

Kids

Disabled children
say we can

On the cliff edge

Disabled young
people and their
journey to adulthood.



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.

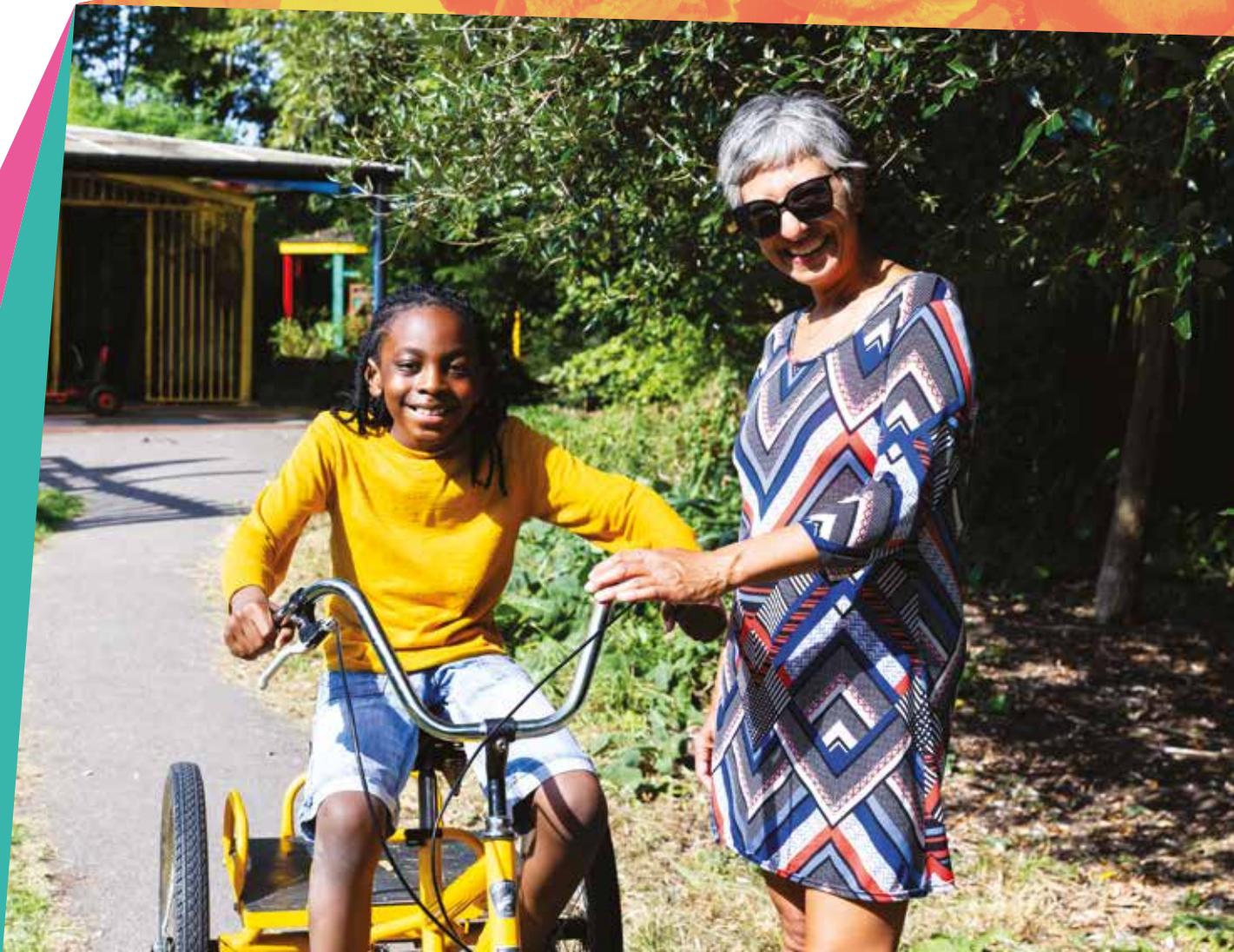
A better system would open doors to different futures, reflecting individuals' strengths and needs.

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



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.

Kids

Disabled children
say we can

Together, we can break down barriers.

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