



Changes and choices: finding out what information young people with learning disabilities, their parents and supporters need at transition

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Accessible summary

- Transition means growing up and becoming an adult. There are a lot of changes and choices for young people at transition.
- We found out what information young people, their families and supporters need at transition.
- Young people with learning disabilities from North Somerset People First did the project with other researchers.

Summary

This article provides an overview of the methods and findings of a project, commissioned by the Social Care Institute for Excellence, to explore the information needs of young people with learning disabilities, their families and supporters at transition. It describes how a group of young people with learning disabilities were trained in research methods and undertook four focus groups with other young people with learning disabilities in England and Wales. Parallel focus groups involving their parents and supporters were conducted at the same time, facilitated by a family carer and professional respectively. The different kinds of information required are summarized: for example, all three groups wanted information about getting a job and going to college and about the transition process generally, but there were also differences in emphasis between the groups, which are described. Key issues in providing information at transition in ways likely to be most accessible to the different stakeholders are outlined.

Keywords Inclusive research, information, parents, supporters, transition, young people with learning disabilities

Background

The problems confronting young people with learning disabilities and their families in the transition to adulthood are highlighted in *Valuing People*, the White Paper on services for people with learning disabilities in England (Department of Health 2001). Transition has also been recognized as an area for further development work by the

Welsh Assembly government (National Assembly for Wales Learning Disability Advisory Group 2001). The difficulties arise as young people confront not only the ordinary challenges of growing up and moving from school to college or employment, but also those associated with moving from children's to adult social support and health services. The lack of co-ordination between agencies, and the minimal involvement of young people in planning their

own future, are key issues (Heslop *et al.* 2002). In an attempt to improve matters, *Valuing People* stipulated that Directors of Social Services should ensure that good links were in place between children's services and adult services for people with learning disabilities.

The local Learning Disability Partnership Boards, set up by the White Paper, were to include a transition champion, while young people with learning disabilities were to be a priority for health action plans and person-centred planning. At the same time, the requirement for transition planning (established by the Education Act 1993 and associated Code of Practice) was strengthened by the revised Code (DfES 2001), along with the expectation that parents should be treated as partners and that young people themselves should be involved in making decisions and exercising choices. It was also hoped that the advent of Connexions, the new advice and guidance service for all 13–19-year olds in England (extended to 25 years in the case of young people with learning disabilities) would provide a full service to young people with learning disabilities by 'co-ordinating the delivery of appropriate supports and opportunities' (DfEE 2000).

Previous research has shown a lack of easily accessible information to be a significant problem for parents and young people with learning disabilities at transition (Heslop *et al.* 2002). Without information it is hard for young people and their parents to make choices about their future. Access to good information is also critical for the staff and supporters – Connexions personal advisers, teachers, learning support assistants, advocates – involved with them. Unless they are familiar with the range of options available over the different sectors involved (social services, health, further education, leisure, employment, benefits and so on) their ability to help young people and their families effectively is severely limited.

So what are the information needs of young people, their families and supporters at transition? The Social Care Institute for Excellence (SCIE) commissioned *The Road Ahead?* project to find out (Tarleton 2004a). The project was undertaken by a partnership of three organizations: the Norah Fry Research Centre, at the University of Bristol; North Somerset People First (a self advocacy group with a special 'transition team' of young people established for this project); and Home Farm Trust (HFT) – a national service provider.

The project was divided into three strands:

- A systematic review of the literature on transition.
- A review of the information resources on transition already available for young people, parents and professionals, and an evaluation of their accessibility.
- Focus group interviews with young people, their parents and supporters to ask them directly about their information needs.

This article focuses on the process – and findings – of the third strand. (For a systematic literature review, see

Townsley 2004; for a review of information resources, see Watson 2004).

Methods

Involving young people with learning disabilities as researchers

There is now growing recognition of the value, and importance, of involving disabled people, and people with learning disabilities, in the research process (Atkinson 2004; March *et al.* 1997; Tarleton *et al.* 2004; Ward 1997; Ward & Simons 1998; Williams 1999). This reflects the move towards including young disabled people as partners in service planning and in planning for their own future (Badham 2004; Cavet & Sloper 2004; Hayes 2004). Given the commitment to user involvement of the funder (SCIE) and all three partners involved in the research consortium, priority was given to ensuring young people with learning disabilities were involved as researchers on the project. Over a period of weeks, the young people in North Somerset People First's transition team and their supporter, met up with the project's lead research worker (based at the University) to discuss the team's own experiences of transition; to think about what the term 'transition' meant to them; and to talk about how 'transition' could be explained to other young people with learning disabilities in a way that would not influence their thinking. The team decided that they would describe transition as 'growing up and becoming an adult' so that the young people interviewed as part of the project would think broadly and not only in terms of what to do in the daytime after leaving school. During these initial sessions, the team also took part in a training day with the Bristol Self Advocacy Research Group, a group of older self advocates who had experience of undertaking research. Here they took part in activities to familiarize themselves with key research issues, like confidentiality, and to learn interviewing, and other research-related skills.

In order to develop materials for the focus group interviews they were going to undertake, the team decided to try out an activity themselves. They thought of things *they* needed to know about transition and represented them either through pictures drawn on to post-it notes or cut from a picture bank. They then placed the pictures on a flipchart with three concentric rings drawn on it: the most important things in the inner circle, the next most important in the middle and the least important in the outer ring. They piloted the materials at two local special schools and made revisions accordingly, adding more pictures and symbols to provide a wider range of options to choose from. They practised open-ended and follow-up questions and made A4-sized 'help'

cards to provide specific choices for young people who needed more support to communicate. Each of the cards presented one open-ended question and a number of possible reply options represented in picture form.

The young people's focus groups

When they had acquired sufficient confidence, the young researchers wrote an easy-to-understand letter inviting young people with learning disabilities to the focus group sessions. In the letter, they used their own explanation of the term 'transition' along with a drawing – of a small person growing up to be a big person – to illustrate the concept. The invitation also included a picture of the research team, their supporter/manager, the lead researcher from the University Research Centre and other illustrations. An easy-to-understand consent form was included with the invitation. Four focus group sessions were held: three in England and one in Wales. The groups were purposively selected to represent a range of different organizations supporting young adults with learning disabilities (such as advocacy and leisure groups, as well as special schools) and geographical spread (both urban and rural areas, England and Wales).

Twenty-seven young people with learning disabilities were involved in the focus group meetings: 13 aged between 14 and 16 years; six aged 17–19 years; seven aged over 20 years. Two of the groups included young people across the whole age range (14–20 years plus); the other two were made up of youngsters aged 14–18 years. Five Black and minority ethnic young people and five deaf young people and one young person who had high individual communication and support needs were involved.

The sessions took the following format. First, there were introductions by the team and the participants and an explanation of confidentiality in an easy to understand way. Next, the young people were asked if they knew what 'transition' meant. In three of the four meetings this was then followed by an explanation. The young people were then asked what they wanted to do when they were older, or what they had done as they had grown up. This was followed by the activity described earlier, to establish what information the young people felt they needed. They selected, drew (or wrote, in the case of one group) representations of the information required and placed it on a chart according to its importance to them. Each young person was given a coloured pen so that they could mark which pictures they had personally selected. At each focus group session the activity was undertaken in two smaller subgroups, each supported by one or two members of the project team. Finally, the young people were asked how they personally found out the information that they wanted, and also what they felt a helpful website about transition should look like.

The focus groups with parents and supporters

The parents' and supporters' meetings were facilitated by a family carer and a professional, respectively, at the same time as the young people's focus groups were taking place. Schedules for each were developed drawing on the facilitators' own experience and expertise but were deliberately planned to parallel the young people's sessions. Each meeting explored how the participants viewed transition and investigated, through the activity described above, the types of information needed during transition and how important each was. During the activity, the parents and supporters often struggled to differentiate between the relative importance of different information needs. On a few occasions, all of the post-it notes were located in the central circle – everything was important. The participants then went on to discuss how they personally would like information provided, what they would like a website on transition to look like and the most important thing they would have liked to have known 2 years earlier.

Nineteen parents participated in the focus groups, all of them parents of young people in the young people's groups, including one Black parent. In an attempt to ensure that the views and experiences of Black and minority ethnic families were included in the project one set of focus groups were expressly organized in an area with a substantial Black and minority ethnic population. The workers here made personal contact with parents to encourage them to attend the group and Jamaican food was laid on. In the event, abnormally cold weather that evening meant that none of the parents attended, with the result that Black and minority ethnic parents were underrepresented in the project. The supporters' sessions involved 19 supporters, four of whom were black. In both the parents' and the supporters' activity, each participant not only highlighted the information that they themselves needed (tracked with a coloured pen) but also indicated what they thought were the information needs of their young person (indicated by YP on the relevant post-it), the supporter (S) or parent (P). This prompted further discussion, drawing out the themes from the three perspectives, and also similarities and differences between them.

Analysis

The material generated by the focus groups with young people were analysed by the young people in the transition project team. They highlighted the most commonly said things in response to each of the questions, as well as overall, and noted down which were most commonly in which ring, and therefore seen as most (or least) important. They wrote up their analysis, with pictures and symbols, in their own report on the project (North Somerset People First Transition Project Team 2004). The material from the

parents' and supporters' discussions was analysed by the University researcher, paying attention to the emphases within responses, again highlighting similarities and differences between them.

Results

Young people's expectations of life as an adult and their information needs

Most of the young people involved in the study did not initially understand the term 'transition'. Nonetheless, their expectations of adult life were similar to those of their non-disabled peers, and those reflected in the literature as markers of adulthood (Townsend 2004), e.g. 'Leave home and live with friends' and 'Go to a college where you live'. They expected to go to work or college, have a social life, continue their leisure pursuits, make friends and have relationships. The topics on which they felt they needed information fell into 14 categories in descending order of importance as indicated by the number of youngsters who selected that issue as being of particular importance: work; college; where to live; money; friends; sex and relationships; safety; being in charge of your life; living independently (i.e. information on practical things like being able to tell the time or find out what was on the TV); healthy living; having fun; music; sport; helping others. The young people did not explicitly mention services, but did say they required practical information and support that would enable them to be in charge of their lives and to live more independently.

Parents' information needs

The parents recognized that transition was about their young person growing towards adulthood and adult responsibility. They were, however, concerned about their young person's ability to take on these responsibilities and about how they would be treated by the wider public. The parents commonly lacked any understanding of the transition process and did not realize that transition planning at school should cover all aspects of the young person's life, not just a move from school to college. They often talked about feeling scared or frightened about not knowing what their role was in the transition 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.

Departments are dealing with so much, too stretched. Children's Team had to pass you on at 16 but assigned an adult trainee social worker at 20. (Parent)

The only way she's got anything is by me ringing. It's lonely. (Parent)

They felt they needed information on each of these areas.

Parents felt that their youngsters needed information about the transition process and their role within it; how their support needs would be met; and the choices available locally. They felt their young people would ask questions like: Have I got a choice? Who would look after me if I left home? Can I get married and have a baby? How will I get to see my friends? Their discussion of their youngsters' information needs reflected their own concerns about what was realistic for the young people to aspire to in the context of their support needs and the services available locally.

Supporters' information needs

The supporters felt that they needed to know the young person, and their home background, very well in order to be able to support and empower them through this emotional and challenging time. They wanted information to help the young people 'make the best of opportunities' and 'deal with change'. They also needed full information about the transition process locally, and the choices, services and supports available – as well as information on how they could best contribute to the young person's planning process. They highlighted the importance of person-centred planning to ensure that the young people's expectations were supported and championed. At the same time, they were sensitive to the realities of current service provision locally and its availability.

The supporters' views of the information the young people needed focussed particularly on their need for empowerment, and for their voice to be heard within the transition process. They felt that young people needed information to help them say, 'This is my life' and 'This is what I want and how I want it'.

The parents' and supporters' views about the information needs of the young people highlight important but different (even potentially contradictory) themes: the supporters focussing on young people's concern with empowerment and being in control of their own life; the parents on the fact that young people do not have control of the process and may feel the need to obtain permission to make their choices.

What information do people need about transition?

Although there were differences in emphasis in the needs for information expressed by the different groups, some detailed information about the transition process was needed by everyone, to answer the following questions:

- What is transition? Who is involved? What are their different roles?
- What rights, entitlements and procedures exist at a national level?
- How is the transition process interpreted locally?
- How can person-centred choices be accessed locally?

- What services are available locally? What options might be developed for the individual young person through different agencies?
- What support is available to young people and families throughout the transition process and into adult life?
- Are there specific transition workers or key workers locally?

Information was also needed to help young people, their parents and supporters to work through a range of other issues, including:

- The changes occurring and their impact on family relationships (e.g. if a young person's benefit levels changed, as they left home).
- Adult rights and responsibilities.
- Empowerment and self advocacy.
- Increasing independence, including taking opportunities, safety and risk.

The young people, parents and supporters also wanted more specific information on areas like work, going to college, where to live, money, friends, sex and relationships, safety, living independently, healthy living, emotional changes and having fun. The parents and supporters also suggested an additional need for information on changes in services.

Presenting information about transition

Information on transition provided for young people, parents and supporters is likely to need to be presented in different formats if it is to be appropriate to the particular needs of each different group.

For young people with learning disabilities, the information needs to have the following features:

- It should be age appropriate – using adult looking images and language which is easily understood.
- Text should be large.
- Sentences should be short, clear and use easy words. Long words should be explained.
- The 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.
- Pictures and text should be tested out with young people with learning disabilities before they are used in a final version to check that they are understood correctly and as intended.

Websites providing information for young people need to use colour, be inviting, fun and easy to use. Colour or symbol coding is helpful, along with easily recognizable

buttons to navigate around the site. Activities and interesting examples help young people understand the text and apply the messages to their own lives.

Information for parents and supporters also needs to be clear, inviting, and not too densely packed with information. Nonetheless, it does need to provide them with an overview of the national and local context, including relevant contact information for services.

All information needs to be developed in conjunction with its target audience whether that is young people, their parents or supporters (Ward & Townsley 2005). Young people and parents will need information in a variety of other ways too, including personal support via a key worker, during the transition process. (For more details on how to write easy to understand information, see the *Information for All* guidelines, Rodgers *et al.* 2004.)

Discussion

The information presented above reflects the findings from the third of the three strands of *The Road Ahead?* project described at the beginning of this article (Tarleton 2004a). So how does the literature on transition, and the information resources available for young people, parents and supporters (both reviewed as part of the project) address the information needs identified here? Many of the themes identified were discussed in the literature, which reinforces the concerns expressed by supporters and parents in this project that young people's dreams and aspirations might not be realized. The literature shows, for example that: few young people have jobs; many young people use day centres; going to college was often an expected route of progression; parents need support to discuss housing issues; there is a lack of clear information about benefits and direct payments (Townsley 2004). Choices may be difficult for young people; some strategies for decision making are suggested. The literature review confirmed that safety and risk is a major concern for families and young people with learning difficulties at transition, although only one study has focussed entirely on this issue (McConkey & Smyth 2003). Similarly, the literature highlights both the importance of support to make choices at transition and the fact that the notion of choice can be very unclear to many young people with learning difficulties (Rowland-Crosby *et al.* 2003). Issues of empowerment, rights and responsibility at transition have received little, if any, attention in the published literature reviewed.

The review of available information resources, also conducted as part of *The Road Ahead?* project, revealed that there were a number of general packs which covered the majority of issues raised by participants in the project (Watson 2004). The *All Change* pack (Mallet *et al.* 2003) most closely addressed the themes emerging from this project. Overall, however, there was much less information

available than might have been expected on employment, while only two packs specifically focussed on transition to college. Meanwhile, no resource was found which focussed specifically on handling money for young people, nor specific information, in an accessible format, on sex and relationships for young people. (The information available for parents about sex and relationships was quite old.) There was, moreover, little information to support young people to be in charge of their lives. The resources available did not include direct information on empowerment or guidance on daily, or healthy, living. Nor did they respond to the emotional aspects of transition, particularly how to deal with disappointment or frustration, if young people's dreams could not be translated into reality. Clearly, there is a good way to go before Recommendation 6.5 of the recent report from the Prime Minister's Strategy Unit on 'Improving the life chances of disabled people' that 'Young people and their families should have access to good quality local information', is to be realized (Prime Minister's Strategy Unit 2005).

Statement on ethics and good practice in research

All those who took part in this research project were provided with appropriately written information about the project and what their participation would involve. This included easy information for the researchers in the 'Transition Project Team' as well as for the young people involved in the focus groups, and an easy-to-understand invitation and form through which they could indicate their consent to involvement.

Key issues arising in ethical research practice – like the importance of confidentiality and anonymity – were expressly addressed in the young people's research training. The concepts were presented and discussed in a concrete way.

After the research was completed, an easy-to-understand, illustrated summary of findings was made available to all the young people who participated in the focus groups, and also posted on the SCIE website (Tarleton 2004b). An executive summary was provided to families and supporters who had participated in the research, and also posted on the SCIE website (Tarleton & Ward 2004).

Families, supporters and young people who participated in the focus group sessions were given a gift token of their choosing as an acknowledgement of their help. The young researchers with learning disabilities from North Somerset People First were paid for their involvement in the project. Overall, the project followed the guidelines to good practice in research developed by the Norah Fry Research Centre, and other relevant guidance on good practice in research generally (Social Research Association 2003; Ward & Watson 2001) and on involving young disabled people

and people with learning disabilities in research more specifically (eg Abbott 2004; Tarleton *et al.* 2004; Ward 1997, 2004).

Acknowledgements

Thanks to all the partners in this research project, namely Anna Meredith, Kath Sawyer, Claire Twiselton, Tim Eden and Mark Smith of the North Somerset People First transition project team and Sue Hogarth their supporter/manager; to Robina Mallett, carer support officer at HFT and to all the young people with learning disabilities, parents and supporters who participated in the focus groups for the project or were involved in the piloting of draft materials.

Disclaimer

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

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