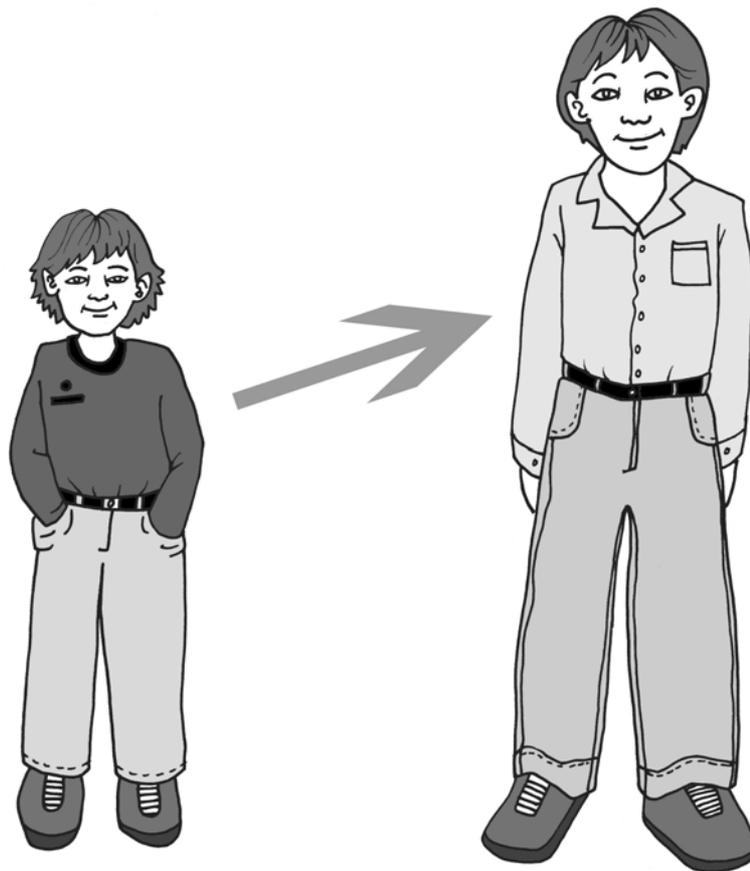


The Road Ahead?

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



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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 for 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.