The University of Strathclyde
Department of Educational Support and Guidance

The forgotten people:
The transition from school to post-school provision for young adults with profound physical and intellectual disabilities

VOL 2

By Anne Haddow
A thesis presented in fulfillment of the requirements for the degree of Doctor of Philosophy
2004

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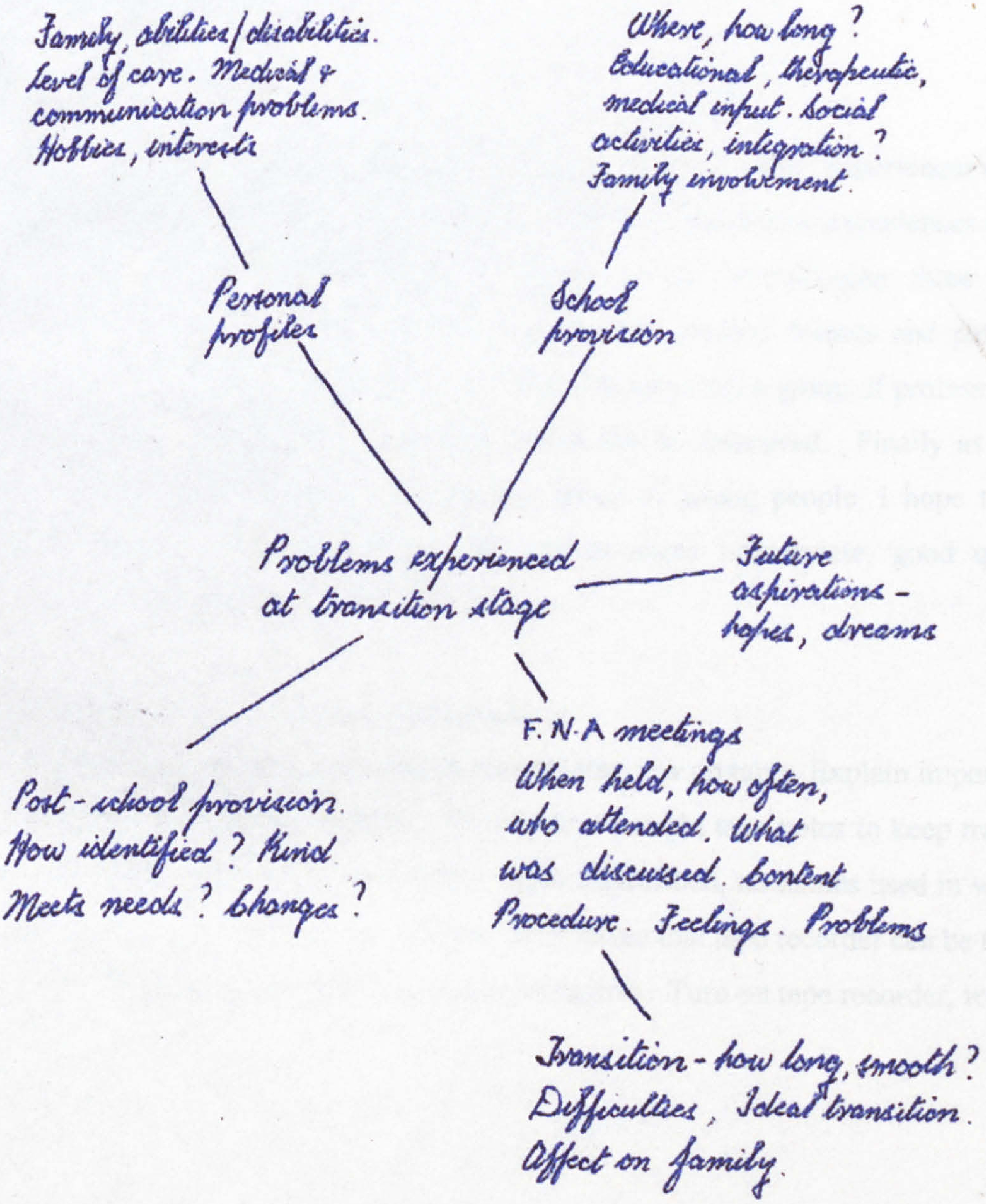
Appendices

Appendix A Initial framework for individual and dyadic interviews with family carers



Appendix B Interview guide for individual and dyadic interviews with the family carers

Introduction

My name is Anne Haddow. My daughter, Jennifer, suffers from cerebral palsy and has profound physical disabilities and complex learning needs. I am doing a PhD degree, part-time with Strathclyde University and my topic is the transition period and post-school provision for young adults with profound physical disabilities and complex learning needs.

Purpose of the study

The purpose of the study is to find out more about parents/carers' experiences of the transition period. Therefore I am interested in hearing about your experiences of the transition period with (son/daughter's name). I am interviewing three other parents/carers and then studying the interviews for common themes and patterns. Then I hope to have a group discussion with the parents and a group of professionals to suggest ways in which the transition period can be improved. Finally as there seems to be little or no provision for this group of young people, I hope to ask parents/carers and professionals for their ideas about appropriate, good quality provision and services for these young people.

Tape recording, note-taking and confidentiality

Reconfirm interviewee's permission to record interview on tape. Explain importance of capturing their words and ideas. Explain that I might take notes to keep track of the interview. Confirm confidentiality – tapes transcribed, no names used in written account, tapes erased after study. Inform interviewee that tape recorder can be turned off at any time during the interview if s/he so desires. Turn on tape recorder, test and rewind.

Interview questions

Description of son/daughter, family

1. To start off, could you tell me about yourself and your family. Describe them for me.
2. .Tell me more about X (disabled son/daughter).

   Probes – disabilities/abilities, hobbies, interests, likes/dislikes, medical problems, communication problems.

School provision

1. What school did X attend? What did s/he do there?
2. Do you think the school met X's needs?

   Probes – educational, social, physical/medical, emotional. Improvements?
3. How did you and X feel about the provision provided by the school?

   Probes – facilities, activities provided, educational programmes, therapies and medical services provided, staff/pupil ratios, involvement of parents/carers.
4. Any thing else you'd like to tell me about X, s school provision?

Experience of transition period

1. Think back to X's first Future Needs Assessment meeting. Describe it to me.

   Probes – What age was X? Who attended? What was discussed at the meeting? How did you feel at the end of the meeting?
2. Tell me about the other Future needs Assessment meetings for X.

   Probes – How often held? Who attended? What was discussed? Did you feel progress was being made?
3. Any transition period in our lives can be a difficult time. Could you describe the difficulties you experienced during X's period from school to adult provision?
4. How did you overcome them?
5. What would you have liked to happen?
6. How did this transition period affect you, your family, X?
7. Anything else you'd like to add about this transition period..

Adult provision

1. What kind of provision is provided for X now?
2. How did this provision come about?

   Probes – How was decision made to send X there? Did you and X have a choice of provision and if so how was it made? Did X have a transition period between school and adult provision?
3. Describe the kind of provision provided for X now.

   Probes – numbers attending, staff/client ratios, facilities/activities provided.
4. Do you think it meets X's needs?

   Probe – educational, social, physical/medical, emotional.
5. How do you feel about the provision provided for X now?

   Probe – Any changes/improvements you would like to see?
6. Anything else you'd like to tell me about X's current provision?

Future aspirations

1. What are your hopes and dreams for X's future?

Conclusion

1. Anything you'd like to add or anything you'd like to ask me about the study?

Switch off tape.

Thank you for your help.

Appendix C Reflections on individual and dyadic interviews with the family carers

Interview with Helen on 5th June 2001

This interviewee wanted a copy of the interview questions before the interview. She wanted time to think about the questions and about what she wanted to say. When I arrived for the interview she had made notes for the interview. She said she liked this method as it gave her time to recollect her thoughts and make sure she included all her experiences. In previous interviews she said she often remembered things after the interviewer had gone.

In this interview I felt I said little. My role was more one of attentive listener. The interviewee was very articulate and had obviously given considerable thought to the topics raised by the interview guide. The tape was stopped twice during the interview – once to enable the interviewee to respond to a caller and once for the interviewee to have a drink of water.

Although Helen is a close friend of mine, I felt very nervous about conducting this interview in case it affected our friendship. Discussing this with her later she admitted she felt the same. After reading "Faye's story", Helen requested that I make some changes and this is reflected in the final work (see Chapter 5 & Appendix Q, pp. 771).

Interview with Maureen on 6th June 2001

This interviewee did not want to see the interview guide before the interview. However, she knew from my telephone call what I wanted to talk to her about - the transition period from school to post-school provision for her son. Moreover, before commencing the interview, I outlined the topics we would be covering in the interview.

Maureen seemed a bit nervous to start with. At first she seemed very aware of the tape recorder and I found it difficult to maintain eye contact with her. However, as the interview progressed, she became more relaxed. I played a more active role in this interview and made more use of probes to encourage Maureen to go into more detail and to clarify events.

Perhaps Maureen would have been more relaxed if the interview had taken place in her own home. However, when given the choice, she opted for being interviewed at my house.

I have known Maureen for nineteen years and she and I actively campaigned for post-school provision for young adults with profound physical and intellectual disabilities. I think this close involvement in our son and daughter's transition from school to post-school provision may have influenced Maureen's responses. I felt that she was not as forthcoming with information as I would have liked, probably because she knew I had been involved with the events. Therefore I felt I had to probe more for information. This was in contrast to the interview with Helen. Although my relationship with Helen is closer, I did not know her well at the time of Faye's transition from school to post-school provision.

With the next interviewees I will encourage them to be interviewed in the more familiar setting of their own homes and encourage them to have a copy of the interview guide before hand.

Interview with Catherine and Roger on 18th and 20th June 2001

Catherine and Roger opted to see the interview guide before the interview and had looked out letters and documents relevant to my visit beforehand. The interview was conducted on two separate days.

The discussion about school provision lasted longer in this interview than the previous two. Partly because of my interest in special school provision in other countries but also because Geri had attended four different schools in three different countries. However, I should not have let my personal interest in special school provision encroach on the main purpose of the interview, namely parents/carers' experiences of the transition period from school to adult provision. Nevertheless, the data collected about Geri's successful transition from junior school to senior school might be helpful in suggesting some ways in which the transition from school to post-school provision could be more smoothly achieved. In addition, allowing the parents to tell their own story in their own time, without hurrying them, helped to make them more relaxed as both seemed nervous and anxious at the beginning of the interview. Moreover, it may also have been cathartic for the interviewees (Reinharz, 1992). Fortunately, as I was working independently and my time was my own, I was able to do this, which might not have been the case if I had been contracted to carry out the study.

In contrast to the previous interviewees, I have only known Catherine and Roger for a short time. I was asked to meet with Catherine by a voluntary organization whom she had contacted after coming to this country.

Interview with Joyce on 29th August 2001

Joyce was sent an interview guide before the interview and expressed a wish to be interviewed at my house. She felt there would be less interruptions at my house.

I felt this interview was more focused than the previous one. I encouraged Joyce to give a brief description of Kylie's school provision by stressing that the focus of my study was the transition period, before commencing the interview. As a result most of the interview centred around the transition period and post-school provision. I used clarification probes to establish more clearly what Joyce was talking about e.g. bunny hopping and elaboration probes to encourage Joyce to tell me more about the "suite" proposed in the day centre. Joyce seemed relaxed throughout the interview and said afterwards that she had forgotten the tape was on.

I have known Joyce for twenty-one years and see her at various clinics and meetings we attend in connection with our daughters' health and well-being.

Appendix D Interview guide for focus group discussion

Introduction

Hello my name is Anne Haddow. Thank you for agreeing to take part in this group discussion. As most of you already know I am studying part-time with Strathclyde University for my PhD. My study is concerned with the transition period from school to post-school provision for young adults with profound physical and intellectual disabilities. In the first part of my study I interviewed parents about their experiences during the transition period. From these interviews I identified difficulties experienced by all the parents and young people during the transition stage. I am now at the second stage of my study – looking at ways of overcoming the difficulties and problems encountered by the parents and young people. Hence the reason for this focus group discussion. I have asked you to take part as you have all had experience of the FNA process and the transition period, either as parents or professionals. The third part of my study involves asking parents and professionals for their ideas about appropriate, good quality provision for these young people using the nominal group technique.

Explain how it is important to capture their words and ideas, therefore I would like to use a tape recorder to record the interview. Explain how the information on the tapes will be transcribed and then the tapes erased. Inform the participants that they will not be identified by name, pseudonyms will be used, and that any information which might reveal who they are will also be changed. Ask their permission to tape record interview. Tell them that the tape recorder can be turned off at any time during the interview, if they so wish. Also let them know that I might take notes during the interview in order to keep track of the interview as it progresses.

Ask if they have any questions for me. Turn on tape recorder. Test.

Introductions

Interview Questions

Information

1. The study showed that the parents would like more information about the FNA and transition processes. How could we do this?
   Probes: Information pack/booklet, Whose responsibility for compiling and distributing information, what information should be provided

FNA meetings

1. How can we involve all the agencies and professionals in the FNA process and ensure that everyone has knowledge and information about the young person's needs and the services available?
   Probes: a policy on transition, joint working, planning, sharing of information, register, profiles of young people, transition co-ordinators
2. How can we ensure that progress is made between meetings?
   Probes: Processes of evaluating and monitoring, transition/action plan, transition co-ordinator

Transition

1. What measures need to be taken to ensure a smooth transition from school to post-school provision?
   Probes: length, procedures, visits, communication, passports

Post-school provision

1. How can we ensure that appropriate post-school provision is established for young people with profound physical and intellectual disabilities?
   Probes: Register of disabled people and their needs to assist planning and provision of services, national legislation – further education a right, FNA – a legal document, joint funding, funding attached to individual

Conclusion

1. Anything you'd like to add or anything you'd like to ask me about the study?

Switch off tape.

Thank participants. Ask if they would be willing to take part in nominal group discussion. Explain the NGT process.

Appendix E Letters of invitation to take part in the individual interviews, the focus group and nominal group discussions

Copy of letter to parents/carers, 30.04.01

Dear

My name is Anne Haddow and I am studying part-time with Strathclyde University for a PhD degree. I am looking for parent/carers of young adults with profound and multiple learning difficulties to assist me with my study.

My daughter, X, is twenty-one years of age and has profound and multiple learning difficulties. We found that the transition period from school to post-school provision was a traumatic and stressful time for us and fraught with many difficulties. I was interested in finding out about other parent/carers' experiences and so I decided to study the topic for my PhD.

I would be grateful if you could spare the time to talk to me about X's and your experiences during the transition period from school to post-school provision. I would be willing to interview you at your home, if that is convenient for you.

If you are interested in taking part in this research I can be contacted at the above address or by phone on 01592 745140.

Yours sincerely

Copy of letter to the managers of the "Same as You?" project, 25.09.01

Dear

I am studying part-time with Strathclyde University for my PhD. My study is concerned with the transition period from school to post-school provision for young adults with profound physical and intellectual disabilities. My study aims to investigate the experiences of these young adults and their parents/carers during the transition stage. It also hopes to suggest ways in which the transition period can be improved. Furthermore, as there seems to be little, or no provision for this group, the study hopes to suggest criteria, generated by both parents/carers and professionals, for appropriate, good quality adult provision for this group.

To date I have interviewed five parents/carers about the difficulties and problems encountered by them during the transition stage. The interim findings can be summarized as follows:

1. Information

Parents/carers are not given enough information about the Future Needs Assessment (FNA) and transition processes.

2. The FNA process

i) FNA meetings do not always involve all the agencies who could contribute to the assessment process or the delivery and provision of services.

ii) The people involved in the FNA process do not always have sufficient knowledge and/or information about the young person, their needs, or the services available.

iii) Little progress is made between meetings.

3. The transition period

i) Arrangements for a smooth transition from school to post-school provision were difficult to plan and organize as either no placement was identified, or a placement was not identified soon enough to allow a period of transition.

ii) Placements offered and accepted by the young people and their families were later withdrawn as it was subsequently found they could not meet the young person's needs.

4. Post-school provision

i) Little or no provision available to meet the young people's needs.

ii) Where provision is available, it cannot always meet all of the young person's needs, especially their medical needs.

iii) Often the provision offered is of an interim kind and the young people and their families are left uncertain of future provision and services.

I would now like to hold a focus group discussion with parents/carers and professionals to discuss ways in which these problems might be overcome. As the SAY stakeholders conferences identified the transition from school to post-school provision as an issue for people with profound and multiple learning difficulties, I thought the SAY Project might be interested in this focus group. Perhaps you could suggest a practitioner from the social work department and the health board with experience in the transition from school to post-school provision for young people with profound and multiple learning difficulties who would be interested in participating as individual members and not as representatives of either the social work department or the health board.

I would appreciate your help and advice on this matter.

Yours sincerely

Copy of letter to arrange focus and nominal group dates, 26.11.01(a similar letter was sent out in October, but no mutually acceptable date was found)

Dear

I have been too optimistic in thinking that we could arrange our focus group discussion before the end of this year! Therefore I have proposed some new dates and times for January and February.

I would be grateful if you could let me know which dates and times would suit you by ticking the appropriate boxes overleaf.

Thank you for your help.

Wishing you a "Happy Christmas and New Year"

Date	10am-12noo	11am-1pm	12 noon-2p	1pm-3pm	2pm-4pm	7pm-9pm
Monday 14th Jan.						
Tuesday15th Jan.						
Monday 21st Jan.						
Tuesday 22nd Jan.						
Thursday 24th Jan.	▨	▨	▨	▨		
Monday 28th Jan.						
Tuesday 29th Jan.						▨
Monday 4th Feb.						
Tuesday 5th Februar						
Thursday 7th Feb.						
Monday 11th Feb.						
Tuesday 12th Feb.						
Thursday 14th Feb.						
Monday 18th Feb.						
Tuesday 19th Feb.						
Thursday 21st Feb.						
Monday 25th Feb.						
Tuesday 26th Feb.						
Thursday 28th Feb.						

Copy of letter confirming the dates of the focus group and nominal group discussions, 11.12.01

Dear

Thank you for agreeing to take part in my focus group discussion and nominal group technique.

From your response sheet I note that you can attend on Tuesday, 5th February 2002 between 10am and 12 noon and Tuesday, 12th February between 10am and 12noon.

Therefore I hope to hold the focus group discussion on Tuesday, 5th February 2002 between 10am and 12 noon and the nominal group discussion on Tuesday, 12th February between 10am and 12noon. Both discussion groups will be held at my house and lunch will be provided.

I enclose copy of focus group schedule for your information and map showing directions to my house.

Looking forward to meeting you then.

Best wishes for Christmas and New Year

Copy of letter to professionals reminding them of the dates for the focus group and nominal group discussions, 12.02.02

Dear

Thank you for agreeing to take part in my focus group discussion on Tuesday, 5th February, 2002 and my nominal group technique on Tuesday, 12th February, 2002. Both will take place in my house between 10am and 12 noon. I hope you can stay for lunch afterwards.

I enclosed a map showing the directions to my house, as well as a copy of the focus group schedule, with my letter dated 11.12.01. If you have misplaced them please let me know and I can forward you more copies.

If you find you are no longer able to attend, I would be grateful if you could ask a colleague to come in your place.

Looking forward to seeing you on the 5th of February,

Best wishes

Copy of letter to carers reminding them of the dates for the focus group and nominal group discussions, 21.02.02

Dear

Thank you for agreeing to take part in my focus group discussion on Tuesday, 5th February, 2002 and my nominal group technique on Tuesday, 12th February, 2002. Both will take place in my house between 10am and 12 noon. I hope you can stay for lunch afterwards.

I enclosed a copy of the focus group schedule, with my letter dated 11.12.01. If you have misplaced it please let me know and I can forward you another one.

Looking forward to seeing you on the 5th of February,

Best wishes

Appendix F Reflections on focus group discussion

Initially I found it easier to engage the parents and the professional from the voluntary agency in the discussion. Perhaps this is because I knew these people and they felt more relaxed. They also knew each other. This helped the group to form but perhaps made the other two professionals feel like outsiders. At first Pauline only responded when directly asked for her opinion but as the discussion progressed she participated fully. Similarly I found it difficult to engage Angela in the first topic of discussion about information giving. However, her non-verbal behaviour, for example, nodding and agreeing with my summaries seemed to indicate that she agreed with the speakers. I tried to involve her more actively in the discussion by establishing eye contact, using prompts, encouraging her to speak and creating space for her. She then took a more active part in the discussion, providing information about learning disability teams, the transition period, action plans and person-centred planning.

Appendix G Nominal group discussion question

What features do you believe are required for good quality post-school provision for young adults with profound physical and intellectual disabilities who also have complex healthcare needs? Consider both the needs of the young people and their family carers.

Appendix H Reflections on nominal group discussion

I felt this technique ensured that everyone had the opportunity to express their opinion. Nineteen detailed items were generated. There seemed to be a lot of consensus within the group about the essential features of good, quality post-school provision and services for young adults with profound physical and intellectual disabilities. I had intended to give the group members four votes but they requested five votes as they found it difficult to choose only four items. This resulted in ten items being identified and the group decided not to take a second vote as they felt all the items they had identified were important features.

Appendix I Interview guide for individual interviews with professionals

Introduction

Hello my name is Anne Haddow. Thank you for agreeing to take part in my study. As you know, I am studying part-time with Strathclyde University for my PhD. My study is concerned with the transition period from school to post-school provision for young adults with profound physical and intellectual disabilities. As part of my study I am interviewing individually, key individuals in health, social work, education and the voluntary sector about service development. Hence this interview to-day.

Explain how it is important to capture their words and ideas, therefore I would like to use a tape recorder to record the interview. Explain how the information on the tapes will be transcribed and then the tapes erased. Inform the participants that they will not be identified by name, pseudonyms will be used, and that any information which might reveal who they are will also be changed. Ask their permission to tape record interview. Tell them that the tape recorder can be turned off at any time during the interview, if they so wish. Also let them know that I might take notes during the interview in order to keep track of the interview as it progresses.

Ask if they have any questions for me. Turn on tape recorder. Test.

Introductions

Interview Questions

A) Background

1. Tell me about your job? What does it entail?

B) Policies

1. In your opinion, what kind of underlying thinking should be involved in drawing up policies for the young people involved in my study?

C) Services

1. What kinds of services do you think these young people need?
2. Do these services exist in Fife? What is needed to achieve them?
3. How do you monitor and evaluate services for this group?

D) Conclusion

1. Anything you'd like to add or anything you'd like to ask me about the study?

Switch off tape. Thank interviewee.

Appendix J Reflections on individual interviews with the professionals

Interview with Jillian on 8th March 2004

This interview took place at my house. Jillian came to the interview with written notes to the questions. She was well prepared and had obviously thought about her responses in advance. My role was one of attentive listener and summarizer.

I know Jillian well. She and I have worked together on responses to national documents concerning people with learning disabilities. We both found the situation strange, as we have often talked together informally about the topics raised in the interview.

Interview with Pauline on 16th March 2004

This interview took place at my house. Pauline was one of the professionals involved in the focus group and nominal group discussions. Pauline and I also know each other from attending meetings about post-school provision for young adults with profound physical and intellectual disabilities.

During the interview I felt that Pauline was being careful to choose her words carefully. She stresses several times that these were her opinions. I had to use probes to help make clear her thinking.

Interview with Margo on 1st April 2004

This interview took place at Margo's office at her request. Although Margo switched off her phone, she was unable to disconnect her colleagues phone, with whom she shares an office. As a result we were frequently interrupted by phone calls and this disrupted the flow and continuity of the interview. In addition, although I had sent Margo background material from my study and profiles of the young people involved in my study, I had difficulty in keeping her focused on issues concerning young people with profound physical and intellectual disabilities. She was also reluctant to give information about post-school provision for this group as this was outside her job domain. She saw post-school provision for this group as the responsibility of the social work department.

Interview with Tina on 19th May 2004

The interview took place at my house. I had not met or known of Tina previously. She was suggested to me as a possible interviewee by a health board manager, whom I had contacted about my study. Tina was very nervous and I found it difficult to keep her focused on the questions. In hindsight, the participant should have been a manger, however they seemed reluctant to take part. Indeed I found it difficult to obtain a health professional for interview.

Appendix K Transcription of individual and dyadic interviews

Interview with Helen

Pseudonym for interviewee: Helen (H)

Cities, places and names described in the interview have been changed in the transcript in order to protect the identity of the interviewee.

Name of interviewer: Anne (A)

Date of interview: 05.06.01

Time: 11.00 – 12.17

Setting: Helen's home

Helen is a full-time carer for her daughter Faye. The interview took place in Helen's home in Devenport. We were sitting in her living room with the tape recorder placed between us on the coffee table. Helen is a close friend and I asked her if she would be interested in doing an interview with me. She agreed.

A: Right could you tell me a little bit about yourself and your family

H: Right, well there's myself, my husband Gordon, daughter Faye and son Garry. Gordon is an accountant. We have been married for 29 years. Faye was born 26 years ago, there was lack of oxygen at her birth and it resulted in profound and multiple disabilities. Garry was born 21 years ago, normal birth, no problems at all and he is a student at Edmington University studying politics and history and hopefully graduating this summer. He now lives in Edmington so he is out of the house, just comes back for visits and that is about our . . . that's us. My parents are dead and Gordon's parents are dead so there is no grandparents now.

A: So when you said Faye had lack of oxygen at birth, was it a full term pregnancy you had...

H: Yes it was.

A: ...no complications.

H: No, nothing at all and there was delay in the second stage and that resulted in the... she was a forceps delivery and there was lack of oxygen somewhere along the way but I mean she wasn't monitored or anything then. There wasn't really the cause, there wasn't any reason to do it, there didn't seem to be anything wrong even with the labour just till the last minute sort of thing.

A: So they reckoned that's...

H: They reckon that's where...

A: She's got cerebral palsy.

H: That's why she's got cerebral palsy, yes and it is quadriplegic cerebral palsy so it is all four limbs and she can't sit up, hold her head up unaided at all.

A: So do you want to tell me a bit more about Faye then?

H: Right well as I say she suffers from quadriplegic cerebral palsy. She also suffers from epilepsy but her fits are well controlled, she hasn't had one for a long long while. Her big problem is her asthma and she also has chronic chest problems and gets chest infections. She needs nebulising twice a day to prevent her asthma attacks and also nebulising if she gets wheezy to alleviate them and she needs suctioning. The secretions build up and she can't get rid of the secretions, she can't cough them up so she needs suctioning to get rid of that and that is increasing, the problems are increasing. She is also gastrostomy fed, the tube straight into her stomach and she got that when she was about 19. We had that operation done and that has made a tremendous difference to her general wellbeing whereas before we struggled to get her to eat anything, drink anything. She just couldn't because of the reflexes and everything being involved in her throat, so that has made a big difference. She aspirates less because she used to aspirate when she was eating and drinking but it still hasn't diminished the chest problems. They have actually increased but I think they would have been more if she hadn't had the tube.

A: So you said she requires suction, what kind of suction is that then?

H: It's... the tube goes into her mouth and you are actually going down into her throat to activate the cough reflex and she coughs. Then and the tube is part way down her throat and whenever the secretions, when she coughs them, you suction them away because it is quite an amount that builds up and she actually... She can be OK for most of the day but if she gets tireder towards the late afternoon and evening, we find we have to suction her more then because she is tired, she can't cough the same and the secretions build up more then.

A: So you have to do that yourself?

H: Yes and I mean it could be... she could come in from the centre, it could be a couple of times in the night, it could be up to a dozen times, there is no hard and fast pattern to it.

A: And did somebody show you how to do this?

H: Yes, yes, we went through, actually she spent an overnight in hospital so that I would be confident. The physiotherapist actually gave me the training for it, she put me through it all and I carried it out but I was in the hospital environment that if I got stuck, if I was in difficulty somebody could come and help me and that gave me the confidence then to come back, show my husband what to do, show the carer what to do and my son and it has worked well from then.

A: So most of your family can all do suctioning?

H: Yes you have to.

A: It isn't just you.

H: If you are in the house for any length of time you have to be able to do it.

A: So what about, you said she used to take fits but thankfully she hasn't had them now. Is she on any special medication?

H: Yes she's on Tegretol anticonvulsant. She did, she always took what they called myoclonic jerks when she was a baby right through her childhood and she was on a drug to dampen that down. It's like wee startled frights and she would take och, 30, 40 of those in a day she could take but then when we came to puberty, the onset of puberty she started taking grand mal seizures regularly every month and it was very soon we saw the pattern although she hadn't started menstruating it was just the onset of puberty when she was about 13,14 that she started taking the full blown seizures and she went onto the medication then and she has only had them if it has been illness related, maybe she has had a very high temperature or if you know she's been quite poorly that way, that's when she's maybe had one and it is a good few years since she has had one now so she is well controlled.

A: So it sounds as if she needs a lot of personal care.

H: Yes she needs 24 hour care. She needs all the personal care. As I said she can't even sit up on her own, she wears a body brace, she wears a collar for her neck and she requires everything.

Tape stopped, caller at the door.

A: Right so Faye needs a lot of personal care then.

H: Yes she does, she needs 24 hour care as I said. She wears a body brace, neck collar, she has got no balance, she can't keep her head up. She is incontinent, she wears nappies so it is constant care that she needs, total care that she needs, 24 hours.

A: So what sort of things do you have to do during the night?

H: She needs turning to prevent pressure sores, also she coughs a lot during the night and her chest again is the problem and the coughing can be so bad that she will cough herself out of her position for sleeping. She sleeps in a special, it is like a U shaped block that her body lies, she lies sideways in this block and she has another block to abduct her legs and keep her hips apart so you have got to turn her in those positions round on to her other side to prevent pressure sores and you have also, she can cough herself right out of the position and right under the covers, so you have got to go and see to that and if she needs suctioning during the night, if the secretions are bad... but we do have her tipped, her bed tipped to drain her and she is also fed through the tube through a machine during the night so if there's anything needs to be done with the machine, which is very little with the machine but there can be problems sometimes but you can be up and down and up and down, it all depends on how she is.

A: And do you have to do postural draining with her?

H: I do postural draining first thing in the morning when she wakens up, she needs postural draining then and percussion as they call it is where you tap her lungs just to dislodge any secretions that are there and we do that first thing in the morning. We give her her... I give her her medicines through her tube then. She is toileted then because we still toilet, have a toilet regime and she can use the toilet, although she does wear incontinence pads, she is incontinent at other times and we also, after having washed her and dressed her, I have to do some exercises, passive exercises to her limbs before we can get her into her chair or because she is so rigid after lying all night and she is quite stiff so she needs to have all that done before we put her in a chair and then we have to nebulise her with the preventative drug for the asthma and then tube feed her and then...

A: All before she is ready to go...

H: All before she is ready to go to school then she gets her teeth brushed. All the normal things have got to be done as well, like brushing her hair, brushing her teeth, getting her coat on to go out to the day centre.

A: So how long does that take you?

H: I get up about half past six, well quarter past six, half past six, I get Faye up about seven and she goes out at quarter past nine so it is from seven till quarter past nine. You are on the go the whole time, it's two and a half hours getting her ready to go out.

A: Do you have any help?

H: Not in the morning because the home carer could come in and wash her and dress her but because of the medication, the physiotherapy and tube feeding and the nebulising they can't. The home carer wouldn't be allowed to do those, so I would need to be there anyway, hovering about while she did one thing. I would be waiting till she did something else so I find it just as easy to carry on and do everything myself. But I have a carer in the evening when she comes home from day centre, she is home about half past three and about quarter past, half past four I have got a carer who comes in then, paid for through the Independent Living Fund and she, because we are employing her, she can carry out all the things that we are showing her to do that statutory bodies can't do. So she'll nebulise Faye, she can suction her, she can tube feed her, she can give her her physiotherapy and she baths her and generally fills in time with her, playing her tapes, you know her CDs, painting her nails, doing her hair, the kind of girlie things that she would enjoy doing anyway, as well as incorporating in the exercises and everything that she needs of an evening and then she goes away about half past seven and Faye has time with us then to watch the television and then we start getting her ready for bed then.

A: Can Faye communicate, how does she do that?

H: She communicates to a limited degree with, she goes to her right for yes and her left for no and so you are breaking down simple questions to be answered with a yes or a no. She can indicate that way and her facial expression is very, she is very good with her facial expression, pleasure is obvious and dislikes are obvious because she will pull a face or... sometimes it can end in tears if things are too much for her it usually ends in tears and you know that she is definitely not happy and that is the way that we... with the eye contact and that is the way that we communicate.

A: Now you said she likes to paint her nails, have her nails painted and do lots of the girlie things and music, is there any other sort of hobbies and things she likes?

H: She likes her music, she loves her music, she also likes to visit the riding centre, we go out to the riding for the disabled, she loves that and has taken to enjoy hearing about horses, although I am not a horsy person, she enjoys hearing all about the horses and everything, she enjoys going there. She really enjoys going out, she enjoys going shopping, going for a walk if it is a nice day and ending up in Dorothy's tea room, the kind of pleasures that we all enjoy as well, mainly being on the go and going out she enjoys the most and she thoroughly dislikes having nothing to do. She gets bored and she doesn't like that so she always likes to have something to do, to be on the go.

A: OK, that's fine then, is there anything else you want to tell me about Faye?

H: I don't think so, she is just in the middle of all of those, with all the medical problems she has still got a really good sense of humour a wicked sense of humour that we would call it and a strong personality, her personality comes through and I think that, you don't want that to be lost, she is still a person. She is not a disability, she is a person first and foremost and the disabilities come second, that is the way that we have always looked at it and that is very much how the whole family sees Faye. I think her strong personality. Strangers very soon get to see that as well so that overcomes quite a bit.

A: Fine then. So can you tell me about the school that Faye went to.

H: Yes, she went to Westfield in Edmington, it was a school specialising in children with cerebral palsy and associated conditions. They worked ah... it was a multidisciplinary team with teachers, physiotherapists, speech therapists, occupational therapists, care assistants, social workers, the whole gamut, everybody was there and they worked together in the classroom in quite a holistic way with the children. Their programmes were all individually set out to bring out the best in that child, the potential that they had. Their targets weren't unrealistic targets, the targets were achievable targets for each child which gave encouragement both to the parents and the children when they were met and they very much encompassed the whole family in the care of the child as well. Their social, they had a social you know life as well where the parents, the family were included and they took the kids away on holiday each year when they were in senior school and very much a relaxed but professional way that they worked and we were very pleased with everything there.

A: So you felt that they met all of Faye's needs?

H: I felt... yes.

A: They coped with her medical care as well as her education?

H: Yes, the nurses were there and they met with everything, in fact they had the paediatricians, the orthopaedic surgeons, dentists, ophthalmologists, all the associated clinics that you would go to hospital for. They all went into the school and the consultants all went into the school, they had their clinics there, the child was never have to be taken out and have to sit in a hospital for a length of time for waiting times and the parents went across at the appointed time and any problems they were all met with there that the consultants went and it was far better than breaking up a child's school day and taking them out and they worked with a diary and the diary went between parent and... home and school so if there was any problems at school they could put it in the diary as well as saying you know what kind of day they had and what they were doing and the same from home, the diary went back the next day saying what they had been doing at night or if there were any problems or concerns and it was a very good system, the diary system.

A: So you were pleased with the school provision?

H: Yes, yes I was very pleased and the main thing that Faye had gone to that school was their high level of physiotherapy and their positioning of the children because without proper positioning they couldn't function and I still feel that with Faye unless she is properly positioned, she will get uncomfortable for a start but eye contact, what she is seeing in the world in a basic level... she would if she was ill sitting... it wouldn't work and also they were able to have eye and hand control far better when they were properly positioned.

A: Anything else you want to tell me about school?

H: Em, I don't think so it was just, you know what they say, you never miss the water till the well runs dry and I don't think I even... I appreciated the school when she went to it but I think I appreciated it even more after she left and I realised just what was the things that they did, it was just it was part and parcel of their day and they did it so well.

A: You haven't got any ideas for improvements from the school, would you reckon that they met all your needs and...

H: I would say at that time, I don't know I can't say how they are now but at the time when Faye went to school they definitely, they met all her needs. There was nothing, there would be niggles, there would be small things but there was nothing major that I would have changed.

Tape stopped to allow Helen to get a glass of water.

A: So can you think about the transition period now when Faye was, we are thinking about Faye when she left school and what would happen to her, so if you think about the future needs assessment meetings, what happened at them?

H: Right, well the big thing that sticks in my mind was consistently no social worker turned up from Fogart, there always seemed to be a lack of social workers there from Fogart. The school always had their one, there would be the nurse, the teacher, the head teacher, I should have started with the head teacher I dare say. Speech therapist, occupational therapist, all the disciplines were there represented from the school. Child psychology, education psychologist from Fogart would be there, he usually always turned up but rarely did a social worker turn up. They would go through what Faye had been doing at school, what her achievements and her goals and everything were and the future needs were addressed in that the school wanted to see a continuation of the stimulation that she was already receiving at school and the phrase that was consistently used then was they didn't want her lying on a bean bag all day which I believe some centres and the profoundly disabled were just left lying on a bean bag watching a mobile and that certainly wasn't for Faye. She had to have the stimulation, the continued education, the continued physiotherapy, speech therapy, really a continuation of school if it was possible but it was very very depressing in that there was nowhere it seemed that could cater for children like Faye when they left school. She didn't conform if you like, she didn't fit into the neat category of just having a physical disability or just having a learning disability, she had both and to cater for both they just didn't have the centres to cater for them. We discussed different centres and we would ask well would they be able to cope with Faye and they would say no because the adult training centres as they were called then, the one in Deptford which was a big centre catering for learning disabilities would not have been able to cater for Faye's physical needs, provide physical needs and the physical disability centres wouldn't entertain a learning disability so it was very depressing but there was always this, they would tell you, something will turn up, something will turn up so at 14 and 15, that might have seemed quite a wee bit a way, you know we are getting to 18, 19 and you would say yes something will turn up, something. We were naive enough to think that something would turn up but I am afraid as the time approached nothing was turning up and they just weren't able to come with anywhere for Faye. It was very very worrying that from a very young age from 2 when she went to nursery, special nursery, that from 2 she had a structured day and a day that she enjoyed, a day that she was stimulated in and a day that I knew she was being properly taken care of, that I had time for the rest of the family and my own needs but suddenly this might stop, it was very worrying, yeh.

A: Did you go to the meetings yourself or did your husband go with you? Or with friends...

H: I went to them myself, my husband had his work to go to and I went thinking that there wasn't going to be a problem. When we thought there was going to be a problem looming, yes, he would come but I usually went to them myself.

A: Did you feel intimated with all these professionals there?

H: It could have been intimidating for somebody going in, like you... it was like them and us, you know it was just you and if it was just your husband and yourself, but the staff at the school always made you feel very relaxed so I never felt intimated in that way. I have in the past gone into a meeting and felt like that but no, the school always made you feel that the parent was part of the team so I never felt intimidated in that way but I could see that it could be, you know for parents and I never, I certainly wasn't made to feel that way.

A: So did you feel able to take part in the discussions?

H: Yes, yes I did.

A: They allowed you, they asked your opinions? (Helen nods). They consulted you? (Helen nods).

H: Yes although there was... I gave my opinions, it was the same opinions that I was giving all the time and there was never an answer really for the questions that we were asking and also... they acknowledged Faye's needs but as to whether they could do anything about it was another, was another thing. It came to the time that she was rapidly approaching for her leaving school, we still hadn't identified a centre so we went to, there was a centre in Edmington next to... in the school building actually but separate from the school, called the Everly Centre and they would have been able to look after Faye's needs and give her the stimulation that she needed but the question was would Fogart pay for Faye to go to there, to Edmington and it was in the very early stages the Everly Centre at that time, would they accept someone from another area because it was jointly funded by Edmington social work and Capab..well it was Scottish Council for Spastics at that time so there were the two problems about would she get there, however we went to see the director of social work in Fogart and put it to him direct, would he send Faye there, would they fund Faye to go there. We never got an answer. They said well let's look at what is on offer in Fogart, so from going from there is nothing to somebody saying oh let's look at what is on offer, we were a bit encouraged, naively encouraged and at the same time he said well put your application into Everly Centre and see if she will be accepted. At that point Faye was the only applicant for Edmington but they decided, I don't know what their reasons were at that, well they gave us the reasons that there was building work going on and they would keep her application on hold. By the time they got round to it there were six applicants for two and a half places, two full time places and a part time one and we were turned down in the end on geographical reasons that they were taking from their area, their catchment area and not from outwith. I later learned that Faye's disabilities were actually greater than the people that they had there, especially her learning disability so... but that wasn't the reason, it was geographical. In the meantime the ball was back into Fogart's court, they had to find somewhere for her now because Edmington had turned us down so a social worker was appointed to go round all the centres and find out would they be able to take Faye. We went to see them all and were, we were a bit discouraged because there didn't seem to be anywhere really that would fit the bill and in the end the social worker identified the Fraser Centre in Glendinning as the best place to look after her physical needs. They thought they would be able to cope with her learning disability but the physical needs were greater so that was where the priority lay and we were told that she had got a place there. This had... it was only word of mouth that yes it would be a place there. The school weren't officially told that this was where she would go and they kept us hanging right till a few days before she was due to leave school. In the meantime the school had pressed the council for a definite confirmation that she would be going to the Fraser Centre because they... an application had been put to the school for an extension of her school year, of her school life if you like.

A: So was she getting to stay on till she was 19?

H: Yes but the school... no, it was only an extra six months they were keeping her, she was 18 in the September and she was due to leave that summer, the August/September and they wouldn't commit themselves to taking her for that extra six months to Christmas unless Fogart definitely said they were giving her a place in a day centre and the extra six months was to allow a smooth transition and the school wanted a smooth transition because Faye was extremely wary of different people and situations and she needed a long time to get used to the difference and they wanted it to be smooth so they insisted that Fogart came up with a place before they would agree to take her for the extra six months so a few days before she was due to leave school Fogart said yes they would have her at the Fraser Centre. So at least it gave us the summer that we felt a bit more relaxed and she went back to school and the process of visiting the centre and the transition began. Meanwhile before that started we had been to the centre, Faye had seen the centre during the holidays and we had met the centre manager and everything you know was fine on that front but the assistant manager came to the school to a meeting and prior to the meeting that day she had spent quite a while observing Faye in the class.

A: So was this the first time they had seen Faye?

H: This was the first time, we had taken her to the centre and she had visited the centre but this was the first time the assistant manager had actually seen her or had observed her at school. So we went into the meeting and the whole meeting was to discuss... and I was there on my own because there didn't seem to be a problem, it was only a formality really to discuss how they would tackle the transition. The social worker was there, the assistant manager came in, there was all the usual people who would attend Faye's meetings from the school and before anybody could even start the meeting this assistant manager launched into what I would describe as a tirade against Faye going to the Fraser Centre. She wasn't their normal client if you put it, she was appalled at the degree of learning disability that she had apart from the physical disabilities, this learning disability really put to her real problems. We even got the occupations of the people who attended the Fraser Centre, like we have bank managers, accountants, we have all these people who were suffering from MS, recovering from a stroke, from head injury, from something.

A: So she was insinuating that Faye wouldn't fit in.

H: Yes, Faye would not fit in. She didn't even hint, she definitely stated that she was not the type of person for the Fraser Centre. While we all tried to pick ourselves off the floor Faye's teacher very much, she managed to regain her composure and come in and say this was not why this meeting had been called, there was absolutely no question of this having been brought up before. It was identified that Faye was going there and they hadn't envisaged any problem, why suddenly had she come up with this problem? The whole meeting was abandoned. By this time, I wouldn't cry in front of her but I did break down for the first time I broke down when I went out. We went into the headmistress', head teacher's room and I'm afraid I broke down then. Meanwhile the social worker from Fogart and this assistant manager had an argument, an altercation in the street. He was fuming, the social worker was fuming. He was completely taken aback by it as well. When I got home that evening I was taking... Faye had been waiting for me in the class as they did if they had meetings that went over the... they were amusing her in the school and I brought her home and the social worker phoned me whenever I got in and said that he was absolutely appalled and all he could do was apologise on behalf of Fogart but he was certainly not apologising on behalf of this centre assistant manager and urged us to put a formal complaint in because he was putting one in. He said it was absolutely appalling that she had gone to that meeting and said what she said about Faye. So we put the formal complaint in and it went through the usual channels. She apologised in the end, a written apology and said that she was very sorry but she had been completely taken aback by Faye which was complete lack of communication and didn't bode well for the future for us but I had to put it behind us, we had to put that behind us and say that we have got to think on Faye positively. Thank goodness nothing... Faye was completely unaware of what had gone on.

A: Did she ever attend any of your future needs assessment meetings?

H: No. I don't think I can ever remember her being at the future needs meeting and she certainly thankfully wasn't at that meeting because she had met her beforehand and the whole purpose of her going into the school was to see her in a classroom setting and to see her there and thankfully she was unaware of what had gone on and we certainly didn't discuss it in front of her. We were upset enough that night. My husband was furious when he got home to see how upset I was and we certainly didn't want it upsetting Faye because we had to think positively, we had her future to think on. There was no choice, that was the only centre, there was no luxury of a choice, well you know, I didn't like what went on at that centre and that manager so we will go to another one, there was no choice, she either went there or she stayed at home with me and I am afraid that wasn't an option, we had to get things sorted out so it was a lengthy... everything was put on hold, the transition period was put on hold until we got things sorted out at the centre and as it was the centre manager left to go somewhere else and this assistant manager became the manager of the centre but we put our differences behind us and she did go on to be quite a fair manager and work it with the dealings that we had with her after that were quite fair but it was a terrible experience and it upset the apple cart completely. So we had then to just... after we got it all sorted out.

A: So how did you get it sorted out?

H: It went through all the channels and, I can't actually think back to who contacted us and what happened but down the line the upshot was you know she apologised and I think she was disciplined on it. There was a disciplinary hearing, she was disciplined about what happened.

A: And did they confirm that Faye was actually going to get a place.

H: And it was confirmed that Faye was still going there if we wanted it because they realised that what had happened was very upsetting but as I say we had no option and they assured us that nothing like that would happen in the future and that it would be... everything would be done positively for Faye then and I have got to say it did go through eventually, the transition period did go through, they had to bend back themselves backwards to make sure that it went through smoothly. She was appointed a key worker from the centre and she along with the physiotherapist that went to the... into the centre, went to the school and visited the school, saw Faye in the school setting and worked with her in the class. The physiotherapist even went with her to the swimming, went with her to the riding, just to be, not to do anything with her but just to be a familiar face then, that they were familiar faces and they had quite a few visits to the school, with the key worker, and gradually got to work with Faye, the physiotherapist went in with Faye's own physiotherapist at the school into the pool and worked with her there and was there with her with the exercises. Then Faye's teacher went to the centre with her and got her introduced to everybody at the centre. They couldn't really spare the staff to go from Westfield from the school to the centre so I said I would go and I stayed with Faye for quite a few days, for the whole day, worked with her, they saw how I worked with Faye and they gradually did things with her and then I gradually withdrew. I would maybe go for the morning then go away. I would have my lunch somewhere else in the building or go away and do some shopping and pick her up later on and gradually over the months running up to Christmas, it was from about October, October/November, over the weeks running up to Christmas she had a day at the Fraser Centre, four days at the school, two days at the Fraser Centre, three days at the school and they gradually did it that way so that it was a very smooth transition because Faye is very much a one to one person and got very very uptight at change so it had all to be... because at that time she was still being fed orally and for a stranger to go in and feed or give Faye a drink it was virtually impossible, it had to be very very gradual that the person was doing this so in the end it went quite smoothly.

A: So how long was this transition period.

H: Well because of the... it was envisaged that it would have been longer but because of what happened it lasted the end of October to December, the middle of December and then she went back to school for her last few weeks there you know to enjoy all the school activities and then she left that Christmas and started after the Christmas holidays at the Fraser Centre.

A: That would be about three months then from the October to the December.

H: Well no, it was towards the end of October so it was really the whole of November I would say, maybe about a week of October, whole of November and a few weeks in December that it carried on.

A: But you had envisaged it would be the six months.

H: Yes uhu

A: But because of this set back.

H: Yes the best laid plans had just gone out the window.

A: So obviously it was quite a stressful time for you wasn't it?

H: It was, it was, it was very stressful, I mean the run up to finding the place was very stressful because knowing there was nothing, what was going to happen to her? We had to go down the line of thinking well could we get carers into the house to care for her because I couldn't have cared for her after having had all those years at nursery and school, for me to look after her all the time, I didn't feel it was good for her, she had to have the different mix of people and we had to look at the scenario of could we get carers into the house and look after her in the house and take her out perhaps if we can't find a centre and that was our only other option. We didn't know how this was going to work but it wasn't a pleasant one but we had to think down those lines and it was very stressful. I couldn't see a future for Faye and I couldn't see a future for me while this was going on and that puts quite a lot of strain, there was my son in the family, there was my husband, it puts a lot of strain between a husband and wife.

A: Did it give you any health problems?

H: Apart from stress and being very depressed about it, I managed to work through it because I think I am quite strong in that sense you know I have got to work it out of my own, my own system in different ways, everybody tackles it differently but I think if I had been less strong it could have affected me quite a lot yes.

A: Did anybody ever say to you well you have the option of putting her into permanent residential care at that stage.

H: No, no it wasn't an option that was put to us. It was put to us when she was a baby that that might have been, if we didn't choose to look after her, put her into care but it wasn't an option that came up at that time, no.

A: Is there anything else you want to tell me about the transition time?

H: I just, I just feel that I think that that still seems to be a very very bad time, nothing has changed. When we were going through that period somebody actually said to me, it was a paediatrician said to me you are pioneering for all the young ones coming behind because Faye at that time, it was still quite... for someone with Faye's disabilities, it was still quite unusual if you like for her to be being cared for at home. There still were the Gogarburns, the Lynebanks where you know she would have been but we... it still was quite a thing that she was leaving school, she had gone through school and she had got to adulthood and now there was the problem of what would happen now that she was into adulthood so yes I thought, I thought nowadays it would be a smooth transition, the place would be identified and that still doesn't seem to happen that it has got to be away down the line at 14, when she was 14 at her future needs assessment it should have been tackled then but I was naive and I dare say everybody round about us must have been naïve at that time that we thought things would have been sorted out, I thought things would have been sorted out, I was very naïve then and I had nobody really to say to me, make sure that you get things sorted out at 14 and identified, I just thought, I just naively thought that things would have worked out.

A: So you felt most at the future needs assessment meetings you weren't getting any further forward.

H: To me it just seemed like another review meeting, that was basically how it came over.

A: A review of Faye's progress?

H: Yes, I mean we had annual reviews and to me it went down the lines of an annual review. It was discussed what would happen when she leaves school but because there was nothing on offer it was just swept under the carpet I dare say.

A: And did you know anything about the actual process of the future needs assessment before you went... nobody explained it to you or anything?

H: No.

End of side 1
Side 2

A: Anything else you want to tell me about the transition period?

H: No I think I have covered it all, that was all, that was enough.

A: Right, now, so would you like to tell me about Faye's provision now. She is at the Fraser Centre, isn't she, in Gordon?

H: Well there's no choice whatsoever, I mean there is no choice. Faye went to the Fraser Centre as I said. Since Faye went there her health has actually deteriorated. She is now tube fed which she wasn't before she went there but they have taken that on board. That has been met adequately by the staff. The fact that she needed nebulising, that was an issue when she went to the Fraser Centre and that hasn't changed, the issue being that social work employees can't carry out medical procedures and this is a medical procedure, indeed a nursing procedure but we actually had spoken about that and spoken to the consultant who was taking over Faye's care about it when she went to the Fraser Centre and it was agreed that it could be met, her needs could be met in the nebulising by the physiotherapist who was in the centre quite a lot and although she wasn't there all the time, if Faye became wheezy, if she was there and she needed nebulising, she could carry it out because she was a health board employee and she was a physiotherapist and she could nebulise her but no-one else could. If she wasn't there it was agreed that I would be contacted and hence the reason I am always on call. I would be contacted and I would need to get up to the Fraser Centre. Now I am half an hours drive away and that was providing that I was at home, it would take me half an hour to get up there to nebulise her. In the meantime if they couldn't get me or they felt that with me going up there it was too long the only option is to take her to the hospital, is to get an ambulance, 999 and get an ambulance where she would be nebulised and they would give her oxygen as well and she would be taken to the hospital. We have managed over the years that she has been there, Faye is now 26, we have managed to get round it by the physio nebulising her or me being on call. There has been one emergency where she deteriorated quickly and they had to hit 999 and get an ambulance and take her to the hospital but all the staff have got to be aware of how Faye's chest problems are and how she reacts to different environments because going from a hot room to a cold room can spark off her chestyness. The only other thing that they can do is posturally drain her. They can't suction her which she now needs suctioned at home, they can't suction her because again that is a nursing policy, eh a nursing duty so they can't suction her there so they have to put her on to a tipped bed and drain her, posturally drain her and that that gets rid... you know the secretions are drained that way. So her needs are met to a certain degree but not fully and I am on call all the time that she is there and if I go out I have got the mobile on because I know if they needed me at the centre I have got to go.

A: So that restricts the distance that you go.

H: It does, it does, if I am going any distance outwith you know the local shopping area or visiting or that, I have got to know that my husband is in the office that day because he can be contacted because he is the second person to contact.

A: Right, so would he go in?

H: He would go in and do it. But if they can't, they have got... they would just take her to hospital, they would need to take her to hospital which is really a waste of resources because it is not as if she has got to be hospitalised when she gets there it is just that the problem has to be dealt with but it is a life threatening thing, it is asthma that we are talking about so they can't take any chances, they have got to deal with it in an emergency way but we get round it in a, you know, in a back door way but it is not, it is not what should be, it is not the ideal way and with Faye's health deteriorating, this is becoming more and more of a problem.

A: And you said, I remember you saying to me one of the reasons they suggested the Fraser Centre would be because they could meet Faye's physical needs and now you feel that they are not able to.

H: They can meet the physical disabilities, they can meet the needs that she has got.

A: So it's her medical needs.

H: It's the medical needs that they can't meet and there is no option, there are no other centres available that would be able to cope with the medical needs. It is the same at all the social work establishments, they can't, care staff can't carry out these things. In fact I think Faye's centre is the only one of the social work establishments that actually do tube feeding and I don't know how they have got round it there to do the tube feeding but they have been given training. They don't have any, they are not recognised as being trained, you know they are not recompensed in any way in their salaries. It is not as if it is... they are doing this training and they will be given an enhancement in their salary through doing that training, they have just done the training and they carry it out. They can do rectal Diazepam which she needs as well if she had a fit lasting any length of time but they can't do the other things so it is very much a wing and a prayer if you like that she goes to the centre but we realise, we have, we realise the limits and the fact that I am on call, that is the only way she is going to get a day centre provision.

A: So has nobody suggested that they train the staff to do these procedures or...

H: It has been suggested, it has been suggested but they can't, it is all to do with unions and training of non- medical staff to do medical procedures, they seemingly, they can't take on board this training. They are not allowed to take on board that training. I have asked if a nurse could be, could work in there...

A: She had a nurse at the school didn't...

H: Yes, because there is bound to be other people in the centre with medical needs, maybe not as severe as Faye's but I know since Faye has gone there there have been people with quite severe disabilities going to the centre as well and they have said no, that it is a social work establishment. They won't put a health worker in, a nurse in, so they have just got to work with the physiotherapist when she is there to carry out Faye's needs, so it is by no means ideal. Faye did have five days when she first went to the centre and was coping well with the five days but about four years ago it was decided, it wasn't decided, it was... we had a meeting to discuss the fact that Faye wasn't coping well. She seemed very lethargic, very tired, switching off, not her usual perky self, not participating in the way that she used to participate with the other members, with the activities and it was across the board that they were finding, in all activities she was very lethargic. We didn't find it at home, we found she was still the same Faye at home so we did agree to a cut to four days to see if the break in the middle of the week would maybe recharge her batteries and she would go back on Thursday with, you know, with a better outlook if you like. They kept referring to her behaviour and this... and they still can refer to her behaviour and this really incenses me because it is not Faye's behaviour, it is Faye, that is part and parcel, that is how Faye is, it is not that she is going out her way to do something deliberately, well maybe she is, maybe she is winding them up but I think they should be looking at it differently, it is not behaviour as in bad behaviour. We had numerous meetings, very heated meetings and arguments if you like about this switching off and this lethargy that they kept describing Faye as having. Her calorie intake was increased, her feeding was changed, her regime was changed, anything that would... we had blood checks, so there was nothing medically, physically wrong to be causing this so we had to look, we asked could they look at it that the activities might be inappropriate for Faye, was her level or learning disability being taken into account and clearly it wasn't when Faye with profound learning disabilities was being given Scrabble you know as a game, included in Scrabble. I may say she still gets Scrabble to do. So were activities, were the attention span, were they expecting too much from Faye so we asked for a psychological assessment because Faye had a psychologist at school, an educational psychologist, that was always reviewed at school. We didn't see that it was any different in the centre, was there something that they were missing. If they weren't going to take it from us as parents would they take it from a psychologist that perhaps some of the things were inappropriate they were doing with Faye? So through my GP, who referred me to the learning disability hospital, we very quickly got a psychologist to do an assessment of Faye. They did quite a lengthy one, they kept a diary at the centre, we kept a diary at home, they observed her at the centre and they had lengthy discussions with us. They met with Faye's carer at home and they just went over everything that we were doing and they went over everything that they were doing at the centre. It was quite a detailed report in the end and it highlighted everything that we had said that she needed one to one, that the attention, her attention span was short and they felt that the activities, the group activities that they were including Faye in were too long, much much too long and that some of the activities were inappropriate for Faye, that they were beyond her comprehension, beyond her ability so it gave the centre, it gave them a more concrete thing to work on, it was in black and white and her timetable was looked at and her activities changed and we settled back into a much better pattern after that but it took quite a bit of pushing, it took quite a lot of arguing you know along the way that they look at this and it is still, they can still slip back into reading Faye a totally inappropriate book, I mean, books that I would probably have bother sitting through, if they have got a reading, you know a story time, they still slip back into different things but we on the whole got is sorted out that they looked more at Faye's learning disability and took on board that.

A: So do you feel that their focus is really on her physical disability rather than her learning disability?

H: Yes, yes but since then they do, they have conceded and they have tried to work in, into perhaps an activity that the others are doing, they will work with Faye, perhaps in a different way round that activity. When it comes to music, when it comes to any of the things that they are participating in, she can manage fine with that. She has got to be like any of the others, she has got to share in everybody else's music, you know they have times that they take in their own CDs so it is, she has got to learn, it is all part of the learning process as well so I don't have any problems there, she's got to... you know it is all part of that process that she can enjoy what other people are enjoying but at the same time if there is something that they feel is beyond her, can they work round and incorporate something that would be more suitable for Faye in it but it is just that they have these lapses when I hear that she has been playing Scrabble but, anyway, they can maybe make it a bit boisterous and she enjoys it if somebody's you know, not very happy or losing or something like that, they can maybe turn it into something more positive in that sense.

A: So the majority of the people that go to the centre, have they mainly got physical disabilities and don't have severe learning disabilities.

H: Yes, yes, there may be associated learning disabilities but much much less an extent than Faye's. They have, the majority of people there are recovering from a stroke, maybe amputees, something physical that perhaps us looking at that person might not see it as a problem, you know they are there for a bit of physiotherapy, the physiotherapist's there. The social element I think is one of the big factors, so Faye is very much... There are or there were a couple of people who were very similar to Faye, one has since left but there are one or two that have the needs of Faye but she is still the one with the greatest learning disability.

A: So how many people go, is it a big centre?

H: Oh it's a big centre, I think it is upwards of, I think there's about 70 in all but they don't go all in the one day, you know they... because they have their... They are leading normal lives outwith the centre so they will go in to the centre for maybe a morning or an afternoon and spend time in there and another day they will have their rent to pay, their shopping to do, that's the kind of mix in the centre. She actually quite enjoys, the other members are very good with her and she enjoys the other members, the more able members so she has got... you know it is a two way thing.

A: Sort of social interaction...

H: She is getting benefit from the mix of people that are there but it is an uphill struggle all the time. There have been members who have resented the level of care that Faye needs. And you know I have heard about that as well through the grapevine but she won't be aware of it, I hope but I know about it that there have been other members that have been there and have resented the level of care that Faye has needed but as the centre has developed more into catering for people with a greater disability, those members have just got to accept that.

A: And what is the age range like?

H: 18 to 65.

A: Right so it is quite a range. You said when Faye was at the school that you regarded physiotherapy as being very important because she had to be properly positioned to function. Do you feel that Faye gets a high enough level of physio at the centre.

H: No, no that has been a struggle as well. When she first went it was very, the outlook was very rosy, the physiotherapy, she had I think it was three sessions of physiotherapy in the week and a session of hydrotherapy. That gradually went down and down. She has no hydrotherapy now at all and she has one session of physiotherapy and it is not with the physiotherapist, it is with a care assistant and it is a 15 minute session on a Monday morning. I have argued till I was blue in the face about the amount of physiotherapy that I felt Faye needed. I felt she still needed a high level of physiotherapy and this tailing down was detrimental to Faye because we were seeing it at home, she was much more uptight when she came home. We had to put more input into her physiotherapy sessions and we noticed it, we noticed it at home. The carer, the carers that have been working with Faye at home have noticed it as well. She has needed a greater input at home with the decreasing amount that she has had at the centre but I have got nowhere, absolutely nowhere with the fight about physiotherapy. I have gone to the consultants, it was a very negative time, it was pulling me down constantly thinking about this physiotherapy and it was negative, it was all negative thinking that I had about it and I had to just make the decision that we tackled this at home through ourselves and the carers and have a bit more positive outlook for Faye and stop the... I had to stop the fighting all the time to try and get more because I was getting absolutely nowhere so the way that we tackled it was to just take it on board at home and keep her level of physiotherapy at home but to say that she needs less physiotherapy as she has got older and all she needs now is maintenance therapy but what is maintenance therapy, there are no... I have looked into it and there are no hard and fast rules about how much somebody needs, it is all down to the individual.

A: What about other therapies, does she have input from speech therapy or...

H: She has input from a speech therapist who was with the technology centre if you like... in Faye... looking at aids for communication but they are very much... Now they have withdrawn in that they are just there on a consultancy basis if you want to consult them about the communication need that Faye has got. They did spend quite a... they did put in quite a bit of time trying to find different switches for Faye, different communication aids and they had to find Faye's level if you like because she was switching off there as well if it was too much that they were trying to bombard her with she would switch off. So she is down to a communication aid in that it is, they call it a big mac, it is a big switch and it is a tape recorded message that they will put from the centre and when she is in the centre, there is different messages will be put on, if she is going from one activity to another, if she wants to say something when she gets into that activity, it is the carer that will put the message on and she will give her message so it is very much on a fun basis if you like that her communication is done and they have withdrawn and as I say they're there if you need any further input. And occupational therapy is only through our local occupational therapy department if we require an aid. There is no ongoing assessments or, you know it is not like assessed every so often about what Faye needs, it is only if you want somebody you have got to contact them.

A: And you said Faye loves music, is there any input from a music therapist?

H: Not from a music therapist but there are, they do have music sessions where they will take their own CDs in and also they have a couple of care assistants who are in a kind of ceilidh band thing, they are quite accomplished musicians themselves and they will take small groups and they will do you know with tambourines and bells and have the involvement in the music like that and she enjoys that and they made a rain maker. She has got her own rain maker at the centre where she can you know do the, turn the thing upside down and it makes the noise, you know it is actually grain, rice that is going through and they call it a rain maker so that they keep that there for her to be her involvement in the music sessions. They had a ceilidh last week, I heard them with that, so that's, it is not from a visiting actual music therapist, it is just very much ad hoc the way that they do it.

A: So how do you feel about the provision at the centre. You have obviously had some reservations and difficulties.

H: We have got reservations. On the whole Faye is very happy. She is very happy there and that is my main concern that she is happy. She is being stimulated, I mean I know, I think it was over stimulation at one point, I think that that can be a problem as well but she is well stimulated, she is happy. They know what to look for with her health problems which is important although they can't actually meet her needs fully they are very aware of what to look for and the actions to take so in that field that is as best as I can get there. It is not ideal, I have got to make a compromise if you like that it is not what I would really want but until I can get what I really want we have just got to accept that this is the only thing that is there for her.

A: And how do you feel you get on with the staff, how do you feel... you know your relationship with them.

H: I did get on a lot better with them to start with. I am afraid because we have had to be quite firm in what we feel we want for Faye it has caused a wee bit of, not an atmosphere but it did cause a few problems but we are on a very good working relationship with them. I would say the physiotherapist is the one that has disappointed me the most, the breakdown there and it was all through the hydrotherapy. She was very much expecting Faye to work where I was looking for Faye to be given exercises.

A: Passive exercises.

H: Passive exercises in the pool and she did, we did have a breakdown there in that she wrote quite a nasty comment in Faye's, to me it was nasty anyway, comment in Faye's book, her diary. We still carry on the diary system with the centre as we did at the school. She wrote one day a very nasty comment that if Faye did not perform and work in the pool she would not be given the chance to go, she would be given one more chance and then the swimming would be stopped. Now to me that was a very unprofessional comment for a start for a physiotherapist to make when she could have been doing passive exercises with Faye if she wasn't getting the co-operation from Faye and by co-operation I mean if you motivate Faye really really strongly in the pool, if you egg her on and you know make it really fun she gets very excited and her bottom wiggles a bit like a mermaid, her bottom wiggles and she can actually move through the water with a neck collar on she can actually move through the water by this movement but you have to really motivate her and she has got to be in the mood and she has got to get excited enough to do this action so you are not going to get it every time so there was the breakdown with that. She apologised that she shouldn't have written that but the deed was done and it stopped Faye going swimming. They have never reinstated it although they said they would. They would look at Faye's timetable and if they could they would reinstate it. It has never been reinstated and the fact that I keep pressing for more physiotherapy doesn't go down well with her but that is all. We get on very well with the staff, the rest of the staff.

A: And how do you communicate, is it through a diary?

H: It is through the diary, yes, through the diary, the same system as we had at school and if there is a real problem they will phone me or I will phone them so we have not... and I can go in at any time, it is not, there's no barrier in the way that she is in the day centre and that is it, it is quite relaxed in that sense and no, I would say on the whole that we get on very well.

A: That's fine. Anything else you want to tell me about the centre?

H: I don't think so. I think we have covered everything. We have had our ups and downs but you have got to... They are professional enough to look at... You have got to take the rough with the smooth, and so are we. Life is like that, I mean you have got to take the rough with the smooth, you have got to just carry on and address all the problems because Faye still is a challenge and always will be a challenge for them but no, I think that's all about it.

A: OK then. Now what would be your hopes and dreams for Faye in the future?

H: Right, my hopes would be that all Faye's needs would be met at a day centre and that I wouldn't be on call. I suppose this is the hopes for me really for my feelings, that there could be appropriate respite for Faye because all we have been offered is a nursing home and that is just not... it is not an option.

A: So do you not get any respite.

H: We don't, no. I haven't pursued it in that the nursing home is the option and I didn't feel it was appropriate for Faye and I haven't pursued it any further. And I dare say I put it to the back of my mind but if there was a good group home and a place in a group home for somewhere in the future but I don't know where in the future that would be, it would be nice to know that Faye was settled and you know that we wouldn't have any worries if we weren't here. But for Faye my dreams for her is that she is happy and that she is healthy and that she is looked after with no compromises. I don't want compromises, I don't want second best, I just want the best for her so that is just... that's my hopes and dreams for her. I don't think too much about the future, getting through day to day is a battle some days but that is for her, happy, healthy and just well looked after. I don't think I could ask for any more really.

A: So is there anything else you want to add.

H: I don't think so I just hope that at the end of the day this will go somewhere to smoothing out the transition period for other people because pioneering for all the ones coming behind was what I was told and it hasn't got any easier, in fact I think it is harder. I think the transition period is harder for parents and young people now even from when I went through it.

A: OK, thank you very much.

Tape turned off.

Interview with Maureen

Pseudonym for interviewee: Maureen (M)
Cities, places and names described in the interview have been changed in the transcript in order to protect the identity of the interviewee.

Name of interviewer: Anne (A)

Date of interview: 06.06.01
Time: 10.45 – 11.20
Setting: Anne's house

Maureen is a full-time carer for her son, Simon. The interview took place in my house. We were sitting in my dining room with the tape recorder placed between us on the dining room table. Maureen is a fellow member of a parents group which campaigned for post-school provision for young adults with "profound physical disabilities and complex learning needs". I asked her if she would be interested in doing an interview with me. She agreed.

A: Right would you like to tell me about yourself and your family?

M:Do I have to describe, like my name?

A: You can say your name if you want but when we write it out, you will just be another name.

M:My name is Maureen and I am married to Stuart and I have two boys, Colin is the oldest and Simon who is our youngest, he is about 21.

A: How old is Colin now?

M:Colin is now 23 and... (laughs)

A: What does he do?

M:He actually works for an engineering company now, he used to be a joiner but he stopped that for a wee while. He is thoroughly loving working with this engineering company.

A: So do you work?

M:No, I do not work unfortunately. I used to work part time when it fitted in with my youngest one Simon but times and basically tiredness.

A: Looking after Simon you were too tired

M:Yep

A: ... and trying to fit it round...

M:Trying to fit round day to day life it's impossible to work basically.

A: So you really need to be...

M:A full time carer, yes.

A: Full time. OK so can you tell me more about Simon, what kind of disability does he have?

M:Simon is profoundly disabled and he also has learning difficulties. He needs 24 hour care, round the clock.

A: So do you have to do everything for him?

M:Every single thing for him, he needs to be washed, fed, toileted, every single thing, he has no ability to look after himself whatsoever.

A: So how would you say he communicates, can he... He can't speak?

M:He cannot speak, no. He communicates more by noises and happy and unhappy phases as in screaming if he is very very unhappy. Sometimes screaming when he is very happy. He basically, it is facial expressions and maybe reaching out to get things that he communicates by.

A: So is he diagnosed as having cerebral palsy or brain injured or what do they say?

M:They don't really know. The bottom line is. They said cerebral palsy with a brain injury possibly at birth but we have never had a...

A: Was it a difficult birth?

M:It was, it was a difficult birth yes. They had to get him out really really quick because the cord was really strapped tightly round his neck and when they got him out quick, they actually ripped me in the process and had to take him away for oxygen because there was no oxygen in the room whatsoever and he was away for about an hour with nobody telling us what had happened etc. etc. so we had to just wait and according to them he was OK and a couple of days later he had this big lump came up on his shoulder where they had cracked his collar bone with getting him out quick and trying to get the cord off his neck but they said that was just a normal process of birth.

A: So it was lack of oxygen then that...

M:Definitely lack of oxygen, yes. That was the cut off point.

A: So what physical abilities has he got, can he walk?
M:He can't walk but he can weight bear just with quite a bit of help. He can weight bear to move him from... he has a circle like a twister board on the floor and if he comes from the wheelchair he can sort of pull up and stand on that and swing round and sit on a chair. He is not too bad that way.

A: So he can sit unsupported?

M:He can sit unsupported, yes. He is quite good that way.

A: Can he crawl?

M:No, he can't crawl at all, he rolls, rolls about to get from A to B but he is uncoordinated. I mean there is not any set direction that he can roll in. If he sees a toy at one end of the room he goes to the other end and he thinks he has got to it. The brain just does not co-ordinate his movements at all.

A: So what about his hands, can he use his hands?

M:To clap his hands, he has not got any... he has not got fine motor skills at all. I mean if he tries to grab something, he grabs with the full hand (demonstrates hand movement) but no and he can't keep a grip for any length of time.

A: So can you tell me the kind of things you have to do for Simon every day in his personal care?

M:Every morning he has to be taken physically out of his bed and washed and fed and then he has, I mean he has his night clothes taken off him, his day clothes put on and to be put in his wheelchair. Day to day in the house as in not in day care?

A:Yes.

M:Then he has to be entertained, either by going out in the car or singing songs or putting some music on for him and it is a constant... to make sure that he is OK. Then it comes round to lunch time, then he has got to be fed again and it is the same process all the way through and then he has to have nappies changed constantly as well. Keep him entertained in the afternoon.

A: Do you have to give him any medication?

M:He has medication for epilepsy, I think it is epilepsy. He has that first thing in the morning and last thing at night and he also has hay fever unfortunately. He has got to have this medication in the morning as well. Then at tea time we have to feed him again but all his feeding, all his food, he actually can't chew so he only can tongue lash so with his food we have got to make sure that it is, not liquidised, but mashed up to a soft consistency. At night time he likes to relax on the floor and we put toys and different things round about him just to keep him happy and occupied, making sure that he is OK and then it comes to bath time or shower time and then we have got to put him in the bath and wash him and dry him, put his pyjamas back on and then it is feeding time again, supper because he likes his food, constantly and then he will maybe have a wee relax watching the television for a wee while before he goes to his bed but it doesn't stop at bed time because then through the night he could become agitated or he just wants company basically because he doesn't like being on his own at all and we have got to get up through the night and we have also got to change him, nappy change him and then every second night before he goes to his bed we have to give him suppositories for the toilet because his bowels just will not... the brain does not tell the bowels to work so this suppository is just like a wee reminder for the brain to make the brain work.

A: OK, what about... Do you have to do any physio exercises with him, do you do that?

M: Yes, at night times, basically at night times. It is more a game than a strict physio routine and we do that at night times, his father or myself.

A: So what about hobbies and things he likes, what is his favourite things?

M: The most favourite things he likes is being out in the car for a run, out for a walk, he loves being outside, basic full time outside. He likes the dog to run round about. We have got a dog to look after as well. He loves the dog, just watching the dog running round and the television. The television, his favourite is Countdown and Blockbusters (A laughs). Lots of videos of them.

A: What about music?

M: He has got quite a wide range and taste in music. He is not too fussy, he is not too bad. He doesn't like it too loud, he just likes it casually.

A: OK that is fine then. So could you tell me about the school that Simon went to?

M: Simon went to Hollywell School in Bamchester. At that time we had sort of looked round about for all the different schools and that was basically the closest and the most... the one that we felt suited our needs basically. Just due to getting on with the head teacher. We felt if we can get on with her we will get things done. And he did, he had quite a good time at the school because everything was provided for him, education, physiotherapy, occupational therapy, music therapy, all the different therapies at the school and it was really good. And he had a good time apart from the long eight weeks holidays, it was a nightmare.

A: So what kind of things did they do with him at the school? You said he had all these different therapies.

M: They have different play therapies just like trying to get him to catch balls, trying to get him to get hold of things, learning to use touch pads and touch screens and he eventually learned to do all that in school, it was really good that way. Basically getting him to use his hands and the physiotherapy kept on at the school every day, making him stand and sit and stand and sit, just to keep the weight bearing up and standing frames and things like that.

A: Did they have input from a speech therapist as well?

M: They did, they had a speech therapist there as well and she helped with, well tried to help with his eating and to see if he would be able to chew eventually but unfortunately it wasn't to be. Just to keep a check on all his eating habits, trying to get a wee bit communication with him.

A: And did the school integrate the medical services with his care as well?

M: Yes, they had a nurse there full time.

A: Did they.

M: Full time nurse, yes.

A: And what about... Did they hold clinics at the school?

M: They did actually, twice a year they used to hold the clinics and the doctor and nurse and that used to be all involved, just progress reports on him and if there was any problems that we felt medically that we could talk to them.

A: And did you feel you had good relationships with the staff?

M: Definitely, definitely, they were excellent staff, really good at communicating back and forward and he had a daily diary as well that things went in that but if there was different things, queries, you can go... It was an open door policy basically at the school. Obviously you couldn't just walk right into the classroom and disrupt what was happening there and then because a lot of kids would be, it would totally disrupt what was going on in the classroom at the time but it was an open door policy, you could go in and... You could actually stand outside the classroom and watch, be there five days a week if you wanted.

A: So were you happy with the provision at the school?

M: I was very happy. I was very happy.

A: Fine, so you felt that the school met all Simon's needs?

M: They did, they definitely did, yes.

A: Social and medical and...

M: Socially they were out and about as well at different things. Plays, concerts and out in the local community. They did this quite a bit, go out to the local community and trying to integrate the kids so they were really good.

A: And is there any way you think the school could have improved the provision?

M: That's a hard one. Em (long pause), I couldn't say that, I really couldn't say that because I also have to say, they had a swimming pool and swimming teachers so there was different therapies that also went on, I really can't say. Simon was quite lucky at school.

A: So is there anything else you want to say about the school provision?

M:No the school provision was good apart from at the end.

A: What do you mean by that?

M:Where he was going to go next.

A: Uhu when it came on to the transition stage?

M:Yes.

A: Right that is what we are going to talk about now. Can you think back to the future needs assessment meetings you had at this school with Simon. What happened at them?

M:Not a lot. His first one was when he was 15 and I was informed it should have been 14 or something but his first one was 15 and the head teacher was there, the social worker was there.

A: Was that the child social worker...

M:The child social worker, yes, physiotherapist, speech therapist, the usual therapists. They were talking about provision for him and future needs and even at that stage of the game it was... I was made aware that there was no provision at all for Simon's multiple disabilities. There was nowhere in our local area, in the Fogart area that could meet his needs so every time we had one of these meetings I was quite despondent and then once when he was 17 we had one of the meetings and we were told that they were now heading towards having sort of small units with people like Simon, young adults like Simon with profound disabilities, that there could well be this in the future but I mean Simon was 17 and he had to leave school.

A: When he was 18?

M: Yes so how long in the future was this to be? We just hadn't a clue and then they had this other wee meeting that they were talking about, care in the community, this was where the parents cared for them every day with so much money to look after them etc. etc. but that all fell by the wayside as well and I thought well we don't need that, we are practically looking after them 24 hours a day, we don't need to be caring for them through the day as well and also we felt that if this did stop, the education that he was having and the input from the different therapies, physio, speech etc. that Simon being Simon, quite a lazy person, that he would just go into a shell. He wouldn't progress, he would actually take backward steps, he would... life really wouldn't be worth living for him, it really wouldn't.

A: And did they never suggest what was going to happen, did they just assume that you were going to continue caring for him at home?

M:Assumed, yeh, definitely, they told us about all the different places that were open like St. Catherine's Centre as in the Ralph Gardener Centre in Longbridge, things like that but these were just not suitable for somebody with Simon's disabilities.

A: And that was them, they told you that.

M:They told me that.

A: That wasn't your opinion, that was their opinion?

M:That was their opinion, it was also my opinion when I went down and had a look at all the places because we had a look at every centre that was available and every centre we were told by the centre person, the management, that they just wouldn't be able to have Simon there.

A: Mhm and how did you feel when you went to these meetings? You said you...

M:Worse and worse, very despondent. I felt like it was coming to the end of my life as well basically. I just felt so depressed and I thought why should I even bother going to another meeting because what is the outcome? Same as the last time.

A: Did you go to the meetings on your own or did your husband go?

M:No my husband also came with me. And he got very angry, I have to admit he got very very angry and told a few home truths that shouldn't be told I suppose (laughs). But he did he got very angry but he was feeling for me because he is at his work through the day and I would be left with Simon and he felt life would be just unbearable.

A: And when you went to these meetings did you feel uncomfortable or intimidated by any of the professionals or did you feel quite relaxed and...

M:No I felt quite relaxed because maybe that is just the type of person I am fortunately, but no, I did not feel intimidated at all because I was still able to get my point of view.

A: So you felt able to say your piece. And did you feel you were listened to?

M:I felt I was listened to but nothing could be done about it, this is the unfortunate thing.

A: So you said that Simon's first meeting was when he was 15 and you found out later that it should have been 14. So did nobody say to you, right these future needs assessment meetings are coming up and this is when they should start and this is what should happen?

M:The school, yes the school did but by the time they got everybody together that they were able to get these people who all need to be in at the meetings, he was 15 by the time everybody could be together.

A: So it took a long time to organise...

M:It took a long time to organise yes...

A: ... the first meeting.

M:Definitely because people were on holiday or they were unavailable and other people didn't want to turn up because they didn't know Simon which wouldn't have been fair either so it was just...

A: So how would you say this time affected your family?

M:Really badly because as time went by we actually were left with Simon at home and I was absolutely shattered I have to admit, 24/7 [looking after Simon twenty-four hours, seven days a week] to look after Simon to try and be a wife and a mother to my other son as well and my husband and I was very tired, absolutely exhausted.

A: So what actually happened? You have now got provision for Simon. So how did you get that?

M: We actually had to go through a series of meetings with the social work department and things like that but this was not through the school, this was through sort of like a wee pressure group. We had to do all this, constant meetings, constantly telling us it would be...

A: And who was on the pressure group?

M: Myself and Mrs Harris really basically to begin with. And constantly at the social work department, to this meeting, to that meeting and then we had the carers, some people from the Carers National and the local carers groups, they were also there at some of the meetings as well. Just to be told... in actual fact we had been to meetings like this since they were about 14 or 15 to be quite honest, this is how long we have been sort of campaigning for about five or six years before anything was actually done and I mean we knew that these young adults were coming up because we had done, well it was actually Mrs Harris that had done studies and reports from different schools to see how many young adults with profound needs were going to be coming up to be in the community when they left the school and it was quite frightening, the numbers. We were always told "Oh it is just one or two, it is just one or two" but no, it was not just one or two.

A: So when you did these reports nothing much was done about it then I gather.

M:Not a lot, no, basically not a lot. They probably were going on behind the scenes but they deemed not to tell us in their wisdom, I don't know, I don't know why but things would be moving. We were always told that something would definitely be in place but when it would be in place nobody knew and they wouldn't be able to tell us when so my son was left at home basically for a whole year and it got to the stage that I was just, I just felt I was hitting my head off a brick wall, I was tearing my hair out, I was absolutely screaming blue murder at them and they weren't listening so I had to go to the Press. So unfortunately it wasn't a very nice thing to do for to display my troubles to the whole of the Glendinning area but I felt it was the only thing that I could do to pressurise, to shame, is that the right word, to shame them into for a place and to let everybody know that this is what was happening to me and my son. So he was front page news of our local newspaper with headlines 'Nowhere to go' which was quite appropriate because he had nowhere to go, he was stuck at home.

A: Did you ask for an extension? You know you can ask for an extension till they are 19 at the school, did you ask for that?

M: Well we had thought about that basically and at the end of the day it wasn't going to do Simon any good. It would have done me good because he would have been looked after and that through the day but the school was at the end of what they were able to provide and I felt quite strongly about that and I felt quite strongly about why should they keep providing when there is no provision for him at the end of the day and I felt it was up to the other agencies to come in and give me a wee bit of help because we have never had any help up until that point.

A: And when Simon was at home with you, did they say right we can provide certain services for you to help you at home?

M:No, no. Nothing was offered whatsoever. Physiotherapist, yes definitely, they came in from the community every week to make sure that I was keeping up with what he was having to do.

A: But nothing else was offered?

M:No, not a thing, no home care nothing.

A: And then you went to the papers and then did things begin to happen after that?

M:Well it was a wee while after that actually, maybe about two or three months but I had got this phone call to say that a social worker was coming out to see me and would I be available blah, blah, blah and of course I would be available because I was at home every day so they said they were having this new service from the Aberlour Child Care Trust which I was a bit dubious about at first because they had only been involved with child care, not young adults before and they got me quite up about starting dates and things like this and that was also put back and back and back. Eventually Simon sort of had one day and then next week he had two days, just to know the people who were caring for him in the young adults group and now he goes four and a half days a week.

A: So is there anything else you want to tell me about this time, this transition time? Was it a year you had Simon at home.

M:More than a year, about a year and three months with him.

A: So how did you feel...

M:The three months to me doesn't feel... because we had known then that something was going to happen so that's kind of... the good bits kind of wiped out that three months but the whole year it was just... I can only describe it as a total nightmare. There is no way that I could cope with Simon full time, 24 hours a day, 7 days a week.

A: And how do you think Simon felt during this time?

M:Simon felt really frustrated because he seen that I was tired and he wanted to do a lot of things and I wasn't able to do these things. To get him out and about for a start I mean it can take sometimes more than one person to put him in the car. I mean it needs two people because he doesn't have lifts and hoists into the car. I mean he has got to weight bear and things like that and sometimes he would do it and sometimes he wouldn't so if he wouldn't do it we would be stuck in the house, depending on the mood he was in and he was in a mood quite a bit.

A: And did he lose some of the skills he had at the school?

M:The weight bearing was starting to tell, definitely the weight bearing was starting to tell and the communication skills, his communication, he was just sort of starting to withdraw slightly into himself.

A: And did you have signs of him being unhappy then?

M:Definitely, screaming every single day, it was more frustration because he wanted to be out and about with different people other than myself. Even if I took him, if we managed to get him down in the town centre and things like that, he still wasn't happy because he wanted to be with his friends and he had no friends at all, he was left with nobody.

A: So it wasn't a happy time for him.

M:It was not a happy time for him and I wouldn't want to repeat that.

A: And how did your husband feel during this time?

M:He turned into Mr Angry, constantly on the phone to the social work department threatening to leave Simon at the door of the social work department because he felt if it kept on any longer I would have to go to the hospital because I would be very depressed and probably mentally imbalanced myself and definitely threatened to leave him on umpteen occasions at the social work department's door.

A: But it didn't really have much affect?

M:Not at all.

A: And what about Colin?

M:He was very good over this period, I mean he tried to help out as much as he could and I mean he also was like his Dad, he was working full time and trying to help out at night times when they tried to take the strain and the burden off of me when they came home from their work which is not very fair really because if they have worked full time all day in a high pressure job they don't need this to come back to at night.

A: So is there anything else you want to tell me about that time? (pauses) I think you have covered everything.

M:To go back to my oldest son again, Colin. I mean he was more a carer than anything else because he used to say "Right mum, away you go out, I'll watch him for such and such a while" and things like that which was not fair, wasn't fair on him at all.

A: So he took over your role.

M:He took over my role, he did.

A: Now if we think about now, about the provision that Simon's got now, could you tell me about that?

M:Yes, he goes Monday to Friday to Kirkhall in Deptford, it is Lemington Court young adults project and I was a bit dubious at first as I say I really was, I didn't know what to expect or what they had in place but as time has went on, they have really, really, it is an excellent place for him to go to.

A: So what were your worries about it then?

M:Basically I was wanting an extension of the school but more young adult appropriate, for them to be with other young adults, more community based but I thought the learning and the education and the...

the things that he had learned so far I thought they would have maybe been wiped out. I really had a vision of it being like the different units that we went to see at first through that transition period and there was not much happening at these units when we went to see them and I had visions of Simon just being looked after, just looked after from Monday to Friday but by this point to be quite honest, I wasn't fussy, I was needing him to be looked after Monday to Friday and I thought well if he gets in there then we can maybe fight to see if we could make things happen when he is there but on saying that the provision that they do provide, I mean they have the speech therapist comes in to see Simon, the physiotherapist. They go out to the physiotherapy and they go out to music therapy and they do bits of drama in the house. They do cooking, baking, take them to swimming, ten pin bowling, they just do all the things that a young adult would prefer to do, the pictures, they go away on holiday, it has turned out to be a very positive experience for Simon, very positive and he loves it.

A: And you and your family are happy with it?

M:Definitely, definitely.

A: And how do you get on with the staff?

M:The staff are very honest people. They communicate well with you. Simon has a daily diary also that we communicate with but again we could pop up there any time through the day and talk to the staff. They are very caring people and they appreciate and they understand the needs of young adults with profound disabilities.

A: And do they review his progress?

M:He has a review once a year and if we wanted to we could have more which the social work department comes in to, different people if we want to, if the speech therapists or physios come in, the staff and the hierarchy from the Aberlour come in also and it is always positive, always positive, never negative reviews.

A: So you said at first that you were a bit concerned that they might just concentrate on his care needs and neglect the educational and social side but you have changed your mind.

M:Yes, I have changed my mind definitely, yes.

A: That's fine then. Anything else you want to say about the provision?

M:Well it was only meant to be an interim position, this is what we were told to start with and that was three years but now that three years is up and there is another three years and the only thing that really bothers me now is what happens after this three years. Do we go back to square one? I don't know.

A: And will they extend it for another three years do you think?

M: We haven't a clue, nobody has been told.

A: So you are left still with uncertainty.

M: With this transition period yes.

A: As to what is to happen next.

M: Interim, how long is interim?

A: And nobody has really told you...

M: No.

A: ... or committed themselves?

M: No because Aberlour the people at Aberlour can't say because they are paid on a yearly basis but they have been told another three years obviously but after that nobody knows.

A: So the future is sort of uncertain then?

M: The future is in the balance at this moment, yes.

A: So what would you like to see happen for Simon in an ideal world? What would be your hopes and dreams?

M:In an ideal world to be similar to where he is just now with the things happening but also to be there full time when he is a bit older, to be in that community, to be with these type of people who would do the day to day caring but also care, a full time placement for Simon.

A: So do you mean like residential?

M:Residential, if they had a residential unit like that, that would just be absolutely ideal because I feel that he is now at the age that we are now looking for his future, his future needs as well, to move on like any young adult would move on with their lives, they don't want to stay with their Mum and Dads for the rest of their lives and I feel that he should be entitled to the same as every other young adult, to move on in life.

A: OK, is there anything else you would like to add?

M:I can't think.

A: Covered everything yes.

M:Yes, that's fine.

A: OK then, thanks very much.

Tape switched off.

Interview with Catherine and Roger

Pseudonym for interviewees: Roger (R), Catherine (C)

Cities, places and names described in the interview have been changed in the transcript in order to protect the identity of the interviewee.

Name of interviewer: Anne (A)

Date of interview: 18.06.01and 20.06.01

Time: 10.30-11.40 and 11.00-12.10

Setting: Catherine & Roger's home

Interviewer: Anne

Roger and Catherine are both full-time carers for their daughter, Geri. The interview took place in their living room. The tape recorder was placed on a coffee table and we sat around it. Catherine and Roger have recently moved to Fogart. They were experiencing difficulties obtaining services for their daughter and contacted the local Carers Centre. The Carers Centre offered to put them in touch with other parents of young adults with profound physical and intellectual disabilities, hence my involvement with them. I told them about my study and asked them if they would be interested in doing an interview with me. They agreed.

A: Would you like to tell me about yourself and your family?

R: Well I am Roger, my wife is Catherine and my daughter who has special needs is Geri. I'm in... I'm 54, Catherine is 49 and Geri is 18. We don't have any other... Geri does not have any other brothers or sisters. We have family living in Fogart and this was one of the reasons we came back to live here after being in Dunness for two years. Prior to that we lived in Ladywell for 28 years.

Geri was born in Ladywell in 1982 and she has had her disabilities since birth.

C: She has been diagnosed with cerebral palsy so she is profoundly handicapped. She is in a wheelchair. She is... her abilities, well she can actually hear. She has been registered blind, she is NG tube fed, she is doubly incontinent. Em...

A: What is her physical abilities like. Can she walk?

C: No, Geri is in a wheelchair, she can't walk, she can't sit up unaided, she can't move her arms to help herself. Em...

A: Does she wear any support like a brace, when you said she has difficulty sitting up.

C: No she doesn't actually wear a brace and she's, she needs help at feeding. Em...

R: She has a curvature of the spine and I am not sure which is which. One is scoliosis and one is kyphosis and she suffers from both but at present she doesn't require any support, body support. Her wheelchair obviously is designed around her...

C: ...structure, body structure.

R: body...yes.

A: So that gives her the support she needs to enable her to sit up.

C: When she is in her chair, mhm but we have actually never had anybody look at or suggest a body support for her.

A: So how about her hands and her arms, you said she was...

C: Geri used to have splints, hand splints, when we lived in Middleburgh but we then moved to Dunness and she was using the splints in Dunness but then she became quite ill so over a period of time she just used them less and less and when we arrived in Fogart, we did look at hand splints for her but we were told that her hands had got so tight she couldn't really benefit from hand splints so I think now she is passed that stage.

A: So has she got any use of her hands, could she hold anything in her hands?

C: Not really no. We actually just sometimes roll up...

R: ...the wipe.

C: ...the wipe...

A: The baby wipe.

C: ...quite thickly and put them into her hands to just open them up but otherwise she doesn't... I think she can hold possibly slightly grasp things when she is at school if she is doing something that... a piece of equipment to help her with music or something but I think eventually that would fall out of her hand so she doesn't have the awareness to know to hold on to it.

A: And she doesn't have the ability to open her hand and let something drop out of it.

C: No, she doesn't have that.

A: So how does... does she communicate with you, she hasn't any speech but...

C: No verbal speech but a lot of body language so that is really what you have to look out for. You have to learn to read her body language and she can do a lot of talking with her eyes. She will smile or frown if she is not happy with something, she can turn her head away from you if she doesn't want to know something, doesn't want to be involved in something. She also will, if it is a form of understanding, she will push her arms down with her fists tight (demonstrates) and she tries to push her arms down and she closes her mouth tight and that is to... it is like she is confirming something, she understands something, that's her way of communicating. The other way of communicating is she coughs, she can cough to communicate which is something that we are trying to move away from we are trying to get her not to cough so much but because of her health she can cough anyway so you have to try and work out why she is coughing but she does use coughing to communicate.

A: So how do you know then with the coughing, is that, does she cough when she is pleased or is that to show displeasure or...

C: It can be displeasure if for instance she is listening to her music and it is finished and she is really interested in listening to her music, she can cough, that is saying 'Could you put my music back on'. If somebody puts pop music on and she really hates it, it's to cough to say 'Please just get that music off, I hate it' and I can't remember, what else does she cough for.

R: Well she can cough just to attract our attention. Perhaps we are not in the room with her and she wants us to be in the room with her so she might cough to attract us.

C: Say 'Come and get me'.

R: Em. Then there is obviously the cough related to having phlegm on her chest and she is trying to bring it up, that's probably more obvious because the phlegm, you can hear the phlegm, the rattle of the phlegm so we use a suction unit to get it from the back of her throat out. She also has in a way a silent cough where she holds her breath and goes through the motions of coughing but no sound comes out and she can go a bit red in the face until she draws breath again. Those episodes I think to anyone who doesn't know her particularly well does tend to panic them. It used to panic us to start with until we realised that she was actually going to draw breath eventually.

A: And is that a way of showing displeasure then or when she is not pleased about something.

C: She will actually cough, I think she has become a lot more aware of her body and as well as using suction to get the phlegm off her chest we actually do postural drainage and there are a lot of times when the suction isn't enough so we actually do postural drainage and Geri will actually cough and cough and cough. It is like she is shouting at you to say 'Look I have got something on my chest, I have got to get it off' and as soon as you put her over your knee to do postural drainage she will get it up, she is just telling you 'Look, this has got to come up, it's here and I need to shift it'. Geri has only, would have got like that since she would have had alternative medicine, we take her for her therapy and that has helped her become more aware of her body and what is going on for her so she will use that cough and it is very obvious now to us as parents, when she has something stuck, that is what she does.

A: Now you said she is tube fed through her nose. Is there any other medical procedures you have to do with Geri.

C: Medical procedures, there's suction, em... medication, em... physio.

A: So you do the physio exercises with her.

C: Suppositories.

A: Suppositories.

R: Nebulisers, postural drainage.

A: And what about, does she take any fits. Do have to give her rectal vallium?

C: No we don't because... she is on an anticonvulsant drug and as far as we are aware or concerned, her fits are under control. The last time Geri had to have rectal vallium, believe it or not, this is true (smiles) was when she was in a hospital, the reason was because she wasn't getting her medication on time and it built up over a few days and we went up to see her one morning and we were told that they had to give her this. We were very very surprised to hear she had to have it and then we were very angry to find out why she had to have it because you don't expect people to become iller in hospital and prior to that Geri had not had to have rectal vallium since she was possibly in intensive care when she was a baby so that was not a nice experience but we spoke to the medical staff about it and they were not happy that we had been aware of the situation.

A: So do you keep it in the house then just in case.

C: No we don't.

A: Because you are quite confident that the drugs...

C: We are very very confident that she doesn't need it in the house. She obviously has to have it at school, that is a legal requirement or a medical and legal requirement. I think if we said no she wasn't to have it at school she probably wouldn't be allowed to go to school so for that reason it is at school for her.

A: So it is just a safety thing then.

C: Yes.

A: Can you tell me something about Geri's hobbies and the things that she likes doing, what activities does she like.

R: Well Geri's hearing is very acute so most of her enjoyment comes from listening to music particularly opera and classical music but it can be a silly song that you might sing to her, a one to one basis.

C: Disney music.

R: Yes she likes Disney music.

C: All the soaps on the television she likes the theme tunes. She loves listening to traffic passing when she is being walked up to school and back from school, I have noticed that about her lately.

R: Yes, I can actually get a squeal out of Geri as I would be taking her out of our car outside the house and traffic would pass, I can actually get a squeal.

A: Because she likes that noise.

C: (Nods)

R: Because she likes that.

C: The other thing she likes, she likes listening to people. She likes listening to children play, she enjoys, well there's very few things that she actually enjoys but she enjoys them, other things... she enjoys things like having a bath, having her hair washed, having her hair cut, having her hair blow dried, having people come to the house, she loves people to come to the house and talk to her, she likes going out in the car, she loves school, she likes having a separate world to Roger and I. She likes meeting new people and I think she likes meeting young people because I think it is because (....), what else does she like?

A: Does she like swimming?

C: Well...

R: She likes swimming, yes.

C: Yes she actually likes swimming in a reasonably heated pool.

A: Has to be warm water.

C: Yes, not cold water and she likes going on outings. She likes when we get it, I think she likes respite care, that's going somewhere different and being with young people and different people.

R: She likes the wind in her hair. She has grown accustomed to that since we moved to Scotland. Bumpy rides, the bumpier the ground the better.

A: So she likes sort of tactile things and things that stimulate her senses.

R: Yeh. You can dance with Geri in her wheelchair and she can get some pleasure from that. I think it depends on the music that is being played but she did seem to enjoy the hokey cokey at a St Patrick's night ceilidh that we took her to so...

C: And a 21st birthday party she went to, she enjoyed after looking miserable for a while, she then enjoyed herself. So she can, I think she is not getting... since we have moved to Fogart I don't think she is getting the opportunity to experience these things. Like at school she would go down to the stables with the children but she doesn't go horse riding because it is a contradiction, it is horse riding for the disabled but because she is disabled, i.e. in a wheelchair she doesn't get to sit on a horse because of restrictions so she goes down to the stables which I think she quite enjoys but she is limited in what she can do. So I don't think she is getting the opportunities to have more enjoyment in life.

A: So have they not got enough helpers or is it a question of equipment?

R: I think it is a case of a hoist they don't have a hoist to raise her onto a horse's back and presumably a special kind of seating arrangement to keep her on. Similarly with swimming, her class goes swimming but Geri is excluded because they don't have enough help and the pool presumably is not warm enough but she does relax in a heated swimming pool, she did have swimming at her school in Ladywell. She used a swim aid and she actually took part in a swimathon which was the school helping to raise money to buy these swim aids so the company who manufacture the swim aids lent them to the school so that they could do their swimathon and Geri took part in that in Ladywell.

C: Which she thoroughly enjoyed to the extent that she stayed ... her head stayed up in the water for quite a long time because she was so relaxed she slept.

A: Did she? (laughs)

C: So she has experienced.... I think she has when we lived in Ladywell she experienced more activities.

A: So do you want to tell me about her school provision then. Tell me about the school in Ladywell, is that the first school Geri went to.

C: The first school Geri went to, she would five? (looks at husband)

R: No, Geri went to Garefield school when she was 3 part time but only for a few weeks. She was going two or three times a week and then after a month or so the teacher said 'I think we can happily take Geri for a full five days.

C: He actually came round to the house to talk to us about it because I personally was very reluctant for her to go to school because I just had her, I would have had her wrapped up in cotton wool and I would have seen school as a bit thing, going out into the big world and I didn't think she would be able to cope. So what was going to be her school teacher came round to the house, drank all the tea and coffee, all the coffee and biscuits, ate all the biscuits but had said he would be really looking forward to her going and felt there was so much opportunities for her so we agreed to have a look round the school and I remember the day going to the school and looking round the school, I came out of that school and I cried all the way home because in the whole of Geri's life I had met people who were so positive and optimistic and I had not experienced that since the day she was born and I was overwhelmed and I thought yes this is for her, this is for her and so Geri actually started to go to school and she was so stimulated that when she came in from school every day she was absolutely exhausted and that was the beginning, I suppose that was the beginning of her life really.

A: So was this a special school.

C: This was a special school, this school had a hydrotherapy pool, it had, as far as I was aware it had everything, it had physiotherapist, it had speech therapist, it had I think had dieticians that were linked with the school, they had a herb garden, sensory herb garden because they actually had, you know the em, what's that television programme, (looks at husband) they do your garden for you...

A: I know the one you mean.

C: They actually got them to come in and do a herb garden.

R: Ground Force.

C: Ground Force, they actually got Ground Force to go in and do a garden. They just had so much activity at that school.

R: Sorry to cut across but I don't think they had a hydrotherapy pool at Garefield.

C: They did. It was actually outside.

R: No that was Mudwood.

C: Well we'll talk about that later, I don't want to waste your tape.

R: I mean the fact was she did get hydrotherapy stroke swimming at her first school.

C: Yeh.

A: Was that a voluntary run school or a state school.

C: State School

A: State school, so you felt it met all Geri's needs. Could it deal with her medical needs?

C: Yes they actually, they did have, the school actually had a school nurse who, if anything happened to Geri the school nurse would be called. If the teacher and the classroom assistant couldn't deal with whatever Geri's needs were. Saying that when

Geri was very young she did have quite a lot of health needs that nobody really knew what was going on initially so it did take quite a few years to get used to what her situation was. I think as parents if you can tell somebody what they need to worry about and what they don't need to worry about then I think it makes life a lot easier but they would have a school nurse who would see to the child and then make a decision as to whether that child had to go to hospital or whether the parents should be phoned, that sort of thing.

R: Of course she was eating orally at the time, mashed diet which was normal so they were able to cope with that.

A: Did she have chest problems that required her to be nebulised or suctioned at that time.

C: Not suctioned but Geri had, when Geri was born she passed mucoid and she inhaled it into her lungs so her lungs were damaged from the day before she was born, the day or two before she was born or the day she was born so her lungs have been damaged since then so she has probably always had breathing problems. But I think it was the attitude of the school, the school's attitude was all of these children in this school have special needs but it is a school and that's how we will treat it. Geri was, it was just a fantastic environment for her and it was fantastic for us as parents for her to go there.

A: And did you have good relationships with the staff?
C: I would say excellent.

R: Yes, yes.

C: I think it is because we expect that anyway and we had a chat book that went to and fro. If ever we were worried about anything we could phone up her teacher, speak to the classroom assistant. We hardly ever saw the head because we just had such a great communication with the staff. We, you know we did socialising in as far as when they had events that went on at school we would turn up.

A: So they involved the parents?

R: Yes.

C: Parents very much, yes very much involved.

A: So you were pleased with that provision.

R: Yes because, although we had no experience of this type of schooling, school for special needs, yes we were happy with it. We had nothing to compare it to but, no we didn't have any problems.

C: It was the atmosphere and the respect. What came over quite strong to me was the respect they had for their children and they had so much, they seemed to have so much respect for the parents. They saw the parents, I felt, this is my feeling, they saw the parents different to what I had experienced from the health profession, they saw the parents as doing a fantastic job and needing help and support and they, it was like they were there to be, they were there for you as well.

R: So they might come up with some tips, maybe if her feeding wasn't going particularly well at home, they would suggest... because they had a speech therapist.

C: Yeh. Also they had, if you were concerned about something or if you were a bit reluctant to try something new, I found Geri's school teacher would for instance when Geri had to move on when she was 11 or 12 they said well she is moving on to a senior school. I was not happy with that whatsoever, I was very reluctant for her to move on. To me then she was going into another world where I felt she had been quite happy at the school and I was very unhappy about that and the same thing happened again, the teacher came round to the house for a chat and, you know parents have got an awful lot of experience and knowledge and they are quite powerful, they do know quite a lot but sometimes parents need to be given, put in the right direction as well. Well personally speaking I think sometimes I need a nudge and as Geri's schoolteacher said she had become complacent and too laid back and too comfortable in her environment and she needed a push. He was her school teacher, she knew that if she went in there every day he would be there and this would happen and that would happen so she needed to move on in a stage in her life and the changeover from... the transition from her junior school to her senior school was fantastic, absolutely, it couldn't have been better, the communication... what was going to be her teacher in the senior school would visit to the junior school and spend some time with the group of children that were going to move on so she didn't just go into the school and meet the children and the staff, she also arranged that when she was there sometimes that the parents could go in and meet her and then, that was done over a period of quite a few months and then there was the trip, we were to take Geri to her new school, what was going to be her new school one evening, the had a parents evening and we took Geri to that. I have to say it was a very old school, it was very busy, there was loads and loads of students. They didn't appear to have very much space for things. The corridors were busy, they were full of different things so I was... when I went into the school initially my first reaction was oh, I am not impressed. We waited to be seen, for Geri to be seen and taken round and then the staff came out to get Geri and us to go down to the classroom where Geri would be and then the whole thing changed completely, the atmosphere was fantastic, the staff were great, we were worried about Geri how she would react to moving on and we were basically being silly parents. In that situation we were being sad parents really because Geri's attitude was right well, show me what you have got. So of course she was taken into the class, she was taken into the sensory room and she was shown everything and it was a great evening, it was very successful and that of course, from then on I wasn't worried about her because I just could see.

R: Geri was ready to go.

C: Yes.

R: After 8 years of junior school

A: She was ready to go.

C: Yes and her teacher was right and we were wrong. She was ready to leave.

A: So how did they do that. You said that the teacher came from the other school into Garefield and visited and did they have a gradual transition that she would go so many days to Garefield and so many days to the other.

C: No, she went straight there. What she did have was over a period of a few months the teacher and possibly, I can't remember now but possibly some of the helpers, the classroom assistants possibly went to Garefield. But because of and I think, I have to say I think the teacher that Geri got at senior school, Jane she had, she was young and she had a great attitude, she had an excellent attitude. She was just so comfortable with herself and she was just so comfortable with those young people and the interesting thing is I noticed that as soon as Geri moved she was treated as a teenager and all the curriculum had changed totally, hadn't it? (Looks at Roger who nods in agreement) She had, you know everything just changed completely and she was just being treated as somebody, I suppose she was actually being treated like all children that go from junior to senior school.

A: So the activities were more age appropriate.

C: Yes exactly.

R: But weren't we taking Geri to Garefield ourselves and collecting her and at Mudwood she went in the school bus with an escort?.

C: I can't remember now because I was working so I wouldn't... we will have to talk about that later because I can't...

R: But certainly she was collected to go to her senior school Mudwood, she was collected in the morning, an escort came to the door and was with her on the journey and the same coming home at 4 o'clock in the afternoon. But the school had slightly different activities. Geri was introduced to music therapy at senior school, she had never had it at Garefield.

C: Well music therapy was a rare thing, I think it wasn't on the priority list financially and Geri's school teacher managed somehow when the school actually said they could get a music therapist for I think something like two afternoons a week, she put Geri's name down and said she has got to have that. So she managed that and at that time for Geri herself this was one to one therapy. The helper on the school bus, she was actually allocated, because she worked at the school, she was actually allocated to feed Geri at lunch time so if there was any problems with her feeding we were aware of it because obviously it was put in her chat book but also when she dropped Geri off in the afternoons she could let you know how the lunch time feeding went.

A: And was Geri still fed orally then?

C: She was being still fed orally at that point, yes.

A: And did you feel the new school could meet all her medical needs and give her physiotherapy. Were they all in place, all the therapies?

R: Well it was a much bigger school, more students in the school and unfortunately there was only one school nurse for the whole of the school although that didn't make a great deal of difference I guess it was the person herself, we didn't feel she was confident at all times and would ring one or other of us up and perhaps had a problem although as often as not the problem would have been dealt with but she still felt she had to ring us at work and tell us which we felt was closing the door after the horse has bolted sort of thing. On several occasions she would have been taken to Hemingway hospital. Her breathing problems were more acute by this stage. The paediatrician actually diagnosed her as an asthmatic.

C: After she had been in the hospital.

R: After she had had whooping cough.

C: Well it took quite a while for somebody to diagnose it.

R: So she would have had Ventolin with her in school but if she didn't respond well to the Ventolin she would be taken to hospital which happened on a few occasions. So things were beginning to worsen in that respect. We think now what was happening to Geri was that she was aspirating on her feed or a drink causing her breathing to be laboured and subsequently getting a chest infection so looking back now, we don't think it was asthma as much as it was aspirating on her feed and the breathing was becoming difficult through blocked bronchi.

C: Also at the time she... the dentist became aware when after doing check ups that she needed some extractions and fillings which he said would cause her to be very cautious about how she ate because if she had a sore tooth or something so that wasn't helping with the situation. But the school nurse I think she was the sort of person she would ring at work and say Geri wasn't well earlier on but she's OK now and then of course being me or being a mother the guilt factor would come in, you couldn't really settle and then you would say to your boss, 'I'm going, I'll go and get her' so she, instead of just putting it in her book so you saw what happened when you picked her up, I can understand her ringing if she was not well and you need to pick her up or something but that's what she used to do so as parents that wasn't really very helpful. I don't think, I think the situation was probably too much for her at that time.

A: Now you said it was a much bigger school and there was more students at it than Garefield so did Geri cope with this bigger number and the bigger premises.

C: Yes...

R: She seemed to.

C: Yes Geri coped very well because her classroom there were, I think there were about seven students in total and they were all quite similar to Geri and others of the age group so, and the fact that she had this fantastic teacher and the classroom assistants, they in that group they were quite successful. When I said about there being lots of students I think Geri enjoyed the buzz that went on and there was a lot of integration with some of the other children that were maybe more able bodied than Geri or more aware than Geri. They had... Geri had certificates in that school for helping...

R: In the coffee shop.

C: ...in the coffee shop. Like say a child with possibly mild learning difficulties would collect the cups and saucers so the tray would be put on Geri's chair and then this other young person would wheel the chair, collect the cup and saucers and they would wheel it over to the counter and so there was a lot of integration like I think it was one afternoon a week Geri would go into another class. So I feel you know that, as I said the building was smaller than the amount of students. In saying that they actually did build a new school just before we left the school, they actually had nearly finished a new school very close to this particular one and that had a lot of input from not just the top but it had input from I think some of the parents and the teachers as to what, you know if they had a wish list what would they like in the school and even to the fact of where... I know Geri's school teacher actually wanted her class to be allocated in the area where it was easier for them to access the swimming pool, the hydrotherapy pool, changing rooms, that sort of thing and she wanted to know if there was any money left over, could she have piped music in the swimming pool.

A: So was this a state school or a voluntary school?

C: State school.

A: And what about, did it have a high level of therapy input from physios and speech therapist and...

C: Yes. I have to say that we have been either extremely lucky but I always up until the time we moved to Fogart I always felt I never had a problem with education. That was one area where we felt we have had support and we did actually experience a problem when Geri's health started to deteriorate and there was the talk about it being linked with her aspirating, it was suggested by her paediatrician she had a gastrostomy tube. We didn't take her to see him about that, we took her to see him about something else and we were reluctant to go down that road and we chose an alternative, we took Geri for alternative medicine to see if that would help. Also around that time her dentist felt that if she had her extractions and her fillings that would help the eating problem but in relation to the eating problem there was meetings held at the school with people like physiotherapist, the school teacher,

R: Speech therapist.

C: speech therapist, head teacher, there was actually what they call a paediatric team where you would get a paediatric nurse coming to your house who would just basically be there for you to talk to and ask what sort of help and support you needed and she would be at the meeting as well. Possibly Geri's social worker.

R: And one of the support workers at respite care because they always...

C: They would feed her.

R: ...feeding her at respite care so there was meetings arranged around Geri's feeding but it was also around that time that she went to Carsea and Winchester hospital to see a specialist with regard to examining her oesophagus and stomach, digestive system basically and he discovered that she had a reflux problem and also a hiatus hernia.

C: Well actually I suggested to the paediatrician that is there no test that can be done to see what is causing Geri to have the problem because his first reaction to asking the question does Geri cough while she is eating or drinking was when we said sometimes, he said well I think she should have a gastrostomy tube and I was absolutely horrified by that solution and I did say if she was a normal healthy child you wouldn't suggest she had a tube in her stomach, do you not think you should try and find out what is causing this and that was the reason she had a barium meal and it was then discovered that she had a hiatus hernia and a reflux but to what extend, how bad it was at that time, we didn't know.

End of side 1
Side 2

A: This was at the Carsea and Winchester hospital.

C: The specialist we saw up there suggested that one of the things we could try was Geri going on Cisapride but he only actually suggested she went on it for something like, no that's not true, prior to that it was suggested she would go on the Cisapride and she was on the Cisapride for something like two weeks and when we spoke to the specialist at the Carsea and Winchester he said two weeks wasn't long enough and he felt that she needed to go on it longer to see if it would improve the situation so that is what we agreed to do rather than Geri have a gastrostomy operation. And we weren't we given the full information on the operation and what it actually meant, we were told basically this operation would be fantastic, it would be straight forward and it would save us time with feeding Geri because she would just have a liquid feed and by asking lots of questions of different people we then found out that the operation wouldn't have worked for Geri initially because she then had to have a hiatus hernia operation to go with the gastrostomy and we spoke to other parents that their children have had this operation and we found out that some of them weren't very successful.

R: This was a much bigger operation to repair the hiatus hernia at the same time as putting the tube in.

A: So this was more like a fundalplication.

R: That's what it was called yes fundalplication and I asked about the success rate and I was told that it wasn't any better than 50:50 for the repair of the hiatus hernia and so what happened if it didn't work the first time they said oh we'll just operate on her again and that was not acceptable to us because Geri's lungs which were affected meant she was a high risk under anaesthetic. So we decided to pursue the feeding orally because that again was something everybody should be able to do. It is a fundamental right and to take something like that away from a person is quite drastic. So we persevered and got help from dieticians or speech therapists and you know various support people. We continued to feed her this way.

C: We actually had support from Geri's school teacher and classroom assistants, the girl that gave her her lunch, the support from the respite care unit and at the end of the day we realised that it wasn't the people making decisions of her to have the operation, it was the people that spent time with her throughout her day in her life, they were the people that mattered because they were on the shop floor so to speak. We also felt that we agreed with the dentist for her to have her dental work done. That was a very interesting situation because when Geri's paediatrician suggested she had a gastrostomy tube there was going to be absolutely no problems whatsoever, it was going to be straightforward it was going to be a wonderful thing and then the anaesthetist that was going to be at Geri's op to have her extractions was very very concerned about Geri having an anaesthetic to the extent that the dentist had to tell him or put it in writing that he felt her quality of life would improve.

Interruption

C: Em, her quality of life would improve once she had her extractions and her fillings done but the anaesthetist was very reluctant to do this operation. The thing about that was, it was actually the dentist, the anaesthetist and [B] and I who actually worked together which is something else that I hadn't experienced with the health service before, we actually worked as a team for the same result and to the extent that I remember we were reassuring the anaesthetist that you know this was the best he would get Geri and providing something obvious didn't happen under the anaesthetic, if something did go wrong, we weren't going to be blaming anybody and the other good thing about it was the concerns that we had if Geri came out of the anaesthetic with more brain damage, this was something that did concern us because the one thing that we didn't want her to lose basically was her ability to hear. That I felt would be the death of Geri. I felt if she lost that then there was no point in her living for herself and the dentist and the anaesthetist were so considerate, they were so compassionate, they didn't have this oh everything will be fine attitude and that is why the whole operation was so successful. We were allowed to go down to the recovery room after Geri had the work done, we brought a tape with us, one of her Pavaroti tapes and so we put her music on to see how she reacted so we could actually tell the staff how she, if she was coming round from the anaesthetic OK or not and she was, all glassy eyed but gave a little smile when she heard music.

A: So they were honest with you and you had a really good relationship.

C: Yes, honest, up front, that was a very good working relationship.

A: So when did Geri have to get the nasal tube.

C: We actually moved to Dunness in 1997.

A: And then you had to move schools is that when you left.

C: Yes we had to move schools, Geri had an assessment. We actually moved into the area where we wanted, we went shopping for schools so to speak in Dunness so we moved into the area of the school that we wanted Geri to go to. Geri had an assessment prior to going into the school which was quite successful so we moved in the August and Geri started the school in the September and that was a very different set up from the school she went to in Middleburgh. Actually in her class she had roughly about 7 or 8 students but her teacher was a qualified nurse and then the classroom assistants and there was...

A: Was she qualified as a teacher as well?

C: Yes.

R: She had a nursing background and also the difference between Deping House school and schools say in England was they did an outreach service because unfortunately after Geri had been at school for about 6 weeks she became quite ill and she was put on antibiotics by the GP and we kept her at home and tried to look after her at home. So her teacher came out to the house to help us, she gave us a break, she actually fed her for us.

C: Or if we wanted to go shopping.

R: We could have gone out yes.

C: I just want to say for the tape, this is the truth because it sounds like a made up story but this is true.

R: But after about a week to ten days Geri wasn't getting any better and it was agreed that she would went into hospital and the teacher even visited Geri in hospital.

A: So they brought the services to you because Geri couldn't go to them in a way really.

(Murmurs of agreement from Catherine and Roger)

R: Although the outreach service was, it was part of their set up because what they do in Ireland is these children with profound and multiple disabilities and complex health needs, they would be known to this organisation. This organisation is a hospitaler order who have schools under their wing as well as other support groups but they would be aware of a child at birth like Geri and would support the family and the child from that stage through the early years with this outreach service and then they would go to a school when they were four or five and they would go through school and then when they turn 18 there is a smooth transition into adult services.

C: This is true.

R: So they take on board...

A: All aspects...

R: ...in the child's life from birth to adult services.

A: And that's a voluntary organisation?

C: That organisation is...

A: It's not state run.

C: It is the hostel order of St John Agauld so it has got religious connections. The order of St John Agauld would have set out to help years and years and years ago in Ireland when babies were born with disabilities, they would try and help families as much as they could and it has just basically grown from there and what they do is, they actually have told us they feel that they are very behind the times and they are very aware that they have to you know, get up to date so they look at, you know they... some of them go to different countries to see what they are doing in America, England to actually see what they can do, if they can improve services but we felt that they were in a lot of ways, they were far more advanced then England. That was before we actually came to Fogart.

R: And on top of that the school and the outreach service, the adult service, they offered respite care. They had a unit five miles away from the school where Geri did go on a few occasions but as we were leaving two years later they were in the process of building the respite care unit in the grounds of the school for ten.

C: Ten beds, this is true.

R: Ten adults. So they seemed to have both the whole thing wrapped up.

A: From birth right through to adulthood they had seemless service you would say.

R: Yes.

C: And the young people, because the school would have a variety of people with learning disabilities, children and adults and the whole service took in, say people with Down's syndrome, they would work in the garden centre, they would work in the restaurant or the coffee shop.

A: And were these open to the public as well.

C: The garden centre would be open to the public.

R: The dining room in the school was obviously for the staff and the students.

C: So the staff and students would eat in the same area. They had, I felt they seemed to have as well, they seemed to show, the attitude was very much respect for the children, the young adults and parents. The whole service, it was like, we are there for you which was such a shock, I mean I didn't believe you know when the school nurse came to the house when Geri was ill and she came and I said to her I'll get you a cup of tea or coffee and she said you do that and she took Geri from me and I went and made a cup of coffee and I came through and she said right well if you need to go shopping you go, I'll look after her. And there would be... any things that happened at the school, we went to a Christmas service, a carol service at the school the first Christmas and it was absolutely beautiful. All the children were there that could be there and the parents and the staff in the school and then there would be the priests and some nuns but then there would be people from different religions who would be invited in and there would be you know the huge Christmas tree and the candles and...

R: The choir from another girls' school would come and sing.

A: So they involved the community as well. Do you feel...

C: Very involved and then afterwards people would go and have tea and coffee and punch and Christmas cake and mince pies and it was very friendly, it was just the whole system, the whole system seemed very geared up to giving a very very good service not just to the young people and the children but to the parents as well. Very helpful.

A: And was that, that was your first experience of them maybe, you would say maybe meeting your child's needs Geri's needs but also meeting your family's needs as well.

R: Yes.

C: Oh definitely although we had experienced, you know in Middleburgh the teachers were good that sort of thing, this was a very different, a totally different set up which was actually, you felt that you had people that, this might sound a bit strange or funny but you actually had people on your side, people who really understood what it was like for you.

R: I could let you have a copy of a report from Deping House school for Geri, July 1999. Tell you the sort of things they did with her at school.

C: Also can I say at this point they do have attached to the whole service, right, a hospice and when Geri did become too ill to be fed orally we didn't really want Geri to go into hospital and we were offered the service of Sarah House which is a hospice for Geri to go there. Initially we wanted Geri, the plan was that Geri would be tube fed in the hospice Monday to Friday and then we would have her home at the week-end.

R: I have got a letter here that I can let you have a copy of with details of that.

C: So she, so we had this service, so they have this service for if your children become very ill they can go on to the hospice or some children that are too ill to go to school would go to this hospice. They live at home they will actually go to the hospice say Monday to Friday 9.00 to 4 o'clock or something and they open up at the week-ends to give the parents a holiday.

A: Sounds great.

C: And this is why we are going to Dunness for a wedding in a few weeks and we have been offered accommodation at the hospice for [B] and I and for Geri and we have been told by the person running the hospice that if we want to we could go away for a day or two ourselves to get a break and they will look after Geri as they were looking forward to seeing her.

A: So they do that for people who are no longer using their service on a daily basis too.

C: Yes, doesn't sound true does it Anne?

A: (laughs)

R: Geri has a lot to do with it though.

C: Och he's prejudiced. You are OK for time?

A: Yes, do you want to stop or do you want to continue?

R: Only if you want a drink.

Tape turned off

Tape turned on

A: OK then so you moved from Dunness to Fogart and did you have any trouble finding school provision for Geri when you moved.

C: Yes. We actually moved to Deptford on a temporary basis. We were there for...

R: Three months.

C: About three months but nobody, we did actually get a district nurse and we registered Geri with a GP, that sort of thing. But I managed to phone an educational psychologist, somebody that we had spoken to in the past and he said that legally Geri was entitled to go to school even if it was on a temporary basis until we moved. And that did cause a lot of problems because we actually phoned the local school and we had a problem just getting an appointment. The head teacher at the school did not want Geri to be in the meeting with us. Asked if we could get a baby sitter and well we had just arrived in Fogart anyway so we didn't know about, if they did have services so we couldn't have got anybody to help. Roger's mum is very elderly so she couldn't have looked after her while we were in the meeting so the three of us just went to the meeting. The attitude seemed to be it was an inconvenience and the if word kept being used quite a lot. If Geri was to go to that school, if we were to do this, if we were to do that and we felt a lot of obstacles were being put in our way like transport to and from the school, they have to put on a nurse on the transport to take Geri down to the school. This school was only about five, ten minutes from your mother's house? (Roger nods in agreement) and we even suggested that we could take, if it caused that much a problem we would take her to school and pick her up. There was talk of maybe her not even going to school full time it would be part time and then it was suggested that the assistant head took us round to possibly one or two of the classrooms that Geri might go to but she wasn't to tell anybody who we were. And...

A: And did she say why.

C: Oh no. And we then went, after we left that meeting we then had an appointment with an osteopath outside Edmington but when we left that school meeting we both were feeling very, we felt the whole situation was very negative and we then came to the conclusion ourselves that we didn't want Geri to go to that school because if that was the head teacher's attitude towards the children, the staff and the parents, then we did feel that maybe Geri would not be given the proper treatment she should get if she went to the school although it would be temporary.

Tape switched off
Tape switched on

C: So on our way to Edmington we were just discussing what had happened at the meeting and we both agreed that we just wouldn't have been happy for Geri to go there even on a temporary basis. We wanted her to go in as far as for her to be at school, to meet with other children, to have all the facilities but I thought, I was very surprised with the head teacher's attitude, very very surprised and I think at the end of it we decided it was probably because she just didn't want the upheaval because it would be on a temporary basis. We have never, after two years she has never notified us. We were told she would let us know whether Geri could go to that school and still after two years she still has never told us she could go or not. I then did get a call because time was passing by and I was told that it would be a good idea to get a social worker to help us get Geri in a school, that was very difficult because of the way, when you phone the social work office, you don't get to speak to somebody who can... your first line is...

R: The duty social worker that is on to answer the calls but that is not necessarily the social worker who would be assigned to your case.

C: That's right. And there was a bit of confusion about what office numbers to ring, that sort of thing and when we did decide that we wanted to go and live in Corton then we drove round and we had a look and then we found that the local school would be

Kogan. I think we then decided to see if we could make an appointment with the school and look at what it was like because we didn't actually want Geri to go a school if we didn't like it. I think we ourselves, we arranged to go to the school. We met up with the head teacher who had a very different attitude. We had Geri with us. She let Geri go into the cookery class while we were in the meeting then the children were being taken into the playground and a member of staff came and told us they were going out would we be happy for Geri to go out into the playground and we said yes. And then we had the problem of arranging for Geri to go to Kogan] school while we were still in Corton... while we were still in Deptford.

R: They agreed to take Geri and we decided that we would live in Corton.

C: But what we actually... what the problem was that nothing was being done to help us find a school for Geri you know to get her into the school and I think what happened was it was a build up of what was going on but I remember one day getting very angry on the phone with somebody and as time was going by nothing was being done and then I got very angry on the phone with somebody and then we were told that Geri would go to Kogan school in Corton. We met up with the head teacher in Corton and we then discovered that the problem was that Geri could be taken by school bus to Corton from

Deptford every day. But the school couldn't pick her up and take her back to Dunning.

A: Why was that?

R: Just not enough or the timings would be unsuitable.

C: It just wasn't going to happen so we had a meeting with the head teacher and she suggested, one of her suggestions was that we actually took Geri to school ourselves and picked her up. We would be paid by Fogart Council.

R: We had a parental contract with Fogart Council to transport Geri to and from school at so much a month until we were settled in a property in Corton which is what we did but that only lasted two, three weeks...

C: So we just felt that if we didn't take Geri to school Geri would not go to school and that was our first experience, we have never really had problems with education in Geri's life in the past and that was the first time we have had these problems with education and I was very very disappointed but once Geri got into the school then we were quite happy. We were happy, it was like we will have to cope with every stage that happens. The school is a very small school. It doesn't have the set up like the schools that she has been in prior to this school but we felt that it was better than nothing. The staff were very nice, the staff had very good communication. Well actually that is not true, there was a lot of problems when she started with her direct school teacher because they had never had a child in a wheelchair. They hadn't had a child in a wheelchair for quite a number of years and all the other children are able bodied and I think the teacher wanted Geri to fit in with her timetable which to a certain extent is understandable but that didn't always work out because of Geri's needs. Also going back to Geri starting the school, they never had a school nurse in the school and because of Geri's health needs they had to get a school nurse. Now the head teacher had been given this child out of the blue and she then had to quickly find a school nurse.

A: And does the school nurse stay there all the time Geri is at the school.

C: Yes. So she managed... she was very lucky, she managed to get a school nurse but it would only be on a temporary basis from I think November time to the end of term.

R: For the first term.

C: The first term and then she obviously would then have to look and try and get another school nurse. She had actually always felt she should have had a school nurse anyway because although the other children are able bodied, they do have health needs. She was never allocated a school nurse.

A: When you say able bodied do you mean more able than Geri, they weren't...

R: They were ambulant.

C: Ambulant, that's the word.

A: But they still needed a special school provision.

C: Yes and luckily through word of mouth the school nurse knew somebody else who was looking for a job who was also a nurse, had a nursing background so she took over from where the first school nurse dropped off so we were very lucky that that happened. The problem there is that if ever the school nurse is ill Geri can't go to school. The school nurse, she has been ill herself and she has had problems within her family where she has had to take time off work and...

R: That is almost acceptable because you can never predict when you are going to be ill but there was another occasion where the school nurse's mother was going into hospital for an operation and she asked for time off to be with her. Now that was, that appointment for the operation was weeks ahead and still there was no replacement for the school nurse on that occasion. I did register my concern, displeasure with that but it has not changed. Geri couldn't go to school a couple of weeks ago because the school nurse was ill this time, em but no replacement.

C: I think that puts a lot of pressure on the nurse herself, the fact that she cannot have time off, she cannot be ill during school term and I don't think that is acceptable. I would also like to go back to the fact that the staff, although Geri's school teacher at the time I think found it very difficult fitting Geri in, after the first year Geri then moved on to a different class, the senior class and the actual school teacher wasn't happy with that, she wanted to keep her in her class. Eventually she had got so used to her and got to know her quite well so had objected to her moving out of her class.

A: And how did you find the activities they provided for her, were they the same high level and variety as she had been accustomed to.

R: Well at the outset it looked very promising. The curriculum included swimming and horse riding, recreational pursuits but the horse riding we eventually discovered was, Geri was going to be excluded from that because of the fact that the riding school didn't have a hoist to get Geri on to the horse and as far as the swimming was concerned there weren't enough helpers and possibly the swimming pool itself wasn't heated to a level that Geri could cope with but she did go out on various, four days out of five which we felt happy with because it acclimatised Geri I think to the weather in

Scotland. So she began to enjoy being out in the wind and feeling the rain on her face. She had not liked those things before. Again there were obviously certain difficulties with where they could take Geri, for instance they couldn't take her on to the beach at Sandcoats because of her wheelchair but to all intents and purposes she did go out.

C: I think they tried to fit her in everything else that the other children were getting.

A: And did you feel they were maintaining the skills that she had already and tried to develop them.

C: Not in her first year, no. But I think because we had such a problem with finding a school for Geri, with trying to get a social worker, with finding somewhere to live, it was like well we liked the atmosphere in the school, we liked the head teacher, her attitude, the staff appeared to be very nice, communication but we felt well we'll let her go there and see how we get on so really I don't think, her first year was very different. She did, as Roger said, she did end up thoroughly enjoying going out so in one way she gained that but in another way she didn't have some of the skills that she would have had prior to that I think possibly got slightly lost for want of a better word.

A: And did you have, did Geri have physiotherapy and speech therapy. Did all the therapists visit the school.

R: Physiotherapy was included, she would get daily physiotherapy from the school nurse.

C: That was something that we initiated.

R: So the physiotherapist from the local hospital trained up the school nurse to be able to do this physio on a daily basis and the physiotherapist then would come in once a week but she also at our request visited Geri during school holidays if she could so Geri wasn't missing out her physio during school holidays.

C: She didn't have a speech therapist.

A: No.

C: No, there wasn't any other therapy.

A: And had she had that previously at her other schools, input from the speech therapist.

R: Yes, there was one allocated to the school, peripatetic therapist.

A: Right then could we move on to the transition stage.

C: Can I just say at this point, when Geri did move into her present class things did change because of, obviously her teacher was different and he had a different attitude and he would then do more hands on with Geri. He started to use different...

R: Pieces of equipment.

C: ...pieces of equipment to get her to do certain things and also what happened was that Geri then was registered as officially blind so somebody from the blind society went into the school to look at ways...

R: No she was actually from the visual impairment department of the education authority.

C: I can give you that name and address if you want... so she went into the school, liased with the school teacher, the school nurse, to work out a programme for Geri and that has been very very successful so you could see the difference in Geri when she moved into the different class.

R: And we have a report from her you are welcome to copy.

A: OK then that's fine. So is that everything you want to tell me about the school.

C: Yes.

R: Basically there was only two classes, the juniors and the seniors, she was in the juniors for a year and seniors for a year.

C: But we were actually, because of all the problems we had we were actually happy with her there although we were aware that there was a lot of activities she wasn't actually getting.

A: That she had previously.

C: Yes.

A: OK, now you said when you were in Dunness that there was provision for Geri when she became an adult and it was a sort of just moving on to the next stage, it was like a seamless process, there was no formal assessment of her needs and the provision was there for her. So when you came to this country you would start to get involved in the Future Needs Assessment process. So how old was Geri then when you started.

C: That is very interesting because as soon as Geri went to start going to Kogan school she went the following year she went November, about November 97 and the beginning of the following year Geri's head teacher told us that we had to start very seriously at looking at Geri when she left school and where she was going to go.

A: And how old was she then?

C: Geri would have been...

R: Last year Geri would have been 18, in the year 2000.

C: So when she told us she would have been about seventeen and a half.

A: That was quite soon after you went to the school.

C: Very soon, she was very adamant that that was something that was very important, it was vital that we had to start looking round and to take it very very seriously because from her past experience there had been major problems. I don't think we actually believed at that time how serious the whole thing was in as far as the complete lack of provision and the complete lack of interest from services involved at actually trying to provide provision for your child and when that did happen we were shocked and amazed at the lack of support.

A: Did anyone tell you about the Future Needs Assessment process and what was going to happen and who would be at the meetings, did they prepare you for that beforehand.

R: Yes

C: Well the head teacher would have mentioned that, yes.

A: So can you think about the very first meeting you went to, to discuss the future needs of Geri and can you tell me about that.

C: The first meeting would have been last year, Geri was 18, we would have had the first meeting last year.

R: I think so I can't find the paperwork for that but she almost had an entrance meeting merged with her leavers meeting because of her age. The first formal meeting that I have a record of was January this year because Geri was due to leave in June of 2001. That was the first formal meeting.

A: And who attended.

C: Well actually there was, the meeting last year we will find but we were told, it was hinted last year, but we were very concerned because we assumed Geri would have to leave school when she was 18 and it was hinted to us that no she probably could stay on for another year but nothing was being put in writing so as far as we were concerned it was hinted to us by a social worker and it was hinted to us by the head teacher but nothing was put in writing so up until Geri was due to leave, up until Geri was going to be 18 we didn't know whether or not she was going to have to leave school.

A: You didn't know you can apply for an extension.

C: No I didn't know actually you could apply for an extension.

A: You can ask for it to be considered.

C: We did ask but we didn't know that we could officially apply for an extension.

A: And they could stay on till they were 19.

C: We didn't know we could do that but as time was passing by the head teacher was saying well you know the chances are she will stay on because there was no provision for her and we felt we were given a reprieve because there had been so much going on at the moment... we thought well if she could get another year then it gives us a bit more space to work something out for her.

A: So how did you feel at these meetings, was there lots of professionals there.

R: Yes, psychologist, school medical officer, physiotherapist, social work were represented.

C: Social worker and the social worker's manager.

End of tape 1
Tape 2

C: Well I actually felt because there was so many people at the meeting that everything would be, Geri's future would be discussed and people would, they would all have their input to help find provision for Geri when she left school. I didn't think that we would be in a situation where the first... I didn't expect after the first meeting we had that people would actually go away and appear to do absolutely nothing about it because when we then had the second meeting which was January 2001.

R: No there was an earlier meeting, last June 2000 which was a follow on from Geri's entrance meeting in January 2000 and this was (reads from minutes of meeting) to deal with two outstanding areas, assessment and forward planning and the timescale being a short one, the group moved on to future needs assessment transition planning meeting.... recommendations at that June meeting, so that was the first meeting that was arranged to discuss forward planning. In January 2001 we had a formal meeting with all the agencies involved which led to a second meeting in March 2001 and from that meeting not as a consequence of anyone's actions at that meeting, but because we actually were involved in finding a day placement for Geri because no-one from the agencies was able to come up with anything so there was no further meeting after the March 2000 meeting, it was all down to parent pressure on social work and our own sort of...

C: Shopping.

R: ...shopping for want of a better word and also pressure from Fogart Carers that led to a day placement being offered to Geri in July 2001.

A: So they didn't suggest places that you could go and visit that might be suitable for Geri.

C: No in actual fact the meeting that was held in January. It would appear that nothing had been done between that meeting and the one prior to that to the extent that I felt, I felt very, I could actually feel myself getting very angry with the fact that all of these so called professional people were coming to these meetings and they were as far as I was concerned, they were of no value to Geri's future whatsoever. There was people from education, there was a psychologist who was actually taking notes. She gave no input. Nobody seemed to know, it all seemed to be very vague. The only people who seemed to be very strongly aware that Geri needed to go on to a day provision was Geri's head school teacher, her classroom teacher and her parents.

A: Did you feel the other people involved didn't have a good knowledge of Geri and her needs.

C: No I think they, I personally think they really really weren't interested. They were at the meeting because that is what you do, you go to these meetings and I think that is in some job description that that is what happens but I have to say there was, although they might try and appear to be concerned there wasn't the determination and the concerns that the head teacher, the teacher and the parents showed at these meetings.

A: So at the next meeting did you feel any further forward.

C: The only, well actually as parents in the next meeting which was March this year, we as parents went to the meeting feeling very enthusiastic because we had done our shopping and we had been told by social services that Geri could probably have the service which would mean two carers would come into the house, take her out every day in Geri's car and that would be Geri's day care provision.

A: And how did you feel about that?

C: Angry and I laughed and I said why would Geri want to have that as day care provision when we can do that any day of the week. That is not day care provision because Geri will need therapies. We actually, what we were looking for for Geri was for Geri to go on somewhere else and it would be like further education. We didn't want her to go to a day care centre where she would sit in her chair listening to her music all day because that is not what we want for Geri. We didn't want someone to take Geri out in the car to take her round the shops and sit in coffee mall all day because that is not what we wanted for Geri. And as I say I think out of routine, I don't know what it is but these professional people were in those meetings twice, three times there was a meeting and they gave nothing of value to the meetings. The last meeting we went to we felt very optimistic because through another family we found out there was a day care centre and we managed off the record or unofficially to get a meeting to go and look at the day care centre and when we did go and have a look round and we spoke to a member of staff we were very happy and we felt Geri would be ideally suited to this place. The plus side was we found that there was space available, there was transport available. We were anxious how we told the social worker because apart from the fact that we weren't being offered very much for Geri there always seemed to be the cost involved, so when we told the social worker about this find she obviously was not as enthusiastic and as happy as we were and the other thing was that she had never heard of the place and her managers had never heard of the place so whereas we thought we were doing their job and it would save them a lot of leg work and that, it didn't seem to be the case.

A: And this provision was actually funded by the social work department?

C: Yes.

R: Yes

A: So you would have expected it to be known to them.

C: I expected it to be known but I have to say the social worker that has been allocated to our daughter does not have any background experience in looking after a young adult like Geri.

A: Then you said too, her manager didn't seem to know about the provision either.

C: That's right, no her managers so that's, that would be a few managers.

A: So maybe at a higher level they didn't, that was the impression you got.

C: That is what we were being told. We don't know if that was, you see we personally feel that we are being told nothing about anything that is or is not available so we are not being told what Geri is entitled to have, what her needs... what suits her needs and then being told well we can't do that because we don't have the money. We just have not been told anything, so we are the ones that are having to do the shopping ourselves. So when we went back to Geri's last meeting, when we went back to the last meeting we were very optimistic because we had found this place, we had actually also found, we had heard of another place that was linked to the RNIB, but both day services that we felt were ideally suited to Geri were met very negatively by the social worker's manager who was at the meeting. The social worker wasn't there because she was ill. She had a very negative attitude towards it.

A: Did she say oh, I have heard about these places or did she take it as a surprise when you mentioned these provisions.

C: The RNIB we were being told that it wasn't a day service and we were actually, we were actually left feeling a little bit confused because we had actually been to the RNIB, we had spoken to one of the managers who had appeared to be very happy to...

R: Well he had written to us saying that Geri would be welcome to go there. However, there was no nursing support for Geri so we had to investigate that further but he saw no reason why Geri couldn't attend that service.

C: The RNIB. The other service was seemed to be negativity coming from the social work manager and the Lemington Court day centre.

R: Well what she said was that there was one place available at Lemington Court. (Reads from letter) At present the needs of Geri and one other child were being looked at with a view to either giving one or other a full time place or both two to three day placement. The social worker's manager was not in a position to be able to provide a timescale for the decision but told us that we would be informed as soon as possible but as we didn't hear anything for perhaps two to three weeks, we decided to push things along and we wrote, sorry we contacted Fogart Carers and asked for advice and the manager of Fogart Carers was very helpful and agreed to prepare a letter to send to social work requesting some answers and lo and behold about ten days later Geri's transition social worker rang up to say that she had a place at Lemington Court but there was a problem with transport and we said oh, why is that. She was under the impression that we would be taking Geri to her day service and collecting her from her day service and we said no, that's not possible so she said well I think that is how it is going to be but I will have to find out a bit more about that.

A: And how far away is this day service?

R: It is 30 miles from where we live so a round trip of 60 miles a day is what it would take however she went off and enquired further and got back to me the same day to say that it was all sorted. Lemington Court had its own transport and they would be collecting Geri.

C: Actually at the last meeting the social worker manager had appeared to be very negative about this place and at one point had said do you not think it is a bit far for Geri to travel and the school teacher said I am sure Mr and Mrs Hobson would be very happy for a service for Geri a lot more local to home but they don't have a choice. Also there didn't seem to be the need for a service to be set up for Geri that was acceptable for her needs and her parents' needs. There didn't seem to be any hurry whatsoever. There seemed to be no time scale set for anything and when we were told that there was a place and the place would have to be applied for, we weren't even told when the place would be applied for and what the procedures would be, we had to push to find out how that would be. We also explained to the social worker, due to the fact that there was a possibility that that other child would get the place at the day centre we then knew that we had to look at alternatives. We wanted, when Geri's case went forward to the panel we wanted the person putting the case forward to say for Geri to go to Lemington Court or the RNIB and if that was not possible she could go a few days to Lemington Court and a few days to the RNIB. Now I think from my understanding social services don't work that way, I think that is too confusing for them. You either put one place forward or the other place, you cannot have an alternative. We wanted them to be aware of the alternative so that the day they were putting the case forward, we just didn't want time to be wasted, we wanted the case to go forward, we wanted to know whether it was acceptable or not so that we knew what was going to happen for Geri but as I say the social services were in no hurry to resolve the situation and we feel what resolved the situation was the letter going from Fogart Carers.

A: So it was them becoming involved that you feel hurried the process on.

C: Hurried the process on because the interesting thing was everything appeared, the social worker then appeared to understand our concerns and she did actually at one point say to us that she hoped to have good news, she was ringing with good news, she didn't say what it was but we assumed that it meant Geri probably had her place and then all of a sudden everything went very quiet and after a week I said to my husband that I thought something was wrong and lo and behold it was then suggested that Geri was assessed to go to another place that was available in Fogart although prior to that we were told that there wasn't a place available. Geri was then assessed for that place and then we were told that she couldn't go there because they couldn't meet her needs and then of course...

R: Diamond

C: No that was em, Gerald House... in saying that we were initially, when we were offered the two carers coming to the house, what social services had done they had actually gone to Diamond day care service in Corton and asked for costings for Geri to go there. Now the actual building itself has not got the facilities for Geri, changing facilities, that sort of thing. The group that actually attend Diamond are a lot older than Geri. There is quite a lot of them that are able bodied [have learning disabilities] and when I say older than Geri you can get people of 50 and 60 years of age going there so that in itself is not acceptable for Geri and I was absolutely disgusted that they would even consider sending her there so that was one of the options for them but not for us.

A: So now you have been offered this place at Lemington Court, have they put any procedures or processes in place to ensure that it is a smooth transition period.

C: Well...

R: Yes, on the face of it yes, they agreed that the key worker assigned to Geri would attend the school once or twice to get to know Geri then Geri would be taken to Lemington Court by her parents once or twice for a couple of hours and we would stay with her. Then if everyone was happy with that then the transport would pick up Geri for one day, would take her in for one day and then that would develop into two days a week, possibly three days the next week and then go full time, so there was an agreed initiation if you like in the service. However, after the key worker attended the school on the first occasion she noted that Geri was having suction and she reported back to the unit manager who called me and said that they weren't aware that Geri needed suctioned. They had no member of staff trained to do that procedure, was it possible that Geri could have her suction before she left for

Lemington Court in the morning. So I said no it is not possible, she could need it any time. Ah right well I will have to get back to you. So this was an anxious time because although we felt Geri was ready and we were ready and the unit was ready to receive Geri she might not now go. I can't remember if, I think I rang in about ten days time to see what happened with regard to giving the suction. Nothing had been put in place, no training had been arranged although they were looking at it and finding someone to do the training for that procedure. Having said that the key worker went back for a second visit to Geri's school and Geri did not have suction that day whatsoever so you just don't know but obviously you have to assume that she is going to need it. The problem was getting training but I was contacted again to say that could Geri go in for a visit for an afternoon and we would stay with her which we did so Geri had a few hours and one afternoon at Lemington Court. The following week she visited one of the units that give her music therapy and the week after that she would go in for the staff to be given suction training which has now been arranged. So everything now seems to be resolved albeit that no-one has actually given Geri any suction at the unit. One thing that was a bit of a contradiction was the fact that the unit manager who was trained as a nurse could have given Geri suction but as she was not employed currently as a nurse she wouldn't be allowed to, which to us just...

C: It's red tape.

A: So are you now confident that Geri will go there, is it after the summer holidays. Is that the timescale?

C: Well the interesting thing is we have had nothing in writing officially. Everybody, like the social worker is aware of it, the school is aware of it, we are aware of it and the unit is aware of it so we are assuming she will go.

A: But you have had nothing officially.

C: We have had nothing officially in writing to say that Geri has been accepted. The other thing is that we have found out through another parent that the unit was opened as a pilot project for three years and it has just renewed their second block of three years so that means that in three years time the young people who go there don't know whether or not they can go again for another three years and on top of that they can only stay there until they are 25 anyway and then they will have to move on somewhere else so when they reach 20 or coming up to 25 it means their parents will have to go through the same procedure if not worse.

A: Because is there no provision then.

C: No there is absolutely no provision at all whatsoever. I feel that in Fogart as young people there is nothing available, absolutely nothing.

R: Certainly there was nothing available in [NEF] which is where we live. This day service is in [WF]. Now we have written to our local MSP asking him to look into this problem, the fact that there is nothing locally for Geri and I have also expressed the concerns that in possibly three years time and certainly when Geri is 25, if she survives, then we have to look again for another day service. So it's never ending.

A: You fear the same thing is going to happen again.

C: Yes from our experience, from the past experience we have we would say definitely the same thing will happen again because...

R: The hope was that the RNIB service would...

Tape turned off

R: So we were looking at the RNIB day service to be able to take Geri and keep her for the rest of her life therefore we wouldn't need to source another service or ask a social worker to do this but it appears that the day service is only for assessment and rehabilitation i.e. it is not a day service it is for assessment and rehabilitation but have no nursing support anyway but that we felt was not a negative, it was being looked at by the unit manager but since Geri has been accepted into Lemington Court there has been no further consultation with the RNIB.

Having said that we would like to try and get Geri in even if it was just one day a week to the RNIB so we will approach the social worker or the RNIB directly to ask if this is possible.

A: So you have obviously had a lot of difficulties through this transition stage so how would you say that has affected you.

C: It is very stressful, extremely stressful. It is to the extent that I feel everything that we have had to deal with for Geri since moving into this part or moving to Fogart has been a problem to the extent that I have regretted moving here. When it comes to her needs, I have regretted moving here because it has been very stressful, very worrying and I think what a lot of people don't seem to understand in these high positions that are supposed to be providing the service is that my daughter is ill, she is ill and she is actually, her life expectancy is not that long so we have to look after her every day 24 hour days a week. She can become ill at any time so this is the last thing we need to worry about. We should be able to spend enjoyable time with her, quality time with her and to be less stressed but we are not, we are extremely stressed and worried and that is why I feel the services just don't support us in any way whatsoever.

A: Do you feel the same?

R: Yes I felt that we haven't been able to rely on services set up supposedly to help people who couldn't help themselves and I don't know why I think that coming home [to Fogart] should have made this easy because it certainly has not and it is just I suppose you know you feel that you know if you are home you would get support and help from the local authorities but it has just not been the case. I'm very stressed, unable to work at the moment because everything that we need for Geri for her to be able to continue in the happy frame of mind and a level of health that she is now enjoying, it takes up so much time that we or I don't seem to have been able to... I can't think of anything else, especially work at this particular moment.

A: So is there anything else you would like to say about this transition period. I think we have covered all the points, is there anything else you would like to add.

So is there anything else you would like to say about the transition time.

C: Well I think in relation to Geri's transition, well actually in relation to anything to do with Geri's needs, the more health needs that you have in Fogart the less help and support you get and it is at a time like that you need as much help as possible.

A: So do you feel that they have been excluded from certain provision because of their health needs.

C: No I think Geri's excluded from having a life. It is like she is being excluded from the society around her.

R: Yes but it is because of her health needs so I would say yes to Anne's question. The day services that have been offered and I am only talking two or three have not had the health input to be able to send Geri to one of those services.

A: So she couldn't go there because they couldn't deal with her medical needs.

R: Even the present, even the day service that she has been allocated to, even they have a problem with suction and that will be resolved but the other problem with regard to replacing an NG tube if it came out accidentally while she was at the day service, there is no-one on the premises that could change that which will mean a call to us so we would have to go down if we were available to change it or if we weren't available, taking Geri to a hospital who are willing to change it because not all hospitals might want to do that procedure or have anyone available on shift to do that procedure so it may not be the nearest hospital that she would be taken to but a hospital that was prepared to do a replacement NG tube. So where we feel that the day service will be good for her emotional and educational needs, it certainly is still not going to be able to cope with her health needs 100%.

C: And the interesting thing is that as parents we are expected to do this and as parents we do it and we are not trained nurses and we are just parents who have been given this role. But I think red tape is saying that the people who carry out these procedures either have to have nursing training whereas we as parents don't have nursing training and we carry out the procedures.

A: Is that it. Right, well the next bit is about Geri's current provision but as she hasn't started Lemington Court yet we will just leave that (Catherine agrees) but at the moment you feel quite confident they are going to meet as Roger said her emotional, educational, physical needs, her social needs as well.

C: Yes.

A: But they can't meet her medical needs 100%.

C: No they can't. The only other thing that we would like to see and as we said earlier on we will try and get is for Geri to possibly spend some time at the RNIB whether she goes herself from Lemington Court or whether the group go as sort of on a day or half a day and they all actually go for the facilities at the RNIB but that's something that we will look into.

A: OK then, so the last bit that I would like to ask you about. What is your hopes and dreams for Geri's future.

C: We want Geri to be very happy. We want her to have a very full life. We want her to meet lots of people, we want her to be highly stimulated. We want her to have a good day centre, we would like Geri to go to a centre that we thought was suitable for Geri's needs for the rest of her life. We would like Geri to have a social life so that would mean respite care. We would like Geri to have holidays. We would like Geri to, wherever she went and the people that she was with, we would like them to enjoy her company and not be afraid of her and we would like the help and support that we need for Geri to have the life that we want her to have.

A: Anything to add or are you quite happy with that. (looks at Roger)

R: Quite happy with that.

A: Is there anything else you want to say.

C: Good luck.

Tape turned off

Interview with Joyce

Pseudonym for interviewee: Joyce (J)

Cities, places and names described in the interview have been changed in the transcript in order to protect the identity of the interviewee.

Name of interviewer: Anne (A)

Date of interview: 29.08.01

Time: 11.30-12.28

Setting: Anne's home

Joyce is a full-time carer for her daughter, Kylie. The interview took place in my house. We were sitting in my dining room with the tape recorder placed between us on the dining room table. Joyce and I met at a physiotherapy clinic when our daughters were six months old. Although not in regular contact, we meet when attending meetings about the welfare of our daughters. I asked her if she would be interested in doing an interview with me. She agreed.

A: Right so would you like to tell me about yourself and your family.

J: OK. Myself, Joyce, Bobby, my husband and two daughters.

A: And what's their names.

J: Katrina the oldest, she's 23 and Kylie is the youngest who is 21.

A: And Kylie is the one who has disabilities.

J: Disabilities.

A: Could you tell me then about her disabilities, what is the label they have been given?

J: She has been labelled with mentally and physically handicapped with cerebral palsy and epilepsy.

A: OK. So what caused her to have these disabilities?

J: Well to the best of my knowledge I had pre-eclampsia and toxaemia when I was pregnant. Also she was lying transversely and forming transversely so with the pre-eclampsia and toxaemia the placenta had stopped functioning, starved of oxygen, starved of food and consequently born three weeks early by emergency caesarean and then nine months later diagnosed as having all these problems.

A: OK then so what physical disabilities has she got?

J: Physically she has scoliosis of the spine, she has dislocated hips, she has club feed and I think that is about it really, physically handicapped, that says it mhm.

A: So what is she able to do then.

J: She is able to bunny hop around on the floor. She could manage up and down a couple of steps as we have got a dropped living room and then you know, it's a what is it you call it...

A: A sunken area.

J: Aye, aye so she comes up and down the two stairs and if she wants you, she can crawl to you and depending on which side, she can sit up and get up on the couch on her left hand side, that's her strong side and basically she is mobile, she has got mobility on her knees in the sense that it lets her go back and forth into any room that she wants to be in. Likes if the washing machine is on and she wants to go into the kitchen she can then proceed to do it on her own or into what we call Kylie's corner with certain toys that she has, plays with. So she has got the mobility that she can keep herself occupied and get from A to B if she needs to be.

A: So she has got a degree of independence.

J: Aye, independence that way.

A: So what do you mean by bunny hopping?

J: Em it's not crawling, it's the fact that she really just sits on the knees and then puts her hands out...

A: Rolls herself along.

J: Ken she actually comes off the floor aye (demonstrates by stretching her arms out in front) and that's the way she gets about.

A: Right OK then that's fine. So what are her abilities, like how does she communicate?

J: Communication with Kylie is easy I suppose when you know her. Likes of we know every movement and gesture. She is not long in letting you know if she wants you to play with her. She will bunny hop over to you, pull on you to get up and she has a repertoire of games that Bobby plays with her. Day care services know her now and they know how to help interact with her. It is hard to put into words but she knows, like she will pull at you and then she will gesture a game, she'll put her hands aside like that as Bobby has taught her and clap to one and then when he says two she brings two so interacting with games like that, with sounds, Bobby does that and he'll say no it's your turn, she does it and then shakes his hand for him to do it again. If she wants a cuddle or that she will come up and put her arm around you or a kiss or likes if Kylie's two wee nieces are about and she wants to kiss she puts her head forward and Marie has to give her a kiss so again she has got a definite level of intelligence to a certain extent that she knows what she wants but to somebody that doesn't know her, wouldn't know what the gestures would mean you know until you were telling them and they can then continue to do it like what we do.

A: So how does she indicate that she is happy or she is displeased with something?

J: Well that's easy Anne because she is always happy. If she's not happy likes if say Mary, that's my grand daughter who is 2½, if Mary is annoying her, she'll grimace her face, scrunch up her eyes and moan and duck away from her or if she sees Mary coming she flinches because she thinks Mary is going to be playing with her and annoying her. But I would say 99% of the time Kylie is always happy, very rarely do you get her moaning. But when she does then you definitely... then you know about it because she will moan or if she is not well with a chest infection, things like that, if she has got a pain she will gesture hand to the head or she will moan you know whimper.

A: You can tell.

J: So you can tell definitely her displeasing as her to pleasing you know.

A: So what level of personal care does Kylie need?

J: Oh well I would say 100%, she is totally incapable of anything, doing anything personal for herself. We have to bathe her, feed her, brush her hair, teeth, dress her, transfer her, I mean she's not bad. She will crawl if you are near her to the buggy and you will take her and support her and she will weight bear so you can get a wee bit help to transfer her onto the wheelchair or buggy but you know she needs lifted into bed, things like that so I would say definitely 100%, she can't do anything for herself.

A: What about during the night do you have to attend to her during the night?

J: No, very rarely. If she is ill obviously aye but on the whole I would say no, you put her down to bed at night and very occasionally although I will say occasionally you will have her wakening up if she is thirsty, then again it is trial and error that you go away get a drink of water, drink of milk, try her with a drink and nine times out of ten that's what she has been needing. If she refuses it which she puts her head down and her hand up and that means no, then it is obviously not thirstiness that has been wrong with her and it has just been unsettled but I would say on the whole no, she is pretty good during the night.

A: So what medical needs would you say Kylie has then.

J: Kylie's medical needs now at this time in her life I would say is only keeping the epilepsy under control and she has really been fit free for nine years now or thereabout but she is still on her anticonvulsant medicines, she is on two and she, her bowel doesn't work properly so every second day, every alternate day I myself administer a full phosphate enema to get the bowel cleaned out and then twice a year she normally takes a bad chest infection but on the whole that is the only thing that we really have any complaints about with her.

A: So do you keep rectal Vallium as a precaution?

J: I keep rectal Vallium as a precaution and make sure it is always kept in date so that there's always some in the cupboard.

A: OK so what would you say Kylie's likes and dislikes are in her hobbies, what does she like to do?

J: She loves socialising and by that I don't mean going out at night after 7 o'clock or anything, I just mean being sociable through the day time hours that she is awake till she goes to her bed, she loves in the car.

A: Do you mean like she likes people and company.

J: People, socialising with people and interacting. She loves the one to one contact that she has with people that they give her, she likes going out in the car or the day care bus if they are taking them out. She likes being out in her wheelchair. She likes television programmes such as Countdown, Blockbusters, Wheel of Fortune, Family Fortunes where you are getting all the noise activated responses, I have that on tape for her and when she is bored of a week-end when she is in the house with us I put it on and it keeps her happy and she jumps and gets all excited when she hears all the noises that she likes and playing with her dad, that is her main hobby, playing with Bobby. He does put a lot of input into her on the play side. I am the one that feeds her and gives her her enemas and brushes her teeth.

A: He does the play bits. Does she like music?

J: No. She doesn't react to music as such. She likes musical toys but that is a difference again from putting a wireless on or a CD, no she doesn't have any response to that at all. She likes the Emmerdale tune, all the soap tunes she responds to that, you will get a response out of her for that. She can be playing and Emmerdale will come on and she just stops and turns and listens and smiles.

A: That's good. Quite a few of the parents have said that.

J: Really aye.

A: It is amazing the similarities in the favourite television programmes and the soap opera themes and things like that.

J: Just some connection with them.

A: Maybe. So could you tell me about the school that Kylie went to?

J: Yes. She went from the age of 6 until she was 19½ to Ralph Harrison school in the grounds of Larchfield Hostipal in Deptford and I have nothing but praise for it, it was excellent. The input that they put into Kylie and it was top class one, right from day to the end of her time at Larchfield eh Ralph Harrison so I have no complaints about that whatsoever, always good, great input great therapy, overall it was great and the teachers and parents, one to one, you could go in any time, there was not any problems so basically that was it.

A: And they provided therapists to the school as well?

J: Yes they were all... worked in connection with the school, physios, OTs, speech therapists, they had everybody, the music, the art input aye, everybody.

A: So you felt they met all her needs then.

J: Oh definitely, definitely.

A: And there is no way you think the school provision could have been improved.

J: No, not in my experience with Kylie, no.

A: That's fine so is there anything else you want to say about the school?

J: Not really, no qualms, no qualms for anything about it, no.

A: OK then, right then we will go on to the transition stage then.

J: Yes.

A: So can you think first of all about your first future needs assessment meetings.

J: Mhm.

A: Can you say sort of what happened at them.

J: The first one was when she was 14 and we had a representative from at that time I believe from the children's team at Glendinning social work department and then everybody at school that was involved with Kylie, head teacher, physio, speech therapist, her immediate teacher in the class, myself and Bobby and it was then at that stage highlighted that the fact that they knew Kylie was going to be leaving school in the year 2000, was it 2000 aye she would have left, 2000 was last year, 1999 she left because she was 19½ right and this was then telling us at this period that they would be looking for to plan and charter out a plan of attack for Kylie leaving school and great expectations were expected after that meeting and we were led to believe that it would be nothing to expect it would be provided and asked what we wanted as a provision for Kylie and I told them there and then at other meetings for the future needs that I knew that I wasn't going to get a continuation or Ralph Harrison and basically I wish that she could have stayed at Ralph Harrison but I wanted something that gave her a continuation of the continuity that she had had from day one there from each, you know, every input from every aspect and every department and that I would still want... and swimming was always one of the highlights, things that I highlighted because Kylie loves the swimming pool and it is great therapy for her. I would say she got more out of swimming than a lot of things so right from the beginning we had put in our opinions that we wanted a continuation of something similar to what Ralph Harrison had been doing with her all the time you know and we were led to believe then when she was 14 that that wouldn't be a problem and that is what they would be working towards.

A: But then you found out that that didn't happen did you...

J: No.

A: You had problems.

J: Definitely. We had a future needs meeting every year and the last one we had was probably... She would have been 18 in the February and we would have had one round about the November time that year and the head teacher put out an invitation to everybody that should have and would have been included to the meeting and one went to social work department up in Glendinning and... or would it be, let me recap, she was 18, she would have been

17 when this meeting went on because there was nobody from the kid's social work team from Glendinning turned up, nobody came and gave their appearance because when she would be 18 it would be them that Michael was involved because Michael was at the last meeting.

A: Is he the adult social worker?

J: He was the adult social worker then and there was still nobody there from the kid's, oh there was, Hamish Lambe turned up to that one, so it was the year before when she was 17 that they realised that time was marching on here so we all turned up as the day approached and everybody was there and a Carrie Yoeman from St. Catherine's Centre was there as a representative from what they maybe thought would have been appropriate for Kylie going into their centre and the meeting went ahead with nobody from the social work department and that was, I just thought that was ignorance and atrocious actually but the meeting got off to a start and she sat and she heard everybody's input to the meeting about what they had been doing with Kylie and what we expected for Kylie and we need to get something that we could have a happy medium with. Then Carrie then introduced herself then proceeded to say that yes they could probably take Kylie, would be quite happy to take Kylie and then proceeded to say that they had calligraphy classes which she could become involved in and that they would take her down to the local... access the local café at the local church, get her used to money and handling money and you know, things like this and you maybe to look forward to one day that she would maybe go independently and stay in a flat herself which at that point I just said right excuse me I have to interrupt you here, I says, but I says have you met my daughter or our daughter because Bobby and I were there, she went no. I says well I think due to the lack of appearances from the social work department and due to the lack of you doing your homework here, I says I think it's a waste of everybody's time being here today and I am drawing this meeting to a close if that's agreeable to everybody and everybody was aye I quite agree with you so then the head teacher advised her to go down to, even Marie said are you telling me that you are here to discuss somebody and you haven't even been to meet them, no, I says well I think that you should do something about it and Marie said well I think you should go down and meet Kylie so of course we went down to the classroom, we met her, well she met her then I gave her a wee while to absorb the environment that she was in and absorb Kylie's needs and then I went to her and I says right then Carrie answer me honestly now, do you think that your centre could accommodate Kylie. She says at this moment in time no and probably never. I says thank you. So that was our meeting at 17 year old and....

A: So how did you feel about that then?

J: Oh terrible, I was so angry that the head teacher from the school put in an official complaint into them and I phoned them up and tore a strip off them and we still never, none of us got a satisfactory answer because they're just, they are needing red out up there and I have told Tony Bruce (commissioning manager for the social work department) the same.

A: So was this meeting at 17 the first time you felt disillusioned with the meetings?

J: Definitely.

A: Before that you were quite optimistic.

J: Aye, well naive I think I was, not optimistic, I think I was really naïve and...

A: That they were going to provide something.

J: That there were going to be provisions because here we were at 17 and she was going to be leaving school in a year and a half's time from there really and em I thought if St. Catherine's Centre couldn't take her, you know where and what, so our next meeting was when obviously the November and she was 18½ish then and Michael Morrison the social worker came and Hamish Lambe was there and even Michael, Kylie was Michael's first client, he had never dealt with a transition young adult coming out of education into adult services before at all so as I said to him right from the beginning Kylie is going to be your guinea pig so we'll try and get it right eh. And he was at the meeting and he was putting it on and they still had a... think Carrie Yoeman came back from the centre and then they were talking about get the care suite up and running you know, that will be the answer to it all. The care suite still in the year 2001 still hasn't had anything done about it and that was gong to be...

A: So what was the care suite?

J: It was initially talked about and it was going to be up and running for young adults leaving education, going in with profound and multiple handicaps but I am afraid it has just never got off the ground and... still, it never will as far as I am concerned, it never will.

A: Why do you think that then?

J: Because basically they are just not interested in providing, it always comes down to money but that day that Michael and I went up to see St. Catherine's Centre and we got taken into the room that was proposed, they were coming out with the plans and this was an old joiner's shop that we were in. Now we were stuck in this old joiner shop while she went away and got the plans and I says to Michael I says oh I am glad that they are thinking about taking Kylie up here (ironic voice) and he said why, I says oh they are so intelligent people.

He says what do you mean and I says well here we are in a joiner's shop with all the machinery and they have put old tins of paint lying about, I says and we have just had a guided tour of the new reception, the new conservatory with the new ceramic floor tiles where they are waiting or their new blinds to be put up. He went oh you are right, I went aye, I said but here we are and I says it is like an old garden shed so then when she came back with the plans Michael says I take it that the money is provided for this that all this cosmetic stuff is getting done first, oh yes yes and still up until then we thought that the care suite was going to be up and running but as I say 2½ years down the line and no way is that going to be up and running. Nope. So basically I felt that the future needs meetings at the school were a total and utter waste of everybody's time and the school especially, they put so much work into it, so much preparation for the meetings, took time out their days, Bobby took time off his work, I took time out of my day and the social work's involvement was absolutely and utterly ludicrous, it was a joke, it was a joke because the children's team said that it was going to be the adult social work department's job to find them placements and that was the first of the adult team, adult side of it, knowing about it and I have to say that they are nothing but a bunch of liars because we were told that it was their job to look for post... em provision for them as they were still in the education, so it came under the children's team so they are just... it's ludicrous, it's just ludicrous, they are a laugh, it's a joke.

A: So was the educational psychologist there at the meetings?

J: Aye yes.

A: And did he or she play a prominent role?

J: Yes. Yes and she said again that Kylie would benefit from the input that the school had given her along the same lines, although I never expected it because Ralph Harrison school was just something else, they were, I mean they were excellent and I always knew that I would never get a continuation of what Kylie needed but I am happy with what she has now really.

A: So you felt that the future needs assessment meetings weren't of much value to you...

J: No value.

A: ...because (1) you didn't have a sufficient input from the social work department.

J: Nope

A: And (2) a lot of people came and didn't have knowledge of Kylie and her needs you would say.

J: Exactly, exactly and as I always say that you could have 50 young adults with profound and multiple handicaps in a room at a school all leaving at the same time and I think that they thought that every one of them was gong to need the same provision. Trying to get them to understand that you had to address each individually, each of them individually and it was like talking to a brick wall. There is no way that Kylie could have went in with her problems into a place like St. Catherine's centre, no' having a care suite provided because they had everybody from stroke victims to men that were in there because they were a wee bit sexually active and there is just no way would I have handed my daughter over to that environment.

A: It wasn't a safe environment for her.

J: No. No' that they would have accepted her and not that they wanted to accept her but I mean that was what was provided and nothing else and as far as the care suite goes, that was just a lot of waffle to keep us quiet and I would defy anybody to come along and deny it.

A: So that was when she was 18½.

J: She was about 18½ at the last future needs meeting and she was leaving school the next summer so the following July which would have been 19... in the February and July leaving school so she was really 19½ when she left school.

A: So obviously they applied for an extension for her to stay on...

J: Yes and it wasn't a problem, they let her stay on. Thank God.

A: So you weren't offered any provision after talking about the suite at St. Catherine's Centre?

J: No nothing.

A: So what happened then?

J: Well I don't know if you want me to go into the fact that I went to a client's relations officer at Edmington eh Glendinning, Glendinning House, up here and got an appointment with him. He was there to hear our point of view, you know we are not happy then he in turn writes and blah blah blah and to the party involved so he was quite aghast actually, goodness sake and I says they have known from she was 14 that she was going to be leaving school and I says there is no provision. She leaves the school then I says, and then what have I been offered? This should be up and running at least six months before so they have got their transition period so the staff get to know them, they get to know this environment and I got a letter back from him to say that he had then in turn enclosed a letter in reply and it was, I told him it was the biggest lot of patronising claptrap I had ever set my eyes on and I wondered if they knew it was me they were replying to and not Kylie that I was the one that didn't have the brain damage. Oh, I says oh do you think I am going to be happy with that like Garry (client relation officer's name), no, what could I do now. Then he informed me that I could take the social work management in Kingliston to a review committee and in public in front of a committee get them to answer, which in turn I did. Which in turn Bobby and I went to and Allan Stewart (resource centre manager), Tony Bruce (commissioning officer) and Angela Hay (team leader) were there as the three sort of head of the social work management because Tony is the head of the service manager eh.

A: They were all social work managers.

J: Uhu and Allan Stewart he was really the one that dealt I would suppose with the St. Catherine's Centre. He had the most to say about it but anything that he did say was just a lot of lies and rubbish which I was then, I was able to prove at the meeting so overall I went with all my grievances and questions and they had to answer to the panel why...

A: Who was on this panel?

J: Well there was a chairwoman, there was two councillors on the panel and then somebody legally taking all the notes eh. So from the councillors to the chairperson and at the end of the day they got together and said well look we think they have done enough but or we don't think you have done enough and you are going to have to... so basically I made them be answerable to somebody else as a neutral party and get them to explain but everything that they tried to come up with was a lot of... it was just a lot of... they were contradicting themselves from one sentence to the next and I was able to prove it from one sentence to the next and every statement they came out with, I let them get the last breath of wind out and I would say right, that's wrong for a start and I had all my evidence in front of me and at one point Tony Bruce just slithered down in his chair like that (demonstrates) because he was just... he knew he had nowhere to turn. Allan Stewart up until that statement, he was still convinced and trying to convince us that the care suite was up and running and I says so one of the committee asked Allan Stewart, he says right I want to ask you something, when is the care suite going to be up and running and he couldn't answer them. Everything went quiet so I just leaned forward, I says I'll answer for you if you want, I says I'll tell you what he could tell you, I says it's never going to be opened, I says and try and deny it. Oh I really had them by the short and curlies Anne and everything and I brought them down at every avenue and he tried to or Allan, not Allan Stewart, Tony Bruce tried to get out of it by saying they didn't know how many young adults were leaving school and we just says excuse me a minute, this future needs meeting has been going on from she was 14 years old, I says and your team at Glendinning are needing a bomb put in there. See if you got rid of three quarters of your social workers up there you would still be left with too many dealing in the input that they are doing, I says because they are no back up to anybody, no support to anybody. So then basically we went through all and every issue that we have ever had with them and not providing so basically at the end of the day we were asked to adjourn and as we were walking out the corridor for coffee to let the panel decide, she Angela Hay who I like now, me and her are like that, she actually congratulated on me the way that I handled the case in there.

A: Is she a social work manager?

J: She is a service manager, she is like Michael's boss sort of thing... and like a team leader type thing, and she congratulated me on the way that I had conducted myself and the case. I says to her well it's like this you just have to because if I can't voice my opinions for her you would just forget about her and I turned to Tony and I says nothing personal, he went no and we all had coffee and that and I thought well they'll not forget us anyway. So then we went back in and they found that they had not made proper provision and they had had plenty of time to consider it and they had better get their finger out because they would be getting looked at again. I think that was in the September and she was leaving school, that would be three year ago, that would be three year ago come September that meeting was, ken, so she would be, that was before the, aye it was after we had been promised about the care suite, aye that's right. So basically that was one September and she was leaving school in the Dec... eh the July the following year. Aye it would be because she is 21½ now and, that's right it was the September and Kylie was leaving school the following July so she would be 18½ at that time which is three years come next month. So...

A: So did that change, did they start to...

J: No, not originally.

A: Because there wasn't any provision anyhow, was there?

J: They couldn't find anything, they didn't have the finances for it and because of the complications of them needing the medical backup as well and the input to a certain extent, I mean they had medicine then, they needed the medicine for the epilepsy, they had the epilepsy so they needed the anticonvulsants so they needed input from the health board as well but then social work, they all tried to blame the health board and the health board were saying it was the social work department and you were really feeling as though you were stuck in the Bermuda triangle a lot of the time and I would say a lot of the time and what they didn't understand or could never understand and they never understood that us as parents and this is even what Michael the social worker said that us as parents have got a hard enough time caring for them 24 hours a day without having to take over the job that the social work management should be doing and the stress and the worry that it put you under, it was just horrific, you just couldn't even start to describe it. And they weren't interested but at the end of the day I spoke to them on my level and they may be social work management but they are just Joe Bloggs like anybody else and Tony Bruce dared, dared to mention at the meeting that it was mentioned that Mrs Sandilands (Joyce) says she'll hand Kylie over into care... and I just stopped him right there, I says excuse me for a minute, I says let's get this on record and on the minutes, I have never mentioned it and he didn't half have egg on his face, I says well I want to know who told you that I says because it has never come from my mouth, I says I have never and would never use my daughter as a pawn in your games because that is what it is to you. So I think we left them under no illusion, disillusion about what we felt. They basically knew exactly what we felt about them.

A: So then how did... what led up to the circumstances, what were the circumstances that led up to you being offered a place.

J: We got a phone call to say that Gordon House in Glendinning had approached the social work management saying that they knew that they were struggling for day provision and they had looked into it and they could provide a small unit for six placements for young adults with profound and multiple handicaps, would we be interested. I says aye if it comes up to our cr... if it meets our criteria and what we want, guidelines, we would look at it so I says you get the meetings up and running and we will come and we will give it our once over and we will listen to see what they are going to put in and what their input would be because basically as I said, although I was desperate for a day provision, I wasn't that desperate that I would just put her anywhere, it had to come up to our standards because we had given Kylie a level of standard from the day she was born and it wasn't high expectations it was only what we would expect as parents, ken what I mean. So it was then suggested that Gordon House was probably going to go ahead and offer this and we then in turn went to a meeting one night and there was myself and another couple of parents there, two or three parents in fact, some social workers that were there of the parents as well, Bobby Telford who was the manager (of Gordon House) at that time, he was there to introduce and propose what he wanted to propose and that was the night that I met the infamous Matthew Smith (head of the social work department) because we wondered... I says, oh, I says to Tony Bruce I says so that's Matthew Smith but he needed, he needed a lot of sort of cutting his wings as well Matthew Smith and a lot of guidance and he got a lot of sort of back lashing where it wasn't really necessary because he really didn't know the client group that was being talked about here and his expectations for them was far too high to what their abilities were going to be and I was really annoyed at him for that and em I felt as though that they were going to decide what we wanted for our kids until I put them right about that. I says no, if I am telling you I want five day placement for Kylie then you will give me five day placement, you are not going to tell me how many days a week you are going to be prepared to give me, I am telling you and so one meeting led to another meeting and oh there was a lot of sort of heated discussions and a lot of heated views went back and forward and you really just had to stick to your guns and stick to you principles and tell them what you were wanting.

A: So what did they want to provide that was different from what you wanted provided?

J: They were trying to say that it wasn't good for them to be in the same environment five days a week. I says and what gives you the right to say that, I says they have been in education, Kylie was just before her third birthday right up until she is 19½, I said she has now left the school, are you looking after her all day, no. And I says what do you mean, he says well maybe not five days here. I says we have not even got this up and running so you are going to tell me that if we agree to three days here you are going to provide somewhere else, I would like to see it. I says I would like to see it, I says you can't even provide one centre, far less numbers of centres so we have a choice, we don't even have one choice at this moment in time, far less two or three choices to pick and choose. Right OK, I says so I think at the end of the day... and then he was going on about we could access the Glendinning Institute (a sports centre), there's a great guy there named blah blah blah and we could introduce them to that and archery and everything and I said excuse me a minute, you are away off line again, I says I am telling you the only thing my daughter and the majority of the young adults that's going to be coming here would ever get out of Glendinning Institute is the wheel chair dancing and that is only then because at the back someone is goading them. I says you have not got a clue what you are dealing with here so again they were left with egg on their faces and it was up to us yet again to stand and fight and argue and bargue and also they talked about the Independent Living Fund (ILF) which for weeks and weeks or meeting after meeting after meeting, they nearly had an uprising, they had an uprising one night on their hands up there because they were social work management, director of social work right across the board did not have the proper information about how the ILF worked and after they brought in Sylvia Murphy (worker for the ILF) that night everything was crystal clear and Tony

Bruce was there and I think, I don't know if Matthew Smith was at that meeting but after Sylvia finished they said well does anybody want to say anything, I went oh I have to say something here. I says, and I think I speak for everybody, I think that what you have put us through, that woman has come in here and made it crystal clear about the ILF, I says you had an uprising on your hands, meeting after meeting here. I says and made us go stress levels through the roof because you didn't have the right information. I says and I think that was totally out of order and he says I put my hands up he says I totally agree with you, he said but that's a lesson to be learned. I says aye at our expense. Oh I had a field day with them.

A: So what was the disagreement about the ILF?

J: Well it was so complicated at the time Anne I really can't mind it. What they were trying to say was that basically we got our DLA (Disability Living Allowance) and we were going to have to pay, hand back about £60 of our DLA and it didn't work like that at all, it didn't work like that, what it was was the ILF considered well you have £90 of your DLA, at that time I was only getting £60 because Kylie was in Larchfield, and I was getting a reduced rate and they turned round and says well basically we are prepared to give you a package of say £60 a week but you are already getting well we'll say we will take £15 off your DLA so we will only give you £45, that's how they work it, that's not what they made out to me and everybody else.

A: So they were wanting to make you pay for the day services that they were providing from your benefit?

J: What they were trying, what they thought, when they were saying what they thought was right was right that we were going to have to hand over, give up our disability living allowance but it doesn't work like that, it means that the ILF take into consideration right they have got X amount of pounds so we can, right we are going to give you a package at £80 a week, OK well we want you to take off your DLA £20 a week to go towards it so we will only give you £60. That's how easy it was to understand but none of the social work management right up to Matthew Smith knew that. They had no information to give us which was correct and true, when Sylvia came Sylvia explained it because up until then I went I don't want it and when Bobby and I walked Sylvia out to the car that night I says Sylvia I says, you have no idea the difference that you have made in here tonight. She says I am glad, so now Kylie does have the ILF and what have you, you know and it was easy as pie but yet again the social worker management team just came in and they were just like a bull in a china shop, this is what we think it works like, it was just giving us all totally wrong information and uprising I have to say is the word that they nearly had in Gordon House that night. And it was an awful job that we are all the type of people that we are and we have got the gumption and the staying power, I am not saying intelligence because you don't need to be intelligent but at least we had common sense, I would say common sense lets you know that wait a minute they are not bamboozling us here and they are not bullying us into taking... and I just feel and felt that they had no business making us go through all these meeting or the arguments or the stress or the sleepless nights. So eventually it was agreed that what Glendinning could offer was in turn, we were happy with what they were talking about. Then it was just a case of right everybody agreed and everybody agreed that we got our five day placement and that the social work department would provide the funding for it and it was a case of right after our last meeting, right we will go away and get things tied up. We will have a meeting back and let you know what is all going on which they did and eventually in September it opened up for the first day and I have never looked back and that is two years come next month that she has been going there. So from July to September we had no day provision at all for Kylie and that is unacceptable because from three year old to 19½, barring the summer holidays, which I think were wrong anyway, this young lassie went into puberty, not puberty, well I suppose puberty, adolescent age, although still in her own descriptive world but still going with the age group, so she has went right through from 3 year old to 9 year old to 15 year old to 18 year old up to 19½ leaving school with a daily input to keep her stimulated and then all of a sudden whoomph nothing. So...

A: So how many months was that then?

J: Well that was from July 2nd so you were nearly all July, August so there was a, I think it was like the end of September so I think near on four eh about 11 weeks near on or more that Kylie had no provision, I had no day provision, no family to come in and help and I think they totally got it totally 150% wrong and I think if they were big enough to put their hands up and admit it, they would admit it.

A: So there was no transition period then for Kylie between the school the....

J: No none whatsoever and it was just as well that I told them that the group of young adults that they were planning on taking were a good group of young adults and it is just by luck they didn't need a transition period but if they were talking about somebody, I mean Pamela's got the knowledge eh, but Kylie and the rest really didn't and it didn't take Kylie long to settle in at all but they had no transition period at all.

A: And you would have liked that.

J: Definitely.

A: So how long do you think a good transition period was, you mentioned before at first you had planned it, the school had planned it for six months.

J: Six months uhu. I am talking about personally with Kylie, two or three months would have done for Kylie because Kylie is a very adaptable young adult, she is a very adaptable person personality-wise but I think on the whole taking everybody into consideration on an average I would say that six months is a definite, maybe even going one day a week to begin with and then working up and I would have liked to have seen them going three days to the new place and two days at the school.

A: And the staff liasing?

J: Yes definitely. Because you have got feeding, you have got the finding out what that shaking of the arm would mean or her coughing would mean so basically it is, I would say that realistically three days a week going prior to them finishing up would be, I would say, an acceptable level but then again we got none, but none and I was quite happy to hand Kylie over for five days to start with because I know what she is like and if I had any qualms at all about her then I would have just had to persevere and take her up and you know take her for a day a week, two days a week but no, she started off at five.

A: So obviously this was a stressful time for you.

J: Totally and utterly horrific. I couldn't start to put it in how I feel about them and I really feel that the social work department gave us a raw deal and making us go to review committees, making us write letter after letter to client relations officers, going to meetings, it was just a total and utter grey area that needs to be looked at so the mistakes that we have went through with our kids don't happen again. I have no faith in them.

A: So how did it affect your family then. You said it was stressful, did it cause you any health problems?

J: Stressful for me in the sense that I have to say that I had to go on anti depressants just the way I was feeling and that I would say definitely affected my health, didn't affect us as a family unit, I mean I wasn't... nobody was falling out with each other or threatening to leave but just in yourself having to take on board all this mentally and having to keep files of everything, I mean having to get this young girl out her bed every morning and...

END OF SIDE ONE
SIDE TWO

A: Has it affected you as a family unit.

J: No it just put horrific and terrible pressure on us as parents that the fact of looking after these profoundly and multi handicapped young kids going from baby right up as I say through their puberty years into the adolescent years and into the adult years is hard and hard enough but for the social work department to purposely not follow their guidelines I just think there is no excuse for them and for us to have to go to the extremes that we did with having liaisons with X amount of people and meetings, that is just unacceptable and I just think that they are not on. They are there in a position, their job is to provide and they didn't provide and that is the bottom line and there's no excuses for it.

A: And how do you think Kylie felt during this period, was she aware of what was going on?

J: No, no she had no experience of it or no awareness of anything like that. Just the fact that it did affect her though because she was in the house every day. I couldn't I mean you can't be mum, housekeeper, financier, psychologist, OT, speech therapist, physiotherapist, you can't be all that in a person so Kylie was, she was neglected in the sense by the social work department, she was the one that was penalised here as well I would say most of.

A: Especially when she had to stay at home and she had no provision.

J: Especially when she was staying just at home and that in turn restricted my daily routine in the sense that if it was raining you couldn't go out with her. If it was too windy you couldn't go out with her. Then you had all the humphing and laying in the car in the wheel chair so basically it had a knock-on affect on me, so I suppose in turn yes it did have an affect on the family but being the type of person I am I condensed I didn't let it escalate into divorce situation or anything like that.

A: And your husband, how did he feel about this time as well, did he share the same views as you?

J: Oh aye, oh aye definitely, 100% what I thought Bobby thought and although the social work management it was always my voice they heard, ken I always took precedence over Bobby, I'll speak here and I'll tell them but no Bobby was 100% behind me and totally agreed on everything we said and done.

A: He supported you and went to the meetings.

J: It was a joint venture.

A: So did you feel that Kylie lost any skills that she had acquired at the school over this period when she was at home when she had no provision.

J: I would say no, I would say 90% of that question I would say no to but I really felt for her when she missed out on her swimming because to see Kylie in the swimming pool was just, just unbelievable and I felt that was what she missed, so much so that when Glendinning eventually got access to a pool at Hollywell School I went with them for the first time in the water to get Kylie's confidence back. Now people would say well why did you not take her to an ordinary pool, well you can't. It has to be of a certain temperature or else they just go into spasm.

A: Sometimes they don't have the changing facilities.

J: And the changing facilities. So on her first visit to the pool but I had nothing to worry about because she just took to it like a duck to water again so I would say that I was more concerned about the swimming input, losing her ability for that you know and it was wrong, it was wrong for them to take that away from her you know.

A: So is there anything else about the transition time, anything else you think we have missed.

J: I don't think we have missed anything but to summarise I really really really feel strongly about the fact that they just mucked us about and they made us go through all the stress and strain that I wouldn't want to inflict on anybody else in our position and I think the social work management team from the top to the team leaders coming down to the social workers, I feel the social workers hands are tied because he did try and he did agree with us 100% that we had been given a raw deal and I would just summarise it in saying that I just think they were out of order and no excuse for the behaviour of them and their non provision of anything for Kylie and Kylie's peers that were leaving school with her you know.

A: So what do you think would have happened if you hadn't taken on this active role to get provision for her, do you think they would have just left her at home with you?

J: Yes I think they would still be dragging their feet, I still think they would be dragging their feet and I would like, I would love to say to them and I have often said to them, you put yourself in our position because I am quite sure if one of your team had a profound and multi handicapped young adult on their hands, yours would be getting provision, I could almost guarantee that. But no, too much money involved, too much money and too much organisation but we got there in the end but no, after a lot of hassle and heartache.

A: OK then that is fine. OK so can we just talk about the adult provision that she has now. It is at Gordon House?

J: It is Glad Centre it is called and it is situated in Gordon House in Pocklington in Glendinning and it is a small unit that takes a placement, there is six placements open and at this moment in time, there is five full time placements and two part time, sadly one young adult died so instead of giving the one placement to somebody five days a week they have split it, somebody gets it Monday, Tuesday, somebody gets it Wednesday, Thursday, Friday so that is actually seven people that are accessing it just now so we count ourselves lucky that we got in there at the beginning.

A: So what happens to these other young adults on the days that they are not there.

J: Nothing.

A: They are at home with their parents?

J: They are at home with their parents.

A: And are their parents happy with this?

J: No, definitely not, they want five day placement and the way you have to look upon it objectively and realistically, they are 21½, 22, 19, 24, what would your young adults be doing at that age if they hadn't been born with this brain damage or the effects of what they have got? They would be left school, they would be left uni, they would be out working, they would be in their own houses. My daughter left home at 19½, 19, and she is now partner with somebody, got a mortgage, two kids. Kylie is never going to do that so why should they expect us as parents to provide and care full time for these young adults. Five day provision is what we want and that is what we have got, thank God and that is what she gets there.

A: OK, so how do you feel about that kind of provision?

J: I am happy with it. I am happy as long as they are giving me five days a week I am happy and I like the fact that it is because it is not council run, it is private, you aren't limited with your holidays, they take hardly any public holidays and you don't have the horrific school holidays to deal with, October, Easter and Christmas holidays so as I said if she was 21 year old she would be working and only taking a fortnight off here and there, so I am quite happy with the provision that it's providing Kylie, talking about Kylie as an individual, I feel that what Kylie needs in a day she gets out of the day.

A: So it is provided by the voluntary sector and then paid by the social work department.

J: No, well it is provided by the private sector being Leonard Cheshire.

A: Are they classed as private?

J: They are private and it is not a council run institute such as a school or such as I suppose the Fraser Centre. It is really I suppose private sector and although it is a charity based thing it's still to be provided money-wise so then that is where the social work department come in and pay it out of the council's money.

A: So how do you feel about the activities they provide?

J: Personally again for Kylie I am quite happy with the activities they provide. They get them out. I suppose socially including them nowadays has a lot to with it, social inclusion as they say and they do get taken out and they go to the pub at the centre (shopping centre), maybe have their lunch there, sometimes or they access the Entrance Centre for their lunch. They go to the wee coffee shop at Stuart's the bakers and access that with them and they go swimming, they go for runs, they go up to Glendinning town centre for shopping so aye I am happy. Again I am addressing it personally for Kylie's needs because she likes this one to one activities and out and about and hearing all the noises and that.

A: And what do you feel about therapy, does she get physio and speech therapy?

J: Yes

A: So that's a follow-on from the school.

J: Yes we have, because again, because they are a special client group we knew and they knew that they would have to provide an input from the therapists so the adult services from Larchfield, physios and that are all in their input and they come in every so often, show the staff if there is any passive physiotherapy to be done. Any problems then the day care, I am quite happy for the day care to deal with anything like that. I just see that, well it is less responsibility for me, they deal with the majority of things like chairs and things like that and if there is any problems then OK I phone up myself but overall I am quite happy with the input that they are doing.

A: And what about the relationships with the staff?

J: It's good. Personally, myself I have no qualms about any of the... the attitude from the staff is excellent and they really seem to, I mean I ken this is not going on record but I would pay them treble what they get paid because it is a pittance, it is not council paid, eh, they don't get the council wages and I would personally myself triple their wages because they are brilliant and I really feel that the majority of them are there, I would say all of them are there because they really like what they are doing and they want to be there.

A: So you think that it can meet all Kylie's needs?

J: Kylie's needs aye.

A: And any medical needs that she has as well.

J: Yes I mean they're quite happy...

A: There's no problems with that.

J: No, they give her her anticonvulsants at lunch time and that is all Kylie's medical input in a day, luckily.

A: OK then, so is there anything else about the adult provision you want to say?

J: No I am happy about it.

A: OK then so the last bit is what is your hopes and dreams for Kylie's future.

J: My hopes and dreams for Kylie's future is for Kylie to stay healthy and me to have Kylie for ever as long as really as the eye could see and be on a daily basis cared for like she is the now, I still want her to go to day care because that gives us, me, well sort of half my life back and it gives us a chance to, as parents, as a mum to go out and about and do some normal things like shopping and visiting or pictures during the day. So my hopes and dreams for Kylie is a continuation of her life the now and if I was being totally and utterly honest, Kylie has got a good life, she is happy, she comes from a good... she has got a good family and her family's friends are all brilliant, I have got good neighbours that will include her, I have got even the neighbours' kids include her, they don't see her as this freak so I would say in general Kylie has got a good standard of living and she has got a happy standard of living so that is what I would want to continue in Kylie's life.

A: Have they said how long the provision is going to continue at Glendinning, have they put an age limit on it?

J: No, no that is for ever now.

A: Is it?

J: Aye, that's forever.

A: That's good, so is that it?

J: Aye.

A: OK then right thank you.

Appendix L Example from analysis of individual interviews

it was possible but it was very very depressing in that there was nowhere it seemed that could cater for children like [F] when they left school. She didn't conform if you like, she didn't fit into the neat category of just having a physical disability or just having a learning disability, she had both and to cater for both they just didn't have the centres to cater for them. We discussed different centres and we would ask, well would they be able to cope with [F] and they would say no because the adult training centres as they were called then, the one in ~~Dunfermline~~ which was a big centre catering for

No provision

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learning disabilities would not have been able to cater for [F]'s physical needs, provide physical needs and the physical disability centres wouldn't entertain a learning disability so it was very depressing but there was also this, they would tell you, something will turn up, something will turn up so at 14 and 15, that might have seemed quite a wee bit a way, you know we are getting to 18, 19 and you would say yes something will turn up, something, we were naive enough to think that something would turn up but I am afraid as the time approached nothing was turning up and they just weren't able to come with anywhere for [F]. It was very very worrying that from a very young age from 2 when she went to nursery, special nursery, that from 2 she had a structured day and a day that she enjoyed, a day that she was stimulated in and a day that I knew she was being properly taken care of, that I had time for the rest of the family and my own needs but suddenly this might stop, it was very worrying, yeh.

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Feelings.

didn't want her lying on a bean bag all day which I believe some centres and the profoundly disabled were just left lying on a bean bag watching a mobile and that certainly wasn't for [F], she had to have the stimulation, the continued education, the continued physiotherapy, speech therapy, really a continuation of school, if

Stresses education & therapies.

Appendix M Transcription of focus group interview

Pseudonyms for interviewees: Helen (carer), Maureen (carer), Jillian (professional from a voluntary organisation), Pauline (professional from the social work department), Angela (professional from the health board).
Cities, places and names described in the interview have been changed in the transcript in order to protect the identity of the interviewees.
Name of interviewer: Anne
Date of interview: 05.02.02
Time: 10.30 – 12.00
Setting: Anne's house

Anne: So one of the things the parents said in the study was they lacked information about the Future Needs Assessment meetings and the whole transition process. So could we think about what we could do to give the parents more information, anybody got any ideas how we could do this?

Helen: Well I can chip in with this one, I thought that leaflet that we got recently sent...

Anne: About the transition co-ordinator (holds up the leaflet) ...

Helen: ...yeh, was good and I thought that was a good idea because quite frankly I didn't know anything about Future Needs Assessments until... before she had hers, I just thought it was a process that you went along, something was identified, you know I didn't... I don't think I realised the implications of it and I do think, I think if other parents were in the same situation as I was, I think I would have appreciated somebody coming and letting me know what the process, you know that it was an ongoing process and what I should have actively been doing throughout because I don't think I did.

Jillian: Had you somebody who was involved with the education process or would you like to see an independent person like Capability Scotland involved, what are your views about where that person should be based...

Helen: I don't think at that stage I would have been particularly bothered Jillian. I think it would just have been... you know, looking back I think I would have preferred to have been better prepared than I was because other than that we just kind of fumbled in the dark trying to find out the things on our own and I didn't really.. you know there would be people not at the meetings and that would anger me but when I look back it was vital that they should have been there and I think that is something... because you don't really know much about it, it just kind of washed over me at the time.

Anne: How did you feel Maureen?

Maureen: I also felt if somebody was there to help you with the process, especially at the beginning, just till you get a wee insight to what is happening but I felt the process was just a big let down for me especially because I was being told the different day care services that were available although they knew Simon's needs, none of these at all were totally suitable and I felt they were just pushing me from pillar to post to different day care services everywhere and none of them would be able to take Simon and like you I just got angrier and angrier and angrier and I mean they knew, to me they knew fine well that Simon wouldn't be able to go to any day care centre that was available for his next step but they just kept telling me about the different places and I think why, I mean why could they have not come up and said well quite honestly at this moment there is nothing.

Helen: We just kept being told don't worry about it.

Jillian: Something will happen.

Helen: I didn't at the time, you know oh don't worry something will be there and I thought something would be there.

Maureen: We were told that at the beginning as well but then I thought, no, there is nothing there and then I was really really getting worried and it proved to be. I was really worried then because Simon was left at home with nowhere to go.

Anne: So you liked the idea of this transition co-ordinator who would help you through the whole process but also identify suitable placements for you?

General agreement

Anne: So do you feel you need a person or would a booklet or some information pack do?

Helen: No I think a person.

Maureen: First off definitely a person.

Helen: I think the personal touch has to be there in that the co-ordinator or who would know the young person, know exactly what their needs were and would they fit in in you know, (a), (b) or (c), if there was a choice of (a), (b) or (c) (laughs).

Jillian: It sounds almost as though you are talking about an advocate on behalf of Faye or Simon maybe, is that an education services advocate, somebody who would think exactly what their needs were and then think about where the services could provide those needs?

Helen: Well I think somebody to take the onus away from the parent, yeh because the parent has to end up doing the leg work if you like. We ended up with a social worker that did the leg work because Faye was the only one at that particular time looking for a service and it was in desperation, well it was instigated because we had to end up going to the director of social work for Fife and he instigated that a social worker be appointed to look specifically for a place for Faye and identify a place.

Anne: So what about Pauline, do you have any feelings about this, how, you know, you could help parents through this period and give them the information, would it be possible to have transition co-ordinators for every family?

Pauline: Well in fact it is something I feel quite strongly about in terms of my own experience. In one of the teams that I manage was that I appointed a worker to work solely with young people in transition and that was her caseload that she carried that singly and she was known locally with health and with education, that was her sole role but that was only in one team in Fogart and that worked particularly well. But for other reasons, other teams couldn't take that on. I mean I think you have already sort of covered the expanse of the responsibilities of community care teams and how that effects their ability to specialise if you like or to have specialist workers but I know that that worked well, so I think it is important to have somebody who specialises in that area whatever their background, (general agreement) that they know about issues for parents.

Helen: Was that somebody from adult services?

Pauline: Yes.

Helen: I think that is the biggest problem getting them together.

Pauline: It was about my commitment to ensure that the young people had the adult social worker prior to the Future Needs Assessment so that the social worker was actually able to meet with the family and the young person prior to the Future Needs meeting because there was the thing about they needed to have some knowledge before they attended that meeting, not just attend the meeting. So about the information, the transition process a few years ago, Veronica Becham did... the parents...I don't know if you were involved in that?

General yes.

Pauline: And out of that I knew that there was a procedure put together but that has never been reviewed or renewed and it is about, I think it is about constantly reviewing the information and making sure that anything written is up to date and making sure that plans are made with parents and I think having a central point like the post-16 group, you know that... because I am chairing that now and I am looking at you know how we get services a representation on to that group and also how we make contact with parents and how we keep them informed so I think... but again things are changing with "Same as You?", with education and I think it is ensuring that the work that has begun to be done and the improvements that have been made albeit gradually, I think sometimes we take a step back but that the transition for them when the organisation changes, that we don't lose that, that if responsibility for younger people moves to a different structure if you like and the "Same as You?", that that work is carried forward so there needs to be a link made with them. But as I say I don't... when we say it doesn't matter... you know it doesn't really matter who it is or what background they are from (general agreement) but as long as they have got a clear role then that's their responsibility and families know who to go to.

Anne: And have all the information available at their fingertips, I think or could go to other people for it (general agreement).

Helen: I have actually got (looks at her notes) that the adult services have to be represented because the adult services never appeared when it was my daughter's meetings, they just were not there.

Maureen: Because they were still classed as children, they just didn't want to deal with them because...

Helen: And I think it is vital that they are there.

Anne: Some of the parents said that they didn't know their legal position either in the Future Needs Assessment, if it was a legal document, they didn't know that their child could have an extension till they were 19 and they didn't know that process. Who do you see as best to give you that...

Interruption with tape machine

Anne: So who do you see is best to give you that information, would that be a booklet you would like to have and be able to keep or do you feel the transition co-ordinator would be someone to give you that information?

Helen: Both. (Maureen agrees). To have it in writing so that you can refer to it but also for somebody to be, you know, there, telling you or explaining to somebody, some of the parents about it.

Maureen: I agree with that, both, definitely.

Anne: So you would like a sort of information booklet but you would also see it as vital to have this transition co-ordinator to see you through the whole process. Who do you think should be responsible then for providing the booklet? (No response). Do you see that as social work department...

Maureen: I think it should be everybody. Because health also comes into well our young adults.

Anne: Everybody. They have complex health needs, so you think health?

Helen: It might all depend on the... you know there maybe have to be variations because of the school because some schools I think finish them at 18 with an extension but I think other schools can take them till they are 19 so I think that would need to be clear as well, what the policy you know was for the particular school that the child was at.

Maureen: That's right.

Jillian: It might be something that could be funded through the Joint Futures I imagine, if it is very much seen as a joint responsibility but it would have to have somebody able to co-ordinate the information and date it as Pauline said and it is very difficult for agencies to find the resources to do that unless it is a kind of a dedicated post I think.

Helen: I think the problem would be too Jillian is if the authority that is doing the booklet is a different authority to the one that the child is actually attending school in. You know I don't think it happens just maybe as much now that the children are in a different authority..

Pauline: No it doesn't.

Helen: but there are maybe still some you know being educated out with the authority that they live in.

Pauline: I think it is a joint responsibility and.. you know if the finance wasn't available for a printed booklet there are other sort of... it is more the information, not the quality of the cover.

General agreement

Jillian: I think the other thing that should be very helpful is that information is a two way process and the information from families and parents would be very important in feeding into the planning process of post-16 services and often the frustration is that there isn't actually the information to give because as Maureen said earlier there actually wasn't a service at the time which was suitable for Simon's needs and I think that was your experience too (looks to Helen who nods in agreement) and I think it is very difficult to... so if the Future Needs Assessments, information that is gathered from that can be fed into the planning process in a very efficient manner and related... or even earlier I think it is really not very much time to set up services is it? It needs to be a lot sooner than that in order to start the ball rolling.

Pauline: I think there are practical issues like systems as well around that need to be addressed and one of the problems is that finance is only available on a year to year basis in local government.

Jillian: That's right.

Pauline: You only get a yearly budget and I think it will make a difference when the budget is changed to 3 yearly and there will be a better opportunity to plan.

Jillian: When is that actually going to happen?

Pauline: I am not sure of the exact date but as far as I am aware it is fairly soon. They have begun to shift some voluntary organisation onto that funding basis, I could check that out.

Anne: OK, so is there anything else anybody wants to add about giving people information.

Maureen: Don't think so.

Helen: Well I had one other idea was you know that parents groups connected to school, you know they could through the other parents, make sure that the parents know in the parents groups at the schools exactly how important...

Angela: Somebody else who has already been through that process.

Maureen: Unfortunately a lot of schools sometimes don't have parents groups.

Angela: No.

Jillian: I wonder whether, thinking along those lines if information is put together about the Future Needs Assessments whether a parent link, who had already been through that process, a parent who was happy to take on that responsibility, information could be put into that booklet so that at least families coming up through the process would have somebody who had been through that system to talk to and...

General agreement.

Maureen: It would have to be in a positive way though (laughs). I am afraid for my experiences it would be totally negative you know.

Helen: I think a lot of parents who might have been through the process would agree with you (laughs). Although sometimes that is not a bad thing, you know you are not trying to be too negative but maybe if they do know that pitfalls, that they are aware, they can be aware of them as well but I just wondered if that was just another idea you know if there were groups within schools.

Anne: Or even a local group, maybe through PAMIS, special interest groups. Right then, one of the other problems that the parents encountered was when they went to their Future Needs Assessment meetings, not all the professionals and the agencies that they felt were involved with their young people, attended the meetings. And there is a problem of how do we involve all the agencies and the professionals in the Future Needs Assessment process and the other thing they sometimes found was that some professionals did not have knowledge and information about their young people's needs or the services that were available to them. So could we think of ways of trying to improve this problem? (No response). How could we get all the agencies and the professionals to the Future Needs Assessment meetings and involved in all the processes? (No response). I think with the group of people that we are talking about, they have complex health care needs as well. There's the educational aspect and there is the social work aspect. There is often psychologists and doctors involved and teachers, speech therapists, language therapists, physios so they sometimes need a lot of professionals there and it is trying to get them all to come together, it is a difficult problem.

Jillian: You will have to forgive my ignorance but at these meetings, are professionals expected to put anything in writing about what their views are about the young person's needs from a perspective of whatever their skills are?

Maureen and Helen: Yes.

Jillian: Do the professionals actually have to put something in writing for their Future Needs?

Maureen: It was actually like it was the school secretary came in as well, took the notes of like what the speech therapist thought Simon would need in the future, the physiotherapist obviously, he has got to maintain what he has achieved and possibly hopefully a wee bit more. Just different things like that. Yeh.

Jillian: But is there a direct responsibility on that speech therapist or physio to actually put a written report in because I know fine well that whenever... myself for instance if you are really busy, the things that you get done are the things where you have got some pressure, you respond to pressure like everybody else and if there is a clear responsibility which is time limited for a meeting where a written report must go in, then I think it does concentrate the attention because there are always conflicting demands and people may not turn up just simply because they haven't prioritised and particularly if they think they have got a couple of years grace before the young person leaves school, they think oh well that can wait till next week when actually the time is really very short.

Helen: We never had any trouble with the school because it was multi disciplinary, the speech, the OT, the physio were all within the school, we never had any problems because it was if they came to, they always came, all those disciplines were represented at the meetings and they went round in turn and gave their report of how

Faye had been and their recommendations. The trouble was the outside agencies if you like, the social work especially, and the well health weren't really involved at that time, to come to the meeting but making sure that the local authority representatives were there whether it be the educational psychologist from that authority and the social work department, that was the problem, it was never within the school the problem, all the disciplines were always represented.

Jillian: Presumably the people who knew your daughter in advance would be committed and have the information (Helen nods in agreement). It is people who are not yet engaged and I have been in the situation so often that you do find yourself prioritising and often it is about you know what seems urgent and it is not a good way of working but that is often people's realities but I am just wondering whether if the process was formalised a little bit more, without wanting to add carrots... sticks rather than carrots just to actually ensure that everybody including the adult services people have to put in a written contribution and at least they are going to also have to meet the young person, meet the family and that at that point they start to prioritise because they have met them, they are beginning to understand about their needs, they are beginning to think about what is going to matter for them and they are a real person but if it is not, if they don't actually have to do anything concrete to a deadline then it tends to slip and it is with the best will in the world, that is what is happening.

Helen: The difficulty might be that that adult social worker (laughs), the social worker for adult services, wouldn't know the person anyway, wouldn't know the young person. So they wouldn't really need to put a report in would they, you know it is just that their attendance was never... you know it was conspicuous by their absence, they just were never there and it was very frustrating to all, have everybody else gathered there and no representative from the authority that was going to take over then...

Jillian: That's right.

Helen: You know you were just sitting amongst yourselves then talking.

Anne: Did you want to say something about that? (Looks at Angela).

Angela: Yes, problems with the health... My background is in community nursing, that you know I worked with the community learning disability team which is a multi- disciplinary team which has speech and language therapy, physiotherapy, adult psychology and the only sort of Future Needs Assessment meetings that we were invited to were people that were known to us, that were active on our caseload at that point because we did work with children... like from the nursing point of view, we worked with children as well, or we did work with children, so in my experience I would get invited to some of the Future Needs Assessment because the child was open on that caseload but of all the other children that we wouldn't get invited because we didn't get notification that there was a meeting about... because I think would have been actually quite useful because that is when we would have been coming in and there would have been a gradual transition rather than all of a sudden this child would have left school, gone into adult services and then perhaps a referral would come our way but unless somebody is referred to us we don't actually work with them so I don't know, I don't know how that could be changed but I mean that is something that needs to be looked at, that we are more joined up with social work and I think that is going to come but the way that we work at the moment in the health is different and unless we get somebody referred to us we won't automatically be invited along to any of these meetings.

Helen: Yes because our connection with learning disability nurse was <u>after</u> Faye had left school but I thought you weren't allowed... well not allowed but I didn't think you worked with children.

Angela: Well historically as a community nurse we worked with children until about two years ago and a colleague of mine, Trudy Wilson, who is a community nurse based in the central area, she started working just with children. She doesn't have any adults on her caseload at all whereas before that we were all working with children and adults that were referred to us. But what happened was that Trudy was inundated with referrals and she was covering the whole of Fife so we have kind of gone back to we will take you know each of the community nurses in each area will take referrals for children. I mean hopefully Trudy's team will expand if you like, there will be more of her but at the moment she is the only nurse working with children so what we were kind of doing was negotiating, I mean latterly I worked up in north east Fife and Trudy would you know, a referral would come in for a child and I would just discuss with Trudy whether she was able to pick up on it or whether it would be me. But the rest... You see that is where it is so confusing because the rest of the professionals in the health learning disability team, some of them only work with adults like the psychologist, speech and language only works with adults, physio only work with adults whereas our psychiatrist will work with children as well and I think that is what makes the transition period really difficult because it is a whole bunch of new professionals suddenly you know arriving on your doorstep (nods of agreement) and they are, well you have already identified what the problems are, I am only telling you what you already know but I mean as a community nurse I used to find that very frustrating because you would be working with parents that you had worked with for a long time, you know you have known for a lot of years and you would go along to the Future Needs Assessment meeting and you felt for the parents of the frustration that we can't plan, we don't know, we don't have the resource. I think again that is something the health need to get involved in because some of their resources have to be coming from health as well. We can't leave it all to social work (nods of agreement) especially with the children you are talking about... your children.

Maureen: I was just under the same viewpoint as you (looks at Helen). They didn't get involved with Simon until he had left the school.

Angela: Well that is the way it is at the moment but I am saying that that is maybe, I don't know how you can change that but that to me would have been so much more useful if we were being invited to the Future Needs Assessment of children at an earlier age but at the moment that couldn't happen, it could from a nursing point of view but not from anybody else's point of view because the speech and language therapist wouldn't be able to...

Maureen: That's right because Simon had to be transferred from the children's one to the adult's one (Angela agrees) like the paediatric physio to the adult physiotherapist.

Helen: OT and everything.

Maureen: Everybody had to be changed over.

Agreement.

Maureen: So it is like starting a new...

Angela: ...system is there to make it even more difficult, isn't it.

General agreement.

Angela: Everything's there to... we should try to address that in some way.

Jillian: Just wondering if there are professional reasons why if some disciplines continue to work with people right through life from childhood into adulthood with no transition as far as that discipline is concerned, you said, psychiatry I think you said and to some degree community nursing but the other ones there is this change, why is that, why do speech and language therapists need to be different for children and for adults, why can't we have the same one, it seems to be a odd feature of the system which makes things more difficult at the transition time. If the staff, rather like the local area co-ordinators who would see people through a continuous process through their lives then why can't other disciplines too, it would certainly help with...

Pauline: I think that is the way forward in terms of specialist services for learning disability. I mean if you... you know if you have a child with a physical disability only then there is going to be major problems there because there is no identified specialist service or that is not being discussed at the moment so... but I mean I think that you should have the multi-disciplinary teams with the specialist worker for children but then they pass on to another specialist worker for the transition because there are different skills in transition. If you are going to commission services, workers have to have a lot of skills if they are going to cover everything, they have to be care managers, they have to be able to negotiate with people and they have to know the financial obligations if they have got to commission and contract with services. They have also got to know about adult financing which is different from child care at the moment with direct payments which I mean I think will... running an ILF and you know the kind of knowledge base becomes different when young people reach 18. And I think a lot of it, as you say it is about human resources and about the fact that for, I mean, I am trying to think, for about the fifteen years that I have been involved in community care teams and prior to that I was in day centres so... that there has been no increase in the number of workers in the teams because of the kind of financial restrictions that local government have worked under for the last ten or fifteen years where there has been no increase in financial resources, it has been pared away and pared away.

Maureen: The client bases are getting bigger and bigger.

Angela: Yes that's right.

Pauline: And certainly the level of need is getting higher and higher and that is not just in younger people, it is across the board and teams are under an incredible amount of pressure (general agreement), I can only speak for social work teams which I manage but... and I know how difficult it is for them to sometimes even get along to meetings because they are under so much pressure. You know it is things like if social workers are off ill or away on training their posts aren't, nobody temporary is brought in to cover, things like that so there really is the resource issue and I think the communication one as well. We work in such big organisations, health, social work and education to get it together in terms of communication, it takes a tremendous amount of effort and work.

Helen: I know staff can change but from the Future Needs meeting through to, you know the actual transition through to the actual moving, there is an inconsistency there as well, you lose the consistency of the person. If somebody was allocated at 14, I know it is not guaranteed that they are going to be there when they leave at 18, but if there was some sort of guarantee that at least you know the consistency of information was at least passed on because you would find that if somebody was... if somebody was involved they very soon moved on or you know the information is lost and you were starting all over again so...

Angela: Is there a reason why it is the age of 14 that the Future Needs process starts?

Pauline: I think that is a long established...

Angela: Because it seems to be, I mean I can appreciate the reasons behind it, it is giving people four years but in the same... you know from first hand experience, in what you are saying is that people can't plan because there is only this yearly budget thing so it seems that four years is maybe... it is raising anxieties too soon if you like.

Pauline: Well quite a number of young people leave at 16, they don't wait until they are 18.

Angela: Right.

Pauline: I would say it is a priority that you begin to get to know the person at least at 14. One of the other problems is that there isn't always a hand over from the children and family disability team to the adults team. If a worker in the children and family team, this is an issue that I have at the moment, closes the case then the information then isn't passed to the adult team and that has been a major issue in the last year or two because they have kind of changed their system of working without referring to the community care teams and it was just by chance that I found out they were doing that so there is a lack of communication there and I think that it had improved slightly before that but because of the pressure they are under they changed the system and so the information wasn't being passed on and in some cases it was but in some cases it wasn't.

Maureen: For some people... that had been sort of closed and then they move on and think at the Future Needs meetings, where is the... but there was nobody there for them because it had been closed.

Pauline: I think there is a... in some schools, it is different from school to school, in some schools they build up a good relationship with social work and there is communication there with some local teams but in other teams they just don't gel. There's a kind of I suppose you could call it attitudes to each other and I know workers who have been along to meetings and have been treated really badly at meetings because everybody has had a go at them and things like that so you know there is sort of issues around professions sorting themselves out too and respecting each other's position.

Angela: And I know working closely with you know social workers in this process that they feel very frustrated because they want to be able to come up with the resource. I mean the people, if it is somebody that has got a good knowledge of resources they often know before they even go out there to start looking that there isn't going to be the resource for these children and they find that very frustrating as well.

Maureen: Honesty on the part of all the professionals (general agreement), if they were to really be honest with you and tell you look I am sorry but at this moment in time we have nothing suitable and available but processes being processes we are working on something etc. etc. It is like I have always thought with doctors, instead of trying to flap their way out of a situation if they would just be honest and tell you the truth but...

Anne: One of the problems that we are all talking about as you said, you don't sometimes know that the young person is there with certain needs. One of the other local authorities have devised a plan to try and overcome this problem and I was just wondering if I tell you about it you could maybe give me your views and see if you think it would work here. They, their health board, their council and their social work department all got together to form a transition policy to see how they could all work together to help people through the transition period and they also compiled information about all the young people that they knew about and put it all together into one register. It wasn't just saying somebody has cerebral palsy, it was a profile of all their needs and what they are likely to need and how these needs will need to be met in the future and they felt this information could be shared amongst all the agencies and they also thought it could be used for planning future services and targeting resources and they also thought it would help with staff training because staff would be aware of all the needs of the people and what services were available and what entitlements that the people would need and they also provided an information booklet for parents and young people. So would you like to comment on that idea, how do you feel about maybe a register, do you think that would help all the agencies to communicate better and plan more effectively?

Angela: I think it would go some way towards it because to plan you do have to identify what the need is but I think probably, well you have probably been the same, over the years, we, as professionals, we have jumped up and down to tell the planners if you like, the managers, you know this is what we need for the future but nobody seems to be listening so I think the data base or register, whatever you want to call it would go some way towards that but there has to be a commitment from the planners, from the budget holders, towards planning to meet these needs and I think that's at the moment that's the bit I feel is kind of like a brick wall that although there have been various working parties set up over the years, I have worked in the community for 16 years, who have identified the children with the profound multiple disabilities and it is not hard to do because they are all sitting in schools somewhere.

Maureen: That's right.

Angela: To me these should be the easiest group to plan for in some ways because we know who these people are but there just seems to be a lack of commitment to actually developing the services that are needed so I think it is almost like I don't know, a political thing, you need to get on to the politicians...

Maureen: Councillors.

Angela: yes and campaign them with something, councillors.

Jillian: I think the difficulty with people with profound and multiple learning disabilities is that they do have a great tangle of inter-related needs and they are a small group but their needs are very expensive to meet and because they are a small group they find it very hard politically to compete with larger groups who have less perhaps intense needs and this is sort of a built-in problem. I think if there was a register then at least the information would be there in one place and having it in one place rather than reliant on professionals to push out information at the system from different parts of Fogart in relation to individual families there would be at least the material there and I think it is really important that that happens. Obviously there are issues of confidentiality and agreement from families about who has access to that information and it is important that it is shared but that has got to be something that has been clearly agreed by the families, all the service users concerned. But it seems to me that getting that information together at 14 or 15 is really too late for people who have got very complicated needs because it is... I don't know how long it took to set up Valley House but it was 7 or 8 years, was it? It was something. I know there were all sorts of very specific delays but even if it was done on a real fast track it is going to be probably three or four years I would imagine to set up a completely new resource if that is what is needed. Given all the negotiation that has to go into it so I think it has got to start quite early on. I do feel that a transition co-ordinator would be a very useful person in gathering information together too, I think that would be extremely helpful.

Pauline: I think the transition policy is a good idea in terms of health, social work and education, getting together and developing that because that is a public statement and people have that to fall back on if they don't get the service that the organisations have promised. I mean there is an agreed procedure but it is out of date and that was agreed across health and social work, eh across education and social work, I can't remember if health did and to a certain extent the post 16 group in Fogart does keep a register if you like but it is not a formalised process because I think there are legal implications about keeping a register of people and how you would set that up but because education and social work and resources get together at the post 16 group, all the information from education about young people leaving school is there at that meeting and we examine situations where there has never been a referral to social work for example and the education now go back and say to the parents would you like a referral to social work and that information is not shared unless the parents agree to that so you know we are on the way with the post 16 group and certainly the profiles for individuals we ask social workers to carry out their assessments now and send them to the post 16 group so that the post 16 group have an overview of all the needs of the young people who are leaving school this year and they hold the budget then for services and they can then say well we can allocate 50,000 to that person or to that person and also negotiate with organisations to provide the care that the person needs but of course that is completely different for each individual, you know if we plan and set up a resource it is not going to suit everybody you know it is like the thing that you can have... I think it is easier with a respite unit because it is not so difficult for people to travel and you know for the break to be away from home but I think most people now really want support close to home and moving away from the traditional five days of day care, people want something that is designed for the individual young person...

Maureen: As long as there is choice there.

Pauline: ...and I think that ILF and direct payments are giving people more choice now in terms of being able...

End of side 1
Side 2

Pauline: So I mean you are talking about so many different variations, you know we can commit to a young person's care, I mean somebody with very high needs and it is £80,000 a year which you are at least talking about a quarter of the budget straight away, things like that so I mean and sometimes we also, you know you don't have the time to plan, a young person can move into the area at 17 and that can then impact on you know what the organisation needs to offer and resources aren't unlimited and you know there is some sort of fairly heavy decisions that have to be made at times and then we have to try and get finance from elsewhere if our budget goes over and things like that so there is lots of implications there.

Anne: OK so if we sort of think back to the question again, how can we ensure that everyone has knowledge and information about the young person's needs and the services available and that all the agencies and the professionals get involved. We were saying, does everybody think a register is probably a good idea to help people be identified and plan services.

General agreement.

Jillian: I think it is built into the "Same As You?" as well isn't it? I think it is a priority in Fogart, there is work being done on it.

Angela: I think the local area co-ordinator when they come about because they are supposed... my understanding of what their role is that they will be sort of working with the families who aren't in crises, they will be aware of all the people that are living in their area who have a son or daughter and I think them having that knowledge might help as well because obviously they will be part of feeding into the planning process as well, I would imagine, certainly from my understanding of what their role is going to be and certainly putting people in touch with specialist teams, because the will have, well they should have local knowledge of what is available in their area so I think that might go some way to help as well.

Jillian: I think that is a key word that you used about crises, I think so much of social work has always been the same and health care no doubt as well, that it is about crises management just because of the very tight nature of the resources and also allocating people's times and that is where groups like people with PMLD tend to fall foul of the system until they get into a crises situation and because they need long term planning and lots of resources and they tend to always be behind in the queue.

Angela: I was just saying the other day that as a community nurse nobody was ever referred to me because they had a learning disability, they were referred because they had a learning disability and there was a problem, so it was a lot of sort of plate juggling as I used to call it.

Jillian: As you say the local co-ordinator may well go some towards...

Angela: Hopefully change that.

Pauline: And the specialist teams will have a clearer role.

Angela: I think they will be more crises intervention.

Pauline: But also the care managers are expected to sit in there which is a more kind of complex skill that they need so if there are care managers in the specialist team that is taking the pressure off because the local area co-ordinators are dealing with people with a lower need if you like and the high need is being addressed so it should free up some human resources in terms of managing situations but again that is just for learning disability. If you have a younger person with a physical disability or you know other behaviour... I think autism comes in the PIP isn't it?

Jillian: I think so yes.

Pauline: But there are you know arguments about that too so I mean it is... it is being able to make sure across the board.

Maureen: It would definitely be handy if it was on a register then everybody would know what the needs were rather than having to go to papers, local papers and put your face right in the local papers to let everybody know what the problems were, if it was down in black and white you wouldn't need to embarrass yourself and others by doing that.

Jillian: And if it is a computerised data base it can be updated...

Maureen: Yep.

Jillian: ...and there would be no need for additional reports when specific problems crop up and the need to divert somebody's time for six months to do a specific report on a particular group of people which at the present time needs to be done and Paul Eden did a report which I am sure was much needed but perhaps if the information was already there, he wouldn't actually have needed to go through that.

Anne: Another problem that the parents face was there seemed to be no progress made between the meetings, they would have a meeting and things were agreed on and then they would come back to the next meeting often six months later and things hadn't progressed, so how can we assure that things keep progressing and things move forward. Can you think of any ways that we might overcome that problem?

Helen: Well just the parents keeping, that seems to be what it is isn't it, the parents have to keep on asking, can, you know what progress is being made, what is happening and the onus always seems to fall back on the parents. I don't know whether, you know if somebody that was a co-ordinator for the transition would be able to check up every month? Two weeks or something like that in between times.

Angela: The meetings, well they are quite structured but they would have to be very structured and everybody went away knowing exactly what it was they were supposed to be doing before the next meeting because often I have gone, well gone along and sat at these meetings and there has not really been an action plan, you know what I mean...

Helen: Yes, that's right.

Others nod in agreement.

Angela: ...laid out at the end you know there has not been a clear decision made, well this is what we are going to do in the next six months or whatever time plan.

Jillian: And this is the person that is going to do it.

Angela: Yes that they are actually responsible for doing something and accountable for doing it and again as you say having the transitional co-ordinator, whoever that person is, being responsible for checking up on people if you like to make sure that that is happening. At the moment my job is resettlement co-ordinator, we are using person centred planning because at the moment we are looking to move people from hospital into community and we are using the personal centred planning. I think that is... well certainly one of the models of person centred planning had been set up initially, this was in Canada, for children moving from specialist schools to be integrated into main stream schools so perhaps that is something that could be part of the future because as you say (looks at Pauline) every child is different. OK you could set up a service and say right OK we will have three kids from that school and three kids from that school and two will bus over from West Fife but it might not actually be matching their needs whereas I think, coming from a nursing background, I am used to very structured assessments that you tick boxes, this is very new to me but it is very... exactly what it says, person centred, it is looking at this individual and what do they need and it does get people to sign up to doing, you know, whatever the action plan is that is decided at the end of it so maybe that is something that somebody could look at you know for using with children in the Future Needs process.

Pauline: I was involved with somebody who used that when she was leaving school and her mum was you know quite heavily into that and it, I mean it completely changed the dynamic of the Future Needs meeting so it was very much focused on the report that the young person had done themselves with their mum and that was really really good and it was interesting that what had been assessed as her needs the year before because that was somebody we actually managed to get involved with quite early, that they had completely changed because she had made a lot of progress which wasn't expected so there is the thing about starting to plan at 14 so their needs will change as well and you have to keep abreast of that.

Angela: I mean it won't suit everybody and it won't be everybody's cup of tea, some people just cannot sign up to it, it is not their cup of tea and that is fine, that is what it is about but I think maybe for some children it might be quite a useful way of doing things but again at the end of the day it is down to the individuals who said that they are going to do something to actually get off their backsides and do it.

Helen: I think we need more of a structure at the actual assessment and people know what they should be going away and doing because I think that is very often, you know instead of just saying och well don't worry something will turn up.

Angela: It is almost like they have got to have a meeting for the sake of having a meeting and again that puts people whose time is limited anyway off, you know put off going along because they think well what's the point, nothing is going to be decided, you know I have got other things I can be doing, I'll be away doing that kind of thing.

Maureen: Because we felt that before, people have turned up and been there just for the sake of being there and half an hour later would scoot because they know find damn well there is nothing to go on to, so I mean it was just I turned up, clock me down, I have been and I am away.

Jillian: I think there is a kind of mixture of panic and despair that hits people too when they feel that there just aren't the resources to meet their needs and professional staff feel very uncomfortable in that situation and it is quite a sort of demotivating thing if you are a caring person, you know the family or if you don't know the family but you know, you have seen an account of the needs of the person and you know there isn't a resource out there to actually match their needs then the psychology is that you put off as long as possible actually confronting that.

Anne: OK so we all think probably having an action plan drawn up and specifying who is to carry out the various tasks and a co-ordinator to oversee it all, but not necessarily the parent.

Helen: No. They can if they like check up.

General agreement.

Jillian: And also an action plan could include a bit about unmet needs if there is a real sense that the person concerned there aren't resources in place to meet that need then there needs to be a direct channel up to, you have probably got these sort of things in place for that but...(looks at Pauline)

Pauline: Not everybody knows about them.

Jillian: No, there needs to be a sort of clear pattern for procedure.

Pauline: And I think it is a thing about if you have workers which have a wide range of responsibility they are not always going to be skilled or in tune to young people with profound needs and they are not going to find it easy and it is about identifying people who are good at that and making sure it is them that go to meetings because there is no point in sending anybody.

General agreement.

Helen: I think that is a very important point.

Pauline: You need somebody who is going to function and take things away too.

Helen: Because we have had, I think we have all had the situation that we have had a worker there who has had no experience at all of young people even, you know they have been moved over from the elderly, you know and the needs are there for a profoundly disabled young person.

Jillian: Presumably in time the local area co-ordinators will be people who will be part of this process as well and they ought to be in position to know the family and the young person well and also have particular skills in the field of learning disability.

Helen: Hopefully.

Anne: OK, well the next thing we are going to talk about is how can we ensure a smooth transition from school to post school provision. Lots of the parents found that there wasn't any transition period at all because provision had not been identified but in an ideal world how could we ensure a smooth transition, what do we need.

Helen: Our transition wasn't too bad, it was cut short because the placement hadn't been identified, you know it had been hoped that it would have been a longer transition because my daughter was very much a one to one person and she did not take to change at all and but once they did do it, once it did get started, the way that they did it was the you know, a couple of workers from the centre who were going to be working directly with her, her key worker and another care worker and the physio, visited the school, got to know Faye there, actually went with her like to swimming to the riding you know were with her for maybe like you know a couple of days spread over and got to know her, got to know how to handle her, how to feed her at that point and then Faye went to the centre with us and saw the centre and saw the familiar faces were there for her. It wasn't just going into a centre that she didn't know anybody which I thought was quite good, they got to know her first and then it was a case of somebody... well somebody was identified from the school to go with her to the centre but that fell through because of pressure on the staff so I went with her and I stayed and I gradually withdrew me from the situation and let her get to know the people more and more on her own and then she ended up going like a few days a week to the centre, the rest to the school and gradually built up that she was going more to the centre than to the school so that she was just used to then going to the centre and it worked out well, it worked out well in that although albeit it was cut short you know it was the timescale they had to pack quite a lot into that, they had to intensify it more than just the gradual... but to me that worked well.

Maureen: I think that would be ideal at least six months before...

Helen: It was supposed to be six months.

Maureen: ...sort of a slow transition period, definitely.

Anne: So six months you feel is the appropriate time.

Agreement from family carers.

Helen: I mean it ended up was it two or three it had to be squeezed into which was quite a big commitment for staff as well you know but I don't know maybe even in that concentrated time you know she wasn't going too long between seeing the people, but it did work.

Angela: It may be that the timescale is different for everybody...

Maureen: That's right.

Angela: ...you know, somebody might need six months, some people might only need six weeks or something.

Helen: Uh (nods head).

Angela: I certainly was involved with a young lady who was leaving school into adult services and she was on the autistic spectrum and that was how it was done and it worked really really well and I think had it not been put in place she would really have had difficulty coping.

Helen: My daughter would have had difficulty coping because I mean a stranger coming into the room at that point in her life would have just... and the fact that she was still being orally fed, she is tube fed now but the fact that it was <u>such</u> a problem feeding her, you know I remember when she did move from one service, I know it was a long while before that but when she moved from nursery provision to school they had two minutes silence at the nursery for whoever was feeding her at the school (laughter), she was so difficult to feed, you know that it was an intense process that had to go through and it was a big thing for her, a huge thing for her.

Angela: The person centred planning, the model that we are using at the moment is the essential lifestyle plan and it is very useful for transitional periods because what... because the person can't communicate themselves because of the degree of disability or for whatever reason, it involved interviewing everybody who is important in that person's life and it is getting like tiny little details about what makes that person's day good for them, you know what you have to do, say for example they have got a very rigid morning routine that everything is put down very very specifically that what you as a supporter or carer or whatever has to do to make this person's day get off to a good start. And it details it all the way through the person's day that they don't take sugar on their cornflakes, they like Canderel sprinkled, you know just little details like that so that might be something again if the person centred planning process was to be introduced within schools that that... and it is laid out in a document that is actually well we hope it will be, we've not got the first person's done yet but what we want it to do is be really eye catching, that people want to pick it up and look at it rather than just be another folder that lies in a filing cabinet somewhere. That it actually belongs to the person and goes with the person wherever that person goes.

Helen: It's a bit like a personal diary, passport [communication passports].

Maureen: Yeh.

Helen: We've all got personal diaries and passports.

Angela: ...personal diaries and there is photographs in it as well so it is like an addition as well as that you know it goes alongside that.

Helen: Because very often I know if... Faye has got a routine and Lord help you if you deviate from that routine you know even if you try, I mean dare I say it is hell for the rest of the day (laughs) but as long as she has got that, it is her security...

Maureen: That's right.

Angela: We all need that to a certain extent, our own routines.

Helen: ...it is her security blanket. She needs that routine.

Angela: And I think as well as, you know as well as having people coming into school and a gradual introduction...

Helen: Probably because the needs are so high and the time to do those needs, it is so time consuming, if you don't have a routine you are lost yourself (Maureen nods in agreement), you would never get through your day unless you had some sort of routine to stick to.

Anne: So we are agreed that what makes a smooth transition is probably a six month period, it could be less but it depends on the individual. The staff have to get to know the young person and the young person has to get to know the staff and the new environment as well and probably to help that we could have person centred planning or passports of communication documents.

Maureen: I have got (refers to her notes) emphasis placed on time, no last minute placements (laughs).

Anne: Yes because that has been a problem in the past and to have a smooth transition you need to have a place identified well in advance don't you. OK, right the last thing to discuss is some of the parents found that at the end of the Future Needs Assessment process there was no appropriate post school provision for the young people. So how could we ensure that there is appropriate post school provision which can meet their needs. Now we have already talked about that already by saying you know we should maybe have a register so that it can ensure effective planning and then somebody said we maybe need to speak to politicians, to the government, so what would help us to get appropriate provision?

Helen: Well I think keeping the high profile of PMLD and I know it seems to be down to parents a lot of the time but I think professionals are taking it on board more now as well but I think just keeping a high profile of PMLD at the front because very often if a place is found, that is fine, we will just forget about it you know, it is swept under the carpet, it is a bit like closing the cases, This really gets me when you know they close a case and you go back and you have either to find a new OT and a new social worker and it just seems so... it is very... I just find that totally, I just can't understand that one at all. So I think just keeping the profile high on the agenda.

Jillian: I think that is extremely important, I think it is a very tall order for parents and I am always extremely impressed by parents like yourself you put a huge amount of energy into keeping that profile high and making sure that the needs of your sons and daughters are listened to at points where people make decisions. I think one of the things we are hoping to do in PAMIS is to provide a wider range of parents with, perhaps some confidence building training about how to deal with meetings and background legislation and this kind of thing so that the numbers of parents who are willing and confident enough to actually take part in the decision making process increases. I don't know how you feel about that but just background information about things like the Adults with Incapacity Act, how to make a presentation at a meeting, that kind of thing so... but it is... your commitments are so substantial anyway to have to act as advocates for additions, all the rest of it is a lot to ask but I do think that that is by far and away the most effective thing if people can do it and...

Helen: I think obviously the parents haven't got a problem with it, most of the workers on the ground don't have a problem and they are fully aware of what we are going through and it is higher up... it is higher up that you find the block and sometimes you know the workers that you do get, the social workers, their hands are tied so very often and it is higher up the decision making ladder that has to know exactly, you know the profile has got to reach them in some way.

Maureen: That's right. My social worker felt that she was on her own constantly.

Helen: Yes, yes.

Maureen: She was just as frustrated as us because there was nothing available for Simon to move on to. And I mean I have seen the poor girl in tears coming to my house because she knew that I would hit the roof and things like that (agreement from Helen).

Helen: And then we get the bad name of being...

Maureen: A trouble maker (laughs).

Helen: Trouble making parents you know because you lift the phone and you don't even need to say your name, they know your voice (Jillian laughs) and but you know it is higher up where the... because all the time well we have got to put it up to committee and we have got to do this and you are hitting the brick wall higher up where the decisions and the money...

Maureen: It all boils down to money.

Jillian: ...actually going to be active and do something rather than just have bums on seats and...

Maureen: Hopefully... I mean there is places now but I am not saying they will always be there but it is a wee stepping stone to build on what already we have got and then the choice is if they could move on to somewhere appropriate or somewhere that their needs are moved on too that they would be able to do that rather than say well you know they will fit into that bracket and we will leave it. Thank goodness, we have found a place. It doesn't always work like that.

Helen: No because nobody stays the same...

Maureen: No never

Helen: Never. You hope it is an improvement but sometimes it can actually be a deterioration because of their health needs.

Maureen: Yeh, that's right.

Helen: It is not to say that what will suit them at 16, 18 is actually going to be the same in 20 or 30 years time.

General agreement.

Jillian: I think the more agencies can get together too because you find that one particular bit of a service you are having to argue with the acute hospital trust, another bit you are going to have to argue with social services, all sorts of things and there are lots of different bits of the system that you have to persuade and hopefully these things will improve with current policy changes but it is extremely worrying isn't it.

Maureen: Even in health I mean it is unfortunate, I mean the transition just now I mean once the consultant...(Makes a cutting movement with her hand) it cuts off at 18, that's it.

General agreement.

Maureen: ...but unfortunately these poor men have got lists as long as their arms, 25, 26 years old... there is nothing else for them to go onto..

Helen: That is right, there is no equivalent [for adults]. We don't have that equivalent.

General agreement.

Maureen: And their health will always have to be at the forefront, I mean always, always.

Helen: It is health that dominates their whole life. I mean I know health is important to everybody but it actually dominates their quality of life.

General agreement.

Pauline: There's no joint financing for that as yet. Again the legislation about joint future, about us having to merge and pool budgets will bring that hopefully into place but in terms of the provision I think one of the difficulties is about the kind of commissioning, you know things have changed over the... we used to have all our own services, all our own resources in the local authority. Things changed and we got into a position where we have some but we purchase new resources or more specialised resources and that process takes time, there is no doubt about that, we have to put together a schedule for what the service is required, they have to be put out to tender because there is legislation that we have to put them out to tender to give, you know to be fair and then there is a contracting period as well and that, I think, in certain, well I mean I think Glenmar, I mean a lot of that will have been a kind of bureaucracy about getting that together in that time. In some ways commissioning is quicker because you know we can have timescales for tendering but it takes at least, I would say, at least a year to set up a new resource to negotiate it.

Maureen: Well the timescale is coming down then because it took at least two for Simon.

Pauline: Yeh. I am saying at least. We are I mean again that is something that you know as an authority we are getting better at but we have only been doing it since '96 really so it is very short.

Jillian: Is the year about setting up a new resource or is that about organising a place, getting an existing resource?

Pauline: Well in terms of organising a place at a pre existing resource it would be whether or not there was a vacancy and whether or not the resource could provide for the need and sometimes the resource has been in contact with the family prior to any assessment process so it is the thing, I mean I was reading some of the experiences people had had where they had been told that a particular day centre could take the young person then they were told they couldn't, I mean that is just... you know there should have been a lot more sort of assessment and negotiation before any promise of any placement was made and so it depends whether or not there is a vacancy in a provision and certainly I can think of at least two situations where we have offered places but parents haven't chosen that, they don't like it so you know we have had to look at... which is fair enough but we have had to look at brand new provision or somebody travelling a distance which has its complications too so I mean these things, I think it is sometimes it can be quick and if there is a vacancy there and the person's needs match or...

Maureen: It has to be completely new...

Pauline: Yes, and the setting up of a new resource takes at least a year where it would be settled quickly in several places. If it is done efficiently it can be set up... and then there are other organisations which are setting up resources completely on their own and then offering it to the social work service or health to purchase places. Leonard Cheshire are doing it.

Maureen: We don't have problems with that at all on that scale like, Aberlour or Leonard Cheshire, things like that, as long as they were appropriate to the young person's needs.

Pauline: There are legal things as well if an organisation sets up. We can't then contract with them because we would be seen as being unfair to other organisations which is fair enough because if another organisation could have set up that service and we had tendered for it then... there's kind of legal issues.

Helen: So do you have to put a bid in to tender just the same as anybody else would. Is that what you are saying?

Pauline: That is how normally you would set up a new resource if the social work service or health or anyone was purchasing, education as well. They would say what they wanted and give different care organisations the opportunity to tender for them. It is just if an organisation goes up and sets up a service and then we contract with them without negotiating with other organisations we are seen as unfair and there could be legal action brought against the council so I mean there are kind of issues.

Helen: So if an organisation sets up a service, you are not allowed to commission places in that?

Pauline: Yes we can commission places but we can't block contract if you like for the whole service.

Helen: Right. You are just doing it on a one off.

Pauline: Because we would be asking other organisations if they could offer a service to that person.

Helen: Right, I understand.

Pauline: You get through choice as well if somebody chooses that and then they ask us to fund it, it is different from setting up a contract.

Anne: So maybe part of the problem could be overcome by having joint funding. Some of the parents wonder, usually the money seems to be there when they are at the school and suddenly there is no money there when they are an adult, is there any... How do we feel about having the funding following them through their life career, their life journey?

Pauline: That would be great.

Helen: Pot of money to follow.

General agreement.

Anne: The other thing that we were talking about, you know if the local authority hasn't got the funding and the resources do you think there is a need for something to happen at national level, maybe us parents we know that the Record of Needs is a legal document whereas the Future Needs Assessment process, whatever is recommended, they are not obliged to take these issues forward or to provide the services, whereas with the Record of Needs there is a certain obligation. Do we feel that that needs to be changed?

Helen: Yeh I think it should be the same as the Record of Needs (nods of agreement from family carers), the Future Needs Assessment, you kind of wonder why you have them if there is no obligation to carry it through.

Maureen: That's right.

Pauline: Is it not more the Community Care Assessment than... you know once the young person becomes 18 they come under the Community Care Act and under that Act the local authority is obliged to assess for need and to provide for those needs within the resources that it has.

Helen: But then it is always within the resources...

Pauline: So it is actually in the Community Care Act that stipulates you know in terms of that, you know once a person is 18.

Maureen: Because in black and white it's they are obliged to, it doesn't say they have to.

Helen: Uhuh.

Pauline: They have to assess

General yes.

Pauline: And they have to meet the needs within the resources that they have as best they can so there is no... (nods of agreement from family carers) the legal requirement for the authority to provide for those needs if they don't have the resources.

Helen: Yeh (nods head).

Pauline: I mean obviously they do try but I mean if the finance isn't there for everyone then you know it is the politicians that have to make the decisions about whether or not local authorities get more money.

Helen: So you mean changing that Act to make it the most...

Pauline: It is not the Education Act that there's a problem with here it is...

Helen: It is the community...

Maureen: Scottish Executive.

Pauline: But I don't know what it says in the Beattie Report and the "Same as You?" about financing, I can't remember if there is any... because I think it is still the Community Care Act is still relevant.

Jillian: Yes, I don't think it has changed (others agree). The other thing of course is the carers assessment which the social work department has to provide if the carer requests it but again they don't actually have to meet the...

Helen: That's the same.

Jillian: They don't have to meet the identified needs.

Helen: That's right.

Jillian: But at least it does... I suppose what it does is it helps to identify the unmet need for planning purposes but again it is...

Maureen: Does it go forward?

Helen: But does it go forward... I was going to ask, you took the words out my mouth(looks at Maureen), does it go forward from there.

Pauline: The carers assessment will because the systems have been set up to ensure that that does. It has only just been launched.

Jillian: I am about to circulate that to the families that PAMIS is in touch with so that people can either do their own assessments or at least get their needs on a data base so that...

Maureen: That will be great.

Anne: So would we like to see further education as a right for all young people?

Maureen: Yes.

Helen: Yes because education is lifelong learning it is called now, isn't it, for adults?

Maureen: They go on about that in the Scottish Parliament. I mean there is a lifelong learning minister, so there you go.

Helen: I find a lot of our young people's education if you like is involved in physiotherapy as well you know it was all part of encouraging you know their daily input of physiotherapy and everything, to me that should be included in lifelong learning because it was part of their education (general agreement) and that stops as well so, you know it seems to be when they get to 18, 19 there is no disability now, that is almost what it is, so I think it should all come under the same umbrella.

Anne: So you would maybe like a commitment for lifelong learning to continue after school?

Helen: Yes, yes.

General agreement.

Anne: At all levels, national, local.

General agreement.

Helen: Mhm, I mean that is everybody's right isn't it, I mean that is our right as well. I mean we can go and access anything that...

Pauline: That is clearly laid out in the Beattie Report and the Education Act but certainly education, there is one person in education who comes to the post16 group and she really has a fight on her hands in terms of putting the case across for profound learning disability. It is just, our education service just don't listen to that post 18. The colleges and everything are great for that sort of thing you know, for younger people with perhaps a less level of need and they have a really good relationship in that but it is almost again like there is nothing really for profound...

Helen: Yes, that's why I'm saying...

Jillian: It's particularly important because people with profound and multiple learning disabilities aren't realistically going to be able to think about employment (agreement from family carers), so education is their key thing.

Maureen: They need a constant stimulus to keep them...

Helen: And that is why I was saying even that physiotherapy was part of their education (general agreement) so you have got to carry that forward, that is part of their lifestyle, that is part of their learning.

Pauline: The Beattie Report says that in all sort of community resources where people with profound disability are placed that there should be education input into those and there isn't at the moment. Some people working in them have backgrounds in education and community services and users skills but that is just pot luck...

Jillian: And that is a driving issue for staff isn't it because a lot of colleges are not going to have the skills necessary to work with people with PMLD so there is a very major skills issue which hopefully the Scottish Consortium will start addressing and developing training modules across the learning disability section and are very keen to get into that so hopefully in a year's time they will have a shelful of things people can use. Staff and primary carer training and all sorts of issues. So em...

Anne: That's fine then, is there anything else anybody would like to add?. (No response). I think we have covered all the points, solved all the problems (smiles).

Helen: I just wondered will your study be carried on to anything. I know you are doing it for your PhD but will...

Jillian: Where will it go Anne.

All talking.

Helen: But I see it as a very valuable process.

Anne: Well Capability Scotland with their transition co-ordinators...

Tape turned off.

Appendix N Raw data from the nominal group discussion

Table 43. Raw data from nominal group technique

Number of item	Ideas generated	Number of votes
1.	Adapted building, wheelchair access, but staff more important than building. Need a special care suite with all the equipment.	0
2.	Provision outside the home, within reasonable traveling distance (half an hour), homely, comfortable, not institutionalized.	0
3.	Staff trained in aspects of personal development, education, healthcare procedures, social care so that they are independent from parents' help and outside professionals.	3
4.	All the needs are met after leaving school – in the home as well as environmental issues, practical things and placements.	0
5.	Continuity of care equal to school provision – healthcare, education. New opportunities, the chance to experience new things (personal development). Experiences outside the centre or home e.g. attend college.	0
6.	Provision has an individual lifestyle plan which is on-going and developed by person-centred planning ~~specifies~~ based on needs and interests.	3
7.	Healthcare – access to health screening, health promotion, healthy living, supporting families in healthcare needs related to disability, support during illness and crisis support. Multidisciplinary team at all levels of care. Practical help. Training and ongoing support for carers in healthcare procedures, use of equipment, moving and handling.	4
8.	Recognition that every family situation is different so need to design a choice or selection of flexible services to meet needs e.g. respite care and to be able to buy and organize them for themselves e.g. Direct Payments, Independent	2

	Living Fund.	
9.	A range of therapies and creative activities individually prescribed e.g. aromatherapy, reflexology, hydrotherapy, physiotherapy, music, art, speech, occupational therapy. Able to use ~~alternative~~ complimentary therapy or medicine.	0
10.	Day services open seven days so people have a choice and respite (in terms of a break for carers, but must be enjoyable for person) linked to the centre with appropriate client mix for reasons of health and safety.	4
11.	Day services centre-based with good programmes. Need to access community resources but they need to be equipped. Outings need a purpose and to be meaningful. Attitudes need to be welcoming. Public need to be educated.	1
12.	Good liaison/relationships between staff and families.	0
13.	Staffing levels must at least be one to one, sometimes need to be two to one e.g. for hoisting. Also need to have good back-up when staff is off ill or if staff meet problem not equipped to deal with.	4
14.	Pre-agreed procedures/protocols between staff and carers in the event of an emergency or crisis e.g. if cannot contact carer. Included in care plan, have contact with local GP centre.	0
15.	People planning services need to accept that good quality care for people with profound and multiple learning disabilities is expensive and that there are more living in the community because of closure of long-stay hospitals and because of improved medical care, so need is increasing. Public services need clear roles and responsibilities, joint funding, joint responsibility. Funds ring-fenced.	2
16.	Transport – flexible, accessible, suitable, used creatively.	0
17.	Need special dedicated services. Healthcare and special needs have to be met first for social inclusion to take place.	1
18.	Recognition that young person and their families may	0

	want to move on - to live independently from family carers with full support. Not institutionalized.	
19.	Parents fully consulted in planning services and choosing staff.	1

Key to table:

~~6~~	covered by another contribution or amalgamated in another idea
Normal text	idea as generated by group member and recorded verbatim
Italic text	addition to original idea
~~Strike through text~~	removed from original idea
Underlined text	underlined on original record for emphasis

Appendix O Transcription of nominal group discussion

Pseudonyms for interviewees: Helen (carer), Maureen (carer), Roger (carer), Jillian (professional from a voluntary organisation), Pauline (professional from the social work department).

Cities, places and names described in the interview have been changed in the transcript in order to protect the identity of the interviewees.

Name of interviewer: Anne

Date of interview: 12.02.02

Time: 10.30 – 12.00

Setting: Anne's house

Anne: Maybe if you could each just say your name first, I am Anne.

Maureen: Maureen

Roger: I am Roger. I would say the provision has to be outwith the home, i.e. the person travels to and from the provision.

Jillian: There is quite a lot of little squeaks on your tape.

Anne: So the provision has to be outside the home so what do you mean by that, do you want it in a... what size and things like that and location.

Roger: Well that was my next point, location was within reasonable travelling distance from the home. I would say half an hour maximum by taxi, minibus etc. Yes the provision ought to be homely.

Anne: By homely...

Roger: Well comfortable...

Anne: By homely do you mean small.

Roger: Not institutionalised. I have seen some places that there are rooms off a central corridor which it is not ideal but....

Anne: Jillian, do you want to just say your name for the tape.

Jillian: Jillian. Thinking about day opportunities or services, Maureen mentioned the importance of staffing to develop that, I think we need to go for staff training particularly in aspects of personal development for the person attending the service, education and importantly health care procedures that they may need so that the staff can be independent of parents coming in to perform procedures which staff are not accredited for.

Anne: Staff training in aspects of personal development, education and health.

Jillian: Healthcare procedures including nursing, I suppose just healthcare procedures would do so that they are independent of support from parents and from outside professionals who may or may not be available...

Anne: Okay, is that fine?

Jillian: Yes that's grand.

Anne: OK thank you Jillian.

Pauline: Some of those are the same but I suppose one that I thought about was that there is no point in having sort of external provision until everything is in place at home to make sure that all the support needs are at home that the person needs after school.... you know once they leave school.

Anne: What do you want me to put for that? All the needs are met at home?

Pauline: Yes I suppose it was the thing that it is not just... it is <u>all</u> the needs sort of after leaving school are met at home and outwith home, so that if there needs to be any changes in the environment or....

Anne: All needs are met after leaving school... in home and did you say environment.

Pauline: Yes I think you know that everybody's situation is different so that when you are going in to look at support needs of a young person that... not to just assume that it is outwith the home that there may be needs in the house that are required (general agreement). I suppose it is sort of any environmental issues. I was thinking about you know practical things as well.

Anne: Is that OK there, all the needs are met after leaving school in the home as well as environmental issues and practical things.

Helen: Helen. I have as well my main one is all the health care needs being met without carers being on call and as well as the health issues being met that people are trained in the social care of PMLDs so that they fully... the staff fully understand... I think that would come under Jillian's wouldn't it?

General agreement.

Anne: Would you like me then to put social...

Helen: Yes please.

Anne: So I'll put in here social care.

Helen: Yes, and where Maureen had adapted the building, the adapted building, the wheelchair access so that there was a special care suite...

Maureen: Yes.

Helen: ... and all the equipment available in the centre so that people don't have to make do.

Maureen: I thought that with any building at all as long as they have got the right facilities inside it.

Anne: I am just underlining that to show that that's bits we have added when we were discussing things. So are all those bits we have incorporated them into the other ones, is that OK?

Agreement.

Anne: OK, will we go back to Maureen, maybe we have covered everything.

Jillian: I don't think so. It isn't just about day opportunities is it, it is about...

Maureen: The overall, the whole picture.

Anne: So is there any one you want to add on? (looks at Maureen).

Maureen: I just feel that for good quality post school provision the continuity of care that they have had throughout their childhood must still carry on, it is a must. It doesn't automatically stop when they leave the school.

Pauline: That is really education.

Maureen: That's right.

Jillian: And health.

Maureen: Health and education really because it can't...

Anne: So continuity of care, do you want from school there or just continuity of care and then list. And what were the things you listed then.

Maureen: Health care and education still goes on.

Anne: OK, is that fine, do you want to say something (looks at Pauline).

Pauline: Sort of new opportunities in that as well that they continue to learn, they don't stop when they leave school. To experience new things.

Maureen: That's right.

Pauline: That is part of your personal development.

Maureen: Yeh.

Pauline: Life experiences.

Anne: Is there a bit, something you were saying to add to that one Jillian.

Jillian: It was really just that educational opportunities shouldn't necessarily all be based in the centre, they could take place in colleges or community facilities.

Maureen: Outreach facilities. Yeh.

Jillian: Yes so it is exploiting whatever is available out there and ensuring people have access to it.

Maureen: Outside centres or home because a lot of people might not want to go to a centre but they should still have the opportunity to go to outreach.

Anne: Is that OK, right Roger.

Roger: I was interested in the provision of... providing or incorporating a sort of a life plan for the individual, for each individual because they are so different, their needs are different from one to the other so I think some, I don't whether you call it person... it is person centred planning which is about to come to fruition.

Jillian: Everybody going off on those courses and...

Talking together.

Anne: So you want the plan produced by person centred planning.

Roger: It probably has to be an ongoing thing and I don't know how soon it could developed, you know whether it could be developed within a couple of weeks of the person going to the centre or whatever but I think it needs to be ongoing as well because things will change.

Maureen: Because their health changes.

Jillian: It is not just about needs too, it is about interests isn't it.

Anne: So do you want me to put specifies needs and interests here.

Jillian: Yes. And perhaps based on rather than specifies, specifies sounds a bit tablets of stone-ish doesn't it.

Anne: Is that OK for that one. Fine now where are we at, Jillian now.

Jillian: Look at health care and that would be about screening and positive health promotion as well as looking after people's ongoing health care needs, illness and crises, a whole range of things.

Anne: So that was screening...

Jillian: ...access to screening, health screening, health promotion, healthy living, whatever you call it. Perhaps the next one is supporting families in healthcare needs related to disability. And support during illness and crises support and I think there is a real role for mixed teams of social care and nursing staff at all of those levels.

Anne: So a multi disciplinary team, is that OK.

Jillian: Fine and practical support, emphasised.

Anne: I'll put at all levels of care.

Jillian: Practical help in capital letters. The other thing is before I finish is access to training for carers.

Anne: Is this a separate one.

Jillian: Well I was thinking of health care procedures but we could make it into a separate one if you want to and refreshing practice.

Anne: I will just put it all under this one. So that is training in health care procedures was it...

Jillian: For carers, training and support sort of ongoing really, updating.

Helen: Instead of you have been shown it once and hope you get it right the rest of the time.

Jillian: Exactly. And not being told about new techniques, new drugs, new pieces of equipment.

Anne: Training and ongoing support for carers in...

Jillian: Health care procedures and use of equipment etc. The one that everybody always mentions is the moving and handling. I don't know if you want to specify that. It is very important for carer's health.

Maureen: Your back.

Jillian: Yes.

Anne: OK, Pauline.

Pauline: I think it is about recognising that every family situation is different (nods of agreement) and designing a choice of high quality resources.

Anne: Recognising that every...

Pauline: Family situation is different. So designing a choice of good quality resources or a selection.

Roger: Would that include therapies like speech and language, music physio.

Pauline: I think it would be... well I was thinking of things like respite care which is different for each, or can be chosen differently, some people want it at home, some people want it while they are away, some people want it at week-ends, some people just want it for a month a year, you know in a block so it is about designing them so they are flexible to meet the needs.

Anne: So do you want me to put flexible.

Pauline: I think every family have different levels of what they regard as privacy and dignity and you know, everyone is different (nods of agreement), so some families would choose say to want to be able to buy care themselves whereas others don't want that so I think it is kind of flexibility, choice, in each family situation. And to be able to buy them themselves if they wish, to organise and purchase themselves if they wish.

Jillian: Use of direct payments.

Anne: Will I put e.g. direct payments?

Nods of agreement.

Pauline: It is usually a combination of direct payment and ILF (Independent Living Fund).

Anne: Is that OK

Pauline: Roger you mentioned therapies...

Helen: Yes, I think that's important...

Pauline: ...because I suppose I think of you know, I know that aromatherapy and reflexology...

Maureen: Music

Pauline: ...and also some people have had a lot of success with homeopathy rather than drugs, you know so it is that kind of open option.

Anne: Do you want me to put that as a separate one then about therapies.

Roger: I wondered if it would come under the person centred planning. I have it down as a separate you know therapies prescribed for the individual but...

Maureen: Put it under the opportunities bit, experiences, because some of them will have had sort of like a music kind of therapy at the school but not real music therapy like Nordoff Robbins that they get now.

Roger: Yes.

Anne: So what do you want me to do, put it there, do a new one or what.

Pauline: I think it is quite a big...

Roger: Well that was one of the reasons we felt this particular post school provision was suitable for my daughter because of the range of therapies that were available.

Maureen: Including aromatherapy.

Anne: So will we put that then as a separate one because it is quite a big...

Roger: Fairly major, isn't it?

Maureen: It is like their daily...

Jillian: It is activities partly too, it is not just about therapies, it is about things that people enjoy and extend their experiences.

Maureen: Yeh, going to, trying...

Anne: So what do you want me to put.

Roger: A range of therapies individually prescribed and you could list them, you could list them all if you like.

Anne: So aromatherapy, do you want that as one of the things?

Roger: Yes, aromatherapy.

Maureen: Because it gives them a different sense, a sense of smell, touch and....

Helen: Reflexology.

Maureen: Touch.

Roger: Hydrotherapy, physiotherapy.

Anne: Did somebody say music.

Maureen: Music therapy, speech therapy.

Pauline: Music and art.

Maureen: Arts and crafts.

Helen: Occupational therapy.

Pauline: About being able to use alternative or complementary medicine as well if it is appropriate.

Anne: Is that an i, I am not sure.

Roger: Yes I think alternative comedians were always frowned upon, they were going to...

Pauline: They are not usually very complementary comedians then are they.

Anne: I'll take alternative out then, is that what you are saying.

Pauline: Is it therapy or medicine because homeopathy is complementary medicine.

Jillian: There is quite a range of things in there, some of which you could see as therapies and some of which you could see as more treatment, some sort of creative activities which are valuable for personal expression rather than just therapeutic in inverted commas if you see what I mean, it is quite an important distinction.

Maureen: And still social as well because they are in a group with peers or...

Anne: Do you want a range of therapies and activities added in there?

Jillian: Yes I think so because I think it is... the two things are interlinked.

Anne: Creative activities.

Talking together.

Maureen: Well going into the pub for a bar lunch isn't quite creative but I mean it is a thing if you enjoy it, it is a social aspect.

Anne: OK, Anne have you got any more?

Helen: Open seven days so that people have a choice.

Jillian: This is day services, Helen?

Helen: Yes.

Anne: I will just put day services here.

Helen: And respite linked to the centre. And appropriate how do I say client mix (nods of agreement from Maureen and Jillian) so that there is no... they are very vulnerable, so that there is no threat if you like. Somebody maybe with a different condition, not different condition but...

Pauline: It's a safety issue isn't it?

Anne: Do you want me to add anything to the centre with appropriate client mix, do you want put for reasons of safety or...

Maureen: Yes, health and safety.

Jillian: That's an example of not mixing of people who are physically very dependent and people with challenging behaviour. Or people who are ambulant and have challenging behaviour.

Anne: Do you want me to put an example or is that clear enough.

Jillian: No I think that's clear enough.

Helen: I am trying to pick out what you know has already been... em, yes I have got all the therapies. The emphasis is on at the moment I think is on accessing the community, whereas, yes, that is a choice but I think if the person, it has to be a building where, building based so that if the person is not up to going out, you know they can stay in the centre and still have a programme developed for them with good opportunities within that centre (general agreement) because I am afraid that everything is going to be too much... accessing outside if you like going out for the sake of going out. Yes if it is a good choice, a good thing that they are going out to do but not just going out for the sake of going out because if it is pouring of rain, oh we have got to go out. I still feel there is a need for a good centre based...

Jillian: I think there are day services where people are just going out to hang around shopping malls...

Helen: Yes.

Jillian: ...and that sort of thing, that is not ...

Helen: I think that some of the things are being misinterpreted I think from the Same as You report. Accessing outside is all very well but not just going out for the sake of going out.

Pauline: I think as well that the community isn't ready.

Helen: No (nod of agreement).

Pauline: I mean our experience as well is that you know re-provisioning day care services for people who are more able isn't too difficult in terms of accessing community resources but when you require specialist equipment and specialist staffing and also there is the privacy and dignity aspect as well...

Helen: Yes, absolutely.

Pauline: ...that none of our community resources are really equipped...

Helen: No (agrees with Pauline).

Pauline: ...so as you say, we can't run before we can walk sort of thing, we can't provide for those people with more sort of profound difficulties.

Helen: And a good liaison with the centre, with the staff and the families.

Anne: Coming back to this one, I have put day services centre based with good programmes. Access community resources but need to be equipped.

Helen: And meaningful.

Anne: Outings need a purpose and I'll put and to be meaningful.

General agreement.

Pauline: It is also about discrimination as well because you know in terms of to be equipped in terms of their equipment but also in attitudes...

Helen: Yes, that's right.

Pauline: ...you can't set people up to go into somewhere where they are not going to be welcome.

Maureen: We have just had a wee taste of that, we were going into somewhere like for a Christmas meal, a bar lunch, people at another table objected to our ones sitting there, wanted them moved.

Jillian: Oh that's terrible.

Pauline: And how did the staff handle it.

Maureen: The staff handled it exceptionally well in that hotel. They actually went and said well look we will ask these people to move because if they are the ones that is upset, nobody else but what our staff did, they actually moved round the corner and the staff went out of their way to make it the best possible Christmas meal and I thought... and you know who it was it was two elderly ladies who had nothing more better to do with their time than be there for a bar lunch. There but for the Grace of God go your grandchildren.

Anne: So will I put public need to be educated.

Maureen: Yeh, big time. I was really upset when they come back and said that to me, I mean I was crying. Anger.

Jillian: I think the difficulty is that it is partly about people's fear of the unknown and if people aren't... if people with complex needs aren't able to get out and about those fears persist and it is only through becoming used to accepting everybody and it is just like...

Maureen: I wonder what they would have said if they had been say a rowdy group of teenagers, they were just sitting there minding their own business, doing nothing.

Helen: I think that incident, that is selfish, that is not even a fear.

Maureen: No, that's ignorance.

Jillian: To actually get as far as complaining is appalling.

Anne: Sorry Anne you said another one.

Helen: Good liaison between staff and families. A good relationship really.

Jillian: Not exactly a Christmas spirit is it Maureen.

Maureen: Not exactly, especially when everybody was there for a Christmas lunch. Can I go on to staffing levels?

Anne: Is that OK Helen?.

Helen: Yes.

Maureen: Staffing levels <u>must</u> at <u>least</u> be one to one (nods of agreement) and on quite a few occasions it has to be two to one for changing etc.

Helen: I think the European laws.

Maureen: The European Standards.

Helen: It has to be two to one isn't it for some, for like hoisting, there is supposed to be two people.

Roger: Yeh, it has to be two.

Jillian: That's for staff, it doesn't apply to parents though.

Maureen: No unfortunately, no.

Pauline: I think linked to that is the thing about having good back up as well. If somebody goes off sick you have got somebody equally skilled to step in.

Maureen: Yes, back-up.

Jillian: And also access to some kind of expertise if you encounter a particular problem.

Anne: Have good back up when staff ill.

Pauline: Or if they can't tackle something.

Jillian: Or if they meet a problem that they are not equipped to deal with.

Roger: What I had down, pre-agreed between the staff and carers, procedures or protocols in the event of an emergency.

Jillian: Yes.

Roger: You know there could be times where staff aren't able to do something.

Anne: Sorry is that OK for that one. Sorry Roger, can you say that again.

Roger: Yes, it was pre-agreed procedures/protocols, pre-agreed between staff and carers in the event of an emergency or crisis. I guess in that situation it would be where carers couldn't be contacted. I mean it wouldn't necessarily... I mean you could agree something but I suppose what is more likely to happen if they couldn't contact the carer because they wouldn't know what to do.

Anne: Right, do you want me to put e.g. holiday contact carer or something.

Roger: Yes.

Helen: I am just trying to think on our one, we have got one drawn up that, I am just trying to think what it is in Faye's healthcare plan, it is all detailed down but even if they can contact us we might not get there in time so they have to have procedures to follow.

Jillian: Does it specify who to contact in terms of medics or...

Helen: It is actually written down, it is actually, we have it written down from the GP what to do. So I mean even if they can't contact us they have a procedure to follow, signs to look for if things aren't working when you do things and then what they do if those things... all the emergency numbers are there.

Jillian: Is that a standard thing in all the day services?

Helen: I don't know but it certainly is on Faye's.

Roger: I don't think so.

Pauline: It is possibly for people with high needs.

Helen: It is certainly in the social work led one, [F]s day plan is listed from the minute she goes in in the morning, what happens with her in each stage of the day and all the contact numbers and the GP has actually done a thing, they have asked for the GP to do something that if their procedures don't... you know that they have followed through in the case of her asthma anyway, if they are not successful, what stages they have to go through and when to contact emergency services.

Jillian: Your day service is a social services one, I was just wondering whether Aberlour has a similar arrangement, it doesn't.

Maureen: Not that we are aware of.

Jillian: It should.

Anne: So is that in the day care plan?

All talking together.

Helen: There's a plan that Faye has you know it starts with the first page when she goes in in the morning, take off her coat, I suppose it is...

Roger: A lot of it is commonsense but I would be happier if it was written down.

Helen: ...you know and it is then somebody going to a system and an activity and then you are on to lunch time, what happens at lunch time and then you have got right through the afternoon but then on a separate page they have the procedures to follow that are related to Faye's problems and they got they asked, it was away back when she first went, the GP had to state the signs to look for when she is in a crisis with her asthma and the procedures to follow and if those things don't work, what next, so that it is outwith, so that it doesn't have to be... yes they contact us but if we can't get there in time because we are half an hour away, you know what has to follow then so that nobody is in any doubt.

Anne: So do you want me to put in there Roger, sort of included in day care plan.

Roger: Yes.

Anne: Do you think that is a good idea.

Pauline: Or any care plan.

Helen: Just care plan.

Roger: Yes.

Jillian: Or to anybody who is providing home care.

Helen: And contact perhaps with local GP centres.

Maureen: I am thinking about that, they could phone up our GP but they are not guaranteed necessarily to get her, it could be anybody and they wouldn't have a clue about Simon if you know what I mean, because ours is so big.

Anne: OK, Jillian have you got anything else still to add?

Jillian: I suppose a general point about finance that people planning services do have to accept that if the needs of people with complex, profound and multiple learning disabilities are to be adequately met, it is expensive. There is no two ways about it.

Anne: So people planning services need to...

Jillian: ...accept that

Pauline: Good quality care is expensive.

Jillian: Well even basic care is expensive but good quality care is...

End of side 1
Side 2.

Anne: Good quality care...

Jillian: ...for people with PMLD is expensive and that there are more of them living in the community partly because of hospital care share programmes and partly because of improvement in medical care so it is an increasing need. Small group but...

Maureen: Healthcare.

Anne: Because of closure of long stay hospitals and what was the other thing you said.

Jillian: Because of improved medical care.

Anne: And then you said something about the need.

Jillian: The need is increasing for that reason.

Anne: Is that OK then? (Jillian nods) Pauline.

Pauline: Similar to that, it is about the kind of joined up health, social work, education organisations. There is still too much, you know when somebody needs something, they can't decide whose responsibility it is to pay for it and I mean that is just in this day, unacceptable.

Anne: Do you want me to put statutory services or do you want me to write health, education and social work.

Pauline: Is it public services? Although I mean, there is housing in there as well.

Jillian: Commissioned services as well.

Helen: I suppose it is really sort of acting to a crisis, there should be protocols set down.

Pauline: Yeh, clear roles and responsibilities but I mean I think you know we are moving along that way, there should be a pooled budget for this group. There should be a single management of that and planning for it.

Jillian: And really I think what it needs is a ring fenced budget like Fife's palliative care services are ring fenced and I think that for people with PMLD that would be a very good idea as well because they are a very small group compared to the elderly or whoever (general agreement), they have very very massive intense needs and the only way that they are going to kind of compete for resources is if there is ring fencing I think.

General agreement.

Pauline: That's discrimination again, just because they are a small group, doesn't mean to say they are any less important than anyone else.

Maureen: And they have not got the loudest voice, like a pensioner group has got really all they need.

Talking together

Anne: Joint funding, joint responsibility, funds ring fenced, anything else. Is that OK for that one. Has anybody got any other points that we can put down that you feel we haven't covered or you want to incorporate into any of the other ones we have got there.

Pauline: Transport was one I had. I don't know if we have mentioned that specifically.

Maureen: No we haven't actually.

Jillian: There is a lot of new money coming into Fife for transport.

Anne: What do you want to say about transport.

Pauline: Again that it is kind of flexible and you know is used creatively and accessible again.

Helen: Suitable.

Pauline: I think it is just a major issue in terms of accessing community resources...

Maureen: One or two evenings. Like buses have the low liners, Simon was on a bus for the first time when he was 20. A public service bus.

Pauline: Did he enjoy it?

Maureen: He did yes, he did. It has taken 20 years to get him on a bus.

Jillian: One general point, I think it is this debate about special dedicated services and inclusion, I think it is really important, particularly for things like health care, to say that people aren't going to be included into the community until their special needs are met first because I think there is a lot of talk about community inclusion which tends to make people who are asking for special services feel guilty and inclusion is not going to be real for people who have got substantial disabilities unless those special needs are met first. I don't now how you put that down but...

Anne: See what you think.

Jillian: And you get criticised as an agency because we concentrate on profound and multiple learning disabilities and people say oh well everybody can do this, this and the other, everybody is equal, everybody can (...) and all that is true to some degree but only...

Maureen: Not in (...)

Jillian: But people aren't going to be included in this unless their needs are dealt with first.

Anne: I think it was special dedicated services, health care and special needs have to be met first.

Jillian: Does everybody agree with that.

General agreement.

Pauline: I was also going to say that you know after school it may be the case that the young person wants to leave home or as a natural stage that the family would want that but you know somebody reaches 18 to 20 when they normally would be thinking about leaving home, well why can't they...

Jillian: Yes I don't think we have mentioned community housing at all have we, it is an important thing to get done.

Maureen: All view point considered, family carers etc.

Jillian: Recognising they may want to move on and...

Talking together

Jillian: Post school provision should be there to meet that need too. Supported living scheme, we may start to address that.

Anne: I have just put housing.

Maureen: It's expensive supported housing.

Jillian: Yes I know but that is there problem isn't it (laughs).

Maureen: Well they should have the choice, they should have the right to move on to like every young person does and it should not be institutional.

Anne: So recognise that young people may want to move on to live independently and you said not institutionalised.

Maureen: Independently. In our group (working group set up by the Same as You Project) we are talking about it would have to independently from family carers because they couldn't possibly...

Jillian: Exactly I was just thinking that yes.

Pauline: With full support. The young person may want to move on but also the family may feel that they...

Maureen: Everybody gets to that stage, they do. I am there already (laughs). Two for the price of one.

Jillian: It is a natural process.

Maureen: Yeh.

Anne: And their families. Is that fine. Is there anything else anybody has got.

Jillian: Somehow if we can get in the thing about ensuring that parents are fully consulted in the development of services and in the selection of staff. That was reminded me about that before you were writing 18 about community housing because we were instrumental in helping another pressure group in Penton and Kiddermouth get a community house set up and the first service provider who went in were a total disaster and subsequently, I am not sure whether the parents were involved in that selection, I don't think they were but subsequently I think parents have been more involved in choosing and that has been really really important and...

Anne: Parents fully consulted in planning services and choosing staff. OK?

Jillian: Yeh.

Anne: Anybody else have any more? I think that is us got 19. Do you want to look at all the ones we have got and see if there is any ones that you think we have doubled, you know we have got doubles of or any things that you think should be combined.

Jillian: Short breaks, we must have that in somewhere.

Anne: You said something about that I think connected to day services, can anybody see what number that is?

Roger: Ten, open seven days, people have a choice, respite.

Anne: Respite at the centre. Is that OK?

Roger: Do we need to define respite?

Jillian: We probably do, yes because there is a dispute about that at the moment isn't there.

Maureen: What people class as respite is day care. To me it is not respite, it is...

Jillian: Perhaps we should make a clear distinction because other people don't always do.

Pauline: It can mean different things to different people.

Maureen: ...to different people, true enough.

Jillian: There is respite and breaks in the home.

Maureen: Everybody I have spoken to with PMLD, I mean day care is certainly not respite, no. But different people I agree, different people do have different aspects of respite.

Pauline: Some people, again, they would rather have somebody in their own home so they could go out or you know, say it can just be a day can mean more to some people than a fortnight.

Maureen: Or a week-end or a...

Anne: So how do you want to define it.

Maureen: To define respite. That is the thing. It is so indefinable, it is just...

Anne: When we had Paul Erdley to our group he defined it as something that is enjoyable to the carers and the cared for person so it is something that both parties enjoyed.

Pauline: Benefit from.

Anne: Yes or benefit from. That is a very wide definition. It could be everything.

Jillian: It doesn't mean any kind of break which is an important aspect.

Roger: What we were accustomed to when we lived in Middlesex was you know every Friday night in the week she went for tea and then a long week-end every month and two week block stay in the summer.

Maureen: Which is ideal. Doesn't work here (laughs). Fife does not have that policy.

Jillian: Did Geri enjoy it too?

Roger: Oh yes.

Jillian: That was children though wasn't it.

Roger: That was children yes.

Helen: Even with children though they wouldn't get that much.

Pauline: They don't have the provision here.

Anne: So will I put in terms for a break for carers and then you want something about it must be enjoyable for the person as well.

Maureen: Definitely.

Helen: Because I think that is something that we tend... I think it is tends to get lost in that it is very much because the caring role is so intense with someone with PMLD, it is emphasised as a break for the carer but I think that it is lost that it has to be, you know you have to look at the young person that is going to the respite, it has to be something that they are going to enjoy. It is not just to get them shunted away out the...

Pauline: Well you are not going to relax as a parent...

Maureen: Well to be quite honest with you, where Simon is for respite, I am not saying things or names or anything but I don't think it is so enjoyable for him if he didn't have his day care to go to as well. Because the staffing levels just are not there.

Jillian: So that won't make you feel particularly relaxed about it either.

Maureen: But I have to have a holiday, I have to.

Jillian: Of course.

Anne: So is everybody quite happy with what we have got up. Now is that OK then. So when I write it up, all these things will go in the report but to maybe prioritise some of these things, I will give you a piece of paper and you can vote for say 4 and that might get us down to a smaller number. You don't need to write the thing out just right a number so you will have four numbers on your piece of paper.

Roger: And that is for what purpose, Anne, why do you need to have just four.

Anne: Well there will be 19 things will go into the report at the end but maybe to show what is the really essential features, that is what we are going to vote on.

Appendix P Analysis of documents

Table 44. Analysis of Geri's Future Needs Assessment meeting minutes dated 29 January 2001 using the open-ended note-taking method

Content of document	Comments or interpretations
1.List of those attending	Multi-disciplinary team (9 professionals) and parents
2. School report and parent's comments tabled as documents	Parents happy with school provision
3. Social worker informs meeting that post-school provision is being considered for Geri at an adult centre in her own town and costings are being carried out.	Lack of involvement of parents in decision-making process
Geri met the disability criteria for a five day placement and respite would be treated as a high priority (to a maximum of 56 nights per year). Plans under way to provide home care support in the mornings	Raises false expectations that post-school provision and respite care services are available. Parents later informed that the local centre lacked resources to meet Geri's needs, this appeared in Brown's report in 1997, suggests lack of knowledge and information on the part of the professionals.
4. Parents express a strong desire to be involved in evaluating placements for Geri. Fear decisions will be finance-led, rather than needs-led.	Parents want to be involved in the transition process
5. Suggested that parents should look at placements if they wished.	No offer to make arrangements to visit placements, no information about other placements was given to the parents
6. Parents express concern that Geri's healthcare needs are not well met by existing provision in Fogart.	The meeting of Geri's healthcare needs seen as important by the parents
Comment on the lack of communication between health and social work services	Suggests difficulties with joint working.

7. Social worker acknowledged that a nurse might be required at the local adult centre to meet Geri's healthcare needs and the school medical officer agreed to write to a consultant from adult healthcare services concerning Geri's healthcare needs.	
The social worker pointed out that providing a nurse at the local centre would have funding implications. The headteacher informed the meeting that at the school nursing support was being funded jointly by Fogart Healthcare and by the education department.	Suggests that there is joint funding of nursing support at school level but not at post-school provision level.
8. Suggested that Geri be assessed for equipment she might require at any post-school provision.. Headteacher agreed to arrange for a formal assessment to be made.	No mention of this at next FNA meeting, suggests failure to carry things forward
9. Date of next meeting arranged, agreed to invite consultant for adult healthcare services to next meeting	

Table 45. Analysis of Geri's Future Needs Assessment meeting minutes dated 14 March 2001using the open-ended note-taking method

Content of document	Comments or interpretations
1. List of those attending.	Multi-disciplinary team (6 professionals) and parents.
Consultant who was invited to attend did not appear at the meeting, "children with teaching difficulties" not part of his remit.	Suggests lack of communication within healthcare services
2. Purpose of meeting – establishing post-school provision for Geri	Three months left before Geri due to leave school
3. Parents have visited two placements, both considered appropriate for Geri	Parental involvement, parents have sought out alternative placements for Geri.
4. Social worker comments on the availability of both placements Confusion amongst professionals about whether one of the placements provided long term placements or only assessments.	Lack of knowledge about post-school placements on professionals' part
Decision pending about Geri's attendance at other placement, other adult being considered for place as well as Geri.	Suggests shortage of provision
Social worker could not provide timescale for the decision.	Only three months of schooling left, not sufficient time for a smooth transition.
5. Transport would need to be arranged	
6. Respite care provision discussed. The respite care Geri received as a child ends at the summer (three months time), shortage of places for adults, social worker to consider places outside the region, nursing home suggested as an "absolute fallback".	Suggests little, or no age appropriate, good quality respite care facilities for this group of young people in adulthood. Although focus was on post-school provision, parents anxious about respite care provision in adulthood.
7. Healthcare needs discussed. No equivalent to Geri's paediatric consultant available to Geri in adulthood. Geri's notes passed to a manager at	Suggests healthcare needs not being adequately met in adulthood. Although focus was on post-school provision, parents anxious about the

the health board.	ability of health services to meet Geri's healthcare needs in adulthood.
8. Home care services being considered.	
9. No date set for next meeting	No monitoring of progress.

Appendix Q Respondent validation

Copy of letter to the parents/carers, asking for their comments on chapter 4, 8.10.01

Dear

I have finished writing up the findings based on my interviews with you and the other parents. I would like to make sure that I have all the correct details about X and the difficulties you had during the transition stage. Therefore I would be grateful if you could read X's profile and let me know if you think it's okay. Please feel free to write on it if you want to make any changes.

I've also enclosed a summary of my findings. I would be grateful if you could comment on them. I have enclosed a comment sheet but again feel free to write on the summary if you want to make any changes. You can miss out the other people's stories, if you like (Simon's on pages 4-7, Kylie's on pages 7-9, Geri's on pages 9-11). In case you want to read the whole draft of Chapter 4 of my thesis, I have enclosed it too. You don't have to read it, it takes about two hours to read! It's only if you're interested.

Thanks for your help.

I hope to arrange the focus group discussion before the end of the year. I'll contact you soon about a date.

Best wishes

Copy of letter to the members of the focus and nominal groups asking them for their comments re chapters 5 and 6, 28.06.02

Dear

Please find enclosed drafts of chapters 5 and 6 of my thesis. I would be grateful if you could find the time to read them over and provide me with some feedback about my interpretations of the findings. For example, what do you think about the themes and issues I have identified? Are there any other issues that you think are important? Please feel free to change the wording and to correct mistakes and inaccuracies.

I have also enclosed a Table from chapter 4 showing the problems identified by the parents during the transition period, as well as a copy of the nominal group technique results to refresh your memory.

I am on holiday from the 1st to 15th July, so there is no urgency for your reply. I also appreciate that some of you may also be going on holiday. Would it be possible to have your comments before the end of August?

Thanking you for your help,

Have a good summer, hope the weather improves!

Best wishes

Copy of letter to the members of the focus and nominal groups asking them for their comments re chapters 5 and 6, 2.10.02

Dear

At the end of June I sent you draft copies of chapters 5 and 6 of my thesis and asked you for your comments.

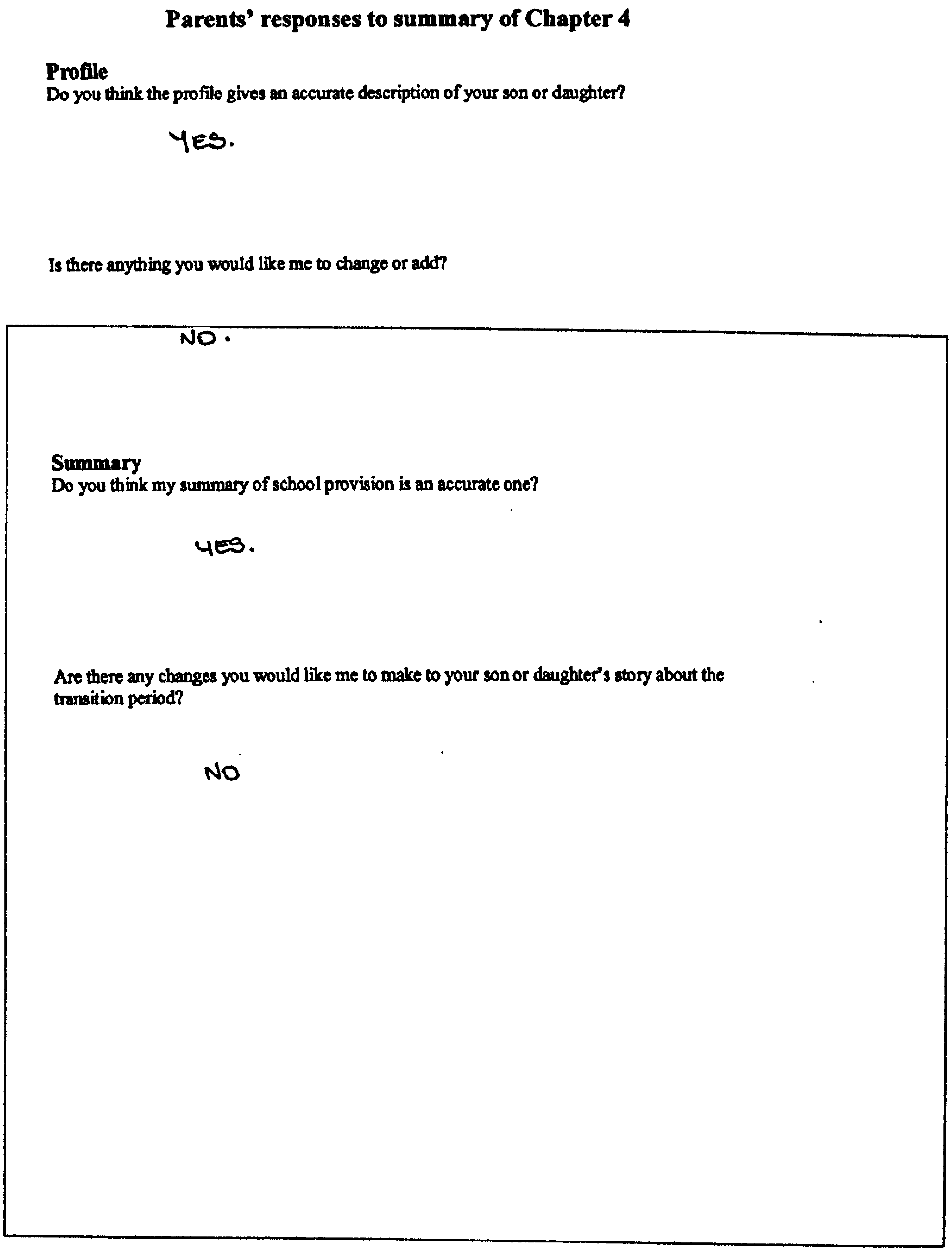
I would be grateful if you could find the time to read the chapters and provide me with some feedback about my interpretations of the findings. For example, what do you think about the themes and issues I have identified? Are there any other issues that you think are important?

If you have mislaid the chapters please let me know and I will send you new copies. I would be grateful if you could send your comments to me before the beginning of November as I am planning to give a draft copy of my thesis to my tutor on Monday 18 November. I enclose a SAE for your reply.

Thanking you for your help.

Best wishes

Examples of respondent validation for chapter 4



Parents' responses to summary of Chapter 4

Profile
Do you think the profile gives an accurate description of your son or daughter?

YES.

Is there anything you would like me to change or add?

NO.

Summary
Do you think my summary of school provision is an accurate one?

YES.

Are there any changes you would like me to make to your son or daughter's story about the transition period?

NO

Do you feel I have identified the main problems that you encountered during the FNA process and the transition period?

YES.

Is there anything else you would like me to include?

NO.

Have I accurately described how you feel about the post-school provision provided for your son or daughter?

YOU STATE THAT THERE IS NO MUSIC OR SPEECH THERAPY INPUT. ACTUALLY WHILST THERE IS NO FORMAL MUSIC THERAPY SESSIONS, MUSIC PLAYS A BIG PART IN THE CENTRE AND THEY DO HAVE MUSIC GROUPS - SOMETIMES INCLUDING INSTRUMENTS OR SHARING THE ENJOYMENT OF EACH OTHERS C.D'S.

SPEECH THERAPISTS DO HAVE INPUT AND HAVE WORKED CLOSELY WITH THE STAFF ON COMMUNICATION AIDS FOR FAYE.. SHE USES A MACHINE CALLED A 'BIG MAC' FOR VERY SIMPLE RECORDINGS THAT WE AT HOME & THE STAFF CAN RECORD, AND WITH ONE TOUCH FAYE CAN DELIVER THE RECORDED SHORT MESSAGE.

Is there anything else you would like to comment on?

THE ISSUE I HAD, WAS ON PHYSIOTHERAPY REDUCTION'. WHILST THERE HAS BEEN NO SIGNIFICANT INCREASE WE FIND THE PHYSIOTHERAPIST MUCH EASIER TO APPROACH AGAIN AND MASSAGE HAS BEEN ADDED TO FAYE'S REGIME. ALSO HER PHYSICAL CONDITION HADN'T ACTUALLY DETERIORATED, AS YOU STATE, BUT HER 'TONE' WAS INCREASING AND CAUSING STIFFNESS AND WE FOUND WHEN WE STEPPED UP THE THERAPY AGAIN THIS DIMINISHED. I HAD SO MUCH I WANTED TO SAY AT THE INTERVIEW THAT I PROBABLY LEFT THESE FACTS OUT.

PTO.

Thank you for your help

I MAY ADD THAT, OF LATE, THERE HAS BEEN AN IMPROVEMENT IN THE CENTRE'S APPROACH TO FAYE'S LEARNING DISABILITY AND THE ACTIVITIES OFFERED. WHILST WE STILL HAVE THE MEDICAL PROBLEMS THEIR OVERALL ATTITUDE HAS CHANGED FOR THE BETTER AND WE FEEL HAPPIER ABOUT THIS MORE POSITIVE ATTITUDE, WE ALSO HAVE A GOOD RELATIONSHIP WITH THE STAFF.

Parents' responses to summary of Chapter 4

Profile

Do you think the profile gives an accurate description of your son or daughter?

VERY ACCURATE, IN FACT SPOT ON.

Is there anything you would like me to change or add?

NOT A THING.

Summary

Do you think my summary of school provision is an accurate one?

IT WAS, WHEN OUR YOUNG PEOPLE WERE AT SCHOOL, THIS WAS WHAT WENT ON.

Are there any changes you would like me to make to your son or daughter's story about the transition period?

NOT ANY, AS EVERY POINT AND EMOTION INVOLVED WAS CORRECT.

Do you feel I have identified the main problems that you encountered during the FNA process and the transition period?

YES, IT WAS ALWAYS DELAYED, AS THERE WAS NOT A PLACE FOR OUR YOUNG PEOPLE TO GO TO.

Is there anything else you would like me to include?

NO, IT WAS VERY ACCURATE.

Have I accurately described how you feel about the post-school provision provided for your son or daughter?

YES WE ARE VERY HAPPY WITH IT AT THE TIME BEING.

Is there anything else you would like to comment on?

MY ONLY COMMENT WOULD BE, 'WHERE NEXT', THERE IS NO NEW, OR WORD ABOUT A NEW FACILITY FOR YOUNG PEOPLE WITH COMPLEX NEEDS SO THE FUTURE IS A BIG WORRY TO US.

Thank you for your help

Respondent validation for chapters 5 and 6

Anne: Comments on Draft Chapters 5 & 6 of Thesis

Chapter 5

P 1: PAMIS has now appointed a transitions worker in Glasgow. She is Jean Fairley, who previously worked with Paul Dumbleton in Glasgow PAMIS as our information officer there. They have developed a transitions pack (not sure whether it is finalised yet). If you want to get in touch, Jean's no. is 0141 572 0782

P 5-6: (quotation from Cohen et al): Key point that transitions team without accompanying services is 'papering over the cracks'. I'm sure that this was the spirit of the group discussion.

I think your whole argument about a protected transitions post is very important, because this kind of work always loses out to crisis work until it becomes a crisis in its own right.

Need for clear interagency transitions policy well argued.

Lack of resources section excellent: lifelong learning, funding (especially lack of financial clout behind CC Act, and FNA outcomes).

Reference to MENCAP's PMLD recommendations v relevant to the group's discussion.

Conclusion is succinct and comprehensive. Obviously the whole chapter is very relevant to local problems in Fife: will you be able to give a copy of your thesis to the powers that be here? That may be a little way off, considering how much of your time Fife demands! Seems to me that they need this kind of clear thinking now!

Chapter 6

Table from nominal group technique: this seems to me to provide the basis for a families' 'shopping list' for PMLD services. When we go to the SAY Project Management Team meeting with all the Chairs to tussle over prioritising spending proposals, perhaps we should base our support for projects on this? Interesting that health, day/respite and staff training are all highest scorers – no surprises there.

Themes: While obviously the discussion was on complex interrelated subjects, some elaborations/additions to the theme headings may be useful – although you deal with them all in the text itself.

Staff: suggest this is amplified to *Staffing ratios and staff training.*

Choice: suggest amplification to *Partnership working with users and family carers: information, consultation and choice.*

Inclusion and specialist services: perhaps add in *Balancing ... with the need for...* (You deal with this immediately in the text.)

One other theme to possibly add: *Person-centred approach.*

Probably clearer to list the themes in the order that you subsequently discuss them.

P 4: Day services – James currently has a researcher, Stephanie Connon, looking at 3 specialist day services for adults with PMLD - White Top, Aveyron and Carisbrooke – you might be interested to see the report when it is completed.

6-7: Uditsky argument about if you include those with PMLD, then everyone can be included, may be useful principle in arguing for provision in Fife, certainly for community/leisure provision.

P 8-9: Dessent/Dissent: what is the right spelling? Maybe there is a psychological spelling error here!

P 12: poems are good – you should reference them.

The chapter is excellent, especially the sections on healthcare and staffing.

Thanks for letting me have a look at it. All the best, Jessie

Appendix R Legislation and policy documents related to the study

The Disability Discrimination Act (1995)

This act describes responsibilities for services, including the requirement to provide fully accessible buildings and information to people. Organisations are to be responsible for providing disability awareness and equality training for staff.

Designed to Care (1997)

This document introduced Clinical Governance to improve quality and service delivery, with social justice and equity of care being seen as central to healthcare.

Social Inclusion: Opening the door to a better Scotland (1999)

This document sets out the programme to promote social inclusion in Scotland.

Beattie Committee Report (1999)

This report recommended that inclusiveness should underpin all post-school guidance, education and training (see also Chapters 1, 2 & 4).

Nursing for health (2000)

This document arose from "Towards a Healthier Scotland" (1999). It makes specific reference to specialist learning disability nurses and emphasis is placed on the need to develop and improve links and services for people with learning disabilities and complex needs.

SEN and Disability Act (2000)

This act extends the Disability Discrimination Act into schools, further and higher education. The main new sections of the act come into effect on 1st September 2002. These sections make it unlawful to discriminate against people with disabilities by treating them less favourably than others. In addition, they require responsible bodies to provide certain types of reasonable adjustments to provision where students with disabilities might otherwise be substantially disadvantaged.

The Human Rights Act (2000)

This act provides a framework around the rights of individuals and sets out how they can exercise these rights.

The Adults with Incapacity (Scotland) Act (2000)

This act provides for decisions to be made on behalf of adults who lack the capacity to act for themselves and will apply to many (but not all) adults with learning disabilities.

The same as you? (2000)

This report reviewed services for people with learning disabilities (see also Chapters 1, 2 & 4).

Moving On: From school to college (2000)

This report was published by HMI Education and identified general principles underpinning good arrangements for transition from school to college.

Regulation of care (Scotland) Act (2001)

This act established a Scottish Commission for the Regulation of Care to regulate care services, including residential and nursing care, day centres, home care services and childcare for all children and vulnerable adults.

Patient focus and public involvement (2001)

This document outlines the commitment to involving people more in decision making about their care and influencing future service provision. The aim is to improve patients' experiences within health services and ensure that people are treated with respect as individuals, regardless of race, class and culture.

Promoting health, supporting inclusion: The national review of the contribution of nurses to the care and support of people with learning disabilities (2002)

This review aimed to ensure that all nurses and midwives recognize the particular needs of people with learning disabilities and work towards promoting and improving their health (see also Chapter 4).

Health Needs Assessment Report: People with Learning Disabilities in Scotland (2004)

This report was undertaken in response to the first recommendation of "Promoting Health, Supporting Inclusion" (see also Chapter 4).