

## Transition to adulthood for young disabled people with 'complex health and support needs'

Although the term 'complex health and support needs' covers a wide range of impairments and conditions, young people with high levels of health and/or support needs experience some common difficulties in their access to services during their transition to adulthood. A review of research, consultation with six local authorities and interviews with young people themselves found:

- f** Increasing numbers of children with health and support needs are surviving into adulthood.
- f** Health and social services organisations generally have inadequate and incomplete information about the numbers of young people with health and support needs.
- f** Information about medical conditions, treatments and impairments was important to young people but they did not always receive the information they needed, or in ways which were useful to them.
- f** Young people who need high levels of support continue to be at risk of moving into segregated (institutional) accommodation as they reach adulthood.
- f** Young people sometimes lose contact with specialist healthcare services when they cease to use paediatric (children's) services.
- f** Some young people would benefit from health services specifically geared to transition to adulthood. However, there is very patchy provision of such services across the country.

## Introduction

There are increasing numbers of young people who have a range of physical, sensory and cognitive impairments, many of whom also have continuing health care needs associated with their impairments. There are also young people who, while they do not have 'multiple impairments', have quite high levels of need in terms of continuing health care. Over recent years, children with conditions associated with poor life expectancy (such as cystic fibrosis) have been surviving into adulthood because of more effective interventions and better quality care.

These young people share a number of experiences, both in terms of their general transition to adulthood and their relationships with services. A key common characteristic is that they all require a combination of health and support services in order to access a good quality of life, and that existing services seem to find it a complex matter to meet their needs. The young people are particularly vulnerable to a failure of health and social services to meet their needs in the context of the transition to adulthood. This review identified a number of important issues.

## Inadequate information about the numbers of young people concerned and their needs

One of the biggest problems facing planners is that local sources of information have varying ways of gathering data: health, social services, education and voluntary organisations work with different definitions of disability and health needs. There is no nationally agreed categorisation which applies across agencies. Another problem is that registers of disabled children and adults often do not allow for the identification of those with 'multiple impairments' or for those with continuing healthcare needs.

Most information gathered does not focus on the actual needs of the young people concerned. Instead planners tend to establish numbers of people who fall into various service categories (physical, sensory, learning disabilities, disabled children), diagnoses (e.g. cystic fibrosis, haemoglobinopathies) or eligibility criteria (banding according to levels of dependency).

Present systems for gathering information about the performance of health and social services organisations are not based on measuring the things which are important to young people themselves,

such as: the provision of information about their condition; being able to go out with their friends; access to communication equipment for those who need it.

## Access to information and peer support

Young people wanted accessible information, given directly to them rather than to their parents. Peer support was also important, particularly for those who required ongoing treatment and/or whose conditions were life-limiting. However, this support was not always available or recognised as important by service providers.

## Education

Some young people interviewed had clearly been discriminated against in their access to education. A number were struggling with the legacy of poor standards of education and spoke of how they had not been given the opportunity for continuing with education and learning in the way they would wish.

## Accommodation and support

People with high support needs face very few options other than some form of residential care because:

- there is a dearth of good quality services in community settings for people who have high support needs, particularly for those identified as having 'challenging behaviour' and those with continuing nursing care needs;
- a shortage of wheelchair accessible housing is still a major barrier to independent living for those with mobility impairments;
- the cost of providing the high levels of support that some young people need can mean that health and social services purchasers will look for 'economies of scale' and are reluctant to consider even small-scale group homes;
- while there has been progress in the provision of supported living projects for people with learning difficulties - enabling them to live in 'ordinary' houses in the community - these initiatives often do not cater for people who also have mobility impairments and/or health care needs.

Young people were interviewed who are effectively being 'warehoused' in residential provision: they have little opportunity for making friends, being involved in their local community, or doing anything

meaningful during the day. To a large extent the scope for any personal development has ceased. Some of the young people placed in residential establishments have little or no continuing contact with their social services department. This includes young people like Jennifer, whose parents were just offered a list of residential establishments when she left school, and who only goes out when she attends a day centre twice a week or to visit her parents:

I only keep in touch with one friend from school. I'm not really happy with what I'm doing here, I want to go out more.

Some young people require housing and support services which are knowledgeable about and sensitive to issues relating to their particular impairments. One service provider interviewed talked of how important it was that those working with, for example, a young man with brain injury, who also had sickle cell anaemia, understand the consequences of these two conditions: "If they don't know how to recognise and respond to his needs, his life expectancy will be shortened".

## Health

Many young disabled people cease to have access to specialist health services once they pass out of paediatric services. In recent years a few 'transition' clinics have been set up but the picture is still patchy across the country and many young people have the kind of experience described by Simon:

When you get to 16 they get rid of you. ... I haven't been to the hospital for a check-up since I was 16. I know I'm OK at the minute but a lot could happen. No one's mentioned to me what happens to my condition as I get older.

Most people with physical or sensory impairments and/or learning difficulties have the same kind of health needs as the rest of the population but they may also have some specific health needs related to their particular impairment or condition. There are a number of barriers to good quality health care - experienced in common by people with widely different impairments and conditions. For example:

- access to primary health care may be poor because the service creates barriers: for example, a GP may

not take the time to understand someone with a communication impairment; one local authority reported how a group home for people with continuing health care needs found the local GP refused to allow them to register with him;

- one label gets in the way of recognising other needs: for example a failure to recognise sight problems for people with learning difficulties or, if recognised, failure to address them seriously;
- a lack of understanding amongst health care professionals about specific conditions: for example, young people with diabetes spoke of how general practitioners often had little knowledge about their condition, and they would prefer to attend specialist clinics.

## Communication needs

Transition to adulthood can mean losing touch with the people who know how a young person communicates. Young people may need communication aids and it is not clear who is responsible for funding these or for their maintenance and updating. Many young people and their families are paying for communication equipment themselves or raising money through charities. There is confusion over whether social, health, education or employment services have statutory duties in this area. Young people may continue using the equipment they were issued with at school and not have access to updated technology and methods.

## Access to employment and leisure opportunities

Young people talked about the barriers that get in the way of employment opportunities, including prejudicial attitudes held by employers about people with conditions such as cystic fibrosis. There is also evidence of disincentives to paid employment created by the means-testing of personal assistance (through social services charging policies and eligibility criteria for Independent Living Fund grants). Lack of transport and inadequate access to support were key barriers to young people going out and enjoying themselves. Michelle had hoped that moving into a bedstead attached to a residential home would give her greater freedom and ability to socialise than she had previously had, but unfortunately faced the same problems:

I was very isolated. Transport was a major problem - if you could get the vehicle you couldn't get the driver -

'we're short-staffed' ... Although I saw it [moving into the bedsit] as a new start, it hasn't been that – it's the same short-staffing, no transport and I still feel isolated.

### Listening to young people

Young people interviewed stressed the importance of listening to them. As Charlotte said:

If anyone were to ask me what message I might have for others I would tell them that they should listen to, believe and respect young people. In my experience it is very difficult to tell anyone how you feel when they won't listen; if you aren't believed then you stop believing in yourself; if you're not respected then you lose your self-respect and everyone needs self-respect.

Young people had clear views on how organisations and professionals could do things better. All of the local authorities said consultation with young people was an area that could be improved upon: "This is an area we need to develop", said one officer. What consultation there was tended to be with parents and to focus on services rather than on needs.

### Conclusion

This review concerns a group of young people who have a wide range of conditions and impairments but whose common characteristic is that they all require a combination of health and support services in order to access a good quality of life. There is evidence that many of these young people experience a failure of health and social services to meet their needs as they grow into adulthood.

A more integrated and needs-led approach to both commissioning and the provision of services is required. The current fragmentation in responses to their needs is not only caused by the divisions between health and social services but also by inadequate liaison with housing, leisure, education and employment services, and the experience of being transferred from children's to adult services within health and social services organisations.

### About the study

The review was carried out by Jenny Morris, an independent researcher. She summarised what is known from existing research about transition to adulthood for young people with 'health and support needs'. Information was also gathered from six local authority social services departments about policies concerning this group, including joint work with health and education services. The report included material from 14 accounts by young people about their experiences and aspirations and 2 accounts by parents of young people who have significant learning and communication difficulties.

### How to get further information

The full report, 'Hurling into a void': Transition to adulthood for young people with complex health and support needs by Jenny Morris, is published for the Foundation by Pavilion Publishing (ISBN 1 84196 001 2, price £16.95).