foundations

Analysis informing change

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Moving into adulthood

Young disabled people moving into adulthood in Scotland

The Joseph Rowntree Foundation recently published a *Foundations* (Morris, 2002) reviewing research, policy and practice relating to young disabled people moving into adulthood in England. This *Foundations* reviews the situation in Scotland which, increasingly, has its own distinct legal and policy framework. A few, but not many, Scottish studies have explored young disabled people's transition to adulthood: not surprisingly, these indicate that young people's aspirations and experiences are very similar to those of their peers south of the border. A number of official documents have identified difficulties around the move into adulthood for young disabled people and a major policy initiative relating to transition, the implementation of the Beattie report *Implementing inclusiveness – realising potential*, is now under way.

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- Many young disabled people see leaving school in a holistic way, giving equal importance to making and maintaining friendships, finding work opportunities and studying. Some professionals, however, may view transition more narrowly - in terms of moving from children's services into adult services.

- Some young disabled people, usually those with high support needs or communication impairments, are excluded from their Future Needs Assessment (FNA) meetings. Those who do attend are not always given clear explanations about the meetings, and some are not fully involved in decision-making.

- Young people and their families often have difficulty obtaining information about post-school options, especially in accessible formats. The availability of translated material and interpreters is variable across Scotland.

- Many school-leavers are still directed towards day centres and segregated FE courses. Transition planning does not always include serious consideration of a variety of opportunities, such as employment and inclusive further education. This omission may reflect a lack of knowledge about such options among those advising young disabled people, a low level of expectation about their abilities, and/or the fact that such opportunities are often very limited.

- However, some positive new initiatives are under way, including the implementation of the Beattie report and the Special Educational Needs and Disability Act 2000. The expected Bill introducing multi-agency FNAs is to be welcomed. The links being made between these initiatives, at policy level, are a positive sign of 'joined-up thinking'. There is a growing awareness of the need to improve practice in supporting young disabled people into adulthood and, increasingly, there are examples of good practice projects.

- Like most young people, those who are disabled want to have fun, experiment and be allowed to learn from their mistakes.

The Scottish context

The Scottish Parliament is responsible for many policy areas relevant to young disabled people, including education, training, housing, most aspects of transport, health, social work, sport and the arts. Employment, social security and equal opportunities remain 'reserved' at Westminster.

An estimated 12 per cent of the adult population in Scotland is aged 16-24. Nine per cent of these young people have a long-standing illness, health problem or disability (Scottish Executive, 2001). Data about the number of young disabled people entering Scottish Further Education (FE) colleges is being collected nationally for the first time this year. About 5 per cent of students in higher education in Scotland have declared themselves disabled, widely seen as an underestimate. Estimated figures indicate that, out of 700 pupils leaving special schools across Scotland in 2000-01, 45 per cent entered full-time further education, 14 per cent training, 8 per cent employment, less than 1 per cent university, while 26 per cent went to 'other' destinations; seven per cent were unknown (personal communication, Scottish Executive). 'Other' destinations are likely to include day centres and, in some cases, no formal provision.

Few Scottish studies have focused on young disabled people moving into adulthood although some wider research has included this topic.

Transition planning and support

The Education (Scotland) Act 1980 requires education authorities to carry out a Future Needs Assessment (FNA) (equivalent of a Transition Plan in England) of children with a Record of Needs. (A Record is the equivalent of a 'Statement' in English legislation.) The process begins when young people are 14 and involves two formal meetings in which the young person and his/her parents should be closely involved. However, a low level of participation by young people has consistently been reported. Young people's comments on planning meetings include:

"Meetings are all talk and happen in somebody's office."
"They tell you to go to college."

(SHS Trust, 2002, p. 23 and p. 24).

Young people are often unclear about the purpose of their FNA. Some feel it focuses on their perceived limitations, others find it intimidating: a few are confident about speaking up. Those with experience of children's rights work are often more comfortable about expressing their views in meetings, as are those whose teachers have explained the FNA process in advance. Young people are often presented with few options during their FNAs. Many are directed to day centres or segregated courses at FE colleges, with few opportunities to join inclusive classes with learning support.

Most young people value their parents' support during the FNA process. Some parents see it as their role to make decisions about their sons' and daughters' futures, and conflict between the young person's wishes and those of parents can arise (Children in Scotland, 2001a). Other parents want to increase the young person's involvement in decision-making. Parents have expressed concerns that FNA recommendations are not always followed up. A voluntary organisation supporting black and minority ethnic families made the following point in their submission to the Special Educational Needs Inquiry:

"Professionals must have due regard to the religious persuasion, racial origin, cultural and linguistic background of the families with whom they are working. This is not possible unless assessments focus on the potential of the child and are not affected by resources."

(Scottish Parliament, 2000, p. 36)

The level and quality of professional input to FNAs varies throughout Scotland. For example, young people in one study thought careers advisors made a positive input but other reports suggest careers advisors tend to communicate with parents rather than the young person. In some areas careers advisors neither attend FNAs nor receive the reports (Children in Scotland, 2001a).

After several official reports challenged the effectiveness of the FNA, the Scottish Executive (2002a) is consulting on new proposals. These suggest that *all* children likely to have significant difficulties in post-school transition should have the opportunity to undergo multi-agency FNAs, which will become "more flexible and responsive" to the needs of individual children. A bill is expected in 2003.

The same as you? report (the review of services to people with learning disabilities: Scottish Executive, 2000a) recommended that from the age of 14 everyone should have the option of a Personal Life Plan. Anecdotally it seems that, as yet, few of these have been developed for younger people. Other recommendations are not specific to young people but will affect them. For example, local area co-ordinators are now responsible for co-ordinating services for up to 50 families and individuals, which may include implementing FNAs.

Little research has been carried out on young disabled people's transition to adult social work or health services, although this is recognised as a difficult area. Social work support is not automatically continued, and parents

sometimes have to 'fight' to have a social worker allocated. Some feel they receive a less sympathetic response from adult services. However, North Lanarkshire has a Transitional Planning Project and some voluntary organisations have appointed transitions workers, for example, PAMIS, which works with people with profound learning difficulties and Enable's Bridging Angus Special Education (BASE) project. Forth Valley Primary Care NHS Trust has a project called 'Smoothing the transition', aimed at teenagers with learning difficulties. Among 12 young people involved, six reported that no one had talked to them about moving into adult health services while eight had not been asked what support they would like from these services (Smith, 2002). The Scottish Executive (2000b) published a guide to developing accessible health services for young people. Among the good practice examples cited is one focusing on the needs of young disabled people.

Choice and decision-making

People cannot make meaningful choices without good quality information. Yet young disabled people and their families often have difficulty finding information, particularity in accessible formats. Young people involved in a consultation exercise about education commented:

"They should get information given to them."
"Use words we understand."
"Don't patronise us."

(Children in Scotland, 2001b, p. 12)

Parents of young disabled people from black, minority ethnic and Gaelic-speaking families have poorer access to adequate information about policies and procedures. Few staff in Scotland are bilingual, interpreting services are over-stretched and translated material not always available.

In addition, young people often have little choice because few options are available and/or others make decisions for them:

"Adults tell you what to do and you have to do what you are told."
"Other people decide you must live with your parents."

(SHS Trust, 2002, p. 31)

These young people, who had learning difficulties, were described as "passive and accepting" of the support they received: they thought it wrong to challenge an adult's opinion. Some individuals may be caught in a state of "permanent mid transition", retaining a 'teenager' identity into early middle age (Baron et al., 1999). Many young people feel strongly about having greater control of and responsibility for their lives but can be thwarted by access difficulties, lack of support or parental prohibition. However, other research has found that young people are active in managing their impairments and the barriers they face, resisting stereotypes imposed by others (Watson et al., 2000; Connors and Stalker, 2002).

Young people with communication impairments face particular risk of marginalisation. Talking Mats is a low-tech pictorial symbol system which has helped some youngsters express their views about transition (Cameron and Murphy, 2001). A Citizenship in Practice project with 46 teenagers used multi-media approaches, including art, music and drama, to enable children with a range of abilities to take part (Children in Scotland, 2002). Playback, a parent-led project in Edinburgh, has also consulted children in ways they enjoy, using play and video. Its new training pack is aimed at staff in social work, health care, housing and recreation, and includes material on transitions.

The legal framework requiring authorities to consult children and take their views into account in decisions affecting them is quite clear. It is set out in The Children (Scotland) Act 1995, the Education (Scotland) Act 1991 and the Standards in Scotland's Schools etc Act 2000. The Adults with Incapacity Act 2000 (implemented in July 2002) changes the system for safeguarding the welfare of adults aged 16 and over, seen to lack 'capacity' to make decisions themselves. With some exceptions, few advocacy schemes are aimed specifically at young disabled people.

Research in Scotland has shown that direct payments can increase disabled people's sense of choice and control in their lives (Witcher et al, 2000). Direct payments were extended to 16- and 17-year-olds through the Regulation of Care (Scotland) Act 2001. Seventeen local authorities currently operate active schemes (Direct Payments Scotland, 2002): under The Community Care and Health (Scotland) Act 2002, every authority will have to do so from June 2003.

Social life and relationships

Friendships and social life are important to all young people, yet some disabled youngsters spend most of their leisure time with their parents. One mother acknowledged:

"They don't want us… they want to do teenagery things."

(Stalker et al., 1999, p. 23)

Young people enjoy:

"Going out with my friends, going to clubs, being able to talk

to my friends near and far away from my house."
"I like going to discos because it would mean I could meet up with my friends."

(Children in Scotland, 2002, p. 14)

Many would like to meet more people and make new friends but lack of accessible transport can prove an obstacle. Only one of the 12 young people in the SHS study could, or was allowed to, travel on their own (SHS, 2002). Some had experienced neighbourhood harassment. The most important source of friendship was school, yet there was no support to continue friendships when they left school. Young disabled people are often denied access to the settings where other teenagers spend their free time, such as clubs and fast food outlets. Those from black and minority ethnic communities have similar interests and face the same barriers as other teenagers, but some settings are not sensitive to their cultural and religious needs (Patel, 2002). Deaf teenagers are more likely than their hearing peers to spend time alone (Dalton et al., 2001). They experience various difficulties accessing social activities, including the attitudes of some service providers. Some young disabled people have personal assistants, also likely to be young, to help them get out and about: they are very positive about this support.

Participants in the SHS study wanted to find out more about sex but had little awareness of consent issues or contraception, raising implications for both personal safety and rights (SHS, 2002). Parents often have concerns about sexuality, particularly regarding sons and daughters with learning difficulties. Barnardo's Family Support Service in Dundee has run workshops for parents and professionals, facilitated by The Family Planning Association, which proved popular.

Peer support groups offer young disabled people a valuable opportunity to meet others with whom they can identify. Examples include:

- Deaf Connections Youth Club for teenagers in Glasgow;
- Ethnic Enable, a new group for disabled young people from black and minority ethnic communities in Glasgow;
- The Lighthouse Youth Project for 12- to 18-year-olds in Edinburgh, run by Enlighten: Action for Epilepsy;
- Plus, which promotes social activities for young people aged 18 and over in Stirling.

Implementation of the Beattie Report

The Advisory Committee on Post-School Education and Training of Young People with Special Needs (the Beattie Committee), was set up in 1998, to review the needs of young people, aged 16-24, requiring additional support in post-school transitions. Inclusiveness was the "single unifying principle" behind its recommendations (Scottish Executive, 1999). Beattie proposed that 'disadvantaged' young people should have a key worker to liaise between different agencies and act as an advocate on their behalf. Following a review of careers services, in April 2002 the Scottish Executive set up Careers Scotland, a 'one-stop-shop' offering careers guidance to all age groups. It is co-ordinating 17 multi-agency 'inclusiveness projects', testing out different models of key worker support. These three-year pilot projects aim to improve young people's skills and employability, although not all of them include disabled youngsters. The Edinburgh and Lothians project, called 15-24, is targeting those leaving special and residential schools and young people with mental health difficulties.

Further and higher education

In reality, disabled young people's choice of college and university is often determined by physical access, attitudinal barriers and limited specialised resources. Finding out about available options is particularly difficult for young people outside the education system, including those whose education may have been disrupted by ill health. Disabled students in FE may find themselves in the same building as mainstream students but have "virtually nothing" to do with them (Riddell et al., 2001). A recent report (Scottish Executive, 2002b) called on schools and colleges to do more to help young people with additional support needs negotiate transitions. Examples of good collaboration exist, including Orkney and Clackmannanshire. Following the Beattie report, the BRITE Centre was set up to improve the expertise of college staff working with students who have additional support needs.

Disabled students in higher education face a range of barriers, including entrance procedures, access to information, the physical environment, assumptions of normality and levels of awareness (Tinklin and Hall, 1999). However, the Special Educational Needs and Disability Act 2001, implemented in September 2002, outlaws discrimination in every aspect of further and higher education.

Training and work

There are 13 Local Enterprise Companies in Scotland (equivalent of Training and Enterprise Councils in England). They organise Skillseekers schemes in which funding is tied to the number of young people achieving vocational qualifications. Because those with learning difficulties are seen as more expensive to train, and less likely to gain qualifications, training places designated for them may be taken by other young people (Riddell et al., 2001). However, in April 2002 the 'special needs' component of Skillseekers was replaced by a new scheme, Get Ready to Work. Young people on this course have a

personal adviser from Careers Scotland to support them through their training.

Many young disabled people are keen to have paid work. Barriers to achieving this include a lack of information among schools about employment options and transport and access difficulties. The Scottish Union of Supported Employment has 85 member organisations, based in about 160 locations from Shetland to the Borders. Short-term funding, often from European sources, is a continuing difficulty. However, the Supported Employment partnership in North Lanarkshire is one scheme targeting disabled school-leavers.

Benefits

The disincentives within the benefits system to disabled people taking up employment are well documented (for a Scottish example, see Riddell et al., 2001). These can be compounded by lack of knowledge among families and professionals about what is allowed within existing rules. Fear of losing benefits which contribute to household income can also deter young people from looking for work, or lead parents to discourage them from doing so (Weston, 2002).

Care leavers

There are about 11,000 'looked after' children and young people in Scotland, about 1,300 of whom are over 16 (Scottish Executive, 2002c). It is not known how many are disabled. In a study of throughcare and aftercare arrangements in Scotland (Dixon and Stein, 2002), over a tenth of 107 young people reported having a long-term physical health problem, nearly 5 per cent reported having a 'disability' and a third, a learning difficulty (including dyslexia). Unfortunately, the study did not look at these groups' experiences separately from those of other young people. However, only 39 per cent of the sample had received a planned throughcare programme while 40 per cent had no formal leaving care review. Health care was given lower priority than other needs.

The report of the Throughcare and Aftercare Working Group (Scottish Executive, 2002c) advises the government on improving services to care leavers. The only reference to disability comes in an Appendix, as an issue to be considered in individuals' assessment and action plans.

Housing

Dean (in progress) is exploring the housing aspirations of disabled people aged 17-25 and their parents. Emerging results from interviews with housing agencies indicate that young disabled people have similar aspirations to any others. However, they may begin thinking about leaving the parental home later than their non-disabled peers, and face particular difficulties achieving their goals. They are more likely to move into social housing than privately rented accommodation or owner occupation. Dean's early work suggests that barriers to young people attaining their housing aspirations include:

- family (in some – though by no means all – cases);
- social attitudes;
- shared living: (This is often difficult for young people with learning difficulties who may find themselves allocated to group homes. They are less likely than other teenagers to be able to choose their own flatmates or decide to move on if house-sharing is not working out);
- personal finances;
- housing design and accessibility;
- housing management and allocations policies;
- support costs;
- service inertia. (It was reported that some organisations take the view that if young disabled people are in a safe and 'adequate' environment, it is not necessary to think about making other, more appropriate, arrangements. An example given was a young person with learning difficulties living in a group home with older, perhaps previously institutionalised, residents).

None of Dean's key informants could identify specific initiatives aimed at supporting young disabled people to access housing. However, Supporting People, the new integrated policy and funding framework, will be introduced across the UK from April 2003, aiming to enable vulnerable people (aged 18 and over) to live independently in a range of accommodation and tenure.

Policy and practice implications

The following points were drawn from the findings of this review, reiterate recommendations in the literature or were made by professionals in the field.

Transition planning: process

The FNA process could be improved by:

- seeing transition as a gradual process, starting preparation earlier than at present;
- for those in care, increasing the average leaving age and extending the transitional period;
- giving young people 'practice' in making choices, and 'permission' to do so;
- thinking ahead how best to maximise every young person's participation, especially those with high support needs and/or communication impairments;
- explaining the process to young people and parents well before meetings;
- ensuring careers advisers take time to get to know the young person;

- providing information in accessible formats, including community languages;
- interpreters being readily available;
- recruiting more bi-lingual staff, especially in educational settings;
- arranging for young people, including those with high support needs, to visit colleges and workplaces prior to making decisions;
- using a range of media to promote participation, such as Talking Mats, video, arts and drama;
- encouraging flexibility in venue and format of meetings;
- ensuring careers advisers, social workers and relevant school staff attend FNAs;
- having a support worker on hand if required;
- where appropriate, offering separate advocacy support for parents and the young person;
- developing better links across different agencies to encourage transition planning that reflects young people's aspirations, as outlined in current proposals for multi-agency FNAs;
- more school-leavers' courses providing teenagers with information about employment, further education, health and sex.

Transition planning: content

FNAs should include:

- serious consideration of a wide range of post-school options, including employment and inclusive further and higher education with learning support;
- plans for nurturing and supporting friendships and social/leisure opportunities;
- informed and open discussion about benefits;
- a focus on young people's strengths rather than limitations.

Areas where practice needs to be developed

- opportunities for work experience for all disabled pupils, including those at special schools;
- more advocacy, befriending, mentoring and community connections schemes;
- more peer support systems;
- active encouragement to young people, from local authorities and voluntary organisations, to apply for direct payments. Help is available from Direct Payments Scotland, set up in 2001 to promote take-up;
- disability equality and citizenship training for all secondary school pupils; for those in special schools, sex education which includes information about consent issues and contraception;
- opportunities for exchange between school-leavers and disabled adults who could act as role models, passing on their knowledge and experience of dealing with the service system, and raising young people's expectations of what they can achieve. This may be a role for organisations of disabled people.

Professional training and development

- Many professionals working with young disabled people, such as careers advisers and social workers, would benefit from disability equality training, with young disabled people involved in delivering it.
- These staff also need training on communicating with school-leavers who have high support needs.
- Youth workers and leisure workers would benefit from training in inclusion.
- More disabled people could be recruited as youth and outreach workers.
- Professionals (social workers, teachers at school or college, careers advisers and keyworkers) with a remit to support young people's transitions into adulthood need to be fully informed about current benefits and able to direct young people and families to sources of accurate information and advice.
- Frontline benefits officers and welfare rights officers should be well informed about benefits relevant to young disabled people.

Inclusion

- The Scottish Executive, the Disability Rights Commission (DRC) and local authorities need to take account of the needs and wishes of young disabled people in relation to a wide range of policy initiatives, including employment, housing and transport. The DRC in Scotland must be active in supporting young people to challenge any perceived discrimination.
- More information should be collected (or analysed from existing data) about the numbers, circumstances and experiences of young disabled people leaving care homes and about the transition experiences of those leaving residential schools.
- Mainstream service providers - shops, restaurants, clubs, etc - need to make their premises accessible and welcoming to young disabled people. There should be on-going systematic monitoring by the DRC to ensure that service providers are meeting their duties under the Disability Discrimination Act.

About this review

This *Foundations* was written by Kirsten Stalker from the University of Stirling. It draws on relevant policy and research papers, as well as informal discussion with representatives of central government, statutory and voluntary organisations and researchers. Many thanks to all who contributed information or comments, especially Children in Scotland, the Centre for Integrated Living in Glasgow and Emma Stone of the Joseph Rowntree Foundation. Further information about the practice projects mentioned is available from Dr Stalker.

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The Homestead
40 Water End
York YO30 6WP
Tel: 01904 629241
Fax: 01904 620072
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