Whatever Next?

Young disabled people leaving care

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and Julie Knowles

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Foreword

Foreward by Peter Hardman (Director - First Key)

It is with great pleasure that I write the foreword for a report that is welcomed and long awaited. The paucity of information and knowledge of disabled young people’s experience of leaving care was first underlined for First Key in 1996 when we were developing the National Standards in Leaving Care. There has been so little research activity in this area that we felt unable to prescribe standards in developing services to meet these young people’s needs. To some extent, in the flourish of campaigning and lobbying activity that has characterised the ‘world of leaving care’ over the past decade, the voice of disabled young people has remained inaudible.

It is with great thanks to the National Lottery Charities Board that we have been able to take some first steps towards addressing this situation through the “Whatever Next?” research project. We have been delighted to work in partnership with the Leeds University Centre for Disability Studies and Bradford Social Services in this endeavour. The involvement and contribution of young people has proved invaluable in producing a report through which their many voices are heard loud and clear. The report not only provides invaluable insight into a rich variety of individual experiences but also demonstrates clearly the role that young people could and should have in helping to determine the services available to them.

This project has also been a timely one. The new legislative framework for support to young people leaving care is due for implementation in October 2001 and heralds a radical and welcome new approach to service planning and delivery. This report highlights many of the issues that will specifically affect disabled young people and offers guidance for the development of good practice so essential if, as a group, these young people are not, yet again, to be left behind.

The campaigning and lobbying activity that has accompanied the progress of the Children (Leaving Care) Bill through to an Act has underlined the importance of research activity in ensuring that debate around needs and services is informed and meaningful. Our hope is that this report will represent an important contribution to national data and be of use to policy makers and practitioners alike.

For First Key, this project has marked the beginning of a challenging process to fulfil our commitment to developing comprehensive national standards in service delivery aimed at improving the life chances and opportunities for disabled young people leaving public care.

Peter Hardman
Director – First Key

Introduction

What is this report about?

This report is about young disabled people leaving care. It is about the decisions they face as they grow up and the kind of support that they receive.

According to Government estimates, around one quarter of all care leavers may be disabled in some way. Yet, very little attention has been paid to their views and experiences.

For this reason, we wanted to find out more about young disabled people who had been looked after away from home, to see what happened to them when they became adults. Where did they go? What choices did they have? What support did they want, and who helped them the most in their transition to adulthood?

With the help of a grant from the National Lottery Charities Board, we spent a year working with young people to answer some of these questions.

The project was carried out by researchers from the Centre for Disability Studies at the University of Leeds, in partnership with First Key (the national leaving care advisory service) and staff at Bradford Social Services.

Much of the material in this report has come directly from the young people involved. They told us their stories and showed us things that were important in their lives. Some of them joined our project steering group and helped to decide what should be included in this report.

Who is disabled?

All of the young people we worked with were regarded as disabled by the local social services department. However, not all of them saw themselves in this way. Some were happy to call themselves disabled, others were not. We discussed this with them.

We were interested to find out what happened to young people leaving care when they were seen as disabled by other people. Were their experiences of growing up similar or different to those of other care leavers?

Almost all of the young people involved in our project were labelled as having ‘learning difficulties’, most of them had attended special schools. Some had physical, visual or hearing impairments.

Who was looked after?

All of the young people we met had spent time living away from home before they were 16 years old. They might have stayed in foster homes, children’s homes, hostels, hospitals, residential schools, respite care centres, secure units, or with shared carers.

Some had lived away from home full-time for many years, others stayed only a few nights every now and then. However, living away from home played a big part in all of their lives.

This report concentrates on those who might qualify for support as ‘care leavers’.

Policy Context

This first section of the report sets out the background to policy and legislation affecting young disabled people and care leavers in the transition to adulthood.

Introduction

The importance of transition is highlighted in a variety of legislation relating to education, disability and health. The significance of involving young people in decisions that affect their lives is further emphasised in the United Nations Convention on the Rights of the Child.

This means that transitional planning with young disabled people leaving care is a complicated business, involving a sometimes bewildering array of initiatives and strategies.

There are different arrangements for future planning with pupils who have a statement of special educational needs; with children who are regarded as disabled; with children who are 'in need'; with those who have continuing health needs; and with those who are care leavers.

It is important to remember that many of the young people we are concerned with in this report may be eligible for transitional assessment and planning under all of these headings simultaneously.

> ***'The transition from children's to adult services needs further attention. So, too, do the special needs of children with complex medical needs, who in previous decades may not have survived and are posing a new and growing demand on community services, which we have to better respond to.'***
>
> ***John Hutton MP, Minister of State for Health, speaking at a conference organised by Joseph Rowntree Foundation, 15 November 1999.***

Educational planning

Under the 1996 Education Act, the local education authority (LEA) is responsible for co-ordinating the transition from school for all pupils with a statement of special educational need, whether this happens at 16 or later (many disabled young people stay at school until they are 19).

All children with a statement will have annual reviews, to identify their needs, and to agree aims and objectives for the coming year. The first review that occurs after a child's fourteenth birthday should begin the formal process of planning for transition.

The LEA must invite the child's parents, relevant members of school

> ***'I'm coming into me own rights and stuff, but I mean, its like sink or swim'. (Beth)***

staff, a representative of the social services department, and a careers officer to this meeting (plus anyone else who the head teacher may feel is appropriate).

The purpose of this process is to ensure that a child's special educational needs are met, and to consider all the options for future training and employment.

The LEA must prepare a report on the meeting and a transitional plan. They must send copies to parents, the head teacher, those who contributed to the review, and everyone who attended the meeting (plus anyone else they feel is appropriate).

A copy should also be sent to the Further Education Funding Council (if special provision needs to be made). The Learning and Skills Act will require an assessment of educational and training needs (during the last year of compulsory schooling) for any school pupil with a statement who will make the transition to post-16 education.

The transitional plan should draw together all the important information needed for a smooth transition to adult life. It should set targets, and consider strengths and challenges in all areas of a child's development.

It should take account of the needs and expectations of parents and carers. It should consider the curriculum, and the knowledge and skills that a young person may need to take advantage of future opportunities.

The post-14 review process is likely to be the first formal encounter with transition planning for most disabled children (whether or not they are 'looked after'). A statement of special educational need ceases when a child leaves school. This means that some disabled care leavers may cease to be 'looked after' before their educational transition planning is complete.

Connexions

The new Connexions Service will provide information, advice and guidance for all young people aged 13 to 19, to help them make educational and vocational choices in the transition to work and adult life. Connexions advisers will give guidance, and help young people to access appropriate support.

The Connexions Service will include a specific role for particular groups of young people, including disabled young people. It will play an important part in educational transition, with specific responsibility to ensure that assessments are conducted for young people with significant levels of need.

Most of these young people will have a statement of special educational need, others may have needs that were identified just before they left school (or after they have moved to further education and training).

'What we have noticed is that, for some reason, at the magic age of sixteen there's lots of things seem to stop.' (step dad)

Where a young person has been assessed under the terms of the new Learning and Skills Act, Connexions will also ensure that they receive the level of support that the careers service currently provide (up to the age of 25).

Disability services planning

Young disabled people may also be entitled to receive assessments under a variety of relevant disability legislation. For example, the 1970 Chronically Sick and Disabled Persons Act, the 1986 Disabled Person's Act, and the 1990 NHS and Community Care Act.

For example, under Section 5 of the 1986 Disabled Person’s Act, the LEA’s post 14 review must determine whether a child is likely to require social services as a disabled person after leaving school.

Not all children with an educational statement will be eligible for such an assessment. It is the responsibility of social services to decide whether a child identified by the LEA is considered as ‘disabled’.

Disabled school leavers should receive an assessment of their transitional needs under the 1986 Act, before they leave school. An assessment of need under Section 47 of the 1990 NHS and Community Care Act should be completed when a young person moves from children’s services to adult services (i.e. before they are 18).

The Secretary of State for Health has announced a new learning Disability Strategy to modernise services for people with learning difficulties. This strategy will also consider the situation of children and young people and will examine the transition from child to adult services.

In addition, direct payments for disabled adults will soon be extended to 16 and 17 year olds. The Government have suggested that this might alleviate the need for short break services for some families.

The Children Act

Section 24 of the 1989 Children Act details the responsibilities and powers of local authorities to provide ‘aftercare’ services to young people who have been 'looked after' on or after their sixteenth birthday.

These responsibilities include the provision of advice, help, moral support, and some financial assistance (particularly with education, training and employment). Planning aftercare services in good time is an important part of ensuring that transition to adulthood is appropriate and as smooth as possible. Young people should participate in all decisions that may affect their future lives.

Any young person who was looked

‘[The authority] are sort of saying well he’s been in another county for eight years...when is he going to be a resident…I don’t think they know between the counties…so I don’t know what’s going to happen’. (foster mum)

after by the local authority on or after their sixteenth birthday is entitled to an aftercare service when they leave care. If, however, the young person was accommodated: by a health authority or education authority, in a residential care home, or in a nursing home, then they are only entitled to aftercare services if they were accommodated there for three months or more.

This would apply to many disabled young people, although not all of the young people we met during our project would have been eligible for aftercare services within the terms of the Children Act. This is true for many disabled children, including those who spend considerable time away from home, and especially for those who make use of ‘short break’ or ‘respite’ services.

> ***'Some young people normally live at home with their families and are only looked after for short periods of respite care in order to give their carers a rest…the Government believes that these young people are the responsibility of their families and should not become subject to this new regime'.***
>
> ***Children (Leaving Care) Bill, explanatory notes***

Children (Leaving Care) Act

In its *Response to the Children's Safeguards Review* the Government promised to develop new arrangements for care leavers, and in July 1999 the Social Services Inspectorate published detailed proposals in a discussion document entitled *Me, Survive, Out There?*.

This document provided the background for our project and suggested that many young disabled people might be excluded from the new arrangements. The implications of these reforms, as detailed in the Children (Leaving Care) Act, are an important part of this report.

This is probably the most important piece of legislation to affect young people who have been ‘looked after’. The Act became law in 2000 and will affect young people leaving care on or after 1 October 2001. The new regulations affect three groups of young people, and local authorities will have new responsibilities to support each group as follows:

‘Eligible’ young people

This refers to young people who are ‘looked after’ by the local authority aged 16-17 and over, and who have been in care for at least 13 weeks since they were fourteen. Eligible young people must be provided with an assessment when they are 16, to consider the level of support they will

> ***‘They weren't there for me when I was young...They won't like us talking about them. They'll probably buck their ideas up... They will listen if they read this book...’. (Helen)***

need to help them in the transition to adulthood and independence.

As a result of this assessment they must be provided with a Pathway Plan, describing the support they need and from whom they should receive it. They will have their own Young Person's Advisor who will make sure that this plan goes ahead and is reviewed on a regular basis.

'Relevant' young people

This refers to young people, aged 16 and 17, who have now left care but who were looked after for 13 weeks or more between the ages of 14 and 16, and who were still in care on their sixteenth birthday. Relevant young people will also be entitled to an assessment, a Pathway Plan and a Young Person's Advisor.

In addition, the local authority will have to give them full financial support (i.e. provide them with, or pay for, their accommodation and assist them with their education, training or employment). The local authority must also keep in touch with them. These young people will no longer be entitled to Housing Benefit, Job Seeker's Allowance or Income Support.

However, there are two groups of young people who will still be eligible to claim benefits – these are lone parents and disabled young people. This is because the benefits system already recognises the particular needs of these young people and the new Act aims to provide similar support to that which they would receive if they were still at home. These young people will still be entitled to financial support as a result of the Needs Assessment (but the benefits element will be subtracted or taken into account when determining the overall financial package)

'Former relevant' young people

This final group includes young people aged 18 to 21 (or 24 if they are in education) who used to be either 'eligible' or 'relevant' (or both). They can claim benefits as before, and so the local authority is not responsible for their accommodation or maintenance.

However, the authority does have a duty to assist with their education, employment or training up to the age of 21, or beyond if identified in the Pathway Plan. They also have a duty to provide accommodation for young people in higher or further education in the vacation, up to the age of 24, if required.

In addition, this group of young people will still be entitled to a Young Person's Advisor, a Pathway Plan and general assistance from the local authority, who must continue to stay in touch with them.

> ***'You can go out more and have boyfriends, go to the pub and smoke. Also you have money in your pocket and get your own place...You also have to learn how to be mature.' (steering group member)***

Issues for young disabled people

According to Government estimates, up to one quarter of all looked after young people may be ‘disabled in some way’. Yet many will not be considered as care leavers under the new arrangements.

When the Children (Leaving Care) Bill was introduced in November 1999, the accompanying notes raised some important issues concerning the eligibility of some young disabled people:

Young people using respite services have been excluded from the new arrangements because it is assumed that their main carers are at home. In many instances however, this is not the case.

For example, during our research we found some young people living full time in ‘respite care’, and it is unclear how they might be regarded within the new arrangements. Mainstream children’s service may not necessarily be aware of such children and, may not budget for their needs accordingly.

High level respite users may spend so little time at home that it is unrealistic for their parents to take responsibility for preparing and supporting them through the transition to adulthood, even if they are classified as the main carers. Many of these young people do not have an allocated social worker to oversee and co-ordinate services to ensure that this work is undertaken.

> ***'Disabled children and young people who live away from home, in some cases from birth right up to the age of 18, are as much estranged from their families as are children who are looked after by foster parents or in a local authority children's home. They are as much in need of a pathway plan and the services of a personal adviser as those other children, and the duty owed to those children by the state is in no way different from the duty owed to children who, in the ordinary sense, are in the care system.'***
>
> ***Earl Howe (speaking in the Grand Committee of the House of Lords)***

This raises a number of questions – should there, for example, be a level of service use deemed high enough to constitute being ‘looked after’? Even if not entitled to the financial elements of the new regulations, should these young people nevertheless be entitled to other arrangements such as Pathway Planning and a Young Person’s Adviser? Although they will be entitled to a Connexions Advisor from the age of 13 to 19, many

‘One moment she was with me, the next moment she was gone...I didn’t get any thank you from the social services.’ (foster mum)

disabled young people do not leave school until 19.

There is, as yet, a lack of clarity about the support for disabled young people who live away from home for 52 weeks of the year in educational or health establishments. Under the Children Act there is a discretionary responsibility to provide after care support if young people have lived in such a situation for more than three months, but there is little evidence to suggest that this happens in reality.

There is little evidence that information and communication systems between services are sufficient to ensure that Children's Services are even aware of such young people's existence. This group of young people is therefore in danger of being overlooked in the regulation of the new arrangements for care leavers.

'Relevant' and 'former relevant' young disabled people will be entitled to the full provisions of the new Act until they are 21 (or beyond) but there has been no formal acknowledgement as yet that transitions for young disabled people may take place over a longer period of time, and extend well beyond the age of 21.

During the Bill's Second Reading questions were raised about the implications for disabled young people. Assurances were given by Government that there would be specific guidance on these issues.

The Government's response has been to highlight provision that might be available through other initiatives (for example, Quality Protects, the new Connexions service, or the Learning Disability Strategy).

Our concern remains that this approach masks the fact that there are a substantial number of young disabled people, spending large parts of their childhood in the care of services away from home, who will not be defined as care leavers within the terms of the new legislation. The stories highlighted later in this report provide examples of this.

> ***'...funding and service structure can work as a straightjacket, demanding long-term decisions, and sometimes enforcing changes in living arrangements, at what may be highly inappropriate times.'***
>
> ***National Foster Care Association***
>
> ***(2000, p.63)***

'He's always in dire need of a bath, a shave. He never cleans his teeth…He's got nobody in the flat. He can't go home and say so, and so he's hitting me or whatever...so lonely.' (former foster parent)

Further reading

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> ***'He wasn't ready to go away from home…he just loves that school…his friends, everything going through 'till he was nineteen'. (foster mum)***

Disabled Care Leavers

We began our research by trying to find out how many young disabled people might be leaving care in the local area. This proved to be a difficult task and we learned a great deal about the ways in which young people can be defined as disabled or looked after. We also found that certain groups were considerably under-represented in the looked after population.

Local estimates suggested that 3.3% of children and young people (aged 0-16) and about 2.5% of those aged 17 to 25 might be disabled in some way (a total population of about 4,500).

Within this population, the authority's Management Action Plan identified 615 'children and young people with disabilities and complex health needs' who were receiving social services (13.7% of all disabled children). Of these, 197 under the age of 18 were identified as 'looked after' (32% of those receiving services and 4.4% of the total disabled population).

Using these figures we estimated that there would be about 11 disabled young people leaving care each year, and that the total number of young disabled people in our age range (14-25) with experience of using looked after services before their sixteenth birthday would be about 130.

Eventually, we were able to identify 131 people in this age group (although some had not used overnight accommodation). The following sections provide more detail about this group and about the 28 young people we worked with more closely.

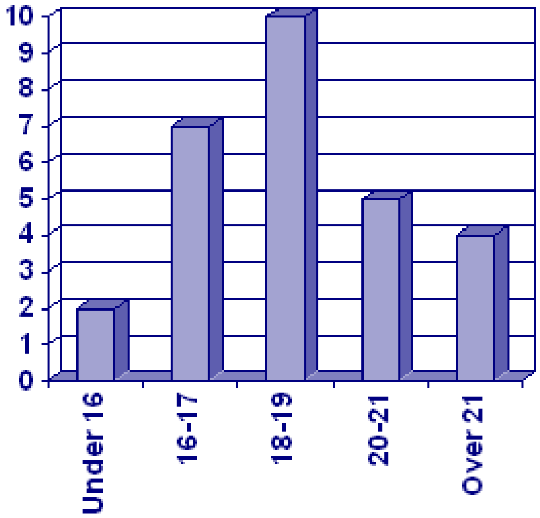
Age

The leaving care literature and government policy focus on young people over the age of 16. However, transitional planning for many disabled children begins at 14, in conjunction with the education authority, and we wanted to include their experiences.

The upper age of 25 was determined by the policy framework for leaving care services, and by the fact that disabled young people are more likely to leave care at an older age than their non-disabled peers.

Most of the young disabled people we identified were aged between 16 and 19 (the average age was 17.87 years). It was harder to locate those older than 19 because their whereabouts were less likely to be known by service providers.

The following graph shows the number of people who took part in our project



Gender

The general population of young disabled people includes more young men than women (about 60% to 40% respectively) and the local authority's Register of Children with Special Needs reflected this (63% to 37%). The same is true of the general leaving care population (more boys than girls are 'looked after' as children). For this reason, we expected to find more young men than young women amongst disabled care leavers.

We were surprised to discover that the numbers were almost even (48.5% were female and 51.5% male). There are a number of possible explanations for this: we may have failed to identify some young men who had been looked after; more young boys than girls may have died before they reached our age group; more disabled young women than men may have experience of using looked after services.

When we looked at the use of overnight services, we found that the proportion of women to men increased with the number of nights they had been accommodated. Of the 36 young people who we knew had been accommodated full-time as children, 20 were women (56%). This was a surprising finding and merits further investigation beyond this project.

Our smaller sample of 28 young people included more men than women (16 and 12 respectively) and was closer to the general population of young disabled people. Our concern to include people with a range of ages, impairments and ethnic origins, meant that we had to choose who to spend time with. There seemed to be a bigger range of ethnicity and impairment amongst the male group, and our sampling is partly a consequence of this. In addition, three young women who we wanted to include decided not to be interviewed.

We met more young men with complex and multiple impairments, and it was easier for some of the young women to participate actively in the research (particularly as the research worker was also a woman). We found that more young women than men became actively involved in the project (for example, all six of the young people who came to our steering group were female). The interviews with women also tended to be longer.

Ethnicity

Local authority statistics suggested that the proportion of young people from ethnic minority backgrounds in the area was about 30% and rising. Amongst young disabled people, the figure was even higher (in the region of 38% on the Authority's Register of Children with Special Needs). Most were from South Asian communities (predominantly Pakistani Muslim). The number of young people of African-Caribbean and 'other' communities was very low by comparison (1% and 2% respectively) but we were keen to include these groups too, together with those of 'mixed parentage'.

Since Asian young people were over-represented in the local disabled population, we hope to find them amongst those using looked after services. However, this proved to be very difficult.

Young Asian people often used after-school or daytime respite services but were less likely to stay overnight away from home (the numbers decreased as children grew older). 17 out of the 21 young Asian people that we identified stayed overnight less that once a week. The average stay was 1.43 nights per week, compared to 3.94 for young white people, and 6.5 nights per week for those with African, Caribbean or mixed parentage (although the numbers in this last group were very small).

Our project was about care leavers rather than looked after children but our experience raises important questions about the use of looked after services. Why should there be such a low take up amongst teenagers from South Asian communities? Our research does not provide answers to such questions, and more work would be needed to examine the use of children's services by different ethnic communities.

It is hard to make comparisons with those of African, Caribbean or mixed parentage, due to the small numbers involved. However, we were able to include four young people from these groups, and their experiences also raised a number of issues. Overall, we found it difficult to include as many young people from ethnic minorities as we had hoped.

Impairment

We found quite a lot of information about the labels used to describe young people's impairments (e.g. in the authority's Register of Children with Special Needs and Children's Services Plan).

This information suggested that most young disabled people were regarded as having some form of learning difficulty (mostly undefined). They were also the largest group using social services (more than 50%). Most of these children had more than one impairment label (such as additional health conditions, communication, physical or sensory impairments).

For our project, we were less interested in medical conditions than in what happens to young people when they acquire particular impairment labels. However, we were keen to include young people with a wide range of impairments.

In practice, it was hard to find looked after young people who did not have the label of learning difficulties. Children with learning difficulties were by far the largest group using respite care and fostering services. We found only eight young disabled people in our age range who did not have the label of learning difficulties and who were looked after (6.2%); four of these had used less than one overnight stay per week as children.

Our experience suggests that children labelled as having learning difficulties (and we would question some of this labelling) were much more likely to use 'looked after' services than disabled young people without that label. We had expected to find more young people with physical and sensory impairments, and this may raise some questions about the way in which the need for looked after services is being assessed.

Care context

Local information indicated that around half of 'children with special needs' who used social services used some kind of respite care. 30 were recorded as fostered and 26 making use of a Family Centre. The local authority's Management Action Plan identified 197 young disabled people who were considered to be looked after, all of whom were said to be accommodated through 'a series of planned short-term placements'.

However, we found a number of disabled children who were accommodated full-time by social services, and others who lived away from home in placements funded by the education authority or in health care settings.

This raised questions about the accuracy of information available to service planners. We also found it very difficult to establish a clear picture of how many young disabled people were fostered (and staff in fostering and adoption services did not always know which children might be disabled).

We wanted to include young people with a range of looked after experiences. These ranged from regular respite care to full-time placements in institutional settings or with foster parents. We met care leavers who had lived away from home in respite units, children's homes, foster homes, hospitals, prisons and educational establishments. We also identified some disabled children who were living in unusual full-time placements (such as living alone in a former staff flat).

Conclusion

The information we gained from trying to locate young disabled people who had been looked after raised a number of questions about assessment, service provision and information systems.

We were surprised to find that disabled girls (particularly those with 'mild' or 'moderate' learning difficulties) were more likely to have been looked after full-time within mainstream children's services than boys.

We noted that young disabled people from South Asian families were much less likely to stay away from home overnight than we had expected.

We found that the information available to service planners did not always match the experiences of young disabled people.

Those living away from home were not always regarded as looked after, and full-time placements did not always show up in the figures on disabled children.

Ten stories

This section includes short studies about some of the young people who were involved in our research project. Each story includes something about that person's experience of growing up away from home, and about their experience of leaving care. We have included something about the decisions they have faced, the people who have helped them, and their hopes and fears for the future.

The stories we have chosen include people with a range of different impairments and life experiences. We have tried to include people with physical, sensory and cognitive impairments, including those with multiple impairments and those who do not use speech to communicate.

The stories were collected during our research (through visits, observations and interviews). We tried to involve young people as much as possible in deciding how they wanted to tell their story. Sometimes, it was useful or necessary to involve an adult as well.

We worked in this way with 28 young disabled care leavers between the ages of 15 and 24, and the ten stories included here illustrate the wide range of their experiences and aspirations.

We have included stories about young people who have lived in very differing circumstances: with foster parents, in children's homes, specialist residential units, residential schools, hospital, hostels, supported accommodation, and so on.

The issues that mattered to young people and the kind of support they had received varied greatly. The stories in this section highlight the kind of support that young people told us they wanted in their transition to adulthood, and the kinds of people they were most likely to turn to for help. For example, relatives, teachers, support workers, friends, or social workers.

Why case studies?

Case studies do not tell us everything about a person or about their lives. They are not the whole story. Some of the important issues demand much more discussion and this is provided in other sections of this report. The reason for presenting a small number of case studies here is to show how different experiences and sequences of events can link together in young people's lives.

Case studies can be a useful way to prompt more discussion about the issues, and about what can be done to make things better. Professionals, politicians, teachers and students often use case studies to help them talk about these things, and to think about what happens in people's lives. We hope that these ten stories may be used in this way to improve practice.

'My name is Alice. I am sixteen. I live with my foster parents I am still in school. I like animals. When you grow up you can wear makeup. Can get more pocket money. My advice is don't be cheeky to your mum and dad.'

Helen

- Court order
- Foster parents
- With parents
- Foster parents
- Pregnancy
- Left school
- Foster parents
- Children’s home
- Parenting
- Hostel
- Own flat
- Second child
- Third child
- Family centre
- Own flat
- Pregnancy
- Own flat

Helen was taken into care when she was 7 years old and was then in and out of foster homes and children’s homes until she was 17 (apart from one year when she lived with her parents). Helen has a label of learning difficulties and went to a special school. She says that she is not disabled.

Helen became pregnant when she was 16, and was moved to a new foster home (without having seen the place or the people first). She ran away after two days. The police took her back and social services placed her in a children’s home.

She gave birth to her first child in a friend’s flat because she feared the baby would be taken away if she went to hospital. The baby was placed for fostering and adoption when it was just a few weeks old and Helen went back to her foster home. She then lived in a hostel for about two years.

Her uncle helped her to find a house in another city and Helen lived there for a year with a boyfriend, before returning to her home town. She had her second child when she was 20, who was also placed for adoption. Her third child was born more recently and taken into care.

Helen says that she did have some support from staff at the hostel but not from her social worker or after care workers. She felt that the social worker was never there for her and she no longer trusts social services to help her. Her best support came from a teacher at the special school, with whom she still has a good relationship. She would choose to go to her for support, or to her mum.

Helen feels she has gained a lot of life experience. She regrets having children so young and would like to go back to school, but does not know how she could do this (she has been too scared to ask). She has applied for a flat and hopes to get a leaving care grant for furniture.

Helen is 22 now and living with her boyfriend. She feels that she can manage and that she does not need help with daily living, but she thinks that young women should get more help to learn about parenting. Helen has just found out that she is pregnant with her fourth child.

‘It would have made a difference if I didn’t get pregnant at sixteen...If I didn’t have kids I would have been a lot better. I would have stayed on at school but...now my life’s totally wrecked. So I don’t know what to do’.

Anne

- Parental home
- Special school
- Residential school (full-time)
- Young adult unit
- What next?

Anne is 22. She lived at home until she was 13, when she went to a special school, and then to a residential school outside the authority. Anne has both visual and physical impairments and uses a wheelchair. She says that she is disabled.

After a few months as a day pupil, Anne began to stay at the school for four nights a week. From the age of 15 to 19 she lived there full-time, going home only for a daytime visit once a week. When she left school, Anne moved into a residential unit attached to the school. The decision was taken by her mum and Anne did not have the opportunity to see anywhere else, and disability services were unaware of her existence. She complained about living in the unit from the beginning, saying that she was bored and that she wanted to move. Anne knows that she can stay there until she is 25 (so long as the authority continue to fund her place) but does not know where she could go then.

Anne's mum is her main source of support. She enjoys one to one support from staff but says that she got more attention from staff when she was at school. She sees her social worker when there is an annual review and would like to see him more often but she does not know how to contact him.

Anne has very little in the way of social life. She goes to college and sometimes to the supermarket but has no other outside activities. She loves to go swimming but has not been since she was 13. She says that the staff do not have the time to take her. While at school she enjoyed going to a youth club but she does not go there any more. Anne used to have a boyfriend, who she met in the unit, but does not sees him now because he never took her out.

Anne has considered herself an adult since she moved to the unit. Adulthood means having more responsibilities, such as cooking and cleaning (although she does not use the cooker for fear of burning herself). She says that no-one except her mum and grandmother has really talked to her about growing up.

Anne would like more contact with her mum and her twin sister but knows that she cannot live with them, now that her mum can no longer lift her. She was given a mobile phone to contact them but the numbers are too small for her to use it alone. Anne would like to have a flat of her own, with support, so that her friends could visit. She likes the idea of helping other disabled people and she would like to have a job caring for others.

'I want to help more disabled…if they are getting uptight or something, I want to be there for them, and that's caring in't it?...I would say let's take you home...and let your parents sort you out.'

Nathan

- Special school
- Care order
- Foster parents
- Respite care
- Behavioural problems
- Fostering broke down
- No foster family available
- Respite care centre (full-time)
- Respite centre (older children)
- What next?

Nathan is 15. He was fostered from the age of eight until he was 14. During this time, he also made day visits to a child respite unit and sometimes stayed overnight with a shared carer. Nathan has learning difficulties and a speech impairment. He said very little about himself and much of his story was told by adults.

Although Nathan is of mixed parentage, the authority were unable to find a black foster family and his foster parents were both white (although he did have a male African-Caribbean key worker for a while). His family placement ended when his foster mum felt unable to cope with his increasingly violent behaviour.

Nathan's teachers argued that it would be wrong to place him with another foster family, thinking that he would have to move again at 18. A potential family placement fell through and Nathan was accommodated full-time in a child respite centre, while the authority looked for an alternative family placement. After two months he was moved to another unit for older children (also full-time).

Leaving his foster family affected Nathan greatly and he was very disoriented by this experience. He still finds it hard to talk about it. Nathan expressed his anxiety through 'difficult' and sometimes violent behaviour. He was confused, especially by contact with so many different staff, and still rarely eats breakfast at the unit where he lives. For months he continued to ask for his foster mum, unsure whether he would be returning to her. Nathan also has a sister, who is adopted, but her parents do not allow contact.

Nathan enjoys his weekly overnight stays with a shared carer, which have continued throughout his childhood. He has friends at school and likes to go out on trips. School is a source of some stability in his life, this has helped him to settle. The school and respite centre communicate daily about everything that happens (through a home school-diary) although Nathan prefers to keep the two environments more separate.

Nathan will stay on at school when he is 16 and would like to go to college. There will not be a transition plan until he is due to leave school at 19 and it is unclear what options he will have at that time.

> ***'We've told him that it's his home now and that's where he lives...I think he understands that that's where he lives. I don't know that he understands that other children don't.' (teacher)***

Kamala

- Parents
- Care order
- Foster parents
- Fostering broke down
- No foster family available
- Child respite centre (full-time)
- Supported living in flat (alone)
- Move to adult respite centre
- Leaving school
- What next?

Kamala is 18 and of mixed parentage. She was fostered for seven years until she was 13. When this broke, down Kamala was accommodated, initially for a weekend, so that children's services could find a more suitable placement. No long term foster family was found, and Kamala was accommodated full-time in a flat above a child respite unit (where she stayed for five years). She is regarded as having severe learning difficulties and also finds motor co-ordination difficult. Kamala does not see herself as disabled.

Two care workers from an employment agency were employed to support her in her new accommodation. The flat itself was unsuitable in a number of ways and Kamala was largely isolated from contact with other children or adults. When Kamala reached 18, social services began looking into adult services options.

There were some attempts to find a supported flat. However, following trial visits, Kamala was moved to full-time accommodation in an adult unit. The decision to move was based on age criteria and the destination seemed to be largely a vacancy-led purchasing choice, going against the recommendations of a needs-led assessment. Although Kamala had little preparation for living with others in a group setting, she is enjoying the company and new friends.

Kamala faces many changes in her life now that she is reaching adulthood. She has had eight social workers in the past four years. However, since leaving children's services, she has had no social worker and has had no further assessment of her needs. At her end of children's care meeting, there were representatives from children's services and from the school. Three representatives from adult services were invited but none were present at the meeting to talk about her future.

Kamala sees herself as an adult. She has not thought much about this but feels that it is better than being a child. She enjoys watching videos and occasional trips out. After several years of minimal contact, Kamala now visits her mum more often. Next year, at 19, she will leave school, where she has had some continuity until now. It is unclear what she will do next.

> ***'It's gonna be moving soon...I'll be living somewhere else...'Cos they told me I'm gonna live there...They asked me if I'd like to go and live there and I said yea. And [staff] might bring my friends from school to go and see the place...And they might have a drink.'***

Josh

- Parents
- Residential school
- What next?

Josh is 16 and has been at a residential school outside the authority for three years. He has just started in the post 16 unit there. Josh is regarded as having severe learning difficulties and also uses a wheelchair. He used symbols and nodding, rather than speech, to tell his story and was supported by a member of staff from the school.

There was no school that could support Josh in his home town and his parents eventually went to court to secure a residential place outside the authority. He stays there four nights a week and goes home for the weekend. The placement is funded by the education authority and Josh has little contact with his social worker.

Josh's life and life interests are dominated by the things he does at school. His friends are all from school (he did have friends from a previous school but does not see them now). Most of his outings, which he enjoys very much, are also with school rather than with his parents. He says that he prefers being at school to being at home. He is involved in school life and is spokesperson for the older residential students' committee.

Josh considers himself to be a young adult. He likes to associate with people older than himself and looks forward to being an adult like them. Josh is very aware of his sexual feelings and enjoys talking about relationships. He has not had anyone to talk to about this yet (although his teacher promised more opportunity next year). He would like to make more of his own life decisions but feels he would need some help with this. He sees the school staff, rather than his parents or social worker, as the best people to provide this kind of support.

Josh has annual review meetings, to which many people are invited (including his parents, teacher, physiotherapist, speech therapist, medical department, social worker and the education authority). Josh says that he enjoys the meetings and that he would object if he was not happy with something, or if things said about him were untrue.

Josh does not have any concrete plans for the future and says that no-one has ever really talked to him about this. He does not know when he will leave the school or where he might go from there. He would like to go to college.

'He wants to know about growing up and changes in life and how you approach the opposite sex, and how you have relationships with people, and not in a giggly way'. (teacher)

Susan

- Foster parents
- Shared care
- FE college
- What next?

Susan is 22 and has been fostered with the same family all her life. She has also had regular overnight stays with a shared carer since she was very young. She does not see her ‘old mum’ any more. Susan has Down’s Syndrome and also uses a hearing aid. She says that she is disabled.

The continuity of a single family placement has given Susan a great sense of stability throughout her transition to adulthood, and her life has changed much less than many other looked after young people.

Susan’s involvement in transition from children’s services was limited. When she was 18, an independent assessor called at the house and asked her if she would like to leave her foster parents. When Susan said no, funding for the placement was continued. Susan says that no-one ever discussed any options for moving out, only whether she wanted to leave her family. A community nurse now visits once a year to review how things are going. Susan is happy where she is and does not want to leave.

Susan attends a local FE college of her own choice and enjoys this more than the college she used to go to. Her course includes a range of activities, including independence skills, IT, catering and work placements. She is particularly excited about her work placement but this will finish when her course ends next year. Her foster mum is worried that the only alternative then may be an inappropriate day centre placement. She wants to extend Susan’s course, while recognizing that this will only postpone difficult decisions about her future.

Susan gets most of her support from her foster parents and says that she would go to them if she had a problem, or alternatively a female friend of the family or her college tutors. Susan’s foster family are also a key source of social contact and support and there is some concern about what will happen as they grow older. She has a number of friends at the various clubs and sports activities she attends and, unlike many other disabled young people, does not have to worry about leaving them behind when her college course ends.

Susan feels that she became an adult since she was 18, because people have told her that she is; and because she goes to college, saves money and travels on her own by taxi. Susan has had boyfriends but is not planning to have a family of her own.

‘I love me Mum and Dad...I can't really live on my own...I want a job...I love college...I chose where I went...I like being adult...I'm not old yet, not married yet...I'm not having no pain no babies.’

John

- Parents
- Various foster placements
- Adoption
- More foster placements
- Repeated breakdown
- Children's homes
- Residential psychiatric hospital
- Moving town
- What next?

John is 17. He had various foster placements from the age of six. He was once placed for adoption but this broke down after three years. Most of these difficulties related to John's 'sexualised behaviour' and to his own experiences of bullying. After two more unsuccessful foster placements, John was placed in a children's home. For the past two and half years he has been living in a residential psychiatric unit outside the authority. He has a diagnosis of Asperger's Syndrome, and has experienced considerable mental distress.

John says that he was distressed about moving from one family to another because it did not give him the chance to settle. He has not seen his mum since he was five and says that she does not want to know him. He does not know why. He would like to know where his sister is and to see her. No one has discussed this with him in the past, although his new social worker has offered to help.

John has had few choices to make about where he lives and what he does with his life (such as the college he attends). He would like to have more say in his life and to be asked what he wants to do rather than being told.

John knows that being an adult means having more responsibility. He would like to be more independent and to have more freedom. He would like to live independently but thinks that he will need some help, particularly with budgeting, cooking, buying food and finding a place to live. He has no idea where to go for information on housing.

John is quite restricted in the relationships he can form in the unit. Boys and girls can mix during the day but are not allowed to go out together. He has a girlfriend who used to be in the same hospital but cannot see her now.

John's local authority have now decided that they can meet his needs in a psychiatric unit in his home town but John feels more settled in the area where he lives now, and does not want to move back. He does not remember anyone talking to him about transition issues. He would like to do a computer course but does not know whether there would be one available in his home town.

'I've been there for just over two year and I feel as if I've got settled. And I don't want to leave...they obviously want me to come back down to [my home town] and get some more help...When I'm able to look after myself I've decided that I want to go back and live there.'

Denise

- Care order
- Fostering
- Residential unit
- More foster placements
- Repeated break-down
- Fostered by staff member
- Community group home
- What next?

Denise is 24 and lives in a group home for people with learning difficulties. She has a hearing impairment, diagnosed relatively late, and it is unclear whether she also acquired the label of learning difficulties because of this. Denise does not think that she is disabled or deaf.

Denise was fostered when she was seven, following a care order. After a year and a half she moved to live full-time in a residential unit for disabled children, until she was 15. During this time she had various foster placements, all of which broke down. Denise was then fostered by a member of staff and stayed there until she was 23. She now lives in a small group home, with overnight staff support, where she is currently the only resident.

Denise left school at 18 and completed a three year college course. She continues to go to college one evening a week. She also attends two prevocational training courses and a literacy class, although these are described by her social worker as ’day care’ placements (rather than training). Denise has found it difficult to sustain these placements, due to her sometimes ‘difficult’ behaviour, and her boredom in the face of low expectations from those around her.

Denise has relatively few choices in her activities. She finds it hard to cope in unsupported mainstream environments but feels bored and undervalued in group activities designed for people with more complex impairments. She enjoys adult environments and going to the pub, but this is not considered by the staff to be a ‘safe’ environment for her. Denise has some friends and a boyfriend but would go to the staff for help or advice.

Denise says that when she was 18 her social worker asked if she wanted to move from her foster home. She said no and the placement was continued. She says that no-one really talked to her about growing up and that she had little further contact with her social worker, apart from periodic reviews. Denise has more independence now and makes more of her own decisions. She has no plans for the future but likes the idea of earning money. She likes her flat but does not know how long she will be able to stay there. She does not want a job but would like to leave her training placement.

> ***‘I get food and cleaning things. Staff choose...They get it for us...Can have chocolate if I get slim first...Now I eat health things...Little bits...don't want to get married...Not ever.’***

Dawn

- Parents
- Respite care centre
- Shared care
- Difficulties at home
- College
- Nursing home for the elderly
- Move to supported flat
- What next?

Dawn is 18. She has learning difficulties and some physical impairments. Dawn says that she is disabled.

Dawn lived with her parents as a child but used some respite care and overnight stays with a shared carer from the age of 14 until she was 17. This amounted to about one night per week plus some block stays at a child respite centre during holidays.

Due to difficulties in relationships at home, social services were keen to find an alternative place for her to live. A residential college was suggested but Dawn also needed an operation and continuing care. So, when she was 17, Dawn moved to live full-time in a residential home for the elderly. She is the only person of her age there (although there are one or two young people using the home for respite stays). She shares a room with two other people and has one friend (an older married woman who spends half the time there). Dawn no longer sees her two friends from the child respite centre.

Despite the isolation from other young people, Dawn has been quite happy in the home. She says that she has more independence now. She can make her bed, make tea and go out. She has learned to count money and has some control over her own spending now. She prefers living there because she did not like being ‘bossed around’ by her mum at home. Dawn sees herself as an adult, and relates this to being 18 and having more control over her life.

Most of the decisions in Dawn’s life have been taken by her mum, including the choice of respite care and the move to the nursing home. Dawn says that she was offered a choice to stay on at school but her mum wanted her to go to the college so she did. The home will close soon, to be replaced by the development of a supported living unit. Dawn will be moving to her own flat. Dawn has no clear ideas about her future. She does not know when her college course will end. She would like to learn to drive and wants to be a teacher at her old school.

Although Dawn would not be considered as a care leaver under the new legislation, service use has played a very important part in her life.

> ***‘I wanted to go there...so I could do stuff on me own...I feel a bit happier...I don’t let my mum to boss me around now because I’m old enough...When I get a friend I can get married.’***

Peter

- Court order
- Emergency foster care
- Long term foster placement
- Leaving school
- What next?

Peter is 19, and is described as having severe learning difficulties. He finds it hard to make himself understood, and many of the details in his story were told by his foster mum.

Peter was taken into care following a court order when he was 12. He was placed in emergency foster care for three months and has since been with his present foster parents, who live outside the authority.

Peter has attended the same special school for many years and has close relationships with staff and pupils there. At 16, his foster parents faced a difficult choice, between residential school (the nearest 40 miles away) or a local special school. His foster mum decided that he was ‘not ready to go away’.

When he was 18, fostering was extended until he left school. We met Peter one month before this was due, at which time his foster parents did not know what would happen next (although they thought he might stay with them as a supported lodger).

The choices open to Peter may be determined by which authority funds his adult support. There has been some discussion about whether Peter should be regarded as resident in his home town or in the area where he has grown up. A recent change of social worker has added to this uncertainty.

Peter’s foster parents are concerned about the lack of adult resources available in the area where they live. Apart from residential colleges, they know of only one adult hostel and feel that Peter would be much happier in a small group home (with full-time staff support). Peter does not want to go back to his home town, because he has bad memories there.

People are very important to Peter and leaving school will be a big step for him, as he will lose many of his social contacts. However, he is easily influenced by some of his peers and this has led him into some difficult situations. He attends a local youth club and enjoys this (although he is technically too old).

Two months after his nineteenth birthday there is little evidence of formal planning for Peter’s future. He may face a number of important transitions at once, such as leaving school, leaving his long term foster home, and starting college. This may be difficult for him to cope with.

> ***‘We’re not chucking him out…they’ll sort something out, I mean [his previous social worker] knows, she wouldn’t leave me in the lurch… I’m not bothered so long as we don’t get bankrupt’. (foster mum)***

What was important?

This section of the report is about the issues that were most important to the young people we met during the project.

Different people had very different experiences and so we have focussed on the issues that were mentioned most often, and on those that raised the biggest questions about leaving care. The key issues were...

Family contact

Friends

Accommodation

Information

Education, Training and Employment

Sexuality and Parenting

Health

Independence Skills

Money

Some of the examples that follow are very similar to those described by non-disabled care leavers and researchers in the past. Others are much more specific to the experience of young disabled people who have lived away from home.

The Government has emphasised the importance of education, training and employment in its guidance on helping care leavers. However, these were not necessarily the most important issues for the young disabled people involved in our project.

Only one of the young people we met had any kind of paid work and many of the others had never been expected to think about employment at all. Health issues were also not very important to young people themselves.

In general, adults did not have high expectations about independence and citizenship for this group of care leavers, particularly those with learning difficulties.

Learning independent living skills was important to some people. Many were attending pre-vocational or life skills training courses at local colleges but there was little expectation that this would lead to paid work.

Thinking about where to live, how to make friends and dealing with money were also important issues.

What is not included?

We have not included any information in this section about developing advocacy, advisory and transition services for young disabled care leavers. This is included in the chapter on ‘Improving Practice’.

‘The report should include both the good things and the bad things.’ (steering group member)

Family Contact

The Children Act emphasises that links with family, friends, culture and substitute carers should be preserved and built upon through local placements, continuity and regular visits (Stein 1991).

In our study, the range of such contact varied considerably, from those who had no contact at all with their birth family to those who now lived with their parents most of the time. Some people had grown up with their birth family; others were taken into care from a very early age. Some were unable to see their families as much as they would have liked.

> ***'A particular cause of concern with regard to children with disabilities 'looked after' by the local authority is the difficulty they may experience in sharing any concerns or anxieties about their lives…the family is crucial in helping them to determine their place in the world and for acting as an advocate when required'***
>
> ***Argent and Kerrane (1997, p. 60)***

Barriers to family contact

Some of the young people we met were prevented from having direct family contact by court orders or other restrictions. Those young people who had been separated from their birth families wanted to know more about them as they grew up. For example, both Alice and Stephen (whose family contact was prevented by court orders) said that they wanted to know more about their birth families. Similarly, Beth says that the first thing she wants to do when she is 18 is to find out why she was taken into care.

Other young disabled people are prevented from family contact not by legal or administrative restraints but because of disabling barriers or lack of resources. Those who had lived in residential establishments for disabled children often missed their families. Denise lived full-time in a residential unit for seven years. She liked the staff and the other people there but missed her grandparents. Anne says that she cannot live at home now that she has left residential school because her mum can no longer lift her. She goes home for a day visit once a week from the unit where she lives, outside the authority. She would like to see more of her mum and sister, and to talk to them whenever she wants, but she does not have access to a phone that she can use by herself.

It can be hard for some young people with communication impairments or learning difficulties to understand an absence of family contact as they grow

> ***'There's only one thing that I really, really want to meet, that's my brother…'cos I've never, ever met him...' (Alice)***

up. Alice, who is only allowed postal contact with her mum, says that she does not understand why she cannot see her. Stephen, who has not seen his mum for 12 years, says that he has no idea why she does not want to meet him. He cannot remember anyone discussing this with him (although his new social worker, who was at the interview, has now offered to help).

> ***'It is never good enough to presume that a child does not comprehend the meaning of relationships and that therefore contact is insignificant.'***
>
> ***Argent and Kerrane (1997, p. 44)***

Continuity of family contact was particularly difficult for those who moved from one place to another, or were placed outside the authority. In this context, it is worth noting that disabled children, and particularly those with complex impairments or health needs, are more likely to be placed at a distance from their family than non-disabled children, and less likely to be able to travel freely or communicate with family and friends.

Substitute families and carers

For young people like Susan, who had grown up in a single foster family throughout their childhood, the significance of 'family' was often transferred to the foster parents. It was the foster family that became important to the young person, and the foster family with whom they wanted to stay in contact. Long-term foster parents also played a key role as advocates for young people with learning difficulties, sometimes continuing their fostering role into adulthood (if funds were available).

Although such family attachment and stability was very positive, it was sometimes taken for granted by social services that young people with learning difficulties would simply stay with their foster families, with little or no change in their lives. This raised concerns about how long transition issues can be postponed, and about what might happen to people when their foster parents became older (see Thomson et al., 1995).

When long-term family placements broke down (especially in adolescence) the impact on the young person could be dramatic. When Nathan's foster mum felt that she could no longer cope, she still wanted to visit him at school or in the residential unit where he was then placed.

However, social services felt that continued contact was 'not a good idea' and school staff saw it as their role to 'help him to forget' about her. Although Nathan's current placement

'I can't stand being separated from our mum'. (steering group member)

provides some stability, there is no continuity of staffing and therefore no one person who can be there for him on a daily basis as he approaches adulthood.

> ***'While there are differences between a child's home and a foster home, there will probably be more similarity between home and foster home than between home and residential establishment'.***
>
> ***Shaw and Hipgrave (1983, p. 8)***

Those who grew up with many different placements were more likely to look to their own relatives for help and support during their transition to adulthood, or to maintain contact with a particular teacher or respite carer. Many who did not have much contact with their birth parents kept contact with other family members (e.g. aunts, uncles or grandparents).

Michelle ran away from the children's home where she had stayed because it was too far from her family. She would go to visit her grandmother or her auntie whenever she had free time. When Michelle was placed with a foster family she left, after just one night, and went to live with her auntie. When she left children's services, Michelle wanted to find a flat of her own near to her family.

Family involvement in planning and advocacy

The Children Act states that important people in a young person's life should be involved in planning for their future. However, a great many different people may have contact with young disabled people who are looked after, and family members may not necessarily be the most familiar with their everyday lives. For example, the most important people in Kamala's life were two agency care workers, who had lived with her for five years, yet they were not invited to contribute to her educational transition review.

In general, young disabled people who lived with their parents, or with long-term foster parents, benefited from much greater advocacy on their behalf than those who relied on service providers to help them through transition. Parents and foster parents often seemed more committed to finding out about the options, and in promoting the young person's choice.

A good example was the refusal of parents to accept adult social care services (like day centres) when more developmental opportunities (like going to college) might be available. Parents and foster parents were genuinely worried about the prospect of young disabled people drifting into adult services, with few prospects for the future.

> ***'If Chris does get a place at college it would all be due to his parents working so hard to get him a place. He would otherwise be sent to a day centre or a resource centre.' (teacher)***

With some exceptions, social workers (particularly in children's services) were more likely to look for long-term residential or day care options than parents or foster parents

It is sometimes hard to judge whether strong parental advocacy is always in the child's best interests. Darren's mum felt that she knew him better than anyone, and has been determined to have a say in what happens to him. However, she has often felt that her involvement was unwelcome, and that she has not been listened to.

Sometimes it was parental pressure that resulted in a young person living away from home in the first place. For example, when the Education Authority sought to place Josh in a mainstream school, his parents were not convinced that this would meet all of his needs. They eventually went to court to secure funding for a place at a residential school outside the authority.

Dawn says that, although she now shares a room with two older people in a nursing home, she has more independence and prefers this arrangement to living with her parents, because her mum bossed her around at home. Similarly, Sean thinks that he could be more independent (e.g. going to school on his own) but says that his mum will not let him.

Conclusion

Young disabled people who do not have parents to argue on their behalf, or whose parents are not as familiar with the system, are often disadvantaged in accessing information and making choices as they approach adulthood. This is especially the case for young people with more complex communication impairments and learning difficulties. There is a case for reviewing advocacy arrangements for these young people in particular.

Further Reading

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Russell, P. (1995), The Importance of Contact for Children with Disabilities, in Argent H (ed), *See You Soon - Contact with children who are looked after by local authorities*, BAAF

J. Fratter (1996) *Adoption with Contact: Implications for policy and practice*, BAAF.

Argent, H. & Kerrane, A. (1997) *Taking Extra Care: respite, shared and permanent care for children with disabilities*, BAAF

> ***'I realised I was stopping her from things I thought she was capable of doing'. (foster mum)***

Friends

Friends and relationships were important to the young people we met (although some of them had very few friends indeed). For those who made use of specialist children’s services, it was often the service context that determined who they knew and who they were able to maintain contact with. Although service decisions had a significant effect on friendships, this was rarely taken into account as a priority in transitional planning.

Making Friends

Meeting new people was important to the young people involved in our project. Yet, as other researchers have shown, many disabled children have few opportunities to make new friends and social contacts. This is particularly the case for those with complex health needs or communication impairments. Young people who have moved from one placement to another may also find it hard to make lasting friendships.

The way that specialist children’s services are organised can make it difficult for some young people to make close friendships. For example, Kieran had been accommodated full-time in a child respite centre, where other children came and went for occasional overnight stays or afternoon visits. It was hard for him to make lasting relationships and he says that he has only one friend there. Helen said that she preferred children’s homes to foster care because there were other children her own age there.

Dan and Sian have many friends, yet all of them are either from the special school or from the respite services they use. Another example is Tariq, for whom children’s services and school have provided the basis for all his childhood friendships. His social contacts outside school are almost exclusively through his immediate family. When he finishes school, it is unclear what other friendships will remain.

> ***‘Staff are not given time and the opportunity to help people develop a network of friends outside services’***
>
> ***Morris (1998, Project Findings)***

The opportunity to make friendships with people of a similar age is an important part of growing up. However, the organisation of services for young disabled people can sometimes make this difficult. For example, although Aquila is 16 and rapidly approaching adulthood, she attends a special school for children up to 13 years of age. There is no one else of her age in the school and this raises questions about age appropriateness as she grows up. Aquila spends most of her

> ***‘I still want friends...not fair on me. I'm a big girl, and have friends’. (Susan)***

time with two adult support assistants and says that she has no friends in school.

Disabled young people often spend more time with adults than their non-disabled peers. In the absence of younger friends, many develop close personal relationships with particular adults, often those involved in service provision. This raises some concerns, about both child protection and transitional planning. For example, Darren's mum said that he has no friends of his own age. He did develop a special relationship with one of his teachers but this contact ceased after allegations of physical abuse.

Kamala sometimes sees her friends outside school, but only when she is with a member of staff. She has swapped phone numbers with one young man, who rings her. Sometimes they are able to meet in town, but only with a staff member present.

Making friends after leaving school or children's services can be challenging. As Beth pointed out, it can be hard to make friends if you are not confident about meeting new people. Michelle has friends in her neighbourhood and goes out sometimes, with her mother, to the pub. However, she is very anxious and does not feel very confident about going out alone.

Disabling barriers and physical access can also prevent young people from seeing much of their friends. Some places are not accessible to people who use wheelchairs and transport can be a major obstacle. For example, Sean says that he only sees his friends at the resource centre because his mum does not have time to take him and he has no other way to travel.

Losing friends

When services change for looked after children, friendships can be affected too. This can be an important issue in transition to adulthood, but is not always taken into account in transitional planning.

Josh lives at a residential school outside the authority and all of his friends are from the school. He no longer has contact with any young people in his home area. Leaving school will also mean leaving his friends.

'Any dislocation from school or peer-groups may have the effect of removing an adolescent from important psychological outlets and supports.'

Shaw and Hipgrave (1983, p. 67)

Martin has met all of his friends either through special school or the resource centre he now attends. However, he feels isolated because his closest friends, including his current girlfriend,

'Nobody wants me...I was moved...[I want] to talk to people my age... I'd love to go [back] again.' (Tariq)

use adult respite services on different nights to him, giving them no chance to be together.

Ann, who lives in a residential unit outside the authority, says that she feels lonely and would like to spend more time with her old friends. She is losing contact with them now that she has left school and cannot phone them when she wants to because she has no access to a telephone that she can use independently. She would like to have her own flat, with some support, so that her friends could come to visit.

Dawn, who lives in a nursing home, says that she only has one friend now, an older woman who stays in the same home. She looks forward to the times when her friend comes to stay. Dawn no longer sees her two close friends from the child respite centre she used to go to. She has little opportunity to mix with anyone her own age.

Richard lives in a residential unit outside the authority, attached to the residential school he used to go to. Staying on in the same place has enabled him to keep contact with some of his school friends. However, funding for his placement will end soon and Richard will move back to his home town, where he will share a supported flat with one other person.

Alice is 16 and has been offered a place at a residential college outside the authority. She is already thinking about leaving her friends behind.

Leaving children's services can sometimes have a positive effect on friendships. Having lived in an isolated flat, with adult care staff, Kamala had little opportunity to make friends outside school during her teenage years. However, she is very excited about the new friends she has made at the adult residential unit where she now lives. She has asked one of the staff at the child respite centre if she can bring her school friends to visit her.

Keeping Friends

Some young people were able to maintain continuity of contact with their friends through leisure activities, or because they remained with the same long-term foster family. In this situation, friendships were less dependent on changing service schedules than for those who relied on respite care or day services for their social contacts. Fostered children had more varied social lives and more opportunities to make friends beyond the services they used.

For example, although Susan had met most of her friends in service contexts, she was able to keep contact with many of them as she grew up through the sports clubs she goes to. Similarly, Alice has friends her own age both in and out of school. Alice's best friend

'[I need to] get in touch with my friends or my boyfriend or something like that. See if they'd like to meet me in holidays and see if they would like to come up to visit me…So I'm trying to get in touch with them'. (Alice)

lives within walking distance of her foster parents, and they visit each other's houses. One day, Alice would like to get a flat with her best friend, although she has not spoken to her about this yet.

Friends as advocates

For some young disabled people, close childhood friends can be important advocates, yet this is rarely considered in planning transitions from school or children's services. For young people with communication impairments, changing services or leaving school can mean losing contact with friends who have also been their primary interpreters and advocates.

We met Stephen and Charles together, at school, knowing that they were special friends. Peer support meant a lot to Stephen, who could communicate much more easily with adults when Charles interpreted his signs and speech. However, when Stephen leaves school to take up a place at college, Charles, who is younger, will not go with him. This means that Stephen will lose one of his important means of communicating, yet this is not recognised in his transitional planning because Charles is neither a member of staff or part of Stephen's care package.

Conclusion

Friends are an important source of support for all young people growing up. Many disabled young people meet most of their friends while they are using services. Some young people rely on their friends for important advocacy and support. Transitional planning should take this into account. Transitional services should be help to develop and maintain peer support networks.

> ***'Some young people want to talk to someone who is going through the same experiences as them. Local and national organisations of disabled people have long recognised the value of peer support but this is rarely something which is funded and organised.'***
>
> ***Jenny Morris (1999)***

Further reading

Jenny Morris (1999) *Move On Up: supporting young disabled people in their transition to adulthood*, Barnardo's

Hirst, M. & Baldwin, S. (1994), *Unequal Opportunities: Growing up Disabled*, HMSO

> ***'I would like to go to explore, can't stay at home all my life can I…I need to come out and see what my friends are doing…I need to see people more'. (Martin)***

Accommodation

Under the Children Act, local authorities have a duty to provide accommodation for children 'in need' who reach the age of 16 and whose welfare remains a concern. Local Housing Departments are responsible for meeting the full range of housing needs in their area. To do this they must work with the private and voluntary sectors, as well as the social services, to provide a range of options (such as specialist housing, ordinary housing, home adaptations and advice).

> ***'Appropriate housing is the starting point for independence. Most disabled young people, with the right preparation and support, could live independently and leave their parental house/residential school, etc.'***
>
> ***(Social Services Inspectorate, 1997, p.29)***

Disabled young people who leave children's services may live in a variety of accommodation. We met those who had stayed where they were (e.g. with foster parents); those who had found their own rented accommodation; those who had been placed in adult residential services; and those whose future housing options were very uncertain. As young adults, many were not able to choose where to live or who to live with.

Although we did not meet anyone who would be considered as homeless, some people had found themselves in this position in the past. More than one in three homeless young people has some need for additional support, either because they experience mental distress, because they are ill or because they have other impairments (see Biehal 1992).

A place of your own

Not everyone we met wanted their own home, but for those who did it was an important part of being an adult. For many, finding a place to live and coping on their own, was a real challenge. Most had not had the opportunity to do this; some had tried unsuccessfully; and a few were managing well.

Helen moved between children's homes, foster parents and hostels until she was 19. Her uncle then helped her to find a flat in another city (she received no financial help to set up home there). Helen was happy to leave the care of social services and felt that she had the necessary skills to look after herself. She is now hoping to move into a flat with her boyfriend.

Harry's relatives and his aftercare worker helped him to find a flat when he was just 17. He was able to use a

> ***'They've tried breaking in while I've been in the flat, it's absolutely been murder up there…I tried putting in for a move but they wouldn't move me from there because I hadn't been there for twelve month'. (Harry)***

a £500 leaving care grant to buy carpets and furniture. However, no-one came to visit him and he soon became lonely. Harry found it difficult to manage his own money, leaving nothing for the gas and electricity. The flat was broken into repeatedly and, after a year or so, he moved into hostels and then to stay with his Auntie.

When care leavers are seen as disabled people, their needs as young people can sometimes be overlooked. For example, there can be conflicts between finding an accessible place to live as a disabled person and finding a desirable place to live as a young adult.

Beth is looking forward to moving into her own home, and has a leaving care grant to help furnish it. As someone with a physical impairment, she cannot easily climb stairs and has been given the most accessible flat on the ground floor. However, she is also a single young woman with learning difficulties, and nervous about how vulnerable this makes her to crime. Beth says that living on your own makes you an adult but she would prefer to have someone else living with her.

Time to plan

For some people, transition can mean an abrupt move from children's services to adult accommodation. For example, Tariq was transferred suddenly to an adult unit at the age of 18 (before his transition plan had been completed and without adequate preparation) due to a shortage of beds in the child respite centre where he had been staying five nights per week.

Tariq stayed in his new home for just three nights before his father withdrew him, feeling that his complex needs were not being met, and being unprepared to hand over Tariq's benefit book to the centre staff. Tariq has now ceased all use of services.

Having the option to avoid a sudden move can be an important protection against uncertainty. For example, Beth (who was fostered with her grandmother) had the choice to stay on after her 18th birthday. This meant that she could take her time in finding a suitable place to live.

'I am glad she is going to use her common sense and wait till she's dead ready…if she moves under a cloud, or forced to move, you don't settle as fast but if you take it seriously when you move you settle down a lot quicker you know'. (grandmother)

Beth has made a housing application but is not planning to move until she knows that everything is arranged properly.

'I'm back on me own again. I don't like it on me own, it's boring...I'd like someone to stay here with me'. (Michelle)

Michelle had her own flat, and a leaving care grant, at 16 but felt that she was not ready to live on her own. For the next two years she kept the flat empty and lived with relatives. She said that no one from the authority offered her support during this time, but was confident that she would have asked if she had needed any help.

Having the option to stay in one place can be comforting but it is equally important to review how long such stability may last. For example, Martin was aware that he might be moved to a residential home if his parents died.

When a transition worker asked Susan if she would like to leave her foster mum at 18, she said no and the placement was continued indefinitely. She does not know where else she could live and says that no one has discussed housing options at her review meetings. Susan does not want to live on her own at the moment, but would like her friends to visit her more.

As time goes on, long-term foster parents may be less able to cope, or feel that it would be in a young person's interests to find a place of their own. When Denise was 23 her foster mum felt that she was missing out on adult life. Denise was reluctant to move into the group home that was offered but agreed to try it once she knew that she could come back if she did not like it there. This sense of stability made it easier for her to try out a new housing option.

All or nothing?

Our research suggests that many disabled care leavers, most with learning difficulties, fall through the gap between mainstream services and disability services. Some young people who need support are expected to live without it and are offered few options between this and a place in a residential institution. Some childcare social workers lack knowledge about independent living options for disabled people and see specialist residential placements as the more appropriate option.

> ***'A lot of "transition to independent living" provision...proves not to be transition at all because there is nowhere for the young person to move on to'.***
>
> ***(Jenny Morris, 1999, p. 30)***

At 18, when Gordon's foster placement ended, he was offered a council flat but would not accept it because he felt unable to live independently without support. He was then placed in a residential college outside the authority, despite his wishes to stay in the town where he

> ***'He'd have slipped through that net and ended up in a flat with no provisions. He could end up homeless on the street selling the Big Issue if he was stuck in something that wasn't appropriate.' (foster mum)***

had grown up. The choice of a college placement was based not on educational grounds but on the lack of a local housing option. Gordon feels that he would be able to cope in sheltered accommodation with someone to give him advice when he needs it.

Alice, who is 16, thinks that she could live in her own flat one day, with a friend. However, her foster parents and social worker take a different view, believing that Alice's learning difficulties and experience of child sexual abuse would make her very vulnerable without supervision. Like Gordon, she will be moving out of her home area soon to live at a residential college. She is nervous but looking forward to the change. It is unclear what choices she will have when she finishes there.

As a young teenager, Kamala lived alone with support from agency care staff because a suitable foster placement could not be found. Although Kamala was able to develop some independent living skills, she was largely isolated from other young people as she grew up. At 18, Kamala was moved to an adult residential unit for a trial period to see how she might interact with others. She now lives there full time, and particularly enjoys the company of other young adults. It is unclear where she will go next.

Kieran has been accommodated full time, both as a child and as a young adult. At the moment he is living in an adult respite centre, while he waits for somewhere more suitable to live. He does not know how long he will be there. Unusually, 15-year-old Nathan, lives full-time in a child respite unit. He will leave by the time he is 19 and his teacher is concerned that he will not have the independence skills to cope in a community setting.

Dawn is 18, and lives full time in a residential nursing home for older people. She is the only young person who lives there full time (the nearest in age is 27). Sometimes other young people come for short respite visits. Dawn's age was not regarded as a significant issue by the residential staff. When the nursing home closes, Dawn will move into a development of supported flats. She is looking forward to this.

Home is where the heart is

When Richard left residential school outside the authority, at 19, he moved into the young adult unit next door. Although this was seen as a temporary solution, Richard feels very settled. Funding for his placement will soon end and Richard will be moved to a small group home in his home town. He is worried that he will have no friends there, having lived away from home for so long.

Similarly, John, who is 17, has been

'You can't send him out into a room in the community because he won't have enough skill...There should be something other than a group home that has four people in it in the middle of a council estate.' (teacher)

living in a psychiatric hospital outside the authority for the past two and half years. In a recent review, it was decided that his adult needs could be met by his own authority and that he should return there. John would like to stay where he is, and hopes to return there as soon as he can to find a place of his own.

Conclusion

The range of accommodation options presented to young disabled care leavers is often determined by vacancies in existing adult services, rather than by the needs or wishes of young people themselves.

Some care leavers, particularly those labelled as having ‘mild’ or ‘moderate’ learning difficulties, are being denied housing choices because of a lack of appropriate support for independent living.

Young people with ‘multiple’ impairments, especially those with communication impairments, are more likely to move into residential care when they leave children’s services.

Further reading

Mental Health Foundation (booklet) *Leaving Home, Moving On: Housing options for people with learning disabilities (in the United Kingdom),*

T. Ryan (1998) *The Cost of Opportunity: Purchasing strategies in the housing and support arrangements of people with learning difficulties*, Values into Action.

Oldman, C. & Beresford, B. (1999) *Meeting the Housing Needs of Disabled Children: an agenda for change*, Centre for Housing Policy, University of York

‘I had to move on, everybody there pushed me out, so can’t stop that can I?’. (Martin)

Information

The Children Act requires local authorities to publish information about their services, and to ensure that this reaches those who might benefit.

Most of the young people we met wanted more information to help them make choices about their adult lives. Some were very independent in finding the information they needed; others found information confusing and difficult.

> ***'Information is a means to making choices, and if it is not received in a way which is accessible to the individual, then this impedes choice.'***
>
> ***(Jenny Morris, 1999, p.30).***

Many relied heavily on a single adult for this information (such as a foster parent, teacher or key worker). Others obtained information from their friends. Leaving school or children's services often meant losing contact with these key people, and raised concerns about access to information during transition.

What, when and how?

The kinds of things that young people wanted information about were not always the same things that adults thought were important (such as information about their birth families). There was little evidence of direct consultation with young people about the sort of information they might want, or the kind of difficulties they might have in getting it.

Sometimes young people wanted information before service providers or carers thought they needed it. For example, Sam, who is 16 and lives in a residential school, was concerned because he had no idea when he would leave the school and where he might go from there. His teacher said that it was 'too early' to talk about this and that it would be discussed in the next 18 months or so. Sam would also like more information about sex and personal relationships.

Alice would like to know more about her leisure interests (the TV soaps she watches and her favourite boy band) but she finds it hard to read and has not been able to fill the forms to join the fan clubs she would like to. Alice knows that she will soon need information about important things, like moving to a place of her own or finding a job. Alice thinks that she may have to ask someone who knows more about it.

Michelle said that she never really worried about growing up, living on her own or getting a job but wished that she had received more information about some of these things when she

> ***'When they are young and go to school…you always get…lots of information…once they get to adulthood it is like getting to the end of a cliff and there is nothing. You are just cut off and that's it'. (mother)***

was younger. When we met Beth, one week before her 18th birthday, she felt that important things were about to change in her life but she did not know what was going to happen to her.

Many young disabled people and their families experienced difficulty in accessing information when they most needed it - in the transition to adulthood (e.g. information about financial benefits, housing options, educational opportunities, job training, and so on).

> ***‘For participation to have any meaning it should include, among other things, giving and sharing information with young people and access to information.’***
>
> ***(Mike Stein, 1991, p.20)***

Darren’s parents felt that they received more information when he was a child and much less now that he was approaching adulthood. Gary’s family told a similar story, noting that much of the information they relied on (particularly about health care) had ceased when he reached 16.

Lack of information about the move from children’s services to adult services can make transition a difficult and uncertain time. There were occasions where lack of knowledge or understanding about a move left people, like Tariq, so disoriented or unhappy that they withdrew from services altogether.

Getting information

The young people we met obtained information from many different sources. Often, they relied on particular people to provide them with information or to help them find what they needed. Some of the young people we met felt that social workers were their only key source of information, and were concerned that they might lose this when they reached 18. Others relied heavily on a particular school teacher or learning support assistant to help them access information. Again, the prospect of leaving school raised questions about future access.

Friends were a particularly important source of information for those, like Harry, who had contact with other people their own age (although this was rarely taken into account in transitional planning). Bernard explained that he heard about the adult respite centre he might be going to, only because his friend from school goes there.

A few, like Susan, had benefited from meeting people with similar experiences at self-help groups. Others had very few opportunities to draw on peer support in these ways. As we discovered, in our own project steering group, creating opportunities

> ***‘Where do I go from here?...I haven’t got a clue what it’s about or anything really, no information on it at all…I’d like to know what rights I’ve got now I’m nearly eighteen…That isn’t clear at the moment.’ (Beth)***

for peer contact and information exchange can greatly increase young people's confidence and choices.

Young people, their carers and social workers talked about problems in getting the information they needed. It was not always easy to know where to go for information, and it was hard to find all the relevant information in one place.

Sometimes people had to visit several places to find what they wanted. This could be confusing, and suggested the need for a single and reliable source of information whenever possible. Important information was sometimes discovered only by chance.

Beth, who left school at 14, felt that she would never have known about local computer training courses if she had not picked up a leaflet in the supermarket, years later. Gary's mum did not know about concessionary bus passes until she discovered accidentally that Gary already had one at school.

Similarly, she learned about RADAR keys for accessible public toilets through a chance conversation with someone from a local disability organisation. She is now able to take Gary out more often when he comes home from school.

Some people did not have easy access to the information they needed in order to make choices about their changing lives. For some, like Ann, this was because everyday information was difficult to access. She would like a mobile phone with larger numbers, books with bigger pictures, and a TV remote control with bigger buttons. Ordinary printed material was not easily accessible to many of those we met.

> ***'…"they wouldn't understand", often really means "I can't think how to explain it to them".'***
>
> ***(Argent and Kerrane, 1995, p. 73)***

We met young people who communicated in a wide variety of ways, emphasising the need to use appropriate techniques in communicating information. Many used adaptive equipment, or other people, to access information and to communicate their choices and views.

This raised issues about the kind of information they were able to access, particularly where adults were in a position to censor and interpret for them.

Information for staff

It was not only young disabled people and their parents, but also staff, who lacked information. For example, key

> ***'It's hard work when you don't even know what you want to ask… We're having to look for all the information all the time. These people who are paid professionals, they should answer the questions before we even ask them'. (step dad)***

staff in children's services often knew very little about the options available to disabled young people moving into adulthood.

This problem was sometimes compounded by a lack of communication between service providers. Social workers without a background in disability issues, like John's, often felt that they did not know where to go for more information.

This situation raised particular problems where such staff were also the main source of information for a young person or their family. For example, Furzana's father relied on her social worker to provide him with information, on which he made decisions about her future. When we spoke to him, he had only been given information about adult day centre places, which he thought sounded 'all the same'.

Gordon's foster mother feels that she is dependent on a particular social worker for information. She is concerned that they will lose a valuable resource if a new social worker is allocated in her place. Interestingly, the social worker in question complained to us about her own lack of information, feeling that she was unqualified to work with young people, like Gordon, who had learning difficulties.

Conclusions

Our research suggested that young disabled people often lacked the information they needed to make informed and appropriate decisions about their futures.

Many disabled young people were dependent upon particular adults for most of their information. The quality and reliability of their relationship with this person was therefore an important factor in the quality and availability of the information they received.

Those, like Sean or Susan, whose parents or long-term foster parents were also their main advocates tended to have more information about their choices during the transition from children's services to adult life.

Further Reading

Morris, J. (1999), Hurtling Into a Void, Joseph Rowntree Foundation

H. Argent & A. Kerrane (1995) *Taking Extra Care*, BAAF

Stein, M. (1991), *Leaving Care and the 1989 Children Act*, First Key

W. Beecher (1998) *Growing Up: A guide to some information services available to young disabled people and their families*, Council for Disabled Children.

'If it weren't for me picking up that leaflet by mistake I'd still be without education to tell you the truth, because I wouldn't have known about it.' (Beth)

Education, Training and Employment

Government figures show that around three quarters of all young people leaving care have no qualifications, and that half are unemployed. Education, training and employment are high priorities in the new arrangements to support care leavers.

> ***‘Education and training is one of the best ways to improve a young person's prospects for a successful future...local authorities should encourage and help care leavers continue in education or training’.***
>
> ***(DoH, 1999, Me Survive Out There)***

Leaving school

Some of the young people we met had left education, despite having an interest in further learning. This was sometimes a matter of choice and sometimes a matter of circumstance.

Beth left school at 14, following a serious physical assault by other pupils, which left her with a physical impairment and regular panic attacks. She did not feel that she could return, and completed her schooling with just one hour per week of home tutoring. Her social worker once suggested going to college but it was a long way from home (Beth cannot travel alone and was ‘petrified’ by the idea of going to a large college). Years later, Beth picked up a leaflet in a supermarket advertising training courses in her home area. She contacted them and began a computer course four days later. She is now studying for a GCSE in English.

Helen left school at the age of 16, when she was pregnant with her first child. She regrets this, and would like to have returned to school and then college. She says that no one discussed this with her and that she has been too scared to ask.

Michelle was excluded from her mainstream school when she was 15, after a violent incident with a teacher. She has never been back, although she would like to have done so.

Harry missed much of his schooling and left at 16. The education welfare officer and his social worker helped him back when he was 17 but he left again at 18. Harry has never done any vocational training. He regrets leaving when he did and would like to work on his reading and writing. A friend has asked him if he wants to train as a window fitter but Harry would have to go to college for this and does not know whether that is possible.

> ***‘I did want to go to school. I love school me. Wish I could go back now’. (Michelle)***

Peter is 19 and has been fostered outside the authority for 8 years. He finishes school this year but he and his foster parents still do not know where he will go next. Furzana is 20, and will finish her education when she leaves school this year. Her father has arranged a place for her at an adult day centre.

Staying on at school

Children labelled as having ‘severe learning difficulties’ are more likely to stay on at school, often until they are 19. For many of them this means that transition may be delayed. During this time, teachers are often the people most closely involved in transitional planning (particularly with those who attend special schools).

Aquila is 16 and attends a special school (where she is currently over the maximum pupil age). Next year, she will move to a special school and her teachers are concerned that she may lose out on her education. Aquila does not like the school she attends or the one she will go to next. She would like to go to college.

Peter’s foster mum described the choice, when Peter was 16, between moving to a residential school forty miles away, or staying on at his nearby special school while living at home. In consultation with Peter, she felt that he should stay where he was until the age of 19.

Going to ‘college’

Going to college was a popular option amongst the young people we met. Yet, their experiences raised some questions about the way in which their education was viewed by others. For example, our findings support the view that more and more colleges are taking on young disabled people, most with learning difficulties, who have nowhere else to go.

Residential institutions that offer full-time accommodation to adults with learning difficulties are increasingly being renamed as ‘colleges’, while some specialist units in FE colleges are functioning as day care centres in all but name.

Tariq hopes to go to college next year. He hopes that people will talk to him if he goes there. He has managed to get some information from his teachers, friends and family, but he has little idea of what to expect (although he has visited two colleges for the day).

John is 17 and goes to college two days a week from the psychiatric unit, where he lives outside the authority. His home authority has now decided that he should move back there when he is 18. John would like to do a computer course but is concerned that he has no idea what might be available locally.

Darren has moved between a number

‘I've been to a place like a college and they've turned round and said I've got disability, and they were on about putting me on a training course for it, and I ain't heard nothing about it yet’. (Harry)

of special and residential schools, amid repeated allegations of abuse. Darren refused to complete the final three months of his residential schooling outside the authority, but was unable to take up a place nearer home because the funding for this period had already been paid.

Susan was luckier than some, in choosing a college she liked even though it was not the closest to her home (she did not feel 'at home' in the two she rejected). Susan is taking a number of pre-vocational and independence skills classes (including work placements). She likes the college and says that it is better than the one in her home town. She is not sure how long she can stay at college.

Other young people were shown more than one college but subsequently denied any option to choose. For example, Sean is planning to leave special school this year. He has been to visit two colleges so far, but his teacher says that if the nearest one can meet his needs, the more distant college will not be an option.

Education or care?

Many young disabled people and their families are choosing to go to college because there are few alternatives. For example, Susan's foster mum wants her to stay on at college because, 'the only option for her is sitting in a centre and she is too bright for that'. Chris currently attends a special school and his parents are hoping that he will find a local college place for next year. However, the colleges Chris has seen so far have rejected him, and the alternative appears to be a day centre placement.

> ***'..Many young disabled people in further education experience a lack of confidence, inaccessible teaching methods and an inaccessible physical and communication environment.'***
>
> ***(Jenny Morris, 1999)***

When Gordon's fostering ceased, at 18, he felt unable to live independently without support. His social worker then arranged for him to live full-time at a college outside the authority. There was no shortage of training opportunities in Gordon's home town, and his 'educational' placement was based on the assessment that Gordon required a residential placement to meet his social care needs.

Adults often talked about colleges in terms of 'care' services. Nathan is only 15, and does not know when he will leave his current school. His teacher believed that he would get an adult residential placement or a place in a training centre, rather than a college place, because he is looked after and such placements require shorter holiday cover.

> ***'Going to school and going to day centre is exactly the same, the only difference is the name…she can pass time and it will be a relief to the parents for at least eight hours…'. (father)***

> ***‘...to have received any sort of special education - even a special course in an integrated setting - may be regarded unfavourably by potential employers.’***
>
> ***(Tomlinson and Colquhoun', 1995 Pg.194)***

Employment training schemes

Many young disabled people will fall short of government aspirations for care leavers because they are expected, like Michelle, to achieve in an unsupported mainstream setting, or, because they are removed from the mainstream of education and employment.

Several people we met were enrolled on pre-vocational training courses yet made no connection between this and the prospect of future employment.

Martin enjoyed work experience (at a burger restaurant and a garage) offered as part of his college course. However, he did not understand why he had been given these jobs, or why he was being moved on from one place to another.

Denise, who is 23, attends three regular training courses (a literacy class, a vocational training course, and an unrelated work experience placement). However, the staff who support her at home view these opportunities as ‘care’ placements, rather than training.

Like many other young disabled people, Denise is subject to very low expectations about her abilities and aptitude for future employment. This may also explain why she has become so bored and frustrated with college courses in the past.

Michelle’s benefits were recently stopped because she refused to take up a training placement. Michelle had already attended the same vocational course (in retailing) four times, without success. She can see no point in repeating it and feels that it offers no prospect of a job. Michelle has also been to college, to do a pre-vocational course in catering.

Education has been a disappointing experience for Michelle. She is constantly regarded as a failure and this has been reinforced through a series of inappropriate, and disabling, training courses designed primarily for non-disabled people.

Finding work

Denise has had various job placements but has not been interested in pursuing any of these as a future job. She would like to earn money but does not know what kind of job she could do. She has not talked to

> ***‘I don't like doing training courses...I'm sick of doing them, that's all I ever do...They give you same training course. I've already done that and I'm not doing it again...I won't do it again. I told them I won't. They can stop my money, I don't care’. (Michelle)***

anyone about this. Alice, who is 16, has not done any work placements and does not know when she will leave school. She would like to train in beauty and hairdressing.

Harry is also looking for a job. His friends have been his main source of information about this. He once helped his step-dad and has been offered some more work there but does not want to go back. His friend has told him about some local factory work but Harry is worried about meeting a relative who works there.

> ***‘Most office jobs is in town and that is just like a five minute bus ride away, five, ten minute bus ride away, and I wouldn’t be able to do it’. (Beth)***

Martin finds using public transport a challenge and this presents a major barrier to finding a job. Taxis are expensive and he is worried that his dad will ‘get mad’ if he gets lost again while travelling on his own.

Using public transport is also difficult for Beth. She does not think that she could work and take care of her baby at the same time, but she would like to find a job in the future near to where she lives.

Michelle is actively looking for a job and wishes that she had received more support with this when she left children’s services. She has had some agency work, and does not feel that her disability status goes against her. Beth also feels that she could work but, unlike Michelle, she thinks that being disabled puts her at a disadvantage.

Susan has been enjoying her current work placement (with young children at her old school). However, as her course finishes this year, she will not have the opportunity to continue. Susan would like to have a job helping 'wheelchair people' and 'little ones'. She is not sure whether she could be paid for this.

Conclusion

Most of the young people we met expressed an interest in further learning. Those who had missed educational opportunities often regretted this later. Some felt that they were prevented from accessing appropriate education and training due to disabling barriers.

Our research suggests that young disabled people with committed parental advocates, like Sam, Josh or Susan, are more likely to obtain their preferred choice of school or college, and less likely to be placed in non-educational day care alternatives.

> ***‘Some employers won’t employ you if you’ve got certain disabilities. You know what I mean, some employers just, you’re an honest hard working person but if you’ve got a disability and you can’t meet their standards its hard to get work these days’. (Beth)***

Key issues

As other researchers have shown, educational placements for young disabled people often focus on provision of care, rather than the development of knowledge, skills and confidence towards independent living. We found evidence of this in our research.

> ***'...many young disabled people, not just those in foster care, do not have adequate access to services which were set up for their benefit. They are not always encouraged to work towards becoming autonomous and are, therefore, not reaching their real potential.'***
>
> ***National Foster Care Association (2000, p.11)***

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> ***‘They [employers] talk as though they [people with learning difficulties] could do those jobs, but they don't take them on’. (foster mum)***

Sexuality and Parenthood

Most of the young people we met were very keen to talk about romantic and sexual relationships. Some had had very negative sexual experiences of abuse; most said they currently had, or were seeking, a boyfriend or girlfriend. A few were in stable sexual relationships, and two had children of their own from previous relationships.

Feelings

Adults do not always believe that disabled young people will have the same sexual feelings as others of their age. This can result in a lack of information and in inappropriate advice, creating confusion for young people, their parents and carers. When young people cannot easily communicate with their parents they may need support from other key people around them.

When Gary was younger, his mum was told that he would never have any sexual feelings as an adult. Her other son, who also has learning difficulties, had lived away from home while he was growing up and so she had no experience to doubt this. As Gary grew up, and started to express his feelings in sexualised behaviour, she doubted her own judgment.

Josh enjoys talking about sexual feelings and relationships. He lives in a residential school, where he has daily contact with a number of female care staff and therapists, some of whom he has strong feelings for. He enjoys their company and looks forward to being an adult like them. However, he does not have speech and sometimes finds it hard to communicate about these things using head movements and a limited range of symbols. He would like to talk about his feelings in a more adult way.

Alice was taken into care after she had been sexually abused. She finds it very easy to fall in love and often interprets attention from men as sign of reciprocation. She finds relationships with men difficult to sustain and says that ‘boys always dump me’.

Her social worker and foster parents have been concerned that her experiences, and her learning difficulties, make her sexually vulnerable. They have encouraged her to take contraceptive pills since she started menstruating. Alice can imagine settling down with someone in the future but she worries that it might not work out, and that they might start ‘shouting and fighting’.

Richard is 20 and will soon move from an adult hostel to a supported flat in his home town. He used signs to tell us that he was not happy about this.

‘I once got told he’d never have any sexual feelings towards people, my god I wish I could see the person what told me that…when he started having sexual feelings I thought there were something wrong with me…I got told it wan’t natural in a Down’s Syndrome child.’ (mum)

The hostel worker said that Richard did not want to live with just one other young man, and that he would particularly miss female company.

Having relationships

The way that services are organised, and the high levels of adult surveillance in young people’s lives, mean that it can be very difficult to sustain close personal relationships. This was true not only for those in full-time accommodation but also for those who used respite care. It was not uncommon for sexual intimacy to be actively discouraged or completely forbidden for young disabled people living away from home.

John is 17, and lives in a residential psychiatric unit. Although boys and girls can mix in the hospital during the day, they are not allowed to be together in their free time. John can no longer see his girlfriend, who left the hospital a year ago. They still talk to each other by telephone.

Martin, attends a day centre and spends two nights a week at an adult respite centre. He is not able to see his girlfriend, who he met at the resource centre, because they use the respite services on different nights.

Denise is 24 and does not want to get married - 'not ever' – although she does have a boyfriend, who she met at college. She also sees him at some of the clubs and training classes she attends. However, they have not been able to visit each other at home (Denise says that she would have to ask the staff first, and that she would be in trouble if she did not).

Becoming a parent

Previous research has shown that care leavers tend to experience parenthood at a much earlier age than other young people.

Two of the young women we met, Beth and Helen, had children of their own. Beth felt that having a baby was both a good and a bad thing. She enjoys the company of her child but would not recommend it to other young people because it has prevented her from doing some of the things she wanted to do while growing up.

Helen has three children and is now pregnant with her fourth. Her first was born in a friend's flat, because she thought that if she went to hospital the baby would be taken into care (all three of Helen’s children were eventually taken into care). She says that she was too young to cope with her first baby but feels that she could have cared for the others, with some help.

Helen felt that her sex education at school was ‘a load of bull’ and that she would have preferred to talk to someone she could trust.

‘We just keep in touch by the phone or write letter...I got told when I first went there that you were not allowed relationships in the ward’. (John)

Michelle found out that she was pregnant at 16, while she was living with her auntie. She decided to have a termination because she felt she was 'too young'. Michelle would like to get married when she is older, although she says that her boyfriend would like to have children now.

Conclusion

Our research suggests that many young disabled people do not have appropriate opportunities to express their sexual needs or preferences. Sexual needs are often ignored in service provision, or thought of in a very negative way. Some professionals still work on the assumption that disabled people either do not have sexual feelings or cannot handle relationships.

Further reading

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‘Every time I have kids they get taken off me…They said that I didn’t have a stable home or some’t, didn’t have everything I needed for a baby, and I did. I had everything. I did have everything.’ (Helen)

Health

Many of young people we met had frequent contact with medical practitioners. Some had significant and complex health needs. However, this was not generally an issue that they chose to talk about. Medical health concerns were more likely to be raised by parents, carers and professionals.

Although Aquila had lived in hospital for almost a year, her parents remained relatively uninformed about her health condition. This led to some misunderstandings with staff. For example, they would like her to feed by mouth and to go swimming, but therapists regard these as too ‘risky’.

Gary’s parents were very unhappy with the advice they had received from health professionals. A doctor told them that he would never walk or talk. Yet, with input from them, he is now walking and can say some words. Another important issue for them was the abrupt break in health services and information that occurred when Gary reached the age of 16.

For those without parental contact, leaving care can mean dramatic changes in lifestyle, which may affect health. Some young people find it hard to cope with independence at first.

When Denise left her foster mum to live in a supported flat, she found it very difficult to control what she ate. She quickly gained weight, leading to additional health problems. The staff are now trying to help her with this.

Michelle was admitted to hospital, after not eating properly, when she first moved into her own flat. She has managed better since then. However, her benefits were cut recently and Michelle is worried that she will not have enough money to eat. She is ill at the moment, and cold (as she has no money for the gas meter).

Since leaving care, Beth has been unable to take up various educational, social and work opportunities because she suffers from persistent panic attacks. She turned down a place at college and is not able to go out much with her friends. Her social worker suggested that he might leave her in a busy shopping area to ‘try and cure it’. Beth did not think this would work. She has been to see her GP but was offered no treatment or referral.

Conclusion

Young people leaving care will need access to information and advice about health issues, in a form that it is relevant and accessible to them. Disabled young people and their carers may sometimes be at a disadvantage in accessing such information, or may feel that they have been misinformed.

> ***‘Up to the age of sixteen he was seen by a consultant , which he’s never seen since he turned sixteen…as if they don’t exist, or their diseases have stopped…As far as they’re concerned the child doesn’t exist beyond sixteen.’ (step dad)***

Independence Skills

Some of the young people we met felt that they had all the skills they needed to live independently as adults. Often, they had learned these skills from relatives or foster parents.

Although many attended training courses that emphasised the development of skills for independent living, young disabled people in care did not always have the opportunity to put such skills into practice.

When we discussed skills for adult life with our steering group, they talked about their practical experiences of looking after money, using a washing machine, cooking and travelling by bus.

Confidence

Few of the young people we met wanted to live on their own but they did want to develop more independence in their lives. Most were aware of the kind of support they needed and could identify particular things that they felt more or less confident about.

Gordon does not think that he could live on his own because he finds dealing with money difficult and believes that people may take advantage of him. Alice thinks that she could live independently, with a friend, if she had some support.

Harry sees literacy, budgeting and counting money as important skills for adult life. Harry finds making decisions difficult, especially when they involve money. His step dad and auntie have been helping him with this recently.

John would like to live more independently but thinks that he would need some help with budgeting, cooking, buying food and finding a place to live. He does not know where to go for information or help with this. Sean thinks that he could do more things independently, like going to school on his own. However, his mum will not allow him to practice these skills.

Learning skills

Denise enjoys being more independent. When she moved from children’s homes to foster parents she had the opportunity to learn more about cooking and doing her own washing. Now that she has moved to a small community group home, she has more independence than ever before. She is more involved in every day activities and decision making. She can choose her own clothes and has more control over her money.

Susan learned to cook from her grandmother and from her tutors at college. She enjoys the 'independence skills' sessions more than her other courses. Ann is encouraged to learn daily living skills in the hostel for young adults where she lives. However, she does

‘Everyone knows how to cook, you shove some chips in the chip fryer and you're away’. (Beth)

not like cleaning her room and does not use the cooker because she is scared of burning herself.

Richard will soon be moving to supported accommodation in his home town, but the hostel staff where he lives now are concerned that there seems to be no programme of skills learning in his new placement.

Conclusion

When services focus on impairment and ‘care’, there may be low expectations about the potential for young people to live more independently. If skills development is not directly related to real life situations, it may have little impact on independence.

It is important to emphasise that independence should never be equated with doing things ’on your own’. Such measures will always devalue the independence of young people who use help to perform daily tasks. Making choices and exercising control over how things are done is a more significant measure of independence.

The acquisition of independence skills should not be viewed as an isolated technical or instructional issue, and will always be closely linked to issues of housing, transport, education and money.

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‘If I had the experience of living on me own it would probably make it easier for us’. (John)

Money

Although a few of the people we met managed their money relatively successfully, most found dealing with money quite difficult. Some felt that they could take more control than they were currently allowed to do by carers or staff.

‘When I can't count I lose my temper, not knowing money. So I get really bad tempered and put it out on the teacher.’ (Alice)

Kamala receives weekly spending money from the staff at the respite centre where she lives and has always had some choice in how to spend or save it. However, school staff would not let her look after the cash payment she received for participating in our steering group sessions.

Chris brings money for school trips, and is encouraged to think about how to spend it. However, he receives no spending money at home because his parents do not think he is capable of dealing with it.

Susan receives about £10 a week spending money from her foster parents, of which she saves £5 (spending the rest on her club membership and coffee at college). Susan knows that she is saving but she is not sure what for. She thinks that her foster mum will decide. Although Susan has no real difficulty in counting money and deciding how to use it, her foster mum controls what she spends.

When Harry moved into his own flat, he found budgeting particularly difficult. Having paid his first gas bill, he had little money left for the electricity and for food. His mum has helped him out with money towards these things.

For some, like Michelle, the real problem was simply not having enough money to live on (Michelle’s benefits were cut because she refused to repeat a training course that she felt was irrelevant).

‘I phoned [my after care worker] up this morning for some money and he wouldn't give me none so I swore at him and put the phone down…If their kids were starving they'd get some money off the social services. They wouldn't let their kids starve. That's what bugs…I'll sell me body if I have to.’ (Michelle)

Further Reading

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‘I have a problem with controlling money…I'd like get money and I'd just go out and spend it all…But I had a bit of a problem with controlling me money for me bills and all that.’ (Harry)

Transition Planning

As the experiences outlined in this report show, transitional planning for young disabled people leaving care can be a complex process. Disabled children have a variety of needs and there is a wide range of relevant legislation and policy to take into account.

The new arrangements for care leavers are likely to add to this complexity, rather than reduce it. For this reason, it will be important for local authorities to take stock of their current transitional arrangements and to actively consider the situation of disabled young people in planning for the new regime.

The purpose of good planning is to ensure that young people have a positive experience of their transition to adulthood. Growing up should mean real changes in people’s lives. Good planning should ensure that these changes happen as smoothly as possible.

The emphasis should be on identifying social and physical barriers to participation in adult life, together with plans for their removal, rather than focussing on the limitations of a child’s impairments.

Aspirations, targets and goals

Our research suggests that while most young people and their carers have many hopes and aspirations for the future, adults in provider agencies frequently hold low expectations for them. Without positive and effective advocacy to challenge such low expectations, young people’s choices and rights are often constrained.

On an individual level, this is a serious issue. Development work will be required to challenge disabling attitudes and assumptions amongst frontline staff and service providers (particularly in adult residential care, further education and employment training).

‘While it is important to encourage students to be realistic about their future options, supporting young people to daydream or fantasise about their future lives can motivate them to engage more fully in the transition planning process. Most of us daydream and fantasise about how we would like to live our lives. This is an important part of the process of setting ourselves objectives and the things we want to achieve. ‘

A Guide to Transition Planning for Secondary and Special School Pupils (DfEE)

‘They didn't tell me I was going to have a review. They just did it without me knowing. I'd get to know on the last day...If they'd put it, to what it was all about, I'd have gone with them, sat down and listened to them.’ (Harry)

It will be important to ensure that young disabled people's options are not unnecessarily limited in the new arrangements for care leavers. Training will be required for personal advisers and pathway plans will need to be monitored to ensure that appropriate yet challenging targets are set for all young people.

Particular attention should be directed at 'educational' and 'training' placements for young adults with learning difficulties, to ensure that any investment in their future is linked to relevant and worthwhile goals and outcomes. Going to 'college' should not be a disguise for otherwise traditional forms of residential and day care placement.

Collectively and strategically there are also important issues. Government has set clear achievement targets for care leavers. The aim of the new arrangements is 'to improve the life chances of young people in care and care leavers and to do all that is possible to ensure their social inclusion and active engagement in society'.

The proposals emphasise the importance of appropriate employment, training and accommodation in the pathway to adulthood. There are specific targets for achievement in the areas of education, employment, social inclusion and citizenship. Yet, disabled care leavers will face many additional barriers in this regard.

Our research raises concerns about the kind of support they receive in transition, and about the barriers to their equal citizenship as adults. We are particularly concerned that many young disabled people who stay away from home will be excluded from the figures altogether. It will therefore be particularly important to monitor how Government's goals are applied to young disabled people leaving care.

Avoiding abrupt transitions

The policy framework for transitional planning is intended to ensure that young disabled people do not leave school or children's services without adequate resources to support them in beginning their adult lives.

However, the complexity of the system, coupled with pressure on staffing and resources, means that this does not always happen. It is not uncommon for looked after disabled young people, including those with the most complex impairments and health needs, to reach the age of 18 without the completion of any formal planning for adult services.

We met young people who were within weeks (or days) of important changes in their lives but who were very unsure what would happen to them next. Without positive forward planning and continued support many face an uncertain future.

'We are not chucking him out…they'll sort something out. I mean [his previous social worker] knows, she wouldn't leave me in the lurch….' (foster mum)

Abrupt transitions can mean a loss of continuity in support. Young people themselves may feel lost, undervalued, or pushed to make a move before they are ready.

Information and consultation

It is important that parents and guardians are informed about the assessment and transition process. Information should be collated and made available through reliable systems. Wherever possible, clear and accessible information for young people, parents and carers should be backed up by a single point of contact for further information.

Young disabled people are frequently absent or excluded from situations where other young people are consulted. Young disabled people should be more involved in strategic consultation and service planning initiatives.

To achieve this, established mechanisms of consultation and involvement will need to become more accommodating to people with a wide variety of communication needs. In addition, there may be benefit in establishing specific consultation and involvement groups with young disabled people who use looked after services.

Transitional planning should involve young people in a meaningful way and include all aspects of their future lives. It should support young people, their carers and professionals in making important and sometimes complicated decisions.

This means planning with young people rather than for them, in an ongoing process where they are supported to gain confidence in their participation over time. It means helping young people to develop a sense of themselves and their futures – being creative, yet also realistic, about their aspirations. Above all, it means taking young people’s views seriously, however they are expressed.

Bridging gaps in services

There are a number of young disabled people (often with learning difficulties) who leave children’s services in an abrupt and unplanned way, with little continuing support to cope in the mainstream community as young adults. While some manage on their own, others struggle to cope with the everyday challenges of housing, money and employment training.

Our research suggests that there is still a considerable knowledge and skills gap between generic children’s services and specialist disability services. For example, positive expectations amongst disability specialists, about the capability of young people with ‘moderate’ learning difficulties to cope in the mainstream, may not be matched by the skills and resources available to support them there.

> ***‘It will not take time [the transition meeting]. All they want is my signature.’ (parent)***

Improving practice

Ironically, it is often those young disabled people who are the most able to ‘cope’ in the mainstream, who also face the greatest uncertainty in their transition to adulthood.

The experience of young disabled people involved in our project suggests some of the potential dangers that might be avoided by improved planning and collaborative working.

Greater collaboration is required to bridge this gap. Mainstream children’s services, aftercare services, housing associations and training agencies should (and must) exercise their responsibility to work more effectively with disabled young people.

Disability specialists and the disability community need to work together to ensure that more service providers have the knowledge, attitudes and skills to support the inclusion of disabled young people in the mainstream,

Staff in many mainstream agencies, particularly in aftercare services and training agencies, could benefit from effective Disability Equality Training. In addition, more work could be done to make such providers aware of their responsibilities under the Disability Discrimination Act.

The roles and responsibilities of relevant agencies, such as health, education, careers, social services and further education, are often unclear. There should be a single agreed transition policy to ensure greater consistency in the treatment of young disabled people in transition.

The link between schools and social services and health authorities is important. In practice, strategic commitments to interagency working are rarely translated into real co-operation at the level of individual cases. Disabled children in schools are not always known to social services and better enforcement of the Code of Practice would assist this.

> ***‘Even now, many disabled children leave home. There are no advisers or advocates, and often there is no involvement in any decision that affects the future of disabled children... The most acute area is probably that of children with learning difficulties. They, above all, are in need of the kind of advice, the kind of pathway plan, that the Bill seeks to achieve elsewhere.’***
>
> ***(Tom Clarke MP, speaking in the Commons, 21 Jun 2000)***

‘I’d like to know what rights I’ve got now I’m nearly eighteen...that isn’t clear at the moment.’ (steering group member)

Planning for Transition: key questions

Is this person aged 13 or over?

Are there any plans to involve the Connexions Service in future planning?

Does this person have a statement of Special Educational Need?

Who was involved in that assessment?

What arrangements have been made for a post-14 review?

Is this person aged 14 or over?

Have the LEA circulated a transitional plan from the post-14 review meeting?

What arrangements are there to review this plan in the future?

Is this person disabled?

Have the LEA asked social services for an assessment under the 1986 Disabled Person's Act?

Will this person be a care leaver?

Will a pathway plan be in place before their sixteenth birthday?

How will this plan relate to other relevant plans?

How is a personal adviser being chosen?

How is the person being involved?

Is this person leaving child health services?

Will they have continuing healthcare needs as an adult?

Will they have new healthcare needs as an adult?

Are the GP and primary care team involved in assessing these needs?

Has the designated medical officer (SEN) contributed to reviews?

Should any additional healthcare professionals be involved?

Have they been estranged from their parents for over a year?

Do they have an Independent Visitor?

Is this person leaving children's services?

What arrangements have been made for a community care assessment?

Is this person in their last year at school?

Will they continue in further education or training?

Has there been an assessment of continuing educational needs under the Learning and Skills Act?

Support and Advice

Deciding on the kind of support and advice that care leavers should receive, and who should provide this, is central to good practice. Our research illustrates the range of support that young disabled people use, and the qualities required of those who support them.

In developing support and advice for young disabled people leaving care, local authorities will also need to take into account the overlap with existing roles and responsibilities—particularly in relation to independent visitors and key workers.

Who helps?

During our research, we were keen to find out who was helping young disabled people in their transition to adulthood, and what kind of support they valued most.

The young people we met were more likely to seek support from someone they already knew and trusted, rather than from the local authority or another service agency. Usually, this was an individual person that they had known as a child and who had shown that they could help in difficult times.

We found that many young people turned to parents and other relatives for practical support (even when they were estranged from them as children). Foster parents were particularly important to those who had lived with the same family for a long time.

Other young people were likely to identify someone who had been important to them in children's services or education (for example, a particular teacher, carer or key worker). Friends were also an important source of support and advice for some people.

Social workers and after-care workers were the preferred choice for only a very small number of young people in our study. There was some mistrust of staff motives, commitment and reliability in the role of confidante or adviser.

The formal status of the person, and their ability to access services directly, seemed less important to the young people we met than the quality of their personal relationship with the person, especially trust and reliability.

Personal advisers

Young persons advisers will play a key role in the new arrangements for care leavers. They will:

- Be the main contact for help and support
- Contribute to an assessment of needs
- Negotiate a pathway plan

> ***'[Young people] should to go to their family or their relative for help, or anyone like a school teacher or a social worker, or anyone, to go get help from them'. (steering group member)***

- Monitor progress and review the plan at least every six months
- Work with other agencies and broker services required by the plan
- Keep in contact with the young person

We asked the young people involved in our project steering group to think about the skills and qualities that would make a good personal adviser, and about the sort of help that person might be able to provide. The following recommendations came from young people involved in our project.

What kind of person?

The participants in our project thought that it was very important for a personal adviser to be the right kind of person, with the right kind of experience and skills for the job.

- A good adviser should have some similar experiences to the young person they are helping.
- An adviser should be not too old (maybe in their mid 20s).
- They might need to be someone of the same sex, if you wanted to talk about personal things.
- Some people would prefer to have an adviser who was also a disabled person.
- They should always be there for you (especially in an emergency).
- You should be able to contact them easily.
- They should be someone you can talk to in private and who understands.
- Once they are your adviser they should stay (and not be swapped or changed about).
- They should have a good personality (happy, cheerful and friendly).
- They should be a good listener.
- They should be easy to get on with and easy to talk to.
- They should be trustworthy and reliable.
- They should be unselfish and put you first.
- They should keep their promises.

What kind of help?

The participants felt that someone needed to give young people more help and support, and look after them. They also made practical suggestions about the things that an adviser could help with:

- Help them with their reading and writing.

'They should know how to help young kids in life'. (Helen)

- Help them with their home work.
- Take them on holiday.
- Help them to buy new things.
- Help young girls learn parenting skills.
- Help people to make friends.
- Help you find a job.
- Help you find the right place to live.
- Help you with money.

Who should choose?

The participants felt that young people should be involved in choosing their personal adviser but that there were other people who could help them with this task.

- Young people should be able to interview about three people and choose the one they like best.
- Birth parents could help to choose the best person (if you have a good relationship with them).
- Foster parents can help (if you have been with them for a long time).
- Teachers might be able to help, or give advice.
- Your boyfriend or girlfriend might be able to help you.
- Social workers should not be involved because they don't listen and will try and choose for you.

The young people involved in our project (predominantly those with learning difficulties) had clear ideas about their preferences and expectations of the adviser's role. They could see the value in having an adviser, and could imagine real situations in which such a person might be useful to them.

In this context, it is important to note that the proposed role of Young Persons Advisers will overlap considerably with those of existing support for young disabled people in transition. Avoiding duplication of roles, while ensuring consistency and continuity of service provision, will be a key challenge for local authorities under the new arrangements.

Independent visitors

Under the Children Act, local authorities are required to appoint Independent Visitors for those young people in their care who have had little or no contact with their parents for more than a year. Independent visitors are volunteers who visit children and befriend them, with a view to helping them participate in decisions that affect their future.

Clearly, there is considerable overlap

'It takes the piss when you're with someone and they change over to the next person. It takes the piss.' (steering group member)

between the role of the Independent Visitor and the proposed Young Persons Adviser. This will need to be taken into account when choosing advisers for young disabled people who are looked after.

However, previous research has suggested that only one in three authorities in England and Wales were using Independent Visitors, and that only about four per cent of eligible young people saw such a visitor. For young disabled people who were looked after, the figure appeared even lower.

The effective implementation of Independent Visitor schemes could make a valuable contribution to the delivery of personal advice and support for disabled care leavers.

Independent advocacy

There has been an increasing interest in the use of independent advocacy services for young disabled people. The development of such schemes nationally has been patchy, but there are numerous local initiatives (particularly in relation to people experiencing mental distress or learning difficulties).

The Government encourages the use of independent advocacy schemes. However, local authority funding for independent advocacy schemes must be met from existing resources.

Models of advocacy vary greatly, from self-advocacy initiatives established by local disabled people, to professional and legal advocacy services. Staff working with disabled care leavers should be aware of the range of independent advocacy services available, and actively consider their involvement in promoting young people's voice and choice during transition.

> ***'...many of the young people involved will have serious difficulties as a result of experiences that many of us cannot imagine; some will be disabled, or have learning difficulties. It is essential to build in a great deal of support for such children, so that they are in a position of strength when working with their local authority.'***
>
> ***Julie Morgan MP (speaking in the Commons Standing Committee)***

Independent schemes may offer particular skills and experience of benefit to young disabled people. Where a young person has specific communication impairment there may be particular merit in involving advocacy services that demonstrate the necessary skills and expertise. Particular attention should be paid to the availability of peer advocacy services provided by disabled people's organisations.

> ***'Why should the social services say their going to be there when they're not.' (steering group member)***

Improving practice

Key workers

A more common role, which also overlaps with the proposed responsibilities of Young Persons Advisers, is that of the key worker.

Key worker schemes may be organised in a variety of ways, involving staff with a wide range of training and experience. The key worker role is generally to provide a single contact point for families with disabled children, and to ensure collaboration with staff from a range of services.

Differences in children's individual need and circumstance mean that key worker schemes must be flexible in their organisation. Research suggests that effective schemes need time, resources and facilitation for staff from different agencies to meet together.

Key workers were most effective where they made regular proactive contact with families, developing open and supportive relationships that responded to individual strengths and needs. Effective schemes depended on managerial commitment, ring-fenced funding and the prior establishment of joint working between different agencies

The lessons learned from established key worker schemes could usefully be applied to the development of Young Persons Advisers schemes.

Further reading

DfEE, *A Guide to Transition Planning for Secondary and Special School Pupils.*

Department for Education (1994) *Code of Practice: The Identification and Assessment of Special Educational Needs*, Central Office for Information.

Sarboro, A. (1997), *Making Connections*, Disability Unit, DfE.

Caldwell, P. & Stevens, P. (1998) *Person to Person: Establishing contact and communication with people with profound learning disabilities and extra special needs*, Pavilion Publishing.

Greene, M. (1998) *Over to us: A report of an advocacy project working with young disabled people living in residential institutions*, Greater Manchester Coalition of Disabled People.

Knight, A. (1998) *Valued or Forgotten? Independent Visitors and disabled young people,* National Children's Bureau.

Morris, J. (1999) *'Hurtling into a void': Transition to adulthood for young people with complex health and support needs*, Pavilion Publishing.

Mukherjee, S., Beresford, B. and Sloper, P. (1999) *Unlocking Key Working: an analysis and evaluation of key worker services for families with disabled children*, Policy Press

'It's gonna be strange not having a social worker behind me. You know what I mean? I've been using social workers for many years now, behind me, and its gonna be strange not having one, you know, at the side of me all the time really'. (Beth)

Recommendations

The findings of our research suggest a number of areas in which action could be taken to improve practice and develop policy for disabled care leavers. This final section of the report details those areas where priority action is required.

It is important to note that significant improvements in the situation of young disabled people leaving care could also be achieved through developments in related policy areas (such as implementation of the Disability Discrimination Act). Our recommendations should therefore be considered within the broader context of disability policy making.

In addition, we have restricted our analysis to improving practice within the existing framework for planning and transition. A more radical interpretation of our research might suggest a more far-reaching agenda for policy change, and in particular a fundamental questioning of the administrative division between the perceived needs of disabled young people and those of young people within the mainstream.

Monitoring

1. It is important to have reliable information and monitoring systems that will identify all children who are approaching their fourteenth birthday and who may be eligible for an assessment under the 1986 Disabled Person's Act. This should involve a multi-agency approach between education, social services and health authorities (including the development of shared information systems).

2. The identification of disabled children with a statement of special educational need at age 14 is an important part of the process, and more effective monitoring is required to ensure that the process of involving these young people in planning for their futures is not delayed.

3. More specific guidance may be required on the completion of Quality Protects data returns in local authority Management Action Plans. There is currently some confusion and inconsistency in recording the numbers of disabled children who are looked after.

4. It would be useful and relevant to include a breakdown of the numbers of disabled and non-disabled children in all statistical monitoring of potential and actual care leavers. This would assist in highlighting potential inequalities in the implementation of new arrangements for children leaving care.

5. Particular care should be taken to ensure that disabled children looked after through mainstream children's services (such as fostering and children's

homes) do not cease to be recorded as disabled children. The philosophy of 'children first' should not be an excuse to mask the existence and specific needs of looked after children who are also disabled.

6. Leaving care policies should be inclusive of disabled children. For this reason, considerable thought must be given to the definition of 'looked after' children. There is a strong case for clearer national guidance on this issue, to ensure the greater comparability of data between authorities. The terms of such definition should not be framed so as to specifically exclude or prejudice the rights of disabled children.

7. There are many examples of good practice in supporting young disabled people who have been looked after, in ways that promote their choice and independence, and it would be beneficial to share these examples more widely during the implementation of the new arrangements for care leavers. There may be a role for the Social Services Inspectorate or the Association of Directors of Social Services in facilitating this.

Planning

1. It is important that all relevant agencies are involved in post-14 educational transition planning. There should be more monitoring of which agencies are invited and those that actually attend transitional reviews, particularly where a child spends time away from home.

2. Subsequent reviews are just as important as the first post-14 review. Representatives from other services, including adult services, should continue to be involved where a young person is likely to require support after leaving school.

3. Practice could be improved by ensuring that related educational, disability and childcare planning for transition are co-ordinated within a single process wherever possible. There should be greater coherence in planning, whether it is health, education or social services that have initiated the process, and irrespective of the primary source of funding.

4. Inter-agency working would be enhanced by the development of a shared planning cycle for transitional reviews with young disabled people, setting out the sequence of activities involved. This should include mechanisms for monitoring the actual input and involvement of all relevant agencies. Inter-agency transition planning for young disabled people should be specifically resourced, and should include specific arrangements for leaving care.

5. Transitional planning arrangements should always include an assessment of benefit entitlement, even where there is to be continuity of placement. Transitional planning should always include a consideration of direct

payments as a mechanism for promoting involvement and independence for young people aged 16 and over.

6. Social life and leisure opportunities are important to young people, and planning should include a consideration of the support required to facilitate continued contact with friends and peers. This should include issues of transport and access, and should not be restricted to the availability of ‘special’ leisure facilities in the locality.

Transition

1. Support for the transition to adulthood should promote positive change in young people’s lives, while ensuring security. The development of policies for risk taking and risk management should aim to ensure that there is always a positive challenge to preoccupations with the presumed vulnerability of disabled young people.

2. Disruption in continuity, and breakdown of trust between young people and local authority purchasers, could be reduced by action to minimise the number of changes in individually allocated social workers. The development and maintenance of positive individual relationships with young disabled people should be treated as a priority.

3. Changes in funding responsibility for young disabled people in transition (for example, between children's services and adult services) should not be a sufficient reason for implementing major changes in people's lives, particularly in relation to accommodation.

4. Greater imagination and flexibility is needed in the funding and provision of services, to ensure that fewer inappropriate life changes are precipitated solely by chronological age. This has implications for policy making that may require action at both national and local levels.

5. Family contact is important to young people, and increased priority should be given to the allocation of resources to support continuing family contact for disabled care leavers.

6. Educational opportunities for young disabled people leaving school should present a range of options that are relevant to their needs and preferences. Such choices should include both vocational and academic options.

7. Extreme care should be taken to monitor the placement of disabled school leavers in specialist residential ‘colleges’. The provision of residential accommodation should never be the main justification for an ‘educational’ placement, particularly where such a placement is outside the young person's home area.

8. Educational and training schemes (including those provided under the New Deal) should allow for a more flexible approach to attendance and completion, so that disabled young people are not disadvantaged by inflexible mainstream provision.

9. Clearer guidance should be made available on the transfer of responsibility from child to adult health services. There may be a case for the development of national rules or criteria in this area.

10. Impairment and disability issues should not be the sole determining factor in decision making. Disabled children and young people should always be recognised as more than disabled. Issues of age, gender and cultural appropriateness should always be taken into account in planning with disabled young people, and in deciding between available options.

Promoting involvement

1. The involvement of young people in transitional planning is a key element of good practice, yet many young disabled people are not adequately supported to contribute. It must always be considered unacceptable to conclude that a young person cannot be involved in making choices and expressing preferences (whatever, their perceived level of impairment).

2. The development of support for advocacy may have an important part to play in this process, particularly for children and young people with complex communication impairments. Existing opportunities for independent visitor schemes could be more fully implemented, with particular emphasis on the potential benefits to disabled care leavers.

3. There is a conspicuous absence of positive adult role models for young disabled people using looked after services. The development of peer mentoring schemes, involving disabled young people and disabled adults with experience of service use, would help to redress this.

4. Disabled people’s organisations should be actively supported to become involved in independent advocacy, visiting and mentoring for young disabled people. They are also likely to be the most appropriate providers of Disability Equality Training for staff working with young disabled people in transition.

5. There should be specific funding for independent advocacy, visiting and mentoring for disabled young people, which might be targeted as a priority at those who have been looked after. Such schemes have resource implications and there is a strong case for central government funding in this area.

Training and staffing

1. There is a worrying lack of confidence and knowledge about disability issues and resources amongst some staff in mainstream children's services. Where such staff will have key roles in supporting disabled care leavers, there may be a considerable need for further training.

2. Particular attention will be required in recruiting, selecting and training those Young Persons Advisers who will work directly with young disabled people. There will be important decisions to be made about the kind of skills and experience that would most benefit young disabled people in transition. There is a case for recruiting advisers who have prior knowledge and skills in working with young disabled people, and who understand social model approaches to their inclusion in adult life.

3. Disability Equality Training should be a pre-requisite for staff and carers working with disabled care leavers, whether or not they are located within specialist disability services. In particular, this would be of benefit to many mainstream social workers with responsibility for young disabled people in transition.

Some Useful Contacts

Action 19 Plus

c/o Scope, 6 Market Road, London, N7 9PW

Tel: 020 7636 5020

Barnardo's

Tanners Lane, Ilford, Essex, IG6 1QG

Tel: 020 8550 8822

British Agencies for Adoption and Fostering

200 Union Street, London, SE1 0LX

Tel: 020 7593 2000

British Council of Disabled People

Litchurch Plaza, Litchurch Lane, Derby, DE24 8AA

Tel: 01332 295581

Council for Disabled Children

National Children's Bureau, 8 Wakley Street, London EC1V 7QE UK

Tel: 020 7843 6061

Childline

Tel: 0800 1111 (24 hour helpline)

Tel: 0800 884 444 (for children living away from home)

First Key (the national leaving care advisory service)

Oxford Chambers, Oxford Place, Leeds, LS1 3AX, UK

Tel: 0113 244 3898

National Youth Advocacy Service

1 Downham Road South Heswall, Wirral, L60 5RG

Tel: 0151 342 7852

People First

Instrument House, 207-215 King's Cross Road, London, WC1X 9DB

Tel: 020 7713 6400

SKILL (National Bureau for Students with Disabilities)

336 Brixton Road, London, SW9 7AA

Tel: 020 7274 0565

Transition Network

National Development Team, Albion Wharf, Albion Street, Manchester, M1 5LN

Tel: 0161-228-7055

Who Cares? Trust

5th Floor, Kemp House, 152-160 City Road, London, EC1V 2NP

Tel: 020 7251 3117

This report is about young disabled people leaving care.

It explains the policy background to transitional planning, and examines how young disabled people may be affected by new arrangements for care leavers.

It includes contributions, stories and quotes from 28 young disabled people who have been looked after, as they make the transition to adulthood.

The authors highlight a number of key issues raised by young people's experiences, and offer suggestions for improving practice in supporting disabled care leavers.

The report is based on research carried out at the University of Leeds, in association with First Key (the National Leaving Care Advisory Service) and with the co-operation of Bradford Social Services Department, funded by a grant from the National Lottery Charities Board.

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Further copies of this report are available from:

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This report is also available online at:

www.leeds.ac.uk/disability-studies/projects/firstkey.htm