

For further information contact the  
Area Community Child Health Department  
Stirling Royal Infirmary  
Livilands  
STIRLING  
FK8 2AU

# *Smoothing the Transition*

## **project report**



Smoothing the Transition  
from child to adult health services  
for young people with a learning disability in Forth Valley

Smoothing the transition from child to adult health services  
for people with a learning disability in Forth Valley.

Funded by the Innovation Fund for Children's Services, Scottish Executive

# Chief Executive's statement

The last three years have been a time of significant change for learning disabilities in Forth Valley. This project on Smoothing the Transition has played a particularly important part in our ongoing review of everything we do in the field of learning disabilities in Forth Valley. It has been particularly timely and I very much welcome the final report which provides an excellent review of the literature and the best practice in this field and gives a very practical approach to be used by young people to identify their aspirations for life after school.

The project was funded by the Innovation Fund for Children's Services (Scottish Executive), this funding was much welcomed.

The report and its recommendations will be formally considered by the Joint Partnership Group overseeing the implementation of the Learning Disability Strategy for Forth Valley. Some of the recommendations can happen without additional resources, others will require to be prioritised and adequately resourced. These will be considered alongside other potential developments for learning disability services as we continue to review our learning disability services in Forth Valley.

Janet Smith, the Transition Project co-ordinator has produced an excellent building on the inputs from many young people, parents and professionals across Forth Valley, my sincere thanks to all of these individuals for their contributions to producing a report which will make a real difference for young people with a learning disability in Forth Valley.

Anne Hawkins  
Chief Executive  
23 September 2002

# Acknowledgements

I would very much like to extend my appreciation to the young people and parents in Forth Valley who contributed enormously to this project via the focus groups and questionnaires. Without their enthusiasm and commitment I would have been unable to make recommendations based on local people's experiences and expectations.

Input from colleagues in Health, Education, Social Services, Careers, Advocacy and the Princess Royal Trust for carers also ensured a truly multi-agency commitment to improving services for this particular client group.

My appreciation is also extended to the gifted extension students at Clackmannan College, who patiently provided the illustrations for the "Help for Health" directory.

Thanks also to the tutors at Clackmannan College, who provided hospitality and supported the project to ensure true user involvement throughout.

A special thanks to Dr Maysoon Aldoori and Hamish Battye for their patience and support throughout this year.

Janet Smith  
Transition Project Co-ordinator  
September 2002

# contents

CHIEF EXECUTIVE'S STATEMENT .....	1
ACKNOWLEDGEMENTS .....	2
CONTENTS .....	3
INTRODUCTION .....	4
Definitions of Learning Disabilities .....	5
SMOOTHING THE TRANSITION PROJECT .....	6
Aims & Objectives .....	6
Literature Review .....	6
Issues and recommendations from the literature review .....	7
RESEARCH METHODS .....	10
RESULTS .....	11
Parents/Carers Survey .....	11
Summary of parents/carers issues .....	12
Parents recommendations and solutions .....	13
Young Persons Survey .....	14
Summary of young persons results and issues .....	14
CONSULTATION WITH YOUNG PEOPLE AND PARENTS .....	17
PROFESSIONAL ISSUES/JOINT WORKING .....	19
Smoothing the Transition Workshops .....	19
Health Workshop .....	20
Integrated Workshop .....	22
GUIDELINES FOR GOOD PRACTICE .....	26
Primary Care Involvement .....	27
"HELP FOR HEALTH" SERVICE DIRECTORY .....	28
Distribution of Directory .....	28
APPENDIXES .....	29
Parents Questionnaire Results Appendix 1 .....	29
Young Person's Questionnaire Results Appendix 2 .....	35
Future Needs Assessment - Medical Report Pro Forma Appendix 3 .....	38
Examples of good practice Appendix 4 .....	40
Examples of models of Key Worker/Co-ordinator Appendix 5 .....	42
References .....	47
Summary of Recommendations .....	48

# Introduction

- 1.1 The purpose of this document is to report on ‘*Smoothing the Transition*’, a 13 month research/service development project funded by the Scottish Executives ‘Innovation Fund for Children’s Services’.
- 1.2 From a parent’s and young person’s perspective moving into a different service and building up new relationships with a wide range of different professionals can be daunting. Young people, at the same time as they transfer from child to adult health services, have to cope with physical and psychological changes as well as changes in how their needs are met.
- 1.3 A wide variety of different agencies can be involved in providing care and support during this period. At what can clearly be a difficult time for both parents and young people, transferring care from child to adult services can bring additional stress and anxieties.
- 1.4 *Our National Health*<sup>1</sup> acknowledges that children with special needs are particularly vulnerable as they go through transition. One of the key recommendations was that:

*“We expect the NHS to work with partner agencies to ensure that this transition is managed sensitively and with attention to young people’s needs”*

- 1.5 Although this project was funded to examine and improve health transitions, it became apparent that in the spirit of the *Joint Future*<sup>2</sup> Agenda, we could not embark on this venture in isolation. To ensure partnership working, local stakeholders were involved from the outset and continued to provide support and guidance throughout the project. A Stakeholders Group was established, which included people with learning disabilities, supported by Quality Action Group (an organisation run by and for adults with a learning disability), parents and professionals from health, social services and education. Members were involved in two workshops (which will be reported on later in the document) and also assisted individually or in council teams.
- 1.6 The draft joint learning disabilities strategy for Forth Valley *Shaping the Future*<sup>3</sup> and the national review report *The same as you?*<sup>4</sup> both identified transition as a key area for service improvement.
- 1.7 During the public consultation on *Shaping the Future*<sup>3</sup>, a key theme that emerged from discussions with parents/carers was the apparent lack of co-ordination and information at the transition stage.
- 1.8 Forth Valley’s Partnership in Practice Agreement – ‘*Words into Action*’<sup>5</sup> highlighted transition to adult services as a specific issue for consideration.

*The same as you?*<sup>4</sup> report suggested that:

*“GPs, paediatric, learning disability and physical disability services should agree arrangements for people moving from child to adult services to make sure people have appropriate continuity in the healthcare they receive.”*

- 1.9 The project commenced in August 2001 and reached completion in September 2002. Funding was provided to employ a full time Project Co-ordinator and part time secretary. The project also accessed sessional input from appropriate clinical staff, such as school doctors and speech & language therapists.

## Definitions of Learning Disabilities

- 1.10 For the purpose of this report, we have used the definitions from the Scottish Executive publication *The same as you?*<sup>4</sup>, which describes learning disability as:

“A significant, lifelong condition that started before adulthood, that affected their development” and which means they need help to:

- Understand information
- Learn new skills
- Cope independently

- 1.11 Part of this document will refer to people with ‘complex needs’. This means that the young person may have needs arising from both learning disability and from other difficulties such as physical and sensory impairment, mental health problems or behavioural difficulties.

# Smoothing the transition project

This section will report on the aims of the project and give a brief summary of the findings from a comprehensive review of the literature.

## Aims & Objectives

- 2.1 The overall aim of the project was to smooth the transition from child to adult health services for young people with a learning disability. Specific objectives were set as follows:
- identify the key issues in transition from the young persons and parents/carers perspective;
  - prepare advice and information for young people in appropriate formats, to support transition to adult services;
  - prepare advice and guidance for health professionals;
  - develop practical tools to assist professionals, young people and parents/carers through the transition process;
  - promote an improved understanding among professionals about the importance of a smooth transition;
  - prepare a report on the project and disseminate the findings and recommendations nationally.

## Literature Review

- 2.2 On searching the literature and networking throughout the UK it became apparent that there was very little research published on health transitions.
- 2.3 Previous research projects found that people with learning disabilities do not appear to consider their health a high priority at this time. Their main issues, according to the literature are around finding meaningful employment and having access to mainstream further education and leisure opportunities.<sup>6,7</sup>
- 2.4 Although the same could be said of most young people, this demonstrates how little this particular client group values health, even though people with learning disabilities are at greater risk of health problems than the general population.<sup>8</sup> Particular health problems identified are epilepsy, mental health, hearing and/or visual impairment, heart disease, hypothyroidism and obesity. Studies by Turner<sup>9</sup> and Parish<sup>10</sup> found that the health care needs of people with learning disabilities were not being adequately met.



## Issues and recommendations from the literature review

- 2.5 Currently transition from paediatric to adult health services happens by default, rather than design.<sup>11</sup> For many young people and their parents/carers, they are moving from what is familiar and safe to '*Hurting into a void*'.<sup>12</sup>
- 2.6 In some cases, due to the perceived lack of expertise and knowledge of adult physicians, paediatricians are holding onto young people with complex health needs long after they leave school.<sup>11</sup> Better mechanism for transferring young people to appropriate adult services is required if we wish to ensure a healthy, more productive and satisfying adulthood.<sup>13</sup>
- 2.7 Person centred planning is a term, which is used frequently in today's climate when involving users in decisions regarding their care. Meaningful user and carer involvement is hampered by a lack of accessible information on the transition process and local adult services.<sup>7,14-17</sup>
- 2.8 Up to 80% of people with learning disabilities have some degree of communication difficulties.<sup>4</sup> To ensure we fully involve young people in making decisions regarding their future, we must address their communication needs and use appropriate tools to assist the process.<sup>6,18</sup>
- 2.9 Finding their way through the maize of professionals and services is a daunting prospect. A single point of contact in the form of a key worker,<sup>18,19</sup> care co-ordinator<sup>4</sup> or a transition nurse<sup>17,20</sup> would assist and support the process.
- 2.10 Parents/carers are faced with many dilemmas associated with 'letting go' while their children are moving into adulthood. Professionals should be aware of this and work in partnership with parents applying sensitivity and tact.<sup>21</sup>
- 2.11 Communication between services and with young people and their parents/carers is described as being poor and ineffective. Integrated transition plans, with high user involvement should be available for all that want one. However research has shown that this is not in place in the way policy makers would have liked them to be.<sup>17,22</sup>
- 2.12 Information about medical conditions, treatments and impairments are important to young people, but they do not always receive the information they need, or in ways which are useful to them.<sup>12</sup>
- 2.13 Young people with autistic spectrum disorder in particular require an individualised, structured, focused and coherent approach to transition planning. The very nature of autism, which often involves difficulty in predicting events; dislike of change; ritualistic and repetitive routines; high levels of anxiety and lack of flexibility of thought means that moving from a safe, predictable environment to the unknown is particularly traumatic. It is important that the young persons history is transferred with him/her, so that should behaviours reoccur, adult services are aware of what kind of support/interaction works for each particular individual.<sup>23</sup>



- 2.14 *The Family Fund Trust* produced a document called *After 16 – what’s new?*<sup>24</sup> which is a guide for young people and families during teenage years and beyond. This excellent document gives the following advice to young people about what they can do to help themselves.
- Start planning early
  - Get information about choices available
  - Get help to prepare for meetings
  - Make a life plan
  - Use pictures, photographs to help you
  - Keep your own information
  - Be involved, invite who **you** want to **your** meetings
  - Get people to talk your language
  - Advocates can help
  - Build your circles of support
- 2.15 **We have used the above as a template, added pictures to aid understanding and called it “Planning for life after school, what can I do?” This will be printed and available for anyone who would find it useful.**
- 2.16 Schultz & Liptak<sup>13</sup> suggests that the basic elements of a transition implementation plan for all young people with additional support needs is:
- Young person assumes central role on transition team
  - Care co-ordinator/key worker is identified and active
  - Transition plan goals, objectives and time frames are agreed upon
  - Comprehensive transition plan is developed involving;
    - Young person
    - Family
    - School
    - Present and future health care providers
    - Community based support
  - Progress towards goals and objectives are regularly evaluated
  - Transition plan is revised as needed
  - Successes are celebrated
  - Difficulties are used positively
  - Integrated transitions ensure;
    - Health status is optimised
    - Young persons self-care and advocacy skills are developed
    - Providers of adult health care are identified
    - Bridges to effective adult care are created
    - Financing for future health care is ensured

## Summary of recommendations from the literature and review of best practice:

- Key worker/co-ordinator should be identified and active
- Joint/partnership working should be evidenced between the young person, their parents/carers and all agencies involved in their care
- A client held transition plan should be drawn up in an accessible format detailing who should do what and by when, and be regularly reviewed
- The communication needs of young people should be acknowledged and addressed
- Information should be shared in an accessible format
- Young people on the autistic spectrum in particular require well planned, supported transitions and their previous assessments and care plans should follow them
- Financial arrangements should be dealt with prior to transfer
- The health care needs of young people should be recognised and services supported to meet those needs
- Parents/carers need to be sensitively supported to 'let go' and allow their child to develop and fulfil their individual potential as independent adults

2.18 These issues and recommendations helped to inform our survey, in an attempt to identify how young people and parents/carers in Forth Valley have found the transition from child to adult health care services.

# Research methods

- 10
- 3.1 Both quantitative and qualitative methods were used in this study to identify issues in transition from the young person and parents/carers perspectives. These included:
    - Postal survey to parents/carers using semi-structured questionnaires;
    - Interviewer administered questionnaires to young people;
    - Parents focus group and
    - Young persons focus group.
  - 3.2 Full ethical approval was granted via Forth Valley Health Board Ethics Committee, prior to commencement of the project.
  - 3.3 Consent was obtained via a standard consent form for parents/carers and a pictorialised version for young people, in order to augment communication. Where the person was unable to sign his/her name, a mark was made and countersigned by someone present who knew him/her well enough to confirm their consent.
  - 3.4 Prior to and during the interview with the young person, the participant was informed of his/her right to stop at any time. On some occasions it was obvious to the researcher (co-ordinator) that the participant was indicating that he/she was unhappy with the situation (via body language or facial expression) and the interview was terminated. No pressure was applied to any participant to take part.
  - 3.5 Confidentiality was assured and anonymity protected. The same researcher conducted the interviews, facilitated the focus groups and analysed the data to ensure consistency throughout.
  - 3.6 The parents focus groups were tape recorded and transcribed verbatim during the initial research phase. The young people did not wish to be video or tape recorded, but agreed to an assistant recording their responses by hand and taking a photograph of their 'mats', which were then returned to them for clarification of their answers.
  - 3.7 To assist the young person with communication difficulties, Talking Mats<sup>25</sup> was offered as a tool to all participants during the interviewer administered questionnaires. Five out of the eleven young people interviewed (45.4%) chose to use them. The researcher had training in the use of talking mats prior to commencement of the interviews. One individual had particular communication difficulties. To ensure the researcher interpreted the responses appropriately, the participant's speech and language therapist was present and assisted throughout the interview.
  - 3.8 **For future research with people with learning disabilities, it is essential that communication needs are considered and addressed prior to commencement.**

# Results

## Parents/Carers Survey

This section reports on the findings from the surveys. Firstly the parent's issues and suggested solutions are documented, then the young persons results are explained.

Recommendations follow at the end of this chapter.

- 4.1 76 semi-structured questionnaires were sent out to parents/carers of all young people with a learning disability and record of need in Forth Valley, who left school in 2000 and 2001. (Information was taken from the Special Needs Register at Stirling Royal Infirmary).
- 4.2 The total number of completed questionnaires was 36, indicating a 47.3% return rate. 17 questionnaires were returned by post, 17 responses were followed up via telephone and 2 were face to face contacts.

**For full details of the parent's responses to the questionnaire see appendix 1.**

- 4.3 From some of the telephone responses it was apparent that some parents/carers felt angry and let down by the service they had received. One mother stated ***"I have had no help for nineteen years, why should I help you now?"*** Her child had behavioural difficulties and she (mother) felt desperately in need of a short break. Although not part of the co-ordinators remit, a lot of time was spent listening to parents/carers and advising on local service provision, which most of the parents/carers appeared to know nothing about.

Parents also felt that they were being continually bombarded with questionnaires from a variety of organisations or had ***"no time to fill out questionnaires, too many clinic appointments in Glasgow and Edinburgh because there's no service here"***. Some parents said they would prefer to have face to face or telephone contacts regarding their views. It was also apparent that some of the parents had reading difficulties and were unable to complete the questionnaires independently.

## Summary of parents/carers issues

4.4 The first two parents focus group meetings were dedicated to further identifying issues in transition, as some of the parents had younger children and were not sent questionnaires, but could indicate what their expectations of a smooth transition would be. Collating information from both the questionnaires and focus groups, the main issues/concerns were as follows:

- **Lack of support** – “we were left to get on with it”
- **Lack of co-ordination of services** – “moved from pillar to post”
- **No key worker to co-ordinate the transfer** – “restructure the whole system, have a contact person for questions”, “if there was someone that could help with co-ordinating health and education”
- **Lack of communication between professionals** – “ensure all parties involved attend each meeting”
- **Lack of involvement in the process** – “let us know future plans”, “it’s as if we don’t exist”, “my GP is very good and says we’ll go with what you want”
- **Lack of information on adult services** – “my daughter has challenging behaviour, I don’t know who to ask for help”, “I desperately need respite, don’t know who to ask for help”
- **Lack of information on child’s health problems/poor feedback after appointments** – “I had an anaesthetist come and stand at the end of the bed asking me why I hadn’t told him that my son had a heart murmur. I said I didn’t know, he was really furious. I went back to the consultant who said we don’t like to give parents more to worry about. I asked my GP, he said he wasn’t aware of it either!”
- **Difficulty in obtaining a diagnosis** – “the problem is getting a diagnosis”
- **Uncaring attitudes from professionals** – “you just feel you are being pushed further and further away”
- **Conflicting advice from professionals** – “you see a different person every time and they tell you something different”
- **No adult neurologist to refer onto** – “as soon as they leave school there is no neurologist anywhere”
- **No assessment/treatment centre for profound/multiple disabilities** – “no matter how good your GP is, they need somewhere where the child could be examined or observed by experts”
- **Long waiting lists for child and adult health services** – “long waiting lists for services like physiotherapy, OT, and speech and language therapy”, “on waiting list for child psychology, have been told she has 14 more weeks to go”
- **Poor adult respite provision for complex health needs** – “would like to see an adult version of Tyavalla” (NCH children’s respite service)

4.5 Many of these issues were applicable to health services in general and not merely at the transition stage.

4.6 On several occasions when talking to parents, the subject of the hospital eye clinic was raised. Parents were asking why their child had not received an appointment for several years (after they had left school). They were not aware that the clinic at the hospital was a school eye clinic and therefore stopped once they left school.

As this appeared to be a common misconception we devised a standard letter, which will now be sent out to all young people leaving school who had previously attended the school eye clinic, advising them to register with a high street optician (unless otherwise directed by their consultant). The Chairman of the Forth Valley Optical Committee has seen and approved the letter.

- 4.7 Similarly, parents were inquiring about benefits and are apparently not routinely advised of changes in benefits at the age of 16.

### **Parents recommendations and solutions**

- 4.8 Nominal group technique (an activity developed to identify individual ideas with a group consensus) was used with the parents/carers (n=10) to prioritise solutions for smoothing the transition, based on the issues presented earlier.
- 4.9 The following are the parents recommendations in their order of importance and presented in their own words:

1. Ensure hand over happens before leaving paediatric services, parent/carer and child know contact name and number, including doctor, before discharge
2. Allocation of a key worker/co-ordinator throughout transition, across agencies
3. Someone to provide emotional support to young person, using appropriate language to reach full spectrum of disabilities
4. Employ more child and adult specialist services within Forth Valley
5. Invite young people in transition to a peer support group so they can learn from and support each other re: adulthood
6. Ensure consistencies in service provision, particularly respite
7. Give honest explanation/information to young person and parent/carer re: how services may change/differ in the adult world
8. Allocate a health care worker to concentrate on health promotion
9. Ensure professionals have a summary sheet at the beginning of young persons notes so they don't have to repeat themselves
10. Support integration into further education
11. Ensure 'open door' policy in adult services. May not require input at time of transition, but may in future need advice/services
12. Ask the parents for assistance when communicating with their child
13. Paediatric wards should accept young people up to the age of 18 years
14. In hospital wards, 1:1 ratio should always be available, when dealing with 'complex health needs'
15. A warm/friendly environment should be arranged to welcome young people and parents/carers. - clinics, hospitals, services in general.
16. Information on benefits, incorporating changes, should be provided to parents/carers and young people
17. Friendly, understanding doctors should be available in children and adult services (with the availability of female doctors if requested)
18. Key worker available from diagnosis
19. Ensure regular reviews take place with all services involved

- 4.10 A recurrent issue raised was that of acute hospital admissions of young people. Parents and paediatricians have stressed the need for protected beds within the paediatric unit for adolescents. Currently, the paediatric ward only takes children up to age 14. Young people with complex health needs do not currently fit well in adult wards.
- 4.11 Parents have also reported having to carry out basic nursing care duties with their children while in hospital because of lack of staff to provide the 1:1 ratio which they feel their children require at this time.
- 4.12 The *Scottish Executives National Review – Promoting Health, Supporting Inclusion*<sup>20</sup> recommended that:

*“NHS Boards should develop and ensure there is access to a Learning Disability Liaison Nursing service within acute general, paediatric and psychiatric hospitals to support children and adults with learning disabilities and their families and care workers throughout their care journey”*

### Young Persons Survey

- 4.13 Previous research indicated that young people were more likely to participate in projects if they had support from their parents. We therefore decided to approach young people whose parents had completed the parental questionnaire. This also gave us information before hand on how the young person preferred to communicate. However, in order to empower the young people, they were approached directly and asked if they would like to participate and where and when would be convenient for them. They were also asked if they wished anyone to be present or if they preferred to be interviewed alone.
- 4.14 17 young people were approached either by telephone or at college (including 1 young person who independently approached the co-ordinator and asked to be part of the focus group and agreed to be interviewed on her own). 11 young people agreed to be interviewed in total.

**For full details of the young persons responses see appendix 2.**

### Summary of young persons results and issues

- 4.15 The young person's survey was mostly made up of closed questions, with some multiple choice prompts for others. As with the parent's results, most of the young people said they were not asked about what services they would like or given any information on adult services at the time of transition. Not one participant was allocated a key worker. Emotions regarding their feelings when moving from child to adult services were variable, many choosing several responses, for e.g. sad, happy, scared. One participant said he was shocked and another was worried. However, some young people felt they could talk to their parents, a social worker or a community nurse about how they were feeling. Some young people found the transfer easy, with no difficulties at all.
- 4.16 When asked what would have made the transfer easier, the responses were as follows:

Prompts	Yes	No	Not Sure	Total
More Information	9	1	1	11
Key Worker	7	2	2	11
Someone to talk to	10	1		11
More Help	8	3		11



## Recommendations

### Recommendation 1

Health and social services should allocate a key worker/co-ordinator to the young person and family just prior to or at the first transition planning meeting. Joint working should continue regarding development of appropriate models

### Recommendation 2

Communication difficulties should be addressed when involving young people in the transition process. Talking Mats is a tried and tested method of augmenting communication at the time of transition and staff should be trained in its use

### Recommendation 3

Accessible Transition Plans should be developed to aid the young persons understanding of what's coming next. They should state who's responsible for what, contain clearly defined goals and be regularly reviewed.

### Recommendation 4

Accessible information should be given to young people at the time of transition so that they can make informed choices about adult services. The 'Help for Health' directory and 'Planning for life after school – what can I do?' are two examples, which have been produced as part of this project

### Recommendation 5

Young people should be informed of their medical conditions and supported to be more independent in their health care, including accessing appropriate health care services

### Recommendation 6

A summary sheet should be available at the beginning of child health records so that parents and young people do not have to repeat themselves when dealing with different paediatricians

### Recommendation 7

Local Action Groups should continue to progress their mission to provide local, flexible short break/respite services so that continuity of support is assured for young people and their families.

### Recommendation 8

Professionals should be aware of and sensitive to the support needs of parents at the time of transition. Expectations can be high and levels of services disappointing. Assistance should be available to manage their expectations and support them to 'let go' and encourage their child to realise their potential for independence

**Recommendation 9**

Young people should not be discharged from paediatric services until an identified adult health service has accepted responsibility for their care

**Recommendation 10**

Acute hospitals should review their inpatient provision for young people aged 14 – 19 years. Nursing staff caring for people with learning disabilities and complex health needs in an acute hospital setting should be adequately supported to meet their needs

**Recommendation 11**

Consideration should be given to the development of learning disability liaison nurses both within acute and primary care settings, as per the recommendations in the Scottish Executive report, Promoting Health, Supporting Inclusion

**Recommendation 12**

At the age of 16 benefits for young people and their carers change. Information should be provided by social services/benefit agencies regarding the changes and assistance offered to complete the appropriate forms

**Recommendation 13**

An Internet web site should be set up and monitored, to display information on Smoothing the Transition and to provide a discussion forum for young people, parents and professionals alike

# Consultation with young people and parents

This section will describe how young people and carers responded to the focus groups. Some additional issues that were raised within the young persons group in particular are also highlighted.

- 5.1 The focus groups were separate because young people and parents/carers can have very different issues, needs and wants, particularly during adolescence.<sup>26</sup>
- 5.2 Consultation with young people and carers was high on the agenda for this project and the parents involved welcomed this, stating that this is the first time they have felt like partners in redesigning service provision. **Parents are calling for more joint working with service providers in the future.**
- 5.3 Two separate focus groups were set up at the beginning and continued meeting monthly until the school holidays at the end of June. The young persons group was later in getting started due to the time it took to organise and conduct the interviews with young people and the organisational difficulties of accessible venues etc. Also due to the time required to ensure real consultation and to produce the directory, the agenda progressed at a much slower pace than that of the parents.
- 5.4 The list of prioritised solutions from the parent's questionnaires/focus group was discussed within the young person's focus group and almost unanimously agreed upon. However some of the young people stressed that some of the recommendations would only apply to those with complex needs, for example, more specialist services (No.4) and parental involvement in the information exchange (No.12). The young people were particularly keen that their views at the time of transition, and not those of their parents/carers were paramount, ***'they should listen to us, not our parents'***.
- 5.5 Additional comments from the young people were:
  - ***"Take us about places to show us the places everywhere"***
  - ***"Instead of one day a week link to college when at the school, you should get at least two days or more to get used to it"***
  - ***"About the school links again, they should get more time and more help, one person (teacher) not enough"***
  - ***"Someone should talk to you about your disability, about what it's like to be disabled"***
  - ***I would like to know more about sex, but I don't want my mum and dad to know"***
  - ***"It took a long time to get an adult physiotherapist, its ok now, but it took a long time"***
  - ***"I miss my friends"***
- 5.6 The young person's focus group had refused to be video or tape-recorded therefore direct quotes are limited.

- 5.7 Both the young people and parents, but in particular the young people had difficulty separating health from education and social services issues. So as not to miss an opportunity, it was agreed that comments regarding other services would be recorded and given to each Local Action Group (Falkirk, Stirling and Clackmannanshire) for discussion and action planning.
- 5.8 Both the young people and parents expressed their appreciation for having the opportunity to listen to and learn from each other's experiences. The parents requested that we set up an Internet Web site, which not only contained information on transition, but also could be used by young people, parents and professionals alike as a discussion forum. This has been discussed with the trusts IT department who are currently arranging this.
- 5.9 Many of the issues raised in the surveys and focus groups were similar to those documented in *Listening to you: Shaping the Future*.<sup>27</sup>

## **Recommendations**

### **Recommendation 14**

Young people should be given an opportunity to develop their sense of well being through health improvement initiatives based in schools or colleges. School nurses, health promotion staff and public health practitioners are in an ideal position to work with education to facilitate this development.

### **Recommendation 15**

Young people should be supported to maintain friendships and relationships with their peers after leaving school. Providers of services should be aware of this when developing a transition/life plan with the young person.

# Professional issues/joint working

As well as issues in transition from young people and parents/carers, it was important to get the views of professionals involved in the process. This section reports on collaborative working with partner agencies and with child and adult disciplines within health. It will also identify gaps in service provision.

- 6.1 Individuals from health, social services, education, careers, carers associations and advocacy services were interviewed, to identify current involvement and practices. One example that led to changes in practice was a request from educational psychology (in one of the local authorities) for more information from child health services at the time of transition to improve joint working /planning. A Future Needs Assessment Medical Report pro forma was devised for school doctors and is now in use as a pilot project (see appendix 3).
- 6.2 While consulting with staff involved in the Future Needs Assessment (FNA) process across Forth Valley, it became apparent that practices in each local authority were slightly different. While there was considerable support in most areas, not all local authorities were keen to discuss health issues at the FNA meeting, or to involve primary care staff, therefore the guidelines which have been produced as part of this project had to reflect this.
- 6.3 Parents, community and hospital consultant paediatricians and school doctors have repeatedly commented on the major gap left in children's services since community learning disability nurses (CLDN'S) were withdrawn. They have asked that this issue be highlighted in the report. Special schools have also reported missing the support previously offered by CLDN's.
- 6.4 School doctors and education staff have also raised concern regarding the current lack of school nurse presence in special schools. Educational staff in schools with young people with complex health needs in particular value their advice and support regarding physical disabilities.
- 6.5 A practical issue regarding the Adults with Incapacity (Scotland) Act arose in clinical practice where health and social services were at varying stages and had different views on when and whether to implement the act with regards to a young person currently going through transition. This prompted a request from general practice to investigate this issue with all young people who are incapacitated at the time of transition.

## Smoothing the Transition Workshops

- 6.6 Two workshops were arranged and well attended. One full day for clinicians from child and adult health services and one half day with representatives from health, education, social services, the voluntary sector and users and carers.

## Health Workshop

- 6.7 Health professionals from child and adult services attended a one-day workshop to explore issues in health transitions, identify service principles and develop action plans to improve the transition process.
- 6.8 Following interviews with health professionals and prior to the workshop, a process map/care pathway was drawn for each discipline showing how young people were currently transferred from child to adult health services on a discipline specific basis, i.e. physiotherapy to physiotherapy. The maps were circulated with the agenda for the workshop to ensure all were aware of current transfer procedures.
- 6.9 Presentations were delivered on the results of the surveys. Professionals shared the views of young people and carers and found no surprises in the findings.
- 6.10 The workshop participants were separated into four multi-disciplinary groups to map out how transition is currently arranged within health.

The four groups were:

### Complex Health Needs

For example, needs arising from both learning disability and from other difficulties such as physical and sensory impairment, mental health problems or behaviour difficulties

### Mental Health Needs

For example, people who have psychotic, mood or conduct disorders, but only mild learning disabilities

### Physical Health Needs

For example, people with Cerebral Palsy who may have high physical care needs but mild learning disabilities

### General Health Needs

Learning disabilities (mild/moderate) but with no significant/specialist health needs identified

- 6.11 This exercise proved difficult for most groups. The **young people with complex health needs group** was the most straight forward, given that there is an established adult Community Learning Disability Service (CLDS) to transfer onto. Also there appeared to already be links in at least one area where the CLDS is informed of and if appropriate invited to transition planning meetings with education and social services one year prior to their sixteenth birthday.
- 6.12 Primary care did not appear to be involved in the process of any of the groups, other than being informed by the CLDS when a referral had been made to them as per normal referral procedure.
- 6.13 The **young people with high physical needs group** was confused as to whom to transfer the young person onto and instinctively headed for the CLDS. The Area Rehabilitation Team was involved in this group but have recently changed their policy and no longer provide a maintenance service. Therefore it is unlikely that they would accept a young person at the time of transition unless an intensive, time-limited intervention was required and the young person was highly motivated to participate. The Area Rehabilitation Team also provides an environmental control service for people with complex physical disabilities of all ages. This service was not well known and was an example of how the day provided an opportunity to raise awareness of what other services have to offer.

- 6.14 **Young People with learning disabilities who have no specific health issues** should have been fairly straightforward in that they should continue to be supported by mainstream health services only, i.e. primary and secondary care, as per recommendations in *The Same as You?*<sup>4</sup>

By the end of the session, this was the overall consensus, however at the beginning there was again a temptation to transfer to the CLDS. Mainstream services were concerned that they did not possess the time or skills to adequately support this client group.

- 6.15 **Young people with learning disabilities and high mental health needs** was the most difficult group to transfer because there are no mental health services for children and young people with a moderate or severe learning disability in Forth Valley. In practice what has been reported is that families are battling on until there child becomes an adult and someone refers them to the CLDS, by which time the young person has well established behaviours which are often too far down the road to be addressed effectively. Years of trying to cope unsupported can cause unnecessary stress and damage to both the young person and the entire family. This reinforced previous concerns from parents and numerous professionals who had tried to refer young people to myself when they heard a learning disability nurse was in post at child health. This highlighted a major gap in provision.
- 6.16 The day proved a valuable source of information sharing and paediatric services in particular enjoyed meeting their colleagues in the adult world. This prompted two later sessions where members of the CLDS and Area Rehabilitation Team met paediatricians from the Area Child Health Department to talk about their service and referral criteria.
- 6.17 Some of the Issues and questions raised in the workshop were as follows:
- Lack of resources in both child and adult services, but particularly Child and Adolescent Mental Health
  - No access to Art & Music Therapies for children or adults in the community
  - Limited transfer of information about the young person during transition
  - The need for single assessment procedures to be rolled out across Forth Valley to avoid duplication
  - Lack of knowledge of other services
  - Communication issues for young people should be addressed to ensure true person centred approaches to care
  - What professionals currently have the time to take on the key worker role?
  - How do we support primary care to deliver a more accessible service?
- 6.18 In spite of concerns regarding resource implications there was great enthusiasm to improve the current situation. The participants came up with seven service principles.

The principles agreed were that we should be:

- Flexible, accessible and responsive to needs of clients
- Person (family) centred
- Equitable in access and standards
- Consistent with clear aims, objectives and purpose
- Transparent, seamless and multidisciplinary
- Proactive rather than reactive
- Sharing information on a need to know basis only



- 6.19 Three main areas to action plan were also agreed and individuals signed up on the day to take forward:
- Managing young people and parent/carer expectations
  - Improving information exchange between services and agencies
  - Identifying the key worker/co-ordinator role and remit

### Integrated Workshop

- 6.20 A half-day workshop was held locally and included representatives from health, social services, education (including further education), careers, advocacy, users, carers and representation from The Princess Royal Trust Carers Centre and the Autistic Society.
- 6.21 Presentations included a talk on 'Person Centred Planning' from a member of the Quality Action Group (an organisation run by and for adults with a learning disability).
- 6.22 The delegates were divided into their council groups to discuss and action plan how they would take forward some of the issues raised from the project, in particular key worker/co-ordinator remits and information exchange, which had also been raised at the health workshop.
- 6.23 The local action plans from the workshop were as follows:

#### Falkirk Actions

##### **Co-ordination issues:**

Development of job description for local area co-ordinator posts

Confidentiality issues reviewed – linked to information sharing

Review of funding streams including packages to support transitions

Review pilot of single assessment during transition

Development of a client held record or communication passport

##### **Communication Issues:**

Review of existing directories/available information

Overview of existing structures/groups and how they link together

Co-ordinate information sharing mechanisms

#### Clackmannanshire Actions

##### **Key worker/Co-ordination:**

Conduct audit of Future Needs process;

- Review information exchange
- Person centred planning
- Roles & Responsibilities
- Communications
- Expectations

Develop Joint Future approaches to service planning and provision

Create Co-ordinator functions through transition

## Stirling Actions

### Care Co-ordinator Principles:

Cross boundaries – who could be care co-ordinator?

Choice of key worker

Access to budgets/resources

Consider young people educated out with the area

Early identification of young people coming through

Advocacy

Commitment and consensus approach

Culture and organisation change implicit

Honest partnership with parents

---

### How they will move this forward:

Form joint sub-group from Children's Services Planning Group and Stirling Local Action Group

Map out transition processes in education and social work

Arrange training in Person Centred Planning

Develop a communications audit tool

6.24 The half-day workshop proved extremely useful both from a networking point of view and in generating enthusiasm to move the process forward on an interagency basis.

6.25 Good practice initiatives in Forth Valley and in other parts of the UK were identified as part of this project. They include the following:

- Southampton's Joint Transition Policy
- Ayrshire's Transition Nurse and Transition Planning projects
- Chesterfield's Transition Nurse project
- Grangemouth's Single Assessment and CLDN's pilot project
- Forth Valley's North Transition Clinic
- Clackmannan's Transition Co-ordinator Project
- Stirling's Joint Transition Policy Group

**For further details of these initiatives see appendix 4.**

6.26 The need for a Key worker/co-ordinator at the time of transition was highlighted in the literature review, by the young people and parents and by professionals as central to smoothing the transition. For this reason a short paper was produced on the various models that have been well documented in various recent reports (see appendix 5).

## Recommendations

### Recommendation 16

Within Forth Valley there are no Child and Adolescent Mental Health services for children and young people with a moderate or severe learning disability. A local needs assessment and review should be carried out to inform future planning of services

### Recommendation 17

Information should be transferred with the young person to avoid over assessment and duplication of services. Single assessment processes and client held records would provide a vehicle to facilitate this

### Recommendation 18

Smoothing the Transition should be recorded as an action in each Local Authorities Children's Services Plan to ensure continued development in this area. A transition planning sub group should be established to review current processes and to develop a Joint Transition Policy for Forth Valley

### Recommendation 19

The North Transition Clinic should be reviewed and redesigned to make it more inclusive of other disciplines/services. The new model for young people with complex health needs should be rolled out across Forth Valley

### Recommendation 20

Any interventions with young people should be person centred. There are many tools now available to assist this approach, e.g. Maps, Paths, Lifestyle Plans and Talking Mats. Anyone assisting the young person to use these tools should be trained in their use

### Recommendation 21

Where there are complex health needs, it may be appropriate to involve community learning disability nurses (CLDN'S) from age 14 to act as key worker/co-ordinator throughout the transition period. Forth Valley Primary Care Trust should consider how this could be put into effect

### Recommendation 22

A review of school nursing's contribution to children and young people with a learning disability should be undertaken to ensure equity of services across schools

#### Recommendation 23

The new Adults with Incapacity (Scotland) Act 2002 has implications for young people becoming adults and making, communication and understanding decisions on their own. Health and social services should agree joint arrangements and ensure that the act is implemented appropriately and only when necessary. We should ensure that decisions benefit the young adult, take account of their wishes and the views of others, minimise restrictions and encourage the adult to develop new skills

#### Recommendation 24

A programme of education, training and awareness raising should be developed to support mainstream services to deliver a more confident, effective and accessible service to people with learning disabilities

#### Recommendation 25

Funding sources should be investigated to pilot a key worker/co-ordinator post in Forth Valley

# Guidelines for good practice

- 26
- 7.1 As part of the project aims we planned to produce guidelines for health professionals in child and adult services. This section describes how evidence was gathered for best practice, the consultation process and the contents of the guidelines.
  - 7.2 The guideline document is called '***Smoothing the Transition from child to adult health services for young people with a learning disability – Guidelines for NHS staff involved in the transition process***' and is available on the *Show Web Site* and in hard copy.
  - 7.3 Evidence was gathered via an extensive literature search, from networking throughout the UK for evidence of best practice initiatives and by talking to local people - users, carers, voluntary organisations and professionals from health, education and social services.
  - 7.4 The guidelines were heavily influenced by all of the above, but in particular from the issues and solutions which local users and carers came up with during the first phase of the project, i.e. the survey and focus groups.
  - 7.5 Included in the guidelines is information and best practice suggestions around the following:
    - Confidentiality and consent
    - Transition planning in health
    - Joint working – linking health transitions with the Future Needs Process
    - Suggested role in the transition process for paediatricians, primary care staff, nurses and professions allied to medicine (a transition process map is available for each discipline)
    - Complex health needs
    - Key worker co-ordinator role and remit
    - Person Centred Planning, including tools to assist the process
    - Communication needs of young people
    - Access to information on services
    - Referral criteria for adult services
    - Health improvement initiatives
    - Respite/Short break services

## Primary Care Involvement

- 7.6 Of particular importance within the guidelines was the inclusion of the primary care teams. GP's told us that they were not involved in the transfer arrangements and would like to be informed when the young person is no longer under the child health department for health surveillance and review.
- 7.7 The draft guidelines were circulated for comment to representatives from carers, health, education and social services. They were also presented for comment at the trusts various clinical effectiveness/governance forums.

On the whole the guidelines were widely accepted and seen as an excellent vehicle to begin to smooth the transition process. The guidelines will be reviewed and evaluated in 2004.

## Recommendations

### Recommendation 26

Primary Care Teams have a crucial role to play in transitions. GP's and/or health visitors should be informed of transition planning meetings so that they can attend as appropriate, contribute to and increase their awareness of the young adult's health care requirements

### Recommendation 27

The 'Smoothing the Transition Guidelines for NHS staff' should be available to all staff involved in the transition process, including staff in education and social services.

# “help for health” service directory

This section describes how young people and parents/carers were involved in producing the directory and how it will be disseminated across Forth Valley.

- 8.1 Both young people and adults alike consistently voiced their concerns regarding lack of accessible information on adult services.
- 8.2 Both focus groups were heavily involved from the outset on the production of the service directory. The young people in particular decided what information would go into the directory and how it would look. Numerous examples of information leaflets/booklets were examined. The group selected the samples they liked best and decided they wanted their directory to have:
  - Pictures and words together
  - A mixture of drawings and symbols
  - Colour coded dividers
  - Preferably coloured drawings rather than black and white
  - Room in the book to put personal health details in if wanted
  - A flap at the end to hold appointment cards/letters
  - Some of the young people also wanted to do the drawings themselves
- 8.3 In response to the later request, the extension students at Clackmannan College, supported by their art teacher produced all the illustrations for the directory. A speech and language therapist from the Community Learning Disabilities Service provided the symbols from Boardmaker.<sup>30</sup>
- 8.4 Each draft of the directory was checked out by both focus groups and amended as required. The young people named the directory ‘Help for Health’.
- 8.5 The directory contains information on adult health services in Forth Valley, covering areas for example, primary care teams, dental, sexual health and specialist services. It also gives information on where to get advice on benefits, respite, housing and advocacy services. All services included in the directory commented on their section prior to publication.

## Distribution of Directory

- 8.6 Names of young people going through transition were taken from the Special Needs Register at SRI. These were cross-checked with the schools and/or educational psychologists’ registers to ensure appropriate distribution. This flagged up an issue of databases not being in sync, as many of the young people on the school register were not on the Special Needs Register under the criteria stated previously.

## Recommendations

### Recommendation 28

The directory will be given to every young person this year (2002) aged 15, 16 and 17 who have a record of need and learning disability. Every 15-year-old in 2003 and 2004 using the same criteria should also be offered a directory. In 2005, the directory will be reviewed.

### Recommendation 29

The Special Needs Register at the Area Child Health Department should be reviewed and updated in line with the national Special Needs System, so that it is in tandem with education



# Appendices

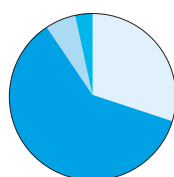
## appendix 1

Responses from the parental questionnaires were as follows:

### Question 1

Were you involved in discussions about planning the transfer of your child to adult health care service?

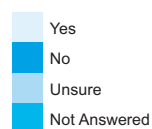
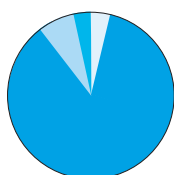
Yes	11
No	22
Not answered	1
Unsure	2
(N=36)	



### Question 2

Were you given information / choice on the available options in the adult health care services?

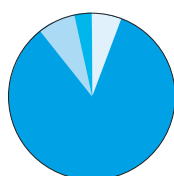
Yes	1
No	29
Unsure	5
Not Answered	1
(N=36)	



### Question 3

Were the different stages of transfer explained to you at the time?

Yes	3
No	27
Unsure	5
Not answered	1
(N=36)	



### Question 4 (part 1)

Did your son/daughter receive input from any of these people before he/she moved to the adult health care services?

	Yes	No	No Answer
Occupational Therapy	9	23	4
Speech & Language Therapy	22	12	2
Physiotherapy	9	23	4
Dietician	4	27	5
Chiropody	2	28	6
Dentist	22	12	2
Consultant	23	9	4
GP	26	8	2
Nurse	17	17	2

### Question 5

Who does your son/daughter see now?

	Yes	No	Why Not				No	Answer
			A	B	C	D		
Occupational Therapist	4	30	19	4		1	2	
Speech & Language Therapist	4	30	11	6			2	
Physiotherapist	6	29	16	2		1	1	
Dietician	5	30	13	3			1	
Chiropody	4	31	15	4			1	
Dentist	26	9	3				1	
Consultant	8	26	11	4		1	2	
GP	27	7	3				2	
Nurse	12	23	8	4		2	1	

A - don't/need want them

B - wasn't offered

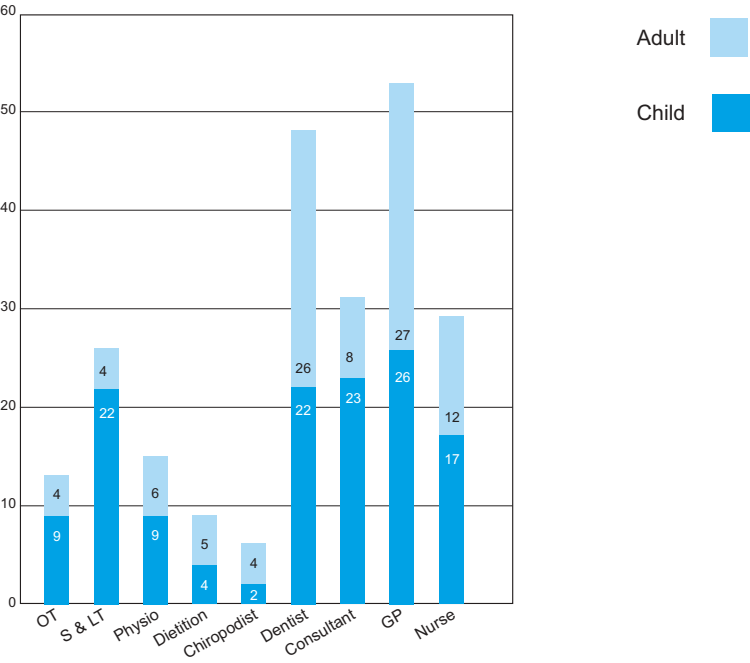
C - waiting list

D - don't see them as often as child services

Due to an error when designing this questionnaire, Psychology was missed out in adult services.

### Comparison of professionals seen in child and adult services

Comparison of professionals seen in child and adult services

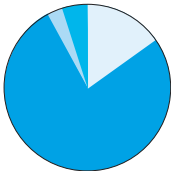


Question 6

Did you have consistent, available staff to answer questions and offer support?

Yes	3
No	27
Unsure	5
Not answered	1

(N=36)

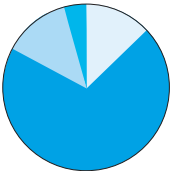


Question 7

Did the transfer appear co-ordinated between all of the key agencies and professionals?

Yes	6
No	22
Not answered	6
Unsure	2

(N=36)

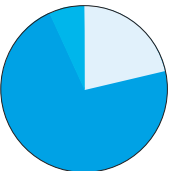


Question 8

Did you find the transfer of care to the adult health care services smooth?

Yes	12
No	20
No Answer	4

(N=36)



### Comments from parents

Ten parents/carers made additional comments in this section. Five comments related to not being aware that any transfer had taking place, e.g. “didn’t know anything about it”. One parent felt she “wasn’t involved” in the process. Two parents acknowledged the benefit of having a community learning disability nurse, “once I got a community nurse, she sorted it out”. One reported the transition as “traumatic, (young person) became a different person”. Another described it as a “constant fight from start to finish for everything (young person) got”.

### Question 9

If you did not find the transition smooth, what difficulties did you experience?  
(Not answered – 6)

This open question produced responses which when analysed could be sectioned into three themes, support, communication and continuity of care.

#### Support

Parents/carers generally felt unsupported during transition. “Had no help what so ever” and “had all services, access to help and advice (when in paediatrics) to nothing, left in the desert”. Two parents reported “if it wasn’t for the help and advice from the community nurse the transfer would not have been so smooth”. Another parent reported “she’s missing her pals”.

#### Communication

“Lack of communication” was reported as a reason for the difficulties encountered. “Not aware that any changes had taken place, have not heard from you for 18 months (child health)”. The child of this parent left school over a year previously but they had not been told that the services had changed.

#### Continuity of care

“Told bye, bye, washed their hands of us”, “moved from pillar to post” and “restructure the whole system, have a contact person for questions” were typical comments.

### Question 10

In your opinion, what needs to happen to ensure a smooth transfer?  
Again thematic analysis produced four areas which warranted addressing:

#### Communication

“More communication between agencies” was a common cry. “Ensure all parties involved attend each meeting” and “let us know future plans” were other examples.

#### Information

There was general consensus that providing and sharing information would be of enormous help. “A booklet giving information and advice on how to access specialist services”, “more information, involvement and be kept informed” and “information should be passed onto the GP” were typical examples.

#### Planning

Many parents/carers did not seem to be involved throughout the entire transition planning process and did not get feedback. They would like “follow up on original discussions” and “earlier planning, not just a hand over like on/off light switch. Everyone should be in tandem”

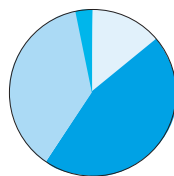
#### Support

Again parents/carers requesting “someone to support us”, “need the support”.

### Question 11

Did you receive advice/input regarding your son/daughter mental health or behaviour?

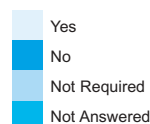
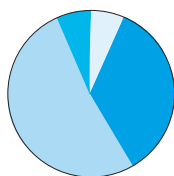
Yes	7
No	13
Not Required	14
No Answer	2
(N=36)	



### Question 12

Did you receive advice/input on your child's sexual awareness/health issues?

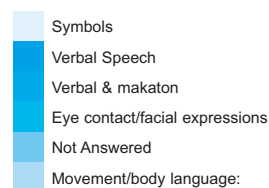
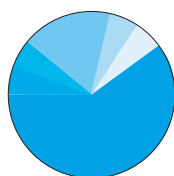
Yes	4
No	12
Not required	16
No Answer	4
(N=36)	



### Question 13

Your son or daughter may be randomly selected for an interview to carry out the young person's questionnaire. To prepare for this, can you write down how your child prefers to communicate?

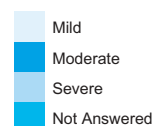
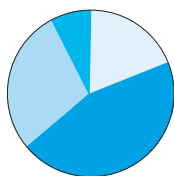
Symbols:	1
Verbal Speech	22
Verbal & makaton:	2
Makaton only:	1
Eye contact/facial expressions:	1
Not Answered:	8
Movement/body language:	1
(N=36)	



### Question 12

Did you receive advice/input on your child's sexual awareness/health issues?

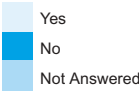
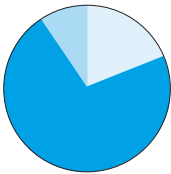
Mild	8
Moderate	15
Severe	9
Not Answered	4
(N=36)	



Question 15

We are setting up a focus group for parents/carers, please indicate if you would be interested in joining or receiving more information about this.

Yes	6
No	27
Not Answered	3
(N=36)	



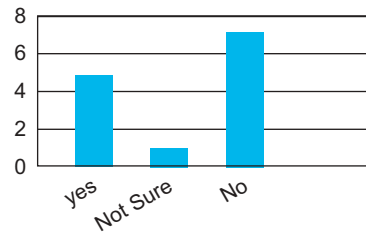
# Young person's questionnaire results

## Question 2

appendix 2

Did anyone talk to you about what support you would like from the adult health care services?

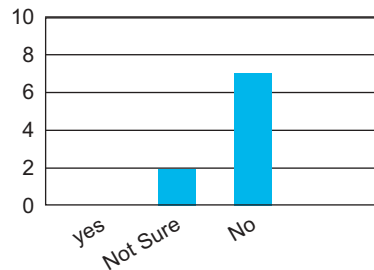
Yes	3
Not Sure	1
No	7
(N=11)	



## Question 3

Did you have one person, a key worker to help you?

Yes	0
Not Sure	2
No	9
(N=11)	

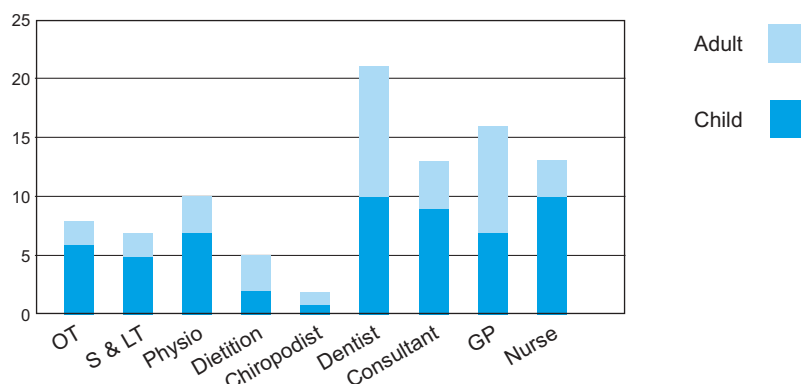


## Question 4 (Part 1)

Did you see any of these people before you moved to the adult services?

	Yes	No	No Answer Given
Occupational Therapy	6	5	
S & LT	5	6	
Physiotherapy	7	4	
Dietician	2	9	
Chiropody	1	10	
Dentist	10	1	
Consultant	9	2	
GP	7	3	1
Nurse	5	5	1

## Comparison of professionals seen in adult and child services





### Question 5

Who do you see now?

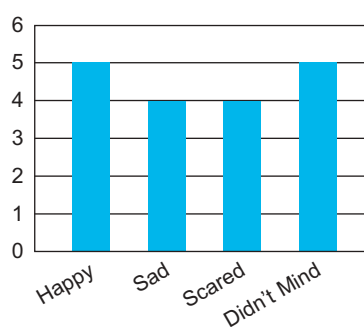
	Yes	No	Why Not				No Answer	Not Sure
			A	B	C	D		
Occupational Therapist	2	9	7	1				
Speech & Language Therapist	2	8	6	2			1	
Physiotherapist	3	7	7				1	
Dietician	3	8	5	1				
Chiropody	1	10	7	2				
Dentist	11							
Consultant	4	5	3	1			1	1
GP	9	2		1				
Nurse	3	8	4	1	1	1		

- A) Don't need/want them
- B) Wasn't offered
- C) Waiting List
- D) Don't know

### Question 6

How did you feel when you changed to the adult services? (can select more than 1 answer)

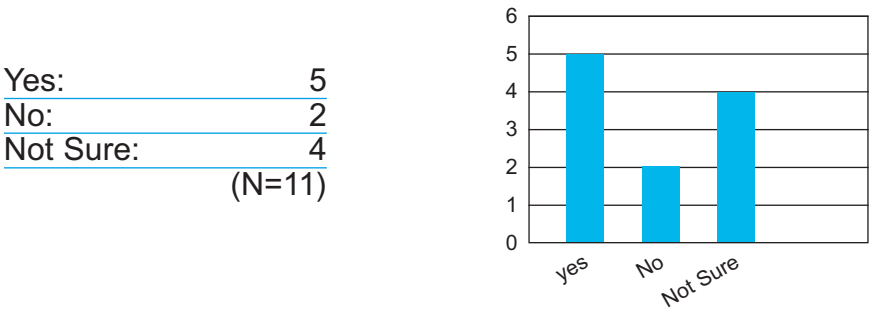
Happy: 5  
 Sad: 4  
 Scared: 4  
 Didn't mind: 5  
 (N=11)



Other unprompted responses were 'shocked' and 'worried'.

Question 7

Was there someone you could talk to about how you were feeling?

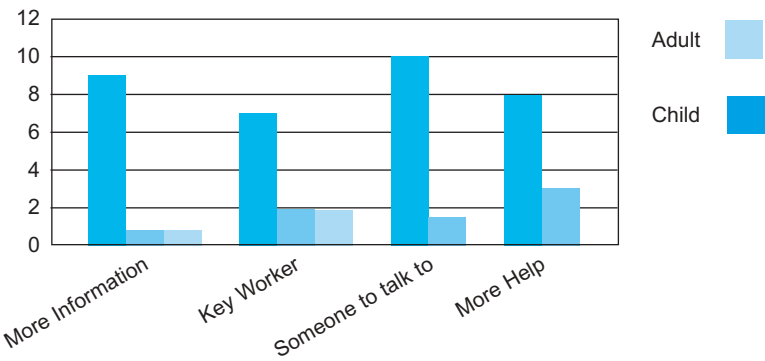


For those who said yes it was usually their mum or community nurse.

Question 8

What would have made the change easier?

	Yes	No	Not Sure
More Information	9	1	1
Key Worker	7	2	2
Someone to talk to	10	1	
More Help	8	3	



One young person said he would have particularly liked more help with transport.

**Forth Valley Primary Care NHS Trust**  
**Area Community Child Health Department**



**Future Needs Assessment - Medical Report**

Name: \_\_\_\_\_

D.O.B: \_\_\_\_\_

School: \_\_\_\_\_

Responsible Council:

Falkirk ☐

Stirling ☐

CHI No \_\_\_\_\_

Clackmannan ☐

Past history/present medical condition:

Current medication: (including information on allergies to certain drugs)

Implications for future i.e. Special health needs which require planning and support from health and social services now or in the future (e.g. epilepsy, mental health, physical disability):

Health professionals currently involved (e.g. speech and language therapy, occupational therapists, Physiotherapist etc):

New professionals who need to be involved in planning for transition (e.g. health visitor, GP, CLDS, Area Rehabilitation Team etc):

New care needs/practical help required for carers (e.g. aids, adaptations, respite or general support):

Any other comments:

Compiled by

Date:

Designation:

Recommendations discussed with young person/carers:

Yes ☐ No ☐

Young person requires continued annual health check  
when leaves school:

Yes ☐ No ☐

# Examples of good practice

## appendix 4

### Southampton Model

In Southampton a similar survey to our own was carried out with young people and carers. They said they would like:

- A named person to talk to at all times
- A package fully agreed with funding 6 months before a young person leaves school
- A joint register so overall planning is effective
- Advocacy for young people so that their needs are listened to

Southampton have produced a joint transition policy, which states that transition care for people with disabilities will be planned jointly with:

- Social services (adult & child)
- Health authority and trust
- Education
- Housing
- Relevant independent agencies
- In partnership with young people and carers

They have stated that “all young people with severe learning disabilities and/or autism will require transfer to the adult services, including transfer to the Adult Specialist Health Care Teams by age 19.

They also produced a local service directory for young people going through transition.

### Ayrshire Model

Ayrshire have developed a transition plan called ‘Planning for the future – after 16 what’s next?’ The plan records key tasks to be undertaken when the young person is 16-17, 17-18 & 18-19 by the young person, parents and workers. Regular review periods are built into the plan.

They are also addressing key worker roles and multi-agency training.

Ayrshire have also just commenced a ‘Transition Nurse Project’, part of which is to develop care pathways for young people and their families, to deliver robust co-ordination of health care needs and to improve information.

A client held record called ‘My Personal Health Record’ has been produced and is currently being piloted with young people.

### Chesterfield Model

Chesterfield has joint Adult Community Learning Disability Teams already established, but have recently appointed two team members as ‘Transition Nurses’. This model is currently being piloted.

## Grangemouth Model

In Forth Valley, a joint initiative between health and social services has produced a Single Joint Assessment document. Community Learning Disability Nurses in the South LHCC will use this document, as part of the Future Needs Assessment process for five young people with complex needs in Falkirk this year as a pilot project. The nurse will act as care co-ordinator throughout the transition process.

## North Transition Clinic

A Consultant Paediatrician from the Acute Trust currently runs a 'North Transition Clinic' in partnership with a Staff Grade Psychiatrist and Community Nurses from the North Community Learning Disability Service (CLDS).

This friendly, informal, local service gives young people with complex health needs and their carers the opportunity to meet some of the staff from a service which they may require support from in the future.

The clinic provides clear clinical care pathways for those who are likely to require continued specialist input. It is recognised, however that the clinic requires to be reviewed and made more inclusive of other disciplines and agencies.

The Consultant Paediatrician has agreed to:

- Facilitate an audit of the current transition clinic
- Consult with other medical, nursing and allied health professionals re expanding the clinic to be more multi-disciplinary, inclusive and person centred
- Identify someone to co-ordinate twice yearly multi-disciplinary clinics
- Be involved in the development of accessible transition health plans

## Clackmannanshire 'Transition Co-ordinator' Project

Clackmannanshire Council has successfully secured funds to run a pilot project for two years. A transition co-ordinator will be appointed to work with a small group of young people who are deemed disabled (within the Future Needs Assessment Process in terms of the disabled persons act). The co-ordinator will:

- Guide & support young people and their families through the network of agencies
- Act on young persons behalf re appropriate package of provision to meet support needs
- Be first point of contact for young person & service providers
- Act as an advocate for young person throughout transition process
- Remain in contact with the young person throughout until he/she is settled into employment or adult provision

Clackmannan Council has also been commended for their initiative to extend their future needs provision by tracking the young person through their two years in further education.

## Stirling Joint Transition Policy

In Stirling, partners from health, social services, education, careers, parents and the voluntary sector are developing a Joint Transition Policy for young people with disabilities. The policy will build on the existing Future Needs structure and incorporate the issues and recommendations from this project, creating a more holistic, person centred approach.

# Examples of models of key worker/co-ordinator

## appendix 5

From the literature review, current legislation and from the research conducted with young people and carers in Forth Valley, it would appear that there is strong evidence to suggest that a Key worker or Co-ordinator, would be hugely beneficial for people with learning disabilities, particularly at the time of transition.

Beattie<sup>19</sup> quotes the Association of Directors of Education as saying

*“Breakdown at transition occurs when there is no link person to offer support, insufficient time for explanation or demonstration; and the need for emotional support is not recognised”.*

*Shaping the Future*,<sup>31</sup> Forth Valley Joint Disability Strategy: Services to Children and Young People with a Learning Disability (2001) highlights the importance of a key worker, where the role would be to co-ordinate and facilitate input across agencies.

*The same as you?*<sup>4</sup> emphasises the need for Local Area Co-ordinators to ensure person centred approaches are evident with social inclusion high on the agenda.

Results from our recent survey demonstrated that in Forth Valley we have a long way to go with regards to implementing the above recommendations.

Parents (n=36)	Yes	No	Unsure	Unanswered
Did you have consistent, available staff to answer questions and offer support?	8	25	1	2
Young People (n=12)	Yes	No	Unsure	Unanswered
Did you have one person, a key worker to help you?	1	9	2	0

The parent's focus groups identified and prioritised solutions to the issues in transition in Forth Valley. Having a key worker/co-ordinator was rated as the second most important factor.

## Examples of models currently being promoted are:

### 1/ Local Area Co-ordinators (The same as you?)<sup>4</sup>

The local area co-ordinator will be responsible for making sure that each person, who wants to, has the opportunity to develop a life plan. The co-ordinator should write down the life plan and each person, their carer and the advocate or representative should have a copy. This plan will replace the existing community care assessment. Co-ordinators should:

- find out whether other people are visiting the person, what they are doing and whether they can use the same information to do an assessment together;
- tell the person that they are carrying out an assessment, what they will do and how long it will take;
- take account of language needs and cultural practices;
- tell the person what kinds of decisions depend on the assessment and what might happen; and
- at the end of an assessment, tell the person, and their family or carers if appropriate, what happens next

The life plan will include healthcare needs including dental, ophthalmic, pharmaceutical, hearing, communication and physiotherapy needs as well as any other special support. It will set out the persons assessed care needs including:

- short breaks for the person or their carer;
- meaningful work or other opportunities during the day;
- further education;
- housing and transport needs; and
- how each of these should be met.

Plans drawn up for the children at the time of future needs assessment must link to any other assessment or Record of Needs. There will be a regular review of the life plan so that the family can get more involved. Everyone who signs up for the plan will be able to ask for a review of the life plan for people with more complex needs.

Above all it is important that a person with a learning disability or carer should not only feel involved in, but also own the plan. The plan will focus on the person. It will spell out their wishes and preferences. The plan must concentrate on how to build on their strengths, to develop them as individuals and to help them lead active and fulfilling lives.

Wherever possible plans should spell out how the person with a learning disability can actively contribute to the community. It should look at what is in the best interests of the person with a learning disability in a very thorough way focussing on needs and what is available.



## 2/ Key Worker/Mentor - (The Beattie Committee Report)<sup>19</sup>

### Roles & Responsibilities

- identify the barriers likely to prevent the young person from making a successful transition;
- provide a single point of contact for the young person in dealing with agencies and to act as a link or 'broker' person with all the relevant agencies and to help the young person, over time, to interact with other agencies independently;
- participate in assessment and possibly to take a leading role;
- act as a support to the young person and his/her family/carers;
- give up to date and accurate information about post school learning opportunities and support arrangements;
- act as an independent and/or mentor;
- act as a befriended or mentor;
- act as an advocate if the need arose; and
- offer a constant figure, possibly from the age of 14 if problems have been identified at school and up to the early 20's.

## 3/ Parents Focus Group (Forth Valley Smoothing the Transition Project)

### Role of Key Worker/Co-ordinator

- carry out the assessment involving the young person and carers. (Not just needs based, but respecting individual views and wishes);
- provide information;
- act as an advocate, helping the young person get his/her views across;
- work with young people to prepare them for meetings, addressing communication issues (map out young persons path);
- provide single point of contact;
- link to wider range of services;
- encourage independence/increase knowledge of health issues;
- support young person and carer;

## 4/ Transition Co-ordinator (Clackmannanshire model 2002)

Establishment of Transition Co-ordinator post for post 16 young people with special needs (those unlikely to find employment). This concept has been promoted in the Beattie Report.<sup>19</sup>

### Co-ordinator role would be to:

- guide and support the young person through the network of other agencies;
- act on his/her behalf in negotiating and agreeing the most appropriate package of provision to meet the identified support needs;
- be the first point of contact for service providers or other agencies if problems arise;
- act as advocate for the young person throughout the transition process (from child to adult services)

## 5/ Transition Planning/Key worker - Chesterfield Model

A key worker will be appointed at the Transition Planning Meeting to oversee and co-ordinate the implementation of the Transition Plan.

Where appropriate, the Key Worker will convene regular core group meetings of the parents, young person and professionals to monitor and evaluate progress and resolve any problems in the implementation of the plan and set new targets.

For most young people this Key Worker will be a member of the Careers Service. Where considerable Social Services involvement is needed the Key Worker will be from Social Services. For young people with complex health care needs the Key Worker would be a health professional.

Planning for the individual should be an ongoing dynamic process, starting at the Transition Planning meeting, continuing until the young person is linked with relevant adult services.

# Chesterfield primary care trust

## Transition Planning Summary

Age	Action	Who
14	<b>Prepare for meeting</b> <ul style="list-style-type: none"> <li>• Prepare young person</li> <li>• Consider trigger criteria</li> <li>• Discuss who to invite to meeting</li> <li>• Send out invitations</li> </ul>	School
	<b>Transition Meeting - Transition Plan agreed</b> <ul style="list-style-type: none"> <li>• Key worker Appointed</li> <li>• Careers Services provide information, advice and guidance.</li> <li>• Consider which other professionals to involve</li> <li>• Where trigger criteria are met children's</li> <li>• Social Services sent Transition Plan to adult services</li> </ul>	All relevant parties Careers Service
15	<b>Review and update Transition Plan Community Learning Disability or Physical Disability team to be involved if appropriate</b>	Key Worker
16	<b>Review and update Transition Plan if leaving school</b> Notify social services Notify GP	Key Worker Education School Health
17	<b>Review and update Transition Plan Adult Social Services attend meeting if trigger criteria met and begin co-working</b>	Key Worker Social Services
18	<b>Review and update Transition Plan if leaving school</b> Notify social services Notify GP <b>Transfer from children's to adult Social Services</b>	Key Worker Education School Health Social Services
19	<b>Review and update Transition Plan if leaving school</b> Notify social services Notify GP	Key Worker Education School Health

## references

1. Scottish Executive (2000). Our National Health: A plan for action, a plan for change. Edinburgh: The Stationary Office.
2. Scottish Executive (2000). Community Care : A Joint Future. Edinburgh: The Stationary Office.
3. Clackmannanshire Council, Falkirk Council, NHS Forth Valley and Stirling Council (2000). Shaping the Future – A draft joint strategy for services for people with learning disabilities.
4. Scottish Executive (2000). The Same As You? A review of services for people with learning disabilities. Edinburgh: The Stationary Office. Clackmannanshire Council, Falkirk Council, NHS Forth Valley and Stirling Council (2001).
5. Words into Action – A Partnership in Practice Agreement.
6. Cameron, L., Murphy, J (2002). Enabling young People with a learning disability to make choices at a time of transition.
7. Gallivan-Fenlon, A. (1994). Their Senior Year – Family and Service Provider Perspectives on the Transition from School to Adult Life for Young Adults with Disabilities. Journal Association of Persons with Severe Handicaps: Vol. 19 (1), pp11-23.
8. Department of Health (1998). Signposts for Success – In Commissioning and Providing Health Services for People with Learning Disabilities. London.
9. Turner, S. (1996). Promoting Healthy Lifestyles for people with Learning Disabilities. British Journal of Learning Disabilities: Vol. 24, pp138-144.
10. Parish, A. (1998). Signposts for Success in Learning Disability Services – British Journal of Nursing: Vol. 7 (4), pp185.  
Blum, R.W. (1991). Overview of Transition Issues for Youth with Disabilities. Paediatrician: Vol. 18, pp101-104.
12. Morris, J. (1999). Hurtling into a void: transition to adulthood for young disabled people with complex health & support needs. Brighton Pavillion
13. Schultz, A., W., Liptak, G.S. (1998). Helping adolescents who have disabilities negotiate transitions to adulthood. Issues in Comprehensive Paediatric Nursing: Vol. 21, pp187-201.
14. Morris, J., (2002). Moving into Adulthood – Foundations: June 2002.
15. Cohen, R., Khan, J.S, O'Sullivan, T. (1998). Transition: Views and Experiences of Young People and Carers – Young Adults Transition Project, draft final report working paper 1. Lewisham and Southwark: Optimum Health Services NHS Trust.  
Stevenson, C., Pharoah, P., Stevenson, R. (1997). Cerebral Palsy – The Transition from Youth to Adulthood: Developmental Medicine and Child Neurology: Vol. 39, pp336-342.
17. Florentino, L., Datta, D., Gentle, S., Hall, DMB., Harpin, V., Phillips, D., & Walker, A. (1998). Transition from school to adult life for physically disabled young people. Archives of Disabled Children: Vol. 79, pp306-311.
19. Scottish Executive (1999). Implementing Inclusiveness Realising Potential. Edinburgh: The Stationary Office.
20. Scottish Executive (2002). Promoting Health, Supporting Inclusion – The National Review of the Contribution of all Nurses and Midwives to the Care and Support of People with Learning Disabilities. Edinburgh: The Stationary Office.
21. Thorin, E., Yonanoff, P., Irvine, L. (1996). Dilemmas faced by families during their young adults transition to adulthood – Mental Retardation: Vol. 34, pp 117-120.
22. Thomson, G.O.B., Ward, K.M. (1995). Pathways to Adulthood for Young Adults with Special Educational Needs. British Journal of Education and Work: Vol. 8 (3), pp75-87.
23. Smith, J.A., & Mitchell, C. (2002). Transition Planning - Through School into Adulthood. The Scottish Society for Autism, Alloa.
24. The Family Fund Trust (2001). After 16 - Whats New? – Choices and Challenges for Young Disabled People. York.
25. Cameron, L., Murphy, J. (2000). Making Choices at the Time of Transition for Young People with a Learning Disability. Stirling University. Childrens (Scotland) Act 1995 – Regulations and Guidelines.
27. Clackmannanshire Council, Falkirk Council, NHS Forth Valley and Stirling Council (2001). Listening to You: Shaping the Future – Feedback from Carer and User Workshop. Adults with Incapacity (Scotland) Act 2000.
29. The Picture Communication Symbols (PCS) 1981-1999. Meyer Johnson Co.USA. Shaping the Future (2001). Services to Children and Young People with a Learning Disability.
30. Shaping the Future (2001). Services to Children and Young People with a Learning Disability.

# Summary of Recommendations

## Recommendation 1

Health and social services should allocate a key worker/co-ordinator to the young person and family just prior to or at the first transition planning meeting. Joint working should continue regarding development of appropriate models

## Recommendation 2

Communication difficulties should be addressed when involving young people in the transition process. Talking Mats is a tried and tested method of augmenting communication at the time of transition and staff should be trained in its use

## Recommendation 3

Accessible Transition Plans should be developed to aid the young persons understanding of what's coming next. They should state who's responsible for what, contain clearly defined goals and be regularly reviewed.

## Recommendation 4

Accessible information should be given to young people at the time of transition so that they can make informed choices about adult services. The 'Help for Health' directory and 'Planning for life after school – what can I do?' are two examples, which have been produced as part of this project

## Recommendation 5

Young people should be informed of their medical conditions and supported to be more independent in their health care, including accessing appropriate health care services

## Recommendation 6

A summary sheet should be available at the beginning of child health records so that parents and young people do not have to repeat themselves when dealing with different paediatricians

## Recommendation 7

Local Action Groups should continue to progress their mission to provide local, flexible short break/respite services so that continuity of support is assured for young people and their families.

## Recommendation 8

Professionals should be aware of and sensitive to the support needs of parents at the time of transition. Expectations can be high and levels of services disappointing. Assistance should be available to manage their expectations and support them to 'let go' and encourage their child to realise their potential for independence

#### Recommendation 9

Young people should not be discharged from paediatric services until an identified adult health service has accepted responsibility for their care

#### Recommendation 10

Acute hospitals should review their inpatient provision for young people aged 14 – 19 years. Nursing staff caring for people with learning disabilities and complex health needs in an acute hospital setting should be adequately supported to meet their needs

#### Recommendation 11

Consideration should be given to the development of learning disability liaison nurses both within acute and primary care settings, as per the recommendations in the Scottish Executive report, Promoting Health, Supporting Inclusion

#### Recommendation 12

At the age of 16 benefits for young people and their carers change. Information should be provided by social services/benefit agencies regarding the changes and assistance offered to complete the appropriate forms

#### Recommendation 13

An Internet web site should be set up and monitored, to display information on Smoothing the Transition and to provide a discussion forum for young people, parents and professionals alike

#### Recommendation 14

Young people should be given an opportunity to develop their sense of well being through health improvement initiatives based in schools or colleges. School nurses, health promotion staff and public health practitioners are in an ideal position to work with education to facilitate this development.

#### Recommendation 15

Young people should be supported to maintain friendships and relationships with their peers after leaving school. Providers of services should be aware of this when developing a transition/life plan with the young person.

#### Recommendation 16

Within Forth Valley there are no Child and Adolescent Mental Health services for children and young people with a moderate or severe learning disability. A local needs assessment and review should be carried out to inform future planning of services

#### Recommendation 17

Information should be transferred with the young person to avoid over assessment and duplication of services. Single assessment processes and client held records would provide a vehicle to facilitate this

### Recommendation 18

Smoothing the Transition should be recorded as an action in each Local Authorities Children's Services Plan to ensure continued development in this area. A transition planning sub group should be established to review current processes and to develop a Joint Transition Policy for Forth Valley

### Recommendation 19

The North Transition Clinic should be reviewed and redesigned to make it more inclusive of other disciplines/services. The new model for young people with complex health needs should be rolled out across Forth Valley

### Recommendation 20

Any interventions with young people should be person centred. There are many tools now available to assist this approach, e.g. Maps, Paths, Lifestyle Plans and Talking Mats. Anyone assisting the young person to use these tools should be trained in their use

### Recommendation 21

Where there are complex health needs, it may be appropriate to involve community learning disability nurses (CLDN'S) from age 14 to act as key worker/co-ordinator throughout the transition period. Forth Valley Primary Care Trust should consider how this could be put into effect

### Recommendation 22

A review of school nursing's contribution to children and young people with a learning disability should be undertaken to ensure equity of services across schools

### Recommendation 23

The new Adults with Incapacity (Scotland) Act 2002 has implications for young people becoming adults and making, communication and understanding decisions on their own. Health and social services should agree joint arrangements and ensure that the act is implemented appropriately and only when necessary. We should ensure that decisions benefit the young adult, take account of their wishes and the views of others, minimise restrictions and encourage the adult to develop new skills

### Recommendation 24

A programme of education, training and awareness raising should be developed to support mainstream services to deliver a more confident, effective and accessible service to people with learning disabilities

### Recommendation 25

Funding sources should be investigated to pilot a key worker/co-ordinator post in Forth Valley

#### Recommendation 26

Primary Care Teams have a crucial role to play in transitions. GP's and/or health visitors should be informed of transition planning meetings so that they can attend as appropriate, contribute to and increase their awareness of the young adult's health care requirements

#### Recommendation 27

The 'Smoothing the Transition Guidelines for NHS staff' should be available to all staff involved in the transition process, including staff in education and social services.

#### Recommendation 28

The directory will be given to every young person this year (2002) aged 15, 16 and 17 who have a record of need and learning disability. Every 15-year-old in 2003 and 2004 using the same criteria should also be offered a directory. In 2005, the directory will be reviewed.

#### Recommendation 29

The Special Needs Register at the Area Child Health Department should be reviewed and updated in line with the national Special Needs System, so that it is in tandem with education



