

Freedom to Live

Transition for disabled young people

Livability's report on disabled young people moving towards adulthood

Rachael Christophides



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Written by Rachael Christophides

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FOREWORD

By Anneka

Member of Livability's panel of young people

My name is Anneka and I'm 20 years old. I have CP but I don't let my disability hold me back. I want to succeed in whatever I do. I'm looking forward to the future because I have my whole life in front of me and there are many doors I want to open.

I want to be free to do my own thing. To make my own decisions and learn from them. I want to choose where to study. To decide where I live and who I live with. I want the freedom to live my life.

The reality is that I have had to fight to take control of my own future. I knew which college I wanted to go to but struggled to make my voice heard. I found a place to live that had everything I wanted but other people thought they knew better.

All disabled young people should be free to make their own choices and decisions about their future. They should not have to battle for control of their life. This is why I am supporting the Freedom to Live campaign.



Introduction

Disabled young people hope for the same things as other young people; to travel, get a good job, start a family and live independently. They want a voice, a leisure and social life, and to be involved as active and valued citizens. However, the stark reality is that for far too many disabled young people their hopes and dreams are thwarted by a system that denies them their basic human rights.

“I just needed people to respect the way I am and realise that they couldn’t change me. I wanted to be treated like an equal person who was able bodied. Although I’m in a wheelchair I would like people to look at me as an adult and not look at me as in a chair.”

(What Beth, now 29, wanted as a young woman)⁽¹⁾

Becoming an adult should mark the opening up of a world of exciting opportunities and possibilities. For most disabled young people, however, it is when their world becomes smaller and more limited. They are denied the opportunities and possibilities the rest of us take for granted. It is less a move from childhood into adulthood, and more a move from childhood to retirement.

“I did settle in a day centre, mainly an older peoples’ day centre. We were in a little room on our own and it was the young persons’ group even though there was a lady of 83. They just said she was young at heart. She didn’t do any of the things we wanted to do.”

(What Neil, now 30, did during his gap year)⁽²⁾

Disabled young people have not always been encouraged to see themselves as having a valuable role to play in adult society. However, huge strides have been made over the last 30 years in raising the aspirations of disabled children and young people. We have become increasingly successful at encouraging them to aim

higher. It is perverse that, at the very point when their aspirations should start to become a reality, they are denied the opportunities and resources they need to make it happen.

“It has been a struggle for young disabled people to gain recognition of their potential and to develop positive aspirations for playing useful roles in adult life. That achievement is certainly to be celebrated. But the fact that equality of opportunity in turning those aspirations into reality is still far from realised leaves no room for complacency. The battle is won but the war goes on.”⁽³⁾

Disappointment and frustrated ambition in early adulthood is devastating for many disabled people impacting on their self-confidence, mental well-being, and belief in their ability to control their own fate throughout the remainder of their lives.

The vast majority of disabled young people have little or no choice over where they live, who they live with and how they spend their time. They are denied the freedom to live their life. This campaign is for them and their families.

Lost in Transition



Lost in Transition

What's the problem?

The move from adolescence to adulthood can be an incredibly daunting time for disabled young people and their families. Impending life changes, combined with uncertainty about the future, can lead to considerable anxiety and stress. This in turn impacts on their health, well-being and self-esteem. The consequences can extend well beyond the transition itself.

Tiffany, a 19 year-old young woman with Downs Syndrome, suffered from alopecia as a result of the distress she endured during the transition from school to college. She, like most girls her age, takes pride in her appearance and wants to work in a hairdressers when she leaves college. The impact of the hair loss on her self-esteem was devastating.

It has taken years for Tiffany's hair to grow back and, as she now approaches the transition from college to employment, her mother is concerned that the experience will be repeated.⁽⁴⁾

The transition plan

It is widely acknowledged that the anxiety and confusion experienced by disabled young people and their families during the transition to adulthood can be minimised by planning ahead. The right to have a transition plan, devised with disabled young people when they are 14 and regularly updated, is enshrined in several pieces of legislation. However, research demonstrates that a significant minority of disabled young people leave school with no transition plan in place.

Investigations by the Norah Fry Research Centre found that, despite legislation and guidance dictating that disabled young people's views must be sought and recorded during transition planning, a fifth of those they questioned left without a transition plan at all.⁽⁵⁾

Staff working in specialist schools and colleges have told the Commission for Social Care Inspection (CSCI) that there is a significant gap between what should happen during transition and what actually happens.⁽⁶⁾ This reveals a worrying disparity between national policy and local practice that needs to be addressed if current and future initiatives are to be effective.

Whose plan is it anyway?

Where transition planning does take place, there are often significant discrepancies between the issues that disabled young people and their families want to be addressed and those which are actually covered. Leisure and social opportunities are repeatedly cited by disabled people and their families as issues of paramount importance. However, these issues are frequently accorded a low priority by professionals involved in transition planning. For over half the families interviewed by the Norah Fry Research Centre, leisure and social opportunities had not been covered at all.⁽⁷⁾ This had serious consequences for disabled young people and their families.

“Many of the young people’s friendship networks were repeatedly disrupted after they left school. Parents themselves were often trying to organise structured activities for their sons and daughters, but were doing so with little information or support, particularly in the area of adult relationships.”⁽⁸⁾

CSCI found that, whilst young people were involved in some reviews, they did not feel meetings were clearly centred on their needs and wishes.⁽⁹⁾ Neglecting to take account of the views of young people at this crucial time in their lives results in many of them feeling unable to influence their fate. This in turn can lead to a sense of helplessness and emotional distress.

The advent of person-centred planning was designed to ensure that disabled young people have a voice in the transition planning process. However, its universal adoption remains a distant goal.

“For the majority of the young people, there was little or no evidence of any person-centred planning. Rather, the overwhelming feeling was that the young people were at the mercy of service provision, policies or procedures that appeared to disempower, rather than serve them.”⁽¹⁰⁾

Timing is everything

Much of the anxiety and distress experienced by disabled young people approaching adulthood can be mitigated by securing a package of support well in advance of the transition itself. It is often the uncertainty of not knowing where they will be living, and with whom, that causes disabled young people distress.

“For some of the young people, the stress noticed by parents and professionals was thought to arise from the fact that they did not yet know where they were going after leaving their school or college.”⁽¹¹⁾

“Uncertainties about future arrangements can be unsettling and a cause of anxiety for families.”⁽¹²⁾

Supporting disabled young people can entail putting in place a complex package of services involving multiple providers. It is essential that the process of negotiation begins well before the actual transition occurs, particularly where more than one agency or authority is involved. Failure to engage in the process early enough has significant consequences for disabled young people and their families.

“The consequences of a short-term perspective could be difficult, especially where some budgetary brinkmanship between different agencies was involved.”⁽¹³⁾

“Parents told us that transition plans were established too late with no clear arrangements between services.”⁽¹⁴⁾



"I did settle in a day centre, mainly an older peoples' day centre. We were in a little room on our own and it was the young persons' group even though there was a lady of 83. They just said she was young at heart. She didn't do any of the things we wanted to do."

Neil

Who's in charge?

The transition process is further complicated by lack of clarity around who is responsible and, given the plethora of agencies involved, this can lead to considerable confusion. The complex task of liaising between agencies is often left to parents who are already providing substantial levels of care and support.

“Our case studies revealed a confused picture about which services were leading on transition and the roles of the professionals involved. Parents wanted experienced professionals ‘in charge’ but rarely did parents know who the professional was, or should be.”⁽¹⁵⁾

“The capacity to take a coherent long-term approach was hindered by confusion and disagreement over responsibility for undertaking the task.”⁽¹⁶⁾

“They were both playing one off against the other and leaving me in the middle to talk to them both. They weren’t talking directly to each other.”

(Father of disabled young man)⁽¹⁷⁾

Where are you?

The failure of key professionals to effectively engage with the transition process repeatedly emerges as an obstacle to genuine progress. The absence of social workers from review meetings is a common theme and, given the importance of their role in the transition process, this is particularly disappointing.

“Social services didn’t turn up. Connexions didn’t turn up. No letter, no apology, no phone call. No nothing.”

(Mother of a disabled young woman)⁽¹⁸⁾

“For many parents and professionals, the attendance, or lack of attendance at meetings by key individuals was an issue.”⁽¹⁹⁾

Social workers are the gatekeepers of services as well as holders of the purse strings. Their commitment and active involvement in the transition process is crucial.

Our research has shown that, in far too many cases, the only attendees of transition planning meetings and reviews are the disabled young person themselves, their family and staff from the school or college where they are currently based. This is woefully inadequate. Many of the parents and teachers we spoke to expressed the opinion that, without the involvement of key professionals from other agencies, very little could be achieved.

“Transition planning for young people with complex needs requires a coordinated multi-agency approach which extends far more widely than the school and family. It also needs to link to the various systems in place for all young people, and it needs to consider the way services change to support and empower the young person’s move from childhood dependence to adult independence.”⁽²⁰⁾

Do I know you?

Where social workers and other key professionals are engaged in the process, their relationship with the disabled young person is often not sufficiently developed. As a result, they are not always fully aware of their needs and aspirations. This is a particular problem for disabled young people in residential schools and colleges located outside their local authority area.

“Not only was the distance to travel to attend planning meetings an issue, but so was the difficulty in knowing what was happening in the young person’s life if the ‘home’ professional only saw them once a year at reviews. The lack of accessibility of the young person meant that professionals did not feel that they really knew the young people and what their own views of their needs and issues were.”

“The difficulties at transition are exacerbated for young people with learning difficulties in out-of-area placements. Contact with the placing authority – from social workers, educational psychologists or Connexions advisors – appeared fragile where it exists at all.”⁽²¹⁾

Do they talk to each other?

As well as building better relationships with disabled young people, key professionals need to communicate more effectively with each other. The need for a multi-agency approach to the transition from childhood to adulthood, supported by closer working relationships between relevant organisations, is widely recognised. However, despite the fact that this approach has been advocated in numerous policy documents and guidance to professionals, its application remains frustratingly limited.

“Local agencies should collaborate to ensure that young people and their families experience continuity in delivery during the transition from child to adult services. However, our evidence is that this is the exception rather than the norm, and that urgent action is needed to ensure that disabled young people’s lives are not wasted in the transition to adult services.”⁽²²⁾

The information gap

The provision of timely and relevant information is critical to the transition planning process. It is essential to help disabled young people and their families navigate their way through a complex maze of services and providers. How can they decide on the future when they do not know what the options are? How can they access the right services and support if they do not know what exists or where it is located?

“Parents wanted information to be offered to them, it to be relevant to their circumstances, provided earlier than in the young person’s final year, and for them not to have to chase people up for information all the time.”⁽²³⁾

“Almost everything concerned with my daughter’s education and different possibilities for life beyond school I have had to find out for myself through friends and searching through different organisations. It has at times proved to be a long and painful experience. At no time has information been readily available.”

(Parent of a disabled young woman)⁽²⁴⁾

The importance of providing disabled young people and their families with the right information, at the right time, has been recognised by the Government in several policy documents and emphasised in guidance to professionals. This has no doubt secured improvements and some local authorities now provide transition packs or guides containing invaluable information on services available in their area. However, this approach is by no means universal and much depends on where the disabled young person lives and the focus given to transition by their local council.

Far too many parents tell us getting the right information when they need it remains a struggle. They often have to hound professionals for even the most basic details.

“So I said, can you send me some information for transition, for moving everything else. He said, we do not send anything like that. So I said, where do we get the information from? Where, tell me?”

(Mother of disabled young woman)⁽²⁵⁾

We hope that the current focus on transition by the Government will drive further improvements with all local authorities providing information packs and guides to disabled young people and their families as a matter of course. Until this has been achieved significant gaps will remain. **Livability** is producing a national transition pack for disabled young people and their families to support those who are still struggling to find local resources.

Who are they planning for?

The ability of local authorities to plan ahead for the move from child to adult services is seriously undermined by a lack of accurate, reliable and up-to-date information on the numbers and needs of disabled children and young people in their area.

Despite legislation dictating that councils must collect and revise this data, and a number of policy documents recognising its importance, local information systems are either non-existent or woefully under developed. What does exist is rarely shared within local authorities, let alone across relevant agency boundaries.

“Councils were not planning ahead or monitoring the changing needs as young people with complex needs grow up. Despite the requirement of the Children Act 1989, for councils to establish a register of children with disabilities in the area to aid planning, data systems to identify who will transfer did not exist or were poorly developed.”

“As well as not knowing exactly who might need a transition plan, who might transfer to adult services and what their needs were likely to be, information sharing within councils and across partner agencies was also patchy.”⁽²⁶⁾

It is not enough to know how many disabled young people are transferring from child to adult services. Councils need to monitor the progress of disabled young people after the transition has taken place to ensure that the services they are receiving meet their needs and they have the freedom to live their lives to the full. Currently, this is only happening in a minority of local authorities.

A staggering 85% of local authorities questioned by CSCI were unable to track the most recent cohort of disabled young people to adult services.⁽²⁷⁾ The consequences can be far-reaching.

“Poor data and monitoring can result in young people with complex needs being hidden within the adult care system so their needs are not addressed properly in the long term.”⁽²⁸⁾

What is being done?

There is an unprecedented focus in Government on services for disabled children and young people and this includes the move from childhood to adulthood. Many of the concerns outlined above are well recognised and understood by Ministers and recent proposals announced by the Government are designed to secure significant improvements to the experience of disabled adolescents and their families during this difficult time.

"It would be good to have somebody that you could talk to if you needed to. To come to you and say, I've come to speak to you because I would like to know how you are getting on and how I can help in different ways. Someone not under the school. A different voice."

Vicky

The Transition Support Programme

The Government has announced the establishment of a Transition Support Programme, backed up with £19 million of investment, which should provide:

- a young person's information pack
- access to an advisor or key worker and advocacy and support
- consolidation and extension of person-centred planning
- a joint team working across agencies and with adult services to encourage a holistic approach, and choice and control for young people.

Public Service Agreement on Disabled Children and Young People

A new Public Service Agreement (PSA 12) commits the Department for Health (DH) and the Department for Children, Schools and Families (DCSF) to:

- establishing the Transitions Support Programme in a new Public Service Agreement (PSA)
- developing a transition planning tool for disabled young people with neurological disabilities.

The PSA also lays down expectations for other delivery partners – Primary Care Trusts (PCTs), local authorities and service providers – including:

- work jointly to develop effective transition plans
- increase engagement with disabled young people
- develop and enhance forums for parents
- work together to plan and commission effective and responsive services.

Successful implementation of the Transition Programme, and effective monitoring of the PSA, will be enhanced through the new Children's Trusts. The Children act 2004 places a duty on local authorities to make arrangements for multi-agency cooperation and collaboration to improve the well-being of children and young people. These arrangements will be supported by joint budgets and will apply to disabled young people up to the age of 25. Children's Trusts must have been in place by April 2008.

These developments are very welcome. They demonstrate the Government's intention to secure real improvements to the transition experience for disabled young people and their families. We would, however, sound a note of caution. Past experience has shown that there is often a world of difference between what should happen and what actually happens.

"Our hearings have taken evidence highlighting the implementation gap between government policy on disabled children and the reality of service delivery on the ground. We have found major gaps in service provision and pervasive inequalities in services and outcomes for families."⁽²⁹⁾

Policy initiatives designed to improve the transition experience for disabled young people are being undermined by the lack of accurate, comprehensive and reliable data. Improved information on the number and needs of the national and local disabled population is vital if current initiatives are to have any real chance of success.

Aiming High for Disabled Children

Work is underway to develop more consistent, compatible and comparable data on disability on which to base service planning, commissioning and provision at both local and national level. The project is coordinated by the Office for National Statistics (ONS) with input from the Office for Disability Issues (ODI). A report will be published in 2008-9.

The Disability Equality Duty

The disability equality duty, introduced by the DDA 2005, requires key public bodies to produce a Disability Equality Scheme. The scheme must contain a statement of the authority's arrangements for gathering information on the effects of its policies and practices on disabled people.

Directors of Adult Social Services (DASS)

Part of the remit for the new role of DASS is to undertake regular strategic reviews of the needs of the local population in order to plan services for the next 10 to 15 years.

These initiatives need to be coordinated to avoid duplication of scarce resources and encourage joint working between child and adult services. It is particularly important that the data collected on disabled children and young people is shared with the DASS. This should inform strategic planning for disabled young people to ensure that the services they need are in place when they transfer to adult social care.

We have already noted the importance of local authorities and PCTs to tracking disabled young people through the transition process and monitoring their progress in adult social care. The Disability Equality Duty should be used as the focus to make this happen.

Recommendations for change

1. Universal adoption of person-centred planning by all agencies involved in the transition planning process.
2. Packages of care and support should be in place well in advance of the transition itself.
3. The various initiatives designed to improve data on disabled children and adults must be coordinated to avoid duplication of scarce resources and encourage joint working between child and adult services.
4. Data collected on the numbers and needs of disabled children must be shared with the DASS to inform strategic planning for disabled young people and ensure that the services they need are in place when they transfer to adult social care.
5. The Disability Equality Duty should be used to track disabled young people through the transition process and monitor their progress in adult social care.

Health and Social Care



Health and Social Care

Health

What's the problem?

High quality and responsive healthcare services are critical to the life chances of disabled young people. Their ability to live independently, study, work and pursue an active social life are all dependent on maintaining good health. It is fundamental to the pursuit of their hopes and aspirations. Poor health robs disabled young people of the freedom to live their lives the way they want to.

Unfortunately, for many disabled young people and their parents, the move from children's health services to adult provision is like falling over the edge of a cliff.

"All we got on her 16th birthday was, three days later, a letter which says 'You are now over 16. You're discharged'."

(Parent of a young adult)⁽³⁰⁾

"Transition in health services was felt to be particularly abrupt, with young people suddenly losing access to key specialists who may have worked with them throughout their childhood."⁽³¹⁾

"Families often report receiving excellent care from specialists such as the community paediatrician and child health team; they are shocked when this model of care stops at transition to adulthood."⁽³²⁾

There is a real concern that adult health services are not meeting the particular needs of disabled young people. Many of the vital services available to disabled young people in childhood simply disappear when they move to adult provision.

Where health services are delivered to disabled young people, they are all too often designed to meet the needs of much older service users. Young people move from a children's or young person's clinic to larger and busier adult centres where they are surrounded by much older patients whose conditions may be very different from their own.

"I'd like to have talked to other teenagers about the problem, because you're just sitting in a waiting room with 80-year-old women, and I'm not being funny but you know you felt like a freak."

(Disabled teenager on the transfer to adult provision)⁽³³⁾

"The children's ward wouldn't accept her because she was over age 16, the adult ward wouldn't accept her because she was under 18, and so we had a hell-of-a-game trying to find a ward for her and in the end she ended up going on a geriatric ward for the night."

(Parent of teenager)⁽³⁴⁾

"I am currently attempting to transfer a 17-year-old to adult services. I am very aware of the trauma of transferring from a cosy paediatric clinic to the busy elderly rheumatology outpatient department."

(Healthcare Professional)⁽³⁵⁾

The impact of the move from paediatric to adult health services is keenly felt by disabled young people and their families.

"Our son is now in transition from paediatric services to adult services. This has been nothing short of a nightmare and is on the whole only being achieved because we are assertive parents who plan ahead and have expectations of the professionals who care for our son."

(Parent of a disabled young man)⁽³⁶⁾

Given the particular importance of health services to disabled young people, and the yawning gap between child and adult provision, careful management of the transition is crucial. Advance understanding of what the transfer will mean for a disabled young person, and what services are likely to be lost, would at least prepare them for what is to come and enable them to plan ahead for the change.

Sadly, the transfer from child to adult health services is covered poorly, if at all, during the transition planning process. The Norah Fry Research Centre found that, for over half the parents who had received transition planning, the transfer to adult health services had not been covered at all. Where it had been included, less than a fifth of parents thought it had been covered well.⁽³⁷⁾ The consequences of badly planned transitions between child and adult health services are significant and far-reaching.

“Poorly planned transition from young people’s to adult-oriented health services can be associated with increased risk of non adherence to treatment and loss to follow-up, which can have serious consequences. There are measurable adverse consequences in terms of morbidity and mortality as well as in social and educational outcomes.”⁽³⁸⁾

“The school was in South Derbyshire and our home address is in North Derbyshire. And between those two Health Authorities they said that the other one was responsible so we got no physio at all during which time David seized up basically. It was a worry.”

(Parent of a disabled young man)⁽³⁹⁾

“There is a great deal of evidence that young people who are ‘lost’ in the transition to adult health services are more likely to present later with avoidable and treatable complications of their conditions.”⁽⁴⁰⁾



"I just needed people to respect the way I am and realise that they couldn't change me. I wanted to be treated like an equal person who was able bodied. Although I'm in a wheelchair I would like people to look at me as an adult and not look at me as in a chair."

Beth

What is being done?

The importance of the transition from child to adult health services, and the far-reaching consequences of getting it wrong, are widely recognised by the Government. Ensuring a smoother transition, and a more positive experience for disabled young people, has been the focus of several initiatives and strategies in recent years.

The National Service Framework (NSF) for Children, Young People and Maternity Services

The NSF states that all young people should have access to age-appropriate health services which are responsive to their specific needs as they grow into adulthood. There is a particular emphasis on disabled young people and the need to ensure high quality and well coordinated provision to enable them and their families to lead ordinary lives.

Transition: getting it right for young people

The Department of Health (DH) has issued guidance for key professionals to improve the transition from paediatric to adult health services for young people with long term conditions. It outlines what a successful transition looks like and emphasises the consequences of failure.

“A transition programme between paediatric and adult-orientated health services must provide co-ordinated, uninterrupted healthcare to avoid negative consequences, ranging from psychological distress and anxiety to medical catastrophe or premature death.”³⁹⁽⁴¹⁾

The guide is accompanied by a DVD made by disabled young people themselves. They share their experiences of the transition to adulthood and their aspirations for the future. The DVD can be a powerful tool in securing the commitment needed by local health professionals.

Transition Champions

In 2007 the DH established a network of 23 Transition Champions including doctors, nurses, therapists from both paediatric and adult services, and youth workers. They are tasked with:

- sharing good practice
- promoting implementation of the transition guide
- raising awareness of the importance of transition within their own organisations and beyond.

A Transition Guide for All Services

The Department of Health and the Department for Children, Schools and Families have jointly published guidance for key professionals from all agencies involved in the transition to adulthood for disabled young people. It is a most useful resource that brings together legislation and best practice across the whole range of relevant disciplines.⁽⁴²⁾

The Children's Plan

The recently published Children's Plan recognises that good health is vital if young people are to achieve their full potential. It sets out the Government's goals for what can and should be achieved by 2020 and includes enhancing young people's well-being at crucial transition points in their lives. It also commits the Government to publishing a Child Health Strategy in Spring 2008. It is critical that the strategy has a strong focus on the transition from child to adult health services.

Valuing People Now

The Department of Health's Valuing People policy was launched in 2001 and aimed to achieve equality of citizenship for people with learning disabilities. It focused on promoting advocacy, person-centred planning and partnership-working to achieve change. However, the Government acknowledges that delivery has been patchy and for many people little has changed.

“Families and young people still say that the transition from children’s to adult services is the most difficult time in their lives and that they feel excluded from decisions. The outcomes are often segregated services rather than helping them to achieve the same things as other young people, that is, an education, a job, and living with their friends in their local community.”⁽⁴³⁾

Valuing People Now is the Government’s response to the disappointing progress made so far and it seeks views on the way forward.

The missing link

The problems associated with the transition from child to adult health services are widely recognised and well-understood by Government. There is no shortage of guidance or examples of best practice for commissioners and key professionals to draw on.

“We know about the problems with the transition process and we know what is needed to make things work. The challenge is to make that happen.”⁽⁴⁴⁾

Improving transition needs time, resources and commitment. We believe that real and lasting change will only happen when doing nothing is no longer an option. The active involvement of health services in the statutory transition planning process is encouraged but it is not mandatory. **Livability** recommends that health professionals are legally required to actively participate in:

- the Year 9 transition review and the subsequent drawing up of the first Transition Plan
- annual reviews of the Transition Plan
- establishing the Year 11 Learning and Skills Plan.

A Health Action Plan should be developed following the Year 9 review meeting detailing how health services will support the disabled young person in pursuing their goals. It should be reviewed annually alongside the Transition Plan and updated in light of the Year 11 Learning and Skills Plan.

Disabled young people's hopes and aspirations are dependent on good health. Without it, their plans for the future cannot be realised. We do not believe that this can be left to chance.

Recommendations for change

1. Health professionals should be legally required to participate in all stages of the statutory transition planning process.
2. A Health Action Plan should be developed following the Year 9 transition review meeting detailing how health services will support the disabled young person in pursuing their goals.
3. The Health Action Plan should be reviewed annually alongside the Transition Plan and updated in light of the Year 11 Learning and Skills Plan.
4. The forthcoming Child Health Strategy must have a strong focus on transition from paediatric to adult health services.

Social Care

What's the problem?

As with health services, the dramatic difference between child and adult social care provision leaves disabled young people and their families without the support they need during the transition to adulthood and beyond. Services that may have taken years to negotiate and secure are no longer available, despite the fact that the disabled young person's needs have not changed.

“The submissions to our hearings from disabled young people and their parents were full of anger at the sense that services that they may have had to fight for simply disappeared at transition to adulthood.”⁽⁴⁵⁾

“For most young people, reaching the age of 18 is a time of hope, opportunity and optimism. It's time for planning their future and becoming independent. But for young people with disabilities, turning 18 can be the start of what some families describe as a ‘nightmare’ as their support makes the move from children's to adult social care services.”⁽⁴⁶⁾

The impact of effective children's services is being undermined by the poor support offered to them and their families during the transition to adulthood. Early gains are often lost in the transfer to patchy and poorly co-ordinated adult provision. This is significant because badly managed transitions between age and needs-related services have a cumulative effect on the life chances of disabled young people.

“At least half the councils in our special study did not provide the level of support for adults as they did for children. This means that many young people are at risk of losing out on their opportunities for a fuller life once the responsibility for their services transfers. This is both a waste of the investment in those young people and a waste of their potential if the support they are given in childhood is not continued into adulthood.”⁽⁴⁷⁾

Social care has long been considered the ‘poor relation’ to health with decades of under-funding having a significant impact on the ability of local authorities to provide the full range of services needed by disabled young people. Whilst this general under-resourcing is widely recognised by service users and providers as a barrier to smooth transitions, the relatively greater under-investment in adult services has been identified as a major factor adversely affecting the move from child to adult social services.

“Funding pressures in adult social care and other services were cited by residential school staff and social workers as inhibiting transition arrangements.”⁽⁴⁸⁾

“Sources [of funding] that are available during the children’s stage are no longer there when they become adults. This is the biggest source of anxiety for families. They [social care] are so concerned about resources that planning and thinking about transition goes out of the window.”⁽⁴⁹⁾

Lack of funding limits choices for disabled young people. The support available, and services offered, is directly dependent on cost rather than need. This can lead to councils only supporting those with very high levels of need and intervening only when a crisis occurs.

“There was a very serious gap between funding received and expenditure required to meet young people’s needs.”⁽⁵⁰⁾

“The lives of people with learning disabilities are restricted because it is cheaper for services to ignore those who are not in crisis, than to intervene.”⁽⁵¹⁾

“Residential school staff felt the choices offered to young people with complex needs were limited – mainly because of the difficulties of meeting needs and obtaining what can add up to large amounts of funding.”⁽⁵²⁾

Given the key role that social care plays in the lives of disabled young people, and the disparity between child and adult services, it is vital that this issue is covered during the transition planning process. Once again, this is not happening for far too many disabled young people.

The Norah Fry Research Centre found that, for over 40% of the parents who had received some form of transition planning, the transfer to adult social care services had not been covered at all. Where it had been included, less than a quarter of parents felt it had been dealt with well.⁽⁵³⁾

The void between what should be provided by the social care system during transition, and what is actually received, is often filled by the parents of disabled young people. Precisely at the point at which their caring responsibilities should lessen, parents of disabled young people find their parental duties become more onerous. For many parents, by the time their child reaches transition, they are already exhausted by years of filling the gaps in services.

“It just seems that the whole thing for the last twenty years has been a nightmare, it really has. In the end you are just a number and a hindrance to people.”

(Father of a disabled young woman)⁽⁵⁴⁾

“I don’t have any respite. Up to 18 the only one available I didn’t like. I didn’t think the care was good enough. I knew I couldn’t carry on indefinitely. I’ve had stress counselling.”

(Mother of a disabled young man)⁽⁵⁵⁾

“For some of the parents, the role of advocate, activist and combatant was immensely difficult and stressful and clearly took its toll. Parents spoke about feeling drained, of feeling guilty, upset or scared, of being ‘in a state’ and of blocking out their thoughts and feelings because they felt they couldn’t cope with them.”⁽⁵⁶⁾

The tasks of lifting and carrying obviously become more onerous as a disabled child grows older and, for some parents, the physical demands of providing care to a young adult are substantial. They are often required to undertake tasks that paid carers would not be expected to do.

“Parent carers are being expected to provide care to disabled young people that professionals would refuse to provide on health and safety grounds.”⁽⁵⁷⁾

“To lift him you need two adults. It never occurred to them that parents would need support for lifting and handling or anything like that.”

(Father of disabled young man)⁽⁵⁸⁾

Ultimately, the highest price is paid by disabled young people themselves. It is their choices that are limited and their independence that is curtailed. It is they who are denied the freedom to live their lives.

“I didn’t get the choice I should have.”

(Beth)⁽⁵⁹⁾

“I was in my room on my own night after night and day after day. I felt a bit isolated. I was like a vegetable.”

(Nicky)⁽⁶⁰⁾

The services that are offered to disabled young people are often designed with much older clients in mind. There is a huge disparity between the needs of a younger disabled person and the needs of an older service user. The disabled young person can end up feeling that they have moved, not from childhood to adulthood, but from adolescence to retirement.

“They did tell us he could have respite but was in a unit with adults up to the age of 70+.”

(Mother of a disabled young man)⁽⁶¹⁾

“I went there and it was old people’s week. It was all old people and I was 18 at the time.”

(Disabled young woman on her respite care)⁽⁶²⁾

Disabled young people must be actively involved in designing services to meet their particular needs but this is the exception rather than the norm.

“The involvement of young people and their families in strategic planning is poor. Councils need to establish partnerships with young people and their families to inform their future transition strategy.”⁽⁶³⁾

What is being done?

There have been a number of green papers on adult social care in recent years and a 20 year strategy to improve the life chances of disabled people. All stress the importance of giving people more choice over the services they receive and greater control over their lives. The main initiative designed to achieve these desirable aims is Individual Budgets.

Individual Budgets

An individual budget is one in which the various sources of funding available to disabled people are amalgamated into a single stream. The budget will include the following:

- Council-provided social care services
- Independent Living Fund
- Supporting People
- Disabled Facilities Grant
- Integrated Community Equipment Services
- Access To Work.

Disabled people can choose whether to take the budget in cash, services or a combination of the two. Individual budgets are being piloted in 13 local authorities throughout the UK to develop an evidence base for national roll out. An evaluation of the results is due in April 2008.

Livability supports the development of individual budgets and believes that they have the potential to transform the lives of disabled young people as they move towards adulthood. However, a number of key concerns need to be addressed before they are rolled out nationally.

"I did go to college for a year, but that was it basically. Apart from college I didn't do anything. I was in my room on my own night after night and day after day. I felt a bit isolated. I was like a vegetable. Just bored."

Nicky

We have seen that disabled young people's ability to live independently is constrained by a lack of services that are specifically designed to meet their needs. As a result, some young people are slotted into provision that is designed for much older people. Central and local Government must ensure that there is a range of services available that meet the particular needs of younger adults. What use will control over budgets be if the services needed are not available?

We are particularly concerned that those disabled young people with the most complex needs will be left behind. The highly specialised services needed by this small but significant minority of disabled young people tend to be more expensive and may not be an attractive option for providers. There is a real danger that these services will not be well distributed or available locally and that individual disabled young people will not have the spending power to shape a more responsive market.

Where providers do invest in specialised services for disabled young people, they may need to charge more to recover the substantial capital expenditure involved and guard against uncertainties and fluctuations in demand. Where there is a limited number of local specialist providers to choose from, the only choice available to disabled people will be to take it or leave it.

Livability believes that the role of local commissioners will be critical to the success of individual budgets. They will have to develop close relationships with local providers to ensure that the full range of services needed by disabled young people are available. They must be supported by comprehensive and accurate data on the numbers and needs of the local disabled population.

The availability of advocacy services specifically designed to meet the needs of disabled young people will be fundamental to the success of individual budgets. There is a real danger that families will be left to assume this role in addition to their other caring responsibilities and this must not be allowed to happen. If disabled young people are to achieve true independence, they must be supported to make their own decisions.

Livability has a track record of providing advocacy services to disabled young people going through transition to adulthood and young adults working towards independent living. We are looking to expand and extend our advocacy services so we can work with local authorities, PCTs, schools and colleges to improve the transition experience of disabled young people aged 16-25. We hope that this work will inform the study being undertaken by the ODI to establish the costs and benefits of providing independent advocacy at this crucial time in disabled young peoples' lives.

Disabled young people managing individual budgets will be vulnerable to financial abuse and it is important to ensure that protection is in place to mitigate against this before budgets are rolled out nationally.

Finally, if individual budgets are rolled out nationally, it will be important to ensure that they are calculated well in advance of the disabled young person's transition to adulthood to allow them to put a package of care in place before they leave school or college.

We hope that these concerns will be addressed as part of the scoping study due to be commissioned by the Department for Children, Schools and Families (DCSF) to examine testing individual budgets for disabled young people.

Children's Trusts

Children's Trusts have the potential to transform services for disabled children and young people. There is, however, a danger that the gap between children's and adult services will become a gulf. To tackle this, the Government needs to ensure that similar multi-agency arrangements, supported by joint budgets, are developed for adult provision.

Recommendations for change

1. Disabled young people should only be offered services designed for their age group. No disabled young person should be offered services that are primarily used by older people.
2. Central and local Government must ensure the availability of a range of services to meet the needs of disabled young adults if individual budgets are to be successful for this group.
3. Local Government must develop close working relationships with providers to actively shape the market and ensure the development of services to meet the needs of disabled young people. Particular attention must be paid to services for the significant minority of disabled young people with complex needs.
4. Commissioners and providers must be supported by comprehensive and reliable data on the numbers, needs and preferences of the local disabled population.
5. Local and Central Government must ensure the availability of advocacy services dedicated to supporting disabled young people during the transition to adulthood and managing individual budgets to secure adult social care services.
6. Individual budgets will need to be agreed well in advance of the transition to adulthood to enable forward planning.

Somewhere to live?



Somewhere to live?

What's the problem?

Young disabled people trying to work towards independent living are constrained by the chronic shortage of suitable accommodation. The dearth of provision undoubtedly restricts choice for disabled young people.

Over 40% of disabled young people aged between 16 and 24 live in accommodation that does not meet their needs.⁽⁶⁴⁾

There is an estimated 300,000 national shortfall in wheelchair standard housing.⁽⁶⁵⁾

There has been a 44% increase in the number of homeless households in priority need because a household member has a physical impairment.⁽⁶⁶⁾

There has been a staggering 77 % increase in the number of homeless households where the priority need is someone with a mental illness.⁽⁶⁷⁾

Over 40% of wheelchair users experience difficult moving around their existing home.⁽⁶⁸⁾

Residential care

We urge the Government to undertake an immediate inquiry into the numbers, locations, needs and preferences of disabled young people who are inappropriately housed. Specific attention should be paid to those who are placed in care homes designed for older people.

“Caring for a younger person with a disability is about helping the person through the transition of being a teenager to move towards adulthood... The carer in these circumstances needs knowledge of helping a person to explore sexuality, manage adolescent frustration and develop opportunities in a wider community. A carer for an older person would, conversely, be helping them to come to terms with deterioration.”⁽⁶⁹⁾

We urge the Government to initiate an investigation into the numbers of disabled young adults placed in care homes designed for older people. A strategy to transfer them to more appropriate provision is urgently needed but cannot be devised before first establishing how many there are, where they are and what their precise needs may be.

Whilst it is critical to ensure that disabled young people are not placed in care homes for older clients, it is equally important that they are not denied access to high quality residential placements that are designed to meet their specific needs. Central Government policy and local commissioning practice need to recognise the valuable contribution that individually tailored care provided in a modern residential setting can make towards enhancing autonomy, extending choice and increasing opportunities for disabled young people with complex needs.

Placing a disabled young person in the community inappropriately, against their express wishes and without the necessary support, can inhibit their autonomy and independence. It can limit their choices and, in some cases, result in enforced isolation. Ultimately, it is for disabled young people themselves to choose which setting they want to live in.

Anneka is 20 years old and attends a residential college in Kent. Her course is due to finish in the summer and she has been trying to plan her future. She has enjoyed group living in college and residential care is very much her first choice of setting for when she leaves.

Anneka visited a newly built residential care home in Southend last year and felt that it had everything she wanted. However, her local authority refused to fund her choice. They believed that placing her in independent housing was more appropriate. Anneka did not agree. She feared that she would be isolated in that environment and dependent upon agency care.

Anneka has fought hard for the right to choose where she lives. She appealed against the local authority's decision and won. She is now looking forward to moving into her new home and starting her life as an independent adult.⁽⁷⁰⁾

Disabled people who have contributed to the Government's recent review of independent living have challenged the meaning of independence. The resulting strategy acknowledges those concerns and emphasises that independent living does not mean disabled people doing everything for themselves or living on their own. Independent living is about disabled people having genuine choice and control over the support they receive to go about their daily life.

Livability believes that high quality residential care, provided in a modern setting and tailored to meet individual needs, must remain part of the spectrum of options available to disabled young people.

Accessible housing

For those disabled young people who are ready for independent living, the lack of accessible housing impacts disproportionately on them. There is a particular shortage of wheelchair standard housing in urban locations close to amenities and what is available is prohibitively expensive. As a result, many disabled young people are faced with a stark choice between inappropriate care in a setting for older people or remaining in the parental home.

Many disabled young people and their families are shocked by the lack of choice available to them in terms of accommodation. They believed, quite reasonably, that there would be a number of options from which to choose. Sadly, this is rarely the case.

“In my experience, young people are offered no such menu and the only choice their parents are left with is to accept what is offered, however inappropriate, or like us, go through the gruelling experience of a legal challenge, enduring unnecessary and unjustifiable stress at an already difficult phase in our lives.”

(Parent of disabled young person)⁽⁷¹⁾

The scarcity of accessible accommodation and suitable residential placements often results in disabled young people being given only one option. Their choice is to take it or leave it.

“The young person had been offered one option only, and it was their satisfaction with this that was gauged, rather than them visiting and actively selecting from a range of choices.”

“Other parents and professionals commonly reported their anxiety that if they did not take up the offer of a placement, there might not be another one.”⁽⁷²⁾

Nowhere to go

Some disabled young people have no choice at all. Their only option upon reaching adulthood is to return to the parental home. Local authorities interviewed by CSCI confirm that this is the fate that awaits the majority of disabled young people in their areas. This goes against both the spirit and letter of the Government's vision for disabled young people.

“Notwithstanding public policy commitments to employment and independent living, and the recognition that these are important for young people with long-term conditions, the reality is that many of them are living at home with one or both parents.”⁽⁷³⁾

More importantly, returning to the parental home often goes against the express wishes of the disabled young person. They have been encouraged to aspire to greater independence, and spent years learning the skills needed to achieve it, only to find themselves back at home with their parents.

“I do get frustrated. I’ve said it before, not meaning to be funny to Mum and Dad, but I’m 20 and I’ve been with them since I was born. It’s like my brother and sister, they get to lead their own lives, but I need them to help me wash and you don’t even get personal time like that, just to sit and you know just to wash yourself or take a shower. They have to be there to do that for me as well. And I need time to kind of lead my own life.”

(Disabled young woman)⁽⁷⁴⁾

Given the importance of finding a home to disabled young people, and the scarcity of all types of accommodation, planning ahead is crucial. It is essential that housing is covered in the transition planning process but, yet again, it receives scant attention. Despite the acknowledged importance of including housing options in the transition planning process, the Norah Fry Research Centre

found that only one in ten of those young people who had received transition planning felt that this issue had been dealt with well.

The situation is compounded by poor liaison between social care and housing agencies with serious consequences for disabled young people.

“Councils emphasised the importance of working together with health and Connexions but work with housing was less widely reported despite it being an important post-transition service. This is a failure that can seriously affect the range of opportunities and choices available to young people in transition, and affect their independence and ability to live ordinary lives.”⁽⁷⁵⁾

What is being done?

There have been a number of attempts to tackle the problem of housing for disabled people over the years. The Government, the voluntary sector and housing associations have all developed initiatives designed to give choice to disabled people.

Part M of the Building Regulations

The failure of the building industry to respond voluntarily to the challenge of meeting the housing needs of disabled people led the Government to extend Part M of the Building Regulations in October 1999. Part M requires house builders to construct new properties to standards that permit disabled people, particularly wheelchair users and those with mobility impairments, to visit a house and have access to a ground floor living space and toilet.

Part M was essentially a compromise solution that satisfied neither the building industry nor the disability movement. Whilst the building industry considered making every building accessible to wheelchair users a waste of resources, disabled people's organisations lamented the wasted opportunity to provide truly

barrier free housing by including design elements far in excess of those contained in Part M.

Livability believes that Part M is fatally flawed because it only requires new housing to be visitable by disabled people rather than suitable for them to actually live in. It does not require the property as a whole to be usable by mobility impaired people as it only guarantees access to the ground floor.

Livability defines a house as liveable for a wheelchair user if he or she can use it as reasonably and flexibly as a non-disabled person. It should allow those who are mobility impaired to fully participate in all aspects of family life from preparing a meal to putting children to bed.

The Disability Discrimination Act (DDA) 2005

It was especially disappointing that the DDA 2005 contained very little related to housing. It made only two main changes, both in relation to properties in the private rented sector:

- firstly, landlords will have to take steps to change a practice, policy, procedure or term of a letting where it would be impossible or unreasonably difficult for a disabled person to use the premises.
- secondly, landlords are now unable to refuse a reasonable request for an alteration to a tenant's property which has to be made due to the tenant's impairment.

It is unfortunate that the benefits gained as a result of these changes are to a large extent negated by the Government's failure to accept amendments allowing alterations to the communal areas of properties. This has led to the absurd situation where a wheelchair user may be able to get around their own flat just so long as they do not want to go out of the shared front door.

Livability believes that the Government wasted an invaluable opportunity in failing to use the DDA 2005 to tackle the chronic shortage of accessible housing. Given the importance of housing



“My friend whose child has gone to this other place, has recommended it highly, but unfortunately she said to get in there you will have to sort of say to Social Services that you are not having your daughter at home, no matter what, and that is the only way to get her in. Once she is home with you there is no way on earth that you will get her anywhere. You can forget it.”

Tiffany's Mum

to the independent living agenda, it is particularly disappointing that the chance to effect real change was lost.

The Lifetime Homes Standard (LHS)

The Lifetime Homes Standard (LHS) emerged from collaboration between Habinteg Housing Association, the Helen Hamlyn Foundation and the Joseph Rowntree Foundation. It incorporates 16 design features which aim to ensure that properties are accessible and flexible enough to respond to changing levels of independence and need.

The Government recognised the benefits of the LHS in its 20-year strategy for disabled people. They acknowledged that improving the suitability of new build and renovated homes for disabled people will increase choice for disabled people and secure considerable savings in future public expenditure.

Building houses to the LHS would only add between £100 and £300 to the cost of a typical three-bedroom house. It would save an average of £1, 100 per house on the cost of major adaptations. This is calculated to be a total saving of £39 million per year on major adaptations.

Further cost savings would be made in terms of expenditure on minor adaptations and equipment, care services, delayed hospital discharge and temporary residential care. The Joseph Rowntree Foundation estimates that over a 60-year period the savings to the taxpayer would be £5.5 billion.⁽⁷⁶⁾

We have been campaigning for the adoption of LHS across all sectors for many years and welcome the recent announcement that it will be applied to all new social housing from 2011. This is a step in the right direction but we urge the Government to ensure that building to the LHS is mandatory for the private sector from the same date.

Whilst the Government hopes that the private sector will adopt the LHS voluntarily, we are not convinced. Experience shows that the needs of disabled and older people will not be met by private house builders unless they are legally required to do so. The sheer scale of the crisis facing disabled and older people means that tackling it cannot be left to chance.

Wheelchair Standard Housing

Whilst the LHS is a good basic minimum, it does not meet the needs of wheelchair users and those with mobility impairments. Only wheelchair standard homes can give them the freedom they need to live their lives. This is why we have been working with Parliamentarians from all political parties to ensure that the acute shortage of wheelchair standard housing is pushed higher up the policy agenda.

An Early Day Motion (EDM) was tabled on our behalf in June 2005 as part of a campaign to build for equality. It called on the Government to require local authorities to set targets for all newly built properties to be built to the Lifetime Homes Standard and a proportion to the higher wheelchair standard. Over 100 MPs signed the EDM in support of the campaign.

Wheelchair standard homes require a larger 'footprint' than general needs housing and so their inclusion within a scheme will reduce the number of houses that can be built and increase the unit cost. However, this must be considered in light of the DDA which seeks to ensure that disabled people have the same range of choices and opportunities as non-disabled people. If we as a society are serious about including disabled people, we must be prepared to invest in them.

Accessible Housing Registers

Given the chronic shortage of suitable housing for disabled people, it is vital that what stock is available is used efficiently. However, with few notable exceptions, local authorities do not generally have an accurate and up-to-date list of the accessible, adapted and adaptable properties in their own area.

To address the problems faced by disabled people trying to find a suitable property, a small but increasing number of local authorities are using Accessible Housing Registers (AHR). This is a database containing a list of accessible properties in an area, a list of disabled people requiring an adapted property and a service to match the two.

AHRs enhance choice for disabled people and help local authorities to develop a more realistic knowledge of the unmet housing needs in their area. This information can be used to set targets for accessible housing in local development plans. Finally, and of particular importance to the Government, AHRs save money. One local authority estimated that they had made savings of £850,000 over a two-year period as a result of its AHR.⁽⁷⁷⁾

It is for these reasons that the establishment of a statutory duty to maintain an AHR attracted the support of the DRC, RADAR and other leading disability organisations during the passage of the DDA. The idea also received the backing of the All Party Joint Scrutiny Committee which examined the draft bill. Despite this substantial support, and the obvious and overwhelming benefits of AHRs, the Government rejected the proposal.

“We have not identified anyone who seriously believes Accessible Housing Registers will be instituted in every local housing authority unless there is a clear statutory requirement.”⁽⁷⁸⁾

“You know, it’s all very well having your own flat, but what’s the point? If you can’t go out or do anything, what’s the point? I’m just going ‘well this is a good life, isn’t it? I’m really enjoying my life sitting in and watching Eastenders?’”

Anneka

Independent Living Strategy

The Government has recently published a five year Independent Living Strategy and one of its key aims is to ensure that disabled people have greater access to appropriate housing. This can only be achieved if the supply of all types of accommodation is increased to meet current and future demand. Unfortunately, the strategy falls far short of what is needed to tackle the accessible housing crisis.

Recommendations for change

1. We urge the Government to undertake an immediate inquiry into the numbers, locations, needs and preferences of disabled young people who are inappropriately housed. A strategy to transfer them to more appropriate provision is urgently needed but cannot be devised before first establishing how many there are, where they are and what their precise needs may be.
2. Legislation is needed to allow disabled tenants to make essential alterations to the communal areas of shared properties.
3. Adoption of the Lifetime Homes Standard should be mandatory for all new properties from 2011.
4. The Government should ensure that a minimum of 10% of new social housing is built to wheelchair standard with further targets set by local authorities based on the outcome of a far-reaching inquiry into demand.
5. Local authorities should be under an obligation to establish an Accessible Housing Register to ensure that what accessible housing stock is available is effectively used.
6. Guidance to professionals on the practical application of independent living, due to be devised by the Government as part of its independent living strategy, should emphasise that residential care must remain a part of the spectrum of options available to disabled young people.

Education and Employment



Education and Employment

Education

What's the problem?

Education is a significant determinant of future life chances for all young people. The persistent gap in educational achievement between disabled and non-disabled young people is of serious concern because it is a substantial obstacle in the path to employment. Low educational attainment translates into poor skills and, therefore, poor employability. This combines with their additional requirements for equipment and support to make the transition to employment an up-hill struggle for disabled young people. This in turn impacts negatively on their ability to achieve true independence.

Whilst there have been some encouraging improvements, with the proportion of disabled people holding a degree or equivalent almost doubling in recent years, the pattern of inequality between disabled and non-disabled people has not changed.

A disabled 18 year old is less than half (40%) as likely to enter higher education as non-disabled person of same age.⁽⁷⁹⁾

Only 23% of disabled men have a higher qualification compared to 48% of non-disabled men.⁽⁸⁰⁾

Only 15% of disabled women have a higher qualification compared to 37% of non-disabled women.⁽⁸¹⁾

Disabled young people are only half as likely to be qualified to degree level than non-disabled young people.⁽⁸²⁾

Disabled young people are twice as likely as non-disabled young people to have no qualifications at all.⁽⁸³⁾

Huge strides have been made over the last 30 years in raising the aspirations of disabled children and young people. However, it is perverse that at the very point when their aspirations should start to become a reality, they are denied the opportunities and resources they need to make it happen.

Disabled young people's early experiences of education are an important factor when they decide whether to continue studying beyond 19. A survey of disabled young people conducted by NOP revealed that a worrying 38% of those questioned reported that they had been bullied at their last school.⁽⁸⁴⁾ It is little wonder that they are reticent to remain in education.

The attitudes of teachers and other key professionals can also impact on disabled young people's decision to enter further and higher education. The results of the NOP survey are particularly alarming in this respect.

- ***20% of disabled young people were discouraged from taking GCSEs because of their impairment***
- ***12% of disabled young people were discouraged from taking A Levels***
- ***A further 12% were discouraged from taking vocational qualifications for the same reasons.***⁽⁸⁵⁾

It is often not lack of aspiration that prevents disabled young people continuing in education. It is the failure of professionals to nurture their ambitions and provide the support needed to make them a reality. This is a particular problem for young people with learning difficulties.

“A small number of the young people expressed personal ambitions and dreams for their future. These did not always seem to be encouraged, and at times it appeared as though they were being overlooked, or dismissed.”⁽⁸⁶⁾

Disabled young people are also deterred from entering further and higher education by the very real fear that they will not receive the services they need. The Prime Minister's Strategy Unit estimates that 60% of disabled young people who did not enter further or higher education believed that they would not receive the support they needed. Other research confirms that this acts as a real deterrent to continuing study.

“Some disabled service users avoided moving into education because they were concerned about the impact that such a transition might have on the services or benefits they receive, or because they felt they could not access the services they would need to be able to undertake the education.”⁽⁸⁷⁾

Despite the important role that education plays in the futures of disabled young people, the transition from school to higher or further education remains problematic. There is a lack of appropriate provision and, even when a suitable college placement is found, the process of negotiating the funding and services necessary is often best described as a battle.

“It was common for the decision-making process around getting a place at a residential school or college to be described as prolonged and acrimonious.”⁽⁸⁸⁾

The situation is compounded by the differing funding structures operating in the further and higher education sectors. Confusion existing around how funding responsibilities are demarcated between the different sectors leads to delays in the provision of services whilst negotiations take place.

Where disabled young people overcome these barriers and take up a college place, they often find that their fears of a negative impact on service provision were entirely justified. Services and equipment required by the disabled young person are delayed or, in some cases, not provided at all. Disabled people often lose a

crucial service or vital piece of equipment as a direct result of the transition into further and higher education.

Loss or delay of services and equipment combined with poor communication between agencies and the negative attitudes of lecturers can make the transition into further or higher education a dispiriting experience for some disabled young people.

“And when I went in there, there was no room at all, no room for the wheelchair. He said, ‘if you come in this college you’ve got to get out of the wheelchair. We won’t allow this wheelchair in the premises’. And I said, ‘if I come to this college, excuse me, I’ve got to be in this wheelchair because I can’t walk. It was the rudeness.”

(Beth)⁽⁸⁹⁾

“For the first six months that he was at college, which is now very good, they didn’t actually know he could walk. They didn’t know that he could get out of the wheelchair. Now there is really bad liaison there somewhere that they allowed that to happen.”

(Parent of two disabled young men)⁽⁹⁰⁾

What is being done?

There have been some very encouraging developments in recent years and initiatives are underway that could make a real difference to disabled young people’s experience of education and training.

Through Inclusion to Excellence

The Learning and Skills Council (LSC) recently conducted a strategic review of its funding and provision for disabled young people during the transition to adulthood. This was the first comprehensive review of provision for disabled young people since the 1996 report *Inclusive Learning*.

The review recognised and endorsed the need for radical change across the sector. A key finding was the need for increased collaboration with partner agencies in planning and funding services for disabled young people.

“We would particularly urge more concerted joint actions to ensure that significant Government policy agendas for the benefit of disabled people and wider society and the economy, can be moved forward.”⁽⁹¹⁾

The LSC acknowledges that progress in exploring joint action with Government departments and other agencies has been disappointing slow. The overarching recommendation of the review was that the LSC should develop a national strategy, in collaboration with partners, for learning and skills provision for disabled young people.

Learning for Living and Work

This is the first LSC strategy for planning and funding provision for disabled young people and sets out how the vision outlined in *Through Inclusion to Excellence* will be implemented. Key initiatives include:

- establishing a National Learners with Disabilities Panel to inform and influence policy making
- conducting detailed analysis of provision for disabled young learners
- working with the DCSF to establish a single vision and strategy for disabled young people agreed by all national partner organisations
- introducing a common funding approach across the sector
- developing capacity within the sector and increasing supply in response to a steady growth in demand.

There is a risk that this valuable work will be undermined by the lack of reliable and accurate data combined with a failure to share relevant information between agencies. How can the LSC meet



"I'd like to find a job but it's difficult. I've got lots of CVs out and I've gone to quite a few interviews. Most of them have been very positive, but then they say about the accessibility issues. I've been looking for a year and I still don't have a job."

Stuart

the growing demand for further education and training if it is unable to quantify it?

The dearth of accurate and up-to-date information on the learning needs of disabled young people has particular consequences for the transition planning process.

“Poor quality data, combined with weaknesses in sharing data, also prevents sufficient planning for transition to and from further education.”⁽⁹²⁾

The LSC has commissioned detailed analysis of current demand for further education and training options by disabled people to identify any gaps in provision. Additionally, they have begun scoping work to develop new data definitions to be used throughout compulsory education and throughout the post-16 learning and skills sector.

It is crucial that this work is developed alongside, and in collaboration with, other initiatives designed to improve data about disabled young people. Most partner agencies are required to collect information on disabled people to inform service planning and delivery as part of the Disability Equality Duty. Further work is underway to improve data for disabled children and young people as part of the Children's Trusts arrangements due to have been in place by April 2008. It is vital that these initiatives are coordinated.

Ultimately, disabled young people want a highly personalised package of education, training and support that meets their individual needs.

“In relation to education, parents and disabled young people were clear that an appropriate individualised curriculum needs to be delivered for each disabled young person, with the right balance of academic, vocational and life skills elements.”⁽⁹³⁾

The LSC is working to develop a new qualifications framework which is more suited to the particular needs of disabled young people. This should offer a more flexible credit system and promote the recognition of cumulative achievement.

This model has important potential to transform the learning experience for disabled people, and particularly those with complex needs, by allowing them to accumulate achievements from different types of provision over a longer period of time and in instalments. It should support more personalised learning programmes by allowing the range of achievements to be given national recognition and portability. This would ensure that the small, but very significant, steps made by disabled young people are given the recognition they deserve.

The Government's recent decision to close the LSC, and transfer its functions to Local Authorities and a new Skills Funding Agency, threatens the valuable work being undertaken to improve the post-16 experience for disabled learners. It is crucial that this work is taken forward under the new regime.

Individual Budgets

Given the pivotal role that individual budgets will play in securing holistic packages of care and support for disabled young people, it is essential that the Government examines how they interact with funding for post-16 education. It will be important to establish clarity to avoid duplication where the individual and funding body are purchasing similar services.

Recommendations for change

1. Every disabled young person should have access to an appropriate individualised curriculum with the right balance of academic, vocational and life skills elements.
2. The Government must ensure that there are sufficient specialist placements to meet the needs of young people with complex and profound impairments.
3. The various initiatives underway to improve the collection and sharing of data on disabled young people must be coordinated through the new arrangements for Children's Trusts.
4. The Government must consider how individual budgets and LSC funding will interact with each other to avoid duplication and prevent wasting scarce resources.
5. The work in progress at the LSC to improve the post-16 experience of disabled learners must be taken forward by Local Authorities and the new Skills Funding Agency.

Employment

What's the problem?

We have already stressed the importance of employment to disabled people and the impact it has on both choice and independent living. The benefits of employment to disabled young people extend far beyond their finances. It boosts their self-esteem and provides opportunities to develop skills and build social networks.

Whilst there has been a steady increase in disabled people's overall employment rate in recent years, inequalities in the proportion of disabled and non-disabled people in employment persist. Disabled young people with learning difficulties fare particularly badly in the job market.

47% of disabled people are in employment compared with 74% of non-disabled people

Employment levels for people with learning disabilities have increased slightly over the last decade, but remain disappointingly low. Indeed, different surveys give figures of between just 5% and 17% of people with learning disabilities being in work.⁽⁹⁴⁾

Employment rates vary greatly according to the type of impairment a person has. Disabled young people with mental health problems and learning disabilities fare particularly poorly.⁽⁹⁵⁾ It is essential that current and future initiatives designed to support disabled people into employment pay particular attention to these groups and focus interventions on their specific needs.

We have previously dealt with the impact of poor educational attainment on the employability of disabled young people. However, even those disabled people who have achieved degree level qualifications still remain disadvantaged in comparison to non-disabled graduates.

According to the Association of Graduate Careers Advisory Services survey, disabled graduates are not achieving entry to all professions to the same extent as their non-disabled counterparts. Additionally, disabled graduates continue to enter part time employment in higher numbers than their non-disabled peers.⁽⁹⁶⁾

It is of particular concern that disabled young people's chances of gaining employment plummet as they progress through the transition to adulthood. Young disabled people at 16–17 are twice as likely to be unemployed as non-disabled people of the same age. At age 18–19 they are three times as likely to be unemployed as their non-disabled counterparts. By the time they reach 26 disabled young people are four times as likely to be unemployed as their non-disabled peers.⁽⁹⁷⁾

The ability of graduates, and disabled young people in general, to fulfil their occupational aspirations is compromised by the misconceptions held by employers.

“Being perceived as having fewer ‘personal’ credentials than other students is the barrier that is faced by students and graduates with impairments who are seeking employment. This can affect both the view they have of themselves and their chances in the job market, and the perspectives of potential employers in relation to employability.”⁽⁹⁸⁾

Employers are frequently looking to see evidence of relevant work experience to compliment qualifications attained and this is another area where disabled young people are at a distinct disadvantage. They often need to invest additional time and effort in their studies and this limits opportunities for them to gain work experience whilst they are at school or college.

“Work experience can be a valuable way of gaining confidence for job interviews or in learning strategies which help to overcome prejudices that may disable job applicants with impairments. However, the opportunities to gain work experience by working part time were limited for some disabled students, who found they needed to spend more time on study than some of their non-disabled peers.”⁹⁹

Livability schools and colleges report significant problems finding work placements for disabled students. The negative attitudes of prospective employers, combined with their misplaced concerns over health and safety, make finding placements for disabled young people particularly difficult. Where work experience is secured, it is not always relevant to the disabled young person’s aspirations for future employment. It is dictated by what is available and how compatible it is with their personal care needs.

Anneka is 20 years old and attends a residential college in Kent. She would have liked to have gained work experience in an art or music shop. Instead she worked in a local supermarket because they were willing to provide a placement and the proximity of the store allowed Anneka’s personal carers from college to assist her when required. She comments:

“It was not what I was interested in. I had no interest in working at a supermarket whatsoever. But that’s where I went because it was easy.”¹⁰⁰

Concerns regarding the impact that taking up employment could have on their finances and the services they receive also affect disabled young people’s decision to take up a job.

“The decision to make an employment transition often involved the individual gauging whether the change would make financial sense and whether they would receive adequate service provision to take up employment.”⁽¹⁰¹⁾

Disabled young people’s concerns regarding the impact of employment on service provision are well-founded. Research confirms that valuable services can be lost as a result of the transition to employment and delays in receiving equipment and support are also a common theme.⁽¹⁰²⁾

Similarly, concerns surrounding the financial implications of taking up employment are justified. Disabled people typically earn less than their non-disabled peers. Even when direct taxes and benefits have been accounted for, they still earn 30% less than non-disabled people. Consequently, disabled people with medium to high support needs in full-time work at the average rate of pay still face substantial unmet costs related to their impairment.⁽¹⁰³⁾

“Serious attention must be given to the question of equal pay, and to the widening gaps between disabled and non-disabled young people’s participation in employment as they move into early adulthood.”⁽¹⁰⁴⁾

When disabled people do make the transition to employment, they are less likely than their non-disabled counterparts to retain their job. One in three disabled people are out of work again within a year of taking up a job, compared to one in five non-disabled people.⁽¹⁰⁵⁾



"I had work experience at a children's day care centre. I was there for 4 months but all I did was sit in the corner and get cold. I feel the cold. I'd just sit there and do nothing and get cold."

Tash

What is being done?

The importance of improving employment opportunities for disabled people has long been recognised and there is a veritable raft of programmes designed to achieve this aim.

New Deal for Disabled People (NDDP)

Offers access to a network of job brokers who provide support and advice to help disabled people and people with health conditions find work.

Access to Work (AtW)

Provides financial assistance towards the extra costs of employing someone with a disability, such as contributing towards the cost of specialist IT equipment, work adaptations to the workplace, some travel costs and the cost of having a support worker.

Work Preparation

Helps people with health conditions or a disability prepare to return to work by building their confidence, identifying suitable types of work for them, offering work experience and providing support. It is often used as a stepping stone into Workstep.

Workstep

Provides tailored support to find and retain work for disabled people with complex barriers to finding and keeping work. Also offers ongoing support to enable permanent employment in the open job market.

Job Introduction Scheme

The Job Introduction Scheme can pay a wage subsidy of £75 per week to an employer for up to 13 weeks when they employ a disabled person.

The bewildering array of programmes has evolved over the last 60 years in response to the changing expectations of society. While each individual element addresses a recognised need, the suite of services taken as a whole is incoherent and difficult for both potential clients and service providers to understand. Differing eligibility criteria and a lack of interaction between programmes can make navigating a pathway through the maze of provision an impossible task. This impacts negatively on the service received by disabled young people who are slotted into programmes rather than programmes being built around them and their particular needs.

“Some participants in our workshops and other stakeholders we interviewed argued that having a number of distinct programmes can be confusing and means that people can be unfairly categorised. It can also lead to lack of continuity, with clients stopping and starting different programmes, with the risk of losing momentum if there are gaps.”⁽¹⁰⁶⁾

It is not surprising that the programmes only support a small fraction of those who could potentially benefit.

Workstep, Work Preparation and the Job Introduction Scheme

In recognition of these concerns, the Government is currently consulting on combining three of the programmes – Work Preparation, Workstep and the Job Introduction Scheme – into a single integrated service. We support this proposal and believe that a merged programme could offer an integrated support package that can be more easily tailored to meet the needs of disabled young people.

The New Deal for Disabled People / Pathways to Work

The New Deal for Disabled People and Pathways to Work are misdirected at younger disabled people as motivation among this group is rarely lacking. Extending programmes such as Work Preparation and Workstep to disabled young people in schools and colleges, as well as widening the criteria for Access to Work so it covers work experience placements, would be a far more effective approach.

Disability Employment Advisers

Given the complexity and number of employment programmes, Disability Employment Advisers (DEAs) have an important role in directing disabled people to the programmes that best suit their needs. However, they are not always fully equipped to fulfil their remit.

“Disability Employment Advisers have a crucial role to play, yet their training is ad hoc. We found some Advisers experienced delays in accessing the training that is available and had to take on caseloads of clients with limited preparation for the role.”⁽¹⁰⁷⁾

The Government envisages an enhanced role for DEAs in assessing disabled people’s needs and assembling a tailored support package. Improved training programmes for DEAs, provided at the right time, will be crucial to their success. If they are to be effective at serving the needs of younger disabled people, training programmes must include modules that focus on the particular requirements of disabled young people leaving school and college.

Given the importance of employment to the life chances of disabled people, and the dramatic decrease in employability during the move to adulthood, it needs to be given greater focus during transition planning. We recommend that DEAs become

involved in the process at an earlier stage than at present. More specifically we would like to see:

- DEAs engaging with the transition planning process at least a year before a disabled young person is due to leave school or college where the individual intends to move directly to employment.
- DEAs building links with local schools and colleges to provide general employment advice and, in particular, to facilitate work experience.
- DEAs fostering links between employers and local schools and colleges to facilitate work placements for disabled young people.

Access to Work

The Access to Work (AtW) initiative has been the subject of considerable criticism by disabled people and employers alike. Awareness of the scheme is very low among disabled people, employers and service providers. There are unacceptable delays in determining eligibility and providing workplace equipment and alterations. Both employers and disabled people are confused about who owns equipment supplied through the scheme.

As a result of these concerns, the Government has commissioned an independent evaluation of the programme. They are also seeking views on improvements to the scheme as part of their current consultation into employment support services for disabled people. We recommend extending AtW, with the necessary improvements, to cover disabled young people at school and college who want to undertake work experience. This would increase the likelihood of them securing a relevant placement and, as a result, enhance their employability upon leaving full-time education.

A partnership approach

Employment is another area where multi-agency cooperation and coordination can make an enormous difference. Local partners need to work together to deliver an enhanced and more focused service for disabled young people making the transition from adolescence to adulthood. This is already happening in at least one area.

The DWP and the Government's Valuing People Support Team are jointly funding a project in the Borough of Newham to support those choosing paid employment over day services at the time of transition from children's services.

The project is aimed at those with learning disabilities in response to the persistently disappointing employment rates for this group.

Other partners include Jobcentre Plus, the Learning and Skills Council, Newham Social Services, Care Services Improvement Partnership, the Learning Disabilities Partnership and local employers.

A report of the project's findings is due to be published in autumn 2008. We urge the Government to evaluate the findings with a view to piloting the model in other locations and with other client groups.

Recommendations for change

1. Extend Access to Work and Work Preparation to disabled young people in school and college to enable them to undertake relevant work placements.
2. Ensure that Workstep is available to disabled young people approaching the transition from full-time education into employment.
3. Training programmes for Disability Employment Advisers (DEAs) should contain specific modules on meeting the particular needs of disabled young people leaving school and college.
4. DEAs should build links with local schools and colleges to provide general employment advice and, in particular, to facilitate work experience.
5. When building relationships with local and national employers, DEAs should increase links between employers and local schools and colleges to facilitate work placements for disabled young people.
6. DEAs should use their relationships with employers to actively market Access to Work to ensure increased awareness of the scheme.
7. DEAs should engage with the transition planning process at least a year before a disabled young person is due to leave school or college where the individual intends to move directly to employment.
8. Evaluate the results of the jointly funded DWP and Valuing People project based in Newham with a view to piloting the project in other locations and with other client groups.

Conclusion



Conclusion

There has never been a better time to campaign for genuine change for disabled young people. There has been an unprecedented focus on disability issues by Government in recent years. A 20-year vision for disabled people has been published, a new Disability Discrimination Act is on the statute books, a new Equality and Human Rights Commission has been established, there is a new Office for Disability Issues and a five-year strategy on independent living has just been announced. We must capitalise on the current political momentum to ensure that disabled young people have the freedom to live their lives to the full.

It is worrying that, despite the focus on disability in general and disabled young people in particular, progress has been frustratingly slow. A recent study into the transition to adulthood for disabled young people by the Commission for Social Care Inspection shows that there is still a long way to go. We are particularly concerned that the system is failing those who need it the most.

“Our study shows that things have not improved enough and that there are still organisational and systemic problems in many areas which makes the experience very difficult for too many young people. It also highlights that for those young people with the most complex needs, and who live away from home, transition does not receive the strategic and operational attention from councils it should do.”⁽¹⁰⁸⁾

A key challenge for the Government is to close the yawning gap between national policy aspirations and local implementation.

Livability believes that compliance with existing legislation and guidance must be rigorously monitored if the transformation of service provision envisaged by the Government is to become a reality on the ground. The Office for Disability Issues and the Equality and Human Rights Commission must work together to ensure that existing commitments are meticulously enforced.

We believe that disabled young people will only have the freedom to live their lives when their rights are enshrined and protected by legislation.

“Waving a Strategy at a Care Manager who wants to cut your package is not going to cut it.”⁽¹⁰⁹⁾

Disabled young people need concrete and legally enforceable rights to independent advocacy, a key worker and support for education, training and employment. Most importantly, disabled young people must be able to choose where they live and who they live with.

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