A long way from home

What the research and evidence tell us about why young people with learning disabilities and/or autistic young people are in residential placements and what can be done to address this.

NDTi report, September 2024

NDTi
Research & Evaluation

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Introduction

The Winterbourne View scandal that came to light in 2011 highlighted acutely the negative consequences that can arise from autistic people and/or people with learning disabilities living a long way from their families and communities in residential placements.

The harmful impact on individuals and their families, as well as the high cost of such placements, has strengthened the commitment within UK policy that people with complex needs and/or behaviour that challenges services should live, be educated and be supported in their own communities.

Sadly, there have been numerous serious cases showing that the issues continue over a decade after Winterbourne View. One recent scandal found that disabled children suffered systemic abuse and serious harm at three residential settings run by the Helsey Group. On average, these children were living 95 miles from home and a review by the Child Safeguarding Review Panel (2022) found that being placed far from home increased their vulnerability. Professionals testified that a lack of suitable local provision contributed to the children being sent to placements far from home.

It is clear that, despite the renewed policy intentions following Winterbourne View, young people continue to enter residential placements away from their families and communities, often in an unplanned way, at a time of crisis and service breakdown, or as they transition from children's services to adult services.

The aim of this report is to support greater understanding of this problem by looking at what the evidence tells us about why it persists and what can be done about it. This paper draws on a range of sources of evidence to identify:

1. Three routes that lead to children and young people being placed in high-cost residential placements away from their families and communities.
2. Eight problems that contribute to the 3 routes.
3. Potential solutions that can address the 8 problems.

We use a combination of sources of evidence from our work over the last few years including literature reviews, primary research with young people and/or their families, professionals and providers, and learning from our own experience working with local authorities across the UK supporting young people in their preparation for adulthood and delivering programmes of work in this area.

Meanings, definitions and language used in this report

This report is about children and young people (up to 25 years old) with a learning disability and/or young autistic people, many of whom who have been labelled as having complex needs and/or behaviour that challenges services.

We recognise that language, terminology and diagnoses can be contentious, debated and fluid. As this report is a summary of evidence, we have broadly chosen to use the language used in the documents, sources or people we cite so that we do not change the intended meaning of authors or contributors. This does not imply that we necessarily accept the language used.

We respect the preference of most autistic people to use identity-first language (e.g. autistic person) rather than person-first language (e.g. person with autism). Where we quote directly from policy documents, we use the original language that was in the document and this may include person-first language.

This report focuses on children and young people in, or at risk of going to, residential placements away from their families and communities. These can include assessment and treatment units, low or medium secure units, residential care homes, residential colleges or residential college move-on units. While we recognise that in some cases residential placements are as a result of positive, informed choices by the child or young person and their family, this report focuses on understanding more about those for whom this is not the case; where the residential placement is as a result of local services not being available or broken down, the placement being made in reaction to a crisis, and/or the placement becoming long-term when it was intended to be temporary.

Throughout this report we refer to a range of sources:

📋	Policy or guidance
📚	Research study
💭	Direct quote from an individual interviewed as part of a research study
📊	Statistic from data source

What does policy and guidance say?

“Children, young people and adults with learning disabilities or autism, who also have mental health conditions or behaviours described as challenging can be, and **have a right to be, given the support and care they need in a community-based setting, near to family and friends**.”

Transforming care: A national response to Winterbourne View Hospital (2012)

For children and young people with an EHC plan: “the local authority must secure that the plan provides for the child or young person to be **educated in a maintained nursery school, mainstream school or mainstream post-16 institution**, unless that is incompatible with (a) the wishes of the child's parent or the young person, or (b) the provision of efficient education for others.”

Section 33, Children and Families Act (2015)

“People with a learning disability and autistic people should live in their **own home** and have the right support in place to **live an ordinary life**. This includes access to **education, employment, and other opportunities** which help people to fulfil their aspirations.”

Building the right support for people with a learning disability and autistic people (2022)

Transforming Care key principles of high quality services for people with learning disabilities and behaviour which challenges:

1. "I and my family are at the centre of all support – services designed around me, highly individualised and person-centred;
2. My home is in the community – **the aim is 100% of people living in the community, supported by local services;**
3. I am treated as a whole person;
4. **Where I need additional support, this is provided as locally as possible.”**

Transforming care: A national response to Winterbourne View Hospital (2012)

"As part of its commitments under articles 7 and 24 of the United Nations Convention of the Rights of Persons with Disabilities, **the UK Government is committed to inclusive education of disabled children and young people** and the progressive removal of barriers to learning and participation in mainstream education. The Children and Families Act 2014 secures the **general presumption in law of mainstream education in relation to decisions about where children and young people with SEN should be educated** and the Equality Act 2010 provides protection from discrimination for disabled people."

Section 1.26 SEND code of practice (2015)

"Children and young people with a learning disability and autistic children and young people and their families should be able to access the support they need. This will ensure they have the best possible start to life and can live the lives they choose... we also want children and young people to receive appropriate care and support that recognises and plans in advance for their transition to adulthood to prevent escalation of needs, mental health crises and avoidable admissions."

Building the right support for people with a learning disability and autistic people (2022)

"As a child or young person, I want good opportunities and experiences as I grow up. For me, this means:

- I have a timely autism diagnosis that enables me to access the support I need to live an ordinary life.
- If I have a learning disability, I can access the support I need to live an ordinary life.
- I feel safe and supported in a school that understands and meets my needs, without living in fear of exclusion and restraint.
- My school enables me to reach my potential by building on my strengths.
- If I need one, I have an Education, Health and Care Plan that me and my family are involved in developing, and my education setting is confident in delivering the support it sets out."

Building the Right Support Action Plan (2022)

What rights do children and young people have?

The UN Convention on Rights of the Child was ratified by the UK in 1991. These rights apply to all children under the age of 18 years.

Article 7 sets out the right of a child ‘to know and be cared for by his or her parents’.

Article 9 sets out children’s right to live with their parents, unless they are at risk of harm.

The Human Rights Act (1998) contains 16 rights that are protected by law. These include:

- Article 3 – the right to be free from inhuman or degrading treatment.

This is an absolute right so cannot be restricted or interfered with by public officials under any circumstances.

- Article 5 – the right to liberty.
- Article 8 – the right to respect for private and family life, home and correspondence.
- Article 2, Protocol 1 of the HRA – the right to education.

These rights are non-absolute, which means that they can be restricted under specific circumstances. Any restrictions on these rights must be considered to be lawful, legitimate and proportionate; they must be the least restrictive option (BIHR, 2023).

The UN Convention on the Rights of Persons with Disabilities was ratified by the UK in 2009. Article 19 sets out the rights of disabled people to live in the community, to choose where they live and with whom; and to be provided with support to make this possible.

Under the Children and Families Act (2014), young people aged 16 and over have the right to be directly involved in decision-making. The SEND Code of Practice states that: “As young people develop, and increasingly form their own views, they should be involved more and more closely in decisions about their own future. After compulsory school age (the end of the academic year in which they turn 16) the right to make requests and decisions under the Children and Families Act 2014 applies to them directly, rather than to their parents. Parents, or other family members, can continue to support young people in making decisions, or act on their behalf, provided that the young person is happy for them to do so, and it is likely that parents will remain closely involved in the great majority of cases.” (p.127, para.8.15)

Numbers and costs

6000 children educated in residential special schools and colleges

(Lenehan & Geraghty, 2017)

35% of children boarding in residential special schools are in other local authority areas

(Pinney, 2014)

190 under 18s getting care in hospitals for their mental health or because they have had behaviour that can be challenging

(NHS Digital, 2022)

£230,000
The average CAMHS inpatient unit bed per year

(NHS Benchmarking Networking, 2016)

£87,724
The average annual cost of residential care for an adult requiring learning disability support

(Personal Social Services Research Unit, 2021)

410 18-25s getting care in hospitals for their mental health or because they have had behaviour that can be challenging

(NHS Digital, 2022)

60 under 18s getting care in hospitals for their mental health or because they have had behaviour that can be challenging are being treated over 50km away from their home

(NHS Digital, 2022)

95 18-25s getting care in hospitals for their mental health or because they have had behaviour that can be challenging are being treated over 50km away from their home

(NHS Digital, 2022)

£167,268
Estimated average cost of placements for a 52-week residential special school placement

(Clifford & Theobald, 2012)

£500 million
Estimated cost of educating children in residential special schools and colleges

(Lenehan & Geraghty, 2017)

Three routes

While all children and young people's stories and journeys are different, we have identified three common routes that lead to children and young people going to high cost residential placements away from their families and communities[1].

ROUTE 1

TRANSITION FROM RESIDENTIAL SCHOOL OR COLLEGE

Children/young people go out of area to residential special school or college and stay out of area.

Residential colleges offer move-on units that young people can move into once they finish college, or they move to residential care in the same area.

What do we need to understand?

What leads to children and young people going to residential schools and colleges in the first place?

Why is the transition from residential school/college poor?

ROUTE 2

TRANSITION FROM LOCAL EDUCATION PROVISION

Young people who attend mainstream or special school education in their local area move to residential care or specialist unit directly on leaving education.

What do we need to understand?

What provision is missing or lacking in the local area?

Why is the transition from education poor?

ROUTE 3

CRISIS OR SERVICE BREAKDOWN

Children/young people in local education or adult services experience a mental health crisis, or behaviour that becomes more challenging for families or services.

Local services are unable to provide adequate support, which leads to family breakdown or the young person being sectioned under the Mental Health Act.

The young person goes into an assessment and treatment unit, secure unit or specialist residential care.

What do we need to understand?

What factors lead to the crisis or breakdown?

What services or support are missing or lacking in the local area?

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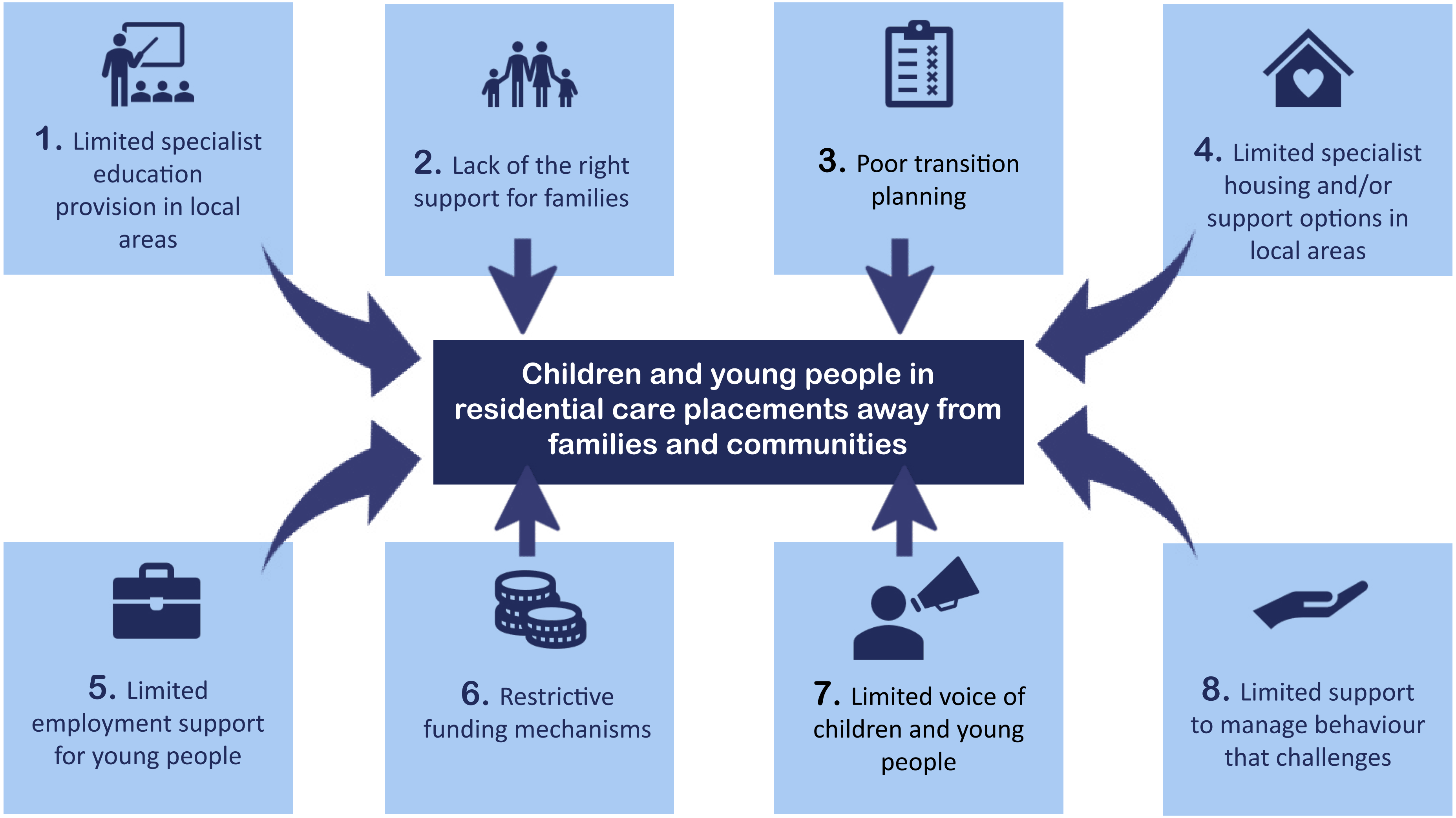
[1] Based on 3 routes identified by McGill, Cooper & Honeyman (2010) and confirmed through our research, evidence reviews and learning from our work

Eight Problems

Through reviewing the evidence and research we have identified 8 problems that lead to these three routes. While some problems are more relevant for one particular route, all work together to contribute to children and young people entering high-cost residential placements away from their families and communities. We cannot address one of these problems on its own; all of them need to be tackled together to be able to create the right conditions to support children and young people close to their families and communities.



1. Limited specialist education provision in local areas

2. Lack of the right support for families

3. Poor transition planning

4. Limited specialist housing and/or support options in local areas

Children and young people in residential care placements away from families and communities

5. Limited employment support for young people

6. Restrictive funding mechanisms

7. Limited voice of children and young people

8. Limited support to manage behaviour that challenges

Problem 1: Limited specialist education provision in local areas

The majority of parents of young people in out of area residential special schools and colleges said that they had looked at residential schools because there was no other suitable local educational provision.

Abbott and Heslop (2009)

Parents of children in residential schools spoke about the lack of appropriate local services, which had ultimately led to a decision that their needs could only be met through a residential school placement.

Office of the Children’s Commissioner (2015)

Interviews with parents found that nearly half of children with a learning disability were placed out of borough owing to a requirement for specialist provision.

Shuwa et al. (2006)

“I’m worried about his transition after he leaves school next summer. The council is suggesting transferring to [local College] but it has a poor reputation and failed its Ofsted report on safeguarding last year... I’ve looked at colleges outside [the county]… but would prefer somewhere within the county.”

Mother of 18 year old who has Down’s Syndrome and is autistic

“Transition from secondary school was first talked about in Year 9. I was taken aback that it was so early – I was told that the reason was that it would take a long time to get the funding in place for residential college. It was assumed that was where he would go.”

Mother of 24 year-old who has been given diagnoses and labels of autism, challenging behaviour, severe verbal learning disability and moderate non-verbal learning disability who was educated in mainstream schools.

Positive Solutions 1: Providing education close to home

Case study:

Post-16 education provision

Until around 10 years ago there was almost no specialist post-16 provision for young people with SEND in Local Authority A. As a result, most young people with SEND had to go to a residential college outside of their home county if they wanted to go into further education. At this time there were only 40 young people with statements of special educational needs attending further education in the county.

This had a number of implications. Firstly, it was a very high-cost way of providing further education. Secondly, there was a pattern of young people staying out of county after further education. Finally, there was little choice for young people who did not want to move far away from their families - many simply left education at this stage rather than leave home to go to a residential college.

> *"It came to a crux when one mother wanted her son to be able to access education locally and continue living at home rather than him having to move over a hundred miles away to a specialist college. [She] quite rightly challenged us and she was right – it was not ok!"* Commissioning Manager

This led to the local authority Commissioning Manager rethinking what they were doing in the area.

> *"I approached the CEO at [Local College] where we acknowledged we were not meeting young people's needs; young people weren't getting an education to prepare them for adult life…. I suggested to the CEO how about we take a radically different approach by taking the young person and building the provision around them; we agreed to go for it!"*
> Commissioning Manager

They started small, supporting ten students and operating from a portacabin. Several years later there are Life Skills Centres on two college campuses, which support 200 young people. A range of new courses have been introduced and young people are supported to find work experience and supported employment. Young people generally start with their own individual timetable covering 5 days a week. This is gradually tapered over 3 years to 2 days a week of education. As their education funding reduces, young people use Direct Payments from adult social care to pay for support for the other days. This has been designed to avoid the "cliff edge" of switching from high levels of support in education to lower levels of support in adult social care.

Over 6 years the numbers of young people on statements or EHCPs accessing post-16 education in the local authority increased fivefold; from 40 to 200. **The proportion going to residential college reduced from 90% to 15%.**

Positive Solutions 1: Providing education close to home

Inclusive education: Hannah's story

Hannah is 18 and likes music, shopping, Zumba and making films. Hannah enjoys school and went on a school trip to Berlin. She is planning to go to college to study media and hopes to go to University in London to do digital music. Hannah has a good group of school friends who she went to prom with. Hannah is autistic and has learning disabilities.

When she was aged 7, Hannah was living in what was meant to be a short breaks residential unit because her birth parents, finding it difficult to manage her behaviour, could no longer manage to look after her at home. This is where Maria and Andy, Hannah's long term foster parents met her. They immediately felt a link with her:

> *"We were warned she is a complicated little girl – that she was trouble, troublesome, she'd come from a difficult background, she'd had every label under the sun. She was a hitting, biting, screaming, bundle of anger… we fell in love with her."*

When Hannah came to live with the family she was in an autism unit at a special school with one to one support and was being restrained several times a week. Her parents felt strongly she should be educated in mainstream education:

> *"All of the specialists came out of the woodwork to say why it was wrong for Hannah to go to mainstream school... We weren't going to accept that."*

After many refusals, one local primary school accepted her. Hannah had always wanted female friends but didn't have the opportunity to meet them in the small unit at the special school. At her new school, she was happy to be among the other girls in her class and soon had learnt all of their names and called them "Hannah's girls".

At her previous school, she'd been allowed to go to the mainstream playground twice a week as an 'inclusion experience'. At her new mainstream school the Head asked Maria if it was ok for Hannah to go out in the playground with the other children. Maria said yes – there was no risk assessment, just the regular lunch time supervisor, and it worked.

On the second day of school, the teachers noticed that Hannah couldn't hold a pencil but by the end of the first week she could. As a result of being around the other children, she quickly learnt new words and her reading also improved.

Hannah continued to be educated in mainstream schools. The move to secondary school went well – she had transition visits and was in the same form as some friends from primary school.

It hasn't all been plain sailing, there have been challenging times. Hannah had to learn to adjust her behaviour, she had to learn to sit down, and not to sing to herself – behaviour that had been acceptable in special school. There have also been incidents, such as biting, and there have been two teachers who have requested not to work with her. But ultimately, every school has recognised the very positive impact Hannah has had in her classes and her schools. Maria is clear that being in mainstream education has been the key to the positive life outcomes Hannah is experiencing so far.

> *"If Hannah had been taken to a 52 week placement at 8, she would be dead or in the most secure of secure units as she'd be hurting herself. I just have no doubt about that."*

Maria feels some of the factors that make mainstream school work for Hannah include a supportive head teacher willing to work in partnership with the family and a good SENCO and teaching assistant.

Problem 2: Lack of the right support for families

Parents of young people with learning disabilities and behaviour that challenges identified:

- a lack of information and advice for families;
- insufficient respite or short breaks provision; and
- a lack of local of training for parents.

McGill et al. (2006a); McGill et al. (2006b); Wodehouse and McGill (2009)

Families of young people aged 15 to 22 with profound intellectual disabilities and behaviour that challenges who live with them found that as their children became adults, the services had become less reliable, poorer in quality and increasingly disorganised. Instead of more help and support at this time, when families needed it, there was generally less during the transition to adulthood.

Hubert (2010)

Consultations with families of people with behaviour that challenges services found that families reported that access to services was extremely difficult other than at times of crisis.

McGill et al. (2010)

> *"One of the reasons for the relatively high use of residential placements outsides the county is that there is little support for parents of young people with complex needs from [local authority], particularly at weekends or in school holidays."*

Senior Social Worker, Transitions team

> *"I was absolutely desperate – I had to call the police, and the GP for sedation. I got no help from social services".*

Mother of young person who went to residential school

Positive Solutions 2: The right support for families

An evaluation of three specialist short breaks and intensive support services for families and young people whose behaviour is challenging looked at information about 123 young people and families. They found improvements in young people's communication and personal care, and reductions in behaviour that challenges and aggression. These improvements were linked with improved parental wellbeing.

McConkey et al. (2011)

Research commissioned by the Department of Education into the impact of short breaks on families with disabled children looked at survey data from 214 family carers at two time points. They found that short breaks have a direct positive impact on the health and wellbeing of carers and how positive carers feel about the future for their disabled child. They were also shown to buffer against the impact of child behavioural difficulties on carer psychological distress.

Hatton et al. (2011)

An international literature review on the impacts of short break provision for families with a disabled child, including 33 articles from the UK, concludes that short breaks appear to have the potential to positively impact the wellbeing of carers, children and their families as a whole.

Robertson et al. (2011)

A study on the social and economic value of short breaks estimated that if effective delivery of short breaks (alongside associated activities, including information and support groups for parents, training for providers and youth clubs) were made available to all disabled children in England for whom short breaks are appropriate, the potential savings to the state could be in the region of £174 million per annum as a result of decreased costs of long-term residential care, decreased health service costs from reduction in parents’, families’ and carers’ stress and decreased costs to schools of educating siblings with behavioural and emotional difficulties.

Nef Consulting (2009)

Problem 3: Poor transition planning

Parents of young people with intellectual disabilities living in their final or penultimate year in residential schools or colleges reported little person-centred planning.

Heslop and Abbott (2007); Heslop and Abbott (2008); Abbot and Heslop (2009)

Staff working in children's services (social care, education and health), adult social care and Connexions believed that person-centred planning was less likely to be taking place in out of area residential schools compared to local special schools.

Beresford and Cavet (2009)

Professionals involved with young people with intellectual disabilities living in their final or penultimate year in residential schools or colleges acknowledged that proper transition planning was inconsistent or 'random'.

Abbott and Heslop (2009)

"I'm not aware of any formal transitions support for him"

Mother of son who went to residential school

"The high turnover and the use of agency workers has been a problem in [local authority] for some time. This has had an effect on the transitions service with often no records of transfer [from children's to adult services] and not always discussions [between social workers] pre-transfer"

Senior Social Worker, Transitions Team

"I just think - you've known for 18 years the date of her 18th birthday! When she was 15 I asked, when she was 16 I asked, when she was 17 I asked but she was between social workers. They eventually started the adult social care assessment 4 weeks before her 18th birthday."

Long-term foster carer of autistic 18 year old with learning disabilities

Problem 3: Poor transition planning

Research about residential special schools has identified poor transition planning; planning that is delayed; or planning that is initiated too late.

Gore et al, 2015; Office of Children's Commissioner, 2014; Pellicano et al. (2014)

An in-depth study of multi-agency transition services across England found that provision of services was patchy and high levels of unmet needs remained. For example, 69% of parents and 82% of young people surveyed reported unmet needs in the area of leisure and social life.

Clarke et al. (2011)

Geographical distance of residential schools and colleges from the placing authority creates problems around planning for transition: it leads to reviews and meetings being short and rushed; a lack of strong relationships with professionals from the placing authority; and a tendency for social workers to file cases away once the out-of-area placement is sorted

Abbott and Heslop, 2008; Beresford and Cavet, 2009; Abbott and Heslop (2009)

A rapid review of evidence looking at transitions in education, health and social care, employment and housing found that for many young people "the transition process is still planned for them, rather than with them and by them" (page 9). Transition from child to adult health and social care services can be particularly challenging due to different eligibility criteria and service fragmentation in adult services. Transition can be a one-sided affair in which staff in children's services help young people to prepare for transition to adult services, but staff from adult services are less involved in this planning process. It is noted that even the best planning will struggle to achieve good outcomes for people when adult social services do not have the capacity and resources to provide similar quality of service as children's services.

Kaehne et al. (2018)

Almost half of young people age 13-20 with special educational needs or learning disabilities and behaviours that challenge said they were not getting help to plan for their futures.

Robinson (2017)

Positive Solutions 3: Transitions planning: What works?

A systematic search of evidence relating to independent advocacy for disabled people transitioning to adult services found that advocacy leads to better quality involvement of young people in transition planning, as well as advocating for better quality opportunities post-transition and improving the knowledge and behaviour of professionals regarding disabled people. Advocacy may also lead to benefits for the young person in terms of personal development, such as increased confidence, more positive self-identity and higher aspirations about what is possible.

Townsley, Marriott & Ward (2009)

A pilot project demonstrated that funding individual budgets for disabled young people with complex needs around the time of leaving school has led to more positive outcomes for young people and their families. For example, one young person used his individual budget to attend college three days a week and work towards setting up a microenterprise on the other two days. This shift in control towards young people and their families has meant that people with complex support needs are finding work, getting more involved in their communities and having better lives.

Cowen, Murray & Duffy (2011)

A survey of all local authority areas in England, exploring transition to adult services for disabled young people identified 34 multi-agency transition services. 23 of these had representatives from health, education and social care. They found that key factors associated with better outcomes were: having a transition worker who supported the young person and their family; the family having a written transition plan and the manager of the transition service having strategic level involvement. Other features associated with more positive outcome were the use of person-centred planning, having clarity on the role of transition workers and having family carers on the service's steering group.

Sloper et al. (2011)

A pilot study suggested that Talking Mats could be used successfully with young people with a learning disability to express their choices during times of transition. The research found that Talking Mats allowed young people to express differences of opinion, that were previously not known to their supporters, and facilitate deeper discussion.

Cameron & Murphy (2002)

Problem 4: Limited specialist housing and/or support options in local areas

A lack of suitable local services was one of the key reasons for people with learning disabilities being in out-of-area placements - either not being high enough quality or unable to support people with higher or more complex needs.

Beadle-Brown et al. (2006)

The reason given for over three quarters of the people from one local authority moving to out-of-area placements was to move to specialist autism units reflecting a lack of local specialist service provision.

Perry et al. (2007)

Positive Solutions 4: Providing housing and/or support close to home

Case study:

Post-16 supported living

To support the specialist education that Local Authority A Colleges have developed to enable young people to be educated in their local area (see above page 12), a supported living transition service for young people aged 18-25 was set up. The aim of this service was to help young people to continue their education and maximise their daily living and social skills, whilst they transition into adulthood and move on to independent accommodation within the local community.

It was recognised that although many young people continue to live with their families while they are in further education, there were a number of families who wanted their sons or daughters to go to residential college for the experience of being independent. In response to this, Alder House was commissioned. Alder House is a supported living transition service for young adults with learning disabilities/difficulties, physical disabilities, mental health needs, sensory impairment and other complex needs aged between 18-25. Alder House offers three levels of support within one building. The low support service consists of a self-contained flat, provided to young people who are preparing to move into their own accommodation.

The emphasis in Alder House is life learning as well as academic learning – young people are supported to practice cooking skills, independent travel and budgeting. There is a clear intention that young people move through Alder House as they move through college – as the college hours reduce, they move to lower levels of support in Alder House. At the end of the three years of college, the intention is that the young person will be ready to move on to independent living with the relevant support in place.

Professionals involved in Alder House have observed positive impacts on young people, particularly around increased confidence and progressing towards independence:

“One young man I work with who’s autistic moved in to [Alder House]. He was very isolated where he was living in a village and [Alder House] gave him a safe way to move away from home. His confidence is the biggest change – I’ve really noticed that. He’s socialising with his housemates, he’s having conversations, making friends. He likes the feeling of having his own place.”
Education support staff

“When you talk to our young people they all want their own place, a job, a partner, a holiday – the same as any of us. We support them to move towards that.”
Alder Hay staff

“I couldn’t believe it. He has his own lounge, lift, his own front door, and a communal area. It’s a lovely company. He has his own car that the four carers drive. There’s a team of four people [who care for him]”.

Mother of son who was in out of area residential unit moved to local supported living

Positive Solutions 4: Providing housing and/or support close to home

Case study: Shared Lives as an alternative to residential care

Shared Lives is a regulated form of social care delivered by carers who are trained and approved by a registered Shared Lives scheme. People who need support or accommodation are matched with compatible Shared Lives carers and families, and move into their home. Shared Lives schemes operate in most local authorities in the UK.

One Shared Lives scheme has no blanket exclusion criteria and supports young people with a range of complex needs including people with learning disabilities, autism, mental health problems, behaviour that challenges, dementia, people with offending behaviour and people with drug and alcohol issues.

This scheme has demonstrated that Shared Lives can be an alternative to high cost out-of-area residential placements for young people, supporting them to enjoy family life and remain part of the community. They recognise that the Shared Lives environment can be better suited to people whose behaviour may challenge services than residential care:

“Our Shared Lives carers know the people they care for. Once they’ve been living with them a long time they know the person’s triggers, if someone displays challenging behaviour there is a reason and the Shared Lives carers can see where it’s come from, they’re living it.” Shared Lives Manager

Paul, a Shared Lives carer, has a background of mental health nursing, managing a residential care home and spent some time working in in a prison. Because of his professional background he particularly likes to support those people who others see as challenging.

James has lived with Paul for over 10 years. James spent most of his life in care and experienced psychosis when he was 16, leading to him spending two years in a psychiatric hospital. He then lived in a series of supported living and residential care homes where he was evicted, before coming to live with Paul in a long-term Shared Lives arrangement. When James had a recent mental health crisis professionals wanted to send him to mental health hospital miles away:

“Paul wouldn’t let it happen, he knew James’ mental health would have deteriorated, he fought for him to stay – you wouldn’t get someone fighting for him like that in residential care. That’s the difference.” Shared Lives staff

“I will advocate for James to the death.” Paul

Paul feels confident that it is his care in the Shared Lives arrangement that has maintained James’ mental health and kept him out of both inpatient and residential care.

Shared Lives arrangements can offer a significant cost saving compared to residential care. A comparison of the costs of long-term Shared Lives arrangements in this scheme in 2016-17 found an average saving of £14,876 per person per year compared to the cost of residential care.

Problem 5: Limited employment support for young people

Family members, professionals and young people in their last year at residential special schools and colleges highlighted a lack of choice for young people's next steps post-school and college.

Abbott and Heslop (2008); Abbott and Heslop (2009)

"I saw a job-coach once but they only suggested a one-off cleaning of the college gym which I didn't feel was suitable for him… I don't think that [the local authority] has any employability provision for young people or adults with complex needs"

Mother of 20 year old with learning disabilities and complex needs

In 2020-21 5.1% of working age adults with learning disabilities in England getting long-term social care support were in paid employment

NHS Digital (2021)

In 2020-2021 9% of working age adults in contact with secondary mental health services were in paid employment

NHS Digital (2021)

Positive Solutions 5: Employment Support: What works?

What is supported employment?

Supported employment is a model for supporting people with significant disabilities to secure and retain paid employment. It is based on the notion that anyone can be employed if they want paid employment and sufficient support is provided. Supported employment is based on six principles: customer engagement, vocational profiling, employer engagement, job matching, in-work support, and career development. A key aim of supported employment is to secure 'employment and training' rather than 'training then employment'. This means that a participant gets a job from the beginning and learns skills on the job.

Individual Placement and Support (IPS) is the name used for supported employment when it is used to support people with long term mental health needs. IPS involves intensive, individual support, a rapid job search followed by placement in paid employment, and time-unlimited in-work support for both the employee and the employer.

Supported internship are a structured study programme based primarily at an employer. They enable young people aged 16-24 with an Education, Health and Care plan to achieve sustainable paid employment through learning in the workplace. Supported internships are unpaid, and last for a minimum of six months. Wherever possible, they support the young person to move into paid employment at the end of the programme.

DFN Project SEARCH is a one-year transition to work programme for young adults with a learning disability or autism spectrum conditions, or both. DFN Project SEARCH internships consist of training in the workplace, fitness for work training, and supported employment in a variety of placements within the host employers departments. At the end of the internship, interns graduate from the programme with a certificate of completion. The host employer may take on the intern as a paid employee.

For more information about supported employment, see the British Association for Supported Employment (BASE) website www.base-uk.org/about-supported-employment

For more information about IPS see the Centre for Mental Health website www.centreformentalhealth.org.uk/what-ips

For more information about supported internships see the Preparing for Adulthood tools and resources www.ndti.org.uk/resources/preparing-for-adulthood-all-tools-resources

For more information about DFN Project SEARCH see the DFN Project SEARCH website: www.dfnprojectsearch.org/

Positive Solutions 5: Employment Support: What works?

A study on supported employment for autistic people in the UK found that it resulted in better employment outcomes than standard care and was also cost-effective.

Mavranezouli et al. (2014)

Evaluation of ‘Engage to Change’, a supported employment project in Wales reported that 284 people had paid work placements of up to 6 months and this had led to a paid job for 58% of them.

Beyer (2019)

The findings from the evaluation of a supported internship trial at 15 Further Education suggested that the supported internship programme was effective in supporting young people with learning difficulties and/or disabilities into employment, with 36% of the interns achieving paid employment, including apprenticeships.

CooperGibson Research (2013)

Project SEARCH data reports that for 2018/19:

- 64% of the 477 interns secured paid jobs
- Interns in England worked for an average of 26 hours a week and were paid an average of £8.71 an hour

DFN Project SEARCH (2020)

A systematic review of 17 studies on supported employment for people with severe mental illness concluded that IPS is an effective intervention that is more than twice as likely to lead to competitive employment when compared with traditional employment support.

Modini et al. (2016)

An evaluation of 17 sites in the UK using Project SEARCH involving 315 young people found that Project SEARCH achieves employment rates of around 50 per cent on average.

Kaehne (2016)

Positive Solutions 5: Employment Support: What works?

Employment Support case study: Jack's story

Jack is 24. He has been diagnosed as autistic and having learning disabilities. He can sometimes behave in a way that is challenging to manage.

Throughout his childhood, Jack's parents followed their instinct that it was important that everything should be as "normal" as possible for Jack. This has guided their decisions about Jack's education, support, care and future. Jack went to mainstream nursery, primary school and secondary school.

Moving on from secondary school was first talked about in Year 9. It was assumed that Jack would go to a residential college. Jack's mum Kate did not want Jack to be sent away to college, preferring a local option. Jack spent the next few years in a special school for autism with a sixth form provision, followed by 'Pathways to Independence' and 'Into Employment' courses.

Eventually, in an annual planning meeting it was noted that there was no reference to employment in Jack's plan. Jack was referred to a specialist employment support project for people with learning disabilities and autism. At the project they did vocational profiling with Jack and noticed that he loved making tea. Jack started with some work experience at a café, followed by a supported internship. The social care support budget paid for his support while he was doing it and the education budget paid for the internship.

"It worked brilliantly, he just buzzed from day one".

At the end of the year Jack had been "so wonderful" at the job and he'd had no sickness, that the café offered him a paid job for 3 hours a day, 4 days a week. After work, Jack goes out for a drink or a pizza with Kate or his support workers. The next focus is to work on plans for Jack to leave home.

"Jack is confident now in the café, he's ready to have control of his own place".

The journey so far for both Jack and for Kate has not been straightforward and has included difficult periods. In light of the battles she has fought, and the personal sacrifices she has had to make, on tougher days Kate questions whether Jack's story is a "success". But she also knows that Jack's level of needs make him a typical "Winterbourne View type". Rather than living in a segregated specialist residential unit miles away from his family and friends, Jack is working in paid employment, enjoying spending time in the pub, seeing friends he's had since primary school and is planning independent living close to his family, friends, community and job.

Problem 6: Restrictive funding mechanisms

Research on young people in the final year of residential special schools or colleges found that even where there is good planning for young people leaving residential schools or colleges plans can come unstuck by last minute funding decisions.

Heslop and Abbott (2008); Abbott and Heslop (2008); Abbott and Heslop (2009)

Staff working in local authorities in England suggest that generic transition issues for all young people in special schools are magnified for young people in residential special schools, including funding issues. In particular, transferring health care between authorities can cause confusion about responsibility for funding and assessments.

Beresford and Cavet (2009)

None of the young people leaving residential school or college or their families used Direct Payments.

Heslop and Abbott (2008); Abbott and Heslop (2009)

Research on funding for young people with special educational needs involving fieldwork in 13 local authorities, identified one of the challenges associated with effective commissioning for children and young people with very high needs; due to the very small number of individuals with profound and complex needs there tend to be few providers in a defined local area that are able to meet their needs. This narrows the commissioning options of the local authority and leads to increasing numbers of children and young people being placed in residential provision a long way from their families.

Parish & Bryant (2015)

Problem 6: Restrictive funding mechanisms

"There are perverse financial incentives in the system. It is just accepted that NHS England specialist commissioning can pay hundreds of thousands of pounds per year to a private provider for a situation which leaves the child and family miserable and outcomes poor. The provider has the incentive of the £, the local area has the incentive that the child is no longer costing their LA/Social Care/CCG very much and the child and family have no say... Surely it cannot be beyond the system to look at how an equivalent sum could be used to set up bespoke packages in the community?"

Interviewee, cited in Lenehan, p29 (2017)

"I've struggled to get £18,000 of care for my son in the community. I can't get any more so he is moving to a placement costing £200,000. What happened to the middle?"

parent of child with complex needs, cited in Lenehan, p29 (2017)

Positive Solutions 6: Funding mechanisms: What works?

3.3 Personal budgets offer children, young people and their families the opportunity to have greater support over their lives. Personal budgets should be considered the default option for those children and young people with an Education, Health or Care Plan or receiving Continuing Care funding. TCPs [Transforming Care Partnerships] should use the development of Integrated Personal Commissioning to offer personal budgets to children and young people outside of these groups.

Developing support and services for children and young people with a learning disability, autism or both (2017)

Research on funding for young people with special educational needs found developing practice in pooling budgets between local health, social care and education services. However, these examples of the system working in a joined-up fashion were the exception rather than the rule. The research also found evidence of some areas beginning to address some of the challenges associated with commissioning for young people with particularly high needs issue through joint commissioning of places with neighbouring local authorities.

Parish & Bryant (2015)

A guide informed by interviews with a range of stakeholders and workshops in sites implementing personal health budgets found evidence that a truly personalised approach has big benefits for people with learning disabilities and their families, especially those with the most complex needs. It recommends that personal health budgets (or joint health and social care budgets) could and should be offered routinely to:

- Young disabled people who are moving towards adult life
- People being moved from unsuitable placements as part of the Winterbourne View action plan
- Other people with learning disabilities or autism who have high support needs and are not well served by conventional service approaches.

Turner & Giraud-Saunders (2014)

Problem 7: Limited voice of children and young people

Research conducted in 17 residential schools found that very few children had any involvement in choosing their school.

Office of the Children's Commissioner (2014)

Families felt that people who do not use words to communicate were excluded from decision-making about their own care and support, and that professionals made assumptions about their views. Families argued that services had failed to recognize that people's behaviour can be a way to communicate unmet needs.

Evaluation of Building the Right Support (2019)

Children and young people in residential schools often reported feeling as if their voice had not been heard at key moments, especially when it came to decisions about the school placement itself or arrangements for care and work experience once school came to an end.

Pellicano et al. (2014)

Access to independent advocacy for children in residential schools is scarce.

Office of the Children's Commissioner (2014)

Young people in residential schools and colleges' involvement in decision-making about the future was a passive, rather than active process.

Heslop and Abbott (2008)

A study of the decision making process relating to transition to adulthood for young people with complex needs found that the final decision of where the move would be to, would ultimately rest with either family or the statutory body that would be responsible for funding any future placements.

Badger (2009)

Positive Solutions 7: What works to enable the voice of children and young people?

Research involving interviews and focus groups with young people from six organisations who had received advocacy as well as an evidence review, survey of advocacy providers and in-depth case studies. The research found considerable evidence that young people had benefited from independent advocacy. Outcomes of advocacy were identified in three key areas:

- improving participation and involvement in decision making
- achieving change and resolving issues identified by young people
- personal changes for individuals (for example, increasing self-confidence and self-esteem)

The Centre for Children and Young People's Participation and the National Children's Bureau, (2016)

Involve Me was a collaboration between Mencap and the British Institute of Learning Disabilities that explored how people with profound and multiple learning disabilities can be involved in decisions that affect their lives. A range of creative approaches were used, such as creative communication, Storysharing (sharing stories in a sensory way with objects and sounds), multi-media advocacy (using audio, video and assistive devices to capture and share preferences) and peer advocacy. Individuals were supported to express their preferences and this led to changes in their lives and routines, as well as enhanced wellbeing. Peer advocates learnt about non-verbal communication and had a better understanding of the needs of people with profound and multiple learning disabilities.

Independent evaluation of the Involve Me programme (2011)

Problem 8: Limited support to manage behaviour that challenges

What is behaviour that challenges?

Behaviour is defined as challenging when it has a significant negative impact on the health, wellbeing and quality of life of people with learning disabilities and important people in their lives (National Collaborating Centre for Mental Health, 2015). Such behaviours may result in life-changing injury and severe trauma and place the person at risk of restrictive practice and exclusion (Emerson & Einfeld, 2011).

For autistic people or people with learning disabilities, living in a world designed for neurotypical people can be difficult and cause high levels of sensory distress (Foundations, 2021). Behaviours that challenge may occur as a reaction to this distress and a way to communicate unmet needs (NCCMH, 2015). For this reason, the alternative term ‘distressed behaviour’ can be used (Foundations, 2021). Behaviour is described as being challenging to services, rather than the problem lying with the individual themselves because it is vital to understand the context in which they occur.

Behaviours that challenge can lead to the person’s freedoms being restricted and exclusion from school, college and other community spaces (NCCMH, 2015). People that demonstrate behaviours that challenge are at heightened risk of being placed in long-term restrictive environments (NCCMH, 2015). However, such behaviours are also known to increase in institutional settings or environments with poor engagement or social support and these places may increase sensory distress. Therefore, responses to behaviours that challenge need to be carefully considered, to avoid creating a harmful feedback loop.

A lack of expertise and capability from local services in understanding and responding to behaviours that challenge was seen by families as an important factor in the use of out-of-area placements.

McGill et al (2010)

Frequency, severity and management difficulty of behaviours that challenge and the impact of these on the family was one of the main factors contributing to a child’s placement in a residential school.

Gore et al (2015)

Behaviour that challenges was given as the reason for over a third of people living in out-of-area placements.

Perry et al (2013)

"Puberty was having a big effect, he was becoming very violent towards his older brother and needed non-stop activity – bike rides, walking and so on – sometimes I was walking with him at 4 am in the morning. I was getting older; I couldn’t cope”

Mother of young person who went to residential school

Positive Solutions 8: Support to manage behaviour that challenges

Currently, interventions that aim to support people with behaviour that challenges can be grouped into interventions that aim to improve the sensory environment around them, and interventions that aim to promote alternative behaviours.

Getting the environment right

If the environment that surrounds a person is not meeting their needs, then behaviour that challenges may occur (NCCMH, 2015). This may include the people, culture, social factors and opportunities that a person has in their life (NCCMH, 2015). Creating a safe sensory environment for the person is key to responding to their needs and providing effective support (Foundations, 2021).

'Capable environments' (McGill et al., 2020) are those that are capable of meeting a person's needs, supporting them effectively and providing them with positive interactions and opportunities. Key features include a suitable home in the community; relationships with friends and family; opportunities to be independent, learn new skills, exercise informed choice and engage in meaningful activity; personalised routines; positive social interactions and proper support for physical and mental health needs.

Getting these aspects of a person's life right, as discussed in other sections of the report, and addressing unmet needs may reduce the occurrence of behaviours that challenge.

A cluster randomised controlled trial looked at the implementation of positive behaviour support principles in 24 supported accommodation settings. The focus was on systemic change and improving the housing environment rather than on individual behaviour. They found that behaviour that challenges reduced by over two-thirds in the intervention group, which had a large effect size and was significantly greater than the control group. Much of this reduction was maintained at follow-up. McGill et al. (2018)

A small-scale pilot study of the cost-effectiveness of home adaptations for children with significant behaviours that challenge. Six families were included in the project and received Disabled Facilities Grant funding along with top-up funding from their local authorities. The primary aim of the adaptations was to provide additional 'safe space' for the young people. The researchers estimated that the adaptations had saved considerable cost savings to the local authority, based on preventing the child from being placed in a residential placement. It was estimated that up to 14 years of funding for care placements had been saved. These cost savings did not account for the improved health and wellbeing of the child and family due to the adaptations. However the families were clear that the ongoing care and support they received from the local authority was inadequate and put into jeopardy the long-term benefits derived from the adaptations. Clements & McCormack (2017)

Positive Solutions 8: Challenging behaviour support

Psychosocial interventions

In response to concerns about the over-medication of people who show behaviours that challenge (e.g. the STOMP initiative launched by NHS England in 2016), there have been efforts to explore psychosocial interventions that may reduce such behaviours. Such approaches are seen to provide an alternative to more restrictive and harmful interventions, such as the person being placed in an institution (Gore et al., 2022).

A meta-analysis included 22 non-pharmacological interventions aimed at managing challenging behaviour, including positive behaviour support, cognitive behavioural, mindfulness, multi-sensory therapy and dialectical behaviour therapy. They found an overall treatment effect with a moderate effect size. Statistically, interventions that focused on the individual and those that focused on the environment were equally effective. Interventions that combined mindfulness and behavioural techniques were found to be most effective.

Bruinsma et al. (2020)

However the research base for psychosocial interventions for behaviour that challenges is subject to a number of limitations. A review of existing research found that much of the research was of low-quality, meaning that studies were based on small sample sizes and relied on observational studies (NCCMH, 2015). There was evidence of selective publication, meaning that studies that show a significant positive effect are more likely to be published than those which do not.

Moreover there is concern about the potential harms resulting from interventions labelled as ‘Positive Behaviour Support’ such as application to behaviours that do not meet the definition of challenging (Gore et al., 2022). Guidance states that approaches based on Positive Behaviour Support should not be used with autistic people or people with mental health conditions (Gore et al., 2022).

More research is needed into strategies to support young people who display behaviours that challenge. Existing research is presented below, but limitations discussed above should be considered when interpreting it.

Positive Solutions 8: Challenging behaviour support

A study of a community positive behaviour support team in Jersey including 39 children and young people reported a reduction in challenging behaviour and an increase in quality of life.

Bowring et al. (2020)

An evaluation of a Family Intensive Support Service providing assessment and intensive community-based interventions for families with a child with a moderate to severe learning disability, looked at the effectiveness of the service in reducing challenging behaviour. The study, involving the family members of 45 children, found that after one year the Family Intensive Support Service successfully reduced problematic behaviours and increased parents' sense of coping and ability to manage the behaviour.

Mulligan et al. (2015)

The Ealing Intensive Therapeutic and Short Breaks Service (ITSBS) aims to enable young people aged 5 to 17 with a learning disability and challenging behaviours who are at risk of a move to a residential placement to remain within their family and community settings instead. It is a model based on intensive clinical psychology interventions including positive behaviour support and short break provision. Research found that it avoided residential care for 15 out of 16 young people, led to a reduction in behaviour difficulties and a decrease in parental concerns.

Reid et al. (2013)

Other studies that looked at the costs of the model found that the cost of the ITSBS was lower than the estimated cost of residential-based care and suggest that it could reduce costs in the long-term through avoiding residential-based care

Lemmi et al. (2006a)

Examples of Positive Solutions

1. Providing post-16 education locally for YP with SEND can dramatically reduce the proportion going to residential college. With the right attitude and adjustments, mainstream schooling can be successful for children with complex needs.

2. The provision of short-breaks has beneficial outcomes for children and their families and could lead to savings for the state.

3. Transition planning can be improved through a person-centred approach and better involvement of families and the young people themselves. Advocacy and individual budgets can lead to more positive outcomes.

4. A supported living transition service can help young people with complex needs move on to independent living with the right support in place. Shared Lives can also be a cost-effective alternative, supporting people to enjoy family life and remain

Positive solutions that can help address the problems that lead to children and young people being placed in residential care placements away from families and communities

5. There is a robust evidence base showing that the model of Supported Employment, which provides personalised support for people with disabilities, helps people into paid work and can be cost-effective.

6. Personal health budgets and joint health and social care budgets are funding mechanisms which can help people with disabilities, particularly those with complex needs, to have the support they need to stay living in their local area.

7. Independent advocacy, including peer advocacy, can help young people be involved in decisions that affect their lives and the use of creative approaches can enable those with non-verbal communication to express their preferences.

8. Ensuring that people live in a safe sensory environment that meets their needs, have positive social interactions and meaningful community engagement can help to reduce behaviours that challenge.

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