OUR LIVES IN YOUR HANDS

Will the SEN reforms deliver 'support and aspiration' for disabled young people?

Ambitious about Autism

pears foundation

About autism

Autism is a lifelong developmental disability which affects 1 in 100 people in the UK. It affects the way a person communicates and how they experience the world around them.

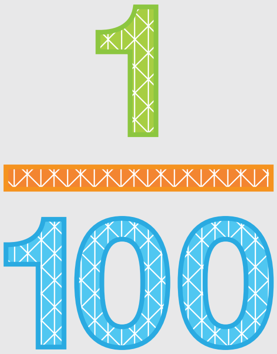
Autism is described as a spectrum condition. This means that while people with autism, including Asperger's Syndrome, share certain characteristics, they will be highly individual in their needs and preferences. Some people with autism are able to live relatively independent lives but others may face additional challenges, including learning disabilities, which affect them so profoundly that they need support in many areas.

Ambitious about Autism

Ambitious about Autism is the national charity for children and young people with autism. We provide services, raise awareness and understanding, and influence policy. We exist to enable children and young people with autism to learn, thrive and achieve.
www.AmbitiousAboutAutism.org.uk

Thanks

We would like to thank all the children, young people and families who have shared their experiences in this report. We would also like to thank Pears Foundation, whose generous support has made this report possible.



Autism is a lifelong developmental disability which affects **1** in **100** people in the UK.

Less than **1** in **4** young people with autism continue their education beyond school.

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Foreword

Every young person is unique.

This is a fundamental truth that should not be overlooked or contradicted just because of a disability. Young people with autism who have special educational needs require different types of support to access school, college, university or a work place. The case studies in this report demonstrate that all too often autistic young people do not get the support they need.

My own disability does not prevent me from having hopes for the future — I wish to lead an academic life in mathematics and English literature — and all those who have contributed to this report have their own goals. I hope the examples of the challenges met by autistic young people and the ideas set out in this report will aid the Government in improving its reforms to the special educational needs system.

We want to ensure every disabled young person is a success story.

Genevieve Fletcher
Youth Patron
Ambitious about Autism

Introduction

Families, Government and professionals are in agreement that we need to improve the system of support for children and young people with special educational needs (SEN) and disabilities.

Currently children with autism are disproportionately bullied[1] and excluded at school.[2] Less than 1 in 4 young people with autism continue their education beyond school;[3] and children with a Statement of SEN are more than twice as likely not to be in education, employment or training at 18 than their peers.[4] The Children and Families Bill is a chance to reverse these trends.

The Green Paper published in March 2011 promised 'support and aspiration' for all children and young people with SEN and disabilities and their families. But will the **Children and Families Bill** deliver that promise in practice?

In this report nine families of children and young people with autism set out their experiences of the current SEN system. We ask: **'what needs to change so that their experience will be better under the proposed new system?'**

These stories provide the acid test for the Government's SEN reforms. They demonstrate where further changes are needed to the **Children and Families Bill** for it to genuinely deliver 'support and aspiration' for all disabled children and young people, for generations to come.

Some of the families in this report wanted to remain anonymous, as they were concerned that being open about their experience might impact on their ability to access support for their child in the future. Some names have therefore been changed.

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1. Batten, A et al (2006), Autism and Education, The National Autistic Society.
2. Department of Education (2012), Permanent and fixed period exclusions from schools and exclusions appeals in England 2010/11.
3. Office for National Statistics (2001), Census Report and Data Service (2011), MI Reports — Regional Learning Disability/Difficulty Report.
4. National Audit Office (2011), Oversight of Special Education for Young People aged 16–25.

Key recommendations

Our key recommendations based on learning from these families' stories are that the Children and Families Bill should be amended to include:

- A clear right for young people to restart their Education, Health and Care Plan if they return to education at any point up to the age of 25.
- A duty on local authorities to provide the support set out in the local offer, as well as publish information about it.
- A duty on local authorities to promote continuity of the support set out in an Education, Health and Care Plan when a child or young person moves into a new local authority area.

Our full set of recommendations is at the end of this report.

Trapped because our Statement of Special Educational Needs won't move with us

Mohammed Elgondi is 12 years old and has autism and complex learning difficulties. He attends TreeHouse School in north London, which is run by Ambitious about Autism. He lives in Westminster in a rented flat with his family, who are desperate to buy a house. However, as his mum Sandrine explains, they are 'trapped' in their current flat because to leave their current borough is to risk losing Mohammed's Statement of SEN, and his place at TreeHouse School which he loves.

"Mohammed has been struggling at home for the last few years as he's got older. There's no outside space in our rented flat, and he runs off whenever we go out onto the street or to the park, which is really unsafe for him. He has absolutely no sense of danger, and it's almost impossible to keep hold of him now he's older. We need a secure garden where he can run about — because of his diabetes it's tricky to get him the right amount of exercise with no garden, so it's compromising his health.

Both my husband and I work full-time, and we want to invest in a home of our own. As we can't afford to buy in Westminster we started to look somewhere more affordable. But we soon realised we can't move out of Westminster for fear of losing Mohammed's placement at TreeHouse School. We would have to start the assessment process from scratch, even though Mohammed has very complex needs. The stress of doing that all over again, along with the risk that we might lose his place at his current school, is terrifying for us. If he loses his place there will be legal battles to go through, and I'd have to quit my job to look after him if he doesn't have a place.

I've approached several different local authorities saying our child is struggling in our current accommodation, that we can evidence this with letters from doctors, and asking if they can transfer the statement so he can stay at TreeHouse School when we move. They have all said 'no'. They won't even consider it. The Statement feels like a prison sentence as it doesn't offer mobility.

We've been stuck this way for three years now, with no way out in sight. The impact on Mohammed gets greater as he gets older and bigger. Where is the social mobility in all of this? I've spoken to many other parents in the same situation too."

Will the proposed reforms improve this situation?

No. The proposed reforms make no mention of the need for families to receive consistent support when they move into a new area. However, the draft **Care and Support Bill** includes plans for adult social care support to be 'portable', so that people can move from one local authority to another without having to 'start from scratch' or risk losing crucial support.

What would improve this situation?

The **Children and Families Bill** should be amended to include a new clause '**Continuity of support when a child or young person moves**'. This clause should be based on clause 31 of the draft **Care and Support Bill** and should ensure that there is continuity of the support outlined in an Education, Health and Care Plan when a child or young person moves into a new local authority area.

Struggling at school with no support

Simon lives with his parents in Manchester. He is 12 and attends a local secondary school. Simon has a diagnosis of autism but does not have a Statement of SEN, and does not receive any additional support at school. Simon's family are going through the process of trying to get a Statement of SEN so that he can get the support he needs. His mum Liz explains the impact of this on Simon's education.

"We had seen the child and adolescent mental health service (CAMHS) when Simon was eight years old. They had simply told me that he was a 'difficult child'. However, when he started secondary school Simon really began to struggle. He had panic attacks before school. When I collected him in the afternoons he was very pale and quiet and not able to eat or drink all evening. It was clear to me that he was not coping.

The school were very unhelpful when we approached them with our concerns. So my husband and I paid for Simon to see an educational psychologist and a speech and language therapist. Both professionals gave a diagnosis of autism. Despite this, the school refused to act and to this day Simon has no support at school.

The problems at school escalated. Simon struggled in particular with PE and modern foreign languages. He explained to me that when he sits in a language class he is not able to connect with the lesson at all and feels totally isolated. I asked the school about making adjustments to my son's timetable, but I was told that 'no adjustments have ever been made to the curriculum of individual students, nor will they ever be'. This seems to be a clear breach of the law.

I received phone calls from school asking me to come and collect Simon early. It became clear that he was not able to manage the noisy school environment due to sensory issues arising from his autism. Spending time out of school became more regular and he started to attend school part-time. It is not right that such simple changes to his timetable cannot be made that would mean Simon could manage a full day. By refusing to adapt the curriculum the school are illegally excluding Simon from school. He simply can't manage the same way other children do without support. I am not confident that when (and if) he does get a Statement, Simon's school will be forthcoming with ideas about how they can help."

Will the proposed reforms improve this situation?

There is nothing in the reforms to ensure young people like Simon will get the support they need without having an Education, Health and Care Plan. The local offer will set out education services the local authority 'expects to be available', but there is no requirement to deliver these services. The reforms will also remove the categories of School Action and School Action Plus,[5] through which many young people in Simon's situation currently get support.

What would improve this situation?

The **Children and Families Bill** should be amended to create a duty to provide the services set out in the local offer, and the **Code of Practice** should set out the types of service that must be provided to children and young people with SEN, including specialist support at school.

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[5] These are categories that schools use to provide additional support for children with SEN and no statement.

Why can't health and education professionals work together?

Owen McNabb is 19 and was diagnosed with Asperger's Syndrome at 14. He lives in Oxfordshire with his mother Isabel, father John and 16 year old sister Alice, who also has Asperger's Syndrome. Throughout school Owen experienced mental health problems. Here Isabel explains the impact on Owen of the lack of appropriate coordination between education and health services.

" We always knew something was different about Owen but didn't know what. Throughout primary school he had anxiety. We pushed for support and when he eventually saw the child and adolescent mental health services (CAMHS) they didn't liaise with the school's headteacher or special educational needs coordinator and so he got no help at school.

At secondary school Owen struggled even more. He would be so anxious about going to school he'd regularly be sick and have diarrhoea. He got into trouble because he couldn't process information and requests from the teachers. In Year 8 Owen stopped going to school.

I pushed CAHMS for an assessment as we wanted to know what was going on. The CAMHS psychiatrist said I was just trying to label Owen. We went to CAMHS in a different town and he was diagnosed with Asperger's immediately. We tried to get him a Statement of SEN at this point, and really had to fight the local authority for it. There was still no coordination between health and education professionals. When the local authority finally agreed to the Statement Owen was 16 years old. By then it was too late. He tried going to the special school we found for him but couldn't manage it and dropped out.

His anxiety got worse and he started to drink cider to try and cope. At 17 he tried to take his own life. We took him to the local mental health hospital when we found him, but they refused to see him because he'd been drinking. We were desperate for help so we took out loans and put him into a private hospital to deal with his alcohol problem. It seemed to work but he started drinking again soon after he came home. He wants friends but he can't manage it without alcohol.

Owen spends every day with me. He feels like he has no future, it's heartbreaking. He sees someone from alcohol services once every four weeks but the drinking is a symptom; it's the fact that he's never had the right education and health support that's the problem."

Will the proposed reforms improve this situation?

They could do if strengthened. It is welcome that health providers will now have a duty to deliver the health support set out in an Education, Health and Care Plan. However, our concern is that there is still very little in the Bill to engage health and care professionals more effectively in a coordinated assessment process. Also, families will have no right of redress if health support is not delivered.

What would improve this situation?

The **Children and Families Bill** should be amended to create stronger duties on health and social care bodies to be part of a coordinated assessment process, and to give families a right of redress if the health and care support set out in an Education, Health and Care Plan is not provided.

Excluded and out of school for almost a year

Lucas Jamieson is seven years old. He lives with his adoptive parents Belinda and Mano in the East Riding of Yorkshire. Lucas has been out of school for the last nine months following exclusion from primary school. He has autism and foetal alcohol syndrome. Belinda describes the 'absolute nightmare' her and her husband have been through over the last year trying to find a school that will support Lucas, and the impact on their son and his learning.

"We knew Lucas had some difficulties from early on. He was excluded from music group and pre-school when he was three. He then got a Statement of SEN and two-to-one support. When it was time to start school we looked at a whole range of options, including special schools, but we decided on mainstream. Initially I felt we had good support in our local primary.

But as Lucas got older, things got harder. In Year 2 his very experienced teaching assistant was replaced with inexperienced and untrained staff. His behaviour deteriorated rapidly and we saw a profound change in Lucas. He became very violent. Due to the many triggers of the environment and the lack of expert staff he couldn't access the curriculum and he couldn't connect with his classmates. He found everything about school almost impossibly difficult, and he lashed out.

The school tried to accommodate him, but they didn't have the expertise in autism they needed. They punished him for things he couldn't help. I asked them to call me when there was a problem, and I would bring him home — for his safety as well as that of the other children and staff.

We were working out how to get input from autism and mental health specialists when — out of the blue — they formally excluded Lucas. We were devastated. The educational psychologist had decided that me picking Lucas up when school were struggling with him was 'unlawful exclusion' and that instead they should formally exclude him. I know the guidance says schools must do all they can not to exclude a disabled young person, but they interpreted it differently.

It caused us so much stress. The exclusion letter said Lucas wasn't allowed out in public during school hours. That is simply not possible for Lucas — he needs to burn off energy outdoors. The letter also said if I failed to attend a meeting I'd be taken to court. It was dreadful after having worked hard to be constructive with the school. It left us really panicked.

It seems like the school are blaming and punishing the child for having a disability. When so many children with autism are in mainstream school, how can we still have such little understanding?

It really impacted on Lucas' self-esteem. He heard the word 'excluded', and he knows what it means. He's nearly 8 now, and he knows that he's different. He just wants to make friends but he doesn't know how. He hates even driving past his old school, but it's in our village so we can't avoid it.

We've been home schooling him since last June, because there is simply no other option, which of course means I've had to give up work. Being out of school is very detrimental for Lucas. He's lost the ability to integrate with his peers. With his communication needs, that sort of social experience is critical, but he's being denied it.

We visited seven special schools, but none would accept him. There's one we thought could meet his needs, but it's out of county, so the school said they couldn't take him — places were reserved for local children. We've had to take the local authority to tribunal to try and get this school to give Lucas a place. The legal battle was the last thing we needed after the trauma of the last year."

Will the proposed reforms improve this situation?

No. We are not aware of any measures in the proposed reforms that will prevent the disproportionately high rates of exclusion for children and young people with special educational needs and disability.

What would improve this situation?

The new **Code of Practice** for children with SEN should explicitly state that exclusion is an absolute last resort for young people with SEN, and that specialist support should be put in place, as agreed with the young person and their family, before any exclusion from school is considered.

Turning 20 this year and the fight continues

Jacque Venables is aged 19. He has autism and social and communication difficulties. He lives in Telford with his parents and sister. Jacque went to a special school from the age of seven, which he thrived in. He then struggled at a mainstream general further education college after funding for his support was stopped. His mum Nikki discusses how he has not been in education, employment or training since.

"In September 2009, when Jacque was 16, he went to a large mainstream further education college to do a Level 2 Foundation course four days a week. He was worried about it being busy and loud but we both felt reassured because the college offered a buddy system to help him navigate around and get to his classes. I thought it was the perfect solution. Although he struggled at the beginning, he started to enjoy college and had lunch with other students in the canteen. He even started to get the bus home two nights a week with a friend instead of me collecting him.

At the end of his first day of his second year I went to collect Jacque and immediately knew there was a problem because he was so distressed. He was very angry, throwing things in reception and totally confused. I hadn't heard anything from the college all day so thought things were fine but, unbeknown to me and to Jacque, the college had taken away his buddy support because funding for the project had been cut. Jacque spent two hours alone in the canteen before his tutor realised he should be in class.

Jacque tried to attend college for one day a week without a buddy but found it too difficult and in January 2011 he stopped going altogether. He's told me he never wants to go to college or study for any qualifications again after what happened, he was such a mess.

I contacted Connexions for help but everything they offered us Jacque was unable to join in with. Without any sort of post-16 plan in place Jacque hasn't got a focus in his life, he sleeps all day and is up all night playing computer games. He has been learning to drive, which is positive, and he just got a personal assistant two days a week to help build his independence but we had to wait a long time for the funding to come through for this.

I feel desperate as Jacque is such an intelligent boy and he's wasted just sitting at home but there really is nothing for him to do. I love my son dearly and would love him to succeed in something because he is amazing with computers and films, and he has excellent literacy and numeracy skills. I know he could do something positive with his life if he was given the chance and had the right support.

The impact of losing something as simple as his buddy at college has cost Jacque the chance to continue his education and that frustrates me and him. The Government need to put more support for people with autism into post-16 education. Jacque is 20 this year and the fight still continues."

Will the proposed reforms improve this situation?

Possibly, but not definitely. New duties on colleges to provide support for young people with special educational needs mean that young people like Jacque might be able to keep the support they need in future. But many young people with autism and other disabilities fall out of education beyond school like Jacque has done, and the SEN reforms provide no system for supporting these young people back into education.

What would improve this situation?

The **Children and Families Bill** should be amended to create a clear right for young people with SEN who are not in education, employment or training between ages of 18 and 25 to restart their Education, Health and Care Plan, and get the support they need to return to education.

Direct payments can be a minefield

Oscar Mottram lives in north London with his parents and his two siblings. Oscar is about to turn 18. He has autism and learning difficulties. Oscar's parents have been receiving direct payments to pay for respite care for the last eight years. His mum Lucy explains how difficult it can be to find the right support to buy with direct payments, and to 'jump through hoops' to account for them.

"16 months ago our local Council agreed to pay for one weekend's respite care each month, but it has taken a considerable amount of time to agree how to provide this. It has only been in the last two months that we've actually been able to use the direct payments to get the support we need.

As Oscar was approaching adulthood, it seemed appropriate for us to try to find him a residential placement for his respite breaks. We hoped that this would help equip him with additional independence skills and that he would enjoy spending time in a new environment. However, when we visited local options it was clear that they were not able to meet Oscar's complex needs. We decided that the weekend respite would have to take place in our home.

Oscar needs two-to-one support and in a house with two other children this is a challenge to accommodate. Having two extra adults in our home for a whole weekend has a significant impact on all of us and is confusing for Oscar who wants to spend time with us. But it's not only space that is the issue. Knowing where to find suitable staff who are equipped to support Oscar has always been difficult, and to cover a whole weekend at least four staff are needed.

I had asked the Council for a list of local carers which they said they would provide, but this never arrived. It is a huge and stressful burden for parents, who already have more than enough to cope with, to have to recruit, interview and train up staff themselves. We are always vulnerable to staff leaving after a few months for better paid work, leaving Oscar very unsettled and us totally unsupported.

For many years I didn't know who to talk to at the Council about any aspect of this as Oscar didn't have a named social worker and no one would return my calls. As Oscar is now approaching his 18th birthday, he has now been allocated a social worker and this has made a big difference. However, for many years we felt we were floundering on our own, receiving the occasional official letter threatening action because of some perceived fault on our part.

The Council have now agreed to employ Dimensions, a not-for-profit organisation who specialise in providing services for people with learning difficulties and autism. Together we are now trying to recruit and train a team of four so that we will always have support, even if staff are ill or on holiday.

Managing the technical financial aspect of the direct payments was time consuming and the use of allocated money had to be accounted for in four different ways quarterly. I know some families really struggle with that. With no one to phone for advice, and so little choice of service providers, it's a minefield."

Will the proposed reforms improve this situation?

Not in their current form. Direct payments and personal budgets can provide welcome choice and control for families, but we continually hear from parents like Lucy about the need for a named contact to help families through the potential 'minefield'. While the reforms will make personal budgets more available for families, they do not set out any support to help manage the payments or find quality services to buy with them.

What would improve this situation?

The **Children and Families Bill** should be amended to ensure that any young person or parent who agrees to receive a personal budget is offered a named key worker to support them in managing their personal budget and finding quality services to buy with it.

Physically and emotionally bullied at school

Lizzy Clark is 18 years old and was diagnosed with Asperger's Syndrome when she was 11. She lives in Shropshire with her parents Nicky and Phil and her 15 year old sister Emily, who has autism and learning disabilities. Lizzy was bullied in primary and secondary schools because of her autism and here her mother Nicky explains the impact it had.

"Lizzy spent years being physically and emotionally bullied at school by other pupils. Her first years at primary school were her happiest because her classmates accepted her when she was five, and she was confident and eager to learn. But the last years were extraordinarily difficult for Lizzy because her classmates became less accepting of her differences. She was aloof in a gentle way and they viciously picked on that.

At 10 years old everything fell apart for Lizzy. The children who'd been her friends since she was five ridiculed her and left her out of things and she became isolated. She wanted to have the same interests as her friends but, because she was different, she became a liability to them. Every single night at home she'd cry and she began to self-harm. She became very withdrawn. Her comments about herself became negative and she didn't believe in herself anymore. As her mum it was devastating to see her like this.

When I tried to tackle the problem with one teacher they ignored it. It was even said, to my shock, that there was no bullying in the school. Lizzy's teachers were at a loss to do anything about the problem making our daughter deeply unhappy. After telling the school repeatedly that Lizzy was being bullied they moved her to a different class, which stopped the bullying. It was extremely challenging for Lizzy to have to move into a new class and away from everyone she'd had been with since she was five.

However in the new class the teacher was more patient and gave her the time she needed to recover from being bullied. They wanted to understand and learn as much as they could about her autism because their teacher training hadn't covered it. But it proved to be only a temporary relief for her.

The bullying continued when she moved to the same secondary school as the pupils who had bullied her at primary school. I suggested Lizzy show her teachers what her typical day was like. She drew a picture of herself surrounded by speech bubbles of what the other children said: "You're a freak", "You're stupid" and "Nobody likes you".

Sadly and after a year of trying to tackle it and watching Lizzy trying to deal with it, Phil and I had no choice but to move her to a single-sex independent school. This transformed her life; and ours too. The bullying stopped because Lizzy was immediately accepted and adored by the other girls; she'd come home saying how much fun she was having. We were so relieved although it's taken its toll on Lizzy and she still fears it may happen again."

Will the proposed reforms improve this situation?

We are not aware that the proposed reforms include measures to address the high levels of bullying young people with autism and other disabilities face. Over 40% of children with autism have been bullied at school.[6] This seriously affects their education.

What would improve this situation?

The **Code of Practice** that accompanies the Bill must include a requirement for schools to make clear in their behaviour guidance the action they will take to promote understanding of disabilities like autism to staff and students, as well as procedures for dealing with bullying fairly and effectively.

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[6] Batten, A et al (2006), Autism and Education: the reality for families today, The National Autistic Society.

Wanted: a place in my local community

Adam Penfold enjoys playing football and going for lunch in the pub. He has a severe learning disability, autism, epilepsy and challenging behaviour. He is now 24 years old and, due to the complete lack of local services, lives in an NHS funded residential placement fifty miles from the family home. Adam's dad Ian explains how much they all wanted Adam to stay in his local community and move into supported living, but how the lack of local services made that impossible.

"Adam attended a local special school from three to 19 years old and was statemented from an early age. Throughout his life we have struggled to get help with support at home and in the community, and access to health services. Adam left school at 19, but due to his severe learning disability, epilepsy and challenging behaviour he was not offered any day services locally. Adam did get two or three regular sessions of local authority funded agency support every week. But at times this service struggled to provide structure and consistency, and as a result had a variable degree of success.

All we wanted as a family was some appropriate and varied day activities for Adam, so he would continue to be engaged in a range of things that would help him mature and develop into his adult life. Our hope was that he could continue to live with us in the family home into his twenties, until he matured sufficiently to be able to manage the transition to supported living close by.

Unfortunately, we were not offered any day services for him, and we didn't have access to any support at home either. As Adam requires 24 hour care and is not a reliable sleeper there were times when we went without sleep or a break for long periods. This was dreadfully hard to manage on our own.

We even created a poster about Adam — his likes, his hopes, and what he was looking for in a day service — and circulated it locally, desperately hoping we would find something for him. But we couldn't find anything suitable.

Eventually, following a continuing care assessment it was decided that the NHS would provide 100% funding for support for Adam, but due to the lack of local day services we had to start looking for a residential placement nearby. Again we were thwarted with no local opportunities for supported living in sight and with none of the nearby residential establishments having the resources to manage Adam's complex care effectively.

Finally, left with no other choice, we accepted a placement 50 miles away with a company specialising in care for those with complex needs. Although he is now settled and seems happy, given his lack of mental capacity he has no idea why he doesn't live with Mum and Dad anymore, misses us terribly and both our hearts are broken. This solution, though the very best currently available, is not what we wanted for Adam. It is also costing the tax payer much more than living locally in supported housing would.

The Government's strategy to provide a single Education Health and Care Plan from diagnosis to age 25 is a very good idea in theory. However if the Government persist in trying to do more with existing funding there is a very real danger that resources will be spread too thinly and result in the deterioration of services which will hit the most vulnerable the hardest."

Will the proposed reforms improve this situation?

Not on their own. The **Children and Families Bill** states that Education, Health and Care Plans will only be available for young people over the age of 18 who stay in education. Because Adam couldn't find any education to meet his needs, he would have lost the support of his Plan, and continued down the same route to residential health care. Alongside this Bill it is vital that local and national Government supports the creation of new specialist provision that will help young people like Adam continue developing their skills, and stay in their local community beyond school.

What would improve this situation?

The **Children and Families Bill** should be amended to include a duty to maintain a young person's Education, Health and Care Plan until their 25th birthday, or until the young person and/or their family feel the plan is no longer necessary. The Bill should also be amended to include a duty to complete a transition to adulthood plan for each young person aged over 16 before the Education, Health and Care Plan can cease to be maintained.

Too able to get support, but unable to achieve without it

Aisha is 16 years old and lives with her mother, Maureen. Aisha has a diagnosis of autism and a Statement of SEN. She had good support at her tutorial college, and achieved excellent GCSE results. But when the family moved house her Statement was challenged by the new local authority, and her support was removed. Maureen explains the negative impact this is having on Aisha's promising academic future.

"Aisha attended mainstream primary school, which worked well for her. But the mainstream secondary school she went to did not meet her needs and the lengthy process of assessing her for a Statement of SEN began. She then moved to a special school, which was a disaster, before attending a tutorial college with personalised support. While there she studied for 10 GCSEs and was awarded A* and A grades in all subjects. She also studied English literature at AS level.

We moved house last summer and I applied to have Aisha's Statement transferred to a local tutorial college, similar to her previous college. But the local Council challenged her need for support. They wanted to end her Statement and place her in a general further education college. We knew from experience this would have been an entirely unsuitable placement and an environment she couldn't manage.

The post-16 arrangements set out in Aisha's statement backed us up, saying she needed 16 hours of personalised tuition per week for her A Levels. The Council informed me these arrangements were 'out of date' because they had been written 6 months ago. They said they had never encountered a child with such high academic potential, and that she was an extremely unusual child to educate in one of its specialist schools.

So the Council failed to support Aisha to continue her education by denying her the support set out in her Statement. Since the move her education has been constantly uncertain and she is very distressed. Her grandparents cover the cost of two hours per week teaching in English literature and maths, so that her education has not ceased completely. Aisha is eager to learn and after her A Levels she wants to attend university. But without the support of her grandparents she would have no access to education at all, despite being just 16 years old.

All through this business the inference has been that Aisha is intelligent and can therefore manage in an environment that is unsuitable for her. But from our perspective, she has a relatively severe disability, coupled with high intelligence. These two things don't cancel each other out. She can't make good use of her intellect without the right environment and support to manage her disability."

Will the proposed reforms improve this situation?

There is a welcome focus on positive outcomes for young people with SEN in the reforms, but no mention of the need to continue providing support where it is required to *maintain* positive outcomes. We are likely to see the same problems as in the current system, where support is removed from young people who are doing well, only to leave them floundering.

What would improve this situation?

The new **Code of Practice** for SEN must clarify that children and young people with disabilities such as autism may be academically able but still need support to access education. The **Code of Practice** should set out examples of the sensory or communication difficulties that more academically able young people may face, and the types of support that may address these difficulties.

Conclusion

The young people and families who have shared their stories in this report want what the Government promised — support and aspiration for every young person with special educational needs or a disability.

Our analysis shows that the Children and Families Bill will not deliver this promise in its current form. We know the Government wants to deliver its aim of 'support and aspiration' for every young person, and we look forward to working with them to improve the Bill to do just that.

We urge Parliamentarians to help the families in this report, and thousands of other families like them, by supporting the amendments to the Bill and the Code of Practice that we suggest.

Recommendations

The Children and Families Bill should be amended to:

- create a clear right for young people with SEN who are not in education, employment or training between the ages of 18 and 25 to **restart their Education, Health and Care Plan** if they need to return to education
- create a duty on local authorities to **provide the services set out in the local offer**, and regulations should set out the types of service that must be provided to children and young people with SEN
- include a new clause '**Continuity of support when a child or young person moves**'. This clause should be based on clause 31 of the draft **Care and Support Bill**, and should ensure that there is continuity of the support outlined in an Education, Health and Care Plan when a child or young person moves into a new local authority
- **create stronger duties on health and social care bodies** to be part of a coordinated assessment process, and give families a right of redress if the health and care support set out in an Education, Health and Care Plan is not provided
- ensure that any young person or parent who agrees to receive a personal budget is offered **a named key worker** to support them in managing their personal budget and finding quality services to buy with it
- include a duty to maintain a young person's Education, Health and Care Plan **until their 25th birthday**, or until the young person and/or their family feel the plan is no longer necessary
- include a duty on local authorities to complete a **transition to adulthood plan** for each young person before their Education, Health and Care Plan can cease to be maintained.

The new Code of Practice for SEN must:

- clarify that children and young people with disabilities such as autism may be academically able but **may still need specialist support** in order to access education
- explicitly state that **exclusion is an absolute last resort** for young people with SEN, and that specialist support should be put in place as agreed with the family before any exclusion from school is considered
- require schools to make clear the action they will take to **promote the understanding of autism to staff and students** as well as procedures for dealing with bullying effectively.

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