



The Road Ahead?

Information for young people with learning difficulties, their families and supporters at transition

Valuing People, the government White Paper on services for people with learning disabilities in England recognised the difficulties confronted by young people with learning difficulties and their families at transition. Previous research has demonstrated that information is a key need at this time. 'The Road Ahead?' project commissioned by the Social Care Institute for Excellence and undertaken by the Norah Fry Research Centre, University of Bristol, North Somerset People First Transition Team and HFT explored the nature of the information needed by young people with learning disabilities, their parents and supporters at transition. It found that:

Most of the young people involved in this study did not understand the term 'transition'. But all of them had clear expectations about what they wanted to do, or change, 'as they grow up'.

- Parents were often unclear what happens at transition and, their role then. They expressed feelings of concern and fear.
- Young people, parents and supporters all wanted the same information during transition. They needed information on:
 - The transition process, their roles within the process and their rights and entitlements
 - The local situation including accessing person centred approaches, the support and services available
 - The young person's rights and responsibilities as an adult including information on self advocacy, empowerment, risk taking and keeping safety
 - All of the choices and changes available.
- Young people need information presented in a way that empowers them and enables them to take more control of their lives.
- Parents need information to respond to their concerns for their young person and the support they need.
- Supporters this information in a way that enables them to support the young person and their family through the transition processes.
- The literature confirms the importance of parents during the transition process and their need for appropriate involvement and support.
- There are many information resources available to support young people and their parents during transition. But these do not specifically attempt to empower young people or parents.

About the project

This paper summaries findings from three interlinked investigations around transition for young people with learning difficulties and their parents, undertaken between October 2003 and March 2004. These included:

- Focus groups interviews with 27 young people, 19 of their parents and 19 of their supporters in 4 different areas of England and Wales
- A systematic review of the literature on transition
- A review of the information resources already available for young people, parents and professionals, including an evaluation of materials by young people and parents.

The project was undertaken for Social Care Institute for Excellence (SCIE) by the Norah Fry Research Centre, University of Bristol in partnership with North Somerset People First Transition Project Team and the Home Farm Trust.

The term 'supporters' is used to represent workers who support young people at transition. The supporters involved in the focus groups included learning support assistants, volunteers and sessional staff at a leisure support service and an advocacy project for young people with learning difficulties, a special school teacher and a Connexions Adviser.

Young people's expectations of life as an adult

Most of the young people involved in this study did not initially understand the term 'transition'. It was explained to them as 'growing up' and 'deciding what to do when you are older'.

For some of the younger people the issue seemed irrelevant as they were staying on at school until they were 19 and they were happy living at home. Others had begun upon the series of changes that occur in adult life: they had part-time jobs, or were doing work experience with a view to getting a job, or were at college to learn about future work options.

The young people had expectations similar to their non-disabled peers and those or

recognised in the literature as markers of adulthood. They expected to go to work or college, have a social life, continue their hobbies, make friends and have relationships. The young people did *not* mention use of services in the future; but they did want very practical information and support that would enable them 'be in charge of their lives and to live more independently'.

The young people recognised that while growing up there were emotional changes, as well as choices, to be made. They wanted information on music, sport, hobbies and socialising as well as information to help them be in control of their lives. One young person specifically highlighted the contribution young people could make to society through helping others.

Parents' information needs

The parents recognised that transition was about their young person growing towards adulthood and adult responsibility. This understanding was contextualised within concerns about their young person's ability to take on the responsibilities of adult life and how they would be treated by the wider public.

Parents often lacked any understanding of the transition process, commonly not realising that the school transition process should cover all the aspects of the young person's life, not just a move from school to college. They talked about feeling scared and frightened, not knowing what their role was in the process. They were aware of the lack of adult services available and that they might have to fight to get their young person the support they needed. They felt they needed information on each of these areas.

Support was a dominant theme within the parents' discussions. They were concerned about their young person getting the right support in all aspects of their life as they moved into adulthood. Some parents discussed the longer term issue of support when they were no longer able to support their young person themselves.

The information needs of supporters

The supporters discussed transition from the viewpoint of the young people. They recognised that transition was a very emotional process for them. It was a time of

confusion, fear, challenge and excitement during which appropriate and realistic emotional and practical support was vital. They felt that young people should have the support of 'trustworthy people' at this time while recognising that the young people's dreams and aspirations might be met with a lack of choices and struggles to get appropriate services.

The supporters felt that they needed to know the young person very well, and know their home background and the wider support available to them, in order to support and empower them through this emotional and challenging time. They needed good information about the transition process locally, the choices, services and supports available, and how they could best contribute to the young person's planning process.

Supporters highlighted the importance of person centred planning to ensure that the young people's expectations were supported and championed, while being sensitive to the realities and availability of current services locally.

Supporters needed detailed information on the one hand about the transition process (both at a national and local level) and the roles and responsibilities of everyone involved, and on the other, about the choices and changes facing young people and how these could be grounded and worked through at local level.

So what information do people need about transition?

The review confirmed that young people, parents and supporters want detailed information about the transition process and how it is implemented locally. They need to know:

- What transition is, who is involved and the different roles they have to play – whether as young person, parent, supporter, social worker, teacher or Connexions Personal Adviser
- What rights, entitlements and procedures exist at a national level. This includes information on changes in funding and benefits and explanation of terms such as: Supported living; Direct Payments; HAPs (Health Action Plans)
- How the transition process works locally:

its structure and process

- How person centred choices can be accessed locally
- What services are available locally and what options might be developed for the individual through different agencies. This information should be up to date and include relevant contact details.
- What support is available to young people and families throughout the transition process and into adult life. Are there specific transition workers or keyworkers locally?

Information also needs to be provided to support young people, parents and supporters to understand, and work through, a range of other issues arising at transition. These include:

- The impact of changes on family relationships
- Adult rights and responsibilities
- Empowerment and self advocacy
- Increasing independence, including taking opportunities, safety and risk taking

These issues need to be presented in a concrete and practical way, using activities to enable young people, their parents and supporters think through the implications of the young people's choices and changes in the context of their own personal and emotional lives.

Information about changes and choices

The young people, parents and supporters also wanted more specific information on the following areas:

- Work
- Going to college
- Where to live
- Money (including handling money and the impact on benefits of getting a job or moving from home).
- Friends
- Sex and relationships
- Safety
- Being in charge of your life
- Rights and responsibilities (including

helping others, playing an active role in the community, and the law and people with learning difficulties)

- Living independently
- Healthy living
- Emotional changes
- Having fun

The parents and supporters suggested an additional need for information on changes in services at transition.

Information for young people, parents and supporters needs to be presented in a format that responds to the particular needs of each different group.

What does the literature say about the information needs identified?

Key points from the literature review (Townesley, 2004) were as follows:

- Transition is a stressful time
- Young people's aspirations may not be met
- Young people are often not involved appropriately in their own transition planning process
- Family support and involvement is very important
- Confusion exists around the transition process, the way it is implemented locally and the nature of the different plans made by different agencies
- As well as clear information, families need a key contact who is independent of services to help them through the process. It is unclear whether Connexions Personal Advisers are in a position to undertake this role
- A holistic approach to person centred planning is essential at transition. Such an approach needs to ensure that young people's aspirations are supported and championed, while being sensitive to the realities of what is currently available locally in terms of services and support.

The literature review also showed that:

- Few young people had jobs
- Many young people used day centres
- Going to college was often the expected route of progression from school

- Parents need support to discuss housing issues with their young person
- There is a lack of clear information about benefits and information about direct payments
- Choices may be difficult for young people; some strategies for decision making are suggested.
- Safety and risk are a major concern for families and young people with learning difficulties at transition. However only one study has focussed entirely on this issue.
- Support to make choices at transition is vital but the idea of 'choice' can be very unclear to many young people with learning difficulties.
- Empowerment, rights and responsibility at transition have received scant, if any, attention in the published literature.

What do the information resources on transition cover?

There are many resources designed to support young people and their families through transition (Watson, 2004). The resources for parents vary hugely in format and detail, ranging from factsheets to a 246 page pack. The most comprehensive of these is the *All Change* pack (Mallet et al, 2003) which describes all of the parties and issues that are likely to be involved in the transition process and has sections for both young people and parents. A number of local resources combine both local and national information in the way which parents said they wanted.

Some resources are aimed specifically at young people and explain the transition planning process. These include resources such as *Transplan*, *Planning My Future*, and the *Big Picture*, (when completed). The *Transactive* website aims to help young people create a multi-media passport about themselves in transition.

There were a number of general packs which covered the majority of issues raised by study participants. The *All Change* pack most closely reflected the themes discussed by the young people, their parents and supporters.

Generally, there was less information available on employment than might have been expected, while only two packs specifically focused on the transition to college. No resource focusing specifically on handling money for young people at transition was found nor any specific information, in an accessible format, on sex and relationships for young people. The information available for parents about sex and relationships was not recent.

Little information was found that would support young people to be in charge of their lives. Although empowering in tone, the resources did *not* include direct information on empowerment, or guidance on daily and healthy living. Neither did the resources respond to the emotional aspects of transition, particularly how to deal with disappointment or frustration, when young people's dreams could not be turned into reality.

While resources *are* available for people with learning difficulties generally on topics, such as housing, employment and self advocacy these themes are *not* covered in the specific information produced on transition for young people.

No resources were found to help schools with the process of transition planning, other than the *Transactive* Website which helps young people develop information about themselves for use in the transition process.

How to present information about transition

Information about transition for young people with learning difficulties should have the following features:

- It should be age appropriate – using adult looking images and language which is clearly understood by young people
- Text should be large
- Sentences should be short, clear and use easy words. Long words should be explained.
- Layout should be clear, with lots of space around the text and pictures
- Small amounts of information should be provided at a time (with links to further information where appropriate)

- Pictures should be used to convey the messages within the text
- Pictures should be clear and simple. Each picture should convey one message. Pictures should *not* use words to get their message across
- The pictures and text should be checked out with young people with learning difficulties to see that they understand them as intended.

Websites providing information for young people should:

- Use colour, be inviting, fun and easy to use
- Use colour or symbol coding and easily recognisable buttons to help navigate around the site
- Use activities and interesting examples, to help young people understand the text and apply the messages to their own lives.

Information for parents also needs to be clear, inviting and not too densely packed with details. It should provide them with an overview of the national and local context, including relevant contact information for services.

All information should be developed in conjunction with the target audiences, that is young people, their parents and supporters, and should recognise that young people and parents need information in a variety of other ways - including through personal support, such as a keyworker - during the transition process.

How to get further Information

There are five other outputs from the project

A full report by Beth Tarleton: *The Road Ahead – Information for young people with learning difficulties, their families and supporters at transition*

A systematic review of the literature on transition for young people with learning difficulties by Ruth Townsley: *The Road Ahead? What does the literature tell us about the information needs of young people with learning difficulties and their families at transition?*

A review of the resources available to support transition by Debby Watson (presented as Appendix C of the full report)

An easy summary by Beth Tarleton of the key themes and findings from the project about transition for young people with learning difficulties

An easy report by the Transition Project Team from North Somerset People First: *The Information World for Young People with Learning Difficulties as They Grow Up* (North Somerset People First, 2004)

Note

This paper summarises findings from a research review commissioned by the Social Care Institute for Excellence. The views expressed are those of the authors alone.

These outputs are available for download from the Social Care Institute for Excellence website ()

References

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