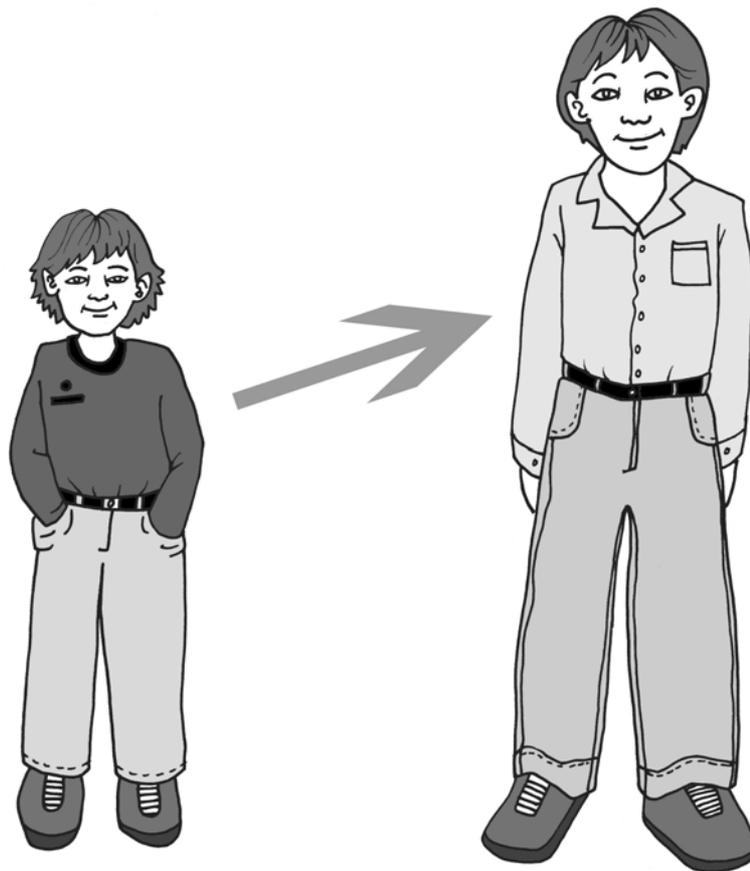# The Road Ahead?

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

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1

Introduction

This report for the Social Care Institute for Excellence (SCIE) brings together the findings from three inter-linked investigations relating to the information needs of young people[1], their parents and supporters at transition. It was undertaken over a six month period between October 2003 and March 2004 and included:

- Focus group interviews with young people, their parents and supporters

- A systematic review of the literature on transition

- A review of the information already available for young people, parents and professionals, including an evaluation of materials by young people and parents.

The project was carried out by the Norah Fry Research Centre (NFRC) in partnership with North Somerset People First (NSPF) and the Home Farm Trust (HFT). Appendix B gives details of the methods used in the project and the tasks undertaken by the different members of the project team.

The report describes what information is needed by young people, parents and supporters and reviews how far these needs are reflected in the literature and in the information packs and materials available to support transition. It also highlights issues which would need to be addressed in the development of a potential website on transition.

The report is one of six publications relating to the information needs of young people with learning difficulties, their parents and supporters at transition, produced as part of the SCIE project.

The other five products are as follows:

- an easy to understand, illustrated summary of key themes and findings from the project (Tarleton, 2004a)

- a systematic review of the literature on transition for young people with learning difficulties (Townsley, 2004)

- a review of the resources available to support transition (Watson, 2004, reproduced as Appendix C)

- a report by the team of young people with learning difficulties who worked on the project arising from their involvement (North Somerset People First Transition Team, 2004)

- an executive summary of the key overall project findings.

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[1] Note – Throughout this report 'young people' means 'young people with learning difficulties'.

This report continues with the following sections:

- What is transition? **(Section 2)**
- What information do young people want at transition? **(Section 3)**
- What information do parents and supporters think young people need at transition? **(Section 4)**
- What information do parents want? **(Section 5)**
- What information do supporters want? **(Section 6)**
- What do the literature and available resources available reflect the information needs identified? **(Section 7)**
- How appropriate is the avaialbe information on transition for young people with learning difficulties and their families **(Section 8)**
- Summary and recommendations **(Section 9)**

The original material presented in these sections is drawn from our interactive discussions with young people with learning difficulties, their parents and supporters[2]. A full write up of the methods used to facilitate these discussions can be found in Appendix B. In addition to their own views on the information *they* needed during transition, the discussions and activities with parents and supporters allowed parents to comment on the potential information needs of supporters and supporters to comment on parents' potential information needs. Both groups also commented on the information they believed that young people would need during transition.

Separate discussions were held with the project team of young people with learning difficulties and parents from North Somerset to discuss the appropriateness of the materials and resources available to support transition.

NOTE: Where resources are referred to in the text, followed by a letter and number in brackets (eg N11) this refers to the location of that resource in the review of resources set out in table form in Appendix C.

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[2] The quotes presented are taken verbatim from post-it notes used by participants during the discussions.

2

What is transition?

2.1   Introduction

This section provides the context for the discussion in the chapters that follow about young people's, parents' and supporters' information needs at transition.

In the parents' and supporters' groups, the question 'what is transition?' resulted in definitions accompanied by emotional reactions. Parents spoke of their 'fears' as they did not have a clear understanding of the process. Supporters viewed the question primarily from the point of view of the young people experiencing transition and linked this to the support they themselves could provide.

2.2   Young people's views of transition

We asked the direct question 'What is transition?' in only one visit with young people with learning difficulties. In this area, one of the participants clearly stated that transition was:

> '*Moving on from being a child to becoming an adult.*'

This young person was herself the Transition Champion for the area (the person seen as responsible for moving things forward on transition locally). She was on the sub-group of her local Learning Disability Partnership Board, (the new multi-agency forums set up following the *Valuing People* White Paper to oversee local implementation of its provisions) and was possibly becoming co-chair of the group.

In the other areas, transition was explained by the project team as 'growing up' and 'deciding what to do when you are older'. When the young people really did not understand this concept, the team resorted to explaining that it was 'when they left school'.

2.3   Parents' views of transition

Parents described transition as their young person becoming an adult. From an holistic viewpoint, one parent recognised that this would involve health, education and social services.

The parents' main response to the concept of transition was, however, emotional. Transition was described as 'scary' and 'frightening'. These emotions were related to a lack of appropriate services and lack of transition planning. Parents felt that transition was very difficult to:

> '*Get your head around particularly without appropriate information.*'

Planning the future was likened by one parent to:

'Crystal ball gazing.'

2.4   Lack of transition planning

Some of the parents commented that they had had little support during the transition process. One parent said that her daughter was now 20; neither mother nor daughter was aware of having had any meetings to discuss this young woman's transition. Another young person had left school with nothing in place. One parent observed:

'*Promises of smooth transition* [by Social Services Department] *then nothing for 18 months.*'

Parents recognised that resources and lack of communication fed into this issue:

'*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.*'

'*Resources a problem, overwork, 5 people on health planning group but GP didn't know who the Community Nurse was.*'

They felt that they needed to 'fight' to get any support:

'*The only way she's got anything is by me ringing. It's lonely. Left friends from residential college. Hard to see her go to residential but I cried when she came home, with nothing.*'

2.5   Lack of services

The parents were aware that there was a general lack of services which were appropriate for their young person; this was a cause of some apprehension. They were also aware that services for teenagers and specific services to support transition would soon stop:

'*Scary – everyone suggests things stop at about 22.*'

'*You lose advocacy, youth centres etc at 25.*'

Some said that they had been warned of 'impending doom' by other parents and they ought to 'get staff sorted' well in advance.

Their concerns were compounded by previous negative experiences of service provision. As one parent pointed out in the past:

'*So many people have let me down.*'

2.6   The young person in charge

The parents recognised that transition was a time when their young person should begin to do 'what he or she wanted' and take charge of his or her own life:

> '*They do change and want to make choices as they come into manhood.*'

Some parents were, however, concerned about this because their young person had:

> '*Difficulty knowing what he wants*'

and he

> '*tends to agree.*'

2.7   Adult responsibilities

While they recognised that their young person was becoming an adult, parents had concerns about them taking on the adult responsibilities which their peers took for granted. One parent said:

> '*Can't picture him voting or understanding how to or doing things adults take for granted.*'

Some parents were concerned that whilst their young person had become adult in terms of age and physical development, they were vulnerable, had not yet attained certain skills and, on occasion, exhibited behaviour that was not regarded as appropriate in a young person of their age.

Others recognised that their young person's apparently appropriate interaction with others was related to their own on-going support.

> '*Difficult when he can appear so able – it's with a huge amount of background support.*'

They realised that as their young person was 'becoming independent', they would be 'embarrassed by Mum checking' and were concerned about how they would 'know how and when to let go'. In one instance, a parent was concerned that the process had gone too far:

> '*Now he's over 21, in supported living, I feel excluded, I don't have any involvement in decisions.*'

Role models, such as older brothers who would help young people understand what it meant to be an adult, were felt to be valuable.

2.8   Risk taking and safety

The parents recognised that while growing into adults their young people would need to:

> '*Test the waters – what's right, what's wrong. What's been acceptable in amid the family isn't with others.*'

This acceptance of the need for young people to experiment with new things was linked to an on-going concern that the parent did not really know how much their young person understood and that their young person was 'open to judgements by public'.

Throughout all of the discussions parents voiced concerns about the provision of appropriate support. One family had found two students for their young person to go out with when no other support was available.

2.9   Increasing awareness of difference

As the young people grew up and compared themselves to others, the parents were concerned about their self-esteem. They felt there would be an:

> '*Increasing awareness of the differences between them and others.*'

2.10   School as a resource

In one area in particular, parents saw their child's school as a key resource at transition:

> '*Since this school opened, only need to ask and information is available.*'

2.11   Advocacy support

In another area, the parents recognised the importance of the local advocacy group in which their young person was involved. They stated that the:

> '*Advocacy group has really helped them move forward – relationships, able to sit and listen and talk, respect each other, hear about others' feelings and difficulties.*'

2.12   Parents supporting each other

Parents also commented on the support that they received from each other and from taking part in this focus group meeting:

> '*Learn things only from another mother.*'

> '*Find talking to other parents very helpful – free to speak, learn, share.*'

2.13   Changes and choices

Within the context of concern, and lack of clarity, about the transition process, parents recognised that a wide range of choices might potentially be available to their young person. These included:

- **Where to live** – including leaving home and keeping in touch when their young person had moved out.

- **Friends** – parents worried that their young person 'needed to have groups of friends or one partner like the majority of the population'.

- **Sex and relationships** –parents were aware of their young person's developing maturity and the guidance that would be helpful around sexuality and relationships.

- **Going to college** – concern that provision might not be appropriate and that the young person might end up repeating courses alongside younger people.

- **Work** – anxieties about whether they could manage, with the hope that this *would* be possible, as having a job would give the young people friends and a purpose.

2.14   Supporters' views of transition

The supporters' views of transition generally began from the perspective of the young people they worked with, rather than their own position as a supporter.

They recognised both positive and negative emotions in relation to the transition process. The negative emotions included 'loss' and 'fear' and the recognition that it was a 'frightening time', a time of 'confusion', 'coping with change' and 'losing stability'.

On the other hand, this time was also recognised as 'exciting' and a 'new and challenging horizon' where the young person could 'feel important'. One supporter commented that it was a time when young people needed to 'trust others' to help them appropriately.

The supporters' definition of transition centred on both becoming an adult and 'becoming more aware of being an adult'. Transition was seen as a development period, a time of change, of confronting problems and different challenges. The changes at transition involved 'new experiences' and 'learning new skills' as the young people made decisions that would affect their life in adulthood, so they needed to learn to 'feel comfortable about change.' For one supporter, transition was seen generally as making changes in life at different stages; by another only as 'leaving school' and 'starting again'.

For young people staying at school until they were 19, the early stages of transition could be summarised simply as 'changing class' with little impact, therefore, on the young person's life generally.

2.15   Becoming recognised in their own right

The supporters felt that transition involved the young person 'becoming an adult' and being 'treated as an adult and not a child'. Transition meant being entitled to their own views and to being 'listened to'. It was a time of growing rights, responsibilities and opinions as young people were 'discovering' themselves.

2.16 Independence and physical and emotional changes

Personal growth and self discovery were related to 'growing independence' and the opportunity for young people to 'explore independence' and 'changing relationships at home'.

The supporters recognised that these changes were accompanied by the physical and emotional changes of puberty.

2.17 Practicalities

The supporters' discussions of transition then turned to the practicalities involved in making changes and becoming an adult. They talked about the 'lack of choice after school' and the 'involvement of lots of different agencies'.

One supporter summarised the situation as: 'a fight or struggle in which parents were involved and also needed support'; another believed that progress had been made around transition planning and that there was more 'preparation and lead-in now'.

2.18 Support required

The supporters were clear that young people needed support and advocacy during transition, in order to make appropriate choices in the different areas of their lives including:

- Work
- Where to live
- Living independently
- Making new friends and relationships
- Getting out and about
- Taking opportunities
- Education
- Changing services.

Summary

This section looked at the young people's, parents' and supporters' understanding of the transition process.

The young people: only one of the young people understood the term 'transition'; the others needed the concept to be explained in a more concrete manner.

The parents were unclear about what happens during transition and their role in the process. They understood that transition was a time when their young person took more control over their life, but were concerned about their ability to take on adult rights and responsibilities, about the changes that might happen the support they needed. They were aware of a lack of services and

supports in their local areas and the need for appropriate national and local information. The parents found discussing transition an emotional process; they felt scared and anxious.

The supporters saw the transition process from the point of view of the young person. They recognised that it was a time of great change, during which the young person needed to:

- Be in control
- Be aware of their own capabilities
- Be able to understand their own emotions.

3

What information do young people want at transition?

3.1   Introduction

This chapter presents the findings from the young people's discussions about the information they wanted during transition. The changes the young people wanted to make as they grew up are presented first, before the more abstract discussion of the types of information they would need at transition. (For full details of the activities used to facilitate the discussions see Appendix B.)

3.2   What changes did the young people want to make as they grow up?

The changes discussed by the young people are described below under eight headings: having a job; college; where to live; social life; interests and hobbies; relationships; emotional and physical changes; 'don't know'. The main changes the young people wanted to make - or had made - were either getting a job or going to college. None of the young people mentioned wanting to go to day services or day centres. Some of the older young people, who had more life experience, were aware of supported employment agencies.

i.   Having a job

The young people had a varied range of ideas relating to work and jobs. They spoke of wanting to work in a flower shop, in Asda, in a kitchen as a cook's assistant, with babies or as a DJ. Three of the young people already had part-time jobs. One young woman commented that she had:

> *'Got a part-time job to get money.'*

One 16-year-old young woman worked in a pub, one had a job at a burger bar and another 18-year-old worked at a day centre for elderly people laying tables for mealtimes.

ii.   College

Attendance at college was already a reality for some of the young people: those who were older or who had left mainstream school (where they had had a support worker) at 16. Mark*, for example, who was 16, was at two different colleges.

Going to college appeared to be an expectation for many of the young people who were still at school. Sarah, aged 16, stated that she would:

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* Not his real name; all names have been changed.

> *'Go to Lufton Manor - a college where you live.'*

She knew that other pupils from her current school had gone there.

iii. Where to live

Six of the young people wanted to live with friends in a house or flat. Darren, aged 15, stated his intention to:

> *'Leave home and live with friends'.*

Of these six, two specifically mentioned the importance of being able to still keep in contact with their parents.

A further two of the young people were clear that they wanted to 'stay with Mum and Dad'.

By contrast, David, who was 22, and already lived with carers in a residential home, wanted to:

> *'Live in Australia'.*

This was where his dad and step mum lived; he had been there and stayed in Sydney.

iv. Social life

Eight of the young people (mainly those still at school) specifically talked about going out and having fun. They spoke of going to clubs, pubs and into town to go out 'drinking' or 'dancing', either with their current friends or with the intention of making friends.

v. Interests and hobbies

Christopher, who was 14, was clear that he wanted to do:

> *'Same as now. I go trampolining and on Wednesday I go to Pied Piper* [music class].*'*

Other activities mentioned included: walking, horse riding, following favourite football teams, doing gymnastics or athletics. One of the older young people wanted to further her sporting interests at an international level.

vi. Relationships

Not surprisingly, the young people wanted to have relationships; indeed, one of the young women's main aims in life was to have a boyfriend. She was currently still at school; having a relationship was her strongest desire for the future.

vii. Emotional and physical changes

Three of the young people talked about the changes that had happened to them, physically and emotionally. Sian, 19, recognised that:

'Your feelings are different as you get older. Feel different things.'

Jane, who was 15, confirmed that growing up resulted in:

'Changes in feelings, lots of changes, a year and a month ago I felt childish.'

She spoke about her growing liking for, and understanding of, boys and boyfriends.

Anthony said he had wanted to:

'Change his attitude [as he grew up] *– not be silly all the time.'*

while Matthew recognised that:

'In year 8 he began to get tall. He was small in year 7.'

viii. Don't know

Four of the younger participants (under 18 years of age) did not know what they wanted to do when they were older. They were still at school and would remain at school until they were 19. The question seemed irrelevant to them. They were focused on their current situation. Robert, who was 16, for example, said:

'Don't know. I'm at school, I like school.'

The young people who were over 20 had experience of making changes in their lives. Their responses clearly show that growing up involves a variety of steps and decisions and that 'transition' is a very individual and on-going process. The changes experienced by these young people primarily involved what they were doing during the day, like going to work or college, or continuing particular interests which they had already developed. The changes they had made reflected the desires expressed by the younger participants in the study, such as wanting to live independently, to have a job or go to college.

3.3   The diversity of young people's paths at transition

The pen pictures that follow illustrate the diversity of the young people's paths at transition.

Mark is working at NVQ level 2 at catering college. He wants to be a chef, but has problems with his joints and finds heavy work, such as holding a big bowl to mix things, difficult. He has been at college for four years. He is now on a full-time, two-year course. The previous two years were like 6th form: part-time catering and English and Maths. Mark was going to cook at the races in March. Next year he was going to London to see 'posh' hotels. He hopes to get a job. Martin had been away at boarding school but was now back home and at college where he says he is: 'very very happy'.

Ellie, who is 23, wants to live independently. She is working on that at the moment. She volunteers in two schools and wants to be a classroom assistant.

She is going to give up volunteering in one school to go back to college in September. She found out about volunteering through knowing a teacher at the convent school she had attended. With their help she went and asked if she could work in the reception class. She had a police check and an interview. She is going to do a basic child care course in September or, if this is too easy, a more advanced course.

Jack, who is 21, wants to get a job with the local supported employment agency. He wants to work on the van that goes out doing gardening. He is at college at the moment. He is in a design company that is making cards: Christmas cards, Valentine cards. They sell them at the college, or in the local area for£1. He left school and went straight to college. He said that:

> *'The school took us to college to learn things'.*

Anthony, who is now 30 and a helper with the local advocacy group, left school at 16. He used to go to college, learning how to use computers. He now attends a work development unit. As we saw above, he had wanted to change his attitude (as he grew up) and 'not be silly all the time'. He likes helping his mum with shopping and cleaning.

Carmel, aged 21, is an athlete and travels the world for her sport. She has visited Portugal, Tunisia and France and would like to further her sporting interests at an international level.

Kingston, aged 20, was at college. He had found out about college from his helper at school.

The changes the young people wanted to make, or had made, in their lives reflect the common markers of adulthood indicated in other studies of young people's aspirations (Barnardo's,undated; Choices Advocacy,undated; Heslop et al, 2002). But while some important aspects of their life would change, that was not the case for everything. Some of the young people wanted to remain living at home, while others made it clear that they wanted to continue with their hobbies.

3.4   What information did the young people want at transition?

All the young people said that they needed practical information that would support them in their everyday life, as well as information which would support their personal development and involvement in the wider society. Their desire for this type of information shows the importance to them of being in control of their own lives and making their own decisions, at a variety of levels.

The types of information the young people felt they needed during transition are grouped together under 14 themes. They are presented in order of importance (in relation to the number of young people who selected pictures/or discussed issues corresponding to the themes). Most of the themes were discussed by young people of different ages, although their importance varied from most

important to less so, depending on the individual. (See Appendix B for a full discussion of the activity used to support the young people's contribution to this abstract discussion.)

i. Work

The young people stressed the importance of getting a job. They discussed working in a hospital, being a chef, and:

'Learning how to be a postman.'

Two young women wanted to work in childcare.

ii. College

The two young women who wanted to work in childcare also discussed going to college, to prepare for work in their chosen field. One stated that she was going to college:

'To learn about how to look after babies to get a job.'

One of the young men [Mark in the pen pictures above] was already on a catering course in order to become a chef. The young people talked about needing information about college open days, from careers advisers or access to the careers library so that they could decide on their options for the future. Interestingly, Connexions advisers were not mentioned.

While college was seen by some of the young people as a stepping stone to work, others merely saw college as the logical next step on from school. Many of the young people were aware of older school mates going on to college; this was often the focus of the transition planning that took place in the special schools attended by the young people involved in the study.

iii. Where to live

The young people also wanted information on the various housing options open to them so, as one young person said they could:

'Have my own space.'

Having a flat with support, living at college and continuing to live at home were all mentioned.

iv. Money

The young people also wanted information on handling money:

'I have a switch card, but I like the idea of having a visa [credit] *card too.'*

 The types of information needed varied from different ways of handling money to 'learning how to pay bills', getting a job and having to 'balance it with benefits and money in the bank'.

v. Friends

Most of the young people mentioned needing information about friendships, and highlighted the importance of social networks and keeping in touch with family and friends when living independently. The information needed included strategies to maintain friendships such as:

> *'Knowing when people's birthdays are to send a card'*

and how to keep in touch with friends from school (particularly if the young person attended a special school some distance from their home).

They also wanted to know how to socialise and:

> *'Get to know people in the world.'*

They saw friendships as developing in traditional social contexts, such as the pub, church and so on.

vi. Sex and relationships

The information required in relation to sex and relationships included advice on getting a boyfriend or girlfriend, sex, having a family, or - as one of the young people pointed out - the importance of contraception:

> *'Having a boyfriend but not having babies yet.'*

vii. Safety

This part of the young people's discussions was summarised by one young person as follows:

> *'Keeping safe on the road, being safe* [generally]*, being safe in the house – having a fire alarm.'*

Being safe also included: 'knowing about strangers', street safety and:

> *'Looking after myself while out clubbing/at the pub – being safe not getting your drink spiked.'*

One young person referred to a talk organised by college about drugs. He felt he had learnt a lot about drugs and knew they were bad for him.

viii. Being in charge of your life

The young people said they wanted information which would enable them to be in control of their lives, to make decisions and to choose what to do. This included:

> *'Knowing how to say no.'*

> *'Knowing how to use taxis.'*

Being in control of their lives also included an understanding of their own capabilities:

> *'Learning what I can handle and what I can do'*

as well as

> *'Learning how to manage [their own] stress levels'.*

ix. Living independently

The importance of information on many of the practical aspects of living independently was also mentioned by the young people. They wanted information on:

- How to do some cooking

- Knowing how one's stereo works

- Knowing what's on the telly (being able to understand the television magazines)

- Knowing about time

- Having a motorbike or car.

They particularly needed information (which linked with the theme of money discussed above) about:

- How to do shopping

- How to pay bills

- Having one's own landline (which was also regarded as a status symbol).

x. Healthy living

On 'healthy living' the young people wanted to know about:

- Allergies

- How to clean yourself

- How to stay healthy

- The importance of healthy food, particularly fruit.

 A specific request included: 'what happens when you are smoking and why you should not smoke'.

xi. Having fun

Information was also required on having fun! The young people wanted information on 'beer and drinking' and 'going to parties'.

By contrast, one young person wanted information on:

> *'Relaxing – and having some peace.'*

xii. Music

Some young people said they wanted information about music – in general, as well as how to go about getting music. One person talked about:

> *'Knowing how to choose music in HMV.'*

xiii. Sport

Other young people mentioned wanting information about sport and how to participate at the general hobby level as well as opportunities for young people who were very serious about sport, like Carmel the young woman competing at an international level (described in the pen pictures above).

xiv. Helping others

The ability of young people with learning difficulties to help others was highlighted by Sarah. She wanted information which could enable her to:

> *'Help other people who need help at home and people who are in wheelchairs who are really ill.'*

Sarah also wanted information about how to look after homeless and sick animals.

Summary

This section described the young people's discussions of the changes they had made, or would like to make, and showed that they expected to lead a full and active life. It illustrated the diversity of young people's paths at transition. It also showed that the young people had similar life expectations to other young people their age and needed information on:

- Work
- Going to college
- Where to live
- Money (including handling money and the impact on benefits of getting a job or moving out of home).
- Friends
- Sex and relationships
- Safety
- Being in charge of your life
- Rights and responsibilities (including helping others and playing an active role in the community and the law and people with learning difficulties)
- Living independently

- Healthy living
- Emotional changes
- Having fun.

4

What information do parents and supporters think young people need at transition?

4.1 Introduction

This section looks at the parents' and supporters' ideas about the information *they* thought young people with learning difficulties needed at transition.

4.2 Parents' views

The parents thought that young people needed information about: the transition process and their role within it; how their support needs would be met; and information about the choices available and how to access choices locally. They felt that young people would ask questions such as:

- Have I got a choice?

- Who is who in this world? Who can help me?

- Who would look after me if I left home? Where can I get support? Who will take care of the personal help needed?

- Can I have a boyfriend?

- How will I get to see my friends?

- Can I get married and have a baby?

- Is information available? How accessible is the information?

Their discussions of their young person's information needs reflected their concerns about what was realistic for their young person to aspire to in the context of their support needs and the services available locally.

One parent, for example, questioned their young person's understanding of the:

> *'Difference between fantasy and reality.'*

Another pointed out their young person's difficulty:

> *'Understanding the world around him.'*

Another questioned:

> *'Would he know what independence means in respect of his age?'*

So the parents questioned their young person's aspirations in relation to the local context (services and support available), their young person's actual ability and their role in the transition process. The parents' phrasing of the questions they thought young people might ask indicated that they felt that the transition process

might, in reality, limit and restrict their young person's choices to those which could *actually* be provided or supported.

These concerns were expressed within the context of their love and concern for their young person. They wanted the best for them and did not want them to be disappointed. A number of parents specifically discussed the need for their young person:

> *'To know their value as people.'*

> *'To be valued/loved.'*

Parents also expressed concerns for their young person's safety and ongoing need for support and protection. One parent specifically suggested that information on disability was required so that the young person was prepared for potential bullying in the future.

Another parent said:

> *'He would like to know he is safe and that the person he is with can understand him and pay attention to his needs and likes and look out for him in general and not treat him like a child, give him confidence and independence.'*

4.3   Supporters' views

The supporters focussed particularly on the young people's need for empowerment and for their voice to be heard within the transition process. They suggested that young people would ask questions like:

- What are my likes? What are my dislikes?

- What does independence mean for me?

- How will I follow my dream – eg to be a DJ?

- Have I got the necessary skills?

- Will I be respected and be treated as a normal person (with no labels attached)?

- How do I feel? How am I going to survive all the changes?

- Will I be able to decide who supports me?

- What jobs are available and how much money will I get?

The supporters' views of young people's information needs confirmed the implicit theme within the young people's own discussions that they should be respected in their own right. Their desire to, and need for, information about work, housing, sex and relationships, living independently and 'being in charge of their life' all indicated their desire to live in the same way as their peers, to be respected as an adult and to hold the rights and responsibilities that come with being an adult.

The supporters' views reinforced the importance of the young people's rights and responsibilities and focused on ensuring that the young people were empowered and enabled to think through their choices and to have their voice heard during their transition. The majority of the supporters' comments questioned the young people's current situation and the lack of appropriate information available, so that decisions could be made by them. The supporters 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'; information which assured them that they were allowed to make choices and be 'able to say no and change their mind.'

The parents' and supporters' perspectives on the information needs of young people highlight important, if different (even contradictory) themes: the supporters' focus was on young people's concern with empowerment and being in control of their own lives; the parents' perspective was that young people do not have control of the overall process and may feel the need to obtain permission to make their choices.

Summary

This section described parents' and supporters' views of the information they think young people would want to know as they grow up.

The parents' perspective focused on the need for information about the transition process and their role within it, how their young person's support needs would be met as well as information about the choices available and how to access the choices locally.

Supporters focused on the information young people would need so that they were empowered and their voice could be heard within the transition process.

5

What information do parents want?

5.1 Introduction

This section discusses the parents' own information needs. It shows that parents were often unaware that transition was more than leaving school and moving to the next day-time activity, the common assumption being that attendance at college was the next step for their young person.

The discussions revealed that parents had fundamental questions about their young person's transition. One parent asked:

'*What choices does the young person have during transition?*

What choices are available?

Who makes the choice about where and what the young person moves on to?'

Another asked:

'*What are the choices? Where do I find out? Who do I ask?*'

Parents' own information needs related directly to their lack of understanding of the transition process revealed in Section 2. Parents found transition a very emotional process and one that was difficult to understand, although they recognised it was related to the young person beginning to take charge of their life. In many cases, parents of older young people had experienced little transition planning. Parents were concerned both about their own role in the transition process as well as their young person's ability to take on adult responsibilities given their vulnerability in the wider society.

Parents' primary information needs fell into the following three key areas:

- The transition process: what rights, entitlements and procedures exist at a national level? How does it work locally?

- The support available for families during the transition period and beyond.

- Information about the changes and choices available to young people locally.

These areas of information need were confirmed by the supporters' discussions of what they perceived to be the parents' information needs.

5.2   The transition process

Many parents were not very aware of the formal process of transition planning and wanted to know:

- What do I need to know as a parent?
- Where do I start?
- What is available next?
- What are we eligible for, what is available and how do I find out about things?

The supporters confirmed that, in their experience, parents wanted to know:

- Why is this change taking place? What is it all about? Do things need to change?
- What are the different stages in transition?
- What transition policies and procedures are there?

The supporters felt that parents needed to know that the transition plan should be 'owned' by the young person, that the plan should reflect the young person's dreams and that while they were involved in the decisions, the young person should be the focus.

They believed that parents would ask questions about their involvement in the transition process, such as:

- Will I be included in any decisions – will I have a say?
- Who can I talk to about my fears?
- Who can I voice my opinion to?
- Will they inform me?

Supporters also recognised that parents would need assurance that the transition process would 'work at their pace as well as that of their son/daughter'.

5.3   The support available to families

Parents wanted information about who was going to support their young person in different contexts, for example, work, home, social life. Their questions included:

- What support is there for jobs?
- Is there any outside social help/supervision, befrienders etc, that is one to one support?
- What support is available to help my son lead an independent life?
- Are support workers qualified to give medication etc?

- Is there any respite available post-18?

The supporters also felt that parents needed, a 'keyworker or advocate they can trust to guide them'. This person would provide continuous support, a single point of contact and regular feedback about the transition process. The supporters also believed parents would need information about 'where to go for information' and that information should be jargon free and easy to understand and include examples of progression or positive outcomes for other young people.

Parents (and supporters) also discussed parents' own needs for support and advice regarding the transition process and the fundamental changes that would occur in their family life. Parents expressed concerns about the young person's potential loss of contact with family and the impact on their family finances, with the loss of benefits, when their young person moved on.

Two parents also wanted information on the availability of long-term support. What happens if a parent dies? In one case the parents were their young person's only family.

The supporters felt that parents would also need support in dealing with the 'feeling that their family was breaking up' and that 'they were not going to lose their child'. These fears were voiced particularly strongly by Black supporters, who stressed the importance of community and the fear that young people would be taken out of the family circle. This fear was compounded by supporters' concerns that the young person's cultural background and their specific dietary, health and personal care needs might not be understood and addressed appropriately.

5.4   Information about changes and choices

Parents wanted information on most of the areas discussed by the young people. However, their discussions were tempered by their personal understanding of their young person's support needs, abilities and vulnerabilities, as well as their own lack of clarity about their role and who was responsible for what during the transition process. It was clear from the discussions that although official guidance says that all of the following areas should be considered in reviews, few parents had experienced such coverage at planning meetings.

Work - Parents wanted to know what opportunities were available for their young person, including training and work experience in the context of their young person's need for support. One parent asked:

> *'What next when he leaves school, what work can he do, and how will he be treated at the job if he gets one? Will he be treated like any other person of the same age if he works or as he's got severe learning difficulties will he be treated differently?'*

Others had questions about work placements:

'What work placements give continued support on a one-to-one or small group basis?'

'Would needs be taken into account when in work and not lost in the humdrum of the work place?'

College – Parents wanted to know whether there was guidance available as to the most appropriate courses and whether residential college was an option.

Day services – These did not feature very prominently in discussions, although they were mentioned by a couple of parents when thinking about what their young person would do after leaving college.

Money – Parents said they wanted information on allowances and benefits and requested that this information should be 'made easier to understand'.

Safety – Parents wanted to know how they could be sure their young people would be kept safe. One parent asked:

'How do I know if he will be safe and happy?'

Housing – Parents wanted information on the types of housing options that would available for their young person. They mentioned Camphill Communities as well as local authority social services support and housing. One parent wanted to know:

'Rural or urban – are services and opportunities, different, better or worse?'

Parents understood that living away from home linked to a need for life skills and 'independence skills at college and after!' and how to live and travel independently.

Sex and relationships - Parents wanted information to help them think about this issue, which they considered difficult. One father said he did not even want to think about his daughter (aged 15) and sexual relationships. He had already observed a situation where an older man had taken advantage of his daughter's lack of 'stranger danger' at a social gathering.

Parents were concerned about how to respond to this issue, what information they should give their young person and how to give it. They asked:

'Do you leave them alone with a girl friend?'

'How personal do you get about sex without giving too much away?'

Having fun – Information on social events and leisure activities that were available for their young person was also wanted. One parent said:

'I would like my son to have a variety of social outings and activities and to meet new friends.'

Health issues - Parents discussed health issues too, particularly medical conditions and attending hospital appointments, rather than healthy living, exercise and having a balanced diet.

Money – Parents spoke of needing 'advice on allowances' and that 'information on benefits should be made easier to understand'. They also wanted to know: 'how much financial help is available?'

Other information - One parent wanted information on the law and people with learning difficulties. Another wanted basic information on learning disabilities, stating that when their child was younger only their physical disabilities were 'dealt with.'

Parents also wanted information about the services and supports available in their local area. Specifically they wanted to know :

- Who is who locally?

- Contact information, such as telephone numbers, for their area's, health, education and social services.

The supporters anticipated that parents would want information on the themes above. They also felt that parents should be provided with information about how young people could be empowered. Parents needed to be informed about self advocacy and the importance of services understanding their young person's needs. They should also be supported to understand their young person's wants and dreams and 'how they can support and help them'.

The supporters felt that parents should be provided with information that would help parents to form a 'realistic understanding of their child' and what they would be likely to manage in adult life. They also thought parents would benefit from information about the advantages and disadvantages of different choices and would also require contact details of their young person's supporters.

Summary

This section focused on parents' information needs. It shows that parents need three key types of information. These are:

- The transition process: what rights, entitlements and procedures exist at a national level? How does it work locally?

- The support available for families during the transition period and beyond.

- Information about the changes and choices available to young people locally.

The parents' discussions of their needs for information on the changes and choices available to their young person, came from their personal understanding of their young person's support needs, their abilities and vulnerabilities, as well as their own lack of clarity about who was responsible for what during the transition process and their role within it.

6

What information do supporters need?

6.1 Introduction

This section presents the themes which emerged from the supporters' discussions about their own information needs. It highlights the central importance of supporters knowing and understanding the individual young person, their dreams and aspirations and their role in empowering young people to speak up for themselves, as well as knowing about the transition process.

The supporters involved in the discussions included: support workers associated with a special school; supporters in advocacy and leisure services; a special school teacher; and a Connexions Personal Adviser.

6.2 Information needed about the young person in order to empower and support them

The supporters stressed the importance of having appropriate information about each individual. They needed to know the young person very well. The kind of information needed included:

- Understanding the young person's likes and dislikes
- Their skills and capabilities and the areas in which they needed support
- Their dreams, any future plans they might have and aspirations for the future
- Health and hygiene support needs
- Behaviour support needs
- The level of support required in social contexts
- Communication needs, including signing or help to communicate their choices
- Potential for development and growth.

Supporters were clear that they also needed to understand the individual's personal context and their family background, including what support was available from the family, friends or a circle of support, as well as the family's hopes and fears for the young person's future.

In their discussions, the parents confirmed that having information about the young person and their situation was central to the supporters' role. One parent said that supporters should 'go in with an open mind and learn as much as

possible by spending lots of time with the young person' so that they built a lasting relationship and they understood their 'capabilities', family and the wider context. This would enable them to adapt their support strategies to the individual and to help and advise realistically. The parents expected supporters to know about the young person in all the areas listed above, as well as in relation to their leisure, decision making and travel capabilities. Parents expected supporters to be able to answer young people's questions such as:

- Will I get the support I need?

- What if I have had enough of college – what can I do next?

A key theme within the supporters' discussions focused on 'empowering young people', through 'building their confidence', supporting them to 'speak up for themselves' and to know what they wanted through developing their security and skills to make decisions. This involved exploring what independence meant for young people, being 'positive about choices and decisions made' and 'when necessary to be able to challenge decisions' as well as supporting them emotionally through a time of change.

The supporters stressed the importance of 'responding to the young person's emotions' by understanding 'how they feel about themselves', 'being supportive to their hopes and fears' as well as appreciating the 'stress they are going through'. Information was required on how to empower the young people to:

'Be the most independent they can.'

'Make the best of opportunities.'

'Deal with change.'

So, supporters needed to know how to get information on all the changes and choices that were available for the young people, as well as what was achievable. They also needed information about their own role in the transition process, 'How you can help as a supporter', along with more specific information on:

'Youth work skills, personal development skills, ie. assertiveness, game, drama etc.'

6.3   Information needed about the transition process

If supporters are to help young people to understand the transition process they first need to have information about it themselves. So they need to know not only about transition policy and procedures but housing and the support services available to young people during transition and beyond and how to access them. They need to know how they can be involved within the transition and person centred planning processes, not only to support the individual but to share the information they themselves hold. One supporter asked:

'How do we and the young person link into other transition work, eg school transition policy?'

Another felt it was important supporters should be aware that a transition plan was a 'living document' - one that grows and changes with the young person over time.

The supporters recognised that they needed to be well aware of person centred planning so that they could support young people to decide on their wider plans for the future and to recognise the importance of targets, goals and timescales. They needed to be fully briefed about what options were realistic, in relation to the young person, and the resources available in the local area.

Within the parents' discussions, parents were particularly concerned that supporters should know about the availability of support and services such as 'respite care' (short breaks) and activities that were suitable for the young person as well as their young person's abilities with money. Parents also expected supporters to understand about partnership as a whole and to work in partnership with parents to understand the young person and support the whole of the family during transition.

Summary

This section discussed supporters' information needs. It showed that supporters need to know the young people they work with extremely well so that they can support them to understand their own capabilities, to speak up for themselves and make appropriate choices.

As well as having a very detailed knowledge of the young person and their personal context, supporters also need information about:

- all the changes and choices available to young people at transition
- the transition process and their role within it
- the local service and support context.

7

How do the literature and resources available reflect the information needs identified?

7.1 Introduction

This section discusses the key information needs presented by young people and their parents. These views are supplemented by insights from the supporters who often help young people and parents navigate through the transition process.

The section begins by looking at how the transition process is understood. It then examines each of the key themes from the young people's discussions (plus additional themes from the parents' discussions) in the context of the literature available and indicates where there are appropriate resource materials providing young people and their parents with relevant information in this area. It draws on the review of literature by Ruth Townsley (2004) and the resources review undertaken by Debby Watson (2004) in the summary tables which are presented in Appendix C. The letters and numbers in brackets relate to the location of the resources within these summary tables.

7.2 The transition process

The young people's understanding of the transition process (as indicated by the themes below) reflected the common markers of adulthood described in previous work on young people's views of transition (Barnardo's, undated; Choices Advocacy, undated; Heslop et al, 2002; Williams, 2003). These markers include: common goals such as going to college, getting a job, earning money, leaving home and friendships; the young people expected these to happen for them in much the same way as they did for their brothers, sisters and non-disabled peers.

The young people's expectations were high. This apparent lack of realism was a cause for concern for their parents, who experienced the transition process with a mix of emotions including anxiety and fear (Ward et al, 2003; Goupil et al, 2002; Mitchell, 1999). Hanley-Maxwell (1995, in Clegg et al, 2001) recognises that parents often experience high levels of stress at this time. With the exception of one resource for young people from the Foundation for People with Learning Disabilities (N9) and the corresponding resource produced for parents (N22), there was little emphasis on emotional issues within the more general resources available and a notable lack of recognition of, or discussion on, how to cope with disappointment or frustration.

Parents in this study had concerns about their young person's lack of understanding of reality and their own abilities, and about whether their

aspirations could be met by services that they knew would have to be fought for or might not be available locally. As Armstrong and Davis (1995) noted, the best laid plans have little chance of realisation if the options and services are not available. The Edinburgh Youth Social Inclusion Partnership (2001) and Ward et al (2003) also highlight the narrow range of options available for young people.

The supporters felt that this issue should be addressed through person centred planning, which would involve looking at the young person's dreams within a context of local provision. The '*Families Leading Planning'* pack (N15) is a major resource in this area and gives comprehensive guidance to parents on how to ensure that their child is kept at the heart of the planning process.

As Carnaby et al (2003) note, young people themselves (including those in the project team conducting this study) are often not involved in transition planning. This further inhibits their realistic understanding of the process. Only one young person in the discussion groups had a detailed concept of the transition process, as she was involved in the local Partnership Board. So young people themselves need clear, appropriate information about the transition process – and to be involved in the meetings and process at all stages. Resources such as '*Transplan'* (N3) '*Planning My Future'* (N11) and '*The Big Picture'* (N12 – when completed) and the '*All Change'* (N13) pack's accessible guidance for young people go some way to address this situation. The '*Trans-active'* website (W7) aims to help young people with learning difficulties to create a multimedia 'passport' about themselves at transition. Young people do, however, need considerable support to be able to do this.

Parents were also confused and disempowered by a lack of understanding of the transition planning process. They were unsure of their role, whether they would be listened to, how the transition process works and who was responsible for what. Supporters confirmed parents' and their own need for detailed information about the transition process and the ways in which the various professionals and agencies were involved in the variety of plans that proliferate in the transition process.

Although the parents in this study were confused, and stressed their own need for information and support in the transition process, parents are seen in the literature as a significant factor in facilitating a successful transition for their son or daughter (McNair and Rusch, 1991). It was also clear from the literature that transition planning, where possible, should be within the context of family support and involvement. Blacher (2001) notes that active family involvement is critical to successful transition. In Hendy and Pascall's study (2001) disabled people in their 20s and 30s said that their parents had been their most important resource at transition; Thorin et al (1996) also recognised the importance of parental oversight and advocacy particularly if services are insufficient or inappropriate.

The literature also confirms parents' confusion about the transition process. It highlights the wide variability in the way the transition process is implemented locally and notes the confusion of multiple plans made for young people by different agencies. These include: the transition plan produced at school, the personal Connexions action plan, an individual learning plan in some areas and, possibly, a care plan (by social services, if using adult services) health action plan or person centred plan. Rowland–Crosby (2003) confirms parents' confusion about the nature of different plans and assessments whilst pointing out that professionals also feel that there is a lot of duplication and extra work. There are, however, a number of resources which are designed to help parents with the transition process (N13, N16, N17, N19, N29, N30, N31, W4, W5, W8, W9 and W10). These vary hugely in format and detail, ranging from factsheets to 246 page packs. The most comprehensive of these is the '*All Change'* pack (N13).

Both parents and supporters highlighted the need for a key worker to provide one point of contact and information about the process of transition. The parents in the discussion groups turned to their child's school as the point of information and contact. They frequently conceptualised transition as moving on from school to college and recognised the school's key role in this. Perhaps surprisingly, the resources available to parents do not fully acknowledge the role that schools play in parents' lives at transition. There are no recent resources that we are aware of that help school staff to work with parents on transition planning other than the '*Trans-active'* package (W7) which is largely aimed at schools working directly with young people, not necessarily their parents.

Grove and Giraud Saunders (2003) point out that the role of key contact could be played by the Connexions Personal Adviser (PA) who should be able to take a semi-independent approach to co-ordinating the transition planning process. But it is unclear whether a Connexions PA responsible for a young person's action plan can hold other parties to account for the overall implementation of the young person's transition plan. Connexions resources (W1, L13, L14, L18 and L22) are locally produced in some areas of England but provide both local and national information. Their website (W1) is not specifically geared towards young people with learning difficulties but does link to the Family Fund's website '*After 16-What's New?*' (W4) which covers young disabled people generally, rather than young people with learning difficulties specifically.

This lack of clarity about who is responsible for co-ordinating the process, continues alongside clear instructions from the Qualifications and Curriculum Authority (2003) that transition programmes (within education) should have a clear focus, coherent provision, a strong emphasis on meeting the individual's needs and exist within a framework of flexible provision.

Hudson (2003) recognises that person centred planning, which includes an emphasis on continuity and a historical perspective about what has happened in the young person's life so far, appears to be a way forward in ensuring that

transition plans reflect the aspirations young people have for their future. Several other recent authors confirm the importance of an 'holistic person centred approach to transition encompassing the broader aspects of planning for adult life' (Ward et al, 2003a; O'Sullivan, 2001; Bond 1999).

Under the provisions of the English White Paper *Valuing People* local agencies should be introducing person centred planning for young people with learning difficulties as they move from child to adult services. The Valuing People Support Team (set up to support implementation of the White Paper) recommends that person centred approaches should be adopted within any of the different agencies' planning processes. This approach seems to be the way forward. The Valuing People Support Team stresses that person centred approaches to transition planning should involve discovering what is important to the young person and the support they want and need, as well as exploring their dreams, aspirations and what could enable them to achieve what they want in the context of what is practical and available locally (Valuing People Support Team, 2003).

The adoption of person centred planning would respond to parents' concerns about the real prospects and circumstances of the young person. It would enable their dreams and aspirations to be both supported yet grounded in their real world, with appropriate steps being taken to move towards their ideal situations. This person centred planning needs to be underpinned by strategic and operational multi-agency working. The draft National Service Framework for Children in England has proposed the development of multi-agency protocols which would actively promote multi-agency working although Russell (2003) recognises that this is a daunting task and would require a level of collaboration and sophistication that has not previously been achieved. Russell also suggests that the forthcoming National Services Framework (NSF) could set standards for transition which could provide a template for Connexions services.

The draft National Service Framework for Wales (National Assembly for Wales, 2004) proposes the development of one multi-agency plan for each young person, covering all aspects of the young person's life, as well as access to a transition keyworker and opportunities for work experience as part of the transition planning process.

As Ward et al (2003a) note, there is still a lack of information about the transition process and the choice and possibilities available at this time. Mitchell and Sloper (2000) confirm parents' need for accurate, up to date, easy to understand information. Parents specifically want local contact information, including contact names, so that they can get the information they need. Information for young people and parents is, however, only one aspect of the support needed. They would also like a keyworker to support the young person, and their family, and co-ordinate the multi-agency working around the young person's person centred transition plan. Ward et al (2003c) underline parents' need to talk to agencies as well as to have information, and to see examples of the choices made by other

young people and their parents. The Valuing People Support Team's '*Information Pack for Transition Champions'* (N36 and W9) gives comprehensive information about all the different agencies involved in transition planning. The '*All Change'* pack (N13) also gives a good explanation of the different agencies that families might expect to encounter at this time. The review of available resources (Appendix C) identified some good examples of resources where areas had combined both local and national information successfully, with Surrey being the most notable (L11). Two other local resources that provide information within a multi-agency context, are the website from Fusion4 (L24) and the Learning Partnership West, South West co-ordination project and SENSE (L25).

7.3   Changes and choices at transition

This section discusses the various changes and choices facing young people and their families, the information that is required by young people and their parents and the extent to which their need for information is reflected and addressed in the literature and resources.

i.   Work

Getting a job was one of the two ways in which the young people wanted to make use of their days. (The other – going to college – is discussed below.) Employment was one of the key markers of having attained adulthood, was linked to having their own money, and could also lead to other markers of independence, such as their own place to live. Three of the young people in the discussion groups already had part-time jobs. Other young people wanted information on how to get a job and recognised the benefit of going to college to learn about work. At least two of the young people in the groups were going back to college in preparation for their chosen career.

Parents also wanted to know what opportunities were available for their young person employment wise, what would be appropriate for them and whether support would be available. Parents also mentioned work based training, recognised as an important second choice for skill development by the Collaborative Group for Learning Disabilities in the North West (undated). Older young people were aware of the possibility of work experience and of supported employment agencies which could help them get a job and support them in it.

The literature recognises that having a job is central to a young person's self esteem, confidence and the way they are perceived by others (Heslop et al, 2002; Hendy and Pascall, 2001; Mitchell, 1999). However, the literature also shows that very few young people actually have 'an ordinary job' (Heslop et al, 2002; Grove and Giraud–Saunders, 2003). Training for, and getting, a job should be central to the person centred planning process (McAnespie et al, 2000). We found only one specific resource about employment, written in an accessible style and produced for young people with learning difficulties from National Institute for Adult and Continuing Education (NIACE); (N7); although several of the more general resources have useful sections on this subject (N1, N13 and

N14). NIACE also produce a resource for professionals (N35) that helps them to plan courses that will help young people to make the transition to work.

ii. College and day services

Going to college was the alternative option discussed by the young people in relation to how they would spend their days. They either saw college as their next step or as a way of preparing for their future career.

The parents wondered whether there was guidance available about the most appropriate courses for their young people, whether certain courses were appropriate or whether residential college was an option (Morris, 2002). Some parents and young people saw college as the only route of progression or the 'obvious next step' (Rowland-Crosby et al, 2002; Mitchell, 1999; Heslop et al 2003). This perception is reinforced by the close contact parents and young people have with schools, which organise and support transition to college. Of the resources located only two focus specifically on college (N5 and N6); neither gives specific advice about what courses might be available.

Day services were only discussed by a minority of parents in relation to the options available after college. The young people did not discuss the use of day services at all; their aspirations were higher. The literature, however, indicates that many young people *do* use day services after leaving college (Heslop et al, 2002). The parents involved in the study by Mitchell (1999) wanted purposeful and meaningful activity for their young person. Hudson (2003) suggests this might be pursued via person centred planning and the use of direct payments.

iii. Where to live

The young people and their parents wanted information on the choices that were available to them, such as their own flat or living with friends, or whether it was acceptable for them to remain in the family home.   Parents required in-depth information about the suitability of each option and the support that would be available for their young person.

The literature recognises that thinking about where a young person should live is both exciting and worrying for both young people and their parents (Cowen, 2001). Parents often do not receive the information they need, yet they are recognised as a vital support to young people as they leave home (Morrow and Richards, 1996). Several authors stress the need for careful support for parents around the issue of their young person leaving home. On the one hand, leaving home is a natural part of human development; on the other, the young person may perceive that support from parents in this way constitutes 'being chucked out'. Morris (2002) points out that for young people with high support needs, there are additional barriers, such as the assumption that they might have to live in a nursing home, as well as a significant lack of options, which further complicate parents' and young people's thinking and decision making.

There are three resources available to families and young people that specifically concern decisionmaking around where to live. One, by the Foundation for People with Learning Disabilities (N4) is written in an accessible style, for the young people themselves. The Joseph Rowntree Foundation (N20) has produced a book and video for families to help with the transition from home to independent living, while Housing Options (N21) have a resource pack which includes a manual, video and photocards. Some of the general resources also include information about a range of living options (N1, N2, N13, N14).

iv. Money

The young people wanted information on handling money as well as other ways in which money would support their independence. These included considering issues such as: 'how to pay bills, getting a job and having to balance it with benefits' and using banks.

Parents were concerned that their young people should be supported in handling and understanding money. They were also worried about the impact of changes in the young person's benefits they receive and their family finances. Parents specifically wanted clear, easy information about benefits. This need for information was also a consistent theme in the literature (Heslop et al, 2003; Ward et al, 2003c; Edinburgh Social Inclusion Unit, 2001). Direct payments, were only mentioned by one parent. Rowland-Crosby et al (2003) suggest that the uptake of direct payments had not been encouraged by local authorities. Within the general resources, there were references to handling money and benefits advice (N1, N2, N13, N14, N17, W4 and W7) but no specific resources had been developed to support families and young people with financial matters.

v. Friends

Most of the young people talked about needing information about friendship. They recognised the importance of social networks and keeping in touch with family and friends when living independently. They wanted information on strategies to maintain friendships, particularly if the young person attended a special school some distance from their home, as well as how to socialise. The young people in the Barnardo's study (undated) confirmed the need for support to promote and sustain friendships.

The parents recognised social activities as opportunities for friendships to grow and that their young people needed to extend their circle of friends. Supporters recognised the support that should be given to ensure young people can maintain and develop friendships.

Work by Heslop et al (2002) also documents that friends come and go and that young people were concerned about leaving some friendships behind and about how to maintain others. While friendships are recognised as one of the most important things in young people's lives (Morris, 2001, 2002; Pennington, 2001; Smyth and McConkey, 2003), the literature documents the barriers to an

independent social life including lack of transport, lack of peer group and a high degree of adult surveillance (Morris, 2002; Rowland-Crosby et al, 2002). It also indicates that young people's friendships are not given a high priority in transition planning (Heslop et al, 2003; Morris, 2003). This was borne out by the resources; very few placed an emphasis on this area. As noted in the earlier section on emotional support there is little attention paid to this subject, apart from resources from the Foundation for People with Learning Disabilities (N9 and N10) and the '*All Change'* pack (N13).

vi. Sex and relationships

The young people wanted information on all aspects of sex and relationships, such as advice on getting a boyfriend or girl friend, sex and contraception. Their parents wanted advice about how to approach the issues and what information to give. The parents involved in Heslop et al's (2002) study were concerned about the difficulties in supporting their young person in a sexual relationship. Parents did not know where they could go for support or information in this area (Heslop et al, 2002; Clegg et al, 2001). Morris (2002) also suggests that professionals overlook this issue during the transition process.

Some information for young people appears to ignore the issue of sexual relationships or refers to it in an oblique way. The young people in the research project team preferred clear practical information. Within the resources reviewed no specific resource for young people was found that addressed these issues in detail and in a clear, accessible way. This was a major gap in the available resources. Some resources aimed at families were found (N23, N24 and N25) but these were not very recent.

vii. Safety

The young people required information on all aspects of 'being safe'. They spoke of needing to know about being safe on the street and while out socialising as well as being safe at home (from burglars and from fire).

Safety, or the management of risks, was also a key theme within the parents' discussion. Parents were trying to balance their young person's aspirations with their personal knowledge of their young person's vulnerabilities and support needs and their concern about the wider society's response to their child. This theme permeated all of their discussions about the information they needed about the different choices available to their young people at transition. However, only one study (McConkey and Smyth, 2003) appears to focus on this issue. This study suggests a model of parental risk taking, which Townsley (2004) describes as an interesting, novel and potentially very significant tool for supporting families and young people to cope with risk and uncertainty during transition: a 'shared risk' strategy where parents, young people and professionals explore their mutual expectations of hazards. This strategy highlights the need to promote and confirm the young person's competences and to continue their education through practising skills in real life situations. Self advocacy and

advocacy for young people is important here, to enable them to demonstrate their abilities, argue for positive consequences and propose conditions that are acceptable to them. Only one resource, from the Citizenship Foundation and United Response (N2) was found that addressed these issues around safety and risk taking in detail. A resource from the Family Planning Association (N27) contains some discussion about 'keeping safe' in the context of relationships.

viii. Being in charge of your life

The young people stressed the importance of being in charge of their lives, understanding their own capabilities and knowing 'what they can handle'.

This theme of empowerment was confirmed by supporters but not explicitly promoted by parents generally in our discussion groups. But parents whose children were involved in a self advocacy group involved in these discussions were full of praise about how the group encouraged their young person's independence and speaking up skills. Within the literature, however, parents balanced their aspirations for their young person against a sense of anxiety regarding the future (Mitchell, 1999). Some of the resources for young people which we reviewed were empowering in tone (for example, N13) but little explicit discussion of empowerment was found.

ix. The right to be treated respectfully and play a full part in society

The young people's ideas about the ways in which their lives would develop, reflected an underlying assumption that they would play a full part in society. One of the young people specifically said she would like to help 'less fortunate people'. The parents believed that the young people needed role models to emulate; the supporters' discussions highlighted the importance of young people both being 'respected' and being aware of their rights and responsibilities. The supporters felt that they had a key role to play in supporting this development, by knowing the individual and their context and helping them to develop their views and skills.

Interestingly, although empowerment is a key information need for supporters, the literature, as noted above, does not specifically discuss ways in which young people can be empowered. It does, however, refer to strategies, to support young people in making choices such as Talking Mats (Cameron and Murphy, 2002). The literature also highlights the importance of real-life examples and role models to help young people think through choices and the importance of discussing dreams and fears for the future through MAPS (Making Action Plans – Goupil et al, 2002). The methods followed in the Transactive Project (Pennington, 2001) reflected the significance of role models. The Transactive Project, as we have seen, was praised by the young people for its clarity of presentation and examples of choices, with one member of the project team stating that they would use the planning sheets provided to plan activities in the community. Amongst the resources, there were a number that were designed to help young people with communication difficulties. The '*Acting Up'* website

(W12) is an example, as are 'Talking Mats' (N39) and the *Transactive* website (W7) mentioned above.

x. Living independently

The young people's needs for information on living independently focused on very practical issues, which often linked with the theme of money. They included information on a wide range of self-help skills such as: cooking, time, understanding technology and television listings, as well as transport.

The parents were concerned with their young person's 'independence skills' at college, how they could live and travel independently in the future and the support that their young person would require to function at an appropriate level of independence in all areas of their life. They specifically mentioned transport issues which are recognised in the literature as having a fundamental impact on young people's ability to work as well as to maintain a social life (O'Sullivan, 2001; Morris, 2002). Supporters were also concerned that young people should have a realistic understanding of their skills and the support they needed.

The resources available to young people and their families do not directly address issues of living independently. A game, '*Going Places'* (N8), has been produced to help young people with learning difficulties with their travel training, but other than this the resources reviewed did not include practical guidance about daily living skills.

Rowland-Crosby et al (2003) are clear about the kind of support young people want from a Connexions Personal Assistant (PA), including treating young people as a grown up and not being patronising. However, there appears to be little literature discussing the skills supporters should have to enable young people to live independent lives. Supporters within the discussion groups stressed that they needed information on 'how can you help as a supporter?' as well as information around 'youth work skills, personal development skills'. Within the resources reviewed, these issues were addressed to a certain extent within the video produced by Empower (N10), which covers how to get a Personal Assistant, what to look for in a PA and difficult issues that might arise. A resource produced by the National Youth Agency (N41) describes the work of the Youth Personal Assistance Support Scheme and includes good practice guidelines.

xi. Healthy living

The young people wanted information about how to have a healthy life, such as healthy food, hygiene and not smoking. Their parents, however, discussed health issues rather than healthy living, perhaps in relation to the support the young people would need in all aspects of their life. The literature discussed young people and their families' need for information checks and health action planning (DH, 2001; Pearson et al, undated; Ward et al, 2003c). These issues were not well addressed within the resources, except as a small part of some of the general resources (N13, N14).

Within the young people's discussions of the changes that occur as they grow up, emotional changes featured strongly. The young people noted that they were provided with information at school or college about emotional changes and that they were supported by friends. The supporters stressed the importance of emotional support for young people during transition. The literature reveals that many young people with learning difficulties experience mental health support needs during transition and that existing conditions can be intensified during this period of a young person's life. It also suggests the importance of friends supporting each other and adults who have the time to listen (Williams, 2003; Morgan, 2003).

These issues were not thoroughly addressed within the resources available to young people and their families. However, a series of projects funded by the Foundation for People with Learning Disabilities under the umbrella title of '*Count Us In*' (P6) may go some way to address this, as resources from them are produced. There is also an Association for Real Change project (P2) around bullying which has produced a leaflet for young people which raises awareness about bullying of young people with learning difficulties.

xii. Having fun, music and sport

The young people talked about wanting information about having fun and accessing music and sport.   They required specific information on how to access social environments and sports clubs etc. A couple of young people specifically mentioned sporting role models. The parents and supporters discussed the young people's need for meaningful and appropriate leisure and social activities. The literature suggests that young people's wider goals and aspirations including leisure should be considered in transition planning and person centred plans (Bond, 1999; O'Sullivan, 2001; Ward et al, 2003c).

Having 'fun' is important to the young person's overall well-being but issues around leisure were only addressed within the resources to a limited extent, for example in a newspaper style publication, *Progress 2004* (N1). However, this resource was produced for disabled young people in general and was not written in an accessible style. Some other resources did cover this issue in an easier to understand way, but only as part of a more general guide to transition (N2, N13, N14, N15, N17 and N19).

xiii. Ethnicity

Issues relating to ethnicity were highlighted within one of the discussion groups as being very important. Black supporters stressed the importance of services understanding parents' fears that services might not recognise young people's cultural support needs and the importance of young people remaining in their local community in their adult life. Within the literature Morris (2002) and O'Sullivan (2001) recognise that young disabled people from Black and minority ethnic communities are particularly disadvantaged at transition. Services

generally know very little about their needs and views and they and their families find it especially difficult to get information about options and possibilities. Low expectations can also inhibit their choices. Rowland-Crosby et al (2002) also report that young Black and Asian disabled people may have very different views from their parents about what they want to do in the future.

A small amount of material was located within the resources relating specifically to issues of ethnicity. A website is in development by ARC (Association for Real Change) (W2) covering issues around transition for young people from Black and minority ethnic communities. They have also produced an '*Ethnicity Toolkit'* (Valuing People Support Team, 2003) for Learning Disability Partnership Boards to use in their local communities as part of the implementation of the '*Valuing People'* White Paper. The Valuing People Support Team have also produced '*Framework for Action'* around learning difficulties and ethnicity (N33) which includes a chapter on transition, highlighting issues that are of particular relevance to young people from minority ethnic communities. The Aasha Project (P1) looks at the involvement of young people with learning difficulties from a South Asian background in post-school education and training. One of the Foundation for People with Learning Disabilities' projects in the '*Count Us In'* programme (P6) is looking at self-defined service models for young people with learning disabilities and mental health needs from ethnic minority communities.

Summary

This section discussed whether the key themes within the young people's, parents' and supporters' information needs are represented in the literature and reflected in the resources available to support young people and their families at transition. A table summarising the key themes and the extent to which they are addressed and reflected in the literature and available resources (Table 1) can be found in Section 9.

8

How appropriate is the available information on transition for young people with learning difficulties and their families?

8.1 Introduction

This section contains young people's and parents' perspectives on the content and appropriateness of existing resources which provide information on transition.

Discussions of the resources was stimulated by questions developed from the *Information for All* guidance on developing easy information with, and for, people with learning difficulties (Rodgers et al, 2004). These questions prompted the young people and parents to give their opinions on different aspects of the information under consideration:

- **Appearance** – Is the resource attractively laid out? Is it inviting? Does it use colour? Is it clearly presented? Does it look easy to use?

- **Content** – Is the information interesting? Does it cover the topics you want to know about? Does it tell you where to find out more information?

- **Ease of use** – Does it tell you what's in it? Is it clear who the resource is for? Is it the right length? Is it in an appropriate format?

In the discussions with parents we also asked about:

- **Relevance** – Does it provide you with the information you need to support your son or daughter? Is the information relevant to your young person's support needs?

- **Usefulness** – Is there a section for your young person? Would you use it or have found it useful?

The findings from the groups' discussions demonstrate the importance of working with people with learning difficulties when developing easy information so as to ensure that it is appropriate to their needs. The young people wanted information that was teenager appropriate, colourful and interesting looking, with the text broken down with clear pictures which conveyed the key messages from the text. Parents wanted their information to be clear, provide information on the transition process overall and how the process worked locally, with contact details for services.

This section presents the findings in relation to the discussion areas identified above, focusing on positive strategies for the development of resources. We begin by looking at the resources available for young people, before reviewing

the resources aimed at young people *and* their parents. The resources for young people were evaluated by the young people in the project team. The evaluation techniques used are discussed in Appendix B.

8.2   Resources for young people

i.   Appearance

Good design is of central importance in ensuring that a resource is attractive to its audience. As teenagers, many young people want to be 'trendy' and fit in with their peers. The young people in the discussion groups had the same life expectations as any other young people of the same age. They expected resources to be age appropriate, with adult looking pictures and to be 'cool' and colourful. Some of the resources were criticised for having 'babyish pictures'.

The 'Teenzone' on the *Transactive* Website was particularly praised for its teenage specific presentation and held the young people's attention for the longest. The music zone was regarded as 'cool' because of the use of appropriate teenage language. The team's comments included:

> *'Like the pictures, the graphics are good.'*

This style of interaction, with games and activities, was regarded as 'fun' and the pictures that moved across the screen were thought to be 'clever'. Interactive activities and games are excellent ways of giving important information in fun ways which will attract teenagers. The young people felt that paper based resources, should have colourful, adult looking front covers which should be plastic covered. This would protect the resource when being taken around and also ensure it was shiny and professional looking.

Resources were regarded as 'boring' if they were black and white, did not have appropriate pictures or graphics, or if the text was too dense. Attractive resources had large amounts of space around the content, the text broken up with appropriate pictures and, where relevant, symbols. A frequent criticism was that there was:

> *'Too much writing, not enough pictures.'*

Resources without illustrations were difficult to use and very off putting to young people who could not read or struggled to decipher even small sections of simplified text. The inclusion of pictures was particularly important if the resources did not have an audio version to convey the messages from the text. A detailed discussion about the use of pictures can be found below.

A CD or audio of a website was also perceived as an 'attractive' feature, which enabled the team to access the material without the need for support. Some of the resources appeared to presume that young people would use the material with a parent or supporter who could interpret the content for them.

Attractive resources also had large writing. There was a general criticism of small font sizes, the team commenting on a number of occasions that the writing should be bigger

> *'The same size as the titles.'*

Helpful information like telephone numbers, also needed to be in a big size.
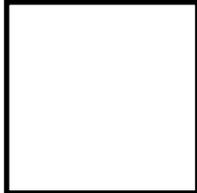
The *Information for All* guidance suggests that text should be no smaller than 14 point and that where used symbols should be at least the size of this box (but preferably larger).

ii.   Content

Transition was defined by the team as 'changes as you grow up'. The illustration of a path or road used in a number of resources was felt to be a particularly appropriate way of explaining the concept.

The team felt that most of the resources attempted to provide a wide range of information that they might need. The one area which was either missed out, or presented in an unclear way, was that of boyfriends, girlfriends and sex.

The young people believed that websites should address the issue of sex and relationships clearly and simply, rather than use oblique references to sex and relationships such as 'Beyond friendship' or 'special friends'. In some resources information about sex and relationships had not been provided; in others the material was complex and often lacking visual explanations.

The young people felt that appropriate explanations and examples were needed of important issues such as contraceptives. They established very quickly that appropriate pictures of contraceptives were easily available on the internet, including simple illustrations on how to use a condom, which could easily be linked to from a website or adapted and included in a learning difficulty specific site. They also discovered websites which explained the importance of contraception through a game (http://viral.lycos.co.uk/games/condomgame.html) which definitely got this essential message across.

Many of the resources provided the appropriate information if the young person could read, but did not if they could not. This was important. As the team frequently pointed out:

> *'Not everyone can read.'*

> *'Pages with all words tell you nothing.'*

Clear, short, unpatronising text with clear pictures was required. Lots of space around text was also needed, with any unavoidable difficult words explained the first time they were used.

The *Transactive* website was praised for telling the young people one thing at a time. There were only a few words on the screen at each time, which were accompanied by a picture or symbol. The *Information for All* guidance (Rodgers et al 2004, www.easyinfo.org.uk) suggests that sentences should not be longer than 15 words.

iii. Appropriate pictures

All of the young people liked the pictures on the *Transactive* website. It had 'nice pictures' which the young people felt clearly explained the information.

The team did *not* like information with only one picture per page. One picture on a page of text was felt to be overly selective and often conveyed just one element of the wider message being presented in the text. There were various examples of this in the resources investigated. In one case a picture of exercise was included whilst the text discussed a whole variety of opportunities available for a young person during the day, which were listed. Smaller pictures of each example could have conveyed a far wider variety of options.

In a number of resources, the pictures/cartoons relied on text included within them in order for them to be understood. This defeated the point of using illustrations to convey messages to people who have difficulty understanding written text:

> *'We don't like pictures or cartoons with words that you have to read to understand it.'*

The North Somerset young people make clear the importance of pictures in their report (NSYPF, 2004).

> *'We look at all the bits of the picture to try and understand it. Some pictures are confusing and more like a puzzle.'*

Pictures need to be clear and simple, rather than a montage of different elements around a topic. While the latter type of illustration may be thought attractive and inviting to some, from the young people's perspective they were actually very confusing.

A particular issue was the way pictures represented education. In a number of resources, a picture of a person on a computer was used to represent learning choices or further education. The young people, however, thought this picture was about using, or playing on, a computer.

The young people were clear that pictures needed to relate to the ways in which they, as young people, interpreted concepts. In pictures relating to work, a

picture of someone doing decorating had relevance, while a more symbolic picture (in another resource) of a workbench for woodwork did not mean anything to them.

This highlights once again the importance of ensuring that illustrations are appropriate to the target audience, through working with them and testing out the choice of pictures rather than using the designers' or writers' assumptions about what would explain a concept or is thought to be a common understanding of it.

The way pictures and symbols were used in *Your Book for the Future* (Partnership with Parents, undated) was considered good. The pictures got the ideas across and the symbols indicated specific things.

When symbols were used from symbol sets these were often well known representations of a concept. Computer symbols might be slightly different but still recognisable. In some resources symbols were *not* so easily recognisable. On one occasion a symbol meant to indicate 'keeping safe' was understood as 'sleeping'. Again, as the *Information for All* guidance suggests, any symbols used within resources should also be checked out with the target audience (Rodgers et al 2004, www.easyinfo.org.uk).

iv. Relevance to the individual

The content and presentation of the resource also needed to demonstrate its relevance to the individual. In one transition plan, for instance, the example of a school girl was used. A young man in the project team did not like this or see its relevance to him. He did not get the concept of making a transition passport from this example. The example of a young male had far more relevance for him. This shows the importance of ensuring that both sexes are included in examples.

Resources which enabled the young people to think about the information provided in relation to their own lives were praised. These included games, choice cards and planning sheets. The planning sheets provided by the *Transactive* website were considered particularly useful by two of the young people. One said:

> *'If I was going somewhere I'd use these.'*

Similarly, the choice cards in the *Your Book for the Future* (Parents in Partnership, undated) were recognised as being helpful for young people who communicated in different ways.

v. Further information

Further information (like contact details) relating to a topic needs to be in the main section of a resource rather than at the back or in another place where its relevance will need to be explained again and where it could be difficult to find. Where information was provided for parents and young people in the same resource, the young people found that the contact details were in the parents'

section. They felt that they should also have been provided with contact information in the section aimed at them. Contact information should include symbols to illustrate telephone numbers and explanation, using pictures or symbols, of what young people can find out there.

vi. Ease of use

Sound on websites or CDs was appreciated and could be accessed without additional support.

The team recognised that contents pages, in paper based formats, varied greatly.   Contents pages without pictures were not initially recognised as providing any information. Colour coded explanations of sections were regarded as helpful, as well as contents pages which used symbols that could be linked to the appropriate section. Colour coded sections or symbols in, or on the corner of, paper or webpages also helped navigation.

Two members of the team did not initially understand the standard web protocol of clicking on the underlined words to get to the information on a subject. They preferred to use forward and back buttons, like those on the *Transactive* site or an appropriate picture link (where clicking on a picture takes you to further information on the subject) or a button with a picture, like those found on the *Plain Facts* website. (www.bris.ac.uk/Depts/NorahFry/PlainFacts/index.html)

The young people recognised that people had a range of impairments which resource producers and designers needed to be aware of. One suggested a paper based resource including:

> *'Feely bits for people who are blind.'*

When discussing paper based outputs, the project team liked a smaller size which would fit in pockets or bags. This finding differs from that of the *Information for All* guidance which suggests material should be larger, to accommodate pictures and make it easier to handle.

The team preferred information for young people to be separate from parent information.   Inclusion with parent information made the resource large, and on occasion heavy, and while recognising that transition is a shared process between young people and parents, as well as other professionals, it did not encourage independence.

Spiral binding was considered easy to use and flexible and did not result in a floppy resource. A plastic front cover on paper based resources was also needed for protection so that the resource could be taken around with the young people and made use of.

vii. Other issues to be aware of

One resource included information about the disabled people's movement. Two of the young people felt that young people might take offence at this. These particular young people were not politicised and did not consider themselves disabled, although they were happy to respond to the categorisation of 'having learning difficulties'. One said:

> *'We're not disabled – we just find things difficult.'*

These young people felt that disabled people, by contrast, had physical impairments and might use a wheelchair. This is a good reminder of the need to avoid making assumptions about young people's perspectives.

8.3   Information for parents

The information about transition produced for parents was evaluated by a mother and two grandparents (a couple) whose child and grandchild attended a special school in North Somerset. Of these participants, the grandparents had attended their grandson's first transition planning meeting but were still unclear about the process and their role within it. The other participant's son was only 13 and had not as yet had a transition planning meeting. These participants came along to the meeting to 'find out about transition'. (Parents of the young people's research team and of young people from the local college had not responded to invitations to attend the meeting: see Appendix B for more details.)

At their grandson's transition meeting the grandparents had got the impression that the professionals were 'filling places' at certain colleges. They had not understood that transition planning meetings were an opportunity to think through a broader range of options. They were aware, however, of the lack of services which would support his inclusion in social and leisure activities.

i.   Appearance

The participants felt that the text needed to be in a large enough font. They were 'put off if the print was too small and too close together'. The resource *Transition for children and young people with disabilities* (Swindon, 2002) was felt to be appropriate in font size and layout, as the text was not too densely presented.

The participants questioned whether the term 'transition' meant anything to anyone. They felt that for parents and young people titles such as *14-25: Your future* would be far more likely to gain their attention.

ii.   Content

The parents confirmed the themes discussed in Section 5 about the types of information they required. They felt that they needed basic information about the transition process including 'relevant national information' as well as information on 'what happens locally' and how they would be involved.

The participants did not know that there were transition workers in their local authority, what direct payments were or that their young person would need an assessment to access services. They felt that they would need to be told 'what would happen'. The parents also stressed the importance of 'talking it through' and being supported through the process by a keyworker or social worker.

The participants felt that the contents of resources should include information on the services and supports available such as :

- How benefits change at 16

- Are there equivalent organisations to the Family Fund who will pay for holidays once young people have become adults?

The parents also felt that the information about services contained in resources should be subject to a quality check, so that the participants could be sure of a quality service.

The '*All Change Pack*' (Mallet et al, 2003) was regarded as covering all of the information that they might need. It was good for reference and 'digesting at home.' The '*Transition for children and young people with disabilities*' pack (Swindon, 2002) was regarded as covering 'everything' but as it was much more condensed, would only take 'three or four hours to digest.' There was 'not too much' on each subject, and parents could 'dip in and out' to gain information.

Transplan CD (Facilitating Inclusion North East, 2002) was praised for its validation of parents' roles and the clear explanation it gave of the transition process.

iii. Ease of use

The parents felt that for ease of use the relevant contact information should be in the appropriate section of a resource as well as in an overall list of contacts elsewhere.

In the '*Transition for children and young people with disabilities*' pack (Swindon, 2002), the participants liked the fact that there were two separate versions, one for the young person and one for the parents, containing the same information but in different, appropriate formats. The parents' section was felt to be a suitable size to take around to meetings.

While the participants themselves did not have computers, and expressed no desire to use one, they felt that the sound on the *Transplan* CD ROM was useful for parents with visual impairments or difficulties with literacy. But they pointed out that it was wrong to assume that 'everyone has computers'. The monthly cost for internet connection was considered 'worrying' when families were on a 'tight budget'.

These participants wanted not only written information but also information to be conveyed in person. This view was confirmed in the more general parents' discussions which also highlighted the need for a keyworker to provide appropriate information at the right time. The parents and grandparents in this group, and the parents in the four groups in England and Wales, noted that they often received information through informal contacts such as other parents at school. Similarly, the young people in the discussion groups recognised that they often found out information from friends, teachers and support workers as well as through visits, videos, leaflets and, on occasion, the internet.

iv. Helpfulness

The participants recognised that relevance of the resources for use by young people with learning difficulties would depend on the young person's level of literacy. The grandparents agreed with the young people that '*Your Book for the Future'* (Parents in Partnership, undated) would be a good resource if the young person could read or if parents were available to guide their son or daughter through it.

The participants (like the young people) did not like pictures that were cartoon like because they did not represent concepts clearly. A resource which used cartoons was considered not to have been successful in meeting the information needs of young people with learning difficulties and was described by one parent as:

'A bit of a mockery.'

Summary

This section presented young people's and parents' evaluations of resources that have been produced to support them during transition.

Key messages were that **resources for young people** should be age appropriate with large text and short clear sentences. The layout should be clear and pictures should be used to convey all of the messages within the text.

Websites about transition should be colourful, inviting and easy to navigate and present the information in interesting ways, for example using games and activities.

Information for parents should also be clear, inviting and not too densely packed with information. It should provide parents with an overview of the transition process, at both national and local levels, and include relevant contact information for services.

9

Summary and recommendations

9.1 Introduction

This report has brought together the findings from three interlinked investigations around transition for young people with learning difficulties and their parents, undertaken between October 2003 and March 2004. It provides an insight into the views of young people, their parents and supporters about transition and the extent to which their information needs were recognised in the literature or reflected in information resources available on transition at this time.

This section begins by reviewing young people's, parents' and supporters' perspectives on the kind of information they need. It shows that young people, parents and supporters require information in the same areas, but that this needs to be tailored to their particular perspectives and be provided within a context of appropriate support and person centred planning. It goes on to summarise the types of information required and the extent to which they are discussed in the literature or reflected in the resources available. Key pointers regarding the development of a website about transition for young people and their families are then provided.

9.2 The information needs of young people

Most of the young people involved in this study did not initially understand the term 'transition'. For some of the younger people the issue seemed irrelevant as they were staying on at school until they are 19 and they were happy living at home. Others had begun upon the series of changes that occur in adult life: had part-time jobs or were doing work experience with a view to getting a job or at college to learn about future work options.

The young people had expectations similar to their peers and those expressed 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. They did *not* mention use of services but did require very practical information and support that would enable them to '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.

The parents' and supporters' ideas of what the young people needed to know reflected their own needs for information on transition. Parents needed

information regarding the transition process and their role within it; they believed that their young person would want to know about the transition process and their role in it also. Supporters were concerned with empowering the young people to make their own choices and to have their voices heard, while having a realistic understanding of their abilities and life choices. They felt that young people would want to know about their options and know that their voice would be heard.

9.3 Information at transition: the perspectives of parents

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, but being aware of the lack of 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 supporters confirmed the parents' apprehension about transition and lack of information about the process, and the parents' concern about support and the choices and options available to them and their young person.

9.4 Information at transition: the supporters' perspectives

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 their home background and the wider support available to them, in order to be able to support and empower them through this emotional and challenging time. They needed full information about the transition process locally and the choices/services and supports available, as well as how they could 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 championed, whilst being sensitive to the realities of current local service provision and availability.

Detailed information was therefore needed not only on the transition process (both at a national and local level) and the roles and responsibilities of everyone involved, but the choices and changes facing young people and how these could be grounded and worked through at local level.

9.5   What information do people need about transition?

Young people, parents and supporters need detailed information about the transition process. 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, 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 is interpreted locally.

- How person centred choices can be accessed locally.

- What services are available locally and what options might be developed for the individual through the 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?

In addition to this basic understanding of the transition process and how it is implemented locally, information 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 changes occurring and their impact 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.

9.6   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 out of 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

- Changes in services.

The information provided for young people, parents and supporters needs to vary in presentation and format to meet the particular needs of each different group.

9.7   What do the literature and available resources say about the information needs identified?

A full review of the literature on transition (Townsley, 2004) and review of the current resources available (Watson, 2004) were also undertaken as part of the project. The findings from the review of resources are summarised in Table 1 (p55).

Key points from the literature review 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.

- An 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, whilst being sensitive to the realities of what is currently available in terms of services and support.

There are many resources designed to support young people and their families through transition. 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 (N13) 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 specifically for young people and aim to explain the transition planning process. These include resources such as *Transplan*, (N3), *Planning My Future, (*N11) and *The Big Picture, (*P36 when completed). The *Transactive (*W7) website aims to help young people create a multi-media passport about themselves in transition.

Table 1
How well do the literature and resources reflect young people's, parents' and supporters' information needs?

Theme	What the literature says	Coverage in resources
Work - getting and keeping a job	While having a job is a marker of adulthood and an aspiration of many young people, few young people actually have a proper job.	There is only one specific resource about employment produced for young people, although several of the more general resources cover the issues. There is also a resource that helps professionals plan courses to support young people in their transition to work.
College – going to college as a step towards a job or the obvious next step	College often seen as the only route of progression.	Two resources specifically around college.
Where to live	Thinking about where to live is both worrying and exciting. Parents need support to discuss the issue with young people. There are additional barriers to moving out of home for young people with high support needs.	Choices and decision making around housing are covered in specific resources, one of which includes a video, while another has choice cards, as well as in a number of the general resources.
Money - Young people were concerned about handling money while parents were also concerned about benefits	Clear easy information about benefits is required. The uptake of direct payments has not been encouraged strongly by local authorities.	No specific resources on handling money, although it is mentioned in a number of the general resources.

Friends – the importance of social networks, keeping in touch with old friends and making new friends	Friendships are recognised as one of the most important elements in young people's lives. Concerns re. leaving friends behind and how to maintain friendships are recognised, while the barriers to maintaining friendships are documented (lack of transport, lack of peer group, high level of supervision). Friendships, however, are not given a high profile in transition planning.	Few resources emphasise the importance of friendships other than the *All Change* Pack and resources from the Foundation for People with Learning Difficulties.
Sex and relationships	Parents concerned about supporting their young person in this area and do not know where to go for information and support.	No specific resource for young people addressing the issues in a clear, accessible way. Some resources aimed at families but these were not very recent.
Safety (in all environments)	Only one study looks in depth at how to cope with risk and uncertainty during transition.	Only one resource discusses issues of risk in detail. One resource covering 'keeping safe' in the context of relationships.
Being in charge of your life – knowing own capabilities and making their own decisions	Confirms parents are balancing their aspirations for their young people with concern about their abilities. Notion of choice is often unclear to young people and strategies to support choice such as MAPs and talking mats are discussed. Importance of parents in supporting young people's choice is recognised.	Little explicit discussion of empowerment although some of the resources for young people are empowering in tone.

Rights and responsibilities The right to be treated respectfully is inherent within young people's discussions and key theme in supporters' discussions	Literature does not specifically discuss how young people can be empowered. Examples of aids to communication given and importance of role models and real-life examples stressed.	A number of resources designed to support communication difficulties and to think through choices.
Living independently – very practical information required related to self-help skills including handling money	Issues around transport specifically mentioned as this impacts on both young people's work and social life.	Little guidance about daily living provided although some guidance available on personal assistance.
Healthy living – young people focusing on healthy eating etc while parents discuss health issues	Information about health checks and health action plans.	Not well addressed within the resources, except a small part of some of the general resources.
Emotional changes which occur as young people grow up	Importance of support from friends recognised.	Issues not thoroughly addressed. One leaflet around bullying.
Having fun, music and sport including information on how to access social environments	Little attention paid in the literature.	Issues covered only as part of a general guide to transition.
Changes in services – mentioned by parents and supporters only	Many young people use day services. Parents want services to be meaningful and have a purpose.	*All Change* pack has a section on services.

Table 1 summarises the way in which the literature and resources reflect the key information needs expressed by the young people, parents and supporters about the changes and choices available at transition. (Full details can be found in Section 7.) The table shows that many of the themes were discussed in the literature, which recognised the supporters' and parents' concerns that the young people's dreams and aspirations might not be realised. The literature showed that:

- Few young people had jobs

- Many young people used day centres

- Going to college was often an expected route of progression

- Parents needed 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.

The literature review confirmed that safety and risk is a major concern for families and young people with learning difficulties at transition (Ward et al, 2003c; Heslop et at, 2002). However, only one study has focussed entirely on this issue. (McConkey and Smyth, 2003). Similarly the literature on transition highlights both the importance of support to make choices at transition and that the notion of choice can be very unclear to many young people with learning difficulties (Rowland-Crosby et al, 2003). But issues of empowerment, rights and responsibility at transition have received scant, if any, attention in the published literature reviewed for this project.

The review of resources showed that there were a number of general packs which covered the majority of issues raised by study participants. The '*All Change*' pack (Mallet et al, 2003) most closely reflected the themes above. Generally, there was less information than would have been expected on employment, while only two packs specifically focused on transition to college. There was no resource focusing specifically on handling money for young people at transition and no specific information, in an accessible format on sex and relationships for young people. The information available for parents about sex and relationships was not recently published.

There was also little information 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.

Clearly, resources are available for people with learning difficulties on these various topics, such as housing, employment and self advocacy etc. But 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.

9.8　Presenting information about transition

This final section summarises the best ways to present information for young people and parents, including on a website.

It was clear from the discussions with the four groups of young people with learning difficulties in England and Wales and the transition project team, that a *website* presenting 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.

- 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.

- The pictures and text should be checked out with young people with learning difficulties to see that they understand correctly.

The design of the site 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, not too densely packed with information, but provide them with an overview of the national and local context, including relevant contact information for services.

Finally, remember that information should be developed in conjunction with young people and their parents. Explaining concepts very clearly can involve a lot of thinking and discussion time. Making a website which is suitable for young people with learning difficulties, their families and supporters will take a great deal of consultation (with all relevant parties), time and commitment. It will need to recognise that young people and parents will need information in a variety of other ways as well, including personal support, such as a keyworker, during the transition process.

Appendix A

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The resources and packs referenced in the text by letters and numbers can be found on the tables in Appendix C

Appendix B

Methods

1.   Introduction

The project was carried out by the Norah Fry Research Centre, University of Bristol (NFRC) in partnership with North Somerset People First (NSPF) and the Home Farm Trust (HFT).

The project comprised three parts:

- Investigating the information needs of young people, their parents and supporters (through focus group interviews)

- A systematic review of the literature on transition

- A review of the information resources currently available for young people, parents and professionals on transition.

The investigation of the information needs of young people, their parents and supporters was undertaken in partnership with NSPF and HFT.

The review of literature on transition was undertaken by Ruth Townsley, Senior Research Fellow at the Norah Fry Research Centre.

The review of the information resources currently available for young people, parents and professionals was undertaken by Debby Watson, Research Associate at the Norah Fry Research Centre.

This report was put together by Beth Tarleton, Research Fellow at the Norah Fry Research Centre, with support from all of the other involved parties and from Val Williams, Research Fellow and Linda Ward, Director of the Norah Fry Research Centre.

This section of the report first describes the partnership working involved in the project and then the methods used in each part of the investigation as follows:

- Finding out about the information needs of young people, their parents and supporters

- Reviewing the literature and consulting on key themes

- Locating and reviewing available resources on transition.

2. Partnership working

The Norah Fry Research Centre (NFRC) was aware of North Somerset People First's interest in research. North Somerset People First had previously been involved in projects with the NFRC.
North Somerset People First had just re-launched and employed a 'manager' and office manager. The term manager was the choice of the management committee who make the decisions and ask their manager to manage the details for them. This gave NSPF the backup to be involved in this project for SCIE.

NSPF's Transition Project team was established to work specifically on this project. The members were asked, by their manager, to take part because of their personal experience of transition.

The Transition Project team developed the methodology and undertook the work with young people with learning difficulties, with support from Beth Tarleton (NFRC) and their supporter/manager, Sue Hogarth. The Transition Project team have written a report of their findings from their work with young people's groups and their analysis of information about transition. This report is called *The information world'*.

Sue Hogarth, the manager at NSPF, is a very experienced supporter and was therefore well placed to run the four focus groups with supporters.

The Home Farm Trust has long had a close relationship with the Norah Fry Research Centre, having previously worked together on a range of projects including the *'Bridging the Divide'* project about transition and young people with learning difficulties which culminated in the production, amongst other things of the *'All Change'* pack (Mallet et al, 2003). The Home Farm Trust runs services for people with learning difficulties and their families, including a carer support service. Robina Mallet, HFT's carer support officer was therefore extremely well placed to run the groups with parents in order to establish their information needs at transition.

3. Finding out about the information needs of young people's parents and supporters

i. Developing the Transition Project team's own skills and ideas

The Transition team met up with Beth Tarleton (project worker at NFRC) over a number of weeks to get to know each other, to talk about the team's own experiences of transition and to think about what the term transition actually meant and how it could be explained to young people with learning difficulties without influencing their thinking. The team did not want to use the commonly used understanding of 'leaving school' as this might mean the young people would only think in terms of what to do next during the day time, with the

common assumption that young people will go on to college. The team decided on describing transition as 'growing up and becoming an adult'.

During these initial sessions, the team also took part in a training day with the Bristol Self Advocacy Research Group, a group of self advocate researchers, where they did activities around confidentiality, questioning and other research related skills.

ii. Developing materials for the focus group interviews

After thinking about what transition was, the Transition Project team began to think about what information young people would need at transition. They decided that young people would need to know what they wanted to know or do as they grew up, in order to know what information they needed.

In order to find out what information was most important, the team tried out an activity themselves. They thought of things they needed to know about and either drew on a post-it note or selected a picture to represent this. They then represented its importance by placing it in the centre of a chart if very important or further out, if less important. Their chart had three rings on it which came to represent the most important things in the inner circle, the next most important things in the middle ring and 'still needing to know' in the outer ring.

A large number of pictures and symbols were collected to help the young people show what information they needed. This collection included various pictures for each item – such as going out or friends - so that the young person could select the one that was most appropriate to them. The pictures were mainly from the *Change* picture pack, an adult orientated picture pack, from symbols or clip art packages (Change, undated).

The team piloted their methods at two local special schools. The refinements required at this stage included: adding more pictures and symbols to provide a wider range of options to choose from, practising open ended questions and follow up questions and a member of the transition team making help cards to provide specific choices for young people who needed more support to communicate.

The help cards were A4 sized, each presenting one open ended question and a number of options represented in pictures.

The parents' and supporters' meetings were planned to deliberately parallel the content of the young people's meetings. The meeting schedule was developed drawing on the facilitators' expertise and in order that the parents' and supporters' meetings ran in the same way. Each meeting explored how the participants viewed transition and investigated through a more detailed activity the types of information a parent, young person and supporter would need to

know during transition. It then went on to discuss how they would like information provided and the most important thing they would liked to have known two years earlier.

iii.   Organising the focus groups

When they felt confident, the young people's research team wrote an easy to understand invitation to invite young people with learning difficulties to the four focus group interviews. They drew their own explanation of the term transition and used a drawing (by one of the project team) of a small person growing up to be a big person to illustrate the concept of transition. The invitation also included a picture of the research team, their manager, the Norah Fry researcher and other illustrations from the *Change* picture pack. The invitation explained that the young people wanted to talk to them about what they needed to know at transition, that the information would be confidential but might be used to make a website, and that they would meet on a certain date. An easy to understand consent form was included with the invitation.

Contact with the groups was then made by the NFRC researcher and after explanation of the project and negotiating access, a date set for a visit during which the transition team would meet with the group of young people. At the same time their parents and supporters were also invited to focus group meetings. Letters were sent to the parents, including an explanation of their young person's involvement (which asked for their consent if their young person was under 16 years of age) as well as an indication of their own willingness to be involved. A similar letter and response/consent form was also sent to supporters. Invitations were arranged so that the young person, their parent and their supporter would be in each of the meetings. This would help form a triangle of perspectives around the information needed.

In each area, a contact (e.g. teacher or project leader) acted as a 'go-between' and in at least two areas wrote a covering letter to parents confirming their organisation's support for the research. In one school, the visit was used to begin a transition support programme for parents.

Iv   Arrangements for the focus groups

Four visits were made to carry out focus group meetings with young people, parents and supporters, three in England and one in Wales. Two visits were based in special schools where access had been negotiated with the class teacher or head of support.

The other two groups were based at self advocacy organisations. One organisation's role was to support self advocacy amongst young people with learning difficulties whilst the other supported young people's social inclusion through leisure activities.

The meetings usually began with drinks or a meal together before separating off into the three different participant groups. At the end of the session, the participants were asked what type of gift voucher they would like to thank them for their participation. In one location, some of the supporters chose to be paid for a session of their time, through their organisation, rather than to receive a voucher. The participants were not told about the vouchers in the early communication from the project. An appropriate thank you letter was sent to each participant afterwards with the vouchers via our contact at the organisation. A thank you letter was also sent to the organisation.

Although an initial aim of the project, further individual interviews with young people with high individual support needs were not undertaken because the Transition Project team would have needed additional support and training to ask the questions in appropriate and individualised ways. This was not feasible within the time frame available. It would also have meant that they were not as fully in control of the research process as was desired.

iv.   Focus group participants

Twenty-seven young people with learning difficulties (including one participant who was a volunteer helper) were involved in the focus group meetings. Thirteen of the young people were between 14 and 16 years of age, six were between 17 and 19, while seven were aged over 20. The groups included five Black young people, five deaf young people, four of whom used a hearing aid worn around neck or belt and one who communicated using Makaton. One of the younger people had high communication and physical support needs.

Nineteen parents participated in the focus groups – all parents of the young people in the young people's groups, including one Black parent. In one area, although our key contact had striven to ensure parental involvement, including the provision of a Jamaican meal, no parents arrived for the meeting. This was unfortunate, but our key contact explained that the extremely cold weather and possibly the fact that the young people's meeting was seen as a break for parents, might have been responsible for the lack of interest. This meant the views of Black and minority ethnic parents were under represented in the study. However, Black supporters were included in the supporters' group and provided some insight into parents' views.

There were 19 supporters involved in the supporters' meeting.   Four of these supporters were Black. The supporters often supported a number of young people in different contexts. One of the supporters was a self advocate who had previously been a member of the advocacy group.

vi   The focus group meetings

The young people's meeting included:

- Introductions by the team and the participants.

- Explaining confidentiality i.e. the research team would tell others what the young people said but not who said it.

- Questioning whether the young people knew what transition was - which led in three of the four meetings to the team explaining that transition was growing up and becoming an adult.

- Asking what the young people wanted to do when they were older or what they had done as they'd grown up.

- The activity to establish what information they needed by selecting or drawing (or writing in one group) representations of the information they needed and placing it on a chart in accordance with its importance to them. The activity was undertaken in two groups, each group supported by one or two members of the team. Each young person was given a coloured pen so that they could mark which of the pictures they had selected and the pictures were then stuck on the chart.

- Asking the young people how they found out information.

- Asking the young people what a website about transition might look like.

The two or three members of the Transition Project team, who attended each meeting, were supported by the NFRC researcher to ask follow up questions, move onto the next aspect of the meeting, when appropriate, and to encourage the young people in the group activity. She also took notes during the question and answer sections of the meeting and recorded the young people's understanding of the pictures they had selected or drawn during the activity.

The pictures selected often represented something different to the young person than the picture artists had envisaged. For instance, a picture intended to represent safe sex was actually chosen to represent the concept of safety as the young person could read the word safe which was written on the picture. The fact that the word sex was also written and that a condom was included in the picture was not recognised.

The parents' and supporters' meetings paralleled the young people's meetings. The meetings included:

- Welcome and introduction

- Discussion of confidentiality (in one instance a tape recorder was used)

- Discussion of what is transition (with the comments being recorded on a flipchart) which often included details of the young person

- The more detailed activity which asked for their views of what the three people in the triangle would need to know i.e. themselves as parents, their young person and their supporter (or themselves as a supporter, the young person and their parent).

- Each participant was again given a specific coloured pen so that their views could be tracked and each participant had their own chart on which to place their post-its at the appropriate level of importance.   The parents and supporters also indicated on the post-it whose perspective they were writing from by adding a YP (young person), S (supporter) or P (parent). When the activity was completed, a discussion was held drawing out the themes from the three perspectives, and if time allowed, an amalgamated chart for each perspective was developed.

If time allowed the meetings also included:

- Discussion of how they would want information provided

- Discussion of what a website on transition might be like

- What they would have liked to have known two years ago.

During the activity, the parents and supporters struggled to differentiate between the importance of different pieces of information. On a few occasions, all of the post-it notes were located in the central circle – everything was important.

The meetings lasted between one and two hours, with young people's groups usually being the shortest.

vii   Analysis

The material developed in the focus group meetings with the transition project team was analysed by the team and documented, with pictures and symbols, in their report (NSPF, 2004). For each of the questions (or activity circles) the team looked to see which responses were the most repeated and therefore most important.

The themes highlighted by the team corresponded with those that emerged from the NFRC researcher's analysis. The NFRC analysis, however, was undertaken in more detail and looked at the specific content and emphases within the responses from the young people, parents and supporters, as well as looking for similarities and differences within groups and in responses in relation to the age of the young person who was the focus of the parents' and supporters' discussions.

The material from the parents' and supporters' discussions was analysed to highlight differences in the parents' and supporters' views of each others' perspectives.

When material from the young person, parent and supporter in one 'triangle' was available, additional analyses of the difference of perspective in relation to the individuals was also undertaken.

4. Reviewing the literature on transition and consulting on key themes

A full write up of the methods used to undertake the full systematic review of the literature on transition is presented in Townsley (2004). A document summarising the main themes from the literature review was developed and sent to key individuals working in the transition field nationally. They were asked to complete a short feedback form to establish whether the themes were appropriate, covered all the aspects expected or had neglected any important issues.

The theme consultation was carried out by email, unfortunately at a time of many difficulties with computer viruses. When no responses were received by the initial response date, the themes were sent to each of the key individuals again. Responses were received from five people. These responses confirmed that the themes generally represented their conceptualisation of the field as it stood. The key players made some minor suggestions for alterations which have influenced the finalising of the literature review.

5. Locating and reviewing the resources available on transition

In order to obtain current, relevant resources on transition, a number of strategies were used.

i Search through existing material collected by researchers at the Norah Fry Research Centre

A number of recent projects at the Norah Fry Research Centre had involved the transition process and resulted in a considerable amount of literature being available within the Centre. An email was sent to all staff members, asking them to pass on relevant resources. This resulted in 26 resources being found.

ii Search of the NFRC library

The library within the Centre is well stocked with relevant materials. A hand and electronic search of its contents were made, resulting in a further five resources being found.

iii   On-line Choice Forum (Foundation for People with learning disabilities) – search on 'Transition' section

A call for relevant materials was put out on the *'Choice Forum'* on-line discussion. This resulted in nine offers of help with resources, including some enquiries about the project. Previous discussions on transition were also followed up to elicit further leads on resources.

iv   Internet search via 'Google'

'Google' was searched for resources, using a range of search terms. This resulted in approximately 10 new resources being found, as well as confirmation of previously found resources.

A sample of the search terms used were:

Transition – 1,280,000 hits

Transition disabled children – 28,000 hits

Transition to adult services disabled children – 29,000 hits.

Due to the high number of 'hits', it was necessary to use more specific terms when searching for specific resources. This was not always straightforward. For example, to search for the *Transactive* website 'transition Mencap' was entered, as it was known to be a Mencap resource. This still resulted in 2,470 hits, with none of the early ones pointing to the *'Transactive'* website. Once on the Mencap website, it was still not straightforward to get to the *'Transactive'* website.

It is important to note that searching via 'Google' using the word 'transition' can be problematic as, without a 'firewall', a number of potentially unsuitable sites for young people result, largely about transsexuals or cross-dressing.

v   Follow up contacts gained via literature, internet searches and responses to call for information on Choice Forum

When beginning to document the resources, it became evident that many of them listed further resources. For example, the *'Valuing People'* website (www.valuingpeople.gov.uk) has a considerable list of resources within it, most of which are available on the website as downloadable documents. This resulted in 24 further resources.

vi   Contact with major organisations

All of the organisations below were contacted, either directly by telephone or email, or by searching their websites:

- Association for Real Change

- Augmentative and Alternative Communication Research Team, Stirling University

- Barnardo's

- Catalyst Education

- Children's Society

- Citizenship Foundation

- Connexions

- Contact a Family

- Council for Disabled Children/National Children's Bureau

- CREDO – Circles network

- DfES

- DoH

- Empower

- Enquire

- Family Fund Trust

- Family Planning Association

- Foundation for People with Learning Disabilities

- Home Farm Trust

- Joseph Rowntree Foundation

- Mencap

- Mencap in Northern Ireland

- National Autistic Society

- National Development Team

- National Youth Agency

- NIACE

- People First

- Royal National College for the Blind

- Scope

- SEN Regional Partnerships

- Shaftesbury Society

- SNAP Cymru (Special Needs Advisory Project)

- Sounds Good

- SWALD – South West Agency foor Learning Disabilities

- Triangle

- United Response

- University College, London

- Valuing People Support Team.

These searches resulted in 40 - 45 resources being identified.

vii   The literature review

The literature review was a source of further information as Ruth Townsley passed on eight relevant materials that were not suitable for the literature review, but were resources that families and young people could use.

viii   Categorisation and description of resources

The resources located were then grouped into categories by main topics covered and briefly summarised. A representative selection of them (reflecting a range of style and formats) was then evaluated by the Transition Project team and parents (see below).

xi   Evaluating the information available about transition

The appropriateness of the information for young people and parents was evaluated by the parents of young people going through transition at a special school in North Somerset and the Transition Project team.

The Transition Project team spent a day thinking about the appropriateness of information that has been made available either on websites or in booklets or packs about transition.

The young people worked in pairs and looked in-depth at each of the pieces of information/material. They were then asked to evaluate the material using an easy version of the questions derived from the draft *Information for All* guidance on the production of easy information (www.easyinfo.org.uk). The young people were asked each of the questions and an evaluation of the resource was given in terms of yes/no/sort of. Their comments about the material were also recorded.

After each of the resources had been evaluated by the pairs, the group then voted on their favourite resources and listed their important features. The group agreed that any resources on transition should have these features. They also discussed the importance of having the right pictures. The team had noticed a great variation in the type and quality of pictures used in the resources.

A consultation morning was also carried out with one parent and two grandparents of young people who were either coming up to, or going through, transition in North Somerset. Setting up the consultation meeting proved very difficult. The meeting was organised twice, once for parents from the local college and once for the parents of the project team, before a group actually met. It was felt by our contacts at college and the supporters at North Somerset People First that parents did not see the relevance of a meeting to them even though the purpose of the meeting and the project overall had been clearly explained in the invitation letter. It is believed that the parents saw transition as moving from school to college.

The participants in the meeting had come along to 'find out' about transition and what it entailed.

The meeting with parents included:

- A general discussion about transition, what is involved and how the process worked locally
- Evaluating a number of resources for parents and young people using questions derived from the draft *Information for All* guidance on accessible information.

The parents' session concluded with lunch and a discussion about which gift vouchers parents would like, to thank them for their contribution to the research.