

foundations

Analysis informing change

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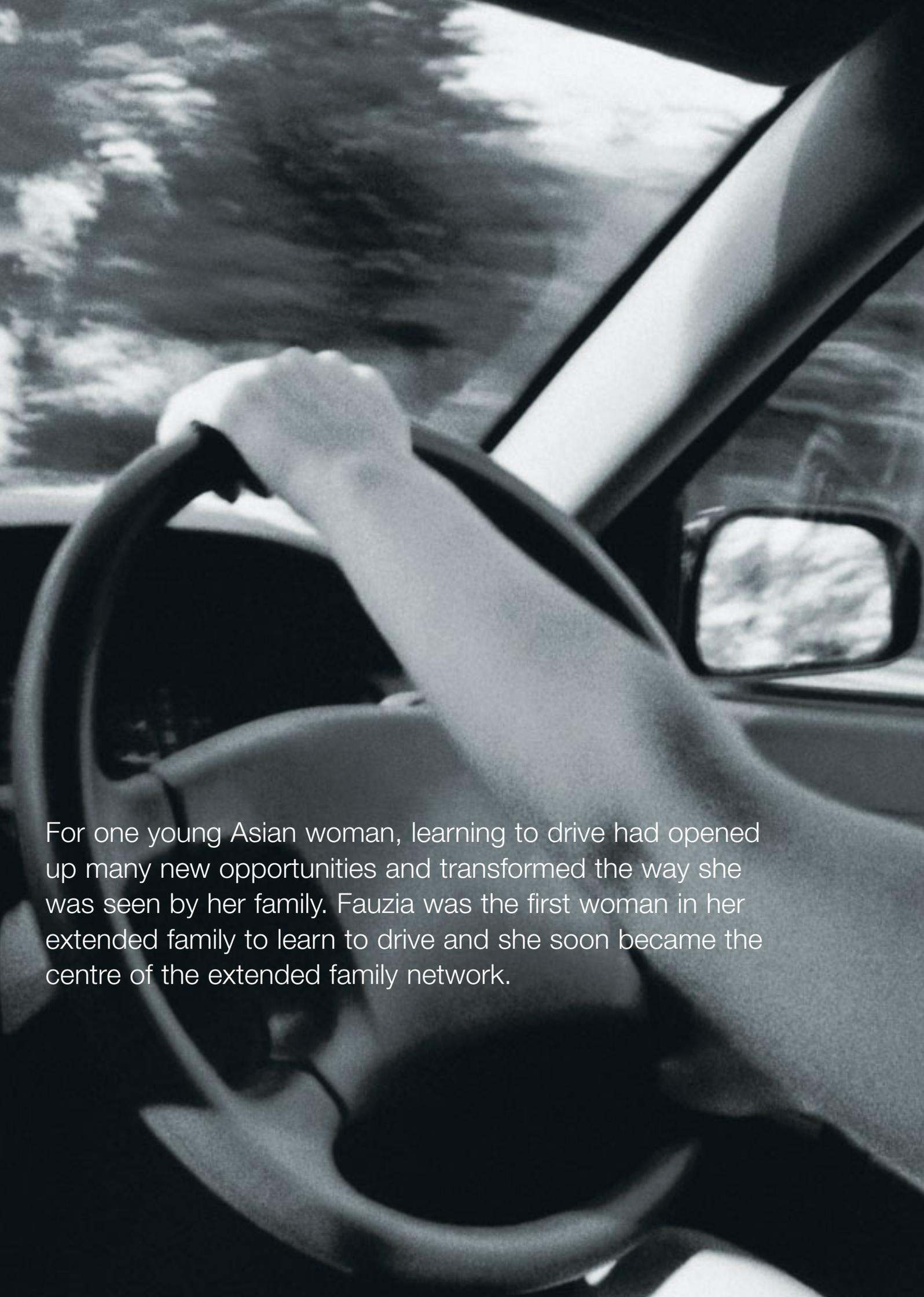


Moving into adulthood

Young disabled people moving into adulthood

In recent years, there has been increasing recognition of the need to improve transition planning and support for young disabled people moving into adulthood, and to co-ordinate this support across a wide range of agencies, including health and social care, youth services, leisure, careers guidance, housing, education, benefits and employment services. In many parts of the country, people are working hard within voluntary and statutory sectors to meet this challenge. Yet, despite these developments and a clear legislative and regulatory framework to help young disabled people, research consistently shows that young people are not getting the help to which they are entitled.

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For one young Asian woman, learning to drive had opened up many new opportunities and transformed the way she was seen by her family. Fauzia was the first woman in her extended family to learn to drive and she soon became the centre of the extended family network.

This *Foundations*, by Jenny Morris, draws on a range of research projects to identify the key barriers that many young disabled people and their families still face.

- Transition planning is often characterised by poor liaison between different agencies and professionals, a failure to involve young people and a failure to cover the issues of most importance to them and their families.
- Young people, their families and those working with them frequently lack easily accessible, comprehensive, up-to-date information about options, choices and possibilities.
- Many young disabled people have no experience of an independent social life and few opportunities to make friends: they spend most of their time with family or paid carers and have no independent access to transport, telecommunications, or personal assistance over which they have choice and control.
- Families, and the young person's role within their family and local community, are very important to young disabled people but this is often not recognised by services. Young people may be moved some distance from their family and community simply to have their support needs met.
- Many young people who have significant communication impairments reach adulthood without proper assessment of their communication needs or concerted action to meet these needs.
- Many further education, training and work experience placements are considered to be 'care' placements for young disabled people, rather than a way of gaining qualifications or paid employment.
- The availability of supported employment (support to enable a young person to do a paid job alongside non-disabled workers) varies geographically and projects are often financially insecure.
- The varied sources of assessment, funding and provision of equipment and support make it difficult for young people to get equipment and support as and when they need it.
- Young disabled people rarely get the opportunity to move into a home of their own. Instead they are more likely to be 'slotted into' available service provision.
- Young people with high levels of support needs often move into residential or nursing care as they reach adulthood, and sometimes have little or no contact with young people their own age.

Transition planning

Although it is a legal requirement that all young people over the age of 14 with a Statement of Special Educational Needs have a transition plan, a third of young people in one study of 283 families did not (Heslop et al., 2001). Education and social services departments are often not working well together in transition planning. There is also often poor co-ordination between children's social services and adult social services. Young disabled people who are in placements out of their local area are particularly likely to experience inadequate transition planning.

There are still significant differences between the intention of inter-agency working expressed at government and policy level and the experiences of disabled young people and their families. Strategic commitments to joint working are rarely translated into effective co-operation in practice.

Young disabled people are often not involved in planning for their future. This is particularly so for those with communication and/or cognitive impairments. A common reason given for not involving young people is that there are very few options for them to choose between.

"It is nice if I can say what I want rather than have people say this is what you want. It is just depriving people of free speech."

Young person quoted in Noyes, 1999, p.66

Assessments often cover what a young person cannot do because of their impairment, rather than identifying disabling barriers which could be tackled. Topics covered in transition planning are frequently not those of most importance to young people and their families. Friends and sexual relationships are important issues for young people but transition planning, assessments and services rarely address these concerns. Families want information about: leisure and social opportunities; benefits; future housing options; options for further education.

Only a minority of transition plans cover transfer to adult health services. When health services are set up specifically for young disabled adults these have been found to be popular with them.



Making choices

Transition to adulthood should be a time when young people increasingly make choices. In order to do this they need information about options, to be consulted and listened to, and to be supported to make decisions.

Many young people rely on a single adult for key information (such as a foster parent, teacher, carer). Leaving school or children's services can mean losing contact with this key person. Standard written information is not accessible to many young disabled people in terms of format (easy language, audio tape) and availability (ensuring the information reaches young people themselves). Parents/carers and young people often find out information by chance. Informal networks of other parents and disabled people are usually the most useful source of information.

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

Parent of a 21-year-old, quoted in Heslop et al., 2001

Young disabled people who do not have parents to argue on their behalf, or whose parents are not familiar with the system, are often disadvantaged in accessing information and making choices as they approach adulthood. Very few young people have the support of an independent advocate.

Some young people with significant communication and/or cognitive impairments reach adulthood without proper assessment of their communication needs. A move into a new service can mean a loss of contact with those who know how they communicate. These young people are particularly in need of advocacy services.

Young people from black and minority ethnic communities are also particularly disadvantaged. Services know little about their needs and views, and these families and young people find it especially difficult to get information about options and possibilities.

We know relatively little about the experience of young South Asian disabled people and their families. This poor understanding is evident in policy and practice and often results in inaccessible and insensitive service provision. ...Young people and their families ... often find services unable to respond to their needs; excluded from services on the basis of language; experience insensitivity to cultural diversity; and subject to myths and stereotypes that deny them the support they need.

Hussain, Atkin and Ahmad, 2001

Professionals in contact with young people similarly do not always have good access to information. They sometimes fail to recognise that the kinds of things young people want information about are not always the same things that adults think are important: for example, information about sex and relationships, about leisure interests, and, for those in care, information about birth families.

Many young disabled people, particularly black young disabled people, have reported that the low expectations of others about their abilities and potential have inhibited their choices. In particular, a tendency to assume that independence is about 'doing things for yourself' can hold young disabled people back. Successful transition to adulthood has been possible when young disabled people are supported to make choices and have a say in the help that they need.

[Young disabled people] are often unused to voicing their opinions. They may have low expectations for themselves or may simply agree to whatever service is suggested. They need to have the support of people they trust who will listen to them, give them informed choices, support them in making decisions and see them through.

Cowen, 2001, p. 77

Families

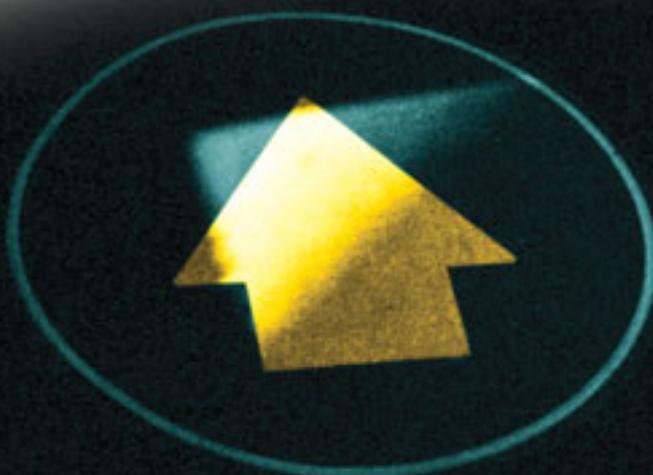
Few young disabled people find their transition to adulthood supported by structures and networks outside their family. Those that make a successful transition to independence in adulthood usually do so because of the material, emotional and cultural support they can draw on from parents and the wider family. However, services and professionals do not always recognise or facilitate this important role that families have. Young disabled people who have spent most of their childhood living away from their families often lack someone who will push to get the best for them.

While family relationships are important to young disabled people, they often face barriers to being part of their family, particularly when there is inadequate local service provision to meet their needs. For young disabled people with the highest levels of need, making the transition to adulthood may mean a move away from their family and local community.

Young disabled people themselves describe how important it is to them to fulfil expectations and roles within their family, and to be part of family and community celebrations. At the same time, they can experience major barriers to this – sometimes as a result of family members' negative attitudes towards impairment. Religious and cultural traditions can also be important but many young disabled people have restricted access to formal expression of such traditions. These important issues are rarely covered in assessments of young people's needs.

For one young Asian woman, learning to drive had opened up many new opportunities and transformed the way she was seen by her family. Fauzia was the first woman in her extended family to learn to drive and she soon became the centre of the extended family network.

Bignall and Butt, 2000, p.49



Friends and relationships

Young disabled people and their families often identify that making and keeping friends is the most important aspect of their lives. Assessments, reviews and services, however, rarely recognise this.

The young people...overwhelmingly saw leisure as either 'hanging out' with other people or 'doing things' with people they enjoyed to be with. Leisure, therefore, was primarily defined as being about mutually enjoyable relationships.

Murray, forthcoming

Young disabled people face many barriers to an independent social life: lack of one-to-one support; independent access to transport and communication technology; negative attitudes of non-disabled peers; and a high degree of 'adult surveillance' in their lives.

...after school and in the holidays you just stay at home at night...Too difficult to do it and nowhere to go. ...And finding a friend is difficult.

(Young disabled person attending conference held in 2000)
Disability Research Unit, University of Leeds, 2000

A move from one service or residential setting to another can mean a loss of important friendships and there is little recognition of the importance of peers as advocates and mentors. Neither do assessments or services fully recognise that someone with no friends is unlikely to have much self-esteem.

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.

Rabiee, Priestley and Knowles, 2001, p.37

Sex and sexuality figure as important issues in the transition to adulthood for non-disabled young people but adults do not always recognise 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.

Projects which enable young disabled people to access peer support are highly valued by young people, particularly when project workers share similar experiences and where young people are actively involved in the development and running of the groups and activities.

Attending the [peer support] groups enabled the young women and men to gain emotional support, make friends and undertake a number of activities where they had fun or learnt new things.

Signall, Butt and Pagarani, forthcoming

It is through ordinary relationships with each other that [the young disabled people] have been able to explore their personal experiences of discrimination and oppression. Sharing experiences with each other has given them the understanding that the problem does not lie within them as individuals but rather within a disabling society. All members of this loose knit group have non-disabled friends, but it is to each other they turn when they encounter barriers to participating in the mainstream.

Murray, forthcoming

Further education, training and work

Further education is, for many young disabled people, an important opportunity to 'catch up', compensating for a poor experience of secondary schooling. They need time to gain qualifications and maximise their potential. However, those with high levels of support needs often leave school at 19 and have no further educational opportunities.

Further education placements are, for some young disabled people, more concerned with meeting their care needs than their educational needs. There are long-held assumptions that young disabled people who have been at special schools will move on to specialist colleges and then into adult day services. Many young disabled people have experienced low expectations of careers service professionals and others.

"I decided at 11 that I wanted to be a fashion designer when I grew up. I've been to Bradford College. It was a two-year course in fashion design.... Then when that finished I wanted to learn more about fashion design so I decided to go to York College for a HND – a more advanced course. My lecturer really encouraged me there because I was the only deaf student, all the others were hearing. While I was studying at York College I received an award at the Bhs fashion show... . It really made me proud... . From that experience I decided to go to York University to learn more about fashion."

My dream, your dream: young, ethnic and deaf, video

There is a range of different, confusing and often inadequate sources of funding support with daily living, as a young person attempts to move through education, training and into paid employment. The use of direct payments and Independent Living Fund (ILF) grants for young people is underdeveloped, particularly for those who have communication and/or cognitive impairments. In addition, the assessment, funding, provision, repair and updating of equipment can depend on where the young person is when they are using it (at home, residential placement, school, college, training placement, work) and this can make life unnecessarily difficult.

Following education and training, young disabled people experience barriers to paid employment. The provision of supported employment varies geographically and many projects are short-term and insecure. Specialist schools and colleges seem to lack information about such opportunities as they rarely refer young disabled people to supported employment agencies. Work placements often reflect low expectations of young disabled people's potential. There are low levels of awareness of the Access to Work scheme amongst employers and disabled young people, and delays and variations in the operation of the scheme.

The recent government decision to disregard earnings (including those of a partner) when means-testing for community care services, direct payments and ILF grants will make paid employment more feasible for young people who have personal assistance needs. The implementation of the Disability Discrimination Act should help to address negative attitudes held by employers but current research highlights the widely held low expectations of young disabled people's potential and how much these attitudinal barriers are holding them back.

"The best thing that I ever did was go out to work because along with a career there comes a social life as well you know, and I would dread to think of sitting at home or going to a day centre, that would kill me off. I just couldn't do that."

Young disabled woman, quoted in Hendeby and Pascall, forthcoming



Housing

Young disabled people wanting to move into their own home face considerable barriers, including:

- Shortage of suitable housing, particularly in the private rented sector – the main source of independent housing for non-disabled young people.
- Suitable housing is often only available in segregated schemes.
- Difficulties in bringing together housing with the support required.
- A common failure of housing and social services to work together.

Young disabled people often find that the only option for leaving their parents' home is not a move into a home of their own but instead into a 'housing scheme' or group home. The decision about where to live is more often determined by what vacancies services have than by young people's choices about where to live and who with. Schemes which aim to offer a transition to independent living often do not because there is nowhere for the young person to move on to.

The house is not really a 'home' (in the sense of the way we usually use the word home) of the people who live there, but a 'scheme'. The shape of the service will have more to do with funding mechanisms than the needs or wishes of the inhabitants. There is often little security (individuals may get moved for organisational reasons) and people have little say in with whom they live, or who works with them. Despite all the rhetoric, these are not services based on the needs of individuals, but largely reflect the concerns of organisations.

Simons, 1997, p.3

A poverty trap, created by high social housing rents, can prevent the progression from renting to owning a home which many non-disabled young people experience as they grow older. Moreover, young people growing up with impairment often reach adulthood without any significant resources. Their family is less likely than the families of non-disabled young people to be able to assist them with buying their first home, because of the financial consequences of having a disabled child.

Young people with high levels of support needs are likely to move into a residential or nursing home, where there is often no one of their own age. This is rarely seen as a transition stage in their lives, the assumption being that they will be there until they die.

Policy and practice initiatives which could help young disabled people in their transition to adulthood

All those involved in trying to help young disabled people make a successful transition to adulthood need to:

- Understand what the barriers are from young disabled people's points of view. Plans, strategies, assessments should all start by finding out from young people themselves what they want to achieve and what gets in the way. It is particularly important to consult with those whose experience we know the least about: young people from minority ethnic communities, and those with significant cognitive and/or communication impairments.
- Recognise that relationships, particularly with their own (disabled and non-disabled) peer group are often the most important issue for young disabled people themselves. Assessments, transition planning and service delivery should seek to maintain and nurture opportunities for relationships with peers, family and significant adults.

Personal Advisers in the **Connexions** service and Young Person's Advisers for young people leaving care (under the **Children (Leaving Care) Act**) have an important role to play in improving transition planning. **Personal Advisers** and **Young Person's Advisers** should:

- Receive Disability Equality Training so that they understand the importance of focusing on the disabling barriers confronting young people, rather than on young people's particular impairment; and recognise that independence is about having choice and control over the support needed, not about needing to do everything for oneself.
- Seek out information about good practice in helping young disabled people achieve independence in adulthood. It is particularly important that they have access to good information about options and possibilities.
- Recognise that transition is a process, rather than a series of assessments and reviews; and that young disabled people's transition to adulthood may well take longer – because of the barriers they face – than that of their non-disabled peers.
- Be supported to work with young people who have significant communication and/or cognitive impairments.

- Recognise the importance of multi-agency assessment and planning for some young people, and ensure that health, social services, education, housing and employment services are actively involved.
- Ensure that young people and their families have access to comprehensive information about options available, and have the advice and support they need to make decisions.

In addition, **Connexions** should:

- Set up a pilot project to deliver the **Connexions** service to young disabled people in residential schools. Such a project should establish good practice and disseminate this to all **Connexions Partnerships**.
- Update *Making connections*, the inter-agency guide for agencies helping with young disabled people's transition to adulthood, and issue copies to all **Connexions Partnerships**.
- Work in partnership with the 'transition champions' to be appointed by each Learning Disability Partnership Board.

The **Department for Education and Skills** and **Ofsted** need to ensure that **local education authorities** are delivering effective transition planning, as required under the Code of Practice on the Identification and Assessment of Pupils with Special Educational Needs. The **Department of Health** has a similar role to play in respect of **social services authorities'** responsibilities under the Disabled Persons Act 1996, NHS and Community Care Act 1990 and Chronically Sick and Disabled Persons Act 1970 (i.e. to provide information, to assess needs, to put in place appropriate responses to assessed needs and to fully involve the young person in assessment and care planning).

Both sets of statutory responsibilities, and strategic commitments to inter-agency working, need to be:

- more effectively monitored and inspected;
- measured by gathering information directly from young disabled people and their families about their experiences.

The **Disability Rights Commission** should ensure that all providers of post-16 education and training are aware of their responsibilities under the SEN and Disability Act 2001 not to discriminate against disabled students and to make reasonable adjustments in order for them to access education and training.

Supporting People could help young disabled people to live more independently in the community by:

- Ensuring that the needs of young disabled people are included in **Supporting People** local strategies.
- Recognising the hidden nature of the homelessness experienced by many young disabled people – when, for example, they cannot move out of their parents’ house because of lack of accessible accommodation, or out of residential care because of lack of housing and support.
- Piloting ‘floating support’ schemes specifically for young disabled people in transition to adulthood.

The implementation of the White Paper, **Valuing People**, could also facilitate successful transition to adulthood for young disabled people, particularly for those with high levels of support needs. In particular:

- Capital funding (from the Development Fund) should be tied to non-institutional provision.
- Revenue funding should be tied to flexible ways of delivering support, including developing ways in which young people and people with high levels of support needs can use direct payments.
- A new priority for the use of the Development Fund should be added: ‘Enabling young disabled people with high levels of support needs to move into a home of their own’.
- Young people should be included in the development of advocacy services for people with learning difficulties.
- The Implementation Support Teams should monitor local transition arrangements, disseminating information on innovative and good practice.

Joint Investment Plans (JIPs) have a role in tackling a range of barriers experienced by young disabled people. **The Department of Health, the Department for Education and Skills, and the Department for Work and Pensions** should encourage local agencies to ensure their JIPs:

- Create or expand, and place on a secure footing local supported employment schemes catering specifically for young disabled people.
- Ensure that community care assessments include employment needs and that the delivery of support services facilitate employment.

Current initiatives aimed at tackling the barriers to paid employment faced by disabled people are welcome, in particular the recent decision to disregard earnings

when assessing charges to be made for community care services (including direct payments) and eligibility for Independent Living Fund (ILF) grants. **Social services departments** have a key role to play in encouraging the take-up of direct payments, facilitating access to ILF grants and ensuring support is in place for young disabled people to employ their own support workers.

Policies aimed at tackling **social exclusion** must include young disabled people – for example initiatives such as **Community Safety Programmes, Neighbourhood Renewal projects** should specify how young disabled people’s needs will be addressed. Currently young disabled people are more likely to merely be the recipients of other people’s charitable works in the context of community involvement. This inhibits their true inclusion in their local communities.

The work of the **Children and Young People’s Unit** provides an opportunity for ensuring that all initiatives aimed at enhancing opportunities for young people fully include disabled young people. Young disabled people have the same aspirations as their non-disabled peers but require specific action to tackle the disabling barriers they experience. Services which seek to support young disabled people in their transition to adulthood can make all the difference to what happens to them. Information, raising their expectations of themselves, support to achieve their goals, tackling the disabling barriers that others create – all these things make it less likely that young disabled people will experience an adult life of dependency and low expectations.

...often the most important thing to the young person is the involvement of someone else in things of concern to them. An exchange with a young man who uses a Liberator to communicate illustrated this:

What would be most helpful to you?

People to help. To advise you? Just people.

Morris, 1999a, p.49

About this *Foundations*

This *Foundations* was written by Dr Jenny Morris, a freelance researcher. It draws on a range of projects, some of which form part of the JRF’s programme of research into issues concerning disabled children and young people.

How to get further information

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