
Bridging the Divide at Transition

What happens for young people with learning difficulties and their families?

Final summary of research findings

The transition to adulthood can be a difficult time for all young people and their families, but young people with learning difficulties face additional challenges. A questionnaire survey of 283 families and in-depth interviews with 27 young people and 27 parent carers in England, undertaken by the Home Farm Trust and the Norah Fry Research Centre, found that despite legislation and guidance:

- A fifth of youngsters had left school *without* a transition plan
- Almost half the young people had little or no involvement in the planning for their future
- Lack of planning led to uncertainty and stress for some families
- The quality of transition planning varied widely; in some cases it was ad hoc, confused and uncoordinated
- The topics covered in transition planning were often quite different from those families considered to be important
- For many young people, key issues (eg. transfer to adult health or social services) had still not been addressed by the time they left school
- Whether or not youngsters had received transition planning made little difference to what happened to them after leaving school
- There were few post-school options available to young people particularly in relation to housing and employment
- There was a lack of easily accessible information for parents and young people about what future possibilities might be
- Concerns raised by the young people and their families which inhibited greater independence focused on
 - personal safety and risk
 - money matters (including benefits)
 - transport

Background

Moving into adulthood is one of the most far-reaching and complex transitions for anyone, but young people with learning difficulties face additional challenges including transfer from children's to adult health and social services.

The particular problems confronted by young people with learning difficulties and their families were recognised in the English White Paper *Valuing People* (DoH 2001); objective 2 focuses specifically on transition to adult life. The new Partnership Boards established to oversee local implementation of the White Paper are supposed to include a transition champion, while the new Connexions service should ensure that every young person will have a Personal Adviser to help them negotiate leaving school and entering adult life (DfEE 2000).

The official duty to undertake transition planning was set out in the Education Act 1993 and associated Code of Practice (DfEE 1994), revised and updated in 2001 (DfES 2001).

The research

The study sought to establish whether legislation and guidance were being followed for young people with learning difficulties and their families at transition.

- A postal questionnaire was sent to 370 families (283 replied: a 76% response rate), asking about their experiences of transition planning, the aspirations of the young people and their parent carers, the outcomes of the process and how far these reflected the views of young people and their families. The young people were aged 13-25, so were at different stages in the transition process.
- In consultation with groups of young people with learning difficulties, a "Growing Up" workbook was developed and used to interview 27 young people with learning difficulties.
- In-depth interviews were also carried out with 27 parents.

- Visits were made to 10 projects across England which seemed to be addressing key concerns and demonstrating elements of good practice at transition.

How many young people had transition plans?

Annual transition planning meetings should be held for all young people with learning difficulties in year 9 (over the age of 14). Although the majority of parents felt there was a need for school-led planning, the survey found that:

- Only two-thirds of those still at school had a transition plan
- A fifth had left school without a plan (despite the fact that the majority had left when planning was already a legal requirement)
- The proportion of youngsters leaving school *without* a plan had *increased* between 1998 and 2000.

Young people's involvement in planning for their future

'He found the process very unsettling and he was bewildered because he did not appear to know what was going on.'

Legislation and guidance direct that the young person's views must be sought and recorded during their transition planning, but the study found that:

- only 29% had been very much involved
- 29% had been partly involved
- 19% had little involvement
- 23% of young people were not involved at all.

Young people still at school were *less likely* to have been involved in their transition planning than those who had already left and were also *less likely* to have had their views reflected in their plans.

Young people were *more likely* to be able to make choices when work experience or link placements could help them make informed choices, when they could look at videos or brochures about possible options, and when

planning timescales allowed them to emotionally adjust to future changes.

'That was lovely when he got his first wage slip ... it was the most wonderful moment, he was so proud.'

Issues covered in transition plans

'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.'

The transition plan should touch on every aspect of the young person's future life. But there was a significant discrepancy between issues that families wanted to be addressed (information on leisure and social opportunities, benefits, future housing options and further education opportunities were the topics most wanted) and those which were actually covered in transition planning (only further education, of the above four topics).

Does transition planning make a difference?

The move to adulthood involves a number of key transitions for young people with learning difficulties. Whether or not they had received transition planning seemed to make little difference to what happened to youngsters in the study.

College, employment or other day activities

Over three-quarters of the young people went directly from school into further education (over half of these to residential colleges), often because this seemed to be what was expected rather than something the young person might choose to do. Very few had worked on a paid or voluntary basis; about a quarter were using day (resource and activity) centres.

'We didn't realize Kath could stay at college till 25, we only found out about that later on ... it gives you a breathing space to find out if there is anything.'

Moving into their own home

Almost three-quarters of youngsters who had left school were still living in the family home. Although most parents wanted housing options to be included in the transition planning process, only one in ten who had had some planning felt that this had been covered well. Families need information and support to negotiate this major transition but where the young person *had* moved away from home, this was largely due to the often stressful efforts of parents themselves..

'Living with my parents I like that, it's good. I'd like to [move out one day] but I'd have to think about it and talk it over with my parents.'

Adult social activities, friendships and relationships

Although leisure and social activities was the topic that the largest number of parents wanted covered in planning, this had *not* been covered for over half the families in their transition planning. Many of the young people's friendship networks were repeatedly disrupted after they left school. Parents themselves were often trying to organise structured activities for their sons or daughters, but were doing so with little information or support, particularly in the area of adult relationships.

'I mean, you know, we thought we had problems when she was younger but this is getting out of our territory really. We really don't quite know how to handle it.'

The move from paediatric to adult health services

The revised Code of Practice sets out a clear role for health services' involvement in transition planning and *Valuing People* (2001) identifies young people at transition as a priority group to receive individual Health Action Plans in the future.

Over half the parents who had received transition planning reported that transfer to adult health services had not been covered at

all, and less than a fifth thought it had been covered well. For parents, adult health services meant a lack of continuity and of regular reviews.

'While Sarah was under the care of child services it was consistent. It was a very good consultant ... when we were handed over to adults ... every time we went we seemed to see a different person. And we'd spend half the appointment going over past history. The continuity had gone completely.'

The move from children's to adult social services

For more than 40% of families who had received some transition planning, transfer to adult social services had not been dealt with *at all*; only a quarter felt it had been covered well. This lack of effective links between children's and adult's services was highlighted by *Valuing People*.

'I think it was when she was 19 when she [the social worker for the children's team] said "I won't be coming any more and I doubt very much if you will see much of the people who are taking over from me"'

Factors inhibiting greater independence

Several issues were mentioned during the in-depth interviews, which affected the extent to which the young people could exercise greater independence in their lives.

Safety and risk

Concerns about safety and risk were spontaneously mentioned by half the parents. A quarter of the young people had experienced serious incidents including severe bullying and sexual assault (though action against the perpetrators had rarely been taken); others expressed concern about personal safety including road safety. Some parents acknowledged they might be 'over-protective' but their fears and anxiety were sadly sometimes justified.'

'I want to know there's people about ...in case someone came to me and have a go at you.'

'They've shown me how to cross the road and I've done it or once or twice on my own but I still don't feel safe.'

Money and benefits

Irrespective of their age, few of the young people managed their own money or knew how to budget; parents often did this on their behalf, although some were aware that work on this could enhance their son's or daughter's independence.

'Ah money – I can sort it out all right. It's just when I go to buy things I don't get it right.'

Young people may be entitled to claim certain benefits when they reach the age of 16, but over half the parents who had received transition planning or whose children had left school said that benefits issues had not been covered at all. Nearly three-quarters of parents who had not been through the planning process saw this as an important issue.

'[Claiming benefits] was like [being] in the middle of a maze ... you're going round and round and back.'

Transport

Almost three-quarters of parents whose children were still at school wanted post-school transport arrangements to be covered in the transition plan, but many found their hopes were frustrated in that such discussions were discouraged until prospective service changes had been definitely agreed. Parents had many concerns about letting young people travel independently and some of the young people voiced concerns about the unpredictability of public transport.

'I'd like to learn to use the bus, yes.'

Young people's views on improving the transition experience

The young people in the study suggested ways of improving the transition planning process, mentioned things they had appreciated, and had messages to pass on to others. These included:

- having someone independent who they could talk things over with and who would listen to them
- having consistent support to enhance their self-confidence and self-esteem
- being treated as an individual
- others encouraging them to having higher (but not overwhelming) expectations of themselves
- being given more responsibility and privacy.

'Have faith in yourself ... and say, this is me now, yeah!'

' ... talk to other people when you feel lonely.'

Parents' views on the transition planning process

Parents described positive and negative aspects of transition planning and suggested changes to the process which they would like to see.

Positive aspects included:

- Work experience or link placements to adult services and opportunities for the young person which provided new experiences, time to adjust to new places and helped them exercise choices
- The young person being able to make informed choices
- Allowing time for the young person to 'emotionally prepare' for change
- Staff in school or adult services who were supportive, encouraging and acted in the young person's best interests
- Being actively involved themselves in the planning process

Suggestions for improvement included:

- Initiating transition planning reviews at the prescribed time
- Regular review meetings to revisit and update the plan
- Advice and guidance on preparing for meetings
- Ensuring that all key professionals attend review meetings
- A transparent transition process with clear accountability

- Provision of accurate, up-to-date information in a range of formats
- A named coordinator for each family

Better practice at transition?

Bridging the Divide also found illustrations of creative and innovative initiatives in a variety of geographical locations across England, which were starting to address the problems described by parents and young people in the study. Between them they exemplified the 5 Cs:

The five Cs: elements in a good transition experience

Communication

which is open, honest and respectful between agencies, and between agencies and families; independent advocacy for young people.

Coordination

effective inter-agency working; joint training initiatives; joint assessment procedures and a cohesive strategic approach to service provision.

Comprehensiveness

an effective transition plan for *all* young people; appropriate race and disability equality training for all staff; expectation that young people with learning difficulties will have access to the same opportunities to realise their aspirations as their peers.

Continuity

key workers to support individual youngsters and their families throughout the transition process; a seamless transition from children's to adult services; a range of options for young people to move into and between.

Choice

more and better involvement of young people and their families in the transition process; access to appropriate information on potential options; development of a range of local post-school alternatives in housing and employment.

References

DfEE (1994) *Code of practice on the identification and assessment of special educational needs*, HMSO, London

DfEE (2000) *Connexions: the best start in life for every young person*, London, DfEE

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Further information

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Further copies of this summary from: www.bris.ac.uk/Depts/NorahFry or www.hft.org.uk or tel: 0117 923 8137.

Growing Up, an accessible, illustrated booklet for young people with learning difficulties, based on the project findings, is available on the BILD website:- http://www.bild.org.uk/publications/booklets/growing_up/growing_up_home.htm

All change: transition and young people with learning disabilities. An information guide. Information pack for parents, professionals and young people available from Pavilion Publishing, Brighton in early 2003, tel: 01273 623 222 or www.pavpub.com.

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