



Disabled Children's Partnership

'This Can't Be Our Future'

Disabled Young People aged 16+ years and their families experiences of Transitions to Adult Services.

Results of a Survey with Parent Carers of Young Disabled People

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Introduction

In March 2022, the government published its long-awaited SEND review green paper '*Right support, Right place, Right time*'¹. It lays out the challenges to the current system, with proposals to ensure that every young child and young person has their needs identified quickly and more consistently. Its stated over-all objective is to create a SEND system that provides excellent provision from early years to adulthood. This report will focus on the transition to adulthood for disabled young people. The survey data used in this report is from a time when covid restrictions were in place, but in discussions with young people and their parent carers they have been clear that the underlying issues pre-date the pandemic. Parent carers we work with feel the current system fails to support young disabled people, jeopardising their future.

An efficient SEND system is not just about securing adequate support for disabled children during their childhood. A fully functioning robust SEND system is vital to ensure that disabled children are not marginalised from society as young disabled adults. A good transition process to adulthood enables a disabled young person to access education or training, with a view to suitable employment in the longer term; access appropriate support from health and social care to manage their disability and maintain good mental health; move towards adulthood living independently or with support; spending time in the wider community pursuing hobbies and interests.

If done well, a transition plan can put needs and hopes of the young person at the heart of the process. If done badly, young people are not just at risk of losing their potential, they risk isolation, loneliness and exclusion from society. Without the correct support in place, as young people move forward into adulthood, their needs are at risk of escalating with more intense provision required, often far from home. A positive transition enables a disabled young person to achieve their potential, achieve their best, becoming confident individuals with fulfilling lives

Local authorities and partners have the responsibility to ensure effective and well supported transition arrangements for education, social care and health services are in place. However, transitions often fail to meet the young person's needs. However, our work with families of disabled young people highlights the lack of accountability within the current system when transition plans are not appropriately produced or adhered to. This age group are at risk of becoming lost in the system². In 2020, 13% of 16-17year olds with SEN support and 11% with EHCP or statement in England were Not in Education, Employment (NEET) or training compared to 7% of their peers without SEND or EHCP³. In addition, the rate of those NEET with SEND and who's activity is not known by the local authority, is twice as high as those without SEND.

Levels of loneliness, social support and social isolation experienced by people with disabilities are significantly higher than their non-disabled peers, with loneliness in particular a driver of poor wellbeing⁴. Loneliness in turn leads to negative impact on physical and mental health⁵. Even before the recent COVID-19 pandemic, disabled people aged 16 and over were four times more likely to report being lonely than non-disabled people⁶.

At risk of falling out of the system, the impact of loneliness on young disabled people's mental and physical health leads to family members providing vital support at a time when structured support should be in place. Absent structured support impacts the whole family, with parent's opportunities to work restricted. In addition, the reduced level of support ageing parents can provide result in siblings taking on further caring roles, again limiting their opportunities work. It has been widely reported that the vast majority of parents of disabled

young people are profoundly worried about what would happen to their child if they were no longer around to look after them.⁷

The Pears Learning Hub is a partnership between Pears Foundation and the Disabled Children's Partnership (DCP) – a coalition of more than 100 organisations – with the purpose to extend the evidence base for disabled children and their families in England. In 2021, the DCP established a Parent Survey Panel to carry out a series of surveys to track the experiences of disabled children and their families.

The *Longest Lockdown*⁸ report (findings from survey 1 of the Parent Survey Panel) revealed that 35% of families reported that the pandemic had affected their child's examination, assessment or transition. In survey 3, *No End in Sight* report⁹, 49% of parents reported that their disabled children's transition had been negatively affected by the pandemic. Of those, more than 69% reported challenges to stages for older disabled children, aged 16 and above. Focus groups and interviews with parents established that this age group is at high risk of experiencing poorer life chances as a result of poor support during transitional age groups 16-25. Therefore, this survey was designed in collaboration with parents of disabled young people and staff at charities with knowledge of transitions. 391 parents for the parent survey were asked to complete a focussed survey regarding experiences of transitions during the pandemic. The response rate was 30%.

This report illustrates absent or inadequate support as a common experience for disabled young people, undertaking transition to post 16 services across education, social care, health, moving towards adulthood. The SEND review must ensure disabled young people receive support appropriate to their needs across all relevant services and agencies to avoid the social exclusion of an already marginalised group. There must be clear lines of accountability when local authorities fail to adhere to their responsibility to young disabled people.

Key Findings.

The SEND code of practice¹⁰ states that the transition process for education post-16 years should begin at age 14 in England. Transition to adult health and social care services at 18 years should begin at age 16. **Despite this more than half of the families responding to this survey indicated that they did not have a transition plan in place.** As a result of the pandemic, a third of parents indicated that their child would now finish education sooner or later than had been expected. For those not able to continue in education, lack of suitable provision, lack of support and increased social anxiety were cited as the most common reasons.

The transition process into adult health services appears to be similarly challenging. Although 25% of parents reported no problems transitioning, 2 in 5 parents reported problems experienced within primary care, 1 in 4 within hospital services and 1 in 5 within community services. Parents reported delays accessing routine appointments for support, with declining health cited as a barrier to continuing in education for some.

Over a third of families reported challenges with transitions to adult social care services. 65% of parents in this survey expect their child to continue to live in the family home in the near future and 66% expect their child to be supported by benefits. This survey took place during the COVID-19 pandemic, with 90% of families using personal budgets reporting barriers to use the funds during the pandemic, with at third unable to use them within the community for leisure activities.

For many disabled young people, access to leisure and community facilities supports the development of life skills, with a view to promoting independence and reducing isolation. The repetition and consolidation of life skills are a key requisite for independence to become a realistic aspiration. Three in five parents reported that the pandemic had had an additional negative impact on their child's friendships.

It is the duty of the local authority and partners to collaborate and develop an appropriate transition plan for a disabled young person. However, a lack of joint working between authorities and services leave parents to be the driving force of young disabled people's transitional activities, placing additional burden on the families when their children should be moving towards independent or inter-dependent lives.

We had an EHCP and received a Continuing Health Care (CHC) budget for education, respite care that included overnight stays at a unit, Day Centre costs, two personal carers for 2hrs each morning. Due to Covid, they're not able to attend college, so place cancelled. EHCP now cancelled too, still have CHC for Day Centre, but CHC team now can't find a care agency to do package. We've had no Carers since December 2020, and respite centre shut due to covid, but company collapsed financially and won't be reopening. There is no other unit suitable that can provide the necessary care as child is complex

All children with special needs throughout their early life into adulthood around age 25 need consistency and support in all settings. They need a person that makes sure everything is in order, funding in place, provision in school, college. Parents are holding on by a thread trying to organise these things for their children, often with little or no support and no one to advise them what they can or can't do.

Parent Carer Quotes

The parent carer comments above and detailed findings that follow, illustrate the importance of enabling families to hold service providers to account. The findings in this survey reveal that without targeted support, disabled young people are at high risk of social exclusion. Inadequate planning for transitions risks the breakdown in adult placements, reduced life opportunities and poor health and social outcomes for disabled young people.

Recommendations

- The proposed new SEND National Standards should include specific standards on transition across education, health and social care, to ensure all young people with SEND have an education or training placement secured and continuity of provision between children's and adult services in both health and social care, and a clear focus on long term outcomes
- All areas' Local Inclusion Plans should have explicit arrangements for transition, including joint working between education, health and social care
- Guidance for the new Integrated Care Systems and Integrated Care Boards should include clear guidance on managing seamless transitions between children's and adult's services
- The proposed new National and Local Data Dashboards should include data on transitions and achievement of outcomes
- Ofsted/CQC inspections local area inspections should report on arrangements for transitions

Detailed findings

Introduction

The DCP parent panel was established in Autumn 2020, with parents of disabled children and young people completing a series of surveys about the impact of the pandemic on their family during 2021 and 2022. 119 parents of disabled young people, aged 16 years and above completed this one-off survey to the DCP parent panel focusing on experiences of the older age group.

- 66% of parents had one child, 29% had two children and 6% had three or more children.
- The most common reported conditions were Autistic Spectrum Disorder (75%), Learning Disability (68%), Speech and Language Communication Difficulties (61%) Social and Emotional Mental Health Needs (51%) and Physical Disability (30%)
- Responses were also received from parents of young people with complex health needs, multisensory impairment, ADHD, rare conditions, visual impairment, life-limiting or life-threatening condition, hearing impairment and undiagnosed conditions
- 90% of parents were white and 10% black, asian or minority ethnicity
- 92% of parents were mothers, 6% were fathers and 2% were grandparents
- 22% of respondents lived in the South East, 16% in the East Midlands, and 14% lived in London with other regions ranging from 12.7% in the West Midlands and 4.2% in the East of England.
- 84% of parents lived in an urban area and 16% lived in a rural area.
- 35% of young people were 16-17, 49% were 18-21 and 16% were 22-25 years.

Transition Process

The transition process should commence for children from aged 14, with a view to creating a transition plan, in particular for post 16+ education or training and at aged 16 for transition to adult health and social care.

More than half (56%) of parents taking part in our of survey, did not have a transitional plan in place. Parents who had started the transition process before the pandemic describe a lack of continuity during the transition period. Updates were minimal or transition meetings did not occur at all.

My child leaves college in June and his transition meeting is in June.

As a parent I thought that transition was meant to start at the age of 16, however my daughter turned 18 last August and we have had 1 transition meeting. Not any more meetings since the first one when she was 16

2 weeks until she is 18 and plan is still not finalised. Draft completed only after a major formal complaint to the head of adult services. The manager is now actively involved in the plan

Education

Young people in England stay in education or training until the age of 18. For young people with disabilities they may continue in education until the age of 25 years if they need longer to achieve their educational outcomes and make successful transition into adulthood. Prior to the pandemic, 82% of young people in our survey were in education. The majority of parents (65%) reported that their disabled child is to continue in education as expected despite the pandemic. However, the pandemic has had an impact on more than a third of young people's education. 20% of parents now expect their child to now leave education sooner than planned and 15% later than planned. In many circumstances, presumed direction and level of provision had altered with increase in support now required as a result :

My son was predicted to transfer into mainstream college (A levels), he will now transfer into SEN scheme with SEN provision

Intention was for son to be at mainstream FE college 2020-2022 and living at home. Pandemic contributed to failure of that placement, so now seeking residential specialist college placement to start 2021.

Lack of community opportunities and the compromises to therapy mean that residential now seems the way forward to all of us.

Of those parents who reported that their children would not continue in post-16 education, 31% stated that this was due to the lack of suitable provision, 23% lack support, 21% social anxiety, 13% reported personal choice or lack of practical help with travel. 1 in 5 parents reported that their child's educational placement had fallen through at the time of the survey.

He was supposed to stay in schools until July 2020, but had to leave March 2020 as shielding and never returned to school. Was supposed to begin college sept 2020, but was a total disaster as was no transition at all, child has complex medical conditions and PMLD and couldn't settle with total strangers

He attended a college part time but with no support put in, the placement broke down because of no support.

Due to change in routine, overwhelming stress during the pandemic and lack of organisation, communication and support from college, my son has been unable to go back and finish his course. His EHCP has rarely been followed and his life skills are minimal.

Parents who expected their child to continue in education expressed concern about their children's progress being halted due to not being in their usual learning environment eg home from residential college or participating in home online learning.

As our son has been home for last year, we are going to have to give him more support just to transition to the stage he was before, then we will be able to start again with long term aims

The backwards steps he has taken due to the effects of the pandemic need to be reversed to enable his move forwards.

Delayed learning skills and lost skills means she has to redo over a year. Maybe longer because of her SEN

Many disabled young people are vulnerable clinically and support arrangements changed in response to the pandemic, with some families losing out on support, as their children were not in their usual educational setting.

Son was in weekly residential specialist college pre pandemic. Then LA ceased EHCP when he came home to shield, against his and our wishes. There was no transition plan in place and most of adult services are only just reopening to new referrals. No support, having to sort it all ourselves

Training, Volunteering and Employment

For young people not in education at aged 16, training may be an alternative route to employment. Life skills can also be developed through volunteering and independent skills through supported employment opportunities. However, there are challenges experienced by young people at educational settings that provide training or volunteering opportunities for disabled young people.

Staff loss effected by illness, holidays, moved jobs has affected my daughter's ability to learn as well as needs with familiar staff.

Volunteering was part of the residential placement for life skills. All now stopped.

Over the course of the pandemic, the lines between education, work and home for the general population became blurred. Addressing the changing level of support needs due to this has not been forthcoming. In addition, for disabled young people, a more distinct challenge was common, for example for a young person with autism:

He was attending a preparation course for the supported internship. This stopped in March 2020, some further work was done online, but as he is autistic, he won't do college work at home. So the course was incomplete. He was intended to complete it in the current academic year, however the college discontinued the course. He's not attended anything during this academic year. The supported internship itself requires him to be in a work placement for the academic year, so obviously that hasn't happened either. Unsure what to do for September or what his options are.

One in five parents responding to this survey expected that their child would be able to work in the future. For many, their child's disability limited this aspiration but for others it was due to cumulative barriers in support accessing healthcare, public transport and staffing through wider services. **Disabled young people require support across a number of services in order to avoid being marginalised by society.** However, poor transitional planning, the delays with health appointments, the lack of visits to new or potential placements, changes to transport or reduced support, mean that young people may be denied the opportunity to progress into employment.

Health set-backs which have not yet been investigated due to pandemic closing services/increasing waiting lists, means employment is even more unlikely currently

Trying to get a better travelling option other than normal public transport (will be overwhelming). Also trying to find some form of supported job / vacancy at their college (to help rebuild some confidence and also to lessen the very real overwhelming situation with moving straight to somewhere else for supported internship).

No idea if she will cope with work without any work experience. None done yet because of pandemic.

Without intense one to one support, my son will not be able to work. I am unaware of where such support will be available especially as my son would like to work in bus or train transport.

Disabled young people who have lost skills in communication and socialisation need support in re-integrating with their peers and regaining lost confidence and life skills. The impact on the transition of Young People's health will be discussed in the next section.

Health

Parents were asked to indicate their experience of the transition to adult health care services. **75% of families reported that they had experienced challenges with health care transitions.** 39% reported challenges within primary care (GPs, Pharmacists, Dentists, Opticians), 24% with hospital services and 20% with community and mental health services (Speech and Language, Physiotherapy, equipment provision).

My child has multiple conditions. One condition's transition has been delayed One transitioned during the pandemic with a referral and a new consultant, no other interaction between the 2 services. For other conditions we have been unable to find an adult service that will accept my child's care

During childhood, the paediatrician pulls all the services together but there is no equivalent when my child moved across to adult service. No-one clinician other than the GP.

So many young people are unique, there is no expertise in adult services because historically children like my daughter have not lived into adulthood. The specialism is within children's services. There is no equivalent expert in adult services.

It (Transition) was never offered to my child. In fact we were told by CAMHS that adult services were rubbish so we wouldn't be referred to it. My son ended up being sectioned for a year and is now cared for at home. We have no support from any services.

Delays to health appointments are affecting disabled young people of this age group who rely on regular reviews, diagnostics and treatment to be able to manage their disability or condition. Without that their ability to attend education or training declines. Parents reported barriers to accessing appropriate support for their child's mental health, with declining mental health such as severe anxiety and depression, attributed to further lost opportunities for many young people in this age group.

Having to stop all education means my child currently has no qualifications and, with it being very difficult and taking a long time to see specialists to try and manage health problems, I don't know if my child will ever return to education

She was doing really well working towards a career choice with 5 GCSEs not in education for nearly a year no OT (Occupational Therapy) or SaLT (Speech and Language Therapy) support isolation mental health issues is a cocktail for failure

He had an urgent referral for acute depression to mental health services during pandemic, we never heard any more. He had been referred already pre-pandemic ... He is on anti depressants and has previously been under CAMHS.

The pandemic and restrictions had a negative impact on the young person's health and subsequently their educational placement. However, as comments from parent's below demonstrate it is the lack of tailored support for young disabled people that have led to breakdown in educational or training placement.

Online education was not a suitable replacement as the added intensity of having to manage technology, and the tutor not being able to pick up on the body language cues of how my child was becoming more unwell and distressed meant the little tuition that was being provided made my child too ill to continue

The SEN provision stipulated in his EHCP failed to materialize with non-existent SEN support during lockdowns and unwilling to attend school due to debilitating anxiety, he completely disengaged with learning activities and now predicted to fail his GCSE's

My son has had no access to support since leaving paediatric services (his needs are unchanged). He doesn't meet the threshold for mental health support despite being under Camhs until 18

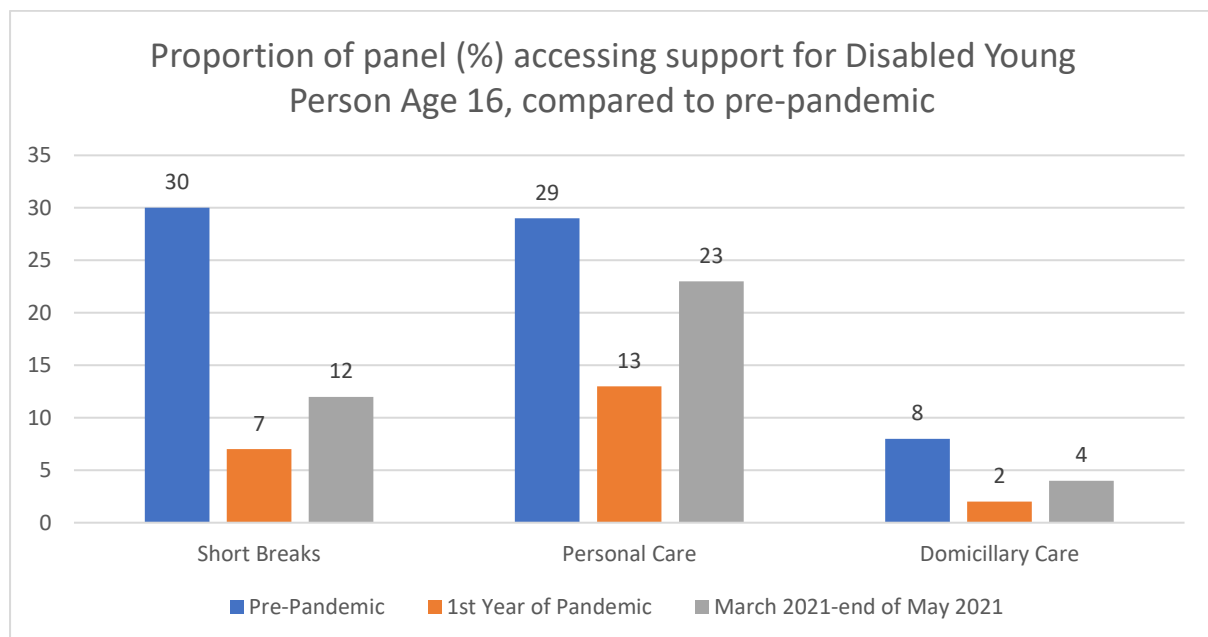
Family Support

Over a third of families (34%) reported challenges and difficulties with social care transitions.

Although the pandemic exacerbated problems families experienced regarding social care support, parent comments below exemplify the lack of accountability within the system when provision and support is lost or inadequate.

Parents were asked to indicate services that they accessed for support before the pandemic, during the first year of the pandemic and currently. Findings demonstrate that support services reduced during the pandemic as previously reported (1 & 3) and have yet to return to the level accessed before the pandemic. As figure 1 below illustrates, access to short breaks are still reduced by more than 50% of the figure pre-pandemic.

Figure 1.



The survey investigated the type of support that families received financially. 65% reported that they received personal budgets, of those 49% usually spent their budget on support in the local community for leisure activities, 23% on support in the community for life skills, and 22% on personal care.

90% of respondents using personal budgets reported challenges in using them. Challenges encountered (more than one may apply) include:

- 36% support in the community (leisure)
- 18% personal care
- 15% support in the community (life skills)
- 13% transport

Struggled with PA's (Personal Assistant) who I employed as they were shielding but she also has an agency and they were able to carry on throughout.

Changes in the way provision had to be delivered, lack of context for therapy was a major problem, periods of no therapy due to illness, lockdowns. There were some positives from outdoor therapy. The Local Authority tried to claw back budget at one point.

It is a total shambles with the Council, the money was awarded then taken away leaving large invoices for respite to pay.

It's a real can of worms. As far as I am aware, direct package payment could pay for cleaner, admin, osteopath, rda, reflexology, passes to parks. Somehow, without my knowledge, it has been changed to weekend respite hours.

57% of parents expected to experience challenges in the future using their personal budget.

We didn't not feel it was appropriate to engage personal care in the home during lockdown.

my daughter needs 1 to 1 care 24/7, we were allocated a small amount of Direct Payments in Sept 19 however as our new house was being adapted we could not hire anyone as my daughter was sleeping in the living room. Adaptations completed in Feb 2020 just as the pandemic started. We have not been able to recruit any PA's till now as my daughter is CEV (Clinically Extremely Vulnerable) and was shielding. It's only now)much later) that we are in the process of trying to recruit PA's

There were challenges to families using personal budgets due to reducing the number of people coming into the home. This had an impact on those using personal care or trying to recruit PAs.

I was told that my daughter would move from childrens to adult services on her 18th birthday. I was told her care package would be transferred over, but 2 days before she turned 18 Senior Managers challenged the price of her care package and now we are in limbo. We don't know if she will be allowed to stay with the carers she knows and trusts.

Respite care is all that we can spend personal budgets on but just found out they will be taken away!

I had to sort direct payments by myself no help through social services. Once my daughter turned 18

23 hours per week were taken away in order to fund college escort. She had just gone back to college after huge battles re shielding. I had no day care during her time shielding yet package had said five days and five nights waking care per week.

Housing

For families with young people living at home, the lack of appropriate supported living provision continued to be an issue. Parents were unaware of options or offer of provision in their local area. As the parent comments below indicate, poor transitional planning and lack of suitable provision limits a young person's options to live safely away from the family home.

There are no assisted living places available so don't know what will happen!

I was going to look what is available for supporting living however we never had any transition as such

My son started to spend time in respite with a view to entering supported living around now but this has not happened so he is still with me.

Our son needs a plan for independent living probably in a bespoke house. There are no plans for this and he has only over a year left in residential college. He made no progress last year as he had no therapies. He was awarded Adult CHC during the pandemic.

Living Life

The previous few years has intensified young disabled peoples' experience in accessing appropriate support within the community to live the type of life they choose. Many disabled young people may require regular outings with support, in order to develop life skills, to repeat activities and consolidate skills required for independence. Disabled young people should have the same social opportunities as their non-disabled peers however, parents reported that challenges persist, preventing young disabled people the opportunities to pursue their interest, hobbies and make and maintain friendships.

My son gets direct payments so that he can access the local community. However, during the provider was not always available due to a shortage of staffing.

Despite restrictions in England ending, 41% of disabled young people are still unable to attend their social activity group such as drama or music; 40% are still unable to access their sport activities; 52% are unable to go on outings parks and museums and 30% are unable to pursue their chosen individual activities. Prior to the pandemic, it was common for disabled young people to find themselves socially isolated, lacking opportunities to socialise due to limited provision and poor accessibility within society.

Service Integration

The transitional age group exemplifies the fragmentation of services and lack of joined up support that families of disabled children report. Despite the SEND Code of Practice placing the duty of transition on local authorities in partnership with parents. The lack of transitional planning creates unnecessary stress on parents who fill the gap by using their time to drive the transitional activities, communicating between services, time that could be spent with the family enjoying social activities.

Assessment for residential was put on hold. Lack of tracheostomy trained escort means I 'work' 15 hour days including escorting to and from college for over five hours a day. Sometimes after my waking night shift and meetings during the day either side. We are now at the point of me physically and mentally collapsing.

Local authority has secured emergency direct payment funding last weekend and this weekend . Assessment scheduled for this Thursday. I have agency carers until Friday night shift. Emergency Direct Payment carers this weekend. Then from Monday 8am, I am expected to do nights, waking, escorting, and MDT meeting, osteopath, 49 page EHCP report to check to try avoid appeal hearing on 28th, orthotics appointments other appointments, general everyday rubbish to correct.

In addition, the local authority has a duty to provide information about the availability of services available, 'the local offer', however parents reported confusion about the options or routes available to their child.

Before my daughter went over to adult services she was classed as a child in care because off her respite hours. Considering that you would think the transition would have been easy for us. I had to find information by myself .

I'm not sure what's available as he has severe learning disabilities.

Unsure of what is available currently due to all the various changes and ongoing changes.

At the moment there is no clear career or work path for my child.

A poor transition of a disabled young person into adulthood, whether across education, health or social care places them at serious risk of marginalisation and isolation. Supplementing structured care and support inevitably falls to parents and siblings, placing additional pressure on the whole family unit.

His support network that he has had since he was 4 years old just stopped with no transition to an adult facility that offers the same consistency and facilities, it's had a massive impact on his mental health. His challenging behaviour increased. His needs didn't change because he turned 18, as his disability hasn't changed for years but his support disappeared and you are told to find your own care for them which is difficult in itself as we are trying to care for them

Conclusion

Transitional planning exists to ensure that disabled young people are able to achieve their potential as adults in education, training or employment, with any health or social care needs supported. Disabled young people aged 16+ are a group, already at risk of becoming marginalised. This survey reveals that more than half of respondents, do not have a transitional plan in place. Those that do are leading the transition process, hindered by a lack of information or joint working between local authorities, health and social care. Clear lines of accountability need to exist between government, local authorities and providers in order for young disabled people and their families to have confidence that the recommended support will be provided in accordance with assessed needs. Without support to develop and consolidate life skills within the community, there is an increased likelihood of the breakdown in placements and move towards independence improbable and more expensive secure placements away from home more likely.

The lack of post-16 planning risks disabled young people falling out of the system resulting in further pressure on the family. Disabled young people are at risk of reduced opportunities and failed aspirations without targeted support to facilitate a route into adult services and adulthood. That is why it is imperative that the government's SEND reforms ensure that young people receive the support they require across all agencies including education, social care and health, with clear lines of accountability in place.

Notes

The DCP panel consists of 1,200 families was set up in 2021 to be broadly demographically representative of the population of families with disabled children across England in terms of geography, disability and ethnicity. Five reports from the panel findings have been published so far^{8,10,11,12, 13}.

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