Westside School, to maintain relationships with young people beyond their initial placement and provide continuity between settings.



Fair Shot Cafe: Training and mentorship through a bespoke Hospitality programme

Fair Shot is a social enterprise cafe that empowers young adults with disabilities who want to make the transition from education to work to develop skills and find jobs in the hospitality sector.

Each year they offer young people aged 16-24 with a learning disability and/or autism the chance to gain real-life work experience through a year long Hospitality Support Internship Programme to develop their skills as baristas and cafe assistants.

Fair Shot partners with Mencap to connect young people with a mentor or job coach, forming a trusted and supported relationship throughout the programme.

The programme is a full-time study programme that teaches young people a range of practical and transferable skills such as effective communication, health and safety in the workplace, and time management.

From day one, they’re on the coffee shop floor watching, practising and honing their coffee knowledge.

Young people also receive a variety of qualifications such as a Speciality Coffee Qualification provided by their roastery partner Curious Roo and a Level 2 Food Hygiene Certificate.

After young people graduate the programme, Fair Shot Cafe works with over a dozen employment partners to find their graduates

paid employment, with ongoing support from Fairshot and Mencap mentors to both their graduates and employers for six months.

At the end of the programme, 90% of learners are employment-ready, and 100% of employment-ready young people are now in employment.



3. Timely:

Planning the next step early

Early engagement and planning with young people with SEND and their families as well as with other services is another key principle of good transition support.

Timely and early support is necessary to provide sufficient space and time for young people and their families to think about and prepare for the future without feeling rushed. Conversely, when this doesn't happen we heard how this can lead to delays in receiving support, or in the worst cases, no support available in a new setting.

For example, one provider told us that more than half of the families they work with didn't have appropriate support in place when they started at a new service or setting, often because of late planning.

This is key for all young people with SEND, but especially important for young people with profound or complex disabilities, where a lack of support can have a significant impact on their quality of life.

Building early relationships with young people with SEND and families was seen as one of the key factors in ensuring early conversations about transition are able to take place.

Stakeholders talked about the need to build trusting relationships so young people and their families have "someone within the system" to go to for information, advice or support.

"Working with families early allows you to build trust and gain success when they've had a really really difficult time.

So if they need more advocacy and support later on they've already had a really positive experience."

Operations Director at a national charity

Early collaboration between services was also key. Providers and schools mentioned the importance of connecting and working with other services and professionals to secure the support young people need in their next step.

Early engagement about transition with other services was reported as particularly critical in ensuring support was secured in a timely manner.



"The earlier you plan, the better.

Young people are less fearful then because they've had the conversations.

It can often be a scary time going somewhere new. For us, it starts with admissions.

We're able to go out and see them where they are... and understand the context and build a relationship before they join us."

Assistant Head of an AP secondary school

"We can only support transition into adult provision if placements are found in a timely manner.

It can sometimes take six months or more to transition from school into college so we know we need that time, but don't always get that.

Sometimes it feels like students are being set up to fail because they don't have enough time or support."

Executive Director at a specialist college

David Lewis College: Planning the next step from day one

David Lewis Centre is a foundation that provides education, residential, day opportunities and medical and therapeutic support for people with learning disabilities, epilepsy, and autism. In their Outstanding-rated specialist college, they start their transition planning from the first day a young person joins. They undertake a 'baseline review' with the young person and their family, and advise parents to start the process of looking for the next placement in two years' time.

Throughout the young person's time at the college, they will hold four to five transition meetings involving the young person (wherever possible), parents, and a range of professionals involved in that person's life. These include a yearly review where they plan next steps with parents and the local SEND officer. In the final year, they facilitate a transition meeting to start the practical steps of a young person leaving and what provision they will have.

The final step David Lewis College provides is supporting the practical transition into the next placement by going to the placement and providing information and support to the staff there. From that point, they gradually withdraw support, starting with being there with the young person for the first hour, and then withdrawing when students are ready.

4. Explorative and collaborative: Exploring meaningful options with young people with SEND & families

Good transition support fully involves young people with SEND and their families.

It enables a young person with SEND and/or their family to explore real and meaningful options based on information about what is available locally and as well as what their aspirations and needs are, especially where independent living or work is not an option.

We heard a number of ways that different services did this, ranging from dedicated transition teams, to teachers or other professionals who acted as mentors, and from large market-style events bringing together a range of services and employers to help engage and decide, to small, school-based focus groups with parents.

For example, one school proactively arranged focus groups with parents of disabled children to explore parents' views on their involvement in their child's support and any barriers they were experiencing, which were then used to inform school policy.

A number of stakeholders specifically mentioned the importance of having a dedicated transition team, from school-based teams to local authority or health teams, who work with young people with SEND and families as well as other local services to connect them and support young people to find the right support at the right time.

One example is Islington Council's

transition team in adults' services, which supports a pathway for young people with learning disabilities, as well as a separate pathway for young people with a range of more moderate special educational needs and disabilities.

Westside School also has a small central transition team, which they highlighted as a key to their improved transition support for young people.

The team is responsible for supporting young people to explore options, connecting with other providers, and managing their alumni programme.

"We had a focus group at the school, alongside the local council, to discuss the whole process of learning skills and how the parents needed to be involved to make it a success.

Most of the things we discussed was a reiteration of parents' involvement and how important supportive people around them can be."

Parent



"It has to have the involvement of a number of professionals.

Education cannot manage the next step other than provide that support to local authorities and potential placements.

It needs to be collaborative, a joint enterprise."

Executive Director of a specialist college



Leeds City Council: SEND Next Choices

'SEND Next Choices (getting ready for adult life)' is a free annual public event for young people with SEND and their parents, carers, support workers and teachers to help them explore options to prepare for adult life.

Organised by Leeds City Council's Employment and Skills Service, in partnership with their Children and Families Service, the event brings together over 60 organisations from education, employment and community sectors in Leeds in one room in a 'market stall' type event.

Young people with SEND and their families can find out about a wide range of potential post-16 options including jobs, training, apprenticeships, college courses, voluntary work, leisure activities, finances, support and benefits available in Leeds. There are also information sessions about supported internships where young people and families can find out what they are and how they work.

The event is widely published and promoted, being advertised on the homepage of the Local Offer.

The Employment and Skills team also offers to visit schools or colleges to deliver an assembly, provide information sessions to students and teachers about career choices and to help students prepare for the event, or attend parents' information sessions.

As a result, the event is typically very well attended by young people with SEND and families with high engagement from schools and colleges who help to organise visits for their pupils, with 85% of young people saying they have more ideas about what they want to do next as they get ready for adult life.

5. Clear and honest:

Clear communication with young people, families & services

Lastly, good transition support is clear and honest about possible next steps.

A number of stakeholders talked about the importance of clear and effective communication – both to young people with SEND and families about what support is available and what to expect, as well as between services about young people’s specific needs and circumstances.

We frequently heard from parents and stakeholders about how poor information for families about next steps can be, as well as how a lack of communication between services and settings can lead to delayed or poor transition outcomes for young people with SEND.

For example, Hammersmith and Fulham Council run a local SENCO forum, bringing together all SENCOs from secondary, sixth form, college, and primary schools.

The transition head at a local secondary school highlighted the forum as one of the key success factors for their transition support, describing it as *“really helpful to find opportunities and placements [for young people]. The SENCOs know me and can call if a young person is struggling in their next placement.”*

“Transition support needs to be open and honest.

Sometimes it’s hard to get information from other schools.

We would provide all the information about the students to a new setting.”

Executive Director at a specialist college



Sense: Ensuring young people, families and new settings know what to expect

Sense is a national charity supporting people who are deafblind or who have a hearing or vision impairment and another disability.

They support 1,400 children and young people aged 0–25 years who have a multi-sensory impairment (MSI) or who have a single sensory impairment and additional needs.

Sense supports them throughout their life, but particularly during specific pinch points, such as the transition into adults’ services.

Sense’s team provides transition support to anyone going into adult residential care to understand what they might need in the home and what might be a suitable placement for them.

Sense prides themselves on great communication and emphasises the importance of clearly communicating what is happening at every stage and being open and honest about what they can get from the service.

Their transition support is focused around communication in particular – both with young people and their families, as well as supporting new services.

All to understand the particular set of communication needs and preferences each individual has, based on their close relationship with the young person and family each staff member has.

This includes:

- Helping young people and families to know what to expect, when, and from who
- Working with schools or adults’ services so they understand how to work with that person’s particular MSI needs, based on individual communication needs support plans
- Supporting young people and families with medical appointments and clinics, EHCP reviews, annual reviews to ensure MSI needs are met
- Providing advocacy and rights advice and support where needed – for example, if a young person isn’t getting the support they need and are entitled to in a new setting



Chapter four

Priorities for action



There are many examples of young people with SEND receiving life-changing support that enables them to move into adulthood ready and supported.

But too often they are exceptions to the norm. As a collective, it is clear we need to do better.

Currently, too many young people with SEND are falling off the cliff edge, left without the support, skills and connections they need to live good adult lives, which will look different for each individual.

As part of this research project, we worked with young people with SEND, parents, and practitioners in a series of co-design sessions to identify and prioritise five key areas for action for the sector. These are areas where providers and commissioners of transition support could have the biggest impact on young people's experiences, but are also within their abilities to do something meaningful about. So, for example, while funding is a key challenge and would make a significant impact, it isn't one of the priority areas for action as it is not something within the control of the sector.

We recognise that others reading this may have a different 'top five' and so we share this as an invitation to others in the sector for a discussion about how we can work together to ensure young people with SEND are supported to live good adult lives.



Top five areas for action to improve transition support

1. Navigating the system:

Helping young people with SEND and their families navigate the system

2. Life skills:

Supporting young people with SEND develop real skills for life

3. Employment support:

Supporting young people with SEND find and keep work

4. Leaving no-one out:

Increasing opportunities for young people with SEND to take part in social activities and connect with their peers

5. Family support:

Supporting parents through peer connection and advice



In response to each of these priority areas, we worked with young people, parents and practitioners to come up with and refine practical ideas and solutions to address these challenges.

We wanted to share these ideas as inspiration for action to show that, although the challenge is big, there are practical and tangible solutions we can develop together.

And we believe this also shows the value and importance of working with people with direct experience of transition support, drawing on their skills, knowledge and experience to develop solutions that really address the biggest needs.

While some of these ideas are novel, others exist in some form or another. We think this tells a wider story about what people want and need and what is currently consistently available across the UK, underscoring the postcode lottery nature of existing transition support.

These ideas are not intended as polished service proposals, but as starting points for conversation and collaboration around how we can turn the transition into adulthood for young people with SEND from a daunting and confusing time, to one of hope and opportunity.

So we present these ideas as an open invitation to readers working in this field to work with Kids to explore these challenges and ideas in more detail over the coming months and years.

1. Navigating the system:

Helping young people with SEND & their families navigate the system

“The impact [of making the transition system easier to navigate] would be astronomical. The system is like a spider web. It’s completely confusing.

I feel like I’ve had to do a law degree to support my son and find out about his condition to get medical support.”

Parent

Parents shouldn’t feel like they need a law degree to navigate the system of transition support. Young people with SEND described it as confusing and scary. Parents frequently reported not knowing where or finding it hard to find out about locally available support options. And both young people and parents frequently weren’t aware of what they were entitled to or what their rights are.

But we also heard multiple positive experiences, where young people and families had support and advocacy to navigate the system. This ranged from personalised emotional support, practical support such as finding suitable housing options, as well as proactively linking with other support, and helping families advocate for provision and rights they were entitled to.

Idea for inspiration: A transition mentor

The ‘transition mentor’ is a trusted adult who would provide targeted support for young people with SEND aged between 16 and 25 years to help them successfully move into adulthood.

The transition mentor would maintain contact and continuity and be the main point of contact to support a young person with SEND navigate the world.

They would provide a safety net; stop escalation of problems; encourage self advocacy; and connect young people to local services as well as the wider community.

A key role for transition mentors would be working with young people and their families to help them avoid the cliff edge that many young people face as they leave school and/or children’s services by supporting early planning, understanding rights and entitlements, exploring real options, and linking up with different services and providers to provide continuity throughout the transition process.

2. Life skills:

Supporting young people with SEND develop real skills for life

“Skills can help make you more independent and take care of yourself and fend for yourself. I got skills when I was still in school and it helped a lot. No-one can take it away from you.”

Young person with SEND

Learning practical life skills, for those who have the capacity, was often the first step towards young people with SEND being able to live more independently as adults. When done well, supporting young people with SEND to develop real life skills they can apply in practice can open up possibilities and give them confidence for the future.

But we heard examples of young people with SEND who felt they weren't given the opportunity to develop these and stories of young people staying in college as a form of 'day care' rather than learning life skills. In particular, practitioners emphasised the importance of supporting young people with SEND to develop real and meaningful skills for life that are applied and practised in a real world context – whether that is learning how to cook, managing your finances, personal hygiene and taking care of yourself, doing genuine work experience, or taking public transport.

Idea for inspiration: the 'Transition House' service

The 'transition house' service would be based in a local building where young people with SEND can come and learn real life skills and prepare for their next steps, including offering workshops, day sessions, and overnight stays to build their skills and confidence and offer respite for parents.

The 'transition house' service could partner with the local council and/or local investors to fund a low cost building where the service can offer placements to young people with SEND or parents. The house would be (re)designed to be fully accessible and equipped with assistive technology to ensure that the transition house is welcoming for all young people.

In the house, young people with SEND would learn life skills through workshops and supported practical activities such as shopping, independent travel, managing money and budgets, cooking meals, personal hygiene habits, plus more.

The service would involve and support families throughout the programme, with ongoing digital support provided through check-ins, advice and information, and signposting to other relevant support.

3. Employment support:

Supporting young people with SEND to find and keep work

For young people with SEND for whom employment is an option, finding and keeping work was a particular priority. We heard from many young people who often felt frustrated by the lack of support they had received. However, we also heard from young people who had very positive experiences and were supported to develop skills and confidence to find work.

This support varied but included things like accessible employment workshops and events to explore options and pathways; employability skills training at school or college; help to find suitable work placements, and working with employers to increase their understanding of how to become disability friendly employers or shaping new roles tailored to young people with SEND.

Idea for inspiration: Disability Confident Pathways

Disability Confident Pathways would be a national programme funding and supporting large, local events and support for young people with SEND. These events would bring together a wide range of employers and community organisations who would welcome and support young people with SEND into their organisations.

The events, like SEND Next Choices in Leeds, would be aimed at young people with SEND who are at the start of their journey of figuring out what path is right for them. Events would be interactive so young people with SEND can try out activities, find out about a range of options, and get involved. The aim is to inspire young people with SEND and give them a sense of direction for their next steps and support each young person with SEND for whom employment is an aspiration and option to create an 'adjustment passport'. This would outline each young person's skills and adjustment needs so they feel confident communicating what arrangements they need to succeed in the next steps.

These could lead to work experience, supported internships or paid work. Or it could lead to other opportunities and pathways, including volunteering and involvement in community-based programmes that provide meaningful opportunities for young people with SEND to take part in community life, especially for young people where work isn't an option.

The events would also be a way to increase community engagement and awareness of disability issues and would be coupled with a support package for employers to help them better understand disabilities in a work context, be more confident implementing reasonable adjustments and creating genuine opportunities for work experience and paid jobs.

4. Leaving no-one out:

increasing opportunities for young people with SEND to take part in social activities and connect with their peers

“The best support was from support groups. You are free to say what you want and how you feel, [my] confidence went up & up. Without the peer groups, I wouldn’t be here today. Online groups, friends, people with similar disabilities to mine, just having a chat with them, makes me more comfortable to live my life and live my life free.”

Young person with SEND

Too many young people with SEND are excluded from society and young people with SEND pay a heavy emotional toll as a result. We heard from numerous young people with SEND who felt left out, misunderstood, lonely, unseen and depressed.

There is an urgent need to support young people with SEND, particularly those with the most complex needs, to connect with other young people and take part in their communities, so that no-one is left out. Areas that young people with SEND said either really helped them or where they wanted more support included:

- opportunities to develop social skills at schools;
- genuinely inclusive social groups and events where they can meet other young people
- peer support groups where they can connect either in person or online with other young people who understand them and their experiences; and,
- supported housing schemes that support young people to integrate into the community and participate in meaningful activities.

Idea for inspiration: social & life skills through a personalised education

A more flexible, personalised and accessible curriculum that has a greater focus on developing key social, life, and vocational skills that will support young people with SEND to take their next step with confidence. Mainstream and specialist schools should be supported to develop personalised, holistic education programmes for young people with SEND that prepares them to thrive in adulthood, based on their aspirations and needs.

This would include a key focus on supporting young people with SEND to develop social, emotional and communications skills, for example through training, mentoring and peer support groups with other young people with SEND. There would be an emphasis on developing practical living skills through real life practice, travelling to field trips, and work experience and partnerships with other organisations and employers in the community.

5. Family support:

Supporting parents through peer connection and advice

“I would be lost without fellow parents. I would be completely at a loss.”

Parent

For most young people, their parents are their primary source of support.

This is especially true for children with the most profound or complex disabilities.

Despite this, parents frequently mentioned how little practical or emotional support they had when trying to support their children or find information relevant to their child.

In fact, parents we spoke to often mentioned connections with other parents as a key source of knowledge and support, typically formed informally through meeting other parents and guardians at their child’s school.

As one parent put it:

“many parents see the experience of parents of older young people as the single most useful source of advice.”

Parents reported supporting each other with a range of topics, including mutual support and information about relevant disability charities, advice on legal rights and processes, information about specialist needs provision and support channels, and even lobbying medical bodies and councils together.

Idea for inspiration: Peer support and celebration network

An online peer network that connects parents of children with disabilities with each other to support each other to *“navigate a way through the rumours, fears and received opinions, to share knowledge, insights and tips, and to celebrate their children”*.

The parent network would create a space where they draw on the collective passion, skills, and experience of other parents. It would be supported to come together at regular events where family, friends and the wider community can celebrate the achievements of young people with SEND in their lives.

The network could also be supported to feed into national policy discussions and development and organise or take part in campaigns around key issues identified by parents and young people with SEND or that showcase and raise the profile of disability.

Our recommendations

With the views and experiences of young people with SEND and their families front and centre:

1. The Government should prioritise action to prevent young people with SEND from falling off the ‘cliff edge’ as they become adults by appointing a Minister for Special Educational Needs and Disabilities (SEND), who will take responsibility for fixing the disjointed transition support system for young people with SEND.
 - a. The minister for SEND should work with named leads from the Department for Education, the Department for Health and Social Care, the Department for Levelling Up, Housing and Communities, the Department for Work and Pensions and any other relevant departments to publish a national, cross-departmental plan.
 - b. Alongside the cross-departmental plan, the named departments should work with Kids and the wider sector to ensure the views and experiences of young people with SEND and their families are at the centre of any plan, by running a nationwide listening campaign with young people, parents, and practitioners to understand and prioritise key challenges and develop ideas for better transition.
 - c. The plan should outline how they will work together with the sector to address the current challenges and close the support gaps by the end of the next term of government, paying specific attention to the rights and needs of young people with the most complex needs.
 - d. The plan should set out national standards for transition support with appropriate support and funding for local authorities as well as meaningful compliance mechanisms, building on the DfE’s SEND & AP Improvement Plan, findings of the House of Lords Public Services Committee inquiry, and insights from Ofsted and the Care Quality Commission (CQC) thematic reviews of preparation for adulthood arrangements in local areas inspections.
 - e. The plan should provide funding to 10 areas to bring local partners together to develop and pilot new models of inclusive, joined up, and meaningful transition support.
 - f. Building on the work of the DfE’s post-16 stakeholder group, the Government should ensure their upcoming guidance is informed by the views of young people and parents and adopts a co-designed shared definition, using our principles of good transition support as a starting point for discussion.

2. Commissioners of local children services and adult services should ensure that every young person with SEND has access to timely, quality transition support by:
 - a. Establishing formal mechanisms for meaningful participation of young people with SEND and families to ensure all transition support is co-produced.
 - b. Establishing and publishing details about the elements that make a good transitions plan and measures that are taken to quality control the support in the plan.
 - c. Reviewing transition service arrangements to ensure they comply with the law and government guidance and identify actions for improvement, drawing on insights from this report and others such as the upcoming Ofsted and CQC report on SEND inspections, as well as local expertise and experience.
3. Led by young people’s and families’ expertise, public, voluntary and private providers of transition support should collaborate to raise awareness of the importance of fixing the broken transition support system by:
 - a. Using their networks to engage local and national policy stakeholders with the importance of transition support in the run-up to the upcoming General Election.
 - b. Registering their interest with Kids to connect and collaborate on how to transform transition support.
 - c. Convene as a new national cross-sector alliance.

Throughout, the strengths and needs of every young person, especially those with the most complex needs, and their families, who are often forgotten, must be recognised and resourced, so that a good transition into adulthood becomes a reality for all.

1. The Government must step up and demonstrate action on a national level to fix the disjointed transition support system.
2. Local Authority Commissioners must comply with the law and catalyse access to timely, quality transition support.
3. Led by young people’s and families’ expertise, a new national cross-sector alliance should convene and collaborate to achieve transformational change.



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