

Evaluating the experience of children with cerebral palsy and their parents in the transition from primary school to secondary school

Submitted by:

Abbi Melanie Noble

A thesis submitted in partial fulfilment of the requirements of Edinburgh Napier University for the degree of Doctor of Philosophy

April 2010

Abstract

The transition from primary to secondary school has been identified as a time that requires further investigation. In particular there is a need to include the experiences of disabled young people, and their parents. With the introduction of the Education (Additional Support for Learning) (Scotland) Act 2004 (ASL) it is envisaged that school experiences and transitions should improve for these young people.

Two groups of participants were recruited via the Cerebral Palsy Register for Scotland, both including parents and young people. The first group was made up of families completing the transition prior to the introduction of the ASL act, and the second group after it. Data was obtained via individual interviews with both parents and young people.

Little difference was found between the transitional experiences of the first and second group. When discussing the transition parents explained how they chose a secondary school for their child to attend. The majority of parents wanted their child to attend the local school, a view supported by the young people themselves.

The main concern identified by this work for both parents and young people is that of mobility. This work also contributed to the knowledge of coping mechanisms, and revealed that parents draw on past transitional experiences of their child as a means to cope with this move.

For many of the young people this transition marks a change in their own personal identity. Throughout the move the young people became more aware of how others perceived them, and how they wished to be portrayed.

Overall both parents and young people felt they had had a positive transitional experience, despite many encountering problems during it. How these problems were overcome was significant to the overall view they formed of the transition. From this work it would suggest that the ASL act has had little impact on this transition.

Acknowledgments

Firstly I would like to thank the participants both the parents and young people, who welcomed me into their homes, and were happy to speak so openly to me.

I would also like to thank my supervisors Dr Sandra Bonellie, and Dr John Davis for their advice, encouragement, and support over the course of this work.

The initial funding for this work was obtained from Cerebra, and I would like to thank them for this, and also to Dr Bonellie for initiating the funding application and her recommendation that I take on this project.

Thanks must also go to my family, friends, and colleagues, who have listened and supported to me throughout the completion of this project.

Table of Content

Chapter 1

Evaluating the experience of children with cerebral palsy and their parents in the transition from primary school to secondary school – An Introduction

1.1 Introduction	1
1.2 Background research- Concepts of disability	2
1.3 Background research – Understanding transitions from primary to secondary school	3
1.4 Addressing the methods	5
1.5 Data analysis – Preparation and choosing a school	7
1.6 Data analysis – Concerns, coping and support	8
1.7 Data analysis – Starting the introduction to secondary school	9
1.8 Data analysis – Completing the move and looking back	10
1.9 Conclusions drawn	11

Chapter 2

Concepts of Disability

2.1 Introduction	14
2.2 Understanding Disability	16
2.2.1 How disability models impact on daily life	22
2.2.2 Children and young people’s experience of impairment	24
2.2.3 Consulting disabled people	26
2.3 The nature of Cerebral Palsy	27
2.3.1 Experiences of services	28
2.4 Chapter summary	30

Chapter 3

Understanding the transition from primary to secondary school

3.1 Introduction	33
3.2 The role of school	34
3.3 How policy influences education for disabled children	36
3.4 School experiences of disabled pupils	41
3.4.1 Experiences of mainstream schooling	41
3.4.2 Children with Cerebral Palsy in mainstream school: Existing literature	48
3.4.3 Disabled children attending Special Schools: Existing literature	48
3.5 Making Transitions	50
3.5.1 Transitions and educational policy	50
3.5.2 The transition from primary to secondary: Research to date	51
3.5.3 What is known about improving transitional experiences?	56
3.6 Parents and their needs during transitions	57
3.7 Chapter Summary	58

Chapter 4

Methodology and Method

4.1 Introduction	61
4.2 Methodology – Theory of research and childhood	63
4.2.1 Participatory Research	64
4.2.2 Disabled people and participatory research	65
4.2.3 Children, young people and participatory research	68
4.2.4 Working with disabled children and young people	74
4.2.5 Multiple family perspectives	76
4.3 Ethical considerations	77
4.3.1 Consent	78
4.3.2 Confidentiality	79
4.3.3 Power	80
4.4 Method	81
4.4.1 Qualitative methods	84
4.4.2 Individual interviews addressed	86
4.5 Participant selection & recruitment	90
4.5.1 Recruiting the Pre ASL Group	91
4.5.1.1 Contacting the young people in the pre ASL group	93
4.5.2 Recruiting the post ASL Participants	94
4.5.3 Participant’s profile	95
4.5.3.1 Parents: Pre ASL	96
4.5.3.2 Parents: Post ASL	97
4.5.3.3 Young people: Pre ASL	98
4.5.3.4 Young people: Post ASL	99
4.5.4 Differences between participants and non participants	100
4.6 Interviewing	101
4.6.1 Interview schedule: Pre ASL group	104
4.6.2 Interview schedule: Post ASL group	105
4.6.3 Interviewing technique	106
4.6.4 Interviewing in the home	108
4.7 Translating Theory	109
4.8 Reflection	111
4.8.1 Reflection on participatory nature of the work	111
4.8.2 Reflection on carrying out family research	114
4.8.3 Reflection on the interview process	116
4.8.4 Reflection on the validity of the work	119
4.9 Data Analysis	123
4.9.1 Reflection on the analysis	124
4.10 Dissemination	126
4.11 Introducing other validation methods	127
4.12 Chapter summary	128

Chapter 5

“He lives in this community; this is where he’s going to school.” – Preparation and choosing a school.

5.1 Introduction	130
5.2 “He hasn’t got one of those [CSP] at the moment. We’re not sure if he should or not.” – Impact of the Additional Support for Learning Act	133
5.3 “It was the only one wae access for wheelchairs.” – Having and making a choice	137
5.3.1 Preparation	137
5.3.2 Influential factors in choosing a school	142
5.3.3 Making choices	150
5.3.4 View of special education	153
5.4 “The fact is I probably didn’t take part in the decision.” – Role of the young person.	155
5.5 Chapter Summary	158

Chapter 6

“I think you are anxious when they move up to secondary school.” – Concerns, coping and support

6.1 Introduction	160
6.2 “I felt worse sending her to secondary than I did primary.” – Concerns	164
6.2.1 Getting around	165
6.2.2 School structure	167
6.2.3 Bullying	169
6.3 “It’s like starting from the bottom all over again” – Coping, the value of experience	175
6.4 “Well, last night my Mum told me a lot about it.” – Support and information	179
6.4.1 Prior knowledge – Young people	179
6.4.2 Information	181
6.4.3 Service input at this time	182
6.5 Chapter summary	190

Chapter 7

“Fun, probably the funnest days of school” – Starting the introduction to secondary school

7.1 Introduction	192
7.2 “Sad about leaving primary school but excited about starting a new school.” – Beginning the journey	195
7.2.1 Tools of familiarisation	195
7.2.2 Induction days- Young people requiring additional support for learning	201
7.2.3 Views on secondary school following the induction	205
7.3 “It was quite weird that everyone knew my name, but I didn’t know them.” – Standing out and fitting in	207
7.3.1 Doing things differently	207
7.3.2 Developing an identity	209
7.3.3 Changing perceptions	212
7.4 “‘ESD’ – I still don’t know what the E stands for!” – Parents involvement	213
7.4.1 Parents view of induction	213
7.4.2 Parents’ reflection on the induction days	216
7.5 Chapter Summary	220

Chapter 8	
“The transition was...okay. I think...I think the transition to, I think it was okay” – Completing the move and looking back	
8.1 Introduction	222
8.2 “Good...better than primary.” – Reflection	228
8.3 “[O.T.’s] been really supportive for us – making sure that he’s got everything he needs.” – Service input throughout the transition	233
8.4 “[I] got the impression they didnae want tae spend the money.” – Encountering problems	239
8.4.1 Revising the Additional Support for Learning Act	239
8.4.2 Encountering physical problems	241
8.4.3 Encountering attitudinal problems	245
8.5 “‘Cause there’s like no-one else that went to [primary school] you can compare me to.” – Who I am	251
8.5.1 Developing an identity	252
8.5.2 Problems of standing out	256
8.5.3 Being invisible	261
8.6 “I would say to ask questions.” – Lessons learnt	266
8.7 Chapter Summary	270
Chapter 9	
Evaluating the experience of children with cerebral palsy and their parents in the transition from primary school to secondary school – Conclusion	
9.1 Introduction	272
9.2 What impact has the ASL act had on this transition?	273
9.3 What kind of transitional experiences do young people with CP and their parents have, and are their needs being met?	274
9.4 Does the ASL act’s call for young people to be involved in service planning have an influence on transition?	275
9.5 Do young people and their parents adopt, or are they influenced by models of disability?	276
9.6 Does the social model aspect of the ASL (removal of barriers) help combat discrimination?	276
9.7 Argument of this thesis	277
9.8 Methods	278
9.9 Evaluation	279
9.10 Future work	284
9.11 Reflection	285
9.12 Chapter summary	287
References	290

Appendix

1. Ethical approval letter
2. Parental letter of invitation
3. Parental information sheet
4. Parental response form
5. Young people's information sheet
6. Table of participants
7. Example of an interview schedule
8. Parental consent form
9. Young persons consent form
10. Pre ASL parental dissemination report
11. Pre ASL young peoples dissemination report
12. Examples of dissemination articles form the CPRS newsletter and website
13. Post ASL parental dissemination report
14. Post ASL young peoples dissemination report

Chapter 1

Evaluating the experience of children with cerebral palsy and their parents in the transition from primary school to secondary school – An Introduction

1.1 Introduction

Transitions are difficult times for families. In particular little is known about the transition from primary into secondary school. Research to date within this area has failed to obtain the views and experiences of disabled young people and their parents. The transition into secondary school requires further study to discover the support required by disabled young people and their parents during this time.

This thesis seeks to address this need by evaluating the experiences of young people with CP of this transition, and also evaluating the experiences of their parents. This introductory chapter provides a summary of the whole thesis with sections corresponding to chapters in the thesis. These cover the following areas;

- Background research
- Addressing the methods
- Data analysis
- Conclusions

This chapter is aimed at assisting the reader as they move through the thesis. Chapters 2, 3, and 4 present the background to the work, and an understanding of its context. Key gaps in the literature are highlighted within this summary, and the methods adopted by this work are set out.

The literature is divided into two key areas; the first addresses issues pertaining to disability, the second the secondary school and the transition from primary to secondary. Following the summary of the literature in chapters 2 and 3 the research questions are presented.

The data analysis corresponds to chapters 5, 6, 7, and 8, which travel through the transitional experience. Starting with the period before any transfer activity has

started, moving through the activities carried out by the school to assist the move, and finishing with a reflection chapter once the move has been completed. Finally the summary chapter 9 presents to the reader the conclusions of the thesis.

There are a number of terms used throughout this thesis. These will be defined within the relevant sections of this chapter.

1.2 Background research - Concepts of disability

'Chapter 2 - *Concepts of disability*' provides the background context to this work, as within this chapter the two main models of disability are debated.

The medical model argues that disabled people require an input from medical professionals to alter them physically in order for their quality of life to be improved. In contrast the social model does not see disabled people as individuals who need to be fixed, but as people who are disabled by the barriers put in place by society.

Both models have limitations and fail to represent the whole picture of disabled people's experiences. The approach taken in this project involved comparing the implications of both models in keeping with Shakespeare and Watson (2002).

There is also a discussion of what Thomas (1999) refers to as 'impairment effects', she argues that not all restrictions to activity experienced by individuals are 'disabling'; but may be due to physical and/or sensory impairments which become the precondition for disability in some social context.

In particular issues surrounding cerebral palsy (CP) are examined. All of the young people involved in this work were diagnosed with CP, and throughout this work the Surveillance of CP in Europe (SCPE) definition is used. SCPE define CP as;

"A group of disorders; is permanent, but not unchanging; involves a disorder of movement and/or posture and motor function; is due to a non-progressive interference/lesion/abnormality; this interference/lesion/abnormality is in the developing/immature brain."

SCPE (2000)

Much of the work discussed in chapter 2 establishes that the research to date has presented a very medicalised views of CP, with classifications based on inability. From this finding, and the dialogue surrounding the disability models, this work made a conscious effort to present CP in a different way, and to avoid specific models of disability.

The central aim of the study is to understand how parents and young people utilise language of disability during the transition, and to define how the transition can be improved.

Research suggests that families with a child with CP will require an input from a range of services, and thus services become very important in their lives. It is established that parents generally feel dissatisfied with services (Darrah et al, 2002, Sloper 1999). They also feel that they are under pressure to 'fight' for services that their children need (Darrah et al, 2002). This work seeks to investigate the implication of combative processes for induction.

1.3 Background research – Understanding transitions from primary to secondary school

'Chapter 3 - *Understanding transitions from primary to secondary school*' addresses the literature related to the schooling of young people, and focuses on the experiences of the transition from primary to secondary.

This chapter also presents a discussion of government policy which has been introduced to improve school experiences. The (Education) (Additional Support for Learning) (Scotland) Act 2004 gives more powers to parents, the right of families to have a contact person, and the recommendation of increased organisation of transitions. Thus this act should be very influential on the transition experience.

Parents and young people in this work talk about attending both mainstream and special schools. Within this project the definition used by the (Education) (Additional Support for Learning) (Scotland) Act 2004 (ASL) will be adopted. Thus a special school refers to:

“A school with the sole, or main purpose, of which is to provide education specifically suited to the additional support needs of children or young people selected for attendance at the school.”

29(1) ASL, 2004

With additional support needs being:

“The child or young person is, or is likely to be, unable without the provision of additional support, to benefit from school education provided, or to be provided, for the child or young person.”

1(3) ASL, 2004

Work to date has highlighted a number of concerns that young people report prior to moving to secondary school. These concerns centre on issues such as the school environment (Anderson et al, 2000), the size of the school, the loss of friendships (Zeedyk et al, 2003), and concerns of bullying (Stradling and MacNeil, 2000).

The majority of the literature suggests that bullying is a major concern for young people (Zeedyk et al, 2003). As the literature also shows young people with CP are more likely to be bullied (Yude et al, 1998), it may play an influential part in the transition of these young people.

It is clear that there are several key points for this research to address. There are also a number of areas which are not represented by the work to date; this includes disabled young peoples experiences, parent experiences, and the process of selecting a school. These are all areas towards which this work can contribute an understanding.

The key questions to come out of this literature review are:

- What impact has the ASL act had on this transition?
- What kind of transitional experiences do young people with CP and their parents have, and are their needs being met?
- Does the ASL act's call for young people to be involved in service planning have an influence on transition?
- Do young people and their parents adopt, or are they influenced by models of disability?
- Does the social model aspect of the ASL (removal of barriers) help combat discrimination?

Due to the research questions being qualitative in nature the methods adopted by this research were also qualitative.

1.4 Addressing the methods

Having discussed the literature, and illustrated key themes and areas this work can contribute knowledge to, the thesis moves on to discuss the methodology and methods of the work in '*Chapter 4 - Methods*'. As the young people participating are disabled young people the methodological issues requiring attention are discussed.

When aiming to give an accurate account of disabled young people transitions, and also the experiences of their parents at this time, it is vital to consult directly with them. This is the ethos followed in this project. This chapter presents the background literature and discusses methodological issues and methods from both the fields of childhood studies and disability studies.

The term 'young people' is used throughout this work, and requires defining. The young people who participated are considered children under Scottish law, as they were under 16 years old (or turning 16 years during the work). However, as they were making the move into secondary school, and on their way to adulthood, referring to them as children seemed inappropriate. There are a number of terms available to describe this age, such as teenager, youth, adolescent. Many of these terms seem to have negative connotations attached to them, such as 'youth justice',

or 'tear away teenagers'. The term 'young people' is appropriate for this age group and covered the other terms often used whilst being more positive in nature. Where specific terms, like children, have been used within individual pieces of published work, such terms have been adhered to.

Working with young people meant that the methods adopted have to be adaptable. This work implemented many of the recommendations made in the literature, such as:

- Adapting language (Beresford, 1997).
- Presenting information in a user friendly way (Goodlet and Moore, 2000).
- Including a photograph of the researcher on the information sheet in order to increase familiarity (Stalker and Connors, 2003).

Qualitative methods are reviewed in chapter 4 and individual interviews were deemed the most appropriate method to answer the research questions. Individual interviews allowed the participants the privacy to speak openly and present their own views. It was also thought that such methods would allow the researcher to focus on the discussion with a single person, and to modify questions and language as required.

Participants were recruited via the Cerebral Palsy Register for Scotland (CPRS). This assisted the recruitment by building on a relationship which existed prior to the research starting. Young people and their parents were approached to participate in one of two groups. The first group consisted of those who had made the transition prior to the implementation of the Education (Additional Support for Learning) (Scotland) Act 2004, and the second those making the transition after it.

An important part of the research process was to disseminate back to the participants. Dissemination is a vital part of being participatory (Zarb, 1992) and demonstrating to the young people that their input was valued. This was done via a report to parents and young people, the CPRS website, and the CPRS newsletter.

1.5 Data analysis – Preparation and choosing a school

Events during the build up to moving are discussed in 'Chapter 5 - "He lives in this community; this is where he's going to school" – Preparation and choosing a school'. The chapter title reflects one of the main key themes derived from the data, namely that parents and young people feel strongly about being educated in the local secondary school. Young people want to stay with friends from the local area, whilst parents feel that through attending the local school their child will be integrated into the local community. This highlights the tension between normality and difference during this move. Parents felt that attending the local school would minimise their child being perceived as different, but at the same time emphasised difference themselves when seeking support.

It was shown that parents underwent a process of seeking information early on in order to choose a secondary school. Parents tended to want control over their child's transition, which was possibly related to their previous experiences of working with services. When making choices the parents own personal histories were highly influential on the choice they made.

Some parents felt that mainstream schools could not fully include their child, and so chose to send them to a special school. This demonstrates that in some areas legislation such as the Standards in Scotland's Schools Etc Act is not being adhered to.

When preparing and choosing a school much of the process is parent led. The young people were aware that their parents were making choices regarding their schooling. For some this resulted in frustration as they were not being consulted directly, for others this was simply the norm. Many of the young people were identified by schools as being part of a homogenous 'disabled' group, which they themselves did not identify with.

Chapter 5 also presents the parents views pertaining to the ASL act. Through the discourse, it is clear that the parents have little information relating to the act, and are, to a certain degree, confused about it.

This chapter underpins the central argument of this thesis that medical discourse is preventing parents and staff from involving young people in partnerships prior to the induction process, and that as a result this limits the impact of the ASL act on issues of choice during the induction.

1.6 Data analysis – Concerns, coping and support

Chapter 6 looks into the concerns of parents and young people prior to moving, the coping skills adopted, and the support that they require. This chapter, '*Chapter 6 - "I think you are anxious when they move up to secondary school." – Concerns, coping, and support,*' illustrated that young people and parents experienced anxiety at this time, and needed to develop coping skills, and obtain support to cope.

The concerns expressed by young people and parents were similar, and focused on social, structural and mobility issues. Most of the young people tended to be concerned about issues that they considered to be 'real', such as moving around the school, navigating stairs, or carrying their school bag, rather than hypothetical events such as bullying.

This is a different finding to that in the literature presented in chapter 3, which identifies bullying as the most common concern of young people (Zeedyke et al, 2003, Stradling and MacNeil, 2000, Kvalsund, 2000). Although these young people did also mention bullying, mobility issues were by far the most commonly discussed.

In order to cope with these concerns it is established that parents drew on past experiences. The experience of their child moving from nursery to primary, or starting nursery, and what they had learnt at such times was presented as being beneficial to them during this transition.

Parents and young people also coped through receiving information and support from services. Most parents wanted an input from service providers who they knew and who knew their children, and therefore who they felt they could trust.

This chapter contributes towards the central argument of this thesis that young people should have more information, and should be involved more in the planning

phase. However, this would involve services recognising the impact of both property and attitudinal barriers on young people.

1.7 Data analysis – Starting the introduction to secondary school

Having fully discussed the preparation for the transition, the next analysis chapter ‘Chapter 7 – “Fun, probably the funnest days of school.” – Starting the introduction to secondary school’, looks at the efforts that are made to prepare and familiarise the young people with secondary school.

The data established that most schools had two kinds of events, visits from secondary staff to primary, and induction days at secondary school. Of these events, the induction days were by far the most popular with the young people. This is inline with the literature in chapter 3 which also demonstrates the success of the induction days (Galton et al, 2000).

For many of the young people, attending the induction day resulted in a rebalancing of power as they were now receiving information about the move directly. Having had this experience a number of the young people felt that there was a need to remove barriers they had experienced, this is despite not having knowledge of social model language.

During the induction period parents were neglected to some extent. Few parents had feedback concerning the induction days and many did not have a named contact to discuss issues with. In many cases the young people returned from the induction days with questions, and turned to their parents for answers. Without the support of a contact person these parents found it difficult to obtain the information they required.

From this chapter the central argument is made that services need to be tailored to the individual needs of the young people, and that processes of induction result in increasing the young people’s sense of independence. This demonstrates that young people can be involved more in decision making and processes of schooling.

1.8 Data analysis – Completing the move and looking back

The final analysis chapter '*Chapter 8 - "The transition was...okay. I think...I think the transition to, I think it was okay"* – Completing the move and looking back', addresses the feelings of the parents and young people about the transition once it was completed.

Chapter 8 concludes that all families viewed the transition as positive, despite many families experiencing problems. It transpired it was how such problems were overcome that was vital to their final view.

Having made the move many young people expressed a preference for secondary school which they associated with the increased independence they experienced there. This highlights why young people must be included in the transitional planning.

For the young people the move to secondary school seemed to impact on their personal identity. Many became more self aware, and conscious of how others perceived them. Whilst some young people felt the need to move away from a 'disabled' identity, others found strength in identifying with it.

This chapter found that throughout Scotland the service provision received by families is not consistent. Where formal support was not available many parents sought informal support from each other. Most parents felt that they would have benefited from the provision of a named contact person at the secondary school; under the ASL act all parents should have such a contact. The lack of information available about the ASL act is a barrier to parents accessing these rights.

Finally, this chapter supports the central argument of this thesis that the aim of the ASL to widen choice and improve the involvement of parents and young people has not occurred. Although some attempts have been made to meet the social model and ASL aims to remove barriers (e.g. through the base and learning assistants), in some cases these attempts have resulted in impacting on disabled young peoples sense of self. Greater staff training is required if young people's sense of a 'normal' identity is to be supported.

1.9 Conclusions drawn

The final chapter of this thesis '*Evaluating the experience of children with cerebral palsy and their parents in the transition from primary school to secondary school – Conclusion*' presents the conclusions of this thesis.

In turn each of the research questions is answered and it is established that when moving to secondary school parents and young people want choice. Being able to access their mainstream local school is important to many and having the option of special schooling vital to others.

However, on making the transition within mainstream many young people encountered barriers at secondary school. These barriers were both physical and attitudinal in nature. The concerns which young people and their parents held at this time were not related to bullying as much of the literature suggests, but were mobility related.

Throughout the transition parents felt that they were in conflict with service providers, and would have benefited from being kept informed. Receiving information was an important aspect of the transition for both parents and young people.

Finally having compared the experiences of those making the transition before and after the implementation of the ASL act, this work concludes that the act has not impacted significantly on the transition into secondary school of young people with CP. Many core aspects of this act are not being fully implemented, such as valuing the opinion of the young people, and identifying a contact person for parents.

This work is able to provide an insight into the experiences of parents and young people during the transition as they were consulted directly and provided the space to give their true accounts.

Chapter 9 also presents recommendations for improving future transitions, and future research work that could be carried out. The final section presents a reflective account by the researcher of the journey through this work.

At the end of each chapter the conclusions highlight how the key findings of this work underpin the central argument of this thesis, which are;

There have been a small number of improvements in different services for some families, but in the main there has been no impact on choice. Schools do not share information with parents and young people, parents have not been allocated a contact person, and service provision across Scotland is variable. As a result the opportunity to build partnerships for planning has been lost.

Families' experiences of the transition are primarily positive when the induction has been tailored to the young person in a flexible way. Through the induction process buddy systems and being able to meet staff prior to moving were all positive experiences. Both parents and young people had similar concerns which were related to property and social issues. Transitions should be improved through the provision of more accessible information, better access to schools, and the building of spaces and processes to develop partnerships.

The ASL act has not resulted in young people being more widely involved in the transition process, schools tended to have a homogenous view of disabled young people and made assumptions about their ability to make decisions. The induction process has a positive impact on the young person's sense of independence, and this should be built upon to develop participatory processes to induction.

The finding of how parents, young people and staff think about disability is important as it helps us to understand how the constructs we hold impact on our ability to make decisions. This thesis found that there was a tension between the adoption of medical model language by staff and parents, and the ASL requirements to involve disabled young people in joint decision making.

There was a relationship between medicalised discourses and negative experiences of property barriers, and parents were more likely to adopt deficit discourses when they had negative experiences. In contrast young people adopted social relational and social model discourses to emphasise their ability to be involved in every day processes.

Finally, if the ASL is to achieve its aim to reduce the combative nature of inclusive education, greater spaces of dialogue between parents, young people and staff, are required to enable such discourses influence the process transition.

Chapter 2

Concepts of Disability

2.1 Introduction

In this chapter existing literature will be explored in order to build the background to this work. This will include what is already known about the area, and where this work can make a contribution. This chapter has two core sections, understanding disability, and the nature of cerebral palsy (CP).

The first section, '*2.2 Understanding disability*', explores the literature which has attempted to explain disability and the impact on the individual. Firstly models of disability are discussed. Both the medical and social models are presented and evaluated. Through the discussion of these models it is established that both models fail to represent the true picture of disabled people's lives. Therefore in order for this work to be able to listen to the young people and their parents views and to learn what issues they see as important to the transition, neither model can strictly be adhered to.

The second part of this section addresses the impact such models have on the lives of disabled people. Shakespeare and Watson (2002) show that disabled people have a positive self image, and the negative stereotypical view assigned to them is done so by society. Similarly Connors and Stalker (2007), report that many young people see themselves as normal teenagers. However, there are issues with many young people attempting to conform (Pratt and George, 2005), often resulting in hiding of impairments.

This work aims to identify how models of disability influence young people, and whether young people adopt such thinking. The work will also contribute to our understanding of how young people view themselves throughout the transition to secondary school.

The final part to this section discusses the research which surrounds the consultation of disabled people. Tisdall and Davis (2004) highlight that disabled people are less

likely to be included in research. It is important for disabled people to be included in research in order to represent the views of the whole of society. It has previously been established that disabled people have clear, strong views about issues, and need the opportunity to express these (Kelly, 2005). This work will strive to provide that opportunity.

The next part of the chapter, '*2.3 The nature of CP*' moves onto address CP. Key to this project is to understand the concept of CP, which will allow for the dialogues within this project to be put into context. CP is presented as being an umbrella term for a group of disorders (Mutch et al, 1992). It is described in terms of its topography, and the various types of CP children are diagnosed with. CP is likely to also exist alongside a number of other disorders, which are discussed. This approach is very medicalised, and this work questions whether such terminology is helpful when applying a mixed social and medical model.

With services playing a big part in the lives of individuals with CP, families experiences of services are also discussed within this section. The current literature puts forward that parents are dissatisfied with services (Darrah et al 2002, Bamford et al 1997). Through speaking directly to parents it will be established from this research whether they feel dissatisfied regarding service provision during the transition.

The final part to this chapter asks what the literature can say about improving experiences for young people with CP and their families. The main approach accepted by the research as making a positive contribution to the lives of families, is the allocation of a link person, research by Greco and Sloper (2004) and Bakheit et al (2001) demonstrate this. A link person is somebody who can assist with the co-ordination of care for the family.

Thus this chapter addresses several key issues, which this work can take further and expand our knowledge of. How are transitional experiences influenced by views of disability, and the young people's feelings of needing to conform, if they have them? Also does the recurring negative experiences of services by parents, transfer to their transitional experiences?

2.2 Understanding Disability

Society tends to group individuals who are dissimilar to the norm as 'disabled', but what is disability, and why within our society is a disabled person often viewed negatively?

Goffman (1968) applied the theory of stigma, the negative reaction to a specific individual trait, to disability. This theory argues that our first impressions, which are based on appearance, shape our view of people. Each society has set parameters and categories, which are attributed to people on first contact. Goffman (1968) sets out that disabled individuals are perceived as having a stigma as they appear different, and that those who are similar to the majority are considered to be 'normal'. Although such views are held by some within society, and lead to the development of negative stereotypes reinforced by the media, society has also come a long way as the Disability Discrimination Act 1995 demonstrates. Despite such developments Watson (2003) stated that the media frequently portrays disabled people as helpless and in need.

The majority of disability research has been conducted within the context of either the social or the medical models. The model adhered to by the individual researcher will influence not only what research questions are asked, but also how the findings are interpreted and reported. Researching childhood disability is no different. Understanding the models which are presented in the literature is important to understanding the context under which the research will take place.

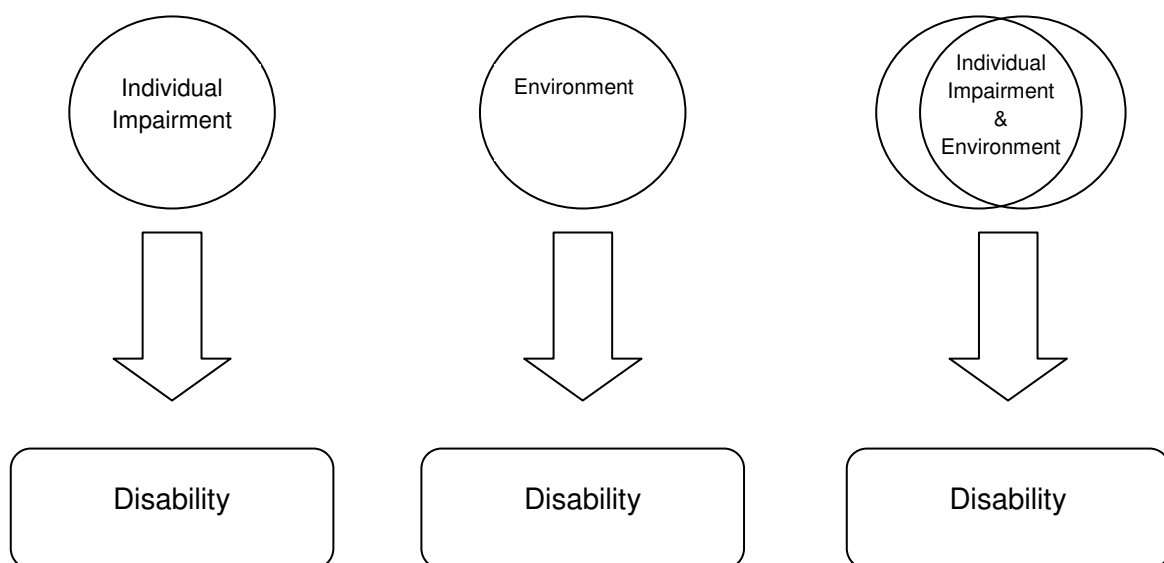


Figure 1: Medical Model

Figure 2: Social Model

Figure 3: Ideal

The medical model of disability (*figure 1*) focuses on the individual's impairment as being the barrier to them engaging fully with society, and it is through change within the individual that these barriers will be removed (Shakespeare and Watson, 1998). The main focus of the model is on medical intervention and rehabilitation of disabled people, such as operating to reduce the need for a wheelchair (Oliver, 1996). Within this model health care is seen as restoring the persons 'normal functioning', which implies to many that disabled people are abnormal (McLean and Williamson, 2007).

Through this model the individual is seen as the problem and the emphasis is on what they cannot do (Oliver, 1996). It is also thought that it portrays a negative image of disability as a tragedy, and disabled people as victims (Oliver, 1996). Despite such criticisms this model has been the main approach to understanding disability in recent times.

An alternative approach is to adopt the social model (*figure 2*) put forward by the disability movement (UPIAS, 1979). Within this model the term impairment is used to describe the functional limitations that disabled people face, whilst disability is seen as the social oppression they face (Shakespeare and Watson, 2002, Barnes, 1998).

The social model recognises the impact of external barriers on the disabling of individuals with impairments, in that people with impairments are disabled due to restrictions placed on them by non disabled people (Shakespeare, 2006). Thomas (1999) categorises such barriers as being socio-structural, organisational, environmental, or attitudinal. The impact of such barriers is the economic or social disadvantage of disabled people (Crow, 1996). Whilst the medical model advocates overcoming impairment as a means to remove these external barriers, the social model calls for social change (Crow, 1996).

Crow (1996) suggests that much of the discrimination and exclusion leading to disability has resulted from the socially created definition of impairment. This definition has taken the broad meaning of impairment, 'the body part-functioning with difficulty or not functioning' to mean the persons body, and so it appears that the person themselves is also inferior.

The social model of disability has therefore been an important political strategy for the disability movement in bringing about the removal of barriers, and also in liberating disabled people (Shakespeare, 2006). It emphasises the social construction of disability, which leads onto disabled people developing a new sense of self. This new view is less inline with the idea that disabled people are to blame for restrictions they faced, and towards the realisation that they face discriminatory barriers from society. The focus is on social change to promote inclusion, following the principals of equality, inclusion, and autonomy (Shakespeare and Watson, 2002).

For example the social model has had a positive impact in addressing discrimination, and it is believed that it will contribute towards the equality of disabled people in the future (Crow, 1996). However, despite a positive outlook Crow (1996) also highlights that the model has not been as successful at representing the diversity of disabled people.

Simply removing barriers will not remove all disadvantages to people with impairments (Crow, 1996). Shakespeare (2006) highlights that removing barriers for some people will lead to others being disabled. He provides the example of drop kerb removing barriers for wheelchair users but creating problems for visually impaired people who may walk unknowingly into the road.

Although the model has raised awareness of societies role in disability, some believe that it has become over simplified since its development in the 1970s (Shakespeare, 2006), with too much focus on socio-structural barriers (Thomas, 1999). In many ways Shakespeare (2006) notes that the initial strength of the model has now become its weakness. Originally formulated as a political intervention, it developed short, simple, political slogans, which worked well in politics but not as a social theory. For many activists within the disability movement the social model has provided them with an identity, which has moved away from being impairment focused and allows them to deny impairment is important to them. Thus they have become attached to the social model, and incorporated it into their identity (Shakespeare, 2006). This makes it difficult to carry out any changes to the model. Finally Shakespeare (2006) draws attention to the issue that the model has not been revisited or developed since its creation.

The model assumes that individuals will identify themselves as 'disabled', and does not account for disabled people wanting to identify themselves by other dimensions, such as gender, race, or sexuality (Shakespeare and Watson, 2002). Although the counter argument points out that there is no evidence that the model could not incorporate these factors (Oliver, 2004). By imposing such restricted thinking however, this model in turn is recreating the errors of the medical model when it defined people in accordance to their impairment (Shakespeare and Watson, 2002).

The most widely discussed limitation of the social model is the lack of acknowledgement given to impairments such as functional limitation or pain. It sees disabled people as being disabled by society only, and not by society and their body (Shakespeare and Watson, 2002, Barnes, 1998).

In response proponents of the social model argue that it does not look at the experiences of individuals but at the collective experience of disabled people (Oliver, 2004). Critics respond that there is too much emphasis on all disabled people having the same experiences (Crow, 1996). This brings us back to Crow's earlier limitation of this model, in that it does not represent disabled people on a more individual level. Impairment is an important part of the disabled experience, whilst some impairments will have little impact others limit activity. Without looking at the role of impairment it is not possible to understand the complexity of disabled peoples lives (Shakespeare, 2006). This raises the question of how will disabled young people in this work view their impairment, and the impact it has on their transition.

The model does not represent the experience of all disabled people, such as those who are deaf, have a learning impairment, or a mental 'illness' (Shakespeare 2006, Thomas, 1999). It assumes all disabled people experience oppression as a result of restrictions by non disabled people; therefore there is no need to distinguish between impairments. However, for some individuals should all external barriers be removed they would continue to experience disadvantage due to impairments, for example through pain (Crow, 1996).

Often similarities between the disability movement and other movements such as gender, race or sexuality, are drawn. For example where feminists illustrate the difference between sex (biological) and gender (socio-cultural), the disability movement makes a similar distinction between impairment and disability (Shakespeare, 2006). However, as discussed above, the experience of disabled people is not as straight forward due to the presence of impairments which result in disabled people sometimes experiencing difficulties without external barriers.

The impact of impairments has been referred to by Thomas (1999) as 'Impairment effects'. Impairment effects describe how not all restrictions to activity experienced by individuals are 'disabling'; but may be due to physical and/or sensory impairments. Impairment effects become the precondition for disability in some social context (Thomas, 1999, Crow, 1996). Thomas (1999) provides an example of her own experience, she cannot hold a spoon in her left hand, which is not a disability following the social relational definition. However, should restrictions to working for example be placed on her due to this impairment, then it becomes disabling. Therefore impairment must be present for 'disability' to be triggered (Crow, 1996). Impairment effects along with disability shape the lived experience of disabled people (Thomas, 1999).

Many researchers feel that within the disability movement there is the fear that through acknowledging impairment support is given to the medical model (Thomas, 1999, Crow, 1996). For example, Swain and French (2000) feel that any focus on impairment could be counter productive for the social model and the disability movement. However, according to Crow (1996) the social model has not discounted impairment, but has only given that impression by not discussing it publicly.

Thomas (1999) suggests that the objections made by many researchers towards the lack of inclusion of impairments within the social model are due to the definition of disability that they are applying. Thomas outlines two social definitions of disability;

- i. The social relational approach – disability exists as a social relationship between individuals. The unequal relationship between those with and without impairments leads to exclusion and oppression, and are therefore disabling.
- ii. The property approach – disability is a result of restrictions to activity due to social barriers. Emphasising the role of barriers in causing restriction over impairment or illness means that disability occurs whenever restriction happens.

Through adopting the first definition, the objections raised regarding the lack of focus on impairment in the social model would not have occurred, as Thomas states, it is impairment effects which restrict lives.

Other researchers have highlighted limitations of this definition outlined by Thomas. Both Shakespeare (2006) and Swain and French (2000) see limitations in defining disability in terms of oppression. Both impaired and non impaired people can be oppressed through racism, sexism, or poverty. It is also noted that disabled people can also be oppressors (Swain and French, 2000).

Shakespeare (2006) concludes that he sees disability as;

“The outcome of the interaction between individual and contextual factors – which includes impairment, personality, individual attitudes, environment, policy, and culture. Rather than reserving the word disability for ‘impairment effects’ or ‘oppression’ or ‘barriers’, I would rather use the term broadly to describe the whole interplay of different factors which make up the experience of people with impairments.”

Shakespeare (2006, p58)

Therefore, when discussing disability it is important to be aware of all contextual factors. From this discussion it is clear that models of disability are attempting to explain a complex issue, which both the medical and social model seem to have attempted to simplify.

Conducting disability research today requires a balanced input from both models (Shakespeare and Watson, 1998) (*figure 3*). For example a young person with CP who wants to attend mainstream school will require that the school is accessible to them, such as having ramps and lifts, therefore the environments will remove barriers and allow this young person to attend. However, if they also experience pain and find it difficult to sit upright the school will remain inaccessible to them, thus they would require some medical or occupational health intervention to fully participate in school.

Not only will such models influence the attitudes of the researcher and their approach to the research, but they will also impact on the young persons experiences of the transition. Shaw (1998) states that education systems are predominately dominated but the medical model, and it will be interesting to see whether families have adopted such an approach. If not, do they experience conflict with the school over barriers, and how are these overcome? With regards to the young people participating in this project, many will be developing their self image at this time, and it will be interesting to see which approach they choose to adopt.

2.2.1 How disability models impact on daily life

Within Western society the medical model seems to dominate the understanding of disability (Llewellyn and Hogan, 2000) which leads to the perception of disabled people as individuals needing to be fixed in order to fit in to society. Disabled people are also thought of as holding a negative attitude, or believing themselves to be helpless (Shields et al, 2007). However, researchers who have investigated such issues have revealed diversity amongst disabled people, as in any sub group of society. Disabled individuals hold both positive and negative attitudes about themselves and the society they live in.

Most disabled people see themselves as being no different to other people within society (Watson, 2002). Some challenge the concept of 'normality', and express the view that their impairment is part of them and had become 'normal' to them. They did not feel that their impairment was central to their identity. Watson also noted however that there were some disabled people, often the minority, who did feel that

their impairment was an important part of their identity. This demonstrates how disabled people are not a uniform group.

Shields et al (2007) work agreed with Watson's findings, and also demonstrated deviation from the traditional view through using matched groups of individuals with CP, and those without CP to investigate self concept in young people. No significant difference was found between the two groups on global self-worth, physical appearance or behavioural conduct. Differences were found on scholastic competence, athletic competence and social acceptance. This study demonstrated that in the main individuals with CP had a positive self concept. This is opposed to the negative one society attributes to them, which is often based on misunderstanding by non disabled individuals.

This misunderstanding may be due to the segregation of disabled people, for example through different schools (Watson, 2003), leading to non disabled people becoming ignorant about impairment. Through interviews with disabled Scottish adults Watson established that they felt that non disabled individuals were unable to speak to them due to embarrassment and fear, and were in need of being educated about disability. Earlier work by Goffman (1968) also noted that communication can be difficult between 'stigmatised' and 'normal' individuals due to an uncertainty over how they are being perceived by one another. One way to move forward is for non disabled people to ask disabled people questions and talk to them. This is what the majority of disabled people wanted concluded Watson (2003).

Thus when working with disabled people through research it is important to approach them with respect and to not see them as individuals who are helpless, or part of a uniform group.

2.2.2 Children and young people's experience of impairment

Disabled people are often segregated and misrepresented. Children develop an identity as they grow older, which can be a difficult process. This may be more difficult for disabled young people if society is making assumptions about them.

For physically disabled young people being disabled is part of life and they simply see themselves as “normal teenagers” (Connors and Stalker, 2007). Often rating other disabled young people as being more disabled than themselves (Lewis et al, 2007). These perceptions can be affected by the environment they are in, becoming more negative if an environment places barriers which highlight their impairment (Connors and Stalker, 2007, Skar, 2003, Baker and Donnelly, 2001). Allan (1999) spoke about how disabled young people carry out a process called ‘transgression’, which is the challenging of boundaries put on them by others. Where some may transgress away from disability, for example trying to carry out a task without aids, others transgress towards it, such as seeking the help of others to complete a task.

In many cases it is the young person with less visible impairments, for example a mild gate problem, partial sightedness or hearing problems, who feel that they do not fit within the disabled category and transgress away from it (Watson et al, 2000). In contrast other disabled young people in the same situation reported finding it difficult when nobody was aware of their impairment, and felt that it would be easier if they had a more visible disability, believing that others would be more sympathetic towards them (Allan, 1999). Some disabled young people felt empowered by accepting the ‘disabled’ label, whilst others felt that it did not apply to them (Lewis et al, 2007).

All young people place importance on belonging and conforming with other young people (Pratt and George, 2005). The importance of belonging can lead some disabled young people to an act of transgressing, and not wanting to be labelled away from the norm and as ‘disabled’.

The desire to be included as the norm can result in some disabled young people choosing to hide their impairment whilst at school, particularly if it is less obvious. These young people report difficulty in doing this all the time, and in particular during lessons such as physical education (Woolfston et al, 2007). Disabled young people may feel under pressure to hide their impairments for many reasons, French (1993) discussed the pressures she felt to deny her impairment as a young person, due to her desire to reduce anxieties felt by the adults around her.

Thus many disabled young people may end up denying their impairment for multiple reasons, which may take different forms such as refusing support, not using special equipment, or pretending to be able to do something.

The experiences of disabled young people differ widely, whilst some feel pressure and a desire to hide their impairment, others feel empowered through accepting limitations. In this work it will be interesting to discover the stance developed by the young people interviewed and also whether moving to secondary school, often a much bigger school with many more pupils will impact on their choices. It will also be possible through this work to look at the views of those young people attending mainstream schools, and those attending special schools, and to compare how these young people view themselves.

One study which explored how children experience disability was carried out by Connors and Stalker (2007). They questioned whether disabled young people were in denial regarding their impairment by focusing on the ways in which they are similar to other non disabled young people, even when experiencing negative reactions and physical barriers. The parents of these disabled children felt that they were aware of being different; however they did not view their impairment as a 'personal tragedy'. Connors and Stalker (2007) concluded that due to their primarily medicalised experiences of their impairment, these disabled young people lacked the positive language to discuss being impaired. Lewis et al (2007) further noted that parents had a tendency to use medicalised language. Thus if disabled children and young people are constantly experiencing their impairment in terms of medical discourse it will be difficult for them to move away from this view. As discussed above this is one of the areas this research will address.

2.2.3 Consulting disabled people

Regardless of how disabled young people view their impairment it has been shown that they have strong views in relation to health, education, and leisure (Joseph Rowntree Foundation, 2001), and wish to be consulted about them (Kelly, 2005, Hill et al, 2004, Detheridge, 2000). In order for a successful consultation to occur the researcher has to have the appropriate skills to work with disabled young people (Cavet and Sloper, 2004).

Disabled children and young people also want to be included and informed by the services they use. For example, Garth and Aroni (2003) reported that children with CP wanted their paediatrician to talk to them, and to inform them of what was going to happen next during consultations. Disabled young people also have the desire to participate (Franklin and Sloper, 2008, Sinclair, 2000), and expressed to Sinclair that they felt being involved in consultation helped them to develop personal skills, such as improved communication, decision making and negotiation. Although the literature has reported ways to improve all young people's participation in research these have not always fed through to practices so that many disabled children still have problems with participation (Franklin and Sloper, 2008).

Research investigating issues important to children and young people to date have been more likely to involve non disabled people. In particular individuals with profound cognitive impairments are less likely to be involved in such work (Tisdall and Davis, 2004, Sincalir, 2004). Disabled people need to be given the opportunity to express their views and to have the opportunity to report them independently (Cavet and Sloper, 2004); otherwise we will not develop knowledge regarding their lives.

Cavet and Sloper (2004) recommend developing a multilayered approach to assist disabled people to participate in research. This approach involves listening to disabled peoples views and tailoring the research to accommodate their needs. They believe this would be a more appropriate way of working with disabled people.

Many disabled individuals have now become disillusioned by research (Stone and Priestley, 1996), and feel that the researcher has adopted the role of the expert, resulting in the experiences of disabled people being marginalised. Stone and Priestley (1996) propose that researchers only carry out disability research when it is of a practical benefit, and that they adopt plurality of methods.

2.3 The nature of Cerebral Palsy

Cerebral palsy (CP) is the most common form of childhood disability and involves a motor impairment. These individuals face multiple barriers in society which may impact on individuals to varying degrees.

CP is used as an umbrella term (Mutch et al, 1992) to encompass a group of disorders of primarily motor function. The Surveillance of Cerebral Palsy in Europe (SCPE, 2000) collaboration defines CP as having the following key elements: it is a group of disorders; is permanent, but not unchanging; involves a disorder of movement and/or posture and motor function; is due to a non-progressive interference/lesion/abnormality; this interference/lesion/abnormality is in the developing/immature brain.

There are three main types of CP which are named by the International Classification of diseases (ICD-10, 1994); Spastic, Dyskinetic, and Ataxic. Spastic CP is the most common type of CP and is characterised by the sudden stiffening of muscles, which make any movement difficult. Sudden movements of limbs is distinctive of Dyskinetic CP. These movements are slow and writhing (athetoid), and/or rigid (dystonic), and/or jerky (chorea). The least common type of CP is Ataxic CP, which involves a difficulty with balance, and co-ordination of the hands.

Further CP is frequently described and categorised in terms of its topography. Bilateral refers to CP affecting both legs and arms, diplegia is used when predominately the legs are affected, and hemiplegia when one side of the body is affected more than the other, more commonly this is the right side.

Children with CP are also likely to be diagnosed with a range of other disorders, such as epilepsy (Gururaj et al, 2003), learning impairments (Jelliffe-Pawlowski et al, 2003), behaviour problems (McDermott et al, 1996), feeding difficulties (Motion et al, 2002), and visual impairments (Visual Impairment Scotland, 2003, Guzzetta et al 2001).

Categorisation of young people in this way is a very medicalised approach to adopt. Many barriers faced by the young people with a specific diagnosis will be common to other young people with a similar diagnosis. For example, many young people with bilateral CP will be wheelchair users and will face barriers to accessing school. Despite such categorisation being of use within some areas, it is vital to be mindful

that regardless of their diagnosis all young people have individual experiences and abilities.

2.3.1 Experiences of services

Due to the variability within CP many of these children will require an input from multiple services (Sloper and Turner, 1992), including health, education and social work. Contact with these agencies will be high for the majority of children, and it is important that these services remain flexible to cater for the different needs of individual children with CP. These services also need to support parents.

Some families living with a disabled child are frequently found to have increased stress scores (Dyson, 1991, Keller and Honig, 2004). In particular this stress has been related to caring for their disabled child (Dyson, 1997), parents seemed to worry about care taking, and also the way others viewed the child's impairment. Specifically, increased levels of stress in families with a disabled child are linked to critical life events such as time of diagnosis, when the child starts school, puberty, and the child's twenty first birthday (Hanline, 1991).

Although these children and their families have a high degree of contact with services, frequently dissatisfaction across services has been reported through research. Problems often centre on the provision of information (Darrah et al, 2002, Sloper 1999, Sloper and Turner 1992), communication and support (Darrah et al, 2002, Sloper, 1999, Bamford et al, 1997), and the lack of co-ordination between services (Darrah et al, 2002, Sloper, 1999). Families report feeling undervalued and not listened to by services (Darrah et al, 2002, Middleton, 1998, Bamford et al, 1997), and express a need for specific services during key life events (Bamford et al, 1997). Terms such as "fight" are commonly used by parents when talking about gaining access to services (Darrah et al, 2002, Sloper, 1999), and they often appear to be confused as to the role specific services play (Sloper, 1999, Middleton, 1998).

A wealth of research has been produced in support of the allocation of key workers, or link persons, to children with CP to co-ordinate care (Greco and Sloper, 2004, Bakheit et al, 2001, Sloper, 1999, Sloper and Turner, 1992). Findings from such schemes recurrently find parents reporting that their needs are being met, and that

they have a greater access to information (Greco and Sloper, 2004). Not only do these schemes improve multiagency working, but they also have the benefit of involving the parents and older young people in the planning of care. Such an approach allows the individual needs of the family to be met, leading to an improved quality of life for the child and the family, and an overall increase in satisfaction with services (King et al, 2004).

Within Scotland services are provided through individual health boards, and research has highlighted the variability in service provision dependant on locality (Smiley et al, 2002). The family centred approach would be the ideal according to research carried out by Bakheit et al (2001), who also lay out core health services children with CP should have access to. These included physiotherapy, psychologists, occupational therapy, speech and language therapy, nurses and orthopaedic surgeons.

For many families one of the major tools for coping with having a child with CP is the provision of information. Families with a disabled child use information to assist them in making proactive decisions to access services (Pain, 1999). Parents of children with CP also saw information as a source of power (Miller et al, 2003). Parents of disabled children felt that there was a need for the provision of more information and advice, specifically in relation to services (Sloper, 1999). Mitchell and Sloper (2001) found that parents of disabled children found information seeking difficult and somewhat confusing, and that a lack of information from medical staff made it difficult for them to make informed decisions. Many reported that other parents were frequently the source of information (Garth and Aroni, 2003).

Young people in general acknowledge their parents as a source of information and expressed that they felt their parents information needs needed to be addressed (Cavet and Sloper, 2004). They valued receiving information and clear explanations (Cavet and Sloper, 2004), although this frequently was not found to be happening from services. Learning disabled children indicated that they wanted professionals to interact and listen to them, as this resulted in them feeling liked and valued (Kelly, 2005). Key factors for disabled young people when accessing services was having welcoming staff, the opportunity to make and meet friends, participating in age-

appropriate activities, and having the opportunity to make choices (Mitchell and Sloper, 2001).

Thus young people are experts of their own experience (Shakespeare and Watson, 1998), and want to be part of making decisions regarding issues that impact on their lives. Despite such attitudes from the young people, their desire to be included, a core theme of the social model, is being denied and their voices not listened to.

2.4 Chapter summary

Through discussing the concepts of disability an insight has been gained into CP, and the experience of disabled people within society. From this literature there are several key issues which will be influential to this research.

- Is balancing the input from the social and medical models important to how disabled young people experience the transition?
- Most disabled people have a positive identity, and need the opportunity to express their opinions.
- The field of CP is very medicalised.
- Parents feel dissatisfied with services, and the need to fight.

Models of Disability: In discussing disability work seems to fall into either the medical, or social model. Adopting a particular model will influence how this work is carried out, and also how the data is interpreted.

Within the chapter the argument of Shakespeare and Watson (1998) is presented, which calls for the need for a balance between both models. Through acknowledging both impairment and environmental factors a more rounded picture of disability can be presented. Having such a view will allow for the data from this project to be interpreted from a more neutral stance, and thus the true voice of the disabled young people heard. It will be interesting to note of this stance remains true having journeyed through the work.

Positive identity: From this review it is evident that although societal stereotypes are that of disabled people as people in need and experiencing personal tragedy, this is

not the view of disabled people themselves. This raises the question for this thesis, what impact will the transition to secondary school have on the young people's identity, and will societal stereotypes have an influence.

Field of CP: Much of the literature presented on CP focuses very much on defining it in terms of medical terminology. A combination of the social and medical model approach brings into question the value of such terms, and whether they play a part in attempting to understand young people and their parents transitional experiences.

Dissatisfaction with services: The research suggests that families with a young person with CP require a vast input from services (Sloper and Turner, 1992). This work will investigate the experiences of parents with services during the transition, and how satisfied they are with such services. It will also investigate whether the feelings of parents that they have to fight for services remains true.

At the end of the chapter it was noted through work such as Greco and Sloper (2004) that having a link person to co-ordinate care is helpful to families. At times of transition, with the involvement of a number of services, it will be interesting to see whether such methods have been adopted, and if so what views parents and young people have of them.

In this chapter disability, and in particular CP has been investigated, from which a number of questions related to the literature have been developed. The next chapter will now move onto examine the role of school in the lives of young people more thoroughly, and ask what is already known about the transition, and which areas this project can contribute to.

Chapter 3

Understanding the transition from primary to secondary school

3.1 Introduction

In the previous chapter concepts of disability and the nature of CP were explored. It was argued that despite societal stereotypical images, disabled people held positive self images. They had clear views, opinions and a desire to be consulted. This work provides the background context to the project.

In this chapter the focus moves onto school and the transition between primary and secondary. Existing knowledge regarding the role of school in the lives of children and, young people will first be discussed, before the chapter moves onto address the transition in more detail.

The first part of the chapter looks into '*3.2 The role of school*', and how children evaluate it. It is established that children like school and value the peer relationships developed there (Connors and Stalker, 2003). Thus it is important that during the transition young people can remain with friends and continue with uninterrupted schooling.

Government policy is then addressed in '*3.3 How policy influences education for disabled children*'. Policy has been introduced to ensure all children have access to mainstream schools, which are accessible to disabled young people. The issue is whether such policy has influenced the transitional experiences of these young people.

The impact of such policy is then discussed within '*3.4 School experiences of disabled pupils*', with the experiences of disabled pupils in mainstream and special schools presented. Many disabled young people in mainstream schools encounter barriers such as bullying (Connors and Stalker 2003), or problems with access (Watson et al, 2000). However despite such barriers young people want to attend such schools with friends from the local area. This work will look into whether these young people encounter similar barriers.

When looking into experiences of disabled young people attending special schools, it is reported that such schools are perceived as having more specialised teaching, and that young people can feel relief on moving to special school. It will be interesting within this research to compare the transitional experiences of those young people in special schools with those in mainstream.

The chapter then moves onto address the transition more thoroughly in '*3.5 Making the transition*'; starting with the policy that should improve transitional experiences. The Education (Additional Support for Learning) (Scotland) Act, 2004 (ASL) aims to, improve educational experiences for those pupils requiring additional support for learning.

Concerns young people have prior to moving are discussed. All of the current research has been carried out with non disabled young people; therefore this project asks whether disabled young people have similar concerns.

The final section '*3.6 Parents and their needs during the transition*', asks how parents needs are addressed during the transition. Very little work to date has asked parents for their experiences, however there is a body of work which suggests parents might find this period difficult, as discussed in chapter 2.

The available work which addresses school and the transition, demonstrates that disabled young people value attending school, although frequently experience barriers at mainstream school. The majority of the work on transitions has been with non disabled young people, and has highlighted a number of concerns. Disabled young people are missing from this research.

3.2 The role of school

School can be viewed as one of the first social structures that all children experience, and provides them with the knowledge of societal social norms (Schaffer, 1996). Within the school environment children will learn the life skills that will allow them to function as an adult, both socially and emotionally, along with academic skills (Backe-Hanson, 2002, Day, 1996, Baker and Gaden, 1992).

As a social structure, interacting with peers is a critical aspect of school. Peer relationships at school influence the child's social development and contribute positively to both the child's attitude towards school (Galton and Willcocks, 1983), and the learning achievements of the child (Day, 1996). These peer relationships at school are also a source of support for children (Day, 1996), and Pellegrini and Blachford (2000) reported that children value these relationships and see them as important.

In addition children are also positive about teachers. They were viewed as someone children felt they could turn to for support (Charlton, 1996). Parents also placed an importance on teachers, feeling that it was beneficial to know their child's teachers. However, once the child had moved to secondary school this was less likely to occur (Backe-Hansen, 2002).

For disabled children school is as important to their development as for non disabled children. It is a place that the children themselves value attending, and which they see as giving them an opportunity to learn and play with other children (Rabiee et al, 2005). School is also seen as a safe and supportive environment whereby they can develop citizenship skills, and are stimulated by an appropriate curriculum (Russell, 2003). Many disabled young people require assistance to attend school, which is often provided by teachers, parents or good friends (Lightfoot et al, 1999). There was an acceptance from these young people that this was necessary for them (Lightfoot et al, 1999).

Therefore for all children, school is an important part of their social development. Early on in their lives it is predominately the social activities such as play which are most important to them. A major part of attending school is the interaction with peers. Understanding the importance of school in the life of the child helps ground this research in the child's world, and also shows the importance of the transition going well so that school life is not interrupted. This study will investigate the extent to which children with CP experience uninterrupted transitions.

3.3 How policy influences education for disabled children

Education (Scotland) Act 1980 enforces that appropriate education must be provided to all children by their local authority regardless of age, ability, or aptitude. In Scotland several acts have been passed to ensure that disabled children have access to education.

Central to the Scottish Executive's aims is the provision of equal opportunities, and the prospect of inclusive education for all children in Scotland. In support of inclusiveness the Implementing Inclusiveness Realising Potential (Scottish Executive, 1999) report states that all services providing learning opportunities need to encourage and promote inclusiveness.

This is a continuation of earlier work carried out by the Scottish Office in implementing 'Effective Provision for Special Educational Needs' (EPSEN) (1994). This policy placed a duty on educational authorities to understand special educational needs and to have effective assessment procedures in place. All children assessed as having special educational needs should have an appropriate curriculum, which includes provision and teaching to meet their needs. There was also to be multiagency working, and the involvement of parents and young people in the development of this curriculum.

This was one of the earlier policies in Scotland regarding education for disabled children. More recently the Standards in Scotland's Schools Etc Act 2000 states that education provided to all children must strive to develop their personality, talents, mental and physical abilities to their fullest potential. Further this act reinforces the aim of inclusiveness for disabled pupils through putting a weighting towards mainstream education;

(1) Where an education authority, in carrying out their duty to provide school education to a child of school age, provide that education in a school, they shall unless one of the circumstances mentioned in subsection (3) below arises in relation to the child provide it in a school other than a special school.

- (3) *The circumstances are, that to provide education for the child in a school other than a special school—*
- (a) *would not be suited to the ability or aptitude of the child;*
 - (b) *would be incompatible with the provision of efficient education for the children with whom the child would be educated; or*
 - (c) *would result in unreasonable public expenditure being incurred which would not ordinarily be incurred,*
- and it shall be presumed that those circumstances arise only exceptionally.*
- (4) *If one of the circumstances mentioned in subsection (3) above arises, the authority may provide education for the child in question in a school other than a special school; but they shall not do so without taking into account the views of the child and of the child's parents in that regard.*

Standards in Scotland's Schools Etc Act 2000 (Point 15)

This Act reinforces the right of disabled children to attend mainstream school, and to have their views about school listened to.

In addition disabled people in the UK are protected from discrimination by the Disability Discrimination Act 1995 (DDA), and as amended Disability Discrimination Act 2005 which has brought about anti-discrimination legislation for disabled people. Within this act discrimination is seen as treating someone less favourably for a reason relating to their impairment (section 5). Under this act disability is defined as:

(1) Subject to the provisions of Schedule 1, a person has a disability for the purposes of this Act if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities.

(2) In this Act "disabled person" means a person who has a disability.

Disability Discrimination Act 1995 (Point 1)

This act has been amended to bring education under its remit, which was previously more employment focused. The Special Educational Needs and Disability Act 2001

(SENDA) has now been incorporated as part IV of the DDA. The main points of part IV are:

- To place a duty on educational institutions not to treat disabled people less favourably for a reason relating to their impairment.
- To make reasonable adjustments to avoid disabled people being at a substantial disadvantage.
- For these adjustments to be anticipatory, in that the establishment should make efforts to reduce barriers rather than wait for a specific alteration request from an individual.
- Applies to all admissions, enrolments and student services, including teaching material and assessments.

However, within Scotland the provisions outlined by SENDA are met by alternative Scottish policy due to education being devolved to the Scottish Parliament. The planning aspect of SENDA is addressed under the Education (Disability Strategies and Pupils' Educational records) (Scotland) Act 2002 (DSPERA).

The main emphasis of this Act is the responsibility of schools to ensure that an accessibility strategy is in place, which would ensure that disabled children receive the same service level as non disabled children.

DSPERA declares that the strategy should consider how increased participation in school education can occur for disabled children, how improvements to the physical environment of the school can enable disabled children to take advantage of education, and also how communication with children with disabilities can be improved.

The most recent education act introduced in Scotland is the Education (Additional Support for Learning) (Scotland) Act 2004 (ASL). Additional needs, under this act, are classed as any additions required to the education provision that is usually provided. This Act came in to address the variations in recordings between authorities with the previous 'Record of Need's' system, and also to address the lack of consultation with children and young people that existed under this system.

The ASL act aims to modernise and improve upon the way that children who require additional support are educated, and complements existing education and equality legislation, such as the Disability Discrimination Act 1995, Children (Scotland) Act 1995, and the Education (Disability Strategies and Pupil's Education records) (Scotland) Act 2002. In particular the 2004 Act links both the Standards in Scotland's Schools Etc. Act 2000, and the Education (Scotland) Act 1980.

Under this act advice from the 'For Scotland's Children' report (Scottish Executive, 2001) is incorporated which recognises there the need to involve multiple agencies in the education of young people considered to require additional support for learning, and to take into account the views of young people. In addition parents are also empowered by this act which acknowledges parents knowledge relating to their child's needs, and the importance of valuing and obtaining this contribution, good practice dictates that working in partnership with parents is essential to achieving the full potential of a child.

Parents are given the right to request specific assessments to determine whether their child has additional support needs, and whether a co-ordinated support plan is required. They have the right to receive advice and information relating to additional support needs, in a language which is accessible to them. The Act advises that parents should be well informed of all processes and decisions linked to their child.

Parents can also request that their child is placed in a specific school, and to be informed of outcomes, and reasons for decisions, made in relation to their child's education. Should parents feel the need to dispute any actions they have the right to free independent mediation, along with the right to attend any meeting with an advocate or supporter, such as a relative, friend, or member of a voluntary organisation.

Any child may require additional support, which can arise due to one or more of the following issues; the learning environment, family circumstance, impairment or health needs, or social and emotional factors. Additional support may take many forms, from the setting of S.M.A.R.T. (specific, measurable, attainable, relevant, and timed)

targets, to developing an alternative curriculum, or providing support within the classroom. It's often the child's teacher who will identify the possibility of a child's requiring additional support, although parents can request that their child is assessed.

One area where the parents as well as the young person will be involved under this Act is through the development of a co-ordinated support plan (CSP). CSP are developed for children who have ASN due to complex, or multiple factors that are likely to be ongoing for more than a year. Often these children will require additional services from the educational authority along with services from outside the authority, such as health or social work. This is a plan which outlines the child's educational objectives along with the support that they will require, and how this support will be provided. The development of a CSP will also result in the appointment of a plan co-ordinator to ensure that information is shared between the professionals involved and the family.

This Act also established a code of practice for a professional which establishes that all children and young people are entitled to the support they require to reach their fullest potential.

Over time there has been a great deal of change in the policy governing education in Scotland, from the EPSEN policy, to DSPERA and now the ASL Act. The ASL act is also being implemented in line with the 'Curriculum for Excellence' (2004) which outlines that all children should follow a curriculum which allows them to achieve to become confident individuals, successful learners, effective contributors, and responsible citizens. Through such policy there is a shift in power back to the young people, with curriculums adapting to fit them to support them to achieve.

Thus policy has been developed to ensure that disabled pupils have the right to access the same services available to those who are non disabled. With regards to education the emphasis is on inclusion within the mainstream setting. Although special schools are still available, these may become more difficult to access for some. What is important is that disabled young people and their parents are given the choice and opportunity to access the education which is best suited to them.

This legislation should mean that all schools are open to young people diagnosed with CP, and that on moving from primary to secondary there should be a choice of schools available and accessible to them. The question asked in this research is whether parents were able to choose and the young person able to attend the school of their choice, if it is inaccessible to them prior to the transition.

3.4 School experiences of disabled pupils

From the previous sections it has been outlined that disabled children and young people enjoy and value attending school, and that policy in Scotland aims to ensure that schools are accessible to them. There follows a review of the current literature, which examines the experiences of disabled children in both mainstream and special schools.

3.4.1 Experiences of mainstream schooling

Many disabled children attend mainstream education. Recent reports from the education regulatory organisation in England Ofsted (Special Educational Needs and Disability: Towards inclusive schools, 2004, Special Educational Needs in Mainstream, 2003) have highlighted that many schools are committed to addressing the needs of children with special educational needs, and that the teaching of these children was generally found to be good (Ofsted, 2003). However, these reports also found that despite the government's recent emphasis on inclusion, this has not led to a significant increase in the number of disabled children in mainstream education (Ofsted, 2004). In Scotland the HM Inspectorate for Education report (Improving Scottish Education – A report by the HMIE on inspection and review 2002 – 2005) noted that the implementation of inclusiveness in schools is variable across Scotland. One possible explanation is that many parents described the process of getting into mainstream school as a 'struggle' (Connors and Stalker, 2003). Such findings raise the question of what implications this has for young people diagnosed with CP.

Disabled children have the right to access mainstream schools in the same way as their non disabled peers. Additionally, theory suggests that, through attending mainstream school disabled children become integrated into the school society. The

contact hypothesis states that increased contact of non disabled children with disabled children will lead to increased familiarity, and eventually increased relationships between them (Goltlieb and Leyser, 1981). This hypothesis has more recently been supported through work by Maras and Brown (2004), and also Shaw (1998), and will hopefully lead to increased social integration in the future. However, purely bringing children into the same school does not guarantee that they will form friendships with each other (Baker and Gaden, 1992). Bringing young people into the same building is an attempt at integration, and does not mean that the child will feel included.

Despite no guarantee of friendships forming, when disabled young people do attend mainstream schools, other pupils report that they regard them as a normal part of school life because of the schools inclusion policy (Ainscow et al, 1999). Earlier Shaw (1998) had also established that young people were positive regarding inclusion, seeing it as a constructive way to increase familiarity.

Thus many young people are supportive of inclusive education. Much of the fears stem from adults who worry that inclusive education will lead to a drop in achievement for non disabled pupils at the school. A study by Farrell et al (2007) did find a slight drop in the academic achievement for students at schools with a high number of students who were deemed to have special educational needs. However, it was also established that the approach the school adopted towards being inclusive had an influence on achievements of the pupils, and not simply the presence of disabled pupils.

Farrell et al (2007) went on to establish some key points to assist schools to be successful at including disabled pupils. This involved being flexible with regards to allowing the student to move between mainstream classes and the support base, for detailed planning and monitoring to occur, and for adult support to be used when appropriate. Mollard (2003) also noted the need for appropriate planning, support, and reviews in order for inclusion to be successful. Farrell et al (2007) recommends that the school needed to adopt an inclusive ethos, which was in turn supported by the staff. Similarly Baker and Donnelly (2001) reported that parents felt it was vital

that the head teacher in particular had a positive attitude towards inclusion, as they felt this was key to whether it is successful or not.

Thus the attitude of schools will influence the experience of the young person, and will in turn directly impact on the transition.

Inclusiveness seems to be more problematic for disabled children on entering secondary education compared to primary. It is felt by many professionals that inclusion is not as successful in secondary school due to the larger class sizes, the increased numbers of staff, the extensive curriculum, and the formal examinations (Mollard, 2003). When disabled children do attend mainstream secondary school their progress has been found to be poorer compared to their progress at primary (Ofsted, 2003). From this project we will hopefully gain an insight into how young people with CP are integrated and accepted by secondary schools.

A project carried out by Shaw (1998) identified the issues which were important to disabled children in mainstream school. The most important issue for these children was remaining with friends from the local area. This led many children who had previously attended special school and now had moved into mainstream school to express a wish to stay within mainstream education, even when encountering difficulties at school. This was also later supported through work by Connors and Stalker (2003).

Parents reported that it was important for their disabled child to be educated with their friends from the local area, and with any siblings (Mollard, 2003). For many children, attending the local school helps them to feel part of the community which is beneficial to their development. Work by Farrell et al (2004) with disabled individuals, and also Prezza et al (2001) with non disabled people have both found that a sense of community has been linked to increased levels of satisfaction, well being and coping, along with a reduction in feelings of loneliness (Prezza et al, 2001). Being part of the community also assists in the development of a social identity (Fisher and Sonn, 1999). Thus there are a number of advantages to disabled children attending the local community school.

Therefore the young people had a desire to attend the local school and to remain with friends from the area, which was also their parents view. However, for many disabled young people attending a mainstream school often resulted in them experiencing a wealth of barriers.

Accessing parts of the school were often difficult for disabled young people. In particular one barrier reported was accessing the playground at school. Not only did this deny the young person access to a communal area, but also limited the opportunity to develop friendships (Watson et al, 2000). For all children it is the physical proximity that determines whether friendships are formed, as they develop friendships through playing together. If disabled young people are prevented from accessing the playground they are less likely to make friends (Baker and Donnelly, 2001).

Not only do disabled young people experience barriers to accessing recreational areas, but in some cases classrooms were also inaccessible (Lightfoot et al, 1999). Again having to be taught in an alternative location separates the young person from their classmates. In an attempt to avoid this isolation some schools allowed the disabled young person to have friends go with them to the alternative classroom. The young people appreciated it when this occurred (Lightfoot et al, 1999).

Another physical barrier faced by disabled young people is the segregation from other pupils in special units within mainstream schools. For some disabled young people being isolated from other pupils made them feel obviously different, and highlighted their need for extra support to learn (Shaw, 1998).

For some disabled young people the presence of a support assistant acted as a barrier to them interacting with other pupils (Connors and Stalker, 2003, Shaw, 1998). However, for other disabled young people the lack of an assistant to support them was a barrier to them accessing mainstream education (Aston et al, 2005). Thus the decision to provide support through an adult assistant has to consider the needs of the child, and how this can be done to maximise their learning, but to avoid barriers to interactions. Similarly if disabled young people are denied access to

resources, such as laptops or adapted chairs, this again acts as a barrier to them in the mainstream setting (Lightfoot et al, 1998).

Some disabled young people are prevented from attending mainstream schools altogether due to the barriers that exist within many of them. While others felt that they would be better off in a special school due to the barriers they faced (Connors and Stalker, 2003). However, despite the experience of such barriers it has been shown more recently by Lewis et al (2007) that disabled young people were generally happy at school and that many wanted to remain within mainstream education to carry out further study.

Conversely recent work has illustrated that access around the majority of mainstream schools is good (Lewis et al, 2007, Woolfson et al, 2007). Therefore there has clearly been some improvement across the UK following the implementation of government policy.

From this section questions are raised regarding whether young people with CP encounter barriers on making the transition into a mainstream school, and also whether they were included at these schools following their transition.

As mentioned above, having support from an assistant at school can be both a positive or negative experience depending on the individual case. There can also be a clash between adults and disabled young people over providing the right level of assistance, whilst also maintaining independence, and safety (Middleton, 1999). It is important that the level of assistance provided to disabled young people within mainstream schooling is matched to their level of need. Disabled young people frequently have clear views relating to the support they would like (Lewis et al, 2007), often being more relaxed about the provisions of care they felt they needed compared to their parents.

As Lewis et al (2007) demonstrates disabled young people would also like to be consulted regarding this support (Woolfson et al, 2007, Lewis et al, 2007). Specifically disabled young people wanted support to be available which they could

request when they needed it, rather than have it automatically allocated to them (Wooldfon et al, 2007).

With regards to the support that young people received, much was provided by teachers. Many disabled young people report forming special relationships with individual teachers who supported them (Lightfoot et al, 1999). Children in general overall felt that teachers in particular supported them throughout the transition (Ross et al, 2006). However, in contrast the school experience of disabled young people can also be made difficult by teachers if they do not understand the young person's impairment (Lightfoot et al, 1999). One example which illustrates this is work by Woolfson et al (2007) who reported how some physically disabled young people found that teachers did not consider that they may require extra time to travel from class to class.

Disabled young people felt that the support from teachers was frequently impairment focused and tending to single the young person out as different (Allan, 1999). An example reported in work by Allan (1999) quoted a young visually impaired person who felt that the teachers at her mainstream school often went over the top, asking her in front of her peers to come up to the front of the class, even though she was unable to see the black board, thus leading to further disabling her.

Although teachers can provide support they can also alienate disabled pupils. Within some schools disabled young people are frequently identified through discourse surrounding their impairment; this then leads to them being treated differently by their peers (Watson et al, 2000, Priestley, 1999). For many young people the problem is exacerbated by being the only disabled pupil in the school, and being left to educate their peers regarding their impairment (Middleton, 1999).

Being in the minority can lead to bullying, and a significant number of participants in the work carried out by Lightfoot et al (1999) and also Connors and Stalker (2007) commented on this. For the majority of disabled young people this took the form of verbal bullying via name calling.

Although such bullying does occur, it is important to also note that bullying was also a problem within special schools (Connors and Stalker, 2003, Shaw, 1998). Disabled young people themselves acknowledge that bullying could occur and was not only due to their impairment (Shaw, 1998). A way to overcome such bullying put forward by disabled young people interviewed by Lightfoot et al (1999), was for health professionals to provide information to the school about their condition, and also to educate staff and pupils about it, reducing the pressure on the young person to do this.

Along with interventions from health care professionals, an improved experience could be achieved through remembering that there is a fine line between adapting mainstream schools to incorporate disabled young people, and isolating them. In many cases disabled young people will encounter problems if treated exactly the same as other peers, as they may, for example, need to leave class early to avoid crowded corridors (Lightfoot et al, 1999). Connors and Stalker (2007) point out that in the case of disabled young people the rules for the majority may not always fit the minority.

As well as the young people dealing with barriers at mainstream schools, many of their parents found they needed to play an active role in their education. Lightfoot et al (1999) reported how parents often had to explain about their child's impairment, and specifically how it could impact on their child's education to teachers. They also played the role of mediator, solving problems between the young people and teachers.

This work will ask how schools adapt and involve young people diagnosed with CP, and whether the young people themselves feel comfortable with this.

3.4.2 Children with Cerebral Palsy in mainstream school: Existing literature

Research conducted within the mainstream setting has found that peer relationships were particularly difficult for children with cerebral palsy at 12-15 years (Darrah et al, 2002), and many children reported bullying at mainstream schools (Shaw, 1998). Yude et al (1998) drew attention in particular to the difficulties encountered by children with Hemiplegia (weakness or lack of control over one side of the body),

attending mainstream school. For these children often their cerebral palsy was not so physically obvious, however they frequently had related specific learning or behavioural problems. It was found that these children were more likely to be rejected and victimised at school, and to have fewer friends compared to other young people (Yude and Goodman, 1999, Yude et al, 1998).

More recent work by Nadeau and Tessier (2006) used matched groups of young people diagnosed with CP and without CP to look at experiences within mainstream schools. They concluded that young people with CP were likely to be more verbally victimised than those without CP, and that the victimisation was more likely to be physical for those young people with less visible CP.

Identifying how young people diagnosed with CP fit into secondary school and how they cope with the transition will be a major function of this project. With bullying identified as a possible problem, young people's views and experiences relating to this will be gathered and how this issue relates to young people diagnosed with CP addressed.

3.4.3 Disabled children attending Special Schools: Existing literature

Although there is a push towards integrating disabled children within mainstream schools many require additional support provided by a special school. Some parents also support the choice of attending special schools as they feel that resources will be targeted specifically to cater for the needs of their child, and teachers will have specialised training in how to educate disabled children (Baker and Gaden, 1992).

On a positive note French (1993) reports feelings of relief on attending a special school and being considered as the norm amongst her peers. A more recent study by Kelly and Norwich (2004) found that learning disabled children at special schools were more positive with regards to their educational abilities compared to similar children attending mainstream education, and were more likely to discuss their impairment unprompted (Connors and Stalker, 2007). However, the parents of disabled children attending special schools were found to have lower expectations of the academic achievements of their child, feeling that school time was more beneficially spent addressing self-care and independence (Rabiee et al, 2005).

Kenworthy and Whittaker (2000) felt that special schools were preventing non disabled young people from learning from young people who were different to them, and that segregating these young people within a special school was leading to the reduction in social tolerance towards disabled people. Segregating disabled children can also make it difficult for these children to then go into environments, such as the work environment, as the only disabled person (Sandstrom, 2007). Kenworthy and Whittaker (2000) went on to state that special schools need to be closed to stop this segregation and that mainstream schools were using the disabled young persons inability to conform to 'petty regulations', such as standing still when a bell sounded, as a means of preventing them from attending.

Middleton (1999) agrees with the stance that special schools reduce interactions between disabled and non disabled children, and questions whether parents who choose special schools are fully informed. She believes that some parents may choose a special school as a safe option to avoid bullying and prioritise the increased physiotherapy and nursing care available there.

The literature to date does not provide a conclusive view of which type of education disabled young people should participate in. In support of mainstream schools is the premise of the contact hypothesis, and authors such as Kenworthy and Whittaker (2000) believe special schools reduce the tolerance and understanding of disability by those non disabled individuals. Young people however want to remain with friends and siblings, resulting in them taking up their inclusion rights. However there is a question over how included they are within mainstream schools.

Young people with CP have widely diverse needs, and for some it may be appropriate that they attend mainstream schools. For others mainstream schools with support, or special schools. Due to this variability issues will be different between young people with CP. Recent work has found that those with milder CP may have specific issues due to their disability being less obvious.

What is clear is that there are advantages and disadvantages to mainstream and special schooling systems, and that each young person will require different facilities, and should be free to choose where they access their education.

3.5 Making Transitions

Transitions can be difficult times for all young people, in particular if more than one transition is occurring at the same time (Simmons and Blyth, 1987), for example when a young person is leaving school and moving into the care of adult services. Research looking at transitions has found that often young people are not directly consulted, which can lead to information not being accessible to them, and issues which are barriers for them not being addressed (Morris, 2002).

It has also been demonstrated that the reality of transitional experiences often do not marry with the recommendations made by the government (Morris, 2002). The fourth edition of the Royal College of Paediatricians and Child Health report 'Health for all children' (2003) highlights the need for service providers to tackle several key areas, with transition periods being one such area. Through addressing such key areas it is envisaged that education, health, and social outcomes will be improved for both children and their parents.

3.5.1 Transitions and educational policy

Following the Standards in Scotland's Schools etc Act 2000 guidance from Scottish ministers has highlighted the requirement of schools to prepare for key transitional points. These include the transition from pre-school into primary and from primary into secondary.

Most recently the ASL act has addressed transitions. Education authorities are required to have appropriate arrangements to deal with transitions, and for the majority of children these should be sufficient to ensure the process goes well. However, for children with ASN other agencies may need to be involved to ensure a successful transition.

Key to a successful transition for all children is early planning, which must involve the parents, the intended school, and the views of the child. In relation to children

requiring additional support for learning all agencies required to support the child need to be consulted, and a relevant person appointed to co-ordinate the transition.

If a child has a CSP in place, and the transition will involve a change to the statutory co-ordinator, the 2004 Act advises that this needs to be discussed with the child at the earliest opportunity.

Young people diagnosed with CP may be considered as requiring additional support for learning, thus this Act should influence their transition into secondary school. With two groups of young people being interviewed in this project both before and after the implementation of the Act, it should be possible to gain an insight into how successful the Act has been.

3.5.2 The transition from primary to secondary: Research to date

The majority of children will experience a transition from one school to another during their educational experience; one of the most common moves for children to make is the move from primary education into secondary education.

The literature on this transition focuses on the experiences of non disabled young people. Disabled young people and parents are frequently not represented, neither are any of the preparations which take place in the build up to moving school, such as choosing a secondary school. There is no literature on how the secondary school is selected, and what factors are important when making this choice.

This transition can be particularly stressful due to it involving learning a new culture (Pratt and George, 2005), and following the transition event there are several first experiences for the young person to cope with (Lucey and Reay, 2000); for example travelling to school by themselves, getting lunch independently and moving classes.

Prior to making the transition many young people will emphasise the choices at secondary school. This is reflective of how young people value having such choices (Lucey and Reay, 2000). Choice has been shown to promote positive results in individuals, such as increasing levels of satisfaction and performance (Iyengar et al, 1999). Young people also value space at secondary school differently to adults, and view areas such as corridors, playgrounds, and around the school gates as areas

that represent 'freedom' to them (Lucey and Reay, 2000). Thus clearly young people are anticipating a more mature change to their life following the transition to secondary school. Having made the transition young people again make reference to choice, and comment on how they like being treated more maturely (Ross et al, 2006, Ainscow et al, 1999).

The literature is mixed regarding young peoples views on the transition prior to it taking place. Although young people do view secondary school positively research has also found that many children find the process lonely and unsettling (Day 1996). However, Galton et al (2000) reports that over the last 20 years schools have increased the organisation and planning of this transition, which has resulted in fewer children reporting anxiety over the move. Many young people now look forward and get excited about making new friends and learning new things (Graham and Hill, 2003). Despite such positive findings many children still anticipate the transition to be a difficult, stressful and anxious time (Pratt and George, 2005).

Thus although it appears that progress has been made with regards to a reduction in levels of stress, it is unclear whether this has gone far enough. Also work so far had concentrated on non disabled young people. It will be interesting to establish the reactions of disabled young people.

Early studies researching the transition into secondary school focused on changes in academic progress of non disabled children. This work established that academic performance was found to deteriorate for some children, in particular for male students following the transition (Nisbet and Entwistle 1969; Delamont and Galton 1986). Research also showed that in some cases children developed a negative shift in attitude towards school (Jennings and Hargreaves 1981), and some experienced a longer term reduction in motivation and acquired skills following the move (Galton and Willcocks 1983). Galton et al (2000) however concluded, that following the transition to secondary school many children had an initial dip in their academic performance, but that this was not a permanent effect.

These studies demonstrate that making the transition to secondary school can affect the child's ability to perform. However, they do not provide an insight into why some

children's performance capacity is reduced, and what can be done to minimise this effect.

Research has now moved the focus on such issues to look at the social and emotional factors related to transition, but again primarily looking at the experiences of non disabled children. Prior to making the transition many children have anxieties concerning moving to secondary school, although there are also some pupils that report having no concerns (Zeedyk et al, 2003). The majority of these concerns are based on rumours and stories (Pratt and George, 2005), and are social rather than academic in nature (Ross et al, 2006, Zeedyk et al, 2003, Graham and Hill, 2003). These fears were reported to disappear almost immediately on starting secondary school (Graham and Hill, 2003). These anxieties can be separated into three categories; the school environment, friendships, and bullying.

Anxiety concerning the school environment are primarily linked to moving to a physically larger school, and the associated factors linked to this (Anderson et al. 2000; Stradling and MacNeil 2000; Kvalsund 2000). Issues such as going from being the oldest children in the school to being the youngest (Kvalsund 2000; Summerfield 1986), the increase in class size, and the physical size of the new school building (Stradling and MacNeil 2000; Anderson et al. 2000; Delamont and Galton 1986) cause concern for many children.

Secondly concerns surrounding friendships centre on the worry of leaving friends and making new friends (Galton and Willcocks 1983). Previous studies cited have shown that children value friendships at school, and that these friendships have a positive impact on attitudes towards school and learning (Galton and Willcocks, 1983, and Day, 1996). Thus the academic and social effects of losing a friendship through transition on a child should not be underestimated (Day 1996).

Beneficial effects of friendships have shown that young people who made the transition with friends had the most successful experiences (Lucey and Reay, 2000), and were also more excited and less worried about the move (Weller, 2007). In particular young people who had primary school friends in their secondary class were more likely to cope well with the transition. For many young people the

possibility of not having primary friends in their secondary class was a major source of worry for them (Ross et al, 2006). Having these friends reassured the young people as they had a shared past and common experience (Weller, 2007).

These concerns of losing friendships were often not addressed by transitional activities, which tended to focus on academic information, such as the curriculum and school rules (Pratt and George, 2005). The importance young people place on friendships is evident in the advice they give on surviving the transition. One key piece of advice given is to make friends (Graham and Hill, 2003).

Bullying is another cause of anxiety for children prior to the transition (Stradling and MacNeil 2000; Kvalsund 2000; Delamont and Galton 1986; Galton and Willcocks 1983). Many children have concerns about bullying due to the increased number of children in the secondary school compared to primary school. One study carried out in a Scottish Highland mainstream primary school reported that 68% of children had some anxiety concerning bullying in secondary school (Stradling and MacNeil 2000). Bullying was the most common concern mentioned by both young people and their parents in research conducted by Zeedyk et al (2003).

Through identifying the issues that children are anxious about before the transition, it is possible to attempt to address these anxieties during the induction programmes both pre and post transition. Participants will be asked about their concerns prior to the transition in this project, and ways to overcome such concerns to improve future transition will be addressed later in this work.

Research has highlighted that the effect of this transition is dependant on the individual child (Nisbet and Entwistle, 1969). However certain children are more vulnerable to experiencing difficulties during the transition process. Children with behavioural problems (Berndt and Mekos, 1995), and children of a lower socioeconomic class (Nisbet and Entwistle, 1969) tend to experience more difficulties with the process compared to other children. Children who are high achievers were found by Berndt and Mekos (1995) to be more anxious about the move prior to it occurring, but settled in well once they had made the move. Simmons and Blyth (1987) also identified females as being more vulnerable than

males. This could be linked to research which found that females are more anxious prior to the transition due to concerns regarding peer relationships (Berdts and Mekos, 1995).

The transition of disabled children from primary school into secondary school has been identified as a time that needs to be researched (Watson et al, 2000). In particular since it has been found that children requiring additional support for learning may be more likely to have difficulties with the transitional process (Schagen and Kerr 1999), and experience increased stress at these times (Hanline 1991).

It is likely that factors which are important to, and which influence the transition for non disabled children are also applicable to disabled children. However for these children considered preparation involving the child, their parents, and school staff is vital (Ofsted, 2003). A range of professionals from a variety of services may also need to be consulted (Prigg, 2002) which may contribute to longer preparation periods.

What are the key issues for the young people on making this transition, and how can these be addressed? The literature suggests issues such as friendships, and the impact of support will be influential. This project will establish the key factors for young people with CP.

3.5.3 What is known about improving transitional experiences?

Schools have made a significant improvement to the transition process, and have succeeded in reducing the levels of stress reported by non disabled children (Galton, Morrison, and Pell 2000). To be successful it is vital that schools recognise the transition as a process and not a single one off event (Sanders et al, 2005). Academic preparation, careful planning and support for the child are key elements to a successful transition (Anderson et al. 2000). Transfer activities and a designated liaison are also vital to marry up the difference that often exists between the child's expectations of the secondary school and the reality of it (Galton, Morrison, and Pell 2000). Other key elements include good communication between the primary and secondary school, and the opportunity to meet new secondary school staff prior to making the transition (Stradling and MacNeil 2000).

According to the main findings from the longitudinal 'Observational Research and Classroom Learning Evaluation' study (ORACLE) the most successful approach in reducing stress in children prior to transfer is the opportunity to experience a full day at the new school (Galton, Morrison, and Pell 2000; Delamont and Galton 1986). This approach allows the children to experience the new teaching styles and school environment, which is one of the major causes of anxiety. Also children in the ORACLE study reported that they believed only the 'nice' teachers were involved in other forms of induction (for example, secondary teachers visiting the primary school), and it was only through attending a whole day at the school and seeing all the teachers within the school environment that their anxieties pertaining to the new staff were reduced. Graham and Hill (2003), and more recently Sanders et al (2005) report that the induction day was the most popular transitional activity reported by young people.

Several activities, such as the induction days and visits by secondary staff, have been identified as helping the transition go well. However, this work has been carried out with non disabled young people. Do such methods work well with disabled young people, or do they require additional activities? This project will aim to identify a response to such questions.

3.6 Parents and their needs during transitions

The wealth of research related to the transition into secondary school has focused on the young person. Although understanding the young persons experiences is vital to improving the transition, it is important not to neglect the parents. Research demonstrated that involving parents in the transition can lead to an increase in the child's motivation at school (Anderson et al. 2000), and a more successful transition (Bastiani, 1986). Involved parents are also key to educating special needs children well in a mainstream setting (Ofsted, 2003).

At transitional times parents of non disabled children report the value of receiving information about their child's new school (Stradling and MacNeil 2000), and that they appreciate a school prospectus or brochure (Worsley 1986). Other recommendations pertaining to transition made by parents of non disabled children

is that they would like an induction programme, more time with the form tutor, and an opportunity to have a one to one interview with the school (Worsley 1986).

Parents of disabled children report the need for more information relating to education in order to make informed decisions (Pain 1999; Haylock, Johnson, and Harpin 1993). With the recent increased emphasis on integration and inclusion of disabled children, parents report the need now is greater for specific education based information, in particular information with an emphasis on the types of schools open to their children (Mollard 2003; Haylock, Johnson, and Harpin 1993). Although disabled children can be educated within mainstream or special schools, parents are reporting that in order to include their child in mainstream school they are having to undertake a great deal of the work (Mollard 2003).

For many parents of disabled children much of the support and information they require at this time is derived from other parents, and not services (Mitchell and Sloper, 2001). Research to date has shown that parents would appreciate more information at transition, but little has been done to look at the needs of parents of disabled children, and whether they require additional information and specific service input at this time. This study will also involve obtaining the parents views, which will provide an insight into such matters.

One study that did ask parents of non disabled children about their concerns and views on the transition was that conducted by Zeedyk et al (2003). From this study it was established that many parents reported the same concerns as the young people, primarily that of bullying, and friendships. This suggests that parents are well informed of the concerns of their children. Zeedyk et al (2003) also suggests that more attention should be given to parents needs during the transition, and suggests a possible causal relationship between the young persons concerns and the parents, as well as the parents concerns and the young persons.

This research will investigate the types of information parents and young people received about the transition, and how helpful they found this information.

3.7 Chapter Summary

From this review the role of school in the lives of young people and, their views of the transition from primary to secondary school has been presented. From this chapter there are a number of core themes which this project will need to address.

- Despite facing barriers in mainstream, many disabled young people choose to attend it.
- Young people have a number of concerns prior to the transition.
- Induction days assist positive transitional experiences.
- Research to date does not represent groups other than non disabled young people.
- The role of policy.

Choosing mainstream: From the literature review the work pertaining to disabled young people in the mainstream setting has highlighted a number of barriers that they face. This raises the question do young people with CP experience barriers when making the transition, and are uninterrupted transitions possible?

Concerns: The research to date highlights a number of areas non disabled young people have reported having concerns about prior to the transition. One of the main concerns highlighted is bullying. This work will contribute to our knowledge regarding the concerns of disabled young people on making the transition, and establishing if they are in line with the findings to date.

Induction days: Within this chapter evidence has been presented in support of induction days (Galton et al, 2000). This work will ask young people with CP and their parents for their views on these days, and whether there is scope to improve them.

Representative research: The literature presented here has focused on the experiences of non disabled young people making the transition. Disabled young people, parents, and events in the build up to the transitions, have all been neglected by the research.

No research within this review asked disabled young people for their experiences of the transition. Thus, this is a major contribution this work can make. This work will also improve our knowledge of parents experiences of the transition, in particular their concerns and needs during this time.

The research available has also not looked into how young people come about attending a particular school. There has been no discussion of the preparation period where the choice, if there is one, of school is made. Again this work will add knowledge to our understanding of this area.

Policy: Finally, policy has been introduced which requires schools to be open to disabled pupils, and for them to be accessible, such as the Education (Additional Support for Learning) (Scotland) Act 2004. Through this work the impact of the Additional Support for Learning has had on the transition will be investigated. This will be done through talking to families who made the transition prior to the act, and also those families making the transition under the act, and comparing these experiences.

Therefore, this chapter has highlighted the areas needing to be addressed and taken forward. There are also areas that this project will be one of the first to contribute towards. From such findings, and also the work in chapter 2 illustrating the service needs of families, the research questions to answer are;

- What impact has the ASL act had on this transition?
- What kind of transitional experiences do young people with CP and their parents have, and are their needs being met?
- Does the ASL act's call for young people to be involved in service planning have an influence on transition?
- Do young people and their parents adopt, or are they influenced by models of disability?
- Does the social model aspect of the ASL (removal of barriers) help combat discrimination?

The following chapter moves on to address the issues of conducting such a piece of work, and how the work will be carried out.

Chapter 4

Methodology and Method

4.1 Introduction

From the literature review in chapter 1 it is clear that disabled people want to be consulted and given the opportunity to participate in research. Through this project the opportunity was given to young people with CP to do this. In this chapter the methodological issues pertaining to working with children and young people, and also disabled young people, will be discussed. This chapter will also illustrate the method involved in conducting such work.

This chapter has two distinct parts, the research methodology, and secondly the methods undertaken.

In the first section, '*4.2 Methodology – theory of research and childhood*', the research paradigm is examined, and how this will influence the methods adopted and the data collected. As a person centred approach was decided upon participatory and emancipatory research methods are debated. Through the presentation of the core principles of these methods it is concluded that participatory research methods will be adopted, as they allow the participants to tell their story without adhering to a single model of disability.

This research involves working with young people; therefore concepts of childhood are addressed. Research is presented which illustrates that how the researcher views children, will influence the data collected. The chapter then moves onto discuss the methods for working with disabled young people.

The final part to this section, '*4.3 Ethical considerations*', is a discussion focusing on the ethical issues of working with children. The issues of obtaining informed consent, the question of whether to grant them full confidentiality rights, and the power imbalance that exists between the adult researcher and child participant.

This research involves obtaining the views of both parents and young people, however, much of the methodology section discusses issues pertaining to children. This is due to such work occurring infrequently and the methods of conducting such work being a new developing field.

The discussion of the above issues went onto shape the methods adopted, which is what the second part of this chapter addresses.

The second part of the chapter, '*4.4 Methods*'; moves through the process of carrying out the research. Beginning with the selection of individual interviews as a data collection method.

The process of selecting the participants using the Cerebral Palsy Register for Scotland is then discussed, in '*4.5 Participant selection and recruitment section*'. Two groups were contacted, those completing the transition before the implementation of the ASL Act, and those after it.

The remainder of the chapter travels though the research process. This includes sections on;

- Interviewing
- Translating theory
- Reflection on the interview process
- Data analysis
- Dissemination
- Introduction of other validation methods

This chapter illustrates the methodological concerns; a researcher has to be mindful of when starting such research. The process the research took is also discussed and the issues surrounding participant recruitment, participation, reflection, and dissemination.

4.2 Methodology – Theory of research and childhood

In order to understand the methods of this research it is important to first address the theory, to illustrate where the research places itself and the stance it adopts.

This research adopted an inductive approach, which incorporates a constructive ontology and interpretivist epistemology. A constructionist ontology accepts that social phenomena do have a reality which influences the perceptions of social actors, but it is also shaped and constantly evolving through the interaction of social actors (Sarantakos, 2005). Thus social phenomena, such as school culture, can not be simply studied independently of the influence of social actors, such as the pupils.

Where a positivist epistemology would only acknowledge data which was observable (Robson, 1993), an interpretivist epistemology embraces the importance of things we cannot see, such as feelings and how these influence behaviour. Through interpretivism it is possible to understand human behaviour by first obtaining an understanding of the meaning of social actions from multiple perspectives (Robson, 1993). As the research is collecting individuals experiences, which are not observable phenomena, an interpretivist epistemology is more fitting to the concept of the work.

Finally the essence of an inductive approach is to allow the formulation of theory from the data collected, and to develop an understanding of the interpretations people place on their social world.

When adopting such a person centred approach to the research, it is vital that the individuals who are part of the research group are involved in the research process.

4.2.1 Participatory Research

Participatory research aims to develop an understanding of the individuals involved in the work, and respect for them. It is acknowledged that these individuals have knowledge, and through working with the researcher there can be a move forward (Cornwall and Jewkes, 1995).

A number of models of participation have been developed over the years. These are typically hierarchical, distinguishing between higher and lower degrees of participation based on the amount of power given to the participant (McNeish, 1999). One of the original models is that of Arnstein (1969) who developed a ladder of citizen participation. This model outlined eight levels ranging through non participation, and tokenism, to participation. The higher levels are characterised by participants having the power to ensure their views are acted upon.

Although such models are useful for understanding participation in general terms, they do not include the impact of barriers to individual participation, or cross over fully to the real world where distinctions between levels are less clear (Arnstein, 1969). Arnstein also notes that some characteristics from each of the eight levels may well be present in other levels, which makes distinguishing a single level of participation difficult.

In evaluating participatory research Cornwall and Jewkes (1995) noted a number of limitations. They highlighted that although participatory research may be the ideal it must be acknowledged that individuals may not desire complete control and that not every member of the group will be able, or motivated, to participate. Where participation does occur this may not be at a continuous level.

It may also be difficult to follow the theory behind participatory research due to social or political environmental factors. Cornwall and Jewkes (1995) note that with participatory research methods communities are often seen as a heterogeneous group which is rarely the case, as they are made up of a diverse range of individuals.

When initiating participatory research we must be prepared for and aware of individual differences and how they might impact on participation. Also we must be prepared to provide choice to individuals as to how they participate, and respect the choices they then make.

Participation can mean taking part, or it can indicate a transfer of power between the researcher and participant, so that the participant has the power to influence decisions being made (Boyden and Ennew, 1997). Hill et al (2004) in his work with

children made a similar distinction, referring to the first interpretation as consultation, and the second as participation.

Both terms are empirical; however tokenism occurs when the first interpretation (consultation) is mistaken for the second (participation) (McNeish, 1999).

There now follows a discussion of how participatory research methods have been applied to disability studies and childhood research.

4.2.2 Disabled People and Participatory Research

Within the field of disability studies two research methodologies have become popular; participatory research and emancipatory research (French and Swain, 1997).

Participatory research methods have developed from qualitative methods, and are in line with the recent shifts in society's view of disabled people, and the move towards a more user-involved society. The aim of participatory research is to;

*“Reflect, explore and disseminate the views, feelings and experiences of research participants from their own perspectives”
French and Swain (1997, page 26)*

The main characteristics of disability participatory research are;

- That the topic of the research can be chosen by disabled people, or alternatively by non disabled people and then brought to the attention of the disabled population.
- That disabled people work with the researcher to analyse the identified issue.
- That positive alliances are formed between disabled people, the researcher and experts in the field, which are beneficial to disabled people.

(Cocks and Cockram 1995, cited by Chappell, 2000).

Thus disabled people are involved in all aspects of the work, from its design, and conduct, through to the evaluation (Zarb, 1992).

Participatory research is often viewed as the first step towards emancipatory research, as it allows researchers and disabled people to learn from each other (Zarb, 1992). However whilst participatory research is conducted with disabled people, emancipatory research is controlled by disabled people, which leads onto empowerment (Zarb, 1992). This approach is central to the social model of disability (Chappell, 2000), and has its origins firmly rooted within the disability movement (French and Swain, 1997).

Emancipatory disability research has developed out of the dissatisfaction with existing paradigms which failed to acknowledge the social causes of disability (positivist) and on leading to any significant improvement in the lives of disabled people (interpretive) (Oliver, 1992). It is based on the collective criticisms from disabled people regarding disability research and also researchers own self reflection (Zarb, 1992).

The emancipatory paradigm aims to empower individuals to contribute towards change. It calls for disabled people to be partners in research as co-researchers (Stone and Priestley, 1996). For empowerment to occur Oliver (1992) notes that the individuals themselves need to want to be empowered. In reference to this work this would call for the young people to express a desire to be empowered. To want to contribute towards change is an individual choice and this work did not require the young people to hold this desire in order to participate.

The core principles of this method consist of the inclusion of disabled people in the whole research process (*control*), the accountability to participants throughout the research and for dissemination to be carried out (French and Swain, 1997). Emancipatory disability research also requires the experiences of disabled people to be reported in line with a clear environmental and cultural context. This will allow these experiences to be viewed within the context they were created in, and will demonstrate the affects of society on them (French and Swain, 1997).

In addition other core principles of emancipatory research include the adoption of the social model, and for the outcomes of the research to improve the future of those participating.

This research aims to be participatory rather than emancipatory. Emancipatory research in its very nature calls for disabled people to be in control of the whole research process, from establishing what will be researched through to disseminating the work (French and Swain, 1997). As this work was brought about through the collaborative workings of the Cerebral Palsy Register for Scotland this has not occurred.

Emancipatory research also calls for the adoption of the social model. The social model is embedded in emancipatory research, however as Priestley (1997), and also Stone and Priestley (1996) stated it would be wrong to impose the social model onto participants if this is not the view they hold. Many of the participants will be young people who are developing their political stand point; to impose one model on them would be wrong. This work is about giving the young people a voice to express their personal accounts and to listen to their political view, not to impose ideas onto them. If the social model was imposed, leading to the view of the participant being ignored, this would be in effect disempowering them (Stone and Priestley, 1996).

In the same way that this project will not advocate the social model, it will also not adhere to the medical model. The concepts of the medical model will be more familiar to the participants, due to the presence of many health professionals in the early years of the young people. However, again it would be wrong to impose ideas of the need to change, and other views which the participant might not hold.

Part of the aim of this work is to discover the stance of the participants, in particular the young people who will be developing an identity. To adhere to a single model of disability would cause problems within the work. What happens if the participant did not agree with such views? Would these testimonies need to be discounted? If this was to happen this would be a failing of the work to present the reality of the issue, and the whole picture.

Davis (2000) warns against attempting to marry the findings from research with a particular theory. The researcher needs to be able to allow the data to lead them and to not be restricted by the confines of a particular theory. This is a view supported by Shakespeare (1997), and will be adopted for this work.

Conducting the work as a PhD led me to feel that it was important to have ownership over it, thus the core principle of passing complete control of the work to disabled people (Stone and Priestley, 1996) would not be adhered to.

From this discussion it becomes clear that there are a number of similarities between emancipator and participatory research, primarily that both aim to put across the clear voice of the disabled person. What this project adopted from these approaches is that individuals taking part in research must do so at a level that is comfortable from them. In this work the opportunity will be given to both parents and young people to contribute at the level they choose.

4.2.3 Children, Young People and Participatory Research

Although children are experts of their own experiences, values and beliefs (Shakespeare and Watson, 1998), most social research has previously focused either on how children impact on adults lives, or has addressed child related issues through communications with the adult gatekeepers.

A shift in attitudes has occurred recently with a realisation that adult perspectives are frequently very different from that of the child (Mishna et al, 2004, Sloper and Lightfoot, 2003, Scott, 2000). Also with the ratification of the UN Convention on the Rights of the Child (1989) in 1991 there came a requirement to listen to the views of children (Article 12), and to give children the freedom to express their opinions (Article 13). In order to fully obtain children's perspectives it is vital that the researcher develop the skills of communicating meaning to children, and also of understanding the meaning they place on things, unless this is successful their perspective will be distorted with adult perspectives (Armstrong and Galloway, 1996).

In order to use these perspectives to contribute to our understanding of society children must be consulted directly (Scott, 2000). They must be viewed as social actors in their own right, with the same complex beliefs as adults, who contribute to the construction of society. They cannot be analysed in isolation from other social variables (Prout and James, 1997), but must be seen in the broad cultural context (James et al, 1998).

There has recently been an attempt to increase the involvement of young people, in particular Cavet and Sloper (2004) note an increased consultation in service development. This increase has been attributed to the importance placed on the consumer's point of view, the introduction of the children's right agenda, and also the sociological acceptance of the child as a competent social actor (Sinclair, 2004).

Participatory research with children must establish how to express views and thoughts of children without them becoming misrepresented by adults (Boyden and Ennew, 1997). Through involving children in the whole research process it is envisaged that the influence of adult perceptions can be avoided, minimising the power imbalance between children and adult researchers (Boyden and Ennew, 1997). This is an important ethical consideration when working with children; how this power reduction can be achieved will be discussed later in this thesis. Working with children in a participatory way not only breaks down power according to Thomas and O'Kane (1998) but also helps the children to recognise that there are not right or wrong answers, thus helping them to relax and become involved in the research.

Again as with earlier participatory work, models of children's participation have developed which illustrate different levels of participation. Two well referenced models are that of Hart (1992) and Shier (2001).

Ideally young people need to be actively involved in research and not just included simply to please adults (Davis and Edwards, 2004). Hart (1992) illustrated this issue through a 'participation ladder' (*figure 4.1*). The bottom three rungs are considered to be non-participation and included situations where young people are used to promote a cause, and included without choice over how they participate. The higher levels are promoted as far more desirable and involve including young people in all

stages of the research development to varying degrees, from identifying the issues to be addressed through to conducting the research.

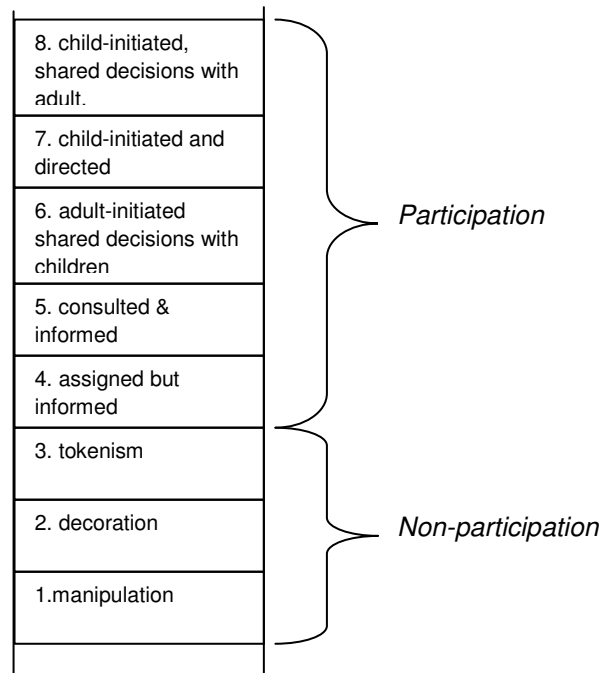


Figure 4.1: Hart's (1992) Ladder Of Participation

One of the main advantages of this model is to illustrate what is, and what is not participation (Shier, 2001). As with Arnstein's (1969) model the linear representation of participation has been challenged, as in the real lives of children such clear divisions between levels do not exist. Hart (1997) himself noted that the model was a simplistic representation of the complexity of children's participation.

In particular many researchers note that this model implies a desirability for the top level of participation (Sinclair 2004). In reality the level of a child's participation will be dependant on the ability of the child (Cavet and Sloper, 2004), and also on the context in which participation is being sought (McNeish 1999, Cavet and Sloper, 2004). McNeish (1999) notes that in some situations the higher levels of participation may not be feasible or even desirable. Most importantly the level of a child's participation is determined by the choice the child makes regarding their own participation (Cavet and Sloper, 2004). Hart (1997) stresses that no level of participation is more desirable than another. It is the child's choice that is the core to true participatory research.

The model presented by Shier (2001) is also linear in nature, but was developed as a series of questions for practitioners to ask themselves to explore children's participation. Here there are five levels of participation, as seen in 4.2 below.

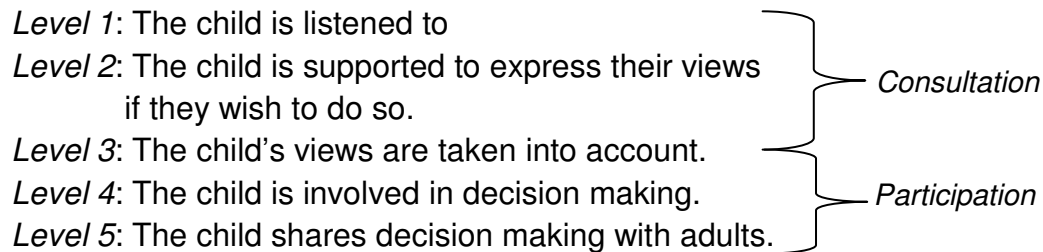


Figure 4.2: Shier's (2001) Model of Participation

At each level Shier outlines three levels of commitment; to be open to working at this level, to have the opportunity to work at this level, and finally to be obligated to work at that level. All levels involve the child being empowered, however Shier makes the distinction that at level three and below the child is simply 'empowered' in terms of being supported, and it is only with stages four and five are they given the opportunity to be empowered in the true sense of the word.

Similar limitations can be seen in Shier's model due to its linear nature. In its defence Shier (2001) acknowledges that it is unlikely that all participation will fit 'neatly' into a single level, and that achieving the top level is not the main aim.

The aim is to develop a culture of questioning and exploring participation. When practitioners find they are not open, do not have the opportunity, or are not obligated to achieve a certain level of participation they can ask should they be and is it appropriate? If they feel they should be achieving a higher degree of participation they can aim for this in the future (Shier, 2001). Sinclair (2004) refers to this model as helping to clarify the purpose of the participation, and that it is only through adults being honest about their motivations for participation that realistic goals of achieving power sharing and change can be achieved.

Although participation with children provides the opportunity to hear children's voices it is not without problems. Many of the issues discussed earlier with regards to

participation with adults are applicable here. Not all children will want to be in control, or feel that they want to participate throughout the whole project. Boyden and Ennew (1997) note that participatory research can also disempower children and young people as not all children will have the desire to participate or have the confidence to do so. Evident here is the issue of ensuring children are given the choice, and that their choice is respected.

As noted earlier participatory research minimises the power imbalance between adult researchers and children (Boyden and Ennew, 1997). However, both McNeish (1999) and Hill (1997) note that complete control is never given to children. Hill notes that children may control the flow of the discussion, but it is adults who generate the main themes. Including children in the analysis phase can limit the impact of this. McNeish questions whether the reluctance to give this power is due to perceptions generated of young people being vulnerable.

Willingness by researchers to incorporate participation can be influenced by how they view children and the methods required to conduct any research with them. James et al (1998) outlined how researchers can perceive children as being of one of the four following different types; the developing child, tribal child, adult child, and social child. The developing and tribal children are seen as being of lower status to adults. Researchers who believe children are developing see children as being incomplete and incompetent, whereas tribal children are seen as being more competent members of society but are still not at the same level as adults.

Adopting the view of children as adult or social sees children as being more on par with adults. Adult children are seen as competent in many but not all social aspects. Social children are seen as having developed many social competencies which, although not necessarily inferior to those of adults, are different to adult competencies.

Along with the researcher's view of children influencing their participation, participation is also more likely in specific groups of children, for example females are more frequently involved than males. Young people with severe impairments, in particular those who use different methods of communication are less likely to be

involved, although they are more likely to be service users (Tisdall and Davis, 2004, Sinclair, 2004).

Hart (1997) emphasises the need to ensure that disabled children can participate fully. He recommends researchers avoid reinforcing a specific level of participation. Therefore no one kind of response or involvement is deemed more desirable than another. This allows the researcher to use multiple approaches, and for children to self select participatory activities.

Although specific groups of children are less likely to participate in research, the number of children generally participating is also very low. This could be due to researchers choosing not to involve children due to their more limited vocabulary and attention span (Scott, 2000). This could result in a misunderstanding between the researcher and young people. Alternatively the young people may be choosing not to participate due to the characteristics of the researcher. The researchers appearance, personality, and where they choose for the interview are more influential to young people than adults (Koocher and Keith-Spiegel, 1994).

Participation can be improved through adults consulting with children and being open to listening to their issues. Researchers need to inform children of the purpose of the research and feedback findings from it. Finally, researchers must be clear on respecting the child and tailoring the research to their needs (Sinclair, 2000).

Young people also benefit from the process through developing communication skills, and empowering their self esteem (Sinclair and Franklin, 2000, cited by Sinclair, 2002, Hill et al, 2004). Davis and Edwards (2004) outline that, through participation, it is possible to hear the voices of young people and to address the issues that are important to their lives. There are many ways in which young people can participate, through individual decision making, contributing to service development, recommending changes to the community, or through influencing policy (McNeish, 1999).

Thomas and O’Kane (1998) also note a benefit to the reliability and validity of research through using participatory methods. As children are participating freely the

reliability of the work is increased, and as children are also involved in the analysis an accurate understanding of behaviour can be developed, thus improving validity.

4.2.4 Working with disabled children and young people

From the above section it is clear that it is often the adult researchers who act as a barrier to children participating in research. In particular there seems to be barriers to disabled children participating with few researchers including them, despite disabled children being independent and having the right to be consulted about the issues that influence their lives (Shakespeare and Watson, 1998).

One problem when disabled children are included in research is the tendency to see “*disabled children*” as a uniform group and to neglect the diversity and difference that exists (Lewis and Kellett, 2004). Another problem with much of the research to date which attempts to address disabling issues is that it is frequently non-disabled people discussing disability, or adults discussing children, where impairment is seen as a problem (Shakespeare and Watson, 1998). This view is supported and promoted through the images depicted by the media of disabled children as children who require constant help to carry out any activity (Priestely, 1999). Where researchers have included disabled children such images have been shown to be inaccurate. Research such as that by Kelly (2005) demonstrated that disabled children have views on how they wanted to be consulted, and showed that they were not passive or incomplete. Consulting with children and young people not only provides a more rounded view of society (Scott, 2000), but also helps to develop a more user friendly policy, and a better understanding of service users (Hill et al, 2004).

To assist the participation of disabled children and young people, it is important that the principles of equality, inclusion, and autonomy are adopted as outlined by Shakespeare and Watson (1998); that is the right for disabled children to equal treatment, to be included as having the same basic needs as other children, and to be seen as experts on their own lives. However if the mobility, communication or understanding barriers are not addressed, disabled young people will have trouble accessing these rights (McNeish, 1999, Russell, 1996).

Often the biggest barriers to obtaining children's views are the adult's perceptions of the child's ability (Hill et al, 2004). Although disabled children may communicate differently, Stalker and Connors (2003) found that communication with most disabled children was no different to communication with any other children.

In line with the autonomy principle, it is important that children are consulted directly, and that secondary data from the child's carer is not used as a substitute. This is important as frequently the child's perceptions have been reported to be significantly different to that of adults (Mishna et al., 2004, Sloper and Lightfoot, 2003). In line with the work of this project, the child's reality of school is likely to be different to parents and professionals perceptions of it (Lloyd-Smith and Tarr, 2000). For instance Sinclair-Taylor (1995) showed that non disabled children reported that they viewed a special unit within a mainstream school as being excluding and marginalising, where as professionals had viewed it as being inclusive.

Along with consulting directly with children, it is essential that issues that the young people want addressed are researched, and that the work does not become impairment focused (Watson et al, 2000).

Along with benefits to society of a better understanding of children's worlds, there are several benefits to children from participating in research. Many will experience an increase in confidence, and communication skills (Cavet and Sloper, 2004, McNeish, 1999). They will also benefit from the development of services in line with their needs. The young people themselves often report that they enjoy participating and appreciate the opportunity to express their views (Punch, 2002).

4.2.5 Multiple family perspectives

As well as working with disabled young people this project will work with their parents. In some instances these members will take part together, and in other families they will take turns to speak to me. Involving multiple family members will raise a number of issues for both the data collection and data analysis.

Many families have a spokesperson who acts as a gatekeeper to the family (Daly, 1992). Although these individuals can be key informants they can also dominate

family discussions. Often the spokesperson will play a role in encouraging other family members to participate in the work. When the members include children, parents can have an influential affect on their consent (Lewis, 2008). Lewis (2008) notes that it is important all family members participating in the research provide consent. Further issues around consent are discussed in more detail below.

When working within the field it is important to remember that each family member will be speaking from their own position. Their position will be influenced by their own individual history, personality, gender and generation (Ribbens McCarthy et al, 2003). These positions will all contribute differently to the data collected, and Murphy (1992) noted the way in which the data collected from parents and children informed the theory into the different aspects of family life that they viewed as important.

Warin et al (2007) advises researchers when working with multiple family members to be prepared to hear both individual and shared stories. In many situations these stories may validate the data; however, they may also contradict and complicate the analysis.

Comparing stories is a widely used approach to analysis (Warin et al, 2007, Ribbens McCarthy et al, 2003), which includes comparing issues such as gender or generation, along side characteristics such as ethnicity and class (Ribbens McCarthy et al, 2003). When conducting such analysis as researchers we must be reflective and consider how we may impact on both the data collected, and how it is analysed. For example, our own gender perspectives will impact on how we perceive certain family member roles (Daly, 1992).

Our own presence during the data collection phase will also have had some impact on the data collected. Warin et al (2007) speaks of the positioning which occurs between researchers and participants when working with families. It is important to acknowledge this occurring and attempt to minimise the impact it may have.

Finally, when conducting research with families, it is important to reflect on why the family chose to participate, and to consider how this might impact on the data obtained (Lewis, 2008).

Through conducting research with multiple family members the role of the researcher is to develop an overall account of the family experience. This account will include the inconsistencies, complexities and different accounts often obtained through family research, but also acknowledge the role of the researcher in the development of this account (Warin et al, 2007).

4.3 Ethical considerations

Conducting research with children gives rise to several ethical issues, namely the child's capacity to provide informed consent, maintaining confidentiality, achieving privacy, and the power differential between child and adult. When participants are disabled children these issues are possibly heightened. It is vital that any research which is being conducted with children should only be done to benefit the child, or other children (Brykczynska, 1989).

This project obtained full Multicentre Research Ethics Committee approval (MREC reference: **05/S0801/104**) (appendix 1).

4.3.1 Consent

Obtaining informed consent from any research participant is one of the foremost critical ethical procedures in research. Participants must be provided with details of the study in order to make an informed decision as to whether to participate or not. In relation to participatory research providing the individual with a choice over their participation is essential.

In the UK when working with children it is usual for researchers to obtain consent from the adult gatekeepers, usually the parents or those in '*loco parentis*'. In this situation the children are seen as the 'property' of their parents, without rights to refuse (Morrow and Richard, 1996). Gatekeepers can in some cases act as a barrier to involving the child, for instance they may be of the belief that the child is unable to provide a point of view, and so see no point to the interaction (Morris, 2003). In these cases the attitude of the gatekeepers needs to be addressed for the research to proceed.

Many researchers believe that children lack the understanding required to provide consent due to their age. Brykczynska (1989) argues that in order to agree to participate children need to have a certain level of cognitive development and social awareness. However, Weithorn and Campbell (1982) showed that there was no difference in the level of understanding shown between 9, 14, 18, and 21 year olds. More recently children as young as 6 years old have been found to understand the aims of research, and what is expected of them along with the risks and benefits (Broome, 1999). What these studies illustrate is that individual differences play a significant role in a child's ability to provide consent. This ability can be improved by the provision of information designed to address their abilities (Dixon-Wood et al, 1999).

Although it remains accepted procedure to obtain consent from the adult gatekeepers, many researchers now see it as good practice to also obtain the child's agreement to participate (Lewis, 2008, Ireland and Holloway, 1996). As with adult participants children need to receive written information to make an informed choice with regards to participation. This information, as stated before, needs to be appropriate for their level of ability, brief, and written in a child friendly way with short lines and words (Ward, 1997). The information should cover what will happen during the research, reasons for the research, how the findings will be used, issues of confidentiality, and the methods to be used during the research (Morris, 2003, Ward, 1997). Obtaining such information will assist the child to make an informed choice regarding participating. Children are more likely to agree to participate when the research is introduced to them by somebody whom they trust (Cree et al, 2000).

Children must be reassured, once consent is given, that the research is voluntary, and that they are free to withdraw at any time (Ward, 1997). This may be difficult for children to do as they are unfamiliar with the process, and see the researcher as someone in a position of power. One way to overcome this is to practice how to initiate a break, or how to stop the research, prior to starting (Ward, 1997).

Finally it is important that children and young people are asked to provide their consent in private, as this will help ensure that they are willing participants, and can reduce the pressure they may feel to conform (Mahon et al, 1996). This is

particularly important then the family is involved in research. As discussed, the family spokesperson could have been influential in volunteering the child. Therefore it is important to gain the child's consent independently.

Obtaining consent following these recommendations is good participatory practice, and helps children and young people feel in control over their involvement in the work.

4.3.2 Confidentiality

As with issues of consent there is a debate as to whether child participants should be given the same confidentiality rights as adults. Morrow and Richard (1996) believe that children should be provided with the same degree of confidentiality as adults. Arguments against providing the same rights centre around possible disclosures made by children during the research. Several researchers propose that confidentiality will be broken if the child discloses they are experiencing serious harm or ill treatment (Masson, 2004, Punch, 2002), or additionally if a medical condition or learning impairment is identified by the researcher (Masson, 2004). It's important therefore to discuss this with the child and to decide on a procedure to follow should this happen at the outset of research (Davis, 1998, Mahon et al, 1996).

Privacy is also difficult to obtain when working with children. Adult gatekeepers may not recognise the need for a private area to conduct the research. They may also request feedback from the researcher, and may disclose information that the young person did not want the researcher to know (Koocher and Keith-Spiegel, 1994). This is why Masson (2004) advises informing the parents who provide consent for their child to participate that the child will be awarded confidentiality rights but they will be informed if any serious issues are disclosed by the child.

Being given privacy was found to be very important to children in a study by Christensen (2004), who reported how children appreciated and valued the privacy shown to them. Christensen (2004) believed that this is reflected in how children form friendships, in that they develop them through sharing and keeping of secrets in private. It is important to negotiate privacy, a lack of privacy may influence what children and young people say due to others around them (Mauthner, 1997). This

may be difficult to obtain if the child chooses a public 'neutral' place to conduct the research, due to noise levels and interruptions (Mahon et al, 1996).

4.3.3 Power

Unlike the issues surrounding confidentiality and consent the ethical issues surrounding power are due to the perceptions children hold. Children will often see adults as people in power, and may strive to provide the 'right' or perceived 'desirable' answer (Mahon et al, 1996). This may be heightened when research is conducted within schools, universities, or hospitals, and is one of the biggest challenges to overcome when conducting research with children (O'Kane, 2002, Hill et al, 1996).

Participatory research, as noted above alleviates this power imbalance through involving the child in decisions pertaining to the research, for example through obtaining the child's consent to participate, or through asking them to choose the location for the research, helps the child feel in control of their participation (Morrow and Richard, 1996).

Familiarity is also key to reducing the power imbalance, through conducting the research in a familiar place, and through the researcher being as familiar as possible to the child, the child can feel less intimidated by the situation. The researcher can also become more familiar to the child through organising an initial meeting, or if this is not possible, through providing the child with a picture of themselves and possibly a tape of themselves reading the research information (Morrow, 2001, Thomas and Beckford, 1999).

In conclusion there are several ethical considerations that need to be looked into when working with children. Conducting participatory methods assists with addressing such issues. In particular reducing the power imbalance between adults and children, this can impact on how the young person responds to research. It also calls for consent to be obtained, which may be more challenging as it can be difficult to establish if they fully understand. Young people have themselves emphasised that when they are approached to participate in research they require appropriate information which will allow them to make an informed decision. On occasion it is the

gatekeepers who are the main barrier, believing that the child will not understand the research.

4.4 Method

As people are the focus of the research questions, Lincoln and Guba (1985) recommend using qualitative methods, arguing such methods come more naturally as they are seen as being a continuation of normal behaviour. Although quantitative methods have also been used successfully with humans, the nature of the research question, and the data needed to investigate led to qualitative methods being adopted. In depth descriptions of individual transitional experiences were required and this would be difficult to obtain via other methods. Qualitative methods involve such methods as conducting interviews, focus groups and observations.

Criticisms of qualitative methods often relate to the method's inability to respond to traditional measurement scales such as those of reliability and validity. Qualitative methods are no less dependable, but to validate them on such scales would be inappropriate (Lincoln and Guba, 1985). Reliability calls for the same findings to be found if the methods are repeated, which when investigating human nature is unlikely to occur. Validity attempts to establish the exact cause of an effect, which again with human behaviour is difficult to do. Lincoln and Guba (1985) put forward more appropriate validation methods in terms of authenticity and trustworthiness. Authenticity asks whether the work has represented everyone fairly, and whether it has contributed to knowledge and understanding. Trustworthiness is made up from 4 aspects; credibility, transferability, dependability and confirmability.

Credibility is similar to internal validity, and addresses whether the researcher has derived the most credible account of social reality. The use of triangulation in qualitative methods is effective in establishing credibility (Lincoln and Guba, 1985). Triangulation involves the use of multiple and different sources and methods, to reconfirm the findings within a project. Transferability asks whether the findings would be true in other contexts. Qualitative methods usually use small groups, and it's down to the researchers detailed account as to whether it can be transferred (Lincoln and Guba, 1985). Dependability, which is similar to reliability, asks about the possibility of reporting similar findings if the research was carried out at another time

(Lincoln and Guba, 1985). Finally confirmability looks at the values of the researcher and whether they have influenced the findings of the work (Lincoln and Guba, 1985).

Along with assessing the data in terms of the criteria above, data quality can be improved through the use of prolonged engagement with participants to increase the researchers' knowledge about them, and to build trust (Lincoln and Guba, 1985). Also, researchers should aim to conduct persistent observation in order to be aware of influential environmental factors, and to use triangulation to validate data.

Other researchers have argued against the criteria set out by Lincoln and Guba (1985). These researchers argue that such validation of qualitative research is in opposition to the nature of the work taking place (Denzin, 1997), and that the criteria are essentially based on those applied to quantitative research and are positivist in nature (Sparkes, 2001), which qualitative research is attempting to move away from.

Sparkes (2001) puts forward the view that with the existence of multiple realities and ways of knowing how is it possible to establish trustworthiness? In order to establish something as true or trustworthy it must be agreed upon. Whether it is agreed upon will be dependant on the time and place. As a result there has been an emergence of a range of different ways to be empirical, including being reflexive.

Such thinking makes it difficult to establish transferability and dependability as they are dependant on the time and context of the research taking place. Denzin (1997) compares a research transcript with a photograph, and views the transcript as being a moment in history.

Within this project suitable methods had to be selected which would allow both the young people and parents to tell their story. Most qualitative methods have successfully been used with adults, the concerns centre on choosing a method that allowed these participants to speak freely about what could potentially be a sensitive issue.

However, the main concern at this time was to choose a method which would be appropriate for young people, and in particular would be appropriate for disabled

young people, some of whom did not use verbal communication. The aim was to incorporate the recommendations of Thomas and O’Kane (2000), through selecting a method which would be most appropriate, incorporating their interests, communicating in an effective way, and acknowledging their emotional needs

4.4.1 Qualitative methods

Observations, focus groups and individual interviews are the most frequently used qualitative methods to obtain the type of data required within this project. All of these methods were investigated for appropriateness of use within this research.

Observation can produce rich data from a natural setting, and involves observing the behaviour of the participant without any intervention. In relation to using this method with children, it has been argued that the presence of the researcher will inevitably influence the data as adults cannot go unnoticed in the child’s environment (Harden et al, 2000, Beresford, 1997).

Focus groups work well with both adults and children allowing for ideas, attitudes and views to be explored. Through discourse and challenges with other group members the participants assess their own views thus resulting in the presentation of clear ideas. Focus groups have particularly been rated as a useful tool for children and young people since they are fun for them, and they receive support from peers (Hill, 2006). Group scenarios also reduced the level of the power imbalance between the young person and the researcher which has previously been illustrated as a concern (Hill, 2006).

One disadvantage however is that this type of work can lead to the generation of the experiences of the group and of a collective response rather than individual responses (Beresford, 1997). It has also been suggested that there is limited scope for using such methods with young people who have verbal communication difficulties (Beresford, 1997).

Individual interviews are very successful in obtaining views from participants that focus groups can miss. There is also the scope to investigate any issues that arise more thoroughly than in other methods, and they can also be more participant lead.

This method also works well with young people who have indicated that they like the privacy since it allows them to express their beliefs without other young people knowing them (Hill, 2006). Individual interviews also result in the young person's experience being expressed in their own words, and provides an insight into their world (Harden et al, 2000).

Having researched the methods available it was important to assess which would allow the research questions to be answered. Central to the research was the priority given to participants having their individual voices heard. It was probable that some of the young people would use alternatives to verbal communication, thus it was important that they were given the space to express themselves. A final consideration was that the participants and in particular the young people, be allowed to tell their own story without the pressure to edit it, and they would need privacy to do this.

It is also likely that the transition process would vary between areas and between young people, and so it would be difficult to coordinate a group session for the participants. This was later demonstrated to be the case. The physicality of a focus group also raised issues within the project, since there were potential problems with participants living across Scotland having to travel to a central point. Finally it was the individual responses that this project wanted to capture rather than the group experience, which can occur within focus groups (Beresford, 1997). Focus groups were therefore ruled out as the main method of data collection.

When considering the use of observational studies I took heed of arguments put forward by researchers such as Beresford (1997), and Harden et al (2000) when referring to observing young people, and felt that my presence at any transition event would inevitably influence the data, and draw unwanted attention to the young person.

On reflection much of the discourse from the young people was about their efforts to limit attention being drawn to their CP it was the right decision to have made. The practicalities of such a method also led me away from conducting observations. Many of the young people had transition events spanning days which often

overlapped, and as a single researcher on the project it would not have been possible to observe all the critical events. Also it would be very difficult to involve the parents point of view through such a method. Finally as part of the project would include a group who had made the transition prior to the implementation of the Additional Support for Learning Act, the opportunity to observe this group had already past.

Unlike focus groups individual interviews would allow participants to talk about issues which were important to them, and also possibly sensitive. It also was a more flexible approach than focus groups as the interview dates could be set by the participants. They also assist young people with alternative methods of communication to put their views across. Individual interviews were also more appropriate than observations due to the interviews being carried out in the privacy of their homes.

I was reassured by Hill (2006) who asked young people about participating in research. The young people themselves reported that there was no best method to use, and that the researcher had to choose a method which worked with the diversity of the young people and was appropriate for the research question. After all methods had been considered, the method most relevant for both the participants, in that it provided space and privacy, and the research question, in that it allowed participants to speak about individual issues, was selected. Quality data should therefore be obtained.

4.4.2 Individual interviews addressed

Having chosen individual interviews as a method, the issues associated with this method need now to be thoroughly addressed. From other work the parents should respond well to interviewing, in particular if these were semi structured and felt like daily discourse. It was important to ensure that double-barrelled, leading or assumption based questions were avoided, and that jargon and very general questions should also be excluded.

The literature suggests that interviews with children and young people would be more difficult. When interviewing this group it is important to remember that some

younger children may require more guidance through the interview. Interviews have been found to be more successful with older children (over 7 years old) (Mauthner, 1997), however, these children may also be well accomplished at editing their answers (Scott, 2000). Punch (2002) and also Ireland and Holloway (1996) point out the importance of being aware of the abilities of the child in particular their cognitive and emotional development prior to interviewing them and to adapt the interview accordingly. They also suggest carrying out interviews in an informal way, which is less rigid and less likely to scare the child. Both Punch (2002) and Lewis and Kellett (2004) propose the use of statements, prompts and stimulus material when interviewing children, as children, unlike adults, tend to give short answers to open ended questions.

There is a lot of advice in the literature over how to structure interviews with children. One area where there is much debate is over the merits of conducting single or multiple interviews. In particular when working with children and young people some researchers believe that multiple interviews are required. A single one off meeting can lead to children not reflecting their true view due to feeling uncomfortable in the situation (Christensen, 2004). Bricher (1999) notes that a researcher needs to establish what type of data they wish to collect and whether they are investigating a single event, or a continued experience which would be more likely to require a series of interviews.

Due to the desire to look at experiences before and after the implementation of the Additional Support for Learning Act, it was appropriate here to carry out both of the approaches; a single interview with the young people and their parents recollecting the transition, and multiple interviews where young people and their parents were being followed through the transition process. Bricher (1999) noted the need to be aware that the type of data produced by a single interview may be different to that from multiple interviews, and this was borne out by my experience.

When interviewing it is necessary to build up a rapport between the interviewer and participant, when working with children and young people this is particularly important. The researcher must build a relationship of trust between themselves and the child. Meeting with them prior to conducting the research, along with reducing the

power imbalance, can help to form this relationship, and also has the advantage of not relying on the parents to explain the research (Hill et al, 1996).

Another advantage to meeting prior to conducting the interviews is the opportunity to ensure that the researcher and participant understand each others communication (Mahon et al, 1996). Sinclair (2004) points out that children can interpret words differently to adults, citing the example of how the government interchanges the word 'protection' and 'being safe', but to children these two words/phrases meant different things;

"To children 'protection' implied over-protection and restriction by adults and was seen negatively, whereas 'being safe' related to the generation of positive environments for children."

Sinclair (2004, page 113)

What this demonstrates, and what Sinclair goes onto emphasise, is the importance of checking back with children for their interpretation, and also getting to know children prior to working with them.

Thus interviewing children and young people will involve some differences to interviewing adults. Research published within this field has brought to the attention some useful methods to adopt in such situations. One useful method put forward by Rassool (2004) is to build a biography of the child first (possibly through survey methods), and then to use interviews as a means to explore specific issues. This allows the interviewer to have a background for the child and to be aware of any sensitive issues, and also to have some knowledge of the child to use as an ice breaker at the beginning of the research. Hirst and Baldwin (1994) adopted a similar approach when interviewing learning disabled young people.

Other methods are to incorporate structured activities such as drawing and story telling, which children enjoy, into research as a means of engaging the child. This is useful as children feel comfortable with familiar task and have a concrete basis for the discussion (Thomas and O'Kane, 2000). Such techniques are particularly useful for younger children (Mauthner, 1997), where it is also important to use short

sentences, and clear simple language (Thomas and Beckford, 1999). However, like all social groups, children vary. Some children may find it helpful to draw or write as a means of communicating, whilst other children may not have this experience, and are more familiar with verbal interactions (Davis, 1998). Thus it is vital to adapt the methods employed to the children and young people who are participating.

Christensen (2004) found it helpful to allow children to bring a friend with them to the interview. This helped them to relax and to feel more secure. Other ice breaker methods involve asking the child to complete a task which is about their likes and dislikes. This helps them to become accustomed to understanding that there is no right or wrong answers and that it is their views, thoughts, or feelings the researcher is interested in (Hill et al, 1996).

When ending an interview it is useful to have a summary of the discussion (Ward, 1997), and to look into the possibility of the participant requiring further support. Although researchers do need to have a clear distinction between research and therapy, they should provide details of where the participant can receive appropriate support (Mahon et al, 1996). The whole process should also be followed up with full feedback on the findings and outcomes of the research (Tisdall and Davis, 2004).

In addition to the recommendations made for interviewing children, when interviewing disabled children extra consideration needs to take place. Stalker and Connors (2003) recommend that tasks or questions are broken down into parts. Abstract questions should be avoided along with open ended ones according to work by Boland et al (2007), as they may be too difficult, and result in a “*don't know*” response. Methods need to be age appropriate, which may require them to be simplified whilst avoiding being too childish (Stalker and Connors, 2003). Time should also be spent finding out the names of key people involved in the child's life, as often disabled children may only know peoples names and not necessarily their job title (Stalker and Connors, 2003). The key piece of advice from the work of Stalkers and Connors (2003) was to

“See the child as a child first, and disabled second.” (Page 27)

Interviewing disabled children requires a great deal of perceptual skills on behalf of the interviewer. Many of these children may not use verbal modes of communication, and may use alternative methods such as eye pointing, facial expressions, or gestures. However, these children should not be excluded due to this. Previous research by the Joseph Rowntree Foundation (2001), has demonstrated that children who were thought of as having 'severe or profound disabilities' are able to participate and express their opinions, and are able to learn the required skills to use multi-media technology to do this very quickly.

As discussed earlier the aim of this work is to be participatory. Through interviews, the parents and young people will be given the opportunity to guide the discussion, to express their view about the transition, the support, information and services they received. This will then be brought to the attention of professionals in the field with the intention of making future change, and recommendations for good practice.

4.5 Participant selection & recruitment

Participants were identified and contacted via the Cerebral Palsy Register for Scotland (CPRS). The CPRS is a research register which records details of children with CP living in Scotland born after the 1st of January 1990. Children with all types of CP at all levels are included on the register.

The CPRS is a voluntary opt-in-register, thus parental consent is obtained in order to register any child. At this time parents also agree to be consulted with reference to further research.

Routinely the register collects information relating to clinical aspects of CP, such as severity, related impairments, and services used, along with details of the impact of CP on the child's daily life.

The impact of CP on daily life is measured via the parental completed Lifestyle Assessment Questionnaire (LAQ) (Mackie et al, 1998). This measures the overall impact of CP on the child and the family at that point in time, along with how the CP impacts on six dimensions; physical independence, mobility, social independence, schooling, clinical burden, and economic burden.

Two different groups of young people were identified from the CPRS and invited, with their parents, to participate. Firstly those who had already made the transition prior to the implementation of the Additional Support for Learning Act (ASL) were contacted and asked to take part in a single interview (Pre ASL group). Secondly those making the transition in 2007, and therefore making the move under the Act, were approached and asked to participate in a series of interviews at different time point during their transition (Post ASL group).

4.5.1 Recruiting the Pre ASL Group

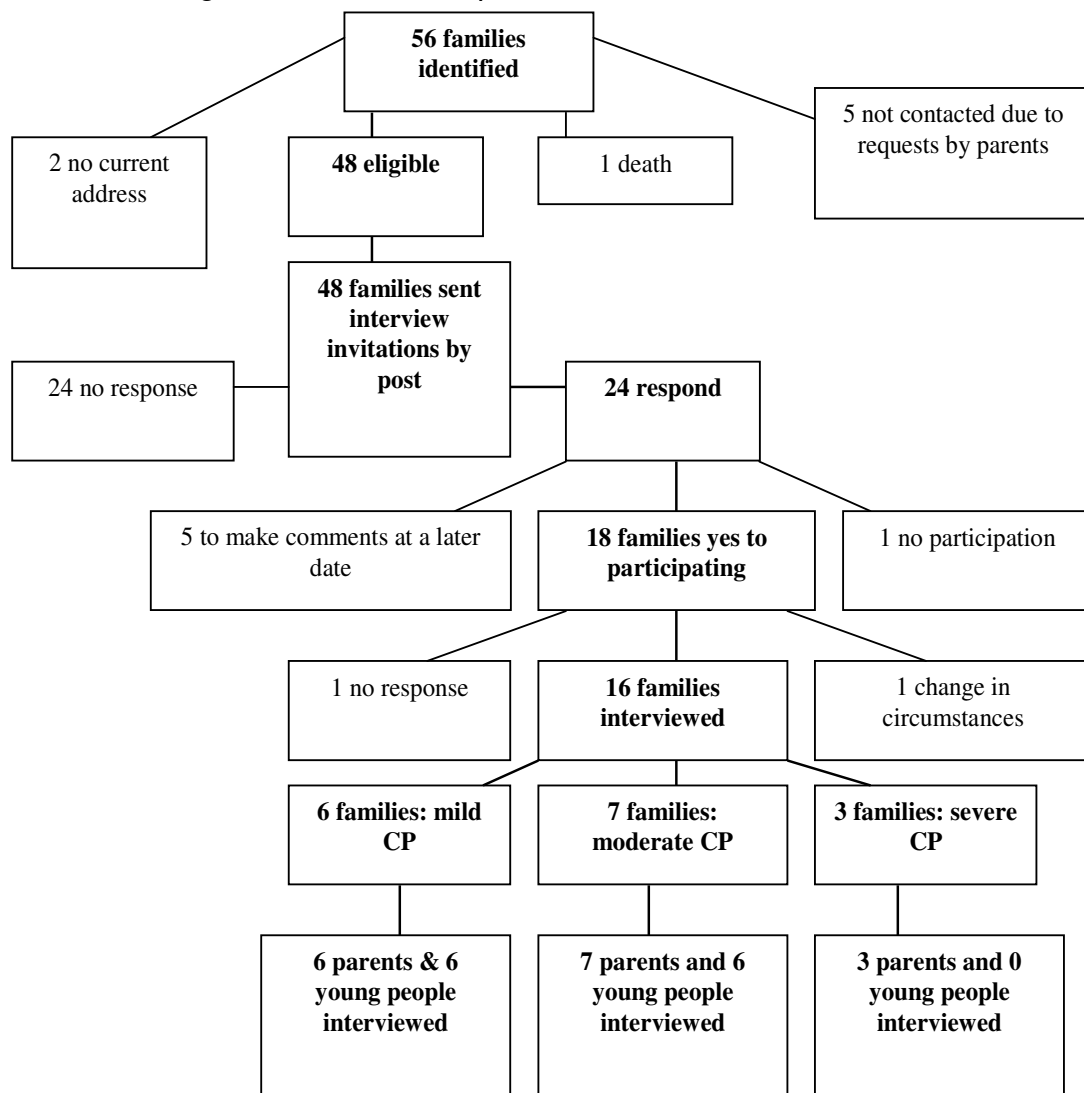


Figure 4.3 Recruitment process for the pre ASL group

Young people aged 14 years or over were identified (figure 4.3). Fifty-six from the register were identified as being within this age range, of whom 1 had died and no current address was recorded for 2. Another 5 were removed from the possible data set due to comments from their parents in their records, for example that the young person had been in long term psychiatric care.

Thus 48 families were contacted by post. A covering letter was written to the parents outlining the project (appendix 2). Along with this letter an information sheet was enclosed (appendix 3). Advice was taken from Capability Scotland and the Special Needs Information Point (S.N.I.P.) when developing the information sheet. These two charities work closely with parents of disabled children, and have a wealth of experience in developing appropriate materials. A named contact from S.N.I.P. was also given in order for the participants to have someone outside of the project that they could contact, to discuss any concerns or questions they may have with regards to participating.

Parents were asked to return a form (appendix 4) to the CPRS (stamped addressed envelope provided), indicating their decision on the level of involvement they wished to have with the project from a choice of three; i) to participate in a one to one interview, ii) to make comments by post on the conclusions drawn from the interviews, or iii) no participation in the project. For parents choosing to participate in an interview the form also collected information as to how they would like to be contacted to set up the interview, post, phone, or e-mail.

Twenty four forms were returned to the CPRS, providing a 50% response rate. Similar studies (Stalker and Connors, 2003), report finding it very difficult to recruit young people into the research, and thus this result was seen as a favourable response rate at this stage. Eighteen agreed to participate in an interview, 5 to make comments at a later date, and 1 who declined to participate. Acknowledgment letters were sent to all parents who returned the form choosing to make comments, or to have no participation.

Parents who were prepared to take part in an interview were contacted via their preferred method. They were given the opportunity to ask any questions about the

study and, if they were happy to go ahead, a time and place convenient to them was arranged. All the participants decided that they wanted the interview to take place at their home.

The day before the interview the parents were contacted again to make sure that they still wanted to go ahead with the interview; this also gave them the opportunity to change the time of the interview, or to ask any further questions.

4.5.1.1 Contacting the young people in the pre ASL group

The aim of the research was to include the views of as many young people as possible, regardless of their physical or mental abilities. However, as the majority of the young people eligible for this study were under the age of 16 years, parental consent was required in order for them to participate, as stated in the COREC 2003 UK Guidance for research taking place in Scotland. Therefore it was decided that the parents would first be contacted about the project and their guidance taken about approaching their son or daughter with regards to participation, which is a comparable method to that adopted by Moore et al (1998) and also Stalker and Connors (2003) when working in a similar situation.

Working in this way would inevitably influence which young people were included in the research as the parent's views and values would have influenced whether their son/daughter was contacted (Lewis and Porter, 2004). Also some young people who would have wanted to participate may have been over ruled by their parents. It is also important to consider that some young people may only agree to participate to please their parents (Moore et al, 1998), thus obtaining consent directly from the young people is a vital part of the project.

Following the receipt of the form from the parents, contact was made and it was established whether the young person could be approached. This method of contacting young people was used successfully by Hood et al (1996) and more recently by Connors and Stalker (2003). Four parents felt that their child would not have the ability to participate (all classified with severe impacting CP on the LAQ), thus 13 young people were approached. To assist the young person to provide informed consent, an information sheet written for young people was sent to them

(appendix 5). This described the project and the role they would play, along with contact details of someone out-with the project who they could speak to regarding participation if they wanted to. Again guidance from Capability Scotland and S.N.I.P. was taken when designing the information. An effort was made to use language which was accessible to young people with a range of abilities. Some picture representations were also included to illustrate points to young people with limited reading ability, which is in line with the guidance from Goodley and Moore (2000) regarding the importance of presenting material in a user-friendly way for participants.

On the back page of the information sheet a photograph was included, along with a blurb about myself. This was recommended by Stalker and Connors (2003) and also Thomas and Beckford (1999) as a means of increasing familiarity between the interviewer and the young person. It seemed to work as one parent and young person replied later in the project "*we know we recognise you from your photo*" in response to me introducing myself.

It was decided that consent from the young person would be obtained at the meeting, in line with the view of Lewis and Porter (2004), and also Moore et al (1998) who state that it was important to respect the young persons right to agree or disagree to participating regardless of the views of their parents, and for some young people this was easier to establish face-to-face.

4.5.2 Recruiting the post ASL Participants

This part of the research required the participation of young people born between March 1995 and February 1996 and their parents. This search yielded 36 children registered on the CPRS. It is common for some young people with CP to postpone making the transition into secondary school by a year; several of the young people in phase 1 of the project had done this. Therefore a second search of the CPRS database was carried out for young people born between March 1994 and February 1995. This identified 29 young people (figure 4.4)

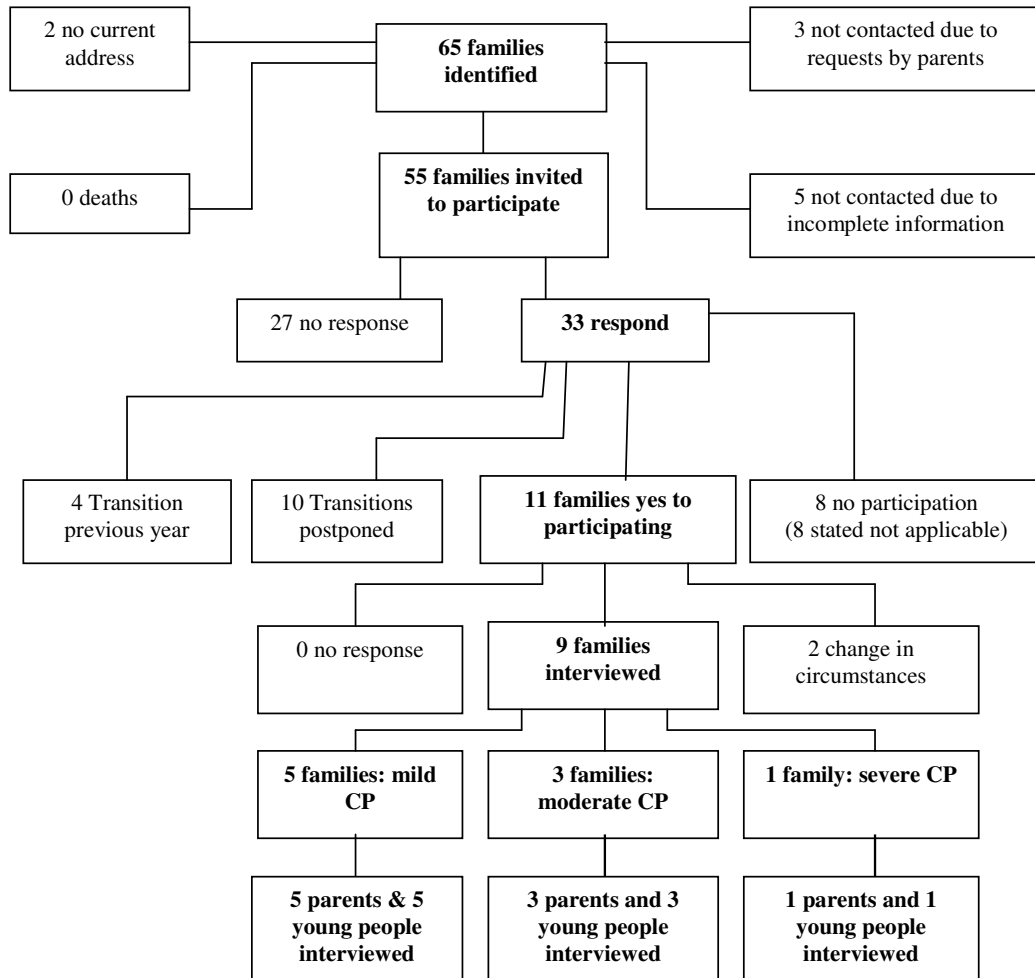


Figure 4.4: Recruitment of Post ASL group participants

Thus in total for the Post ASL group 65 families were identified. Of these there was no current address for 2 of the families, 3 families were not contacted due to parents comments and 5 other families were not contacted due to incomplete records, which left 55 families to be contacted.

As with phase 1 of the project a covering letter, information sheets, and response form were posted out to parents. Thirty three of the families replied, which is a response rate of 60%, which is again very positive. However, of these families only 11 had agreed to participate. Ten of the young people were postponing the transition until 2008 (although if the project was running then they noted that they would be interested in participating), and 4 of the young people had made the transition in 2006. Eight families replied saying they would not participate due to the project not being applicable to them. Six of these families noted that this was due to the young

person attending a Special Educational School, despite indicating clearly on the information sheet that these young people were an important part of the research and were invited to participate.

The same process of contacting the family occurred as with phase 1. All of the young people agreed to participate and, as with the Pre ASL group, all of the families chose to participate at their home.

4.5.3 Participant's profile

In total 25 families participated in this project, from across Scotland. A table demonstrating the characteristics of all the participants has been included as appendix 6. There follows a description of the participants in accordance to whether they were a parent or young person, and whether they were participating before or after the implementation of the ASL act.

4.5.3.1 Parents: Pre ASL

		<u>Number of participants</u>
<u>Interviewed</u>	Both Parents	3
	One parent	13
<u>Gender</u>	Male	4
	Female	15
<u>Ethnicity</u>	White	19
	Other	0
<u>Location*</u>	East	6
	West	4
	South	4
	North	2

Table 4.1: Parent participants Pre ASL group

* East: Fife, Lothian, and Forth Valley Health Board regions

West: Ayrshire & Arran, Lanarkshire, Greater Glasgow & Clyde Health Board Regions

South: Borders, and Dumfries & Galloway Health Board Regions

North: Highland, Grampian and Tayside Health Board Regions

Of the 18 parents who showed initial interest in being interviewed, 16 were successfully interviewed, 1 did not respond to the contact following return of the form, and 1 decided that they would be unable to take part in an interview due to a change in circumstances, but agreed to make comments at a later date.

Table 4.1 shows a breakdown of the groups characteristics. Fifteen mothers and 3 fathers participated in a whole interview; 2 of these fathers participated with the mother, whilst one father participated alone. In a further 2 interviews initially the mother was participating, and the father joined the discussion for part of the interview only. It has been a common finding for more mothers compared to fathers to participate in research of this nature. Possibly this could be due to the mothers being the child's main care giver (Garth and Aroni, 2003).

Of the parents 6 had a child with mild CP, 7 a child with moderate CP and 3 a child with severe CP, as classified by the LAQ. Parents were primarily located in the central belt, and southern Scotland. All of the young people were white, which is similar to other studies conducted in Scotland (Connors and Stalker, 2003) and reflects the ethnic make up of Scotland, where 98% of the population is white (2001 Scottish Census).

4.5.3.2 Parents: Post ASL

		<u>Number of participants</u>
<u>Interviewed</u>	Both Parents	0
	One parent	9
<u>Gender</u>	Male	1
	Female	8
<u>Ethnicity</u>	White	9
	Other	0
<u>Location*</u>	East	4
	West	3
	South	1
	North	1

Table 4.2: Parent participants Post ASL group

Of the 11 parents who showed initial interest in the project 9 participated in a series of interviews. One participant withdrew prior to participating due to a change in circumstances, and a second withdrew having attended a school meeting and deciding that their child would be postponing the transition until 2008. The characteristics of this group are shown in table 4.2.

Eight mothers participated in a series of 3 interviews, and 1 father participated in 2 interviews. This was due to the nature of his daughter's transition, in that the Special Education School she was attending developed a transitional class for her to move into prior to moving to the secondary side of the school. Thus an interview was conducted before and after the move into this class, but not following the induction event as there was not one.

Five of the parents had a child with mild CP, 3 with moderate CP and 1 with severe CP as classified on the LAQ. There was a good geographical representation with families from the central belt, North and South Scotland. Again all of the participants were white.

4.5.3.3 Young people: Pre ASL

		<u>Number of participants</u>
<u>Participated</u>	Yes	12
	No	4
<u>Interviewed</u>	With Parent(s)	9
	Alone	3
<u>Age</u>	14 years	7
	15 years	4
	16 years	5
<u>Ethnicity</u>	White	16
	Other	0
<u>Gender</u>	Male	12
	Female	4
<u>Location*</u>	East	6
	West	4
	South	4
	North	2
<u>Severity</u>	Mild	6
	Moderate	7
	Severe	3

Table 4.3: Young People participants Pre ASL group

Details of the young people participating in this group are given in table 4.3. Twelve young people agreed to participate in the project, of which 10 were male and 2 female. There were more males than females, which is what was expected as CP is more common in males. Nine chose to participate at the same time as their parents and 3 on their own after their parent's interview, of which 2 were interviewed with their parents present. Eleven of the children used verbal communication, 1 used eye blinking. Six were classified as having mild CP and 6 with moderate CP. None of the young people participating in an interview had a LAQ score of severe. Again all of the participants were white.

4.5.3.4 Young people: Post ASL

		<u>Number of participants</u>
<u>Participated</u>	Yes	9
	No	0
<u>Interviewed</u>	With Parent(s)	9
	Alone	0
<u>Age</u>	11 years	5
	12 years	4
<u>Ethnicity</u>	White	9
	Other	0
<u>Gender</u>	Male	7
	Female	2
<u>Location*</u>	East	4
	West	3
	South	1
	North	1
<u>Severity</u>	Mild	5
	Moderate	3
	Severe	1

Table 4.4: Young people participants Post ASL group

Seven males and 2 females participated in the project, with 8 of them participating in all 3 of the interviews and 1 participating in two interviews. Eight of the young people used verbal communication and 1 used eye pointing. Again as with phase 1 all of the young people were white. Further details regarding the participants are shown in 4.4.

Below is a table (table 4.5) of the participants grouped in accordance to their schooling situation. Although all of the young people were individuals with distinct attitudes and ideas, for many of them the barriers they faced were similar. For example, those young people attending mainstream schools who were wheelchair users encountered barriers to access. Whilst many young people attending

mainstream schools who were not wheelchair users felt pressures to hide their impairment. This table is meant to help the reader identify the situation that the young people faced, so that their discourse and that of their parents may be put into context.

<i>Mainstream</i>	<i>Mainstream, wheelchair user</i>	<i>Special school</i>	<i>Special school, non verbal</i>
Andrew Craig Gareth Harry Helen Ian John Kerry Kyle Matthew Zack	Darren Ellie Elliot Leon* Nathan Rebecca* Toby* William	Ben Freddie Peter Victoria*	Olivia Steven

* - young person did not participate themselves, parents participated.

Table 4.5: Schooling situation of the young people

4.5.4 Differences between participants and non participants

Figures 4.3 and 4.4 shows the recruitment process of the participants. As demonstrated, the response rate for the Pre ASL group is 50%. Of the total group 29% participated in the project. The response rate for the Post ASL group was 60%, with 16% of the total group contacted participating in the project. It is important to establish whether these participants are a representative sample of the whole group.

On comparing the participants and non participants statistical analysis demonstrated that there was no significant difference between the participants and non participants for both of these groups. Independent t-tests were carried out on the age and severity data. As the gender and area data is nominal chi-squared tests were carried out.

Table 4.6 shows the values of t and χ^2 (chi) for a number of variables. As all p-values are greater than 0.05 it can be established that there is no significant difference

between the participants and non participants. As the numbers of participants and non participants in the four areas were very small a joint analysis for the pre and post ASL groups was carried out to look at the total number of participants and non participants from the four areas. Again there was no significant difference established between the participants and non participants across the areas.

	Range	Participants	Non Participants	t or χ^2	Significance
<u>Pre ASL Group</u>					
Age	13-16 years	15.99	15.86	t (df 50) = 0.510	p = 0.612
Severity	0-100	50.08	52.48	t (df 50) = -0.385	p = 0.702
Gender	Male Female	75% 25%	56% 44%	χ^2 (df 1) = 1.769	p = 0.183
<u>Post ASL Group</u>					
Age	11-12 years	11.85	11.99	t (df 53)=-0.672	p=0.505
Severity	0-100	38.15	46.72	t (df 53) = -0.953	p = 0.345
Gender	Male Female	78% 22%	57% 43%	χ^2 (df 1) = 1.417	p = 0.234
<u>Combined Group</u>					
Area	North South East West	3 5 11 6	10 14 31	χ^2 (df 3) = 1.810	p = 0.613

Table 4.6: Participants and Non Participants similarities

4.6 Interviewing

All of the interviews followed a similar interview schedule (appendix 7) and took place at the participants homes. This was their choice of venue, and somewhere they felt comfortable. This facilitated the interview (Whitehurst, 2006), and was convenient for them (Morris, 2003). Being in their home also reduced the power imbalance between the researcher and the young people who were participating.

Another advantage of being at home is, as Lincoln and Guba, (1985) recommend, the research is conducted in a natural setting that reduces the influence of context on what the individual says, and the experience becomes more of an extension of

everyday behaviour. However, Ross and Ross (1984), and more recently Hood et al (1996) pointed out that often parents and young people experience of having professionals to their home was in the context of carrying out assessments, and so it was vital to put the participants at ease and for them to know, and feel, that this was not an assessment, and that I had a non- judgmental stance.

On arrival at the participants home some informal conversation took place with the parents and young people. This helped to relax them and allowed them to see that I would not be assessing them. It was also aimed at building a rapport with the young person, striving again to reduce the power imbalance further. This conversation usually centred on the weather, how the researcher had got to the house, the summer holidays, or the football World Cup which was underway at the time of the Pre ASL group interviews. Many of the young people participating were Scottish males and they did seem to enjoy some banter regarding England and the World Cup. These few minutes of informal chatting proved to be invaluable for putting both the young person and parents at ease, and was a good foot to start the interviews on. I also shared some informal experiences at this time, which Agar (1996) reported was a good way to build rapport with participants.

On one occasion, early on in the project, one set of participants were going out following the interview. In order to ensure we did not run over time the informal conversation was missed out. The discussion started but both the mother and son seemed tense and gave very short answers. I decided to make a few friendly comments regarding school holiday times in other parts of the UK and a short, informal, off-the-topic conversation took place. After this both the mother and son were more vocal and gave more detailed responses. Following this experience I ensured I did not undervalue the importance of these few minutes chatting, and did not miss them out of the interviewing process again.

Once we had had an introductory chat it was established whether the parents and young person would do the interview together or separately. Either I would ask the parent and young person together, or the parent would ask me, how to conduct the interview, at which point I would give the options to the young person to decide. Here there was a difference between the Pre and Post ASL groups. Within the Pre ASL

group many of the young people seemed to have previously discussed this with their parent and opted to do the interview together. This is not what I had expected following research such as Koocher and Keith-Spiegel (1994) who found that adolescents often took the opportunity to experience new things away from their caregiver, and also Connors and Stalker (2003) who report that very few of the young people they spoke to chose to be interviewed with a parent. The young people in the Post ASL group acted more inline with these findings, with all being interviewed separately from their parents. Although the parents were often present in the background for the first interview. This illustrates one of the benefits of multiple interviews, which built the confidence of the young person in their ability to participate. They also built a rapport with the researcher which was important, and was previously noted as advantageous by Christensen (2004).

Following the decision on how they would be interviewed the participants would take me to the room they had chosen to use. I allowed the participants to choose their seats before I sat down myself, to ensure they felt comfortable with both the seat they chose, and also where I sat. Often they would gesture towards a certain seat. As most of the participants chose the living room the seating arrangements were informal with everybody facing each other.

Once everyone was settled the purpose of the discussion was outlined. Following this there were several points explained to the participant, firstly I asked that they spoke freely about their experience and that they were free to bring up things they were thinking about when they occurred to them, and not to wait for me to ask about something. It was also explained that there was no right or wrong answer, that I was just interested in hearing their experiences, and that at any time either one could leave or decide to stop the interview. I also reassured them that what they said would remain confidential.

The interviews were audio recorded, to ensure the recording of accurate experiences. This was explained and oral consent was obtained. Finally my note taking was explained, and they were reassured that I was doing this as a memory aid to myself.

If they were happy to proceed with the interview both the parents and young people were asked to sign a consent form (appendix 8 and appendix 9), which stated that they agreed to participate in the discussion, that I could record the discussion, and that I could use anonymous quotations from the discussion at a later date. Separate consent forms were made for the parents and young people who were able to write. Ten young people were able to sign the form in the Pre ASL group and 8 in the Post ASL group. For the other young people verbal consent was obtained and they were asked if they were happy for their parent to sign the form on their behalf.

4.6.1 Interview schedule: Pre ASL group

With the Pre ASL group the interview started off with questions about which school they were attending, which primary they had attended, and the support they used at school. These were straight forward questions that most of the young people answered easily and it gave them the confidence to start the discussion, a suggestion of good practice put forward by Ross and Ross (1984). Many interviews took a little time to warm up, which reflects others experience in situations of this type (Bricher, 1999).

Topics moved onto why they had chosen their secondary school, the transition process (induction days and visits by secondary staff to the primary school) and any worries prior to the transition. We then moved onto discuss support and information they had received. To close, the parent and the young person were asked in turn what advice they would give someone in a similar situation to themselves moving into secondary school. They were told that this was the last part of the interview, and this gave a clear ending to the interview, which is an important thing to do when interviewing young people (Bricher, 1999).

Participants were then given the opportunity to add anything extra, and were thanked for their participation. In early interviews after thanking them I turned off the tape with the intention of a small informal chat before leaving, but found that sometimes the parent or young person wanted to recap, or added something which added to their experience. Often they did this as a way to unwind after the more formal interview experience. So I learnt to thank them for their initial participation, and then had a short chat to recap what was said, and then to thank them again and clearly turn the

audio recorder off. The recorder was always in the view of the participants, and they were aware when it was turned on and off.

4.6.2 Interview schedule: Post ASL group

For the Post ASL group there was more of a separation between the young people and their parents. In the early interviews a lot of the participants chose that the parents would be interviewed first and then the young person, however by the second and third interviews the young person was often excited to tell me about their new experiences and often asked to go first.

The structure of the first meeting was the same as for the Pre ASL group, in that the procedure of the interview explained and consent was obtained. The first interview covered views of primary school, feelings about secondary school and what was known about secondary school at this time. It then moved onto discussing if they had decided on a secondary school and what they thought it would be like.

The focus of the second interview was the induction event that the young person had participated in, what had happened and how they felt about secondary school now. The final interview was carried out once the young person had settled into secondary school and discussed how they felt the move had gone, if they had had any problems and how these problems had been resolved.

The final session ended in the same way as the Pre ASL group interview had in that the young people and parents were asked to give their advice on how to achieve a smooth transition. However, for this group of young people this question was far more difficult for them to answer. This could possibly be due to their age, or that they had not had enough time to reflect on the transition and decide what had been helpful.

At the start of the second and third sessions consent was reviewed with the participant, in that they were reminded of what they had signed and asked if they still agreed to that. They were also reminded that they could stop the interview at any time.

4.6.3 Interviewing technique

Following the interpretivist epistemology, interview questions covered the feelings and thoughts of the young people and parents, and did not simply gather the facts about what happened during the transition.

Throughout the interview in the Pre ASL group, questions were asked openly to both the young person and parent, but occasionally questions were specifically directed only at one of the participants. This was done more so when some of the parents were contributing more than the young person to bring the young person back into the discussion. Also this emphasised to the young person, in particular to those with additional learning impairments, that their views and experiences were important, and that I wanted to hear them. This is important according to Harris (2003), as it helped the young person to believe that they were being listened to and that they could influence future change. This was not so necessary with the Post ASL group as either the parents or young person were interviewed first followed by the other, thus there were more clearly defined questions.

To encourage the young people in both the groups the use of verbal communication techniques as suggested by Beresford (1997) were used, these included using maintainers such as “right”, “uhh huh”, and “good”, along with clarifications. When asking questions I was careful not to focus too much on their impairments, as I was conscious that many of the young people tended to not focus on it themselves. Stalker and Connors (2003) suggests not asking directly about impairment as this can lead into drawing attention to it and making it into a ‘big deal’.

Throughout the interviews information provided by the young person was verified with them through feeding it back and asking them to confirm I had understood them correctly. This was to ensure that the data was an accurate portrayal of their views. This is a method recommended by Costley (2000) to ensure accuracy, as when working with young people, particularly those with cognitive impairments, it is very difficult to ask them to verify the data at a later date. I was also careful with regards to the responses I gave, although I was aware of a need to encourage the parents, and more so the young people, to respond fully I did not want to guide their answers. The literature has demonstrated that young people (and also children) can

sometimes fall into reporting what they think the researcher wants to know, and so I did not want to lead the participants into focusing on a specific aspect of the transition (Moore et al, 1998).

Before leaving, the parents and young person were given some leaflets on organisations that worked with disabled young people in case they felt the need to talk further about the issues raised. These leaflets included one by Enquire, a charity providing advice on education for individuals requiring additional support for learning, Capability Scotland, a charity working with individuals with CP in Scotland which provides advice and support, and S.N.I.P. a charity which provides support for parents and young people with impairments. I briefed all of these organisations about the research prior to providing the participants with their details.

For those in Post ASL group these leaflets were given at the end of the third interview. This was done due to the concern that the information might influence how their experience developed. I did question whether it was ethical of me to hold the information to the end of the interviews, but I decided that I was not withholding anything that the parents and young people would otherwise have routinely received, and I was there to collect information about the natural course of the transition and should observe the events and not interfere.

4.6.4 Interviewing in the home

As previously mentioned when entering a participant's home to carry out interviews, researchers must put participants at ease so that they do not view the interview as an assessment.

Whilst interviewing within the home is beneficial to parents and young people, as they tend to feel more comfortable, do not have to travel, or find alternative child care for any siblings, it can also bring many additional factors to contend with during the interview. In some of the interviews the young person's father joined the discussion part way through, often leaving again to tend to other siblings or other household chores. This was sometimes helpful to the discussion as it triggered memories, but at other times it influenced the dynamics that has been established between the participants and myself. There was also the issue of using the data from these

participants. For these participants consent was obtained verbally at the end of the interview.

Siblings were also a confounding variable on the interview process. At times these siblings came into the room to speak to the parent participating, or made a noise in another room sometimes distracting the young person and their parent. One young person had argued with a sibling prior to the interview, and this needed to be resolved part way through the interview as the young person brought it up and became upset.

Other distractions came in the form of the telephone ringing during the interview. Some participants would ignore it, other gestured to see if it was alright for them to answer, keeping to a short conversation if they did. Other issues arose with visitors to the house; in particular with the Post ASL group the family became more familiar with me, and more relaxed with me visiting their home. Although this was positive in that they spoke more freely and gave rich dialogue, there was also some negative aspects in that they felt able to invite other family members into the discussion, for example during one interview the young persons grandmother and auntie arrived and were invited into the room, which resulted in the young person becoming excited and unfocused for a short time.

Although these additions to the experience were not ideal and at times could possibly have deterred from the research process, it was important to remember that the participants had volunteered their time and as a researcher I had entered into their home environment. Fathers, siblings, guests and phone calls were all part of this environment, and requesting that they be excluded would be unfair. Again I was also mindful of the comments made by Alderson and Goodey (1996) with regards to becoming dictatorial towards participants.

4.7 Translating Theory

Much of the pre interview research carried out focused on the implications of working with children and young people as this is viewed as being more complex compared to interviewing adults. As the young people involved in the project had a range of impairments it was vital to be flexible in the approach I used.

Some of the young people had shorter concentrations spans, or required simpler questions. This was easy to pick up on through the informal conversation at the start and also through observing how they interacted with their parents. In two of the interviews it was necessary to involve the parent asking some of the questions as the young people had particular communication needs, for example if the young person was using eye blinking. This is where the multiple interviews within the Post ASL group were an advantage as they allowed me to build up the skills to link with the young person and to communicate better with them. I was mindful that involving the parents could have influenced the responses the young people gave, as Moore (1998) pointed out.

It is widely recommended that adult researchers attempt to modify their language to be more in line with the children or young people that they are interviewing (Beresford, 1997). Throughout the interview I attempted to use the same language as the participants, both the young people and parents, using school and teacher names in questions, and abbreviating school names or subjects as they did. For example, there are many different ways to refer to secondary school; high school, comprehensive school, senior school, so I listened to how the participants referred to the school and used their terminology.

I was also aware through reading the literature prior to commencing the interviews, that I had a number of more technical terms that related to the transition. Again I made a conscious effort to avoid these terms which could have alienated the participants. If I did use such terminology, I ensured I explained what I meant before looking to the participant to respond, thus avoiding any embarrassment if they were not familiar with the particular term.

Advice on starting the interview with warm up questions and also having a clear ending to the interview were very helpful (Bricher 1999). This structure helped the participants feel comfortable in the interview situation. The clear ending to the interview was helpful as it gave a warning to the young person in particular and gave them the awareness that they needed to say anything they'd been thinking about. Also for those young people who found it hard to concentrate for long periods the

awareness that they were near the end seemed to help them re-engage with the interview.

Much of the literature on interviewing children suggested methods such as playing games, role play or picture drawing. This was not something that I adopted in this study. Here participants seemed to appreciate being treated the same as their parents; I also felt that such activities would be inappropriate with this age group. Davis (1998) talks about how children will have different experiences, and so as a result may not be familiar with expressing themselves through such methods, for some children and young people their most comfortable method of expressing their experience will be verbal.

Research which demonstrates that such methods work well are often carried out with younger children. For example Mauthers (1997) asked participants to draw food as part of the Healthy Eating Project, which worked well with the 6 year olds participants. Mauthers (1997) also notes that such methods work well in focusing the issue for younger children in particular. I felt that the informal conversation prior to the interview worked well as an ice breaker for the young people to feel comfortable in my company. Within the Post ASL group the young people seemed to build up a familiarity with me through the interviews and were noticeably more relaxed as the interviews progressed.

4.8 Reflection

When conducting qualitative research, in particular when working with children, young people and families, it is important that as researchers we reflect on our work and be reflexive as to how we could have impacted on the data.

4.8.1 Reflection on the participatory nature of the work

This project aimed to be participatory, which provides a challenge since this work involved both disabled people and young people. There were two locations of participation in this work, firstly in the interview, and secondly in the dissemination process.

An issue of concern when working with young people was the power differential that existed between the researcher and the young people. Evidence suggests (Scott, 2000) that young people may not be familiar with being consulted, and so the experience will be new to them and possibly daunting. Also as I was associated with a University, some of the young people, and possibly parents, might find this intimidating. Earlier work by O’Kane (2002) established that children often perceive adults as being in power which is heightened when research is conducted in a hospital or university. Being associated with a university may have the same impact. Through recommendations from the literature (e.g. Morrow, 2001, Morrow and Richard, 1996, Thomas and Beckford, 1999), and using participatory methods it was hoped this power imbalance would be minimised.

The young people involved in this work had a range of cognitive abilities; some had no cognitive impairment, others quite severe cognitive impairment. This raised challenges over ensuring that the young people understood the nature of the work, and were able to make an informed decision over their participation.

For these young people it was ensured that the information provided was broken down, and was also explained verbally to them with the assistance of a parent if necessary. Similar to what Hart (1997) recommends, multiple approaches to the interview were used. This involved the researcher adapting questions to the young person and breaking them down into parts if required. This will be discussed more thoroughly later in this chapter.

Although all control of the work was not going to be given to the young people, as the area to be researched had been selected, the aim was to be as participant led as possible.

Originally it was envisaged that prior to meeting the parents and young people a focus group would be held with a group of parents, and also with a group of young disabled people to discuss the methodology and direction of the research. This would contribute to the core principle of participatory methods through including participants in the planning phase of the research. The focus groups would have provided an insight into the participant’s lives, and would highlight the topics which

would be addressed at the interviews. It would also have allowed feedback on the information sheet, and given guidance on how to interact with the young people with regards to issues such as the type of language and the communication style (Moore et al, 1998).

Two local charities working with parents and young people were contacted, and the process seemed feasible. However, after liaising and working together it was established that it was not possible within the time frame available. As an alternative several individuals working within these charities, who were also parents to disabled teenagers, were happy to comment on the material. One member of staff not known to myself agreed to participate in a pilot interview and to give guidance and insight into their experience of participating.

Although this assisted in achieving a level of participation for parents, this resulted in the young people only being involved in the interviews and in receiving feedback on results. However, Hart (1997) notes that:

“Projects can be designed and run by adults yet still have virtue as participatory projects if children understand the process, are consulted, and have their opinions treated seriously.”

Hart (1997, page 43)

In this work the young people had information sheets which were written in an accessible format (described later in this chapter). They were willingly participating in the research, this was done by ensuring consent was obtained, that they understood the study and were happy to take part. The principle of double consent was applied; in that once parental consent was obtained the young person also had to consent, which is seen as good practice when working with young people (Ireland and Holloway, 1996). At the beginning the young person was asked if they had any questions, and it was made clear to them that participating was a voluntary process and that they could stop the interview at any time. Consent was obtained verbally, and written consent was obtained from those who were able.

The young people were consulted directly for their views, and could shape the course of the interview, as it was explained to them that they were free to bring up any issue or topic they thought was relevant to their experience. Mayall (1996) states that although young people can be involved in the path the interview takes, fundamentally all research is structured by the researcher to a certain degree, as they have specific topics that they would like to discuss, and this has to be acknowledged.

Finally their opinions were listened to and will be disseminated to those who have the power to act off them. This was demonstrated specifically to the young people through the preparation of a report designed for them.

Therefore, although what McNeish and others refer to as participation was not achieved, the young people were consulted and informed and were given choices, with tokenism and non participation avoided.

As noted earlier within this work parents were consulted prior to the research commencing which was a way of incorporating an input from the relevant research group, and provided some preparation to working within the field. In particular the pilot interview helped to develop a better understanding of the appropriate language, along with the need to break down questions into smaller parts. Through the discourse new areas and possible ways of framing topics was also developed.

The parents participating were also provided with information so that they could make an informed decision over their participation, and were fully informed of the findings from the work. Thus the parents arrived at a stage which was participation.

Another note to make is that some of the parents and young people took part in the interviews together. A full discussion of how this could impact on their findings occurs later in this chapter. At this point it is important to remember that this may have influenced how the young people and their parents participated, and also the discussions themselves. However, as this was what some of the participants chose, it needed be respected.

4.8.2 Reflection on carrying out family research

The advantage to using qualitative methods to carry out this research is that they are able to accommodate multiple family perspectives (Daly, 1992), which can be complex (Ribbens McCarthy et al, 2003).

In family research conducted by Murphy (1992) she noted how parents and children's data informed theory in different ways. Here the young people and parents contributed perspectives on different aspects of the transition. Where parents were focused more on services and communication with schools, the young people discussed the impact on them personally, specifically concerning their identity.

Generational differences were also evident within the work as discussed by Ribbens McCarthy et al (2003). Parents often disclosed and discussed aspects of the transition that the young people were not aware of.

Table 4.7 indicates how many of the young people were interviewed with their parents in the pre and post groups, and also overall for the project, showing that nine young people in total were interviewed with their parents, and that 12 were interviewed by themselves.

<u>Pre ASL Group</u>		<u>Post ASL Group</u>		<u>Total for the project</u>	
With Parent	Alone	With Parent	Alone	With Parent	Alone
9	3	0	9	9	12

Table 4.7: Young people participating with and without their parent (s)

Originally interviewing young people in the presence of their parents was a concern for me as I wondered whether the young people would speak freely in front of their parents, as research has demonstrated that they often do not (Alderson and Goodey, 1996). However, further reading disclosed that there can also be advantages to working in this way. For example, Whitehurst (2006) discussed how an interview can be aided by having someone familiar present. I did find this to be the case with some of the young people. For example it assisted the young people

with more severe CP with their communication, and having a familiar person present is what Beresford (1997) suggests as a method for working with young people with learning or communication impairment.

Similarly Hood et al (1996) points out that children can feel more comfortable talking to adults with other people present. In Hood's study other children were used, however, I believe that the parents in this case acted as a similar source of comfort and support to the young people. Research has also demonstrated that a familiar person can help to reduce anxiety and the perceived risk through providing emotional support to the young person which I felt would help the young person to tell their story (Lewis and Porter, 2004).

A final reassurance came through the work of Roker and Shepherd (2007). When working with families they found that where families participated together there were benefits for some individual sessions. Where families participated independently there were benefits to participating together in some sessions. Thus it is clear that there is not a single method that is more successful than another when working with young people and their parents.

Lewis (2008) recommends being mindful of the motivations for families to participate in research. Within this work there did not appear to be a clear motive to the families participation. I might have expected families with poor experiences to participate to voice their experiences, but this was not the case. Some families commented that they had participated to help others; one parent noted that she had been involved in conducting research and so felt that she should now participate.

Throughout the work I attempted to insure that both the parents and young people had the opportunity to express the issues they felt they wanted to talk about. This insured that the both perspectives and individual family histories could be represented.

4.8.3 Reflection on the interview process

As this project was my first experience of interviewing, before starting I was apprehensive about generating rich data. I read a great deal of literature on the topic

and sought advice from more experienced researchers. However, once I started interviewing, I found that both the parents and young people wanted to share their experiences and seemed to value someone listening to them and being interested in their story. Many commented that they were happy to be part of the research as they felt they wanted to help other families with a child with CP. Thus even though they were aware that their children would not directly benefit from it, but it would be the future transitions of young people that would hopefully be improved, they were happy to participate.

My previous experience of working with young people with both physical and cognitive impairments assisted me with the interviews. As Whitehurst (2006) noted, I found that some of the young people with more severe CP had limited attention and could easily be distracted by noises or events happening outside the room. For these young people it was important to keep questioning short and concise and to be flexible with the wording or setting of the question. My previous experience made this way of working easier to adopt.

Having the data from the LAQ assisted me with preparing for the interviews, as it gave a rough idea of the impact of the young person's CP. However, it also demonstrated how the questionnaire is affected by parental perceptions, as vast variations were found between young people who scored a level of moderate on the LAQ, and also those scored as severe. Although this project is not about assessing the LAQ, such experiences of finding personal perceptions influencing the data is similar to the work by Abberley (2001). Abberley (2001) assessed the OPCS disability surveys and questioned the reliability and validity of it, due to its vulnerability to be open and influenced by personal perceptions.

Throughout the interviews the young people would frequently disagree with their parents, or would correct them. This gave me the confidence that the young people were talking freely.

Abbi: *How was that when the bell started ringing?*

Ben: *eh..*

Ben's father: *Panic!*

Ben: *No, it was alright.*

Kyle's mother: *He's not on the same homework as everyone else – aren't you?*

Kyle: *No.*

Kyle's mother: *I thought you told me you got different homework?*

Kyle: *No, I get the same homework.*

Kyle's mother: *Does the teacher make it a bit easier for you, no?*

Kyle: *No.*

Kyle's mother: *So you're getting on okay with the homework?*

Kyle: *Yeah.*

Interviewing young people also raised many challenges. During one interview the young person became very high spirited, shouting into the Dictaphone. At first I tackled this with humour, but later he continued to behave in this way. I asked him if he had had enough of the interview, which he had not, and so I asked if we could carry on. This was a difficult situation to deal with as I did not want to tell the young person off, but I also needed the interview to continue in a sensible way.

[Discussing the induction day]

Abbi: *Do you feel like now when you start after the summer you know them [other pupils] a little bit already?*

Freddie: *YES!* (shouting into the Dictaphone)

Abbi: *That will be loud for me to hear.*

Freddie: *Yeeeeesssss!!* (again shouting into the Dictaphone)

Abbi: *Don't do it too loud, it will hurt my ears when I'm listening to it later...*

Freddie: *Yeeeeesssss!!* (Continuing to shout)

Abbi: *Have you had enough?*

Freddie: (indicating no)

Abbi: *How do you feel about going to [secondary school] now?*

Freddie: *well, it's good.*

A further challenge was for me to become familiar with the young people and to understand their communication style. This was definitely a learning process and showed me the advantage of multiple interviews.

The extract below from the first meeting with William (11) demonstrates how difficult the researcher can find this, and how frustrating it can be for the young person. During this discussion I wanted to ensure that I was reflecting William's experience

and so was checking back with him. Unfortunately during this discussion I was unable to understand him and he chooses to move the discussion on.

William: *Aye...although not a...not a big lift...but then, there's this [unclear] hold, like a chair lift.*

Abbi: *So they've got those as well, the chair lifts.*

William: *No*

Abbi: *No?*

William: *how do I describe?...[unclear]I go upstairs...and I go round and back.*

Abbi: *round a different way?*

William: *No, I go, then I go round and I go up. It's quite soon. And I go up there.*

Abbi: *So you go round the back?*

William: *No...I'm not sure. [unclear] there's a lift though. I know I can get there.*

In future meetings having become familiar with each other this did not occur again. I continued to check back with him, as recommended by Sinclair (2004), and he corrected or confirmed his responses for me.

Another surprise for me was that some of the young people would turn the table and start asking me questions. I had to be prepared for this and to answer them as honestly as I could.

Abbi: *so, looking forward then to starting?*

Elliot: *yeah*

Abbi: *it looks like it'll be good fun.*

Elliot: *Did you like high school?*

Abbi: *I did like it when I was there, yes. I had a lot of fun there. But my high school was in Wales and we had to speak Welsh.*

Elliot: *Is that the same as English?*

Abbi: *No, it's a different language.*

On reflection, I believe that there were some unavoidable interviewer effects taking place throughout these interviews. These possibly resulted in some of the younger male participants feeling a bit embarrassed talking to me, or choosing to do the interview with their parent. However, these were unavoidable to a degree due to the desire to maintain consistency between interviews. To the best of my abilities I tried to limit the impact these effects may have had, mainly by increasing the participants feeling of familiarity with myself. I had included a picture and blurb about myself on

the information sheet, through the informal discussion at the beginning of the interview, and through conducting the interview in a user friendly way, through adopting the young persons terms and names for classes and school.

4.8.4 Reflection on the validity of the work

Once the data had been collected and analysed it is important to critically think whether validity has been achieved. As discussed earlier in this chapter, the conventional validity scales are not easily transferable to qualitative work, thus it is recommended that the alternative scales of authenticity and trustworthiness (Lincoln and Guba, 1985) are applied. However, whether trustworthiness can ever be established has also been debated (Sparkes, 2001).

Authenticity questions whether the work represents everyone fairly and contributes to our knowledge and understanding. I believe that this was achieved through this work. The transcripts from both the parents and young people were kept true to the words they had spoken.

When reading some of the transcripts after the interviews it was tempting to add in additional words to make the participants message clearer. Some researchers argue that this is a legitimate action as it assists in conveying the message of the participant. However I agree with the stance taken by Stalker (1998), and also others, that it is not the place of the researcher to put words into the mouths of participants, even if that was what the participant was attempting to put across. I decided that I would keep the transcripts pure, and supplement them when necessary with notes and comments I made during and after the interview. For example, adding in that something was said with a smile or said whilst angrily waving a finger.

The work also contributed to our knowledge of this area, through being one of the first to record accounts from disabled young people and their parents regarding the transition.

Trustworthiness is made up from the concepts of confirmability, dependability, transferability and credibility.

Attempting to derive the most credible account was accomplished through basis the analysis on the transcripts of the discussions, and sticking to what was actually said by the participants. This was more difficult to attain with the young people with communication impairments, as they were limited by the questions I asked. Two of these respondents used eye pointing or blinking to convey their response. With these young people each positive or negative response was explored as much as possible. For example if responding yes/no to the question of whether they enjoyed school, multiple possible reasons for their answer were explored with the young person through a process of elimination. Questions such as whether they liked different lessons, being with others in their class, or interactions with the teachers were used.

Although such responses were not as detailed as others, and were more researcher led, they remained to be along with all responses, the words of the participant.

Achieving a transferable and dependable account was difficult to guarantee due to the existence of multiple realities. Attempting to work towards this was also impacted on by the communication skills of some of the young people. For those young people with communication or learning impairments it was important to break down questions into parts, and to be aware that they may also have difficulty with dealing with time or frequency questions (Beresford, 1997), extracts below from some of the discussions illustrate this.

Abbi: If you met someone now in primary school with CP and they were going to secondary school, what advice would you give them?

Ian: Um...um...that's quite hard...I don't know...

Abbi: OK. If they were worried about things, what would you tell them?

Ian: Not to worry, and to go to your pastoral care teacher. And other teachers for help going around the school.

Abbi: Right, so not to worry and to ask for help.

Abbi: *Is [secondary school] different to [primary school]?*

Freddie: *yes*

Abbi: *Is it different in a good way, or in a bad way?*

Freddie: *um, a good way*

Abbi: *What things are good?*

Freddie: *Science and PE. And, um what do you call it...it was um...cooking, um cooking and French and science.*

Abbi: *So it's the lessons that are better?*

Freddie: *French and science and English*

Abbi: *so doing the different lessons are better at [secondary school]?*

Freddie: *yeah.*

Also Beresford (1997) notes that individuals with such impairments may be able to make a choice and have a preference for something, but might not be able to explain why they have this preference. I found that this occurred with several of the young people, and more frequently with the younger Post ASL group.

[Discussing the question and answer session held at Kyle's primary school]

Abbi: *Did you think that was helpful at all?*

Kyle: *yes*

Abbi: *Do you know why?*

Kyle: *No*

I also found, as much of the research in this area notes, that many of the young people found it difficult to remember the events we were discussing as for some it was up to 3 years ago. For these participants it was necessary to take them along a path to remembering the events, taking them step by step further back. In many cases the parents assisted me with this, naming teachers involved in the move, for example, to help the young person place themselves at the time of transition. However even with this support many young people in the Pre ASL group still complained that "*that was ages ago!*"

Nathan's Mother: *Do you remember [alternative secondary school] where you went in and they had the big lift, and you could operate it yourself. Couldn't you? Remember you could go in and you went up and [carer] went up the stairs, and you went up in the lift.*

Nathan: *That was ages ago!*

Parents in the Pre ASL group also experienced difficulties with recall. For example some parents were unable to recall accurate details regarding the information they may have received regarding the transition.

However, in attempting to establish whether transferability and dependability were reached, I believe that through breaking questions down and taking each participant on a journey back through the transition, resulted in detailed accounts. However, it may never be totally possible to guarantee that they have been established.

Finally confirmability questions the impact of the researcher on this work. Throughout this chapter my possible impact on the data has been discussed. Simply through being a female researcher from a university I may have impacted on the data I obtained and analysed. Through being reflexive I believe that the impact of some of these interviewer effects were minimised.

Therefore when questioning whether validity has been achieved it is important to note the differences that existed between the data collected. For those in the Pre ASL group there was a need to recall events that had occurred several years earlier. For some of the participants this was difficult to do. For those with communication impairments questions were broken down, in some cases to yes/no responses. This limited the scope for these participants to bring up their own thoughts and views on the topic, or to introduce a new direction to the interview. However, it did provide them with the opportunity to express their own views, which was important to this work.

Although the information collected from each participant varied, this project provided the space to each participant to contribute to the work according to their own abilities. As the researcher I attempted to provide the assistance required to each participant to have their voice heard. It is questionable whether trustworthiness can ever be truly established (Sparkes, 2001), in this work the methodology allowed for detailed, accurate accounts, and for reflexive practice to take place. Such ways of working allow for the projects to provide valid accounts of moments in history.

4.9 Data Analysis

Following the completion of each interview the recordings were send off for transcription. Therefore the analysis on the data from the pre ASL group occurred prior to that from the post ASL.

On receiving the transcripts a period of time was spent on re-familiarising myself with the data. As I carried out each interview myself, reading the transcripts triggered visual cues which helped to put the dialogue into context.

Having spent some time becoming familiar with the data a small sample was taken. For each of these transcripts the main themes were highlighted. All of the themes were brought together and grouped into common themes. Being so close to the data I appreciated the input of my supervisor, to discuss the transcripts with and to compare themes that we had both identified. This reassured me that with the large amount of data available I was not missing any major themes.

The main themes and ideas were then applied to the remaining transcripts with the aid of the computer package NVIVO. Where new themes came up in these transcripts the themes were added to the list of themes.

At this point the advantage of using an electronic storage system became apparent. For each theme the extracts of dialogue associated with that theme were extracted.

Through reading the associated extracts it was possible to group the themes further into main themes. For example, the themes '*rejecting labels*', '*hiding impairment*' and '*standing out*' became '*move away*', whilst '*informing others*', '*language used*' and '*comparing self*' became '*relate to others*'. At this point a clear description of each theme was written. The data coded under each main theme was again read and moved if it did not fit with the picture of the theme.

Following this process the main themes were further categorised into groups, therefore '*move away*' '*personal impact of transition*' and '*relate to others*' became '*identity*'. These groups were taken forward in the following analysis chapters.

When analysing the data from the post ASL group I was thoroughly familiar with the main theme groups derived from the first part of the work. Again a process of familiarisation occurred, and the main theme categories were applied to the transcripts. However, these transcripts also have new occurring themes, and the process of grouping them and categorising them into main themes as described above was applied.

4.9.1 Reflection on the analysis

I found developing the coding structure for the transcripts a difficult task to carry out due to the multiple perspectives represented in the work. With retrospective and prospective voices of young people and also their parents there were many individual and sometimes conflicting stories. For each parent or young person who made a specific comment, there were often others who contradicted it. This demonstrated the nature of the topic, although some dialogues could be drawn together, there was no categorical one view.

On receiving the transcripts back at the end of the first stage of the project, the amount of data generated felt intimidating. On familiarising myself with the data it seemed that I would come across new concepts in the transcripts every time I read them. This highlighted the value of spending time reading and re-reading each transcript.

A difficulty I found with approaching the transcripts was that many of the participants tended at times to discuss aspects that moved away from the transitional experience. However, much of this information was very interesting and helpful to explain the context of decisions and outcomes of events. I spent a lot of time reading each transcript and ensured that amongst the off the topic discussions no relevant historical or personal data was missed.

When attempting to group the themes into main themes it was difficult to make the jump into broader headings. Each theme seemed to contain a unique aspect of the transitional experience. For example, the theme '*move away*' discussed how some young people felt the need to hide their impairment and were actively trying to avoid being labelled. Therefore it was about the need to fighting and avoiding negative

attitudes. The theme '*relate to others*' was about how the young person compared themselves to their peers, and the language they and their parents use to discuss their impairment. Thus it was discussing how they put their views across, and how they saw the world. However, essentially both of the themes were discussing the development of identity, and how it is shaped through social interaction and discourse.

It was at this stage that I particularly appreciated discussing this was a second person (my supervisor). Through discussing the themes it became clearer how they were connected and could be brought together.

Once the post ASL interviews were completed there was more data to add in to the analysis. By this point I had become very familiar with my core themes, and was somewhat protective of them. When applying them to the new transcripts it was validating when the discourse fitted with the ethos of the themes. When the new data did not fit the realisation of having to expand my core theme group seemed disappointing at first.

However, on reflection I realised that this represented the different ways I had gathered the data. One group had participated in a single interview recalling an event, whilst I had journeyed through the event with the second group. Thoughts, feelings, and views were all experienced in detail and in their raw state, which added a different dimension to their transcripts. I realised that generating new core themes contributed a new insight into the transition, such as the them '*parent's induction*' which discusses the parents reaction, involvement, and feedback from the induction days. I was appreciative of having this opportunity and the contributions it made to the work.

4.10 Dissemination

Within participatory research it is important that participants are informed of the findings and have the opportunity to comment on them. It was important in this study to ensure that the young people felt part of the project. In particular, I wanted to feedback to the young people that their voices had been listened to, which is one of the things Sinclair (2000) found was missing from many interactions with disabled

young people. Frankin and Sloper (2008) also noted the importance of disseminating to the young people directly, as often this is only done to parents and the young people end up feeling not valued.

Individual transcripts were not sent back to the participants to comment on. Research suggests that young people find it very difficult to validate their responses after an event (Costley, 2000). Also, it can be embarrassing to hear the actual words you have spoken during an interview, leading to a desire to alter some parts of the transcript when you read it to make it more socially acceptable. I felt that during the interviews the participants had spoken freely and honestly about their experiences, and I had validated the information with them throughout the interview, and also through recapping at the end of the interview. Thus I felt that returning the interviews would not add to the richness or validity of the data.

A report on the findings from the Pre ASL group was written for the parents (appendix 10) and another one for the young people (appendix 11). These were sent out to the families before the results were disseminated in other CPRS forums (the newsletter and website (appendix 12)). Participants had the opportunity to make comments on the findings at this point. None of the participants choose to do so. The process was repeated with the post ASL group (appendix 13 and appendix 14), and again none of the participants chose to make any comments.

As mentioned above the results were also summarised and published on the CPRS website and in the newsletter which is sent to parents twice a year. This allows for a constant update on progress and findings, and would also inform other parents of the forthcoming parts to the project. Previous research (Lewis and Porter, 2004) has demonstrated that newsletters in particular are a good way to feedback to participants.

4.11 Introducing other validation methods

I was aware from reading the literature (Thomas and Beckford, 1999), and through interactions with parents, that many families were unable to take part in an interview due to other commitments. I felt that a postal questionnaire would give these families the opportunity to contribute their experiences, a method successfully used by other

researchers in this field. It was envisaged that the questionnaire would provide additional data to investigate some of the emerging issues from the interviews, such as the possibility of services differing between areas, and would also contribute towards addressing the trustworthiness of the work as highlighted by Lincoln and Guba (1985).

The interview transcripts were used as the basis of the questionnaire, and a parental and young person's version were developed. Ample space was given for participants to contribute their unique experience and emphasis was given to the fact that I was as interested in hearing their story as I was interested in those who participated in an interview.

However, the response rate to the questionnaire was very low (33%) which resulted in its contribution to the work being limited. Following much reflection it was decided not to include the questionnaire data in this work. The interviews had provided rich dialogue, and although following up some of these issues further would be advantageous to our understanding, this is possibly an exercise for a future project.

4.12 Chapter summary

This chapter has detailed how the research was conducted, and explained why it was carried out in such a way. From this chapter there are a number of methodological issues which shaped how this work was carried out.

- The selection of participatory methods.
- Conducting individual interviews.
- The advantages of using a research register to identify participants.
- The importance of the researcher being able to adapt.
- The need for findings to be disseminated.

Participatory methods: Although this work agreed with many of the principles of emancipator research, it could not adhere to all of them, and concluded that the work needed to be participatory. Primarily it was the emphasis on adopting the social model, which leads this work away from being emancipatory. Imposing a model onto

the work would inevitably influence the analysis of the data, and has been cautioned against in the literature (Davis, 2000).

Interviews: Having discussed the merits of qualitative methods to answer the research question, individual interviews were finally adopted. Individual interviews allowed individual views to be expressed, and did not directly impact on the transitional experience.

Advantages of the CPRS: Families on this register have built up a relationship with it, and so as a result the response rates for this work were higher than comparable work.

Need to adapt: During the course of the interview stage I learnt the importance of being able to adapt my questions and language to the individual participating, and to follow recommendations from the literature.

Dissemination: A vital part of participatory research is disseminating the findings, which demonstrates to the participants that they had been listened to and appreciated.

Thus this chapter has explored how the data was generated and collected. The next chapters now focus on the findings, and attempt to establish the influential factors to achieving a successful uninterrupted transition from primary school to secondary school.

Chapter 5

“He lives in this community; this is where he’s going to school.¹” – Preparation and choosing a school.

5.1 Introduction

The transition into secondary school is a routine move for young people throughout the UK. All young people will need time to prepare for this transition, decide which school to enrol at, and attend induction events. However, for young people with CP, there are several additional factors that impact on this progression. For many, preparations for the move can involve several meetings and assessments; choosing a school focuses on issues of accessibility, moving around the school and carrying the school bag, whilst visits are concerned with highlighting possible individual access problems.

This chapter will discuss the experiences of families in preparing to move to secondary school. As a means of evaluating the Additional Support for Learning Act, the experiences of parents and young people will be compared between those who made the transition before and after the act’s implementation. Throughout the chapter both the retrospective and prospective voices of young people and parents will be presented.

Within this chapter there are four main sections; these discuss the Additional Support for Learning Act, choice, choosing an alternative school and the role of the young person in this phase of the transition.

The first section, ‘5.2 *“He hasn’t got one of those [CSP] at the moment. We’re not sure if he should or not.” – Impact of the Additional Support for Learning Act*’, discusses the knowledge parents have of the act, and the impact this has on the transition. From the review of the act presented in chapter 2, it was suggested that the act would improve the transitional experiences for young people and their parents.

¹ Nathan’s mother

In this section it is demonstrated that parents have very little knowledge of the act, and that there is confusion surrounding it, summed up in the quote in the section title. Although this act advocates multiagency working, involving a range of services consulting with parents and young people, throughout this chapter it is demonstrated that this is not occurring for all families. For some families it is shown that they are taking on the role of proactively seeking information, rather than services providing them with information.

Many parents discuss the co-ordinated support plans brought in by the act, and it is put forward that in many ways this suggests that the parents feel the need to have some control over the care of their child. It is discussed that the need for control is heavily influenced by the parents personal histories. This chapter concludes that in order for the ASL to be fully implemented partnerships with families need to be built.

The next section moves onto discuss how families make the choice of secondary school. From the section heading '5.3 *"It was the only one wae access for wheelchairs."* – *Having and making a choice*', one of the key themes is represented. It is apparent that despite the legislation discussed at the beginning of chapter 2, such as the Standards in Scotland's Schools Etc Act, 2000, for some families there was no choice of school available to them.

This section illustrates that primarily parents rather than the young person make this choice, and that they adopt the role of 'responsible parents' by seeking information early in the process in order to make an informed choice.

In this chapter many parents speak about feeling that they need to start the transition planning earlier than other parents. This may suggest that parents are acting on their personal histories and have a lack of trust in services. If parents do have a lack of trust in services this could suggest problems for the implementation of the ASL and collaborative working.

One of the key points made by the parents is that they want the young person to attend the local school within their community (Connor and Stalker, 2003). This is

also the view of the young people. The parents in particular prioritise their child being educated in the local school in order for them to integrate, and develop a sense of community. As illustrated in chapter 2 there are many positive outcomes of having a sense of community, such as the increased level of satisfaction, well being and coping (Farrell et al, 2004, Prezza et al, 2001) along with reduced loneliness (Prezza et al, 2001). This is what parents desired for their children. Later in chapter 8 we see how not being able to access local schools can result in the parents support networks being broken down.

This chapter highlights the tension in this work between normality and difference. The parents felt that through going to the local school their child would not be perceived as different. However, when discussing support for their child parents emphasise the difference of their child. This can result in confusion for service providers when attempting to engage with parents.

This section also highlights that although policy is moving towards mainstream education for all disabled children, as outlined in the Standards of Scotland's Schools Etc Act 2000; many parents feel strongly that their child would benefit from attending a special school. There are echoes within this section of the work presented in chapter 2, such as that by Baker and Gaden (1992) when they discussed parents' views on special schools, and established that they saw them as having specialised teaching and resources. The parents' views were also similar to the accounts by French (1993), who discussed how at special school she was the norm. All of the young people who participated in this work report being happy at their special school.

This study found that for many parents the inclusion that their child would experience at special school is why they choose this option for them. In chapter 8 the discussion of special and mainstream schooling is further developed.

The section concludes that parents make choices about schools based on the dimensions that they value, such as location or accessibility. These dimensions are socially constructed and are shaped by personal histories.

Finally the chapter addresses the role of the young person at this stage in the transition. Earlier it was noted that primarily the parents took charge of making the choice of school, within '5.4 "*The fact is I probably didn't take part in the induction*" – *Role of the young person*', the actual part the young person plays is investigated along with their views on their involvement. This section highlights how, in many cases, the young person had little participation at this stage. There was also a divide amongst the young people, with some reporting that they wanted more involvement, which is inline with earlier work discussed in chapter 2 (e.g. Garth and Aroni, 2003), and others happy for their parents to take the lead.

This section puts forward that in order to improve the transition, and follow the guidelines of the ASL act, schools must work with young people. Many schools adopt a homogeneous view of disabled young people, but as this chapter shows young people have different views and issues that need to be discussed. Through consulting with young people as the ASL puts forward individual needs can be addressed.

Throughout this chapter both the parents and young people express strong views relating to making this choice. The young people's voices can sometimes be lost due to the parents striving to obtain a place at the school they deem best. For many of the young people their role involves consultation once the decision has been made. This chapter aims to represent these views through extracts of the participants' dialogue, and draws attention to those issues which they highlighted as important to this choice.

5.2 "*He hasn't got one of those [CSP] at the moment. We're not sure if he should or not.*"² – *Impact of the Additional Support for Learning Act*

As illustrated in Chapter 2 the Education (Additional Support for Learning) (Scotland) Act (2004) (ASL) came about to combat the variation between local authorities in recording additional needs. It also aimed to empower parents and to listen to children and young people.

² Harry's mother

The aim was that all school experiences would be improved, with parents, young people and multiple services (when required) involved in decision making and planning of education. Transitions were one of the areas targeted by this Act.

Thus the requirements of authorities to consult children and young people, and to give more powers to parents will be explored throughout this project. In this first phase of the transition when choices were being made and plans put into place, both parents and young people, in accordance with the Act, should be involved.

Many of these themes will be discussed throughout this chapter, however to provide a bench mark the parents were asked if they had seen any change in the education of their child since the Act's implementation in 2005. At this point several of the parents indicated that they had not heard of the Act, while others were uncertain what it meant for them. Thus for these parents of young people who would be considered as requiring additional support for learning information about this Act and these new rights had not filtered through.

Of those parents who were aware of the Act all of them felt that there had been no change with its introduction.

"No material difference to Olivia's education."

Olivia's father

The main concern for parents who were aware of the new Act was whether their son or daughter should have a co-ordinated support plan (CSP) which outlines the care plans for the young person's educational, health and social care needs.

"He hasn't got one of those at the moment [CSP]. We're not sure if he should or not"

Harry's mother

"It hasn't really affected Elliot yet, but he needs to be assessed for a CSP, so I suppose that'll be when we find out."

Elliot's mother

Several other parents had been told that the young person did not qualify for a co-ordinated support plan, which angered some of the parents.

“They can’t send a child with his level of disability with no plan at all. It’s ridiculous.”

William’s mother

Some parents chose to appeal the decision.

“The only slight thing that we had is that he was turned down for a support plan...so we had to appeal for that. But , when I say ‘appeal’, all I really had to do at that stage was say I’m not happy and they sort of came round pretty quickly...But apart from that, I’ve had no change at all.”

Freddie’s mother

These parents were aware of the importance of having plans set in place for their son or daughter. Previously under the ‘Record of Need’s’ system nearly all of the young people had a ‘record’ which outlined requirements for their care. With the different criteria for a co-ordinated support plan some of the parents were worried that they would lose out.

“Well we’ve found in the past that if you mention the ‘Record of Needs’ then they’re much more likely to, you know, jump and do what you ask. So we hope that it’s there for back-up if we ever need it, you know, if we ever felt they weren’t giving Kerry the support that she needed then...But I’d hate to think that we’d have to fight our way through High School as well!”

Kerry’s mother

At this point in the transition there seemed to be very little difference between what the pre and post ASL groups were reporting. Therefore it would seem that the implementation of the ASL Act has had little impact so far.

What is interesting from this section is the desire expressed by parents for their children to have a CSP in place, as we see with Freddie’s mother above.

One explanation could be that the parents in this work have been influenced by the medicalisation of impairment. Although the ASL act aimed to have more of a social perspective, which emphasises inclusion and ‘sameness’ there remains the need for

parents to highlight impairment in order to get a CSP for their child. Therefore there is something of a paradox in that the process of obtaining a CSP reinforces a medical approach, which emphasises difference and impairment. This may reflect a gap between the meaning in the ASL act and the real world knowledge of parents.

For many of these parents their personal histories impacts on their desire for a CSP. All of these parents had previously been involved with the 'Record of Needs' system which was very impairment focused. These parents have the expectation that their child will require a formal intervention medically, socially, and educationally. As a result parents seek such input and feel reassured by its presence.

Through requesting the development of a specific plan these parents seek to gain some control over the situation. Burger (1985) proposed that individuals either have a high or low desire for control. Individuals with a high desire for control will adopt leadership roles, avoid being dependant on others, and want control over events. For these parents, rather than be dependant on the support provided to them by services, they want explicit instructions in place that they can then enforce and ensure are carried out. In this way they would be able to gain a sense of control. Needing control in this way creates a 'them and us' situation between the parents and services. The ASL act advocates multiagency working between services, parents and young people, and attempts to move away from the creation of the 'them and us' situation.

The parents personal histories impact on their actions, as we see with Kerry's mother. Having come through earlier systems these parents have been forced to become fighters, and it is not necessarily their own desire. Such histories can also inhibit the parents from taking part in multiagency working.

If the ASL act is to be successful we need to move beyond the influence of personal histories and towards a process of developing partnership with parents and young people, which have to acknowledge the social context of disability. This issue will be further developed in chapter 8.

5.3 “It was the only one wae access for wheelchairs.”³ – Having and making a choice

Individuals value being provided with a choice. Having a choice has been associated with higher satisfaction, motivation and performance (Iyengar and Lepper, 1999), thus for a choice of secondary school to be available to families is highly beneficial. Despite evidence demonstrating that young people value having choices (Mitchell and Sloper, 2001), for most of the young people in this project it was the parents who made the choice of secondary school.

5.3.1 Preparation

In order for a choice of secondary school to be made there was a period of information gathering which was parent focused. Parents reported feeling that it was necessary to start researching appropriate schools early, most starting a year or more before the transition was due.

These parents felt this was necessary because of their child having CP since they felt that schools would need to prepare for the arrival of their child.

“Well we, I think, broached the subject first because we wanted to make sure that the transition was quite smooth and we wanted to make sure that the high school were aware of Kerry’s needs and that she was coming up.”

Kerry’s mother

Similarly Harry’s mother felt it was necessary to start the process early due to Harry having CP. She felt that this would not be necessary when looking at schools for Harry’s younger siblings.

“I don’t think that we would do the same that we did. I think it was only because of Harry that we were starting to get a bit apprehensive about high school that we went out at primary 6. But that’s just because it suited us... for me, just to get my head round what he needed and what he had to do. So I think, with all the other kids getting prospectuses in primary 7 would have been fine but, for kids like Harry, the review meetings much earlier.”

Harry’s mother

³ Darren (15)

Having researched appropriate schools Elliot's mother decided that she would not send him to the local school as they did not have a special unit. Her information gathering resulted in the selection of a school which she thought had the best ethos regarding mixing mainstream classes and the use of the support base. Elliot (12) had previously moved away from mainstream education having felt isolated there, and was currently at a special school. Now that he would be accessing mainstream education again he was looking forward to having the opportunity of attending mainstream classes whilst maintaining the security of the unit.

Abbi: *Do you think [secondary school] is a good school for you?*

Elliot: *Yeah, because you get to go to the actual school...and when you, eh, if you need extra help on work you go into the unit.*

Elliot (12)

Parents generally felt that the secondary school would need to adapt in order for their child to attend, however they were under no illusion that this would be straightforward and it was this that contributed to them starting the process early. All of the parents attended planning meetings with relevant services involved in their child's care. Most parents approached these with practical expectations. Although they were often offered a plethora of services at earlier meetings these frequently decreased as the planning process progressed.

"At the first few meetings, they were promising everything and I was just thinking "This is great" but, at the back of my mind, I just thought it's not going to be the way they said "Oh, and transport would be no problem and yes, he could get the bus if I was really (unclear)" and I thought no, it's not going to be that easy. And, gradually, as the meetings have gone on, it's sort of been brought down to a more realistic level."

William's mother

Initiating transitional preparations varied between the two groups. As we see from Kerry's mother and Harry's mother above, the parents in the post ASL group were more likely to initiate actions at the start of the transitional process. For parents in the pre ASL group initial steps in preparing for the transition usually occurred in consultations with services. These services would initiate the discussion about the

transition. It would then be usual for parents to go and visit the prospective schools by themselves.

“Well that was the record of need [review], the year prior to her going to school. They sort of brought it up that, you know, the move was having to take place and would we go and see where would we like to go and have a look at, and what was our ideas.”

Rebecca’s mother

“The educational psychologist advised us to go and have a look at different schools. And just kind of prepare ourselves ‘cause it’s a huge step”.

Helen’s mother

Parents noted that it was during this early planning stage that many of the schools would try to anticipate the types of problems the young people would be likely to encounter, and suggest ways in which these could be overcome. Suggestions made were such things as the young person leaving class early to go to the next class or lunch, having a locker for their school bag, and in some schools a pass for the lift.

Although parents, and the young people themselves, in both groups made comments that they appreciated knowing that such services would be on offer they also felt that they would like to try and do things in the same way as their peers, and use such facilities only if required.

“We would rather she tried to just fit in with everybody and do everything as everybody does.”

Kerry’s mother

What we see during this preparation phase is that parents feel they need to be informed of the choices available to them. This supports previous work by Echols and Willms (1995) who found that parents valued obtaining information via visits and booklets prior to making the choice about secondary school.

Some parents may feel under pressure to be seen as a ‘responsible parent’. Bowe et al (1994) described how choice making relating to schooling was linked to being a responsible parent, through ensuring the right school was chosen. With the

introduction of newspaper guides and school league tables, Bowe et al argued that responsible parents are under pressure to become the ideal consumer. In this work there is evidence of parents taking on the role of 'responsible parent' by doing research into schools for their child. Such actions highlight a tension between the parents being responsible and taking control, with the goal of the ASL act to initiate multiagency solutions.

It is to be expected that parents would seek information in this way. As discussed in chapter 4 in relation to consent, in order to make informed decisions individuals must have detailed information pertaining to the decision to be made.

Parents in the post ASL group were more likely to start the transitional process off independently. It is interesting that these parents felt it was necessary to initiate the planning process themselves, whilst those in the pre ASL group were more likely to be approached by services. The ASL Act aims to improve school transitional experiences, and so the group making the move under the Act should have had increased input from services. However, from these parents' accounts it seems this was not the case.

An approach such as Burger (1985) would suggest that the leadership roles adopted by some of the parents in the post ASL group could again be perceived as reflecting a desire by these parents to have some control and to take charge over the transition. Such behaviour by parents could indicate either that these parents did have a high desire for control, or that these parents held a lack of trust in services, preferring to take charge themselves to ensure things were carried out correctly.

When these parents' actions are viewed in the context of past experiences their behaviour represents a logical response to the barriers and challenges of accomplishing things for their children. They have therefore been forced by past experience to be fighters. Thus it is important to be cautious when making interpretations of behaviour which do not account for social context

Discourse in this section also demonstrated that parents felt it was necessary to start the transitional process early because of their child's CP. Parents continued to feel

that there would be barriers in the way of their children when they came to accessing secondary school. Here many parents emphasised that problems could occur due to the difference between their child and other non-impaired children. This is despite legislation such as the Standards in Scotland's Schools Etc Act (2000) reinforcing the aim of inclusiveness for all disabled pupils, and also DSPERA (2002) emphasising the responsibility of schools to ensure they have accessibility strategies.

For these parents their previous personal experiences lead them to realise that it takes time to overcome disabling barriers in school. As demonstrated earlier with the discussion surrounding the CSP, several parents seem to have a low expectation of services and mistrust them to adequately provide access and support to their children.

Further evidence of parents having low expectations from service providers comes through the extract from William's mother. She discusses how proposed services were taken away from them during the consultation process, she was resigned about this.

From these observations it would appear that there is a lack of trust between parents and services. Most of the parents felt that it was necessary for them to carry out roles that service providers should be doing. This would imply that for future transitions, and also in other aspects of life, there needs to be exploratory work surrounding this relationship to identify the issues and ways of improving it. It could be an issue with communication and information provision, or possibly the nature of being a parent means that they will always feel they are better placed to carry out such tasks. This finding has implications for the ASL act. If collaborative working is going to take place services must investigate why parents hold these views, and how the needs of young people can be responded to. It is also important that both parents and service providers acknowledge the role of young people in this process. It could be that the drive for power leads both parents and services to exclude young people's views. This issue is returned to in chapter 8.

One issue that did arise during this phase of the transition was the families encountering attitudinal barriers. On being informed of the arrival of a disabled student many of the schools demonstrated views which reflect a medical model of disability. Prior to establishing the ability of the pupil, the school made recommendations of how to overcome potential issues. Many of these recommendations would result in the young person being identified as different which would lead to them missing out on social situations. Many of the young people and their parents expressed a desire to try and cope without such recommendations. In this way they hoped to reduce the perceived difference between the young people and other pupils. The school's attempt to foresee barriers and overcome these reinforced the view that these young people were different from their peers and would need to behave in a different way.

In this situation the school seemed to be seeing all disabled people as being a homogenous group, rather than working with the young people to identify the real and individual issues. The schools stereotypical beliefs of disabled pupils reinforced inability and difference. Research has previously shown that for many disabled young people their inabilities are often reinforced by others' perceptions prior to them attempting something (Davis, 2004).

5.3.2 Influential factors in choosing a school

When making the choice of secondary school there were several issues which parents noted influenced the choice they made. In the majority of cases this was the proximity of the school from their home, with most families favouring the local school.

One of the main reasons for favouring the local school as shown by Ellie's mother was a feeling that the young person should be part of the local community.

"We'd been asking since primary 5 if Ellie could go to [local school]...we knew the school wasn't accessible but we didn't know whether they could make it accessible...One of the disadvantages or the big, big disadvantage, I mean the school's great, they really have been good. It's not our local secondary school.... Ellie wanted to go to high school with her friends, it's the local school."

Ellie's mother

Nathan's mother felt so strongly about her son fitting into the local community that she chose not to send him to an alternative school suggested by the local authority.

"He lives in this community, this is where he's going to school. And we didn't want him to be taken away six miles away. Who was going to be his friends, you know, when he then goes out at the weekend?.. I had actually been in [alternative school] which is a new school and physically would have suited him well. But didn't look at any other schools, no. It was the community and the local school."

Nathan's mother

It is interesting to note here how there is a tension between normality and difference underpinning this research. On the one hand parents highlight difference when they are seeking support; however they also believe that the process of education that is going to the local school will enable their children to be perceived in a similar way to non disabled children. The issue of normality and difference is discussed further in chapter 7 and also chapter 8. It is possible for this work to conclude, as stated earlier, that parents are able to juggle complex and apparent contradictory views concerning such issues.

Being part of the community has been shown to increase an individual's well-being, life satisfaction and reduce feelings of loneliness (Farell et al, 2004, Prezza et al, 2001). Having a feeling of belonging to the community assists in the development of a social identity and reinforces norms and values (Fisher and Sonn, 1999). The community also provides social support to individuals. Thus it is clear why Nathan's mother, along with others, felt such a need for him to be accepted as part of the community. These parents felt that through attending the local school their children will be accepted as part of the community, in particular by their peers.

It was not only the parents who felt strongly about belonging to the local community, many of the young people also made references to wanting to stay with local friends, that friends who lived locally went to that particular secondary school, and that that was the norm within their community. For the young people who had to attend schools outside of their community due to access issues, one of the big disadvantages that they spoke of was that their friends lived some distance away making it difficult to meet outside of school.

It has been well documented that friendships play a vital part in school life, and that maintaining these is beneficial to the young person (Connors and Stalker, 2003, Pellegrini and Blachford, 2000). Specifically friends increase positive attitudes to school (Galton and Willcocks, 1983). Young people themselves feel strongly about maintaining these friendships, as Shaw (1998) showed when disabled young people expressed that they wanted to remain in mainstream schooling despite experiencing problems there, because it meant they went to school with friends from the local area.

“It [secondary school] was where all his friends were going.”

John’s mother

“The primary school that she went to, the children from that school, in the learning unit at that school, went to [secondary school]. And therefore she would know children there that she’d come through primary with...[to] take her away from people she knows which was one of the most important things to her, you know, it was being unfair.”

Rebecca’s mother

“If your child has formed friendships and relationships...in their primary years it generally goes that they follow their friends.”

Toby’s mother

Through sending these young people to schools outside of their local community they were slowly becoming isolated from their peer group. This raises the question of how these young people will cope once they finish school.

Attending school with siblings was also more likely if the young person was remaining within the local community. This was something that parents reported to Mollard (2003) as being important, and was again found in this work. These parents felt that having siblings at school with the young person would be a source of support for them.

“We were looking at the local school, and also that, you know, we knew that his younger brother would be going along sort of two years later. So, you know, there was that level of support.”

Gareth’s mother

“He was quite happy to be going there because it was, you know, the school his sister was at.”

Leon’s mother

“I’ll be safe with them [brothers]”

Zack (11)

The young people also felt strongly about this, and for Darren (15) a lot of the disappointment surrounding not attending his local school was connected with that school being where his siblings were. Darren expressed views of being the ‘odd one out’ going to a different school. Such experiences of exclusion highlighted feelings of difference in the young people.

“Aye, well, that’s where all my family went and it was like where all, everybody from [primary school] went. I was the only one that went from [primary school] tae [his secondary school]”

Darren (15)

Research has demonstrated the influence environmental barriers can have on a young person’s view of themselves. Many young people hold a positive self image, however when environmental barriers highlight their impairment this image can become more negative (Connors and Stalker, 2007, Skar, 2003). Through having to attend an alternative school these young people were constantly reminded of their impairment. This could lead to further issues arising in the future.

Some parents felt so strongly about young people attending school with siblings that they did not even consider a school outside the community; most of these were parents to children with milder CP.

“Well he’s got a bigger brother who went there as well...so there was never any idea of going anywhere else, no.”

Andrew’s father

“He has a twin brother and, you know, to even consider kind of separate schools is just a, a non-starter.”

Matthew’s mother

However, for other parents the young person with CP attending the same school as a sibling was a source of concern. This concern related to worries over possible bullying of the sibling due to their relationship to the young person. This was a concern that Rebecca's mother had due to both her children attending the same school for the first time when Rebecca made the transition into secondary school.

"Secondary schools a different ball game cause the kids are at that horrible, horrible stage where, and especially girls, you know. And that worried us because we actually thought of sending [Rebecca's sister] to a different school"

Rebecca's mother

Not only was being part of the community important to parents when choosing a school but also remaining within the community meant that travelling was at a minimum. Alternative schools were often a distance away from the home and this raised the concerns about travel and road safety. This was a concern parents had regardless of whether they were choosing a mainstream school or special school.

"One of them is at the other side of town so that was out the window. The other one was the middle of town so that was out of the question. Cause of safety, road safety and what have you. It's right smack in the middle. So we only picked two."

Helen's mother

"I had choices but I was just concerned about our winters and stuff like that and him travelling up and down the road, and when there's a school just like ten minutes from us that provides the same at school, curriculum."

Steven's mother

These concerns around travelling were also echoed by some of the young people.

"I didnae fancy travelling to [town 7 miles away] every day."

Darren (15)

"Toby felt he would like to go to the local high school. There's no point him going to another town, for what reason would he do that? And he certainly didn't want to travel any further afield"

Toby's mother

The issue of distance not only raised concerns about the travel for Gareth's mother, but also the matter of liaising and working with the school regarding Gareth's education. She felt that this would be difficult to do over a longer distance.

"[Alternative school] is twenty miles away...so we wouldn't have, I mean and also, you know, we really needed to have continuity with people he did know. So we felt... and also because they are travelling by bus, you know, we obviously wanted him to be as close as possible. Certainly I wouldn't have wanted to try to deal with the school at the distance that the other schools are.....and also because they are."

Gareth's mother

Many of the young people who were attending mainstream schools simply put forward that the school was chosen due to its proximity to where they live. However, often the parents would then bring in other information which suggested that there had been other possibilities but a choice was made that the young person was not part of. For example John's stated that he went to his school because it was the "nearest place", however, his mother expanded on this.

"There were a few schools mentioned, but I think everybody was in agreement that maybe, you know, he, he's got a good group of friends and that was just as important as the school."

John's mother

Where families found that their first choice, their local school, was not accessible to them other factors became influential to choosing a school. Initial receptions at the schools were vital to the impression the parents formed of the school.

"All the children with special needs had packed lunches together in a classroom. And with the SLA. And we said 'well Ellie likes the school dinner.' And they said 'well it would be much easier if she had a packed lunch in the classroom with all the' And I thought well that's not what we are looking for. I can see some parents might be. But it wasn't what we were looking for."

Ellie's mother

“The other two schools that we’d visited, one of them he probably wouldn’t have got in because it was kind of full. The other one we just decided no because we’ve got a really bad reception at that one. As much, come away with the feeling that, you know, she didn’t want him there...so I thought well there’s no way he’s going there, you know, with somebody with that attitude.”

Leon’s mother

Other parents spoke not necessarily about encountering negative attitudes at school, but more about a gut feeling that they got about a school. Choosing the school that gave them the right gut reaction reassured them that it would be the right school for their child. Ben’s mother had chosen between two special schools. Having visited them both she went with her gut feeling.

“Yet [chosen school] is the awfulest looking building, but it was what I wanted. It’s funny that, you can just feel the difference, you know.”

Ben’s mother

Another parent to speak about this was Helen’s mother; again she had visited two schools, this time both mainstream, and felt that either would have suited Helen’s (15) academic and physical needs. However it was a feeling about the headmaster at one school which swayed her decision.

“He gave a talk and I don’t know, just, while the headmaster of the other school was lovely I didn’t know he, you just get a feeling don’t you?”

Helen’s mother

Parents are often influenced by the head teacher at schools as they believe them to be influential on how the school implements the inclusion of disabled pupils (Baker and Donnelly, 2001). In turn they acknowledge this will influence the experience their child has.

The theory of reason-based choice (Shafir et al, 1994) asserts that when individuals are required to make a choice the decision is made based on the dimension they value the most. This applies to all parents in the process of choosing a secondary school. However, for parents of disabled children, the choice is more complex as there are more dimensions to that choice. In this study parents expect their child to

go to a school which can respond to their child's specific needs, and aspire for their child to be part of the community. It was not always possible to achieve both of these desires.

In this situation the sense of belonging to the local community was valued higher than the school being readily accessible, as seen in Nathan's mother's quote. Nathan's mother valued this element more highly than the accessibility of the school. The Disability Discrimination Act has not resulted in all schools becoming accessible, resulting in parents and young people having to make difficult choices, sometimes choosing schools that are less accessible, which runs counter to an assumption that parents will always choose the school with the best access.

Shafir et al (1994) theory also indicates that once an individual has made a choice they must seek a convincing rationale for it. In this chapter we see parents producing reasons to justify their choice, such as travel or a gut reaction to a school.

The findings in this study support earlier work into parental choice of secondary school which illustrated that parents of non-disabled children base school choices on location (Bast and Welberg, 2004), and rarely make requests for their child to attend a school outside of their local area (Echols and Willms, 1995). Thus in this work these parents are also basing their first choice on location, although for some parents they will not succeed in achieving this for their children.

The theory of reasoned-based choice is somewhat limited as an approach to understanding choice as it does not consider the social context of making a choice. Although the dimensions parents valued were socially constructed the theory does not account for parents existing in social arenas, and thus understanding how they make choices requires the consideration of all their personal resources (Bowe et al, 1994). Bowe et al (1994) put forward a '*landscape of choice*' as a means of understanding how choice is made which is much more focused on the social aspects of choice. This landscape is impacted on by the lived environment, finance and knowledge of how the system works (cultural capital), local circumstances, as well as class, gender and race. In order to understand parents' choices we cannot lose sight of all of these issues, which must be considered in context.

Although Bowe et al state that class impacts on decisions, and Echols and Willms (1995) found that individuals of a higher socio economic class were more likely to make school choices. In this work there is no data to suggest that choice was related to social class. This is interesting as it would suggest that structural barriers reduce the influence of social class on choice. The ASL act tries to remove barriers to learning including the issues of social class.

The young people also aspire to express choice with the view that they would be going to a specific secondary school, as their friends would be doing.

In discussing school choice it becomes evident that some young people were not party to some decisions, and were unaware of the actions their parents had made to ensure they were in a specific school, as seen with John and his mother. Here many young people saw themselves as normal and as making the transition in the same way as their non disabled friends, they were unaware of the debate that had gone on about them. The ASL act however calls for decisions to be made with the young people, which may impact on their experiences of future transitions.

Whilst making the choice of secondary school we see parents again experiencing attitudinal barriers to their child attending specific schools. Some parents discussed how schools they visited reinforced segregation by excluding disabled pupils from participating fully in school life. Such attitudes contravene policy such as the Education (Standards in Scotland's Schools Etc) Act (2000), DSPERA, and the ASL act, and should not be occurring within Scottish schools.

5.3.3 Making choices

In making the choice of which secondary school to send their child to there were some parents who fought for a specific school and achieved this, whilst there were others who lost this fight.

Most parents felt that they had a choice of secondary schools, and that they were able to make the final choice of school. In some cases the parent's final choice was different to the opinion of the local authority, as Freddie's mother experienced. For

most of these parents a process of discussions resulted in their child attending their first choice of school, which is what happened in Freddie's case.

"They quoted a part of the Education Act, which was that the school [the parents wanted] doesn't meet Freddie's abilities.....and when I went down...I was sure that it wasn't right for Freddie before I went down, just from what I knew of the school; but when I went down, then I was convinced 100% that it wasn't right for Freddie...I just asked around people who had been in that situation before, and put in the appeal. I had actually went ahead with it...it is quite straightforward. It probably would have become more difficult but I didn't need to go that far."

Freddie's mother

Only Victoria's mother felt that the choice she and her husband had made was not listened to. Eventually she gave in and sent Victoria (15) to the school being suggested by the local authority.

"I went to see them [school B] and we hated it. And we said like point blank that she's not going there. And we looked at [school A], we looked at [school B], and it was [school A] was the one school that we wanted her to go to...but the education board said 'oh it's not appropriate for her' and like...she's kind of, there was no way she was going. We actually got the letter that I sent to education which I think is up the loft now right enough. Just kind of saying that I was really unhappy with the school, and that the things that I'd seen in the school was like a disgrace and all this kind of stuff...so eventually I kind of reneged and said 'we can try it [school B] and see how it goes and things.'"

Victoria's mother

Other families discovered that the choice of secondary school had been taken away from them. Some parents in particular felt that they had no choice of school for their children due to where they lived.

"In this area that we're in if there is, there's no point in thinking is this okay, is it good enough, because there is no choice. It's that or nothing."

Toby's mother

"There isn't choice for him, its [town] High School".

William's mother

“He’s going to [secondary school] which isn’t the best school for him, but it’s the best one in our local authority. We’re actually on the border of [district], so there’s [alternative school], which is not much further down the road and it’s actually much better equipped but, because it’s a different local authority.”

Harry’s mother

Other parents felt that their choice had been taken away due to the poor access at some schools forcing them to choose an alternative school for their children. Both the parents and young people expressed disappointment regarding this. This was something that was unique to the pre ASL group, and possibly a sign of improvement over the past few years.

“It was because...because [local secondary school] isn’t accessible...“yeah, that’s really annoying because a lot of my friends actually go to [local secondary school] now. There’s only like one or two that go to other schools.”

Ellie (14)

“It was the only one wae access for wheelchairs.”

Darren (15)

“I would rather he went tae the local school but...if it boils down to it they were nae doing up that school at the time. And [current secondary school] was mair accessible even without putting a lift in.”

Darren’s Mother

For some young people there was no debate over which school they went to. For these families there was no reason to consider an alternative school as they did not see CP as a barrier to accessing secondary school.

“That’s my designated school for here, so I just went”.

Andrew (16)

“Well it was closest one”

Craig (14)

For Kyle’s mother, who had been part of the local community since she was a child, there was no question of Kyle attending a different school out with the community.

“Well, I attended that high school, my brother went to it, my eldest...he went to it and all Kyle’s pals are going up there. And I don’t particularly want him to go to a special school because he’s already been to a mainstream primary school so I would like him to go there. And if he couldn’t cope, at the end of the day, then I’ll think again but I would rather he had the chance.”

Kyle’s mother

This demonstrates that at this point in the transition, like Thomas (1999) notes, impairment effects do not have meaning at all moments of choice. For these young people their impairment had no influence on the choice they made regarding choosing a school.

This section suggests is that many of the parents are seeking to obtain an element of control over the transition. Research discussed in chapter 3 showed successful transitions involving parents can improve a child’s motivation at school and results in more successful transitions (Anderson et al, 2000, Bastiani, 1983).

Some parents perceived that, due to where they lived for example in a rural community, they had no choice of school. However, this could be because of the value they placed on remaining in the local area. Similarly Bowe et al (1994) emphasises some parents can fight for a choice where they understand how the system works, as we see with Freddie’s mother. However, there were other parents such as Harry’s mother who tried to fight not to go to the local school, and were unsuccessful. This shows that for some parents their rights under the Standards in Scotland’s Schools Etc Act depends on whether they lived in a rural or urban area. This suggests that the need for each local authority to have an accessibility strategy has not resulted in greater choice for parents and therefore young people.

5.3.4 View of special education

Parents whose children attended a special school had a clear view as to why this was an advantage to their children. They felt that their children’s impairment would be obviously different at mainstream secondary school.

“Like ‘oh hi Victoria’ just because she’s in a wheelchair, she’s that little bit different or whatever. They might not be that tolerant when they are trying to do like kind of work or whatever.”

Victoria’s mother

“Certainly, when he was in mainstream, I think that would have been something that would have arisen, definitely. As the kids got older he would have realised more and more that there was big differences between him and the other kids in the class, whereas it’s not such a big issue.”

Freddie’s mother

Parents were also concerned about a perceived culture of bullying at mainstream secondary schools. These parents felt that at special school their children were accepted for who they were.

“There’s a bullying problem in secondary schools, which is a lot lot lot greater than the special schools. And the kid’s that are going to suffer the most are them [disabled young people].”

Ben’s father

Middleton (1999) believes that many parents choose a special school due to the belief that it will reduce the possibility of their child being bullied as Ben’s father has. She also believes that parents prioritise the physiotherapy available at special school, and questions whether parents who are making the choice of special school are fully informed.

French (2003) has written widely on the feeling of being accepted at special school, where all of the school and all lessons within the school are accessible, and disabled pupils are not segregated within a special unit. Parents in this study echoed such ideas, and felt that it was the case for their children.

“What’s Olivia gonna go to a mainstream school for? You know, you can’t... it would be nice if she was integrated, but she’s completely different from everyone else that’s there. That’s just a simple fact of Olivia’s existence. And, in some ways, putting her in mainstream school is denying that of refusing to recognise something like that. Plus (unclear) integrating and having an adult with you all the time – in some cases, a couple of adults. In some ways, she’s even more integrated in special school, because Olivia goes to a class. She goes with an assistant but the assistant isn’t needed at that moment. She can go and do something else. They don’t always have to be there.”

Olivia’s father

“When they say integration and inclusion are they going to be in mainstream classes or in a unit by themselves? So that in effect, you are saying it’s inclusion but are they actually going to be included but within their own little confines or whatever.”

Ben’s Father

From parts of the discourse it would appear that many of these parents reinforced the perception that their child was different.

The parents here have demonstrated concerns regarding the issue of integration. They do not feel that their child would be fully included into social aspects of school, such as fitting in with their peers. These parents view contrast with the views of those parents who sent their child to mainstream school, and also with that of Shaw (1998), who found young people saw inclusion as a way to increase familiarity. Therefore from this work it would seem that much of the fear regarding inclusion stems from adults.

It is evident from the parents quotes above that many who chose special schools did so because they wanted inclusion for their children, and not token integration into mainstream school. This is very clear in Ben’s father’s extract.

Although many of these parents were not opposed to the concept of inclusive education, they felt that currently it was not happening in schools. Many mainstream schools remain segregated with disabled pupils in separate units. In order for inclusion to fully occur in line with policy there needs to be a significant change in attitude by the school and education authority (Davis and Watson 2001).

5.4 “The fact is I probably didn’t take part in the decision.”⁴ – Role of the young person.

There has been more recent shift in thinking which aims to include young people more in decisions which directly involve them. This is inline with policy such as the UN Convention on the Rights of the Child. Involving young people in such decisions also ensures that issues which are a concern for them are addressed. This however does not frequently occur (Morris, 2002).

With regards to the transition from primary to secondary school parents and young people reported that in most cases it was the parents who were consulted and who took the lead. The literature illustrates that young people value making choices about their care (Mitchell and Sloper, 2001) and in particular the varied choice that secondary school gives them (Lucey and Reay, 2000, Ainscow et al, 1999), and would appreciate having a choice related to their education.

The young people played a minor role, with some parents trying to involve them in visiting the school only once they had selected it. Only a few of the young people were consulted by services to discuss the transition prior to it occurring.

“The fact is I probably didn’t take any part in the decision to go to [secondary school].....I really didn’t, not that I didn’t care but I didn’t really...”

Gareth (16)

“It was like mum and stuff who got all the stuff in place, and I was like a normal kid.”

Harry (11)

Some of the young people, like many of those above felt that it was the norm for their parents to organise the transition and to not be involved. This shows that young people are not used to being consulted, and expect their parents to take control.

Other young people felt that they were not involved enough and would have liked to have been more involved.

⁴ Gareth (16)

“A bit more involved...it’s all going to my mum, and I say ‘what happened?’”

William (11)

Like William above, other young people expressed a need to know more about secondary school. The young people felt reassured when they had answers to their questions, and worried when they did not know things.

“I like to know”

Elliot (12)

Visiting possible schools was one of the vital tasks that parents took on independently. Many of the parents felt that the young person was not able to deal with this task as they felt that visiting a number of schools that they would not be going to would confuse them. Once the parents had completed this task many of them took the young person to have a look around the selected school.

“We went by ourselves to start with cause we didn’t see any point in her going and then us thinking it wasn’t right and confusing her.”

Rebecca’s mother

“We didn’t take Ellie when we went visiting the different schools cause we thought that was a bit confusing for her...And we went to [chosen secondary school] and they were very accommodating. And when we went back with Ellie to look round [secondary school] and they insisted that two of the pupils showed her round.”

Ellie’s mother

Some parents did try to include the young person more in this task. Having narrowed the possible schools in the search themselves they then took the young person to visit the remaining schools and made a selection together.

“Well three of us went and had a look and Helen, we went to them both. And we went on open nights when we went individually and we, you know had personal appointments....and Helen liked the staff in [secondary school]!”

Helen’s mother

There were high hopes when starting interviewing that the young people participating would report high levels of consultation with services regarding their move to

secondary school. Literature and policy demonstrates the need to consult with young people, and the advantages obtained from doing so (Davis and Edwards, 2004, McNeish, 1999). However in reality the young people had little control or involvement in the transition, and it was the parents who were involved at this stage.

What is interesting from looking at the role of the young people is that many of them do not see their parent taking the lead as a problem; rather they see it as what should happen, as the norm. We see an example of this in Harry's quote "*I was like a normal kid*".

Seeing parents as the people in authority and as having the skills to make decisions is a common belief held by young people (Mayall, 2002). However, some of young people were beginning to question this norm, and were voicing a desire to participate more, such as William.

It is the finding of this study that there is scope to increase the involvement of young people in decisions being made rather than feeding back everything via parents. This finding is supported by Garth and Aroni (2003) who established that disabled young people wanted to be involved in consultations with their paediatricians, reporting that they wanted to be spoken to and included in decisions. Consultation at this stage would also ensure that the young people have their concerns addressed during the preparation period, and may result in a reduction of fear surrounding the process of transition.

Therefore consulting with disabled young people would improve their transition into secondary school. Consulting in this way could also lead to an improvement in this transition for non disabled young people, and should be adopted as a way forward.

5.5 Chapter Summary

In this chapter the aim was to answer questions pertaining to the important factors that lead to the choice of secondary school, and also what roles the parents and young people played in the transition at this stage.

The key findings of this chapter are:

- Services need to build partnerships with parents and young people.
- Special schools need to share their knowledge with mainstream schools.
- The requirements of the ASL act are not being met.

Partnerships: This chapter demonstrates that parents adopt the role of responsible parenting through seeking information to make informed decisions when choosing a school for their child. The discussion suggests that this information could be improved to make it accessible to all parents and young people to assist them with making this choice. However, if real choice of school is to be available to all families every school needs to be fully accessible.

For some parents their personal histories resulted in them feeling the need to lead their child's transition. It is clear in this chapter that parents exist in social arenas, and their behaviour cannot be removed from the impact of aspects such as the lived environment. Theories which attempt to account for behaviour in isolation are shown in this chapter to be somewhat limited.

At this time some young people expressed the view that during this phase they felt removed from the transitional planning.

Through developing partnerships with parents and young people, service providers can share information and control of the transition. This would help parents and young people build trust with services, which would benefit future working. Partnership working is also in line with the requirements of the ASL act. The need for such partnership working is a key theme throughout later chapters in this thesis.

Knowledge transfer: In this chapter some parents felt that within mainstream schools their child could not be included, and as a result they opted to send their child to a special school.

Other families found that mainstream schools saw disabled pupils as a homogenous group which reinforced inability. Mainstream schools need to work with disabled

pupils on an individual basis to identify if and what support they would like to remove barriers they encounter. Through working with disabled young people inclusion and not integration can take place.

This chapter argues that, until all schools are fully inclusive, there will be a demand from some parents for special schools. It would help a move towards better inclusion if these schools would share their knowledge regarding the implications of various impairments on education with mainstream schools. This issue is returned to in chapter 8, where it is argued that teachers at mainstream schools would also benefit from specialised training.

ASL: The above findings combine to demonstrate that the requirement of the ASL to remove barriers to schooling, and to involve parents and young people in decision making, is not being met at this stage.

In this chapter there is evidence that parents are confused about the ASL act and as a result are missing out on services they are entitled to. Such services, like a contact person, would help support these families through this time.

The key arguments from this chapter are that the medical discourse used by parents and staff is stopping young people from being involved in the planning of the induction process. As a result this limits the impact of the ASL act on issues of choice during the induction.

Through conducting this work attempts were made to use existing theories to explain the behaviours of the parents and young people, such as how parents made choices. From the data some interesting questions were derived.

When discussing parental choice a question arose as to whether parents make choices based on their own personal histories, or are influenced by what is expected of them. Further work to explore this question would be advantageous to fully understanding the factors surrounding this transition.

In starting the transition process the first activity is to choose a school. At this time parents and young people are also entering the unknown. This is where support and coping mechanisms will be vital to families, and this is what the next chapter moves onto investigate.

Chapter 6

“I think you are anxious when they move up to secondary school.”⁵ – Concerns, coping and support

6.1 Introduction

In the previous chapter it was shown that parents make the choice of which secondary school their child will attend. This is the first major activity of the transition.

During this preparation time many parents and young people will experience concerns about the move, and will try to develop methods of coping with these concerns. Throughout these early stages of the transition support from services will be important, as will the provision of information. This was demonstrated in the previous chapter through parents seeking information early on in the transitional process.

There are three key areas addressed within this chapter; the concerns expressed by the young people and parents, the development of coping skills, and the provision of support and information at this time.

The first area to be addressed is the concerns the parents and young people have about the transition prior to making it. The transitional concerns of the young person have been widely reported in the literature. However, little has been done to discover the concerns of disabled young people or parents.

“6.2 “I felt worse sending her to secondary than I did primary.” – Concerns’ demonstrates that parents have worries as well as the young person. Throughout this section it becomes evident that both parents and young people have similar concerns about transition.

These concerns focus on social issues such as friendships and independence, mobility issues such as concerns about accessibility, and structural issues such as

⁵ Peter’s mother

time tabling and moving around the school. Some of the young people were also concerned about the increase in work load at secondary school.

It was disappointing to find in this chapter that many of the young people in the pre and post ASL groups had similar mobility concerns. Such issues should have been addressed in the accessibility strategies implemented by local authorities under the Standards in Scotland's Schools Etc Act.

Interestingly this section clearly demonstrates that the main concerns of the young people are with mobility issues. Predominately the literature has highlighted bullying as the main concern, through work such as Stradling and MacNeil (2000), Kvalsund (2000) and Zeedyk et al (2003), and this was put forward as possibly being the case at the end of chapter 2. However in this chapter, it is established that for these young people bullying is less of a concern compared to mobility issues.

Here it would appear that the young people are worrying about the lived experience, which are problems they know are a reality such as accessibility issues, rather than potential negative occurrences that may happen, like bullying. Although some young people did refer to potential name calling, discussions about bullying tended to be more hypothetical where as those surrounding stairs, using the lift, or carrying extra school materials around were a reality and caused concerns for the young people. This is a new contribution to our knowledge of the transition.

This work concluded that as discussed by Thomas (1999) there is a tension between disabling barriers which are property related, and those which are attitudinal. In order to move forward as much emphasis needs to be placed on property barriers as there is on attitudinal ones.

Further, it is concluded that through building partnerships between services, parents and young people such concerns can be addressed. This may be achieved once the collaborative working ethos of the ASL is implemented.

In this section some young people stated that they had no concerns at this time, and explanations are discussed surrounding this issue. Once possible conclusion put

forward is that at this stage the young people are yet to develop the positive language to discuss impairment, as Connors and Stalker (2007) state disabled young people often lack such language. Later in chapter 8 we see that young people base choice on experience, spaces of dialogue are required for them to discuss choices in relation to the ASL act.

Having illustrated that both parents and young people have several concerns prior to moving, the next section within this chapter moves onto address how they cope with such concerns.

One of the key coping mechanisms is represented in the section title, '6.3 "*It's like starting from the bottom all over again*" – *Coping, the value of experience.*' The majority of parents reported drawing on their previous experiences to cope with the transition. It is also shown that the young people seem to use a similar method by recalling experiences from primary school, or from peers moving to secondary school. Again little work has been published looking at this area.

This chapter concludes that professionals need to work with parents and young people to alleviate these fears. Within this chapter there is evidence that some parents are aware that they may be perceived by service providers as being over dramatic, but acknowledge that they must also be prepared to work with services to address both the positive and negative issues of the situation.

It is put forward in this section that services could consider working with groups of parents, which could result in the development of support networks for parents. For some young people their peers play a vital part in their school life and involving them in the planning of the transition could be a positive move forward.

This work concludes that as parents draw on previous experiences to cope with events, it is possible that in the future this transition into secondary school will be drawn upon. Therefore through ensuring this transition is a success it may be possible to aid future adult transitions.

The final key area to be addressed is that of support and information. This section looks at how parents and young people are supported at this time, and what information they are being provided with.

This section, '6.4 *"Well, last night my Mum told me a lot about it." – support and information*', shows that most of the support and information at this time is aimed at the parents. The heading draws attention to one of the key findings of this section. Despite most information and support being aimed at parents, young people also need it and tend to rely on their parents for it.

Throughout this study there is evidence of how the secondary environment promotes the independence of the young people, which they themselves value. It is concluded that more effort needs to be made to develop materials which are accessible for young people, and also that any developments introduced by the ASL act need to directly involve young people. Thus allowing young people to become independent and plan their futures.

A further conclusion made in this chapter is that of how parents strive to control aspects of the transition, and seek information to feel in control. This may be problematic to the implementation of the ASL act as it encourages control to be shared between services and families. It is therefore important that services do include parents in the transition process to open dialogue which can lead onto the sharing of control.

This section also demonstrates how parents want support from services that know their child, and value the relationship they have formed with such people. With regards to information most parents felt that there was a need for additional information regarding the transition, which is similar to previous research discussed in chapter 1 regarding parental information needs, such as Sloper (1999).

Thus the key questions this chapter sets out to answer are what concerns do parents and young people have prior to the transition, how do they deal with any concerns, and finally what is the level of support and information provided. These questions will

be answered through using the data from both the parents and young people in the pre ASL group and also those in the post ASL group.

6.2 "I felt worse sending her to secondary than I did primary."⁶ – Concerns

Concerns prior to moving to secondary school have been widely reported in the literature and were expressed here by many of the families. These families spoke about concerns which were mainly linked to the physical and social environment of the school and were less likely to be academic in nature. This is something that has been previously reported with non disabled young people (Zeedyk et al, 2003, Ross et al, 2006).

Both the parents and the young people spoke about similar concerns at this time. Research to date has mainly focused on concerns reported by the young people, with little known about the concerns of the parents. Zeedyk et al (2003) however did ask parents of non disabled children about their concerns regarding the transition to secondary school. Zeedyk et al found that both the parents and young people independently reported similar concerns, thus supporting the findings of this work with parents of children with CP.

In this study, parents of young people attending mainstream schools reported more concerns compared to those whose child was attending a special school. Some of the parents however reported that they had no concerns about moving into secondary school. This is something that Zeedyk et al (2003) also found in their research. The main reason parents here gave for this lack of concern was that they had previously experienced the transition with other children and so were not worried the second or third time around.

"I'd been through it all before, well a few times before, wae wains going from primary to high school"

Darren's mother

⁶ Helen's mother

Some of the young people also reported having no concerns at this time. Indeed some of these young people spoke about positive emotions instead, such as being “happy” (Kyle, 11) or “excited” (Elliot, 12), rather than being worried about the move.

“I just feel more grown up at high school than I could be at primary school”

Elliot, 12

“It’s just ‘cos I don’t, um like the school I’m at now. ‘Cos the playing field isn’t that good.”

Kyle (11)

Other young people reported feeling a bit worried at this point and they went onto speak about specific concerns.

“A wee bit, um like, a wee bit worried, yeah.”

Kerry (12)

Thus clearly both parents and young people experienced some concerns at this time. There now follows a detailed discussion of these concerns.

6.2.1 Getting around

One concern for young people attending mainstream school and their parents, in contrast to those going to a special school, was the issue of access to the school, in particular moving from class to class along with other pupils. Access was of a particular concern to parents of young people who were wheelchair users.

“I think I would use my wheelchair more than I would walk...Because at primary school, like the one I’m in now, I walk with crutches, but I don’t walk with my crutches at, at high, I probably won’t walk with my crutches as high school that much.”

Elliot (12)

“I was just more anxious at how Peter would manage to get to class to class.”

Peter’s mother

“People pushing to get into the class”

Harry (11)

“The sheer mass of people on the staircases that worries me about her moving about”

Kerry’s mother

Concerns about getting round were common to young people and parents. They persisted despite policies such as the Standards in Scotland’s Schools Etc Act (2000) coming into place since the transition of the respondents in the pre ASL group. It is disappointing that young people in the post ASL group had similar concerns to the pre ASL group when local authorities should have addressed such issues in the accessibility strategies.

Another concern relating to the physical environment was the size of secondary schools which tended to be much bigger than primaries. Earlier research with non disabled young people has highlighted that they tend to worry a lot about the size of the school (Stradling and MacNeil, 2000, Kvalsund, 2000, Anderson et al, 2000). One of the issues relating to this was the concern of getting lost (Zeedyk et al, 2003). Similar concerns were reported in this project by both the parents and young people.

“More for the sort of safety side, because primary to nine hundred and thirty pupils, you know, a high school.”

John’s mother

“It was a big school so...I was scared of getting lost and silly things like that.”

John (15)

Concerns pertaining to access and mobility tend to be underplayed in the literature in favour of discussions concerning bullying (Stradling and MacNeil, 2000, Kvalsund, 2000). This highlights the tensions that Thomas (1999) discusses between disabling barriers that relate to property and those that relate to attitudes. It is the finding of this study that as much emphasis needs to be placed on property barriers as attitudinal ones.

6.2.2 School structure

Along with concerns regarding access and the size of the school, the young people and their parents spoke about concerns regarding the structure of the school. This

included more lessons and a heavier work load, new teachers and the ethos of the school.

With regards to teachers, concerns were linked to there being an increased number of teachers, and to the possibility that not all teachers would be aware of the young person's impairment. It was mainly the parents who spoke about this concern.

"The number of teachers that would be involved. Whereas with one teacher at primary school, obviously it's much easier to build a relationship and for that teacher to be aware."

Matthew's mother

"I think really your main worry is that they are going from somewhere that they are comfortable. Everybody knows them really well. And like you are so, you are happy that the people that are working with her know her inside out.... We felt that was, that was our main concern was that, you know...how was she going to take it working with new people."

Rebecca's mother

In contrast to their parents many of the young people reported looking forward to the new teachers that they would meet at secondary school. Zeedyk et al (2003) in their work also reported that non disabled young people looked forward to meeting new teachers.

Abbi: *"What sort of things were you looking forward to [on starting secondary school]?"*

Helen: *"Making new friends and seeing all the different teachers."*

Helen (15)

Although parents and young people share many of the same concerns they have very different ideas regarding other aspects. Young people were more likely to mention particular issues such as subjects becoming more difficult, homework and there generally being *"a lot more work"* (William, 11). This highlights the need to speak to the young people directly to obtain an insight into their world, and to not assume that their parents can speak for them. This means that any new structures resulting from the ASL act that promote dialogue will have to also include young people as active participants.

A number of authors argue that the ethos of secondary education differs from that of primary school, as it is directed towards independence and future adult life (Backe-Hanson, 2002, Day, 1996, Baker and Gaden, 1992). This independence was causing worry for some of the parents, and was more likely to be expressed as a concern by parents of young people attending special schools.

“I think it was the fact that you, instead of having a full time helper he was suddenly going to be sort of in classes where he didn’t have somebody sitting next to him to help him.”

Ben’s mother

For Steven’s mother the heightened emphasis on independence and maturity that the move to secondary school brought had led her to think about the future. Steven (14) attends a special school which caters for young people from 4 to 18 years old and so his mother did not feel too anxious about him progressing onto the secondary phase at the school. However, it was pointed out to her at several planning meetings that he was moving on and that it would be the equivalent to moving into secondary school in mainstream education. This made her think about the move less in terms of education and more within the social context.

“Just mainly because you realise, and as I say it’s purely, not, I wasn’t even thinking about it from an educational point... But more as a mother, I was thinking he’s twelve an he’s going into high school, and it’s just like where have the years flew by, and where have they went to? And then you start thinking about he’s getting bigger now, he’s getting older and what does the future hold for him, and what does that mean for him. And so you start thinking about all these kind of things as well, which you don’t really think about when they are younger.”

Steven’s mother

The school’s policy on including disabled pupils was also a concern for some parents, such as Toby’s mother. Toby (14) lives in a fairly rural part of Scotland, where there is an allocated secondary school for each area. His mother felt that there was no choice of school available to them and that he had to attend this allocated school. She had heard rumours of the school having a poor record on including disabled young people.

“The school doesn’t have a particularly good reputation...I had heard from other parents of children, not with cerebral palsy, but with other conditions that...basically it was a waste of time, you know, that the school...did nothing. They weren’t interested, they didn’t care.”

Toby’s mother

Finding out such information was particularly worrying for her, especially as she felt that they had no alternative available to them.

Thus prior to moving to secondary school there are a number of concerns which are linked to the structure of secondary schools. These involve the increased number of teachers, the independence it promotes and the implication of this for disabled young people. Mayall (2002) indicates that such fears are usual for parents. This suggests that professionals who are involved in planning inclusion need to work with parents to minimise their concerns and fears. Later in this chapter we look at the forms of support parents receive and the extent to which this is achieved.

6.2.3 Bullying

One of the major concerns reported in the literature relating to this transition is about bullying taking place (Zeedyk et al, 2003, Strandling and MacNeil, 2000, Kvalsund, 2000).

This was not the case for families in this project. When asked about their concerns prior to moving the parents and young people were more likely to name physical aspects, such as worry about crowds or stairs.

Parents were more likely than the young people to go on and discuss bullying as an additional concern. This is possibly an insight into the different perceptions the parents and young people hold. Research previously published has emphasised how parents hold bullying concerns (Connors and Stalker, 2007, Nadeau and Tessier, 2006).

“I mean, high school’s hard enough for any child, let alone one that’s obviously gonna stick out from the crowd in a lot of ways...I’m not worried academically...it’s just more the other kids, I suppose.”

Harry’s mother

“Just with him fitting in, I get worried about him getting bullied or anything. That’s the main worry...A lot of people laugh at the way he walks and that.”

Ian’s mother

Many parents mentioned such concerns in a way that suggested they expected bullying to happen as part of the norm because *“kids will be kids”* (Andrews Father).

“Just the normal, you know, the name calling and, you know, people. Just kids being kids”.

Craig’s mother

There is a question of whether this was related to the child having CP or whether all parents had this concern. Revisiting the transcripts it became clear that many of the parents did feel that the bullying their son or daughter might encounter would be related to them having CP, as Ian’s mother demonstrates in the quote above mentioning other children laughing at his gait impairment.

“I mean, alright Andrew was easier pushed over and he’s a wee bit wae the balance.”

Andrew’s father

“Kids who are, you know, who do name call, they are ignorant because they don’t know why. And if they did know why that would maybe help them, you know.”

Craig’s mother

Parents of children who would be attending special school were less likely to have concerns pertaining to moving around the school or bullying. As seen in chapter 5, one of the reasons parents gave for choosing a special school was their perception that there would be less bullying there.

Bullying of disabled young people often focuses on how they appear different to others. Middleton (1999) warns that this type of bullying can be particularly

destructive to the young people as it can lead to them internalising negative feeling and ultimately lead to a reduction in their self worth. This is because the young person themselves may acknowledge the difference the bully highlights, and become focused on this one aspect of themselves.

Despite many parents linking bullying to CP, Gareth's mother felt that bullying concerns were universal to all parents and young people regardless of whether the individual has an impairment.

"You were a bit, you were a bit worried about that [bullying]. I suppose, you know, everyone is. And I remember Mr Jones saying that that's always the question he gets from anybody not just people with different abilities."

Gareth's mother

Although the young people did not discuss bullying concerns as much as the parents, some did make references to it. Again there was a sense that bullying was part of the norm, and young people in mainstream schools were more likely to discuss bullying compared to those in special school.

"Well I was kind of worried in case something happened [bullying]. But nothing did happen...in the back of your mind you always think in case something happens. But nothing did happen, so it was alright."

Andrew (16)

"Sort of perceived culture of head down, you know, bullying, head down the toilet sort of thing."

Gareth (16)

"Bog washing...it's when they sick ya head into the ... and then flush it."

Kyle (11)

These concerns about bullying arose from the young people feeling vulnerable on making the transition. This vulnerability stemmed from the change in their status at school. They were going from being the oldest in the school in primary to being the youngest at secondary school which was a much bigger school.

“Like being the babies that were going to high school, it was a bit worrying. I know that like all the like rumours and that that were going round, with the P7s were whatever, false cause there was no way they could be true. Well, they could have been true but personally I didn’t think they were true.”

Craig (14)

It is interesting to hear how Craig and other young people were concerned about being considered the young children in school, whilst in contrast we saw earlier in chapter 5 that their parents are concerned about their children growing up. Involving the parents and young people in dialogue, as recommended by the ASL act, throughout the transition could lead to these concerns being addressed.

It is important to realise that this study captures a snap shot of the young peoples’ lives and discussion concentrated on experiences during transition from primary to secondary which is a very short period of their school life. It may be that bullying was more prevalent in later years.

When thinking about the issue of bullying, I did wonder how forthright the young people were being. Research, such as Strandling and MacNeil (2000), and Kvalsund (2000) provide evidence that non disabled young people widely report bullying as being a major concern prior to the transition. I questioned whether the young people here were withholding this from me and, as Andrew described, it was in the back of their minds and not something that they wanted to address.

Through later discussion on providing advice to other young people starting secondary school, which I’ll discuss later, many of the young people did make reference to bullying, establishing that they did see it as a possible issue.

For these young people the main concern seemed to be the physical environment of the school, the access around it and the practicality of moving from class to class. They saw this as a real problem whereas bullying was only something that might happen.

Another explanation for the Pre ASL group being reluctant to speak about their concerns prior to moving is that they felt this time was “ages ago” (Nathan, 14), and

found it difficult to place themselves back in that time and recall what they had been thinking and feeling. Some of the young people may also have been reluctant to disclose any concerns because of embarrassment, as John (15) demonstrates when he refers to his concerns before moving as “silly”.

In chapter 7 accounts are given by the young people regarding bullying initiatives at secondary school. The impact of similar initiatives at primary might also have contributed to the lack of concern showed by the young people pertaining to bullying.

There was a clear difference during this phase of the transition between parents who had previous experience with children making the transition and those for whom this was their first time. The parents who had previous experience were more likely to report that they had no concerns during this time. This would suggest that concerns could be related to whether the individual has prior knowledge of the transition process.

It could be proposed that, for those parents for whom this was their first experience of a child making the transition into secondary school, their lack of knowledge about the reality of secondary school resulted in a feeling of a lack of control. Control allows an individual to form action-relevant schemas, which are important to planning behaviour and coping (Mandler, 1990). In particular Mandler (1990) noted the importance for individuals to have control during transitions, as it reduces the negative impact of the change. However, the aim of the ASL act is to encourage collaborative working where ‘control’ is shared by service users and providers. Writers such as Moss and Petrie (2004), who advocated partnerships between services, parents and young people, believe this would be more advantageous to assisting parents cope with the transition.

Having no past experience of transition resulted in the parents and young people being unable to picture how they would cope with moving around the school, lessons, and the increase in pupil numbers. They were unable to plan for dealing with these issues, and so they developed concerns linked to them.

Some of the young people reported having no concerns at this time – these were the ones who thought it normal to go to their local secondary schools. When Zeedyk et al (2003) found similar results amongst non disabled young people they associated it to ‘a show of bravado’ (p 72), and it is possible that this is the case here also, particularly since many of the young people were males. However it is also possible that, at this time, impairment effects are not relevant, and as Thomas (1999) suggests impairment does not always lead to concerns. That is, prior to the young people gaining experience of secondary school through induction days, they cannot perceive the barriers they may encounter.

As Connors and Stalker (2007) note, young people often lack the positive language to discuss impairment. Here it is not so much the language, but experience which is the barrier. It is important to note that a lack of experience of transition was also an issue for the parents.

Through the discussions with the young people there was an awareness of their impairment, and how this may impact them at secondary school. However, this did not result in the young person seeing themselves as being significantly different from their peers and so vulnerable to bullying.

The parents however would have experienced a wealth of medical input into their child’s impairment (Swain and French, 2000), which could have resulted in them having more of an aware of the difference between their child and others and therefore as seeing bullying as something that was likely to occur.

The parents’ greater experience of society and discrimination compared to the young people, may contribute to why they feared their child being bullied. Such fears are inline with writers such as Thomas (1999) who highlights the attitudinal barriers disabled people encounter. In reference to the ASL act, if inclusive education is to be achieved, such fears need to be addressed by professionals.

The challenge is to achieve a balance where inclusion and removing difference is achieved, whilst recognising the physical and social challenges that do require adaptations and change. In order to achieve inclusion it may be necessary to first

recognise specific needs and actions and to address them. For example, for Elliot his CP makes him tired, it is essential that the school acknowledges this and addresses it, in order for him to participate in school life on equal terms with the other pupils.

What was interesting about the concerns voiced by the parents was the realisation that the transition marked a real change in the parents' lives. Many parents spoke about how this move signified that their child was growing up and resulted in them reflecting on their parental role.

Through the methodology used in this project, it was possible to observe a difference between the accounts of concerns given by the parents and young people. Whilst they both voiced similar concerns around mobility issues, parents were more vocal about their concerns and tended to have a greater number of them. This could be due to the parents being more comfortable with the interview situation, and so discussing issues in more detail. Alternatively it could be due to the parents having a heightened involvement in the transitional process and so they were more aware of situations that might arise.

What is clear from this work is that parents and young people have a number of concerns prior to making the transition. How they cope with such concerns will be discussed in the next section.

6.3 "It's like starting from the bottom all over again"⁷ – Coping, the value of experience

Transitions have been identified as times of increased stress in families (Simmons and Blyth, 1987), with a number of reports such as the Health for All Children and policy like the Education (Additional Support for Learning) (Scotland) Act (2004), which have recommended a focus on improving transitional experiences. This transition into secondary school increased anxiety for some families.

⁷ Zack's mother

"I think you are anxious when they move up to secondary school. You definitely are anxious"

Peter's mother

"I felt worse sending her to secondary than I did to primary. Just because I thought you expect them to get looked after in primary but you don't in secondary".

Helen's mother

Parents had to develop coping skills to deal with their stress at this time. One method used by parents was to draw on past transitional experiences and what they had learnt from these experiences. For example having had to deal with issues during the transition into primary school was beneficial to some parents at this time.

"We fought a wee bit for them [nursery] to take her because, obviously, she was at an age where she was starting...she was four years old and should have started nursery...And at the time, with her being our first child, we hadn't had any experience beforehand to base it on so we found that you didn't know how loud to shout, as it were."

Kerry's mother

"Even going up to secondary is maybe the same as when your child goes up to primary school. You are anxious on the first day they go up to primary and you are exactly the same the first day they go up to secondary yeah. It's just the exact same feeling I think".

Peter's mother

For these parents reflecting on the move to primary and how that had turned out, and then comparing it to how they felt about their child starting secondary school, was reassuring and helped them cope. Experience of having other children who had previously made the transition was also helpful to other parents.

The young people were less likely to directly discuss this method as a way of coping. However many of them did make reference to the similarities between starting secondary and their experiences of primary school. Some of the young people also recalled the transitions of older siblings or friends.

“Cause I would like say to people, they would be like ‘how was your move to high school?’ And I would be like ‘it was much better than primary school.’”

Ellie (14)

“He was saying that earlier on, it’s [moving to secondary school] like starting from the bottom all over again.”

(Zack who’s also in the room nods in agreement.)

Zack’s mother

Negative transitional experiences were influential to Victoria’s mother. Victoria (15) is attending a special school which is for 5 to 18 year olds; she started at the school mid term due to moving house. Her mother felt that when it came to the transition into secondary education she learnt from this earlier school move. She chose to remain within the same school for secondary, but dealt with the transition into the secondary part of the school by changing the way that she communicated with the school.

“Yeah, because of the hassles that we’d had kind of before, like the transition. And...once we got used to the school we did feel that there was things within [current school] that were much better than [previous school]...We transferred from [previous school] to [current school] and I felt as though I just winged a bit. You know, I’m really not happy with this and you, you must do something about it. There’s like kind of overdramatic mother, kind of therefore I was a bit more kind of professional...so I think I was more able to put it across that way so I didn’t feel as intimidated, felt more supported... I think changing from being negative ma ma ma type thing to just kind of being positive while...’yes I’m happy with this but only if.”

Victoria’s mother

An important aspect which helped parents was the feeling that their child could cope with the transition themselves.

Some parents involved in the project had deferred sending their child into primary by a school year, whilst other parents, like Peter’s, chose to hold their child back from secondary for the year, because they felt he required additional time to develop and thus be ready for the move.

“I mean [the school] were pushing Peter towards moving the year before, but we weren’t kind of...we didn’t think he could move, you know. And they felt that he was going to be a young eleven to go the year before, you know, I mean Peter is able to communicate and tell you if there’s something wrong with him obviously. I mean most, all of the ones up in [secondary school] can do that anyway, but it was just we felt, you know, the other year wouldn’t have done him any harm. But we kept him back...I don’t think he would have adjusted as easy if he had went the year before”.

Peter’s father

In order to cope with the increased anxiety both the parents and young people drew on past experiences. When these experiences were negative, parents were more likely to assess why this had been the case and what they had learnt from it. They then went on to apply this knowledge to the current transition. Parents were also less likely to be worried about the move if they felt that the young person was psychologically ready. Both parents of young people in mainstream and special education spoke about these coping mechanisms.

Within this research several parents clearly state that they are drawing on past transitional experiences, such as the move to nursery or primary school, to help cope with this transition. When faced with this transition the parents draw on previous experience to appraise the situation and use this knowledge to help them to cope.

Brammer (1992) describes a process of restorative practice, which is a process of positive self-talk, involving an internal dialogue of positive statements reassuring, that coping is possible. As seen with Peter’s mother who reassures herself that the feelings of moving into secondary school are the same as the feelings she had when he was starting at primary school.

To some extent this appraisal process is also carried out by the young people. Although these young people do not recall previous transitions, they do draw on their personal experiences of coping at primary school.

Such processes explain the parental method of coping through focusing on the individual’s actions. In contrast Kerr and McIntosh (2000) propose that individuals use a group network to obtain emotional support, such as their partner, family, friends and other parental groups. Many multiagency approaches promote group

support and dialogue between parents, professionals, and voluntary groups (Moss and Petrie, 2004). The parents in this study did not discuss group networks, and this raises the question regarding how successful the ASL act approach in calling for multiagency working has been. For parents to benefit from positive reinforcement from others the networks have to exist, be visible and easily accessible.

It is interesting to note that parents identified drawing on their past experiences to cope at this time. There has been a tendency in the literature to disassociate such experiences, and to consider each experience in isolation (for example Galton 2000, Day 1996). However, from what the parents are saying, if the transition into secondary school is a success, then the transition into adulthood is also more likely to be a success as parents and young people can draw on their earlier experiences. Morris (2002) has highlighted the lack of support there is for adult transitions. In order for these adult transitions to be a success, service providers need to ensure that earlier transitions, such as that into secondary school are a success. Service providers must participate in dialogue with young people and their parents to discuss the pros and cons of earlier transitions and how these can be addressed in the next transition.

6.4 "Well, last night my Mum told me a lot about it."⁸ – Support and information

Previous research has highlighted how transitions are stressful times for families (Pratt and George, 2005, Hanline, 1991), and so having support is important to help families cope.

A major part of this support is through the provision of information. Parents in particular value information, seeing it as power and as an aid to making informed decisions (Miller et al, 2003, Pain, 1999). Young people also expressed a desire to have knowledge about secondary school.

6.4.1 Prior knowledge – Young people

As the young people in the post ASL were going through the transition it was possible to find out how much they knew about secondary school prior to going.

⁸ Freddie (12)

Most of this information came from informal sources and could be seen as 'common knowledge'.

It was interesting to find out what the young people were focusing on. The main point that the young people reported on was the size of the school with most of them describing it as "big" or "massive".

Another common piece of knowledge they had was that they would be moving classes. The knowledge that they recalled was linked to their concerns about mobility. Many of the young people reflected on how they felt this information would impact on them at secondary school.

"It was more exciting than primary school. Because it's a lot bigger."

Kerry (12)

"I think I would use my wheelchair more than I would walk."

Elliot (12)

"...more faster, having to change about, changing about"

Kyle (11).

Some young people also knew about the pending induction days, which they were all looking forward to. Elliot (12) for example, described what he understood an induction to be like.

"They give you a look at the work you usually do, when you went there for your little visit... But not, not like for as long as we usually say do it there for, full time. But you do it for a wee while. And then you do a little bit more another day, so you do more that just one little bit of a lesson thingy...."

Elliot (12)

Induction days at this point were seen as a good thing and something to look forward to. Elliot (12) went onto describe why.

“Because it gets you used to the, the school. Rather than just not, not wanting to go there. Or even over the summer. I don’t think that, I’m just saying it, but you could, you could um go through the summer holidays trying to know what its like.”

Elliot (12)

Many of the young people were aware that they would be put into new classes at secondary school. Many of them had been given the opportunity by their school to nominate names of friends that they would like to be placed with. It was not clear whether these young people had been specifically asked this due to their CP or whether all pupils were given this opportunity. It is possible that the secondary school felt that having a familiar friend would be a support to the young person. Having made this request the young people were anxious to find out if this had been granted or not.

This demonstrates that some schools had an awareness of the value of peers when making the transition, which earlier work has also noted (Weller, 2007, Lucey and Reay, 2000). Interaction with peers is a central aspect of school life (Rabiee et al, 2005, Pellegrini and Blachford, 2000, Shaw, 1998), therefore although peers may not be central to the transition it would be beneficial if the implementation of the ASL act could incorporate the role of peers into the planning of this transition.

6.4.2 Information

Parents require information on transitions (Pain, 1999) and in particular information on the types of school which are available to them (Mollard, 2003). Work by Stradling and MacNeil (2000) demonstrated that parents liked receiving information on the chosen secondary school. Here parents’ experience of information was variable and satisfaction depended on what was covered by the information provided.

The most commonly mentioned source was the school prospectus. This is an improvement from earlier work carried out by Worsley (1986) which reported parents wanted a school prospectus during the transitional period. The prospectus provided many families with information on the school, however many regarded it as being fairly general.

Gareth's mother: *There was a, a brochure... Yes, and I mean, you know quite a bit detailed which...*

Abbi: *Did it answer the questions that you had?*

Gareth's mother: *Yeah, I think so, in general terms, yeah.*

Gareth's mother

"We only got information like the names of all the teachers, what our timetable would look like. That's all we got really. We never actually got... what they do."

Darren (15)

A lot of families reported that, having received the prospectus, there were unanswered questions regarding additional needs these young people had. Both parents and young people felt that there was a need for additional information on top of what they had received.

"You get a prospectus that tells you what are the subjects and stuff and what you can do after school... And what supports are available. But again you get it in more detail when you get there."

Andrew (16)

"It would be very useful if it was also compacted! 'These are all the independent schools and these are all the schools for special needs, these are all the schools that have units', and you know..."

Elliot's mother

Access was an additional issue not addressed by the prospectus. Parents noted that there was a specific need for this information.

"Yeah we get, you know, I mean you get a sort of prospectus, you know, telling you what happens at the school. You know, we've got this, we've got that. I mean the only, the only other thing we had to find out was that Craig needed the lift."

Craig's mother

"There's a guide to [secondary] School but I don't think it has anything about, you know, wheelchair accessibility in it. I can't remember now... It tells you how the day is structured, you know. About the [unclear] office and guidance teachers and canteen and... I'm not sure that that's necessarily going to help a lot."

Toby's mother

“Would have been useful perhaps if, you know, in amongst all the booklets if you were given something that said if you need help with...going to the toilet or if you need help in the class with doing your school work there will be somebody to help you.”

Ellie’s mother

Parents reported that simply receiving the prospectus did not answer all of their questions, this was true of parents with children with all levels of severity. They felt further questions needed to be asked in person at the school. This is inline with previous studies such as Darrah et al (2002), Sloper, (1999), and Sloper and Turner (1992), which reported that families needed to receive more information in order to support their decision making.

When parents received a prospectus which included additional information regarding access, support and facilities they felt satisfied and no longer felt the need for further information.

“There was a section in the prospectus that covered that...It told you what happened in the learning centre.”

Helen’s mother

“I think there was a leaflet. I think we got, you know, and then we got the normal... what’s it called again?...Prospectus and things like that you know...No I think like we’ve had more than enough information, you know...I think it [leaflet] would be something like special needs and your rights or, you know, that sort of thing.”

Rebecca’s mother

One way schools can improve transitional experiences is to include this additional information as standard procedure.

In one instance a parent’s need for more information and a request to the education authority for this in order to make an informed decision was not taken sympathetically.

“I think I knew roughly where to go but it’s finding your way through it. And it’s very easy for somebody in the local authority to say ‘yes these are your rights’ and they present you with...I think when we wanted Nathan to go to [special school] at first and they didn’t want us to go when he was very young. I remember being sent the actual act by the, the director of education. I mean there’s no way I could have sat and read that. And that was obviously an off putting gesture, you know.”

Nathan’s mother

Here it would appear that rather than sharing information in order to work with the parents, the local authority is inhibiting the parent’s ability to make an informed decision. Through the ASL act and the emphasis on education services, parents and young people working together there should be an improvement in the opportunities parents have to make informed decisions.

It was less common for the young people to receive written information at this stage; however some of them did receive a pupil targeted leaflet. The young people who received such information generally found them to be a useful addition to the transition.

“Well we got like a booklet like something like what the school is about and all the teachers that are in the school and like what subject is this and what subject is that. And it was just like the normal basic stuff like when you go up to high school like what pupils want to know about....It was written for like the P6 or the first years coming up and that”,

Craig (14)

“Kind of like, I don’t know, about the classes and things...School uniform...And policies. It was written in quite a child friendly way.”

Ellie (14)

The young people were more likely to report verbal sources of information. Parents were one of the main sources. The young people would ask their parents questions pertaining to the transition, despite knowing that they might not always have the answer.

“Well, last night my mum told me a lot about it.”

Freddie (12)

Abbi: *If you've got a question about what high school would be like who do you ask?*

William: *My Mum*

Abbi: *Your Mum, does she know most things about high school?*

William: *no, but I ask her anyway!*

William (11)

Some parents felt that being one of the main sources of information for their children resulted in them being more proactive in information seeking.

"I mean, I'm quite able to go and find it all out myself and I wouldn't be shy doing it, but I don't know how it would be if you were maybe more inclined to sort of sit back and just let it happen."

Freddie's mother

This emphasises the need for parents to be well informed regarding the transition, which is something young people have previously acknowledged (Cavet and Sloper, 2004).

Along with asking their parents, the young people could also name a range of sources where they could find information related to secondary school. Having such a wide option of sources was beneficial to the young people.

"My friends or something"

Kerry (12)

"Eh, you would, um, tell your teacher, um and they would um put it on a bit of paper and send it up to high school."

Kyle (11)

"Physio who does my exercises and quite a lot of my friends."

Ian (11)

There is the tendency for the ASL act to focus on parents rather than young people; however this study found that both parents and young people need to be involved in the planning of the transition and also need to be kept informed.

There is also the issue when discussing information of who informs the school. For many young people explaining about their CP to different teachers was difficult. With an increase in number of teachers explaining the same issues to all of them can become draining for them as they become impairment focused. For some young people health services were involved with the development of a book which explained about themselves and their CP.

“We made a little book that I take to each of my classes...just to tell the teacher what help I might need and stuff like that.”

John (15)

“They [services] did a book which, I can’t remember the name they gave it, but it told all about Rebecca and how she communicates. The, I think the speech therapist actually made this up, but obviously all the different people that had worked with her put input into this book.”

Rebecca’s mother

These books were made to assist the staff at secondary school to understand the needs of the child; they simplified the medical jargon, which John’s mother felt would have “*baffled*” the teachers otherwise. Other books, like Rebecca’s, provided her with some independence, as she has communication difficulties. This is a clear attempt to attempt to aid the transition for these young people, however the books seemed to be primarily impairment focused and could have benefited from the inclusion of more social aspects. Also the books were aimed at the adults in the school environment, such as teachers and assistants. The young people however valued social interactions and it would have been advantageous if the book had included information for their peers.

6.4.3 Service input at this time

Input from services is vital for parents and young people to feel supported and to have a successful transition. During this transition there is often a plethora of services involved with the young person, which is vital according to work by Sloper and Turner (1992). However, reports from the parents and young people in this project demonstrated that this input was variable, with some families feeling like they

had no support or input. This is despite the ASL act aiming to reduce the variability in service provision.

For the parents the main source of this support was the primary school.

“I think probably we would go to the primary school first, because they have said to us ‘look, if there’s anything that you want to know about the transition, come to us’ and they will find out for us, you know, through the high school.”

Kerry’s mother

Many of the parents felt that the teachers already involved in their child’s education were a good source of support due to their knowledge of the young person. Likewise when services had been involved in the young persons care for some time parents appreciated hearing their opinion.

“The teacher of the link class is the same teacher that Olivia had last year, and we trust her judgment. We like her and we think she’s good with Olivia so her opinion in this regard counted for a lot.”

Olivia’s father

“Just taking advice really from people, and people that I think knew Freddie.”

Freddie’s mother

Most parents reported support from health, education or social services. Very few parents made use of support groups. It was unclear whether this was because parents chose not to use them or whether parents simply did not know about them. The few parents who did access parental support groups found their help to be “*fantastic*” (Freddie’s mother).

Other families felt that they had little input from services at this time, despite services being involved in the young persons care. Some of the parents found the input from services generally had been poor; these parents lived throughout Scotland and were not restricted to one geographical area. They felt that they had been left alone and “*fumbled along*” (Harry’s mother). These parents felt unsure of who they could turn to with questions and to gain support.

"I suppose, if I phoned [secondary school], I'd be able to talk to them there. I would think there would be someone there I could talk to, yeah...hopefully, yeah".

Ian's mother

"Yeah, I had asked a few times, and it was kind of, you know, 'yeah well we'll have to start', you know, it was always kind of 'we will be, we will be', and nothing was ever happening so we just went ahead and done it ourselves."

Leon's mother

"No the whole thing with physio, the therapist...Yeah we didn't get, they didn't have any input in the transition to school."

Gareth (16)

The need for service input and support has been widely reported. In this project what was found was a variable experience, possibly dependant on location. Some families received a wealth of support whilst others received very little.

This could be due to the area the families lived in or possibly that some families were more proactive in seeking and requesting support. Their personal histories with support may have resulted in some families learning the value of becoming more proactive. With the implementation of the ASL act, which aims to reduce the variability and promote services working with families, past experiences and location should have a minimal impact on service provision in the future.

In some cases families felt they had received additional support and input because of the transition.

"O.T.'s a bone of contention because we should get it, but he doesn't...he did recently because he's moving to high school, so we insisted that they have to go to the high school, so they came out then."

Harry's mother

"We haven't had much input from O.T. over the past few years, but they're more prominent now due to changing school."

Zack's mother

Some young people also had input into psychosocial development with a Psychologist being involved in their transition.

“What happened was we had Child Psychology Department as well and they had decided and spoke to Zack about his opinions about where he would like to go...she had Zack in for a meeting last Wednesday and were discussing his fears and his worries and trying to put him at ease a wee bit... I've got my own worries, obviously, but it's quite nice that they've actually spoken to him about it.”

Zack's mother

This case is a good example of multiagency working as advocated by the ASL act; appropriate services were brought in to support and meet the needs of the family during the transition.

Some authors argue that social support is the psychological resource available to individuals (Cutrona and Suhr, 1990). They suggest that there are two types of support: instrumental (practical support and information) and emotional (Cutrona and Suhr, 1990). Doland (2006) refers to four types of support for families; concrete, emotional, advice and esteem. These different types of support have three qualities – closeness, reciprocity, and durability. Social support provides parents with the information and support to feel in control of the transition, assisting with development of coping mechanisms.

Although there is a need to carry out multiagency working, parents wanted the professionals involved in making decisions regarding their child's move to know their children.

“There was reports from everyone at the time. John's physio, the OT report. I'd say it was a good mix of everybody... You have people like child psychologists who turn up at these meetings. And I know for a fact they've maybe met John for 10 minutes in that year, find that come along and give their expert opinions. And they don't know, you know, they don't know the person, you know.”

John's mother

“There was a community paediatrician that assessed him before he went to high school, and just to see if there was any concerns....And then it was a kind of one off so there was kind of nothing then when he was there”

Matthew’s mother

For Matthew’s mother the input from the paediatrician was not valued as the support had no on going commitment attached to it.

The problem with social support is it emphasises the relationship between the service provider and user, therefore if a problem is not resolved it is due to the actions of one of these individuals. In contrast writers such as Thomas (1999) call for the emphasis to be placed on the social context rather than individuals.

Doland (2006) states that there is a need for us to move away from a deficit approach, which views families as a problem, and towards an approach which emphasises the need to build relationships with service providers. In order to achieve the multiagency approach in the ASL, there needs to be a change amongst service providers towards being willing to share power with parents (to achieve reciprocity) and to commit to working with families, which will allow the development of closeness and durability.

For parents that the most valued support comes from an input from services who know the young person. This suggests that parents could have more trust in professionals who know their child, and they therefore value their input more.

Research has demonstrated that, in order to trust services, parents need to have previous positive experiences of them and a shared history with them (Reiss et al, 2005). The degree to which families trust services will impact on their level of satisfaction with the service provision. When new services were introduced during this transition these parents tended not to trust them as they do not always attempt to work with the family and acknowledge their expertise (Reiss et al, 2005). For example in the case of John, the child psychologist had not previously worked with John, therefore there was no trust relationship and John’s mother did not value their input.

Poor input from services had resulted in some of the parents feeling disillusioned and not expecting much help at this time. Some parents chose to access private services so they had more continuity of care. Other parents felt that service provision in general was too far stretched thus reducing the input they received.

“Mainly because of the lack of continuity in the NHS because they can’t guarantee that they’re going to be there every week”

William’s mother

“You should be saying ‘I wonder what we can do to make things better?’ or ‘I wonder who I can write to, to improve this service?’ but, believe me, we’ve done that. And, in the end, it doesn’t make any difference...you know. If I had a pound for every letter I’ve written to someone...I’d be driving a Rolls Royce!”

Olivia’s father

When support is not available, individuals encounter higher levels of stress and are more likely to become dissatisfied with the individuals they perceive should be supporting them. Parents of children with CP showing dissatisfaction with service provision has previously been found in a number of studies, such as that of Darrah et al (2002), Sloper (1999) and Bamford et al (1997). From such work it has been demonstrated that service provision for parents and disabled young people could be improved, in particular with improved support and communication.

This project demonstrated that parents expect, and want, somebody to guide them through the process. When this support is unavailable parents can feel very alone. The advantage of a link person to co-ordinate care was highlighted by Greco and Sloper (2004) and showed that through this method parents felt as though their needs were being met.

6.5 Chapter summary

This chapter set out to identify concerns that parents and young people may have prior to moving into secondary school, and how they coped with such concerns. The issue of support for the family was also discussed. From this chapter the central findings are:

- Both attitudinal and property barriers need to be removed.
- Services should consider working with groups of parents.
- Services need to form relationships with parents and young people.

Barriers: In this chapter it is shown that both parents and young people have concerns which are property and attitudinal in nature. Young people are less likely to focus on worrying about hypothetical situations such as bullying, and worry more about real structural, social, and mobility factors which act as barriers to their full inclusion in school life.

This chapter concludes that equal effort must be made to reduce both attitudinal and property barriers for disabled young people making this transition. This chapter also highlights the tension between removing difference, whilst acknowledging that for some young people physical and social changes might also need to take place for inclusion to occur. This discussion is further developed in chapters 7 and 8.

In order to cope with such concerns parents deploy a tactic of drawing on past experiences. Therefore the lessons parents learn through this transition into secondary school can be put into practice when their child moves out of school. If this earlier transition is successful it will assist parents to cope with the next transition in a positive way. It is concluded that to assist coping to achieve a successful transition, the levels of support and information parents receive could generally be improved.

Groups: Parents feel the need for support during this transition. It is argued in this chapter that if services worked with groups of parents, this could lead onto the development of support networks for parents. This argument is also linked to chapter 5 and chapter 8, where it is noted that when young people are unable to attend the local school, parents often lose their parental network of support.

Relationships: Parents reported that they wanted an input from service providers who knew them and their child. Such relationships result in the development of trust between parents and providers, making it easier to share power. It is argued that

services need to consistently work with the same families, and build a relationship with them in order to successfully build trust and improve parents experiences of receiving support.

As demonstrated in chapter 5, parents are influenced by their personal histories. For several parents their history with services was predominately negative, for example having to challenge services to gain access to primary school. Through building trust between parents and services, parents can begin to think more positively towards services. This can lead to more partnership working in the future.

From this chapter the central argument of this thesis is that young people require more information and in an accessible format, The young people should also be involved in planning. In order for this to be achieved services need to recognise the impact of both property and attitudinal barriers on disabled young people.

This chapter and the previous one have addressed the issues leading up to the transition. The discussion now moves onto the important factors of the transitional activities.

Chapter 7

“Fun, probably the funnest days of school”⁹ – Starting the introduction to secondary school

7.1 Introduction

From the earlier chapters it is evident that choice is an important aspect of the transition. It is the parents who have this choice and who are in control of the transition at the early stages. From the previous chapter it has been established that young people and parents have concerns prior to the transition. During the visiting stage of the transition the process moves on to become far more focused on the young person, involving introducing the young person to secondary school. This chapter will look at how concerns are affected by the induction days. It will also continue with the theme of support from the previous chapter and look at who is supporting the young people and their parents at this time.

This chapter will address three key areas linked to the young person being introduced to secondary school; their first experiences, issues of standing out and fitting in, and their parents involvement.

The first section ‘7.2 “*Sad about leaving primary school, but excited about starting a new school.*” – *Beginning the journey*’, describes the systems adopted by the secondary schools to introduce the young person to secondary education. For many young people this was a period of mixed emotions. In this section the young people describe having visits at primary school from secondary staff and also induction days.

This section outlines how most young people enjoyed the induction experience, which supports the work discussed in chapter 3 such as Sanders et al (2005), who reported that the induction day was the most popular transitional activity.

⁹ Matthew (14)

It is demonstrated that for many of the young people induction day attendance resulted in them gaining the knowledge required to cope with the transition to secondary school. As discussed in chapter 6 much of the information available at the beginning of the transition went to the parents and not the young people. For some young people this was a source of concern.

It is also established in this section that the '*buddy*' system implemented in many schools to increase interactions between the new and older pupils, has been successful in addressing the young peoples concerns about older pupils.

From this chapter there is evidence that involving the young people in the transition process has a positive impact on their perceptions of secondary. As discussed earlier in chapters 5 and 6 there is great scope for the ASL to build partnerships between the young people, services and parents, which would also support the participatory aims of the 'Curriculum for Excellence' discussed in chapter 3.

However, it is also found that young people experienced accessibility issues related to their impairment, such as poor access, or timetables they were unable to read. In some cases the parents and young people were required to have additional visits to the school to address accessibility issues, which many parents were angry about. Again, as concluded in chapter 6, this shows that the accessibility strategies required by the Standards in Scotland's Schools Etc Act are not being fully implemented.

It was the finding of this chapter that the key advantage of the induction days was that they could be adapt to the young persons needs.

The second section moves onto look at how the young person felt they stood out at secondary school, and their developing desire to fit in. The heading '7.3 "*It was quite weird that everyone knew my name, but I didn't know them.*" – *Standing out and fitting in*', demonstrates how some of the young people felt they were identified as being different at secondary school, through doing things differently to their peers, such as going a different way to classes. This is despite many of the young people in this work seeing themselves as just another pupil, regardless of the level of their impairment, and wanted to be treated in this way. This was also the conclusion made

by Connors and Stalker (2007) who established that many disabled young people saw themselves as 'normal' teenagers, and were keen to have both property and attitudinal barriers removed.

During the induction days many of the young people were accompanied by their assistants from primary school. They felt that they would have liked the opportunity to meet their new assistants, and to start to form a relationship with them during this time. Some of the young people had had this opportunity and appreciated it.

This chapter demonstrates that the young people have opposing views, just as there is in the literature, concerning whether assistants are barriers or remove barriers for them. In this section it is not clear if the young people or adults were making the decisions about the allocation of assistants. The impact of assistants is readdressed in chapter 8.

This section also demonstrated that through the process of the transition the young people start to question how others see them, and their discourse draws similarities with work discussed in chapter 2 such as Allan (1999) regarding the process of transgression, either moving towards or away from a disabled identity.

The final section within this chapter discusses the involvement of the parents. This stage of the transition is primarily young person focused, and to some extent the parents are left out. This is illustrated in the section title, '7.4 "*EDS – I still don't know what the E stands for!*" – *Parent involvement*'. This section shows how parents have positive views of the transition, although they felt that the visiting stage of the transition raised a number of questions, with nobody to answer them.

Many parents report having to rely on their children to feedback information to them. As noted earlier, this is again a shift from the beginning of the transitional process where parents were receiving the majority of the information. This demonstrates why both parents and young people must be involved and informed throughout the transition.

It is interesting how despite the lack of information parents still had a positive view of the induction process. The chapter introduces the issue of parent-child relationships, and how children might influence their parent's perceptions. It is concluded that further work would be needed to explore the matter further, but that both parents and young people need information to cope with transitional events.

The ASL act introduced the right of parents to have a contact person. Parents in the post group reported that they did not have someone to talk to, concluding that the act has not been fully implemented.

Much of the data in this chapter is derived from the Post ASL participant group. As they were going through the transition during the study, there was the opportunity to collect more detailed and vivid accounts.

7.2 "Sad about leaving primary school but excited about starting a new school."¹⁰ – *Beginning the journey*

The main emphasis of this stage of the transition was familiarising the young people with secondary education. Two main methods are used by schools; secondary teachers visit the young person at primary, usually giving a question and answer style session; young people have hands on experience of secondary school by spending a few days within the secondary environment. For many of the young people it was this second method that they rated most highly.

7.2.1 Tools of familiarisation

For many of the young people, staff and pupils from the secondary school visited them at primary school. This usually involved the teachers and pupils giving a talk about making the transition and answering questions. Early research in this area had questioned how helpful this activity was in assisting with the transition, as young people often thought that only 'nice' teachers would participate in it (Galton et al, 2000); that is they did not meet the teachers who might cause them problems in the future. Therefore they felt that they did not get a full insight into all the teachers at secondary school.

¹⁰ Elliot (12)

Despite this the young people and parents seemed to suggest that these visits were a beneficial part of the induction process, when used in conjunction with other methods. The teachers came to visit all of the pupils making the move into secondary school, therefore the young people in this work were not treated any differently to their peers.

“This guy who’ll be their guidance teacher has come down, not to talk specifically to him, but to talk to all the kids.”

Harry’s Mother

In some of the schools the visit by secondary school teachers was more informal. In these situations the emphasis was on key members of staff getting to know the young people.

“Helping with activities in class...really making sure that the children got to know the staff that were at [secondary school]”

Ellie’s Mother

This was often the form these visits took within special schools.

“The [secondary school] teachers came down to Peter’s school as well....There was a good hand over, they get to know the different teachers and things like that”

Peter’s Father

“[Secondary teachers] come down and work with the kids.”

Victoria’s mother

Thus in both mainstream and special schools there was an effort to familiarise the young person with the new teachers at secondary school and to give them the opportunity to ask questions within a familiar environment. This process also gave the teachers the chance to become familiar with the new pupils. This was particularly useful if the young person had additional handling needs for example as they could observe and learn from current staff. For these young people it was helpful for the new assistants to observe how to help move them in a way that was comfortable for the young person and offered them dignity.

“Oh yeah, I had a couple of boys, no a boy and a girl...came in to speak to us and we asked them all the questions and they just told us the basics of the school and stuff. How long periods lasted, how long you get for lunch and stuff like that. Cause that’s the kind of stuff you are interested in.”

Andrew (16)

Here Harry’s mother felt this was a beneficial action specifically as Harry was participating in the same way as his peers. This highlights the value the parents place on their children being able to participate along with their peers. Mollard (2003) found that parents of disabled children felt it was important that their children be included and educated along with non disabled children from the local area. It was the finding of this work that parents valued their children also having the same school experiences as non disabled pupils.

Although many young people found teachers visits helpful it is possible that it was too detached from secondary school to leave a lasting impression, as it was the induction days that they were most enthusiastic about.

One of the main findings from the longitudinal ORACLE study was the benefit of induction days in reducing anxiety surrounding the transition (Galton et al, 2000, Delamont and Galton, 1986). These were a feature in all transition programmes in this study that the young people spoke about. All of the young people spent time at the secondary school, attending classes, meeting teachers and orientating themselves with the layout of the school. This applied in both special and mainstream schools.

Many of the secondary schools had taken steps to make lessons exciting for the young people during the induction days; in particular stories of science lessons were recounted.

“Well...the teacher did, got a gas flame and filled a fairy liquid with gas...it was cool, there was this big flame going up”

William (11)

“...And my teacher said, he was showing us how to do it. He turned on my gas tap; just before it went bang he turned it off and went ‘BANG!’”

Zack (11).

The role of the induction was for the young people to orientate themselves within the school, meet teachers and class mates, and experience some lessons. During these days there was generally a tour which helped to address one of their main concerns relating to getting lost.

“You get taken around by the school prefects cause obviously it’s a huge school so you wouldn’t have a clue where you are going. So you get taken by the sixth year prefects.”

Andrew (16)

Another important part of the induction was to introduce them to the older pupils in the school. Some writers, such as Kvalsund (2000), argue that older children can seem intimidating and a source of worry. In this study in some schools older children were given the role of “buddies”, and the young people felt that they would talk to them “*about anything*” (Craig (14)).

Some within the pre ASL group were pleased to tell me that they were now taking on this role themselves, and it was clearly something that they took pride in.

A final role of induction was to provide an environment for young people to ask about things they had been concerned about.

“[I wanted to know] about how many people there were, and I found out there was 890 people.”

Elliot (12)

Like Elliot, for many of the young people having their questions answered was of great importance and reassurance.

The main aspect of the induction days was that it gave the young people a hands on experience of secondary school and hence the ability to base their knowledge of secondary school on reality.

As with the research published by Sanders et al (2005), all of the young people spoke positively about the induction and found it to be a helpful experience to prepare for secondary school.

“Because if you never had a visit, you might get lost and worry”

Kerry (12)

“They gave me my timetable when I went for the week so I knew what all, what my timetable was going to be when I started first year. So I knew I was going to be alright so it wasn’t too bad.”

John (15)

“Fun, probably the funnest days at school cause it was just a bit of fun trying out things in each subject and you get like shown round by all the sixth years.”

Matthew (14)

During the induction the young people tended to do the same activities as their peers. Within mainstream schools little or no time was spent on issues relating to their CP, such as whether there were any barriers to them accessing any of the school areas, how to use the lift if they needed to, or whether accessible facilities were available. Additional visits were arranged for some to address such issues.

A few of the parents felt angry that such a follow up visit was required, as they felt their child had a right to access the school. They felt that the school should be accessible to all students and should not discriminate against any future pupils. However, in many cases the parents, and sometimes young people, were required to re visit the school and highlight any barriers to their access or learning.

“I think the main rhyme or reason or plan was to identify whether there were any areas that were dangerous...for a wheelchair. Any doors that were too narrow. Any, you know, curbs that were non-existent...it should be something that is, that the school is aware of, that the council is aware of...I don’t think it was the responsibility of Toby and myself to wander round and say ‘is this safe, is that safe?’”

Toby’s Mother

As schools have previously been thought of as being dominated by the medical model (Shaw, 1998), the fact that the schools wanted to remove the barriers to these young people can be seen as a positive.

However, these schools should have an accessibility strategy in place as required by the Standards in Scotland's Schools Etc Act. This act also calls for such strategies to anticipate any changes; therefore parents such as Toby's mother should not have to identify barriers themselves.

All of the young people experienced an induction, which tended to be between 2 days and a week in length. Many of the young people found that the induction had a positive impact on their ability to cope with the transition.

For example, prior to the induction days, many of the young people had limited knowledge about secondary school, and could only imagine what it would be like. As a result of the induction the young people were better able to carry out Restorative Practice (Brammer, 1992) in relation to secondary school. Elliot's experience demonstrated to him what would happen in gym lessons. He had previously been concerned about gym lessons now he could picture the lesson.

Through providing the young person with the opportunity to experience secondary school and to gather first hand knowledge they were able to prepare for secondary school. The young people also now had the knowledge of secondary school which previously only their parents and the school had. Such knowledge would allow the young person to engage in conversations with their parents and school regarding their needs. As discussed previously in chapters 5 and 6, there is clearly great scope for the ASL to build partnerships between schools, parents and young people and to enable them to work together.

7.2.2 Induction days- Young people requiring additional support

One of the key components to the success of the induction days was the ability of schools to tailor the induction day process to individual pupils. Sanders et al (2005) call for the transition of disabled young people to be considered as a process and not simply a one off event. A number of the disabled young people in this study had

additional induction days to help them to adapt. Other young people in this study attended a prolonged induction period which introduced them to secondary education over a longer period of time. This occurred with young people attending both mainstream and special schools, and also within both the pre and post ASL groups.

“John spent a week at [secondary school] I think other children have maybe two or three days but you got a full week.”

John’s Mother

“[Primary and secondary] interact every Friday, and at least once a week anyway, so you knew everybody didn’t you [speaking to Steven], because you go to assembly with them on a Friday don’t you? Remember what you usually getting on a Friday.....Star pupil!!!!”

Steven’s mother

The focus of these additional induction days was an effort to introduce the young people to the new concepts of secondary school, for example moving between classes, and ensure that they felt confident once they made the fulltime move to secondary education.

This way of adapting the induction day’s echoes that of the ‘Curriculum for Excellence’ (2004) discussed in chapter 3, which calls for curriculums to fit with the young persons needs. Through adapting the induction process to fit with these young people, there is a shift in the power back to the young person. As the ‘Curriculum for Excellence’ acknowledges, feeling in control of their secondary school lives from the beginning is important for the young person to have the confidence to achieve at school.

The induction days gave some young people the opportunity to visit the support unit that they would be making use at mainstream secondary school. For many it was during the induction days that they first experienced going to such a unit. For some it was not what they had expected.

"[The base is] tiny... 'cos there's hundreds of desks and books...um...oh a PC when you come in the door and turn left, there's a PC there. Come in the door and turn right, laptops. So there's hundreds of laptops and PC's"

Zack (11)

A number of the young people and their parents had concerns pertaining to access and inclusion prior to the transition. For several of the young people their experiences during the induction days alleviated many of their concerns. A number spoke about how pleased they were to be included in lessons.

"I can't really do football that well, but the PE teacher said 'you can't do it very well can you Elliot, do you want to play referee then?' Okay! He stuck his fingers in his mouth and whistles 'time out!'"

Elliot (12)

William (11) had a similar experience at his school. These experiences were important to the young people as through the teachers removing barriers they made them part of a lesson they could not participate in the conventional way.

The induction days not only gave young people the opportunity to experience the lessons, but also allowed those who would be having learning support assistants to meet them at this time.

Parents in this work felt that it was important that the young person built up a relationship prior to the transition and felt comfortable with their assistants. This study found that for several of the young people, such as Victoria and Nathan, their assistants were identified prior to the transition and were able to visit them at primary school. This gave them the opportunity to build a relationship within an environment where they felt safe and secure.

"They also did a week in August before they went...I think the transition...the plan was very good and this week they had in August was wonderful"

Nathan's mother

Some writers, such as Connors and Stalker (2003) argued that assistants can act as a barrier to young people interacting with each other. However, in this work it was

established that for some young people and parents saw assistants helped the young person to overcome barriers. Such a finding is more in line with the work of Aston et al (2005) who stated that, for some young people not having an assistant was a barrier.

Unfortunately for some of the young people the induction days were not always as useful as they could have been due to circumstances, such as the turn over of staff and changes to the lay out of buildings.

“They were also having a lot of work done so no parent actually saw the schools because there were so many workmen and things in it. So again he was in the school before we got shown round.”

Matthew’s mother

Victoria’s mother suggests that the school prepared well for transitions because they made the effort to have teachers from the secondary section working with Victoria before she moved. However she went on to say that the planning worked well until a change in staff; following this the good work was undone. This study complements the work of Garth and Aroni (2003) who found that parents of young people diagnosed with CP viewed continuity of care as very important. Continuity of care is essential for disabled young people; in particular it aids communication with the young person, and also with parents.

Most of the families had good experiences of induction; however there were a few who felt that the induction process had not gone well.

“All the children have an induction...you know, a few days that they go across. There were a number of meetings to discuss his...welfare, you know, his care needs and his educational needs. However they were fairly unprepared.”

Toby’s mother

Here the school had not succeeded in tailoring their approach to meet the needs of the young person.

Zack's mother also felt that the school had been unprepared for him. The school had not considered all issues relating to his needs. For example his timetable was in small print, and there were no dark lined jotters available for him.

Thus, despite policy such as the Standards in Scotland's Schools Etc Act being in place, this school had not been successful in achieving inclusion for Zack. This raises the issue of inclusion versus integration within mainstream secondary school. Here it would appear that Zack had been integrated into the school, but due to the lack of an inclusive ethos being adopted by the school was not fully included. In chapter 3 the work of Farrell et al (2007) was discussed who noted that schools must adopt such a policy in order to achieve inclusion. Although the parents in this work did not speak about the induction days in terms of the social model, we can see that by removing barriers inclusion can be achieved for these young people.

Prior to the induction days many of the young people who were attending mainstream schools were concerned with mobility and access at secondary school, whether they would cope or whether they would need to do things differently. For many of the young people in this study the induction days confirmed their concerns. For example Kerry, had been worried about walking around secondary school. When she was asked what the worst thing about secondary school was, she replied;

"The worst thing is doing, em...the worst thing was climbing up steps all the time."
Kerry (12)

Zack was also worried about the stairs prior to his induction. Zack has a visual impairment along with his CP and finds it difficult to navigate stairs. As his school was an old building he had heard that there were no banisters. Following his induction he reported;

"It's hard to get up and down stairs...it's hard to get around...when there's no banisters, I kind of panic. 'Cos when I'm walking down stairs I think I look off to one side...and people run down them!"
Zack (11)

Realising these difficulties led many young people to start thinking how they would cope full time at secondary school, and how they might have to do things differently.

The induction days also reinforced worries about specific subjects for some of the young people. Ian (11) was worried about science at secondary school having found it difficult at primary school. Ian was due to undergo surgery on his leg and would be in secondary school in a plaster cast after this, during his induction he had a science lesson which only added to his worries.

“The science teachers said for me to sit [in the] back [when I start] because if I went near the Bunsen burners my plaster cast was gonna just melt.”

Ian (11)

Therefore although the induction days set out to alleviate concerns, for some young people concerns were reinforced. Experiencing the social context had for some young people triggered the realisation of impairment effects.

7.2.3 Views on secondary school following the induction

Unlike the pre ASL group the post ASL group were currently experiencing the transition and so were able to give a clear picture on how the induction had influenced their feelings towards starting secondary school. When asked at this time how they felt about starting secondary school many agreed with Harry’s response of; *“can’t wait to go up.”* (Harry 11). Others implied it was no big deal and simply thought it *“fine”* (Kyle, 11). Only Ian said he was scared about the prospect of moving to secondary school.

The young people also reported that they were happy to be leaving primary school. Freddie had originally been concerned about leaving his primary school and going to a special secondary without his primary school friends. However following the induction days he felt reassured.

“Well, I feel great, great...because [secondary school] is better than [primary school]!”

Freddie (12)

Although all of the young people had indicated that they were looking forward to secondary school, there were a range of emotions concerning leaving primary school.

“Sad about leaving primary school but excited about starting a new school”.

Elliot (12)

This was due to a number of reasons, but for many of the young people was related to missing friends who were going to other schools, or who were in different classes.

“Because I have some friends there going to other schools”,

Harry (11)

“[I’ll] miss all my friends...[because] I won’t see them as much because we’re in different classes.”

Kerry (12)

Another aid to help the young people settle into secondary school was to place them in classes with friends from primary school. Several of them had previously been asked to supply names of friends they would like to be in a class with. It was during the induction days that the young person found out who was in their class. Although the literature suggests friendships are a big support to a successful transition (Lucey and Reay, 2000), and that being placed in a class with friends from primary was advantageous (Ross et al, 2006) some of the young people were not placed with the friends they had chosen, which raises the question why they were asked to carry out the activity. Despite this disappointment many of the young people coped well and remained positive.

“[I’m] not with the people I wanted...but it’s alright.”

William (11)

William’s mother felt that this would be beneficial to William’s development.

“There’s about two or three people in his class that he knows, that he’ll hang around with. But there isn’t somebody in there he’s say was his friends. But I think that’s a good thing if I’m honest, because it gives him a bit of space to meet other people, and his friends space to meet other people.”

William’s mother

“It turned out...that...it was, the one thing that we were very upset about was that really because it was such a small school, generally pupils are put together in groups. That’s always happened. We know that obviously they try and keep friends together or at least have, you know, several people because it’s, because this is a very small school and obviously you are mixing with children that are coming from much bigger primary schools. And...unfortunately with Gareth, well we all had every expectation that that would happen because that happens with every child. With Gareth during his induction days was placed in a class without, without anybody else from the village school. And although he didn’t have any specific friendships he did, obviously he knew them. “

Gareth’s mother

In chapter 3 work such as Galton and Willcocks (1983) was discussed in reference to the value young people place on friendships, and the positive impact friendships have on this transition. This issue was also readdressed in chapter 6. This raises the question of whether friendship groups could be incorporated into future transition planning.

7.3 “It was quite weird that everyone knew my name, but I didn’t know them.”¹¹ – Standing out and fitting in

For nearly all of the young people in the project one of their main desires was to be considered the same as their peers. For some young people this involved going to a special school where they could attend classes without adult support. Other young people attended mainstream schools, and here many of them encountered barriers which resulted in them standing out.

7.3.1 Doing things differently

Following the induction days the young people were mainly concerned with the physical aspects of the move rather than social aspects such as bullying, which they

¹¹ William (11)

had spoken a little about earlier. This is different to previous research, such as that by Stradling and MacNeil (2000), which would suggest that bullying was the major source of concern for young people prior to the transition. It seemed that following the induction the young people gave precedent to what they had seen in secondary school rather than what might be. Thus they were concerned with what they saw as real problems. Prior to moving many of the young people worrying how they would need to change in order to fit in with the school structure, rather than asking how the school could adapt and remove the barriers for them.

As noted earlier in this chapter the young people felt that it was important to meet their new assistants prior to making the move into secondary school. Some authors raise the issue that these assistants can prevent social interactions (Davis and Watson 2001). However, for some, although they appreciated a familiar assistant, they also wanted to meet their new assistants that they would have when they moved to secondary school. For example Elliot (12) had support from primary assistants but felt he would have liked more input from secondary school assistants.

“Maybe one [assistant] should go, but not three [from primary school].”

Elliot (12)

It was interesting to hear that the young people accepted that the assistants were necessary for them to be able to fully participate at mainstream. This is inline with research carried out by Lightfoot et al (1999), who also reported that disabled young people were aware that they may require assistance to attend mainstream schools. These young people acknowledged that their impairment led to the need for assistants, and although they felt an equal right to access mainstream they seemed to realise that they may require some assistance for this to happen.

However, this raises questions pertaining to choice and control. It was unclear from the discussion whether the young person had made their own choice regarding having an assistant, or whether an adult had taken the control and made this choice for them. This issue is addressed later in chapter 8 where some of the older young people speak about the negative affects of an assistant on their identity.

7.3.2 Developing an identity

Following the induction many of the young people had started to develop more of an awareness regarding their CP. Zack (11) experienced an incident of some girls laughing at him during his induction; he initially thought it was because he wore glasses. However, he later concluded that they were laughing because he had a limp. This raises questions regarding normality and difference, and how the social context can result in impairment effects.

Thomas (1999) as discussed in chapter 2 highlights that identity is socially created through our interactions and discussions with others. We see through Zack's experience that following his encounter with other pupils laughing at him he begins to realise how others might perceive him.

Many of the other young people started to develop an identity which lead to them not wanting to be lumped into what they called the '*disabled group*' at school, possibly as a means to counteract the medicalised perceptions of their peers. Allan (1999) described this action as the young person transgressing away from the disabled label. Watson et al (2000) noted that young people with milder impairments often wanted to exclude themselves from the '*disabled*' category as they did not identify with it. We see this through the dialogue with Harry and William and their parents. Harry has mild CP; William has more severe CP and is a wheelchair user. Here, regardless of how much their CP impacted on them, both Harry and William saw themselves simply as another pupil in the school and did not want to be highlighted as different. This echoes work by Connors and Stalker (2007), and also Skar (2003) who speak about how disabled teenagers simply see themselves as normal teenagers and want to be treated the same as their peers.

Both William (11) and Harry (11) indicated that they did not want to accept the offer of a special taxi to school; Harry chose to manage on the bus, whilst William requested that his mother take him to school.

“They did offer to, um send him, there is, there is a bus a special taxi. There’s a set of taxis that take all special needs, or additional needs as they like to call it now, and he, he was just like ‘no I’m not’, he would have loved it if the bus that comes outside [area] with the thing that lowers, and he could get on. That would have been fantastic, but it’s not likely. Until something like that happens I’ll take him there. He’s not wanting to be classed as part of a particular set or group of people, he’s just him. And he doesn’t want to be lumped in with, what I’m afraid he calls ‘those idiots’. So he’s not very politically correct about it.”

William mother

Through the discussion surrounding the experiences of both Harry and William, it appears that these young people are experiencing a conflict between how they view themselves and how others have a more disabling view of them. For both of these young people the effort by their schools to provide transport for them reinforced that the school saw them as part of the ‘disabled’ group. Both of these young people however do not identify with this grouping, and view the other pupils who would be using this transport as being different to them.

Therefore, through the process of the transition and the interactions with the school, it would seem that these young people are starting to question and develop their own personal identity.

Elliot (12) had to deal with a developing identity which saw him wanting to, as Allan (1999) described transgress away from some of the other disabled young people moving up with him from his primary school. Elliot is physically impaired whilst many of the pupils from his primary have learning impairments. His mother felt that spending time in mainstream classes during the induction developed a realisation of how other people saw him and led him to a feeling of wanting to distance himself from his peers at primary.

“Those friends were slightly embarrassing. I don’t think he wants them with him all the time....So I think it’s his fear of how people perceive him...I think he’s starting to notice. He wants to be treated like everybody else and not younger than he is.”

Elliot’s mother

His mother felt that this was a difficult time for Elliot and that he was looking to find people who were like him; he wanted to see how pupils he thought were similar to

him were enjoying secondary school. During his induction Elliot did see an older disabled pupil at his secondary school which he was pleased about.

“All the kid’s he’s with at the moment, their disabilities are more behavioural, sort of Aspergers, that sort of thing, but what he’s always looking for is, you know, the dodgy leg or dodgy eyes! But he can relate to that...He was quite chuffed because he saw a boy about sixteen kicking around [at secondary school] and, in fact I saw him as well. And he looks just like Elliot and he’s using his chair and he said ‘that boy was just like me’, which is great.”

Elliot’s mother

Here Elliot was looking to identify with people similar to him, a concept Goffman (1968) discussed when explaining stigmatisation. Goffman (1968) explained how individuals develop an identity through comparing themselves with others who are similar to themselves; here Elliot was developing his social identity, identifying with people who are similar to himself to boost his self esteem.

Although William tried to move away from his disabled label he was also aware, like Elliot (12) and Zack (11) that his impairment made others see him differently. During his induction the teachers were all saying ‘hello’ to him and were using his name and yet he did not know them.

“It was quite weird that everyone knew my name, but I didn’t know them”,

William (11)

Here there is evidence that the young people are beginning to think about how they are perceived, and how they relate to others (Pratt and George, 2005). Mandler (1990) found that during events like transitions an individual’s perception of themselves is likely to change.

This is similar to work published by Allan (1999) which highlighted how teachers could disable young people by reinforcing their impairment. Here teachers knew William as he was one of the few wheelchair users in the school William did not know these teachers and their actions made him feel identifiably different from the other pupils.

Developing a self awareness and identity is part of maturing. Following the induction many of the young people seemed to be developing, and many of their parents commented on this.

“I felt she had grown up. And she was, you know, and you could just tell in herself that she was really really excited about it and pleased about it [making the transition].”

Rebecca’s mother

The fact that these young people were growing up and changing made analysing this data complicated, as the young peoples perceptions were rarely constant, establishing whether their perceptions were reality or not was difficult.

7.3.3 Changing perceptions

The induction days also led to a change in the young person’s perception of secondary school. Realising the reality of secondary school and changing perceptions of it, is one of the aims of induction programme. Galton et al (2000) felt that young people often had higher expectations than the reality. Both Ian (11) and Zack (11) felt that parts of secondary school had been different to what they were expecting, mainly concerning the structure of the lessons;

“A little bit different, but the rest was what I thought it would be...the PE I thought was sort of different.”

Ian (11)

“Different...um, in science you get this big bench to work on, then you get stools. Their different”

Zack (11)

Other changes which occurred were more significant to the young persons overall perception of secondary school. Elliot (12) was moving from a special school to a mainstream secondary school. Prior to visiting the school he thought he would probably like to spend more time in the special support unit at the school rather than in the mainstream classes. However, after his induction days his opinion had taken a major shift.

“I was in the unit. The unit tends to be more...it could be a bit baby-ish, that’s why they’re testing me at the moment. I like the unit. Before I went to [secondary school], I would have though I would have like to spend more time in the unit than I would have in mainstream, but now it’s the other way round...because I thought that the unit would have been just like people like me...it’s like the first year at primary to S5 or S4 or whatever. So it’s like you’re finished primary school, but you’re still doing the primary work.”

Elliot (12)

To make such a decision was difficult for Elliot. He had previously been in a mainstream primary school but became isolated and moved to a special primary school. There he felt similar feelings to those French (1993) describes; he was now the norm and felt a sense of relief. Now he was moving to a mainstream secondary school he had thought that he would like to remain within a more specialised environment, but found himself wanting to move into the mainstream environment where he had previously been unhappy.

This example again reinforced the findings made in chapter 6 that experience helps in overcoming concerns. Here there is a shift in Elliot’s identity and he now sees himself as more ‘normal’ than he previously thought he was. At this point it is important to remember that if the adults involved with Elliot did not support his thinking this decision may be problematic.

7.4 “‘ESD’ – I still don’t know what the E stands for!”¹² – Parents involvement

Having been the main focus for much of the early transitional period, many of the parents felt relatively isolated from the transition process at this point. Although some parents attended meetings at the secondary schools, the focus was very much on the young person. To some extent the knowledge that the parents had of the induction days was based on discussions with young people. This is in contrast with the pre induction phase when young people rely on their parents for support and information.

¹² Kerry’s mother

7.4.1 Parents view of induction

Prior to the induction days the majority of parents attended a meeting at the secondary school. Although this meeting was at a similar time to the induction days, it tended to be more of a general meeting and gave little information to parents regarding the induction days;

“They had a parent’s meeting at the high school...And we got a few talks about the sort of discipline for learning and support for pupils and stuff like that. So that was quite good...again, you saw around a wee bit more of the school and we got their uniforms and all that sort of stuff, so we got some of the information then. But they didn’t really hand out any information about the induction that they were gonna be on.”

Kerry’s mother

“It was general things for parents of children who were starting. It was more about in general the school really, class sizes and that sort of a thing, rather than what was actually happening on these two days [the induction days].”

William’s mother

Thus parents knew little about what would take place on the induction days prior to it happening, and without formal feedback parents were left with questions and concerns.

Obtaining answers from written material was limited. As previously mentioned the information in the prospectus received by the majority of families was fairly general. Kyle’s mother however received an additional booklet about the school giving names of teachers and their roles along with term dates and the structure of the school.

“It tells you everything – it’s a fantastic book this.”

Kyle’s mother

Here Kyle’s mother really appreciated receiving such information which is evocative of work carried out by Stradling and MacNeil (2000) where parents of non disabled parents appreciated receiving similar information.

Despite feeling isolated most parents overall viewed the induction days as something beneficial to their children as they felt that it would reduce worry and fear in their children;

“I believe they then have all the kids who are going next year down for a half day and, you know, just so when they go for the first day its not such a scary thing.”

Freddie’s Mother

“They did a brilliant job, they really did. You know, like I feel it’s down to them that things have gone so smoothly”

Rebecca’s mother

Possibly due to a lack of knowledge some parents admitted to feeling apprehensive about sending their children on the induction.

“On her induction I just felt awful when I sent her. I thought they will make mincemeat out of her.”

Helen’s mother

Many of the parents felt that the induction would be a learning process, and until the young person started at secondary school it would be difficult to anticipate all the issues that would need to be addressed.

“[It] opens up more questions that they want answered, that you can’t answer until they’re actually there”

Elliot’s mother

“[It will] take a bit of ironing out”

William’s mother

In this section the parents discuss a lack of information, and as a result many of the parents raise uncertainties that they have. For example due to a lack of feedback and communication with the school Elliot’s mother is left uncertain how Elliot’s assistants will be organised at secondary school. As an assistant is vital to Elliot’s participation, this causes concern for his mother.

This again shows that the ASL act has had little impact on the transition, as parents are not being included as they should be. In order for the ASL to influence this move there needs to be a shift towards including parents as the act requires.

Despite parents historically being perceived as having power over their children (Bonner, 1998), children are able to influence their parent's attitudes. Attitudes are impacted on by our emotions and also by significant others (Ajzen, 2001). Through observing the positive reactions from their children, these parents in turn react positively, which resulted in the formation of positive attitudes towards the induction days. Understanding parent-child relationships is a complex matter and this research only represents a partial view of the family dynamics. Further work would need to be carried out to establish how the interactions between parent and child influence opinions.

Such reactions could also be linked back to the parents making the decision of which school the child should attend and the sense of relief when the child enjoys the induction days. Society places a lot of pressure and responsibility on parents (Bonner, 1998), and they feel under pressure to choose the right school for their child. Having made a choice parents look for a convincing rationale that it is the right choice (Shafir et al, 1994). Receiving positive feedback from their child, acts as reassurance for the parent that their child will be happy at the school.

Not having the necessary knowledge and losing control during the transition can lead onto experiencing more negative impacts of the change (Mandler, 1990). This was seen through some of the parents expressing new concerns following the induction period, such as Harry's mother worrying about the perceived lack of experience the teachers at secondary had of working with children with CP.

7.4.2 Parents reflections on the induction days

Having someone to answer questions to gain information is important to parents (Miller et al, 2003, Pain, 1999). However, at this time in the transition some parents seemed to be unsure who to contact regarding questions they might have. The majority felt that it would still be the primary school, others felt uncertain over who to contact.

"It would probably be the primary school to start with because the high school's quite busy! Quite hard to get hold of! Time's precious!"

Elliot's mother

Ian's mother: *I presume I would get put through to his Partial Care teacher. If not, it'll be somebody...*

Abbi: *but they haven't given you names?*

Ian's mother: *No*

Abbi: *you know, just somebody you can contact if you have a question?*

Ian's mother: *No, nothing like that.*

Abbi: *Just sort of phone the office, and...*

Ian's mother: *Hope for the best!...They're not awful well at communicating. Hopeless!!*

Ian's mother

Many parents, following the induction days, had a number of questions that they needed answered. In particular how working between mainstream and special units would work, or how the learning support assistants would work. Not having such a contact person had left many of these questions unanswered.

"There are things still to be asked, like how often there would be an SLA with him in class. I'll probably have to try and get some answers before the summer holidays because he's very curious on that sort of thing, you know."

Elliot's mother

Not having a contact person also left the parents without feedback concerning how the induction days had gone.

"Just what Zack said. No feedback at all from the school."

Zack's mother

"It was just through Kyle, I've not had any. I don't think they actually give the parents any feedback, it's just what your own child gives you."

Kyle's mother

Harry's mother was one of the few to receive any feedback, having gone into the school to discuss the induction days. Feeding back to parents would have been a beneficial addition to the induction day. The lack of feedback was disappointing as

research has demonstrated that the more parents are involved in the transition the more likely the transition is to be a success (Bastiani, 1986). Involving parents also leads to the young people being more motivated at secondary school (Anderson et al, 2000). In order to support their children parents need to have information about the school. These findings here are more inline with work by Darrah et al (2002) and also Sloper (1999) which highlighted parents' views of services as providing poor communication and support along with a lack of co ordination.

Feedback would give parents the opportunity to ask questions and to clarify issues that have arisen during the induction. For example Zack (11) spoke about how small the support unit at his secondary school was. With reference to this his mother later noted that she was unclear about the role of the unit.

"I don't know whether they actually hold lessons in there. I don't know whether they actually go there for lessons as such, or whether they just pop in now and again."
Zack's mother

After the induction days, several of the parents were left confused as to the new subjects their children were now doing. Having the opportunity of dialogue following the induction could have clarified this.

"'CDT' – that's craft, design and technology. I worked that out! But 'ESD' – I still don't know what the E stands for!"
Kerry's mother

As noted above many of the parents had unanswered questions, along with concerns at this time. The induction days confirmed earlier concerns for some of the parents, but had also raised new concerns for others.

"I mean, basically it just reinforced the problems that I thought there probably would be about the stairs and she said that she kept getting pushed out the way and, like, everybody kept overtaking her, which I thought probably would happen."
Kerry's mother

For Zack's mother the induction introduced new concerns. Prior to the induction she was mainly concerned about how Zack would cope with moving around the school,

but following an incident during the induction her concerns had moved to more social aspects;

“When he saw the girls pointing at him, he did feel a bit self-conscious. At first he said it was because he wore glasses, then he thought it’s because he’s got the built-up shoe on and we explained to him that they might not have anyone with a disability around them so they didn’t know....so that’s a bit worrying, how he’s gonna be accepted by other schools.”

Zack’s mother

Harry’s mother had also developed new concerns following the induction.

“There aren’t any of the teachers who have experience of kids with cerebral palsy....the staff haven’t actually been trained in how to deal with kids [with CP], which is obviously completely different to kids with normal ability to needing extra support”.

Harry’s mother

Thus for many of the parents gaining an insight into secondary education had led to new concerns. Many parents questioned how the school would deal with such issues.

These concerns along with having no definite point of contact put these parents in a very unsupported situation, which is neither beneficial to the parent or young person.

As discussed in chapter 6 many of the concerns expressed by parents throughout the transition were due to lack of knowledge preventing them from being able to plan future behaviours and to cope. This highlights once again the importance of information to parents through this move. By being informed of the schools actions, skills and resources, parents could plan how they could overcome issues and implement actions. For example, had Harry’s mother been provided with information regarding the teachers experience or of pending training for staff, she would have been reassured and been able to plan future actions.

What this demonstrates is the importance of involving the parents in the transition and keeping them informed. Not only does this help the parents cope but it will also

improve the success of the transition for the young people (Bastiani, 1986). Also, as demonstrated in chapter 6, the parents were a major source of information and support to the young people. It is vital therefore that they are kept informed in order to be able to carry out this role.

Keeping parents well informed of the processes involving their child is also a requirement of the ASL act and communication between the school and parents could be improved. As seen here with Harry's mother and Elliot's mother both of whom were in the post ASL group.

If there is to be an improvement in the relationship between parents, young people, and services there needs to be an improvement in the supply of information. Currently, throughout the transition, there are periods where the parents are informed and the young person is not, and periods where the young people needs to inform the parents. Service providers are the only ones who have the required information, and therefore power.

As noted in chapter 2 parents of children with CP report problems with information from services (Darrah et al, 2002), and a lack of communication and support (Darrah et al, 2002, Sloper, 1999). If the ASL act is to improve this transition multiagency working and collaboration with parents and young people needs to be implemented as the act calls for it to be.

7.5 Chapter Summary

The aim of this chapter was to identify which methods of familiarisation the young person found the most useful, and also determine if such methods answer their questions and deal with their concerns. The following key findings were derived;

- Young people need to be included.
- Parents benefit from a contact person.
- Young people hold views in line with the social model.

Inclusion: In this chapter it is shown that through attending the induction, young people acquired the knowledge to prepare for the transition into secondary school.

As noted in chapter 5, at the beginning of the transition most information goes to parents; with the induction days there is a shift towards the young people receiving transitional information rather than their parents. An advantage of the induction process is that it can be tailored to meet the individual needs of the young people.

The argument put forward is that the young people value being informed during the transition and that this contributes to their feelings of independence, which is further supported in chapter 8.

Efforts need to be made by services to ensure young people are included in decisions being made through the transition, and that they also receive accessible information. Such action to include young people is also called for by the ASL act.

From this chapter there is evidence that schools approach disabled pupils in a medicalised way. The school identifies an issue, such as the young person cannot access an area of the school because of a flight of stairs, and a solution offered, such as the young person is allowed to use of a lift. Although this is the first step, schools need to develop past the approach of seeing a problem and fixing it. This is not enough on its own to promote an inclusive approach. Schools need to start thinking in a more socially inclusive way and aim to adapt the school and their attitudes to remove barriers. Schools also need to consult with the young people and identify how they would like to address issues.

The young people in this chapter begin to discuss how they are perceived as different. This awareness partly comes from factors such as the use of assistants and of alternative routes. Thus necessary steps aimed at removing accessibility barriers become means by which the young people are differentiated from their peers.

To move beyond the approach of finding purely physical solutions to accessibility problems will require an acknowledgement and an understanding of the individual nature not just the young people's impairments but also their perception of these impairments. This requires making sure that each young person is involved in the discussion and the decision making process of how barriers are overcome.

Contact person: During the induction phase of the transition parents felt a lack of involvement in the transition, and that they needed someone to whom they could ask questions about the move. This chapter concludes that as the ASL specifies, parents should have access to a named contact person. This is also discussed in chapter 6 when parents are choosing a school, and is further supported by the advice parents would give to other parents in a similar situation to themselves in chapter 8.

Social model: Through the induction day experience many of the young people felt that they were identifiably different from their peers at mainstream school, as they had to do a number of things differently to them. It is argued in this chapter that even though young people do not have the knowledge about the social model of disability, they express views in line with this model calling for the removal of attitudinal and property barriers. This issue is further developed in chapter 8 in relation to the young peoples identity.

In conclusion this chapter contributes to the central argument that services need to be tailored to meet the individual needs of disabled young people. Through experiencing the induction days and the increased independence at secondary school, young people demonstrate that they can make decisions, but need schools to give them the spaces and opportunities to do so.

Following the induction days the next stage of the transition was to make the final move into secondary school. The following chapter will address the issues the young people and parents brought up concerning that stage.

Chapter 8

“The transition was...okay. I think...I think the transition to, I think it was okay”¹³ – Completing the move and looking back

8.1 Introduction

This chapter presents the data from two moments in time, firstly data from the retrospective accounts of the pre ASL group, and secondly from the third interview with the pre ASL group which was carried out once the young person had been in secondary school for approximately a month.

The previous chapters have followed the young people and their parents through the build up to making the transition into secondary school. They have highlighted how parents make choices over secondary schools, and shown that young people and their parents have a number of concerns and need support at this time. The induction days were seen by most as being the most successful and beneficial method of familiarisation, although in some cases they highlighted possible future problems. This chapter takes all of the build up on board and asks the parents and young people to reflect on their transitional experience and to evaluate the process.

This chapter has four key sections which look at the overall views of the transition, the impact of the transition on the young people, the assistance families got throughout the process and what advice parents and young people would pass onto others.

The first section asked the young people and their parents to reflect on the process. ‘8.2 “*Good... better than primary.*” – *Reflection*’ demonstrates how, for many of the young people, the evaluation of the transition involved comparing secondary to primary school. All of the young people reported that they still felt they had had a good transition.

¹³ Gareth (16)

When the young people reflected on the move many of them expressed a preference for secondary school. This preference was mainly based on the increased independence the young people felt they had at secondary. Such a finding supports earlier work discussed in chapter 3 (Lucey and Reay, 2000, Ainscow et al, 1999).

It is the conclusion of this work that the aim of the ASL to work with parents and young people is positive; however services need to acknowledge the power relationships that exist around choice. The ASL act needs to ensure that young people are given the spaces to make such choices.

The parents also felt that the transition had gone well, and put this down to the success of the induction days, and the willingness of the secondary schools to adapt. In particular they advocate the tailoring of the induction process to their child's needs, and that young people spend as much time as they needed in secondary school to address any concerns they had. In chapter 2 Farrell et al (2007) noted the importance of the school in being flexible and how this helped disabled young people to be included.

All of the families reported a good transition, despite many encountering problems along the way, such as having to fight to access a specific school, or encountering negative attitudes from school staff. For these families it was how these problems were overcome which influenced their overall view of the transition.

Throughout the process of reflecting, the parents and young people were asked about the involvement of services in their transition. The section title '8.3 "[O.T.'s] been really supportive for us, - making sure that he's got everything he needs." – Service input through the transition', represents the view of some of the families, and what the ideal situation would be. Despite the aim of the ASL to improve the consistency in service provision between areas, this chapter concludes that service provision is variable across Scotland.

Families in the post ASL group were more likely to experience support from services out with education, which possibly indicates that the ASL is having a small influence

for some parents. However, most families were not consulted during the process which demonstrates that the ASL is not being fully fulfilled.

For the majority of parents and young people most of the input and support that they received was from teachers. Parents who were dissatisfied with services were generally those parents who did not have a school contact to keep them updated with progress and to ask questions to. This chapter further supports Thomas' (1999) argument that the social context is influential in shaping disabled peoples experiences. In particular it concludes that parents and young people would benefit from working with a contact people at the school to address 'contextual issues'.

Where support was not available from service providers' parents sought support from less formal routes such as other parents. This becomes an important issue to parents when their child cannot access the local school, as many parents then lose their support network. As discussed in earlier chapters this would highlight the benefit of local authorities working with groups of parents.

This work demonstrates that parents and young people value receiving information, which would support the work presented in chapter 3, such as Pain (1999), and Stradling and MacNeil (2000), who emphasised the value that parents placed on receiving information.

This section highlights how schools also need to be better informed. Parents and young people discuss problems that arise when impairment specific information is not communicated between and within schools. This point also raises the tension between the desires of parents and young people. In some cases the young people are reluctant to pass on information to the school, although sometimes this information would be beneficial to their learning. This is an important issue and raises questions about choice and power. This is particularly troublesome as there is little evidence of power sharing between parents, young people, and schools.

The chapter then moves onto address the problems encountered by the young people on making the transition. '8.4 "[I] got the impression they didn't want to

spend the money” – Encountering problems’ discusses both property and attitudinal barriers encountered by the young people.

At the start of this section the ASL act is revisited, this act should have improved this transitional experience and removed barriers for the young people. However as in chapter 5, parents are unclear regarding the role of the act and its impact on their children’s education. It is put forward in this section that this lack of knowledge about the ASL reflects the power imbalance that exists between parents and service providers. Without information sharing with parents the act is unlikely to reach its goals.

A number of parents and young people discuss property barriers that they encounter at secondary in this chapter. For many young people there were problems with access in and around the school. Some families felt that schools were reluctant to spend money to make adaptations. Such restrictions demonstrate how the social context can lead to disabled people encountering impairment effects and would suggest that at these schools integration and not inclusion is occurring.

It is discussed that for some parents this lack of inclusion at mainstream schools was the trigger for them to choose a special school for their child. This chapter concludes that until all schools are fully accessible mainstream schools would benefit from special schools sharing their knowledge about the impact of impairment on education with them. It is disappointing that policy such as the ASL and DSPERA has not resulted in the reduction of such property barriers.

Young people also report encountering attitudinal barriers in this chapter. For some young people this was due to school staff being poorly informed. In many cases this chapter concludes that teachers at mainstream schools would benefit from specialised training. This supports earlier work by Farrell (2001) which suggests that the poor training of teachers could lead to the development of anti-inclusion attitudes.

The issue of assistants is revisited in this chapter, and conflicting views are presented from the young people. As discussed in chapter 7, some of the young

people felt that their assistants supported them at secondary whilst others felt they prevented them from becoming independent.

The following section '8.5 "*Cause there's like no-one else that went to [primary school] you can compare me to*" – *Who I am*' addresses how making the transition and coping with what Thomas (1999) defines as property and attitudinal barriers, impact on the young peoples identity. It is also acknowledged that these young people will also encounter specific barriers associated to their impairment, such as tiredness.

This chapter concludes that many of the young people had different views of how they are perceived. Some young people decide to transgress away from the disabled group, whilst others found strength in identifying with it.

This comes across in this section through a number of situations. For example some young people found reassurance in mixing with disabled peers and being able to identify with them. These young people used this comparison to shape their identity. Other young people removed themselves from interacting with other disabled peers and were pleased to be seen as 'normal' by their non disabled friends. This chapter concludes that both situations are valid, and that what is important is for young people to make the decisions about peer groups for themselves.

Views on the support base at secondary also highlight a difference in opinions. Many of the older young people felt that the base segregated them, whilst at this stage in their school life many of the post ASL group, having just made the transition, saw it as a place of retreat. The chapter puts forward that such attitudes could possibly be related to the young peoples experience of school, and that schools need to address how such complex issues are discussed.

The chapter then returns to the political debate discussed in chapter 2, whereby disabled people are expected to be seen as a 'collective'. This work concludes that these young people are all individuals and not all would be happy to conform to such a stance. What is important is that young people are given the space to develop their own identity.

What is evident from this chapter is that for some young people impairment is a clear part of their identity, whilst for others it is not. The conclusion put forward is that such issues need to be addressed by policy makers in relation to the transition. In some cases young people may need to develop the language to discuss such issues, and there may also be the need for specific spaces to be found for such dialogue to take place.

Many of the young people in this work seemed to be aware that their school needed to adapt for them. The chapter concludes that future work needs to be carried out to establish the impact this may have on the young persons identity.

Finally this section again discusses the tension between normality and difference, as discussed in earlier chapters. Young people make reference to the desire to not stand out and to be seen as 'normal', whilst earlier they felt their 'difference' needed to be highlighted to teachers. Again this causes difficulty for service providers, getting mixed messages not just from the parents, but also young people.

The final section asked the parents and young people what advice they would pass onto others making the transition. This task was another way of focussing the parents and young people onto what factors were important. One of the main pieces of advice from them is used in the section heading '*8.6 "I would say to ask questions". – Lessons learnt*'. Both the parents and young people recommended that other people in a similar situation ask questions to service providers in order to be keep informed throughout the transition.

Parents emphasised being informed, and along with asking questions, recommended visits to schools and having a contact person. There was also the general feeling amongst several parents that there was a need to fight for services. This was also observed in chapter 1 through work by Darrah et al (2002), and Sloper (1999). Unfortunately it would seem parents still feel this way.

Thus key to this chapter is collecting the transitional evaluations from the parents and young people. Along with this, it asks what role services play in the process and how the transition impacts on the young person.

8.2 "Good...better than primary."¹⁴ – Reflection

The parents and young people were asked to reflect on how they felt the transition had gone overall. All of the young people felt that their transition had gone well.

"Very well, it went really well. Cause I would like say to people, they would be like 'how was your move to high school'? And I would be like 'it was much better than primary school.'"

Ellie (14)

"I quite enjoyed the move."

Kerry (12)

"The transition was...okay. I think...I think the transition to, I think it was okay."

Gareth (16)

Many of the young people attributed this success to their transition period preparing them for secondary school, in particular having the induction days.

Abbi: *"remember when you went up for your visits, do you think that was helpful?"*

William : *"yes, definitely, because it gave you an idea of where everything was and things like that."*

William (11)

Abbi: *"do you think that it [the induction days] helped when you started?"*

Elliot : *"yes"*

Abbi: *"why do you think that?"*

Elliot: *"I got used to going there."*

Elliot (12)

The majority of the parents agreed with their children that overall experience had gone well. Like the young people many of the parents attributed this to the induction period.

¹⁴ Harry (11)

“It seems to have gone okay actually. She seems to have settled in quite well. There were a few tears the first week, but I think that...it wasn't anything to do with anything the school weren't doing for her, I think it was the whole change and everything. But, yeah, I was quite impressed with the fact that they seemed to have it all in place, you know, and I didn't have to go and complain about anything.”

Kerry's mother

“I was worried and I wish now I hadn't been because he's doing good. That was my main concern, how would he cope? And he's coped extremely well without any problems at all. I think it was just me over-reacting because children can be so horrible at the best of times, but I was just getting too wound up. He's been doing good.”

Kyle's mother

“Yeah, it was what we call an 'enhanced induction', and yeah, it was good. Better than just the two days, you know, that a lot of the other kids had. It was good, the transition period was good.”

Elliot's mother

Thus, although for some of the parents this was an anxious time, they felt that, overall, the transition had been a success because their children were happy. As we see from Kerry's mother, attending a school which is prepared to adapt in order to cater for the young persons needs is very influential to the view formed of the transition. The positive impact of the transition provides further support for the work carried out by Galton et al (2000), where improvements in planning and organising of the transition had reduced the anxiety associated with it.

As discussed in chapter 7, through attending the induction days the young people obtained the valued prior experience and information that they required to cope with the move. The induction days allowed the young people to accurately assess and plan future behaviour, as demonstrated in the extract from William. Parents seemed to value these induction days due to the flexible approach they offered their children by allowing them to spend additional time at secondary school.

Here the parents appreciated the school addressing the individual needs of their child, and acknowledging that, due to their CP, they may require additional time to

adjust. It was reassuring for parents during the initial stages of the transition that the school was prepared to adopt an approach to their child's education which was individual to their child.

Despite the positive reports from the families some young people did experience problems whilst preparing for the transition. Most problems were encountered by young people with moderate CP attending mainstream schools. The main difficulty was that for some of these young people the local school was not accessible.

Having made the transition the young people felt that it took them a few days to settle into secondary school which is not unlike the experience on non-disabled young people. This does not seem like a very long time and indicates that the young people seemed to adapt relatively quickly to secondary school. However, many of the young people found the new school physically tiring to move around and it took them more time to adapt to this.

Zack: just really...you have to move around!

Abbi: is that quite tiring, or is it OK?

Zack: well, my first week, I went to my bed at about 6 o'clock!

Zack (11)

From Zack's comment we see the impact of impairment. Thomas (1999) argues that the social context is vital in influencing the experiences of disabled people. Whilst in the primary environment Zack did not encounter this problem as he was in only one classroom, not at secondary school he had to move around which he found made him tired.

Despite their children encountering problems during the transition, what was important to parents was how such problems had been overcome.

"But I mean, these things are easy to sort out. It's a matter of just getting in touch with them and sorting these things out. I phoned up about a couple of things, and everything seems to get sorted out straight away. They've been good that way."

Kerry's mother

Parents, such as Kerry's mother who had a system for addressing problems as they arose, did not see them as major issues to the transition. This shows how parents can work well with service providers, and how having a contact person is beneficial. For some parents the requirements of the ASL act are being met and are working well.

Whilst reflecting on the move several parents felt that the transition had resulted in their children becoming more grown up and independent.

"Quite a, quite an independent boy, Craig though, which is good. But you know, I mean he will try and do it himself. School wise, no not in the house right enough."

Craig's mother

Parents reflected on how their child had matured during the move, and what this meant to them as parents. Not only were they experiencing the physical change of their child going to a different school, but also there was the issue of seeing their child growing up and the implications this had for them and the family dynamics. As noted in chapter 6, there is scope for future studies to carry out further work to understand the impact of such changes on parents and family dynamics.

Many of the young people commented that they preferred secondary school to primary. One of the main reasons given for this was that secondary allowed them to become more independent.

"It's different and you are more grown up."

Ellie (14)

Abbi: So, do you like your Senior Base? Yes or No

Olivia: yes (eye pointing)

Abbi: Yes? Yes, you like it.

Olivia: yes (eye pointing)

Abbi: And do you like Senior Base better than The Base? Yes or no?

Olivia: yes (eye pointing)

Abbi: Yes. So it's better

Olivia: yes (eye pointing)

Abbi: So, Senior Base, is it good or is it very good?

Olivia: Its good (eye pointing)

Olivia (12)

"I really liked getting away from the all the babies, like getting away from baby school and that."

Craig (14)

"It's much funner than primary school 'cause it was much different, you just have one teacher. And they treat you more adult and stuff."

Matthew (14)

This research found that the young people liked to be treated more like an adult at secondary school. This compliments the work of Ross et al (2006) who found that non disabled young people liked being treated more maturely at secondary school. For many of the young people it was the increased independence that they valued. Becoming independent is an important part of identity, and allows the young people to explore who they are. The issue of identity will be discussed further later in this chapter.

A number of secondary schools encouraged independence in the young people through allowing them to choose the level of support they used. Many young people were given the opportunity to decided when to reduce support, and when specific support was required. For example Craig (14) is able to walk up and down stairs, however if he is feeling unwell or tired he can request to have access to the lift at his school. This is something that the school allows him to control and decide upon.

As discussed in chapter 3, research has previously illustrated how important young people rate having a choice at secondary school (Lucey and Reay, 2000, Ainscowe et al, 1999). Through this heightened independence and availability of choice the

young people feel more in control of their school lives, and more powerful in relation to the adults in it.

The role control plays within our lives, and particularly during such new experiences, has been a theme running through this project. In order to reduce any negative impact of this during the transition it is important that both parents and young people feel that they have some control over the events occurring.

The ASL act aims for parents and young people to work with services. In order to further improve these transitions such ways of working must take place. There have been examples in this study of such collaboration, which has resulted in the parents and young people reporting positive transitional experiences.

8.3 "[O.T.'s] been really supportive for us – making sure that he's got everything he needs."¹⁵ – Service input throughout the transition

One major issue related to the transition was the support parents and young people got from service providers, such as educational psychologists and occupational therapists. Previous research has suggested that parents are dissatisfied with support they received (Darrah et al, 2002, Sloper, 1999, Bamford et al, 1997). The Additional Support for Learning Act aimed to improve support through establishing multidisciplinary working, and calls for local authorities to identify a member of staff to liaise with families.

Within both the pre and post groups of parents and in both mainstream and special schools, individual teachers took on the liaison role and were named as a good source of support. Many parents felt that they could phone the school with any questions that they had. Many of the liaison teachers were often the learning support teachers.

¹⁵ Harry's mother

“Probably Mrs Brown. She’s the pupil support teacher for S1 but she’s taken a special interest in him. When I say ‘special interest’, he’s not getting any special treatment – he’s just get treated the same way as any normal S1 - but she knows what he can’t and can do.”

Kyle’s mother

For parents whose children where in special school the individual class teacher where more likely to be mentioned as being supportive.

“So, from that point of view, at least, from this class and these teachers, the communication with us, we feel, is very complete.”

Olivia’s Father

The young people were able to name a specific teacher who was supportive, and somebody they could go to if they had a problem.

“I would talk to Mrs McGregor, because that’s what she say’s”

Kyle (11)

“My teachers or the helpers”

Zack (11)

From such findings it would appear that the young people are well supported and included at secondary school. These teachers actions would be reflective of the recent ‘National Framework for Inclusion’ from the Scottish Teacher Education Committee, which reinforces that teachers need to be supporting inclusion, participation, and access to all pupils.

For many parents, and more frequently mentioned by those in the post ASL group, support was also received from services out with education.

“He also had about three or four days right up - didn’t you? Rehabilitation, through the Social Work took him in the week before so he could get a real feel for the place beforehand.”

Zack’s mother

“When he started at high school his occupational therapist and his physio’ had a meeting with the school. And he had went up to make sure that everything was going to be in place.”

Craig’s mother

“Yeah, she’s [the OT] been really good over the transition period. She’s been really supportive for us – making sure that he’s got what he needs. She’s been a big help...I think that all the things that happened were us or Lisa, the OT. I think the only person who approached us was the OT and she said, back at the start, ‘I’ll see him then’ but every other meeting, consultation has come from us.”

Harry’s mother

It is interesting to note here that some young people were receiving an input from a range of services such as social and health services. This is evidence that for some young people the conclusions of the ‘For Scotland’s Children’ report which was implemented into the ASL act, have been adopted. As discussed in chapter 3 this report calls for the involvement of multiple agencies in the education of young people who require additional support for learning.

However, for other families there was a lack of support and information available.

“Nobody’s been in touch... nobody really spoke to me about it. Because, I filled in the form but they never got back to me.”

Ian’s mother

“I’d say, actually, that’s been something that they haven’t been very good at saying. You know – ‘This is such and such and, if you’ve got a problem or a question, then come and ask us’. And I think he’s not too sure either actually.”

Elliot’s mother

Both Ian and Elliot made the move once the ASL act had been implemented. Through comparing their parents’ experiences to those parents above, this work concludes that the availability of support and input from service providers is variable across Scotland.

In order for young people to be fully included in schools there needs to be a partnership of discussion and planning prior and during their transition. The 2001-

2005 HMIE report concluded that the implementation of inclusiveness in schools is variable across Scotland. It would appear that this remains the case.

The lack of consultation with families demonstrates that in some areas the ASL act is not being fulfilled. Thus in conclusion although there have been some improvements in parts of Scotland, this is not the case for Scotland as a whole.

There tended to be more input by services, and a wider range of services, for young people attending special schools. For Ben's mother the transition into secondary marked a reduction in service provision.

"It seems to be when you are at primary you get all this help thrown at you. But when you go into secondary school it tends to disappear."

Ben's mother

Despite the need of parents at this time for information and support, in some areas there was a reduction in services. For example, Ben's mother found that services were reduced for Ben when he moved into secondary. His mother felt that this could be reflective of the misconception that, as the child is growing up and as the parents have more experience of coping with their child's impairment, services can be reduced. This work demonstrates how, specifically during this transition, parents require more service input and support which is also highlighted by policy such as the Standards in Scotland's Schools Etc (2000), and the ASL act. Although parents may be familiar with their child's impairment, these are new experiences and challenges that they are facing and they require support to negotiate their way through them. This would be a recommendation to take forward for future good practice.

When formal routes of support are unavailable many parents seek support elsewhere. In chapter 5 it was noted that only a few parents accessed support groups, however it was found that through the transition parents were more likely to seek other parents for support, particularly when there was a lack of a contact person in their child's transition.

For example Leon's mother got very little input from services at the time of choosing a secondary school, and so she was basing her decision on "*knowledge from, you know, other parents we'd met.*" Other parents spoke about talking to other parents about which school would be best for their child. This finding is consistent with other work such as Mitchell and Sloper (2001) and Garth and Aroni (2003).

When parents were not successful in obtaining access to the local school for their child, they felt that they missed out on the support from parents they knew from the community. Ellie's mother was in this position and he compared this to her experience with her son who was attending the local secondary school.

"As a parent that's part of a big support network. I mean I go up to [local secondary school] for something for my son. I know all the, well not all, I know a lot of the other parents there. You know, there will be somebody that I know that goes to the same gym as me or, you know, I don't necessarily know them from school from being a parent but you know them from your local community. We miss, we miss out on that."

Ellie's mother

Such findings would suggest that there is value in bringing groups of parents together to provide support for each other throughout the transition.

Of the few parents that had accessed support groups, it was more common amongst parents of young people at special schools. Some parents accessed support groups specifically during the transition for advice on issues arising due to the move, Nathan's mother accessed one educational group for advice on his rights to be educated at the local school; Matthew's mother contacted a similar group for help with how to deal with his reluctance to tell the teachers about his CP once he had moved to secondary. These groups were a source of support for families, although finding out about such groups was a matter of chance as there was no requirement from any service to supply such information.

For many parents there is a sense of a shared history with other parents, and also support groups that include other parents, which is important to the development of trust in the information and support received (Reiss et al, 2005). As seen with Ellie's

mother having a shared history with other parents contributed to the feeling of available support. Providing parents with access to support groups and also the opportunity to meet and interact with other parents would be beneficial to their feelings of being supported during the transition. This is something that could possibly be incorporated into future induction day schedules.

Therefore what this study found was that as well as working with individual parents, there is scope for local authorities to also bring groups of parents together and to address problems together.

Although many parents did receive support from the school and other services, a number of parents were left feeling that they would have benefited from additional support. On reflection several parents felt that it would have been helpful to have had the input of somebody with knowledge about CP during the transition. This was often missing if their child's CP was mild.

“Somebody with experience, you know. So maybe somebody actually from the support base who had specialist experience could have been involved in overseeing Matthew. I think it would have been much better than a mainstream guidance teacher.”

Matthew's mother

“Somebody that knew their way through that kind of maze because, you know, it is, you do get people that try and put you off by not talking down to you but loading it with this act, that act and according to this, that and the next thing.”

Nathan's mother

A few parents thought this support would have been best delivered through the provision of information.

“The more information they have the easier it is a lot of the time. And it's these silly little things, you know, like where the toilets are – they didn't know where the toilets were for weeks!...It's the little things that they worry about during the Summer holidays before they start and, em, it's reminding them, you know?”

Elliot's mother

“I think, certainly from the high school perspective, I think it’s been very good, and I couldn’t really fault them as far as they’ve been concerned...The primary school were (pauses) were okay, I mean, they were all right, but I don’t think they give out enough information, really, to all the parents.”

Kerry’s mother

Such an emphasis by parents on impairment can sound very medicalised. However in order to realise the potential impairment effects, it is important to have the input of a professional who has knowledge of the impairment, which has also been argued by other authors such as Davis and Watson (2001).

It was mainly the parents who wanted such an input and this raises the tension between what parents wanted and what the disabled young person wanted. At times the views of adults and young people have been found to be very different (Middleton, 1999). As noted above, Matthew was reluctant to discuss his CP at school, therefore would he have wanted attention drawn to him through discussions with teachers?

Throughout this transition parents emphasised wanting to be included and informed. This is the key message to take forward to service providers, who should aim to work with both individual parents and groups of parents.

8.4 “[I] got the impression they didnae want tae spend the money.”¹⁶ – Encountering problems

Many of the young people making the transition into a mainstream secondary school encountered problems on moving school. These problems were both environmental and attitudinal in nature. The ASL act was implemented in 2005 to address the variability in service provisions between areas and to improve the transitional experience. If implemented fully the ASL act should result in the removal of barriers for young people who require additional support for learning.

¹⁶ Darren (15)

8.4.1 Revisiting the Additional Support for Learning Act

In the main there has been little difference between the pre ASL group and the post ASL group with regards to their transitional experience. This is consistent with what was discussed in chapter 5, when parents were asked about the ASL Act at the start of the transition. Having made the transition into secondary school parents were no more informed about the Act.

At this final stage in the transition many of the parents were still uncertain of the additional support for learning Act. Many of the young people did not have a coordinated support plan, and parents seemed unsure about them. Some young people were still waiting to be assessed for one.

“I’ve just got a letter to say that she’s not gonna get one so, basically, that’s her. I think it’s because they don’t think she has enough outside help.”

Kerry’s mother

“He doesn’t and I don’t know whether he needs one or not because our Local Authority are actually very against them for obvious reasons. I’d actually agreed with them before that I was quite happy for him to not have one because I’m not sure with, giving everything that the school does, that I really... or the way that I’ve been so far, that I want someone from the school to be responsible for co-ordinating everything. But we’re now getting to a point where Harry’s actually really tired by the time he comes home at night... So I think I’m now gonna have to look at... I’ve talked about it with my husband whether maybe we need to look at some special timetable or try and juggle something. So I think we might need to look at the Co-ordinated Support Plan. It’s because it’s so new and it’s not something I know, I wonder if I should get in touch with the local authority”

Harry’s mother

“I don’t know. I’m supposed to have a meeting at the end of October about CSP so, I suppose, they’ll look at that at the same time.”

Elliot’s mother

Therefore, not only has the Act had little impact on the transition of these young people, parents are also poorly informed about the Act, and at times seemed confused about it. For Elliot’s mother the decision regarding Elliot’s support plan would be after he had made the transition, and thus would be of no help to him during this time.

This lack of information was mainly important for families who experienced problems during the transition. One aspect in particular parents were unclear about was the role of the co-ordinated support plan. Specifically they did not understand what a plan did, and what it meant for their child. From this work it can be established that parents require a significant increase in the information they receive relating to the Act, and the implications of it for them.

Limited information pertaining to the ASL Act reflects the power imbalance between the parents and service providers. The power differential is in favour of the service providers who hold the information parents require. Despite the ASL Act specifically focusing on providing more power to parents, until there is an improvement in information provision to parents the Act is unlikely to reach its goals, such as working with families and removing barriers.

8.4.2 Encountering physical problems

On making the transition into secondary school there was a process of coping with and resolving environmental problems.

One of the areas schools needed to address was to improve the access. This was far more common amongst the pre ASL group than the post ASL group, which demonstrated a positive change over recent years.

Several schools made physical adaptations to the building which usually took place following the induction days. It could be that schools assess the young people during the transition and identified barriers during this time. Examples of adaptations made were such things as adding ramps or lifts into schools.

“At one of the doors there was only one ramp to access the building. But there was three doors to the one building. But only one door had a ramp. But now there’s a ramp at all three doors. And there two ramps to access the other building whereas there was only one before.”

Darren (15)

Several schools had made adaptations, and many of the young people were highly aware of these changes which had been made to accommodate them.

“I think its really good that we found it [secondary school]. I think that’s really good. It is a really good school. And it’s good that it’s accommodating for me, that is good.”

Ellie (14)

Some families felt that there was a reluctance by schools to carry out such work, despite it being part of Scottish legislation (Education (Disability Strategies and Pupil Educational Records) (Scotland) Act (2002)). Some parents were required to attend several meetings in order to secure some adaptations.

“[I] got the impression they didnae want tae spend the money. Cause the education department is like that. I mean it’s, they’ll no spend the money if they dinnae really have tae. They’ll get the cheapest and they’ll put that there rather than make what they should have done”.

Darren’s mother

“Architects told us it was an impossibility to put in platform lifts in the school, which turned out it wasn’t. And they have put them in”.

Nathan’s mother

Leon’s mother decided on a secondary school that she knew would be accessible for Leon as she was aware of older pupils with similar impairments to Leon attending it. However, following a fire at his secondary school Leon’s school was relocated to an old school building in the town. Here access around the school was far more difficult for Leon. In particular he faced problems with accessing the social areas within the school, such as the dinner hall and playground; this meant that he was forced to spend these times in a different place to the other pupils.

“The dinner hall he couldn’t get in at all because the stair climber, there was like two separate buildings. The stair climbers were in the main building. And they weren’t allowed to take them out on to the ground outside...So it couldn’t be taken into the other one for to get into the dinner hall...So he was having to have his meals, his lunches in a classroom and sit on his own basically at lunchtime.”

Leon’s mother

His mother felt that the lack of access was a barrier to Leon making new friends. Literature has emphasised the need to spend time with peers, and also to be in close proximity to them in order to form friendships. Such barriers to forming friendships faced by disabled young people within mainstream schools have previously been highlighted by Watson et al (2000) and Baker and Donnelly (2001), who discussed the importance of disabled pupils being able to access social areas.

Through preventing full access to all areas of the school in these situations only integration is occurring. Work discussed in chapter 3 highlighted how young people wanted inclusion, and the need for schools to adopt an inclusion policy (Ainscow et al, 1999, Shaw, 1998). However, from these examples we see that neither inclusion nor the core elements of the ASL act are being achieved.

Thomas (1999) referred to such experiences as impairment effects. In the primary school setting, these young people had not been disabled by their CP. However, on moving to secondary school many schools were inaccessible with crowded communal areas. As a result these young people now found that they were being disabled by the secondary environment.

Stairs were one area of the school which caused difficulty for the young people. Zack in particular felt that the stairs in his school were difficult. Zack's school is a listed building and he was told that the school was unable to put handrails up due to this. However, over the summer holidays handrails were installed, which greatly increased Zack's confidence in using the stairs.

"They actually went in during the summer holidays and put handrails up. After saying they couldn't because it was a listed building."

Zack's mother

It was interesting that many of the young people were aware of the changes the school had made for them. It is unclear what impact being aware that the school is spending resources to adapt for them has on the young person. This is something that future work should look into.

Following the social relational approach put forward by Thomas (1999) and previously discussed in chapter 2, the relationship between the young people with CP and other non disabled pupils became unequal. The non disabled pupils were able to move around the school and participate in lessons barrier-free. However many of the young people in this project encountered inaccessible classrooms and school areas and problems on stairs. Due to these disadvantages and the unequal relationship that emerged, we can see that these young people were disabled.

This is disappointing as policy is in place to ensure disabled people do not encounter such problems. SENDA as incorporated into the Disability Discrimination Act, requires schools to make adjustments and for those adjustments to be anticipatory. DSPERA also calls on schools to have an accessibility strategy in place. Clearly some schools need to improve to meet the requirements of such policy.

Parents' whose children were in a special school thought the fact that there was no need for changes to be made was one of the major advantages of such a school. Ben's father highlighted these when speaking about the fact that the local special school was being replaced by units in mainstream school he questioned whether such schools would be as accessible.

"Like I'm assuming that the buildings will be all regulations so they will have disabled access and stuff like that."

Ben's father

He went on to refer to his son's school as being a "*community*" because he was able to access the whole of the school and interact with all of the pupils.

Olivia's father felt that making the move in such an environment was beneficial to Olivia. Her school had developed a transitional class which would slowly introduce her to secondary education over the year.

“I think the teachers have done a good job. And this is a new idea – it seems so obvious! But, for some reason, they haven’t done that in the past. In fact, until they did the transition class last year, for the most part, the children just went straight from primary into secondary. And it was explained, if it looked like it was going too fast for Olivia, they would just slow it down again. Just kinda how you want it to be – if it’s working, you know, press ahead with it.”

Olivia’s father

From this work, and also the experiences of some disabled writers such as French (1993) who reported a sense of relief on starting at special school, the question is raised as to why disabled pupils are not receiving similar experiences in mainstream. Special schools are well experienced in reducing the barriers for disabled pupils, whilst at mainstream schools these barriers remain for some. The way forward would be for special schools to share their knowledge with mainstream schools to assist them to remove barriers for disabled pupils.

The debate between special schooling and mainstream is a complex issue. Although I may be sympathetic towards researchers such as Kenworthy and Whittaker (2000) who feel that special schools only succeed in maintaining segregation, in this work many young people were happy at mainstream whilst other were positive about special schooling. Until all schools are fully accessible and provide real choice for parents, sharing skills amongst teachers is a positive way forward.

8.4.3 Encountering attitudinal problems

In addition to the physical barriers encountered by many of the young people, there were also a number of issues with the attitudes of school staff.

The increased number of teachers at secondary school resulted in the young people encountering varied attitudes towards mainstream education for disabled young people. For some of the young people certain teachers made it difficult for them once they had transferred.

“There was certain, you could, people in the education authority that you know just wanted us to stop being a nuisance and go away. And I think it’s the same with certain teachers. You know, some think mainstreaming is not a good idea. Some have open minds. And others are convinced by the argument already”.

Nathan’s mother

“We’ve always told him that, em if he has a question about the subject, even though he’s got someone there helping him, he should put up his hand and ask the teacher the same as the others, which wasn’t what they wanted, what the teacher wanted...I only found out about it because he came home saying he’d been getting into trouble for asking questions...sometimes our idea of inclusion and theirs aren’t quite...it just seems very out of date. And we’re getting past that hurdle of ‘teacher knows best’ all the time.”

Harry’s mother

Due to poor lift facilities at his mainstream school Darren (15) found that he was being told off by teachers for arriving late to classes.

“There was five wheelchair users using that [the lift]. And say I was third in line that made me ten, fifteen, twenty minutes late for class...that’s how slow it was. And I was getting kept on at the end of classes for being late and it wasnae my fault...’cause some of the teachers were complaining as well, ‘look I’m trying to teach a class, somebody is coming in late means I need to explain, explain it all again.”

Darren (15)

For several young people the problem stemmed from teachers being unaware that they had CP.

“And as I say the main thing was that the teachers didn’t know he had a disability...I think the way it was meant to work is a sheet is handed round each teacher that highlights any issue. But I don’t think the teachers actually read the sheet. So what we discussed and agreed was that the guidance teacher would stand up at the beginning of each term and say ‘Matthew has cerebral palsy’. That sheet did come from the primary school. But then the sheet that then goes round, you know, it’s like a newsletter that goes round high school teachers every term, I don’t know, was he on it, I don’t know, was it read, I don’t know.”

Matthew’s mother

In special schools most of the teachers are specifically trained regarding the educational implications of various impairments (Baker and Gaden, 1992). Matthew’s

experience of the teachers being unaware of his CP again demonstrates how mainstream schools could learn from special schools. Writers such as Farrell (2001) stress the importance of training if full inclusion is to be achieved. Here we see evidence of the impact on young people when teachers are not fully trained.

There was also a problem with information being supplied to the secondary school during the transition, or with information not being passed on to all the teachers at secondary school. Research has highlighted the problems that parents have previously experienced due to a lack of communication between services (Darrah et al, 2002, Sloper, 1999).

“The primary had led them to believe that he couldn’t be involved in any classes and he would have to be in learning support bay and, all the time. That was my major worry that he would feel isolated from his friends. In actual fact...in first year especially he was in every class. And they found he was happier there and worked better there.”

Nathan’s mother

In this project, the young people, as well as the parents, felt there had been a problem in communication between their teachers.

“None of them knew I don’t think really... Well it’s okay sometimes if they are aware but I don’t want them to treat me differently...But most of them didn’t know and didn’t have a clue...and my parents had to go and speak to them and stuff. Cause they didn’t really understand...it’s hard to do it like in front of your friends and that.”

Matthew (14)

“I don’t know if they know I’ve got CP. But all my friends do, know what I’ve got. But the teachers I don’t know.”

Andrew (16)

This lack of information often led to the young person being excluded from the lessons.

“PE was another issue because they were doing rugby training at the beginning and Zack felt he couldn’t join in with a lot of it, he was kinda left to his own devices, instead of the teacher giving him a ball or something to do, a specific thing.”

Zack’s mother

As argued above, this again demonstrates the need for teachers at mainstream schools to receiving training to assist the process of inclusion.

Once the young people had moved to secondary school many of the young people found that their assistants had a good understanding of impairment. Several of the young people felt that the assistants were individuals who provided support to the young people, some named the assistant as someone they could turn to for support; Kerry (12) felt that she would ask for help from “*probably one of the learning assistants.*” Her mother also felt this, and was reassured that Kerry had someone to ask questions to at her new school.

“Her learning assistants seem to be very supportive of her. She comes back and tells me about wee conversations that they’ve had and stuff like that. So she seems to be able to ask them things”

Kerry’s mother

Nathan (14) built up a really strong relationship with his allocated carer who came down to primary school to meet him before he made the transition. For Nathan (14) his mother felt that the assistant had helped him make new friends once at secondary school as the assistant was young and considered to be “*cool*”. Helen (15) also spoke about chatting with the assistants and felt it did not interfere with her forming new relationships, although she would have liked to have had more male assistants as most at her school were female. Leon’s mother felt that Leon (16) had benefited from being allocated an assistant following the transition; she felt that this had helped Leon to integrate into secondary school.

“Like his first day he went in and they had a seat sitting for him away on his own, you know, at the back of the hall. But the care assistant from [Primary school] that was there, she turned round and she said ‘no, that’s not on’. She said ‘oh no I’m...’ and she was away, she moved the seat and everything and got him in amongst everybody else, you know.”

Leon’s mother

Many of these young people, like Leon, had positive experiences of assistants. However for other young people their experiences were negative. Some writers such

as Evans and Lunt (2002) argue that assistants work against integration, and for some of these young people this was their experience.

Elliot experienced negative comments from his assistant which he found difficult to deal with. In particular they questioned the way Elliot chose to move around the school.

“I think it’s good that they’re [assistants] writing for me, but I’d like to find a way that I can do it. Or find a way I could try, on a computer or something...like teach you more independent”

Elliot (12)

Elliot’s mother expanded on the issue during her interview.

“I know he feels that his independence is compromised because they want to push him, whereas, he wants to do it himself...I think, if you don’t come across it yourself, you don’t know very much about the condition. So I think, they sort of ‘I’ll help you. Poor you.’ They [assistants] are really nice to him but, I think, sometimes he feels it can be a bit suffocating.”

Elliot’s mother

Both William’s and Elliot’s mothers told of a similar situations where an assistant showed a lack of understanding.

“There was a slight hiccup where, in computers, he uses a computer all the time, and one of the auxiliaries mentioned that perhaps he shouldn’t do computers. And I just thought I need to put the full stop on that one because he is doing it. So, you know, I went in and said it’s like saying to a child who has a French father or mother, don’t do French.”

William’s mother

“People see him walking and they’ve said to him ‘oh, but you can walk.’ And they’re not taking into account that he can walk, but it’s not like you and I walk. It’s hard work...It’s hard work...it’s the SLA’s [questioning him] actually.”

Elliot’s mother

Gareth (16) was allocated an assistant when he first made the transition from primary school. Having made the transition Gareth attempted to cope without his

assistant in order to try and obtain some of the independence his peers had. However, his assistants were not supportive of his decision.

“I remember one of the times, when I decided to try and, I think one of the, sort of the streaks of independence, I think I heard Mrs Marshall the auxiliary saying, you know, ‘what’s he going to be like on stairs’.”

Gareth (16)

Becoming independent is one of the key differences between primary and secondary school. Like Gareth several of the young people talked about how their assistant prevented them from becoming independent.

“We had a couple of blips with auxiliaries didn’t we. We had one auxiliary that wasn’t.....too hot at, she forgot who she was speaking to. And she treated John as if he was five. She kept telling him he was a good boy.”

John’s mother

“A couple of times he’s been sent home and I’ve got in and they’re carrying the bag and it’s a case of ‘let him carry it’...they’ll have to kinda step back a wee bit. Because, another time, he was fantastic at promoting his independence but they seem to be mothering him an awful lot just now.”

Zack’s mother

As seen earlier becoming independent was one of the main aspects the young people liked about secondary school, and again these young people were missing out on this.

Many of the young people had experiences of sharing an assistant with another pupil. Harry (11) was relieved that his assistant mostly sat at the back of the classroom and also helped other people in his class. This made him feel less excluded from his peers. Gareth (16) had been placed in a secondary class with this other pupil who had an impairment and without any of his peers from primary school, his mother specifically felt that this was in order for him to share an assistant.

“Mr Harris eventually apologised to us because.... He had been focusing on getting Gareth into a class with Philip. Who was the other disabled boy. I’m sure to some degree because of staffing because thereby they could share an auxiliary”

Gareth’s mother

Elliot (12) also shared an assistant, however this led to him being grouped and paired up with other pupils with additional needs rather than integrating into the class and allowing him to choose his partners.

“I get the impression that there’s four of them with special needs in his class and they seem to – because there’s one SLA for the four of them...He seems to be pairing up with one boy who’s in the main body of the class from another school in some of the lessons, which is quite good.... But, as a whole, there seemed to be a little bit of ‘them and us’ going on, you know.”

Elliot’s mother

Therefore having to share an assistant reinforced to the young person that they were different and limited their opportunities to seek and develop other friendships. Shaw (1998) reported that often assistants can act as a barrier to forming friendships; in this study some of the young people and their parents felt that possibly their school experience had been affected by having an assistant.

The need for assistants as well as teachers to receive specific training is clear. Despite many young people encountering problems at secondary school, several families noted the advantages of being at a bigger school. One such advantage was the secondary schools approach to including the young people. Many parents felt that having a diverse range of pupils at secondary was an advantage where the young person benefited and also the school had more experience, which Nathan’s mother referred to as a ‘revelation’.

“They will send home a form...permission slip for a trip. And you fill in, you know, has your child any additional needs. You put wheelchair user. And the first couple of times I phoned them and they said of course we’ve got transport [laughing], you know”.

Ellie’s mother

“The teachers know about the problems and they know about his illness, and they’re very understanding.”

Kyle’s mother

Helen’s mother also noticed a big difference once Helen (15) had moved to secondary school. The experience of the school in working with pupils with impairments, and also the diversity of pupils within the school had a big impact on Helen (15).

“Whereas at secondary there’s more like Helen. There’s people that are better than Helen, there’s people that are worse than Helen. And Helen helps people now at [secondary school] whereas I mean we’ve just discovered she can sign. We’ve discovered loads of things that in seven years in primary we’ve never noticed.”

Helen’s mother

It is clear that some schools, such as Helen’s, there has been an adoption of an inclusion policy as Farrell et al (2007) argues for. Such an experience had a positive impact on the young people attending these schools.

In these situations the parents felt that they could rely on the school to ensure that the appropriate provisions were made for the children, which meant that they no longer had to be concerned with it. This resulted in these families building a relationship of trust with the school.

8.5 “Cause there’s like no-one else that went to [primary school] you can compare me to”¹⁷ – Who I am

Through making the transition many of the young people began to look at how they were perceived, and how they perceived disability.

During this time many of the young people began to develop their identity. Through this process the young people had to address issues of standing out and being perceived as being identifiably different from their peers. The young people also attempted to monitor the impairment effects of their CP at secondary school, such as a lack of energy. Thomas (1999) refers to property and attitudinal barriers, however it

¹⁷ Ellie (14)

is also important to recognise that some disabled young people will also encounter specific impairment effects which impact on their ability to interact with their peers.

8.5.1 Developing an identity

For many of the young people on making the transition into secondary school there was the opportunity to meet and interact with other disabled young people.

Several of the young people had previously been the only disabled pupil at their primary school. Helen's (15) situation for example was common to many of the young people. She was enjoying having a mix of disabled and non disabled friends. In particular Helen spoke about how she shared transport with her disabled friends at secondary and also had their company during lessons she did not participate in, such as PE. This could be perceived as a problem due to Helen being separated out and put into a disabled group.

Helen's mother felt that being able to interact with other disabled people of a similar age, along with non disabled young people was an advantage to Helen. On reflection she felt that Helen had not really enjoyed primary school because, being the only disabled pupil, she stood out. Helen herself found having the opportunity to make a range of friendships had given her more confidence at secondary school.

“And it's like we are not all singled out...It's...because we have cerebral palsy there's nowt wrong with us. And it's like I talk to my friends as well ‘I've got cerebral palsy yada yada yada’ and then I ask them would you treat me any differently? And they say no, we would treat you all the same.”

Helen (15)

From Helen's experience it becomes clear that decisions in education are complex, on the one hand we want young people to mix with individuals who are similar to themselves. However we also want to integrate groups of young people and not to segregate one individual group. From this experience it appears that it could be best to leave the young people decide for themselves. Here Helen has both disabled and non disabled friends, which result in having a positive impact on her self esteem.

William (11) also had a positive reaction from new friends he had made at secondary. These friends had accepted him as himself. He was pleased to give an account relating to his recent birthday party.

“One of my friends forgot to tell his mum that I was in a wheelchair. And then when he came, when he came for my birthday party it was a shock!”

William (11)

We gain an insight into the young peoples’ identities through the stories they tell, this is referred to as ‘identity as narrative’ (Shakespeare, 1996). Several of the young people make reference to being normal, as seen in William’s account. William was very pleased with this situation as it suggests that his friends did not focus on his impairment. In telling this story William reinforces that he does not want others to perceive him as ‘disabled’.

For Ellie (14) being at secondary school did not make her feel that she stood out as she had at primary school. Ellie recalled being the only pupil at primary school to use a wheelchair, now that she was at secondary school there were several others. She remembered feelings of being different at primary school, because she was the only wheelchair user. This is evident when she speaks about another pupil arriving at her primary school who was also a wheelchair user.

“You can compare me to her. ‘Cause there’s like no-one else that went to [primary school] you can compare me to.”

Ellie (14)

Being able to compare herself to her peers was a positive experience for Ellie. As Goffman (1968) argues an individual’s identity is developed through the comparison with others. When these young people were the only disabled pupil in primary school there was constant reinforcement that they were different. Being able to compare themselves to other pupils was reassuring for these young people, and contributed to feelings of inclusiveness at school. We also saw this earlier in this section in the extract from Helen, and again with Darren below.

"I think he got mair of it in the first year. All the kids werenae used to wains wae wheelchairs. And all of a sudden there was five of them, ken?!"

Darren (15)

Being able to identify with other young people and not being the only pupil with a difference enabled the young people to feel more included in the school community. This emphasised the importance of becoming part of a 'sub-group' to the young people, where previously they had experienced being a single outsider.

From this work there was the opportunity to see how the young people viewed themselves.

In line with literature such as Connors and Stalker (2007) and Skar (2003) a few of the young people saw themselves as being no different to their peers.

"Just normal"

Ian (11)

"It was like mum and stuff who got all the stuff in place, and I was like a normal kid"

Harry (11)

As noted in chapter 5 we see here how there is a tension between normality and difference. Here the young people are expressing the desire to be seen as normal; however earlier in the chapter we see how young people want teachers to be aware of their difference. In chapter 5 the emphasis was on the parents highlighting the tension, however here we see the young people themselves doing it.

Also, as discussed in chapter 6, for the young people there are no impairment effects at this time as they do not perceive their impairment as impacting on the transition. Thomas (1999) argues that impairment effects do not automatically result in disability but must be present for disability to occur. For these young people at this stage in the transition the social context did not lead to the impairment effects resulting in disability.

Many of the young people involved in the project had a positive view of themselves, regardless of the level of severity of their CP. This included having plans for the future which often involved university. These findings support work such as Shields et al (2007) who concluded that young people with CP do not have a more negative global self worth compared to their peers.

“I’m doing higher PE. And they all thought I couldnae dae half of the things. And I’ve stuck with it for five years. And if I get my higher at the end of the year then that’s good enough to get to Uni.”

Andrew (16)

“I think I’m sort of on the way, on the way to a job, university and a job. I do hope the exam results are good though. You know”

Gareth (16)

Despite such positive views there was a tendency amongst the participants to use medicalised language and categories when talking about impairment. Most participants referred to individuals who were non disabled as being ‘normal’, and the feeling of needing to be ‘normal’, that is not to make their impairment obvious.

“He was determined that he was going to be as normal as everybody else. That’s cause that’s what you are eh?...But if you focused on it more I think then people will think ‘oh there’s maybe something wrong with him’. He’s really just determined that he’s normal.”

Andrew’s father

When speaking with the families it became clear that they did not see themselves as one big group under the heading of ‘disabled’. This would be in contrast to the social model thinking, which Shakespeare and Watson (2002) note does expect disabled people to identify themselves as part of a ‘disabled’ collective. Parents tended to place their children into smaller groups with others who where impaired in the same way as them. Many of the young people also adopted medical groupings introduced by the parents to distance themselves away from negative connotations of disability.

“It’s different if you’re in a wheelchair where it’s blatantly obvious. Some do like discriminate or whatever eh, against people like that eh. ‘Cause they are not as mobile and you would have to help them and...you would have to wait on them coming...”

Andrew (16)

“He has a significant problem with dealing with people with leaning difficulties...He finds them very hard and slightly threatening. He’s frightened by them because obviously he knows that they don’t really understand what they are saying and what they are doing. But physically they are quite able and he can’t, he, you know, he is threatened by them, he’s vulnerable if he’s in those sort of children around him...which is why he’s not keen on going to the units.”

Toby’s mother

“All the kids he’s with at the moment, their disabilities are more behavioural, sort of Asperger’s, that sort of thing, but what he’s always looking for is, you know, the dodgy legs or dodgy eyes! (Laughs). But he can relate to that. So he sees them sometimes more of a, not nuisance...he did feel the children around him were a bit sort of, you know, those friends were slightly embarrassing (laughs). I don’t think he wants them with him all the time!”

Elliot’s mother

This phenomenon of young people using adult discourse to label other children was also noted by Davis and Watson (2001). This raises issues for young people with regards to establishing their own views and discourse to discuss disability; for many young people this will take time and having experiences. For example as we will see later, several of the young people chose to make use of the support unit on arrival at secondary; however once they build up their experiences of secondary school they may choose not to.

It is interesting how many of the parents and young people discuss impairment in a medical way, despite discussing issues such as access and inclusion through more of a social approach. For example, a number of young people, such as Andrew, referred to those without impairment as being ‘normal’. Connors and Stalker (2007) attributed such dialogue to young people’s medicalised experience of impairment and a lack of positive language to discuss it.

To some extent there is also evidence of how the parents' language influences the young peoples' dialogue. Lewis et al (2007) noted that parents tended to adopt medicalised language to discuss impairment and disability, and as noted earlier young people often adopt the language of their parents. How such language impacts long term on the young person's identity is unclear, and would be an interesting issue to investigate with the young people in the future.

8.5.2 Problems of standing out

Having moved to secondary school a number of the young people at mainstream school were very aware of standing out from their peers. In an attempt to overcome access problems, schools often made provisions for the young people which meant they were required to do things differently to their class mates.

Most of the young people in this project did not want to be seen as different, and did not want to be identified as someone who needed to do things in a different way. They were attempting to avoid being identified through disabled discourse which can commonly occur within mainstream schools (Watson et al, 2000, Priestley, 1999).

"I think I remember in first year John, because there was no gym hall because it was being built they had initially arranged for one of the teachers to drive John to the sports centre. And then for an auxiliary to walk John down to the sports centre. But that quite quickly got dumped because John wanted to go down with his friends."

John's mother

The volume of people moving around the school led many of the young people to change their behaviour to accommodate this. For example Elliot (12) can walk but requires walking sticks or uses his wheelchair for long distances or if he is feeling tired. He was finding that at secondary school he was choosing to use his wheelchair more.

"There's some teachers and stuff who push past, and I don't like that."

Elliot (12)

"He's happier; actually, in the chair because there's so many children coming towards him, his sticks get knocked."

Elliot's mother

The result of such attitudinal barriers impacted on the young person's self concept. As seen with the accounts from Elliot's mother, his assistant's attitude reinforced Elliot's difference by assuming because he could walk that he would conform with other students and walk around the school. Earlier work has also found examples of such expectations of disabled young people occurring within schools (Davis and Watson, 2001).

It was suggested that these young people leave class early as a way of coping with the amount of human traffic. Not all of the young people chose to take this up, some only left early for lunch or if the next class was on the other side of the building. Other young people chose not to leave early at all.

"For the first year or two he left class early with [another disabled pupil], about five minutes early to get to his next class. So we didn't have to deal with crowds, you know, and stairs."

Gareth's mother

"If my next class is like down or up the stairs I will have to leave a bit earlier...and that's also good about leaving early you don't get caught in the crowd."

William (11)

"It all seemed to have been sorted out between the three days that she had before the Summer and then the first day that she started, because they didn't do the lift pass and coming to get her between the classes on the three days before. So, whether they sussed all that out during the three days that she would need that, that all seemed to be in place as soon as she started after the summer."

Kerry's mother

Having to leave early to move freely between classes was not ideal, not only did it make the young people stand out as different, but it also could result in the young people missing information from the end of the lesson. Some parents thought that this was working well, whilst other parents felt that this might be a problem in the future.

"I think, sometimes, yeah. I think a few occasions he felt he might have missed something. But, I think, you know ... that could be an issue at times"

Elliot's mother

"I think somebody gets her a few minutes before the bell rings, and just takes her. So they're all pretty much packed up at that time anyway, I think"

Kerry's mother

Other young people had slight changes made to their timetables to help them keep up with work. For example William (11) went to the support base during certain lessons to give him the opportunity to catch up on any work. Using a lap top he occasionally needed extra time to complete work.

"I get...I get [an extra] period each week to catch up. Like when the rest of my group, class are doing art. I won't do art I will go to the unit."

William (11)

Attempts made by schools to assist the young person often resulted in them missing out on social time with peers, for example moving from class to class usually involves the pupils interacting along the way. Experiencing the transitional spaces between classes has been identified as being important to maturation (Lucey and Reay, 2000), which the young people were missing out on.

This would suggest again that many of the young people were integrated and not included into mainstream school. Researchers such as Evans and Lunt (2002) argue that inclusion is not occurring due to practitioners with a lack of clear direction and government irregularity. In this case aspects of both the ASL act (a lack of information and inclusion of parents and young people) and DSPERA (accessibility issues not being addressed) are not being fulfilled.

Many of the young people spent lunchtimes in a different way to their peers, often going early to avoid negotiating the rush of other pupils, other young people found the dining room inaccessible and had to eat their lunch at an alternative venue. In many schools, the pupils were allowed to go to the local shops during lunch times. Toby (14) who is a wheelchair user felt unable to do this, his mother believed that as a result Toby was fairly isolated during lunch times.

“Certainly at lunch time all the children from S1 onwards are committed to meander off wherever they feel like out of the building to go for their pie from the butchers or whatever it is they go... You can’t really blame them for going out. But he does have one friend...he will always sit with Toby and they have lunch together and chat. So I think though, I think he’s feeling a bit vulnerable, you know, that if anything happened, you know, if Richard is off sick he’s really stuck, you know.”

Toby’s mother

Some of the young people also found lunch times difficult at secondary school. With all of the pupils out of classes the social areas became very busy. A number of the young people spoke about starting to go to lunch time clubs, such as “pony club” (Helen (15)) and “bat and ball club” (Nathan (14)) following the transition.

“I go to the lunch club...It’s just like em, well, if you want you can go to the lunch club. It’s like puzzles and games and playing the computer.”

Kerry (12)

A number of the schools made facilities at the support base available during lunch times, where many of the young people reported that they went.

Abbi: Are you using The Base much at all or...?

Zack: Lots.

Zack’s Mother: The Base at [secondary school] isn’t so much as a learning area, it’s more somewhere they go at break-time or lunchtime and things like that.

Zack (11) and Zack’s mother

Although many of the young people felt positively about the support base, most of these young people were in the post ASL group. The young people in the pre ASL group held a different view of the support base.

“After the transition I think probably...I was sort of in terms of character I was...think I was sort of aloof from the other people in my class, slightly aloof because I was, well in my opinion identifiable as learning support.”

Gareth (16)

A study by Sinclair-Taylor (1995) demonstrated how young people can view support units very differently to adults. Where adults see them as inclusive allowing the

young person to be part of the mainstream school whilst also receiving the support they require, Sinclair-Taylor (1995) reported that many young people saw them as being excluding, in that they isolate the young people away from their peers.

It is interesting how the young people in the pre and post ASL groups viewed the support base differently. For many of the young people in the pre ASL group the base represented being different and segregated from the main student body. This may be a perception they have developed through their lived experience of secondary school.

The young people in the post ASL group were far more positive about the support base, and in one way saw it as a retreat away from the busyness of the school. As these attitudes had been developed early on in their secondary experience it could be that we are seeing the continued impact of their concerns. Having only recently made the transition many of these young people could possibly still be adapting to cope with their concerns regarding moving around the school and the increased number of students. Through retreating to the support base at times when the social areas are busy, they could be experiencing a sense of relief and safety. Possibly, once they have spent longer at secondary school, these young people might experience an attitude change in line with those young people in the pre ASL group.

It is interesting that here the young people are choosing to segregate themselves. Middleton (1999) found that many parents choose a special school because they see it as somewhere safe for their children, therefore alleviating their parental fears. However, whilst at special school their children will not mix with non disabled children. In this example the young people are at a stage where they are choosing to segregate themselves to somewhere they perceive to be safe. However, many of the older young people in the pre ASL group have a different view. It could be that with time and prolonged experience of secondary, the young people in the post ASL group will also decide not to attend the base as much. In chapter 7 we saw that Elliot had already made this decision.

From the literature, such as Lewis and Kellet (2004) it is not surprising that young people hold different perceptions of the support base. Disabled young people are not a uniform group, but are diverse social actors.

8.5.3 Being invisible

For many young people there is a desire to belong and conform to other young people (Pratt and George, 2005). As disabled researchers have reported before, there can often be pressure on young people to hide their impairment (French, 1993). This was evident in this project, often predominant in the young people with milder CP, and was often linked to the desire to fit in with friends and not to appear different to them. Andrew (16) explained why he felt it was necessary to down play his impairment;

“You have to try and be yourself and not, not attract too much attention to your disability. Just try and act as much like everyone else that you can...’Cause if you, if you show a weak link then some people will pick on it like. They can see it. And they’ll think you’re just an easy person, you’re easy meat.”

Andrew (16)

Social norms are reinforced in this section through the acknowledgment that many of the young people avoid discussing their impairment in order to comply with other pupils. This is expanded on by the affect control theory (Heise 1979 cited by Stryker and Burke, 2000). This theory suggests that society defines individual roles, and individuals carry out identity-confirming behaviour related to such roles.

For many of the young people in this work there was the desire to be seen as a ‘normal’ pupil within the school. To fit in with this role, as defined by society, they hid their impairment and avoided actions which resulted in them being identifiably different. Following the affect control theory such actions would be deemed as ‘restorative behaviour’; that is behaviour which prevents a conflict arising between the defined roles and the young person’s behaviour.

Many of the parents, more often of young people attending mainstream schools, commented that it was difficult for their child to hide their impairment at secondary school as the difference between their child and others was more apparent. They

made reference to how younger children did not seem to notice any difference, and how other pupils used to be able to push their children in their wheelchairs, which helped them to be part of the group.

Matthew (14) told how he was reluctant to speak about his CP in front of his friends. His mother felt that it had been easier for Matthew at primary school when his CP was more obvious since he wore splints. Now he no longer required them she felt he had gone unnoticed at secondary school. This is reminiscent of work by Allan (1999) where individuals found it easier when their impairment was more visible as they found others were more understanding of them.

“He doesn’t have support but he does have a disability. And he’s kind of in no mans land a wee bit, he got lost a wee bit at high school.”

Matthew’s mother

Kerry (12) was also reluctant that her friends know she had CP.

Abbi: And do they know why you leave a little bit earlier?

Kerry: Mhmm

Abbi: Did you tell them or did they ask you?

Kerry: They asked me.

Abbi: Do they know that you’ve got cerebral palsy?

Kerry: No. Not at all!

Kerry (12)

Some of the young people also found it difficult to deal with questions from other young people about their impairment, in particular if they wanted to know why they got help in the classroom.

“They’ve not asked me, but they’ve asked the person who’s...[scribing] and they ask ‘why doesn’t Elliot write?’...I don’t really know what to say when they ask questions.”

Elliot (12)

“Um, some ask questions...how come I’m disabled and that. But I don’t know, so I can’t answer.”

Ian (11)

This is different to previous literature which concluded that disabled people wanted non disabled people to ask them questions so that the process of educating non disabled people about their experiences could begin (Watson, 2003). It could be that these young people have not yet reached the point of feeling comfortable discussing their impairments, in particular with people they had just met, or possibly, as writers such as Connors and Stalker (2007) argue, these young people do not currently have the language to discuss impairment.

Leon's mother felt that on moving to secondary school and seeing the opportunities available, Leon, in some ways, was in denial regarding his impairment. She felt that as he used both a wheelchair and walking frames there were some activities he was unable to do, which he could not accept.

"'Cause he was quite, you know, 'I could do it, I want to do it'. And, you know, for a long time he couldn't actually, it was as if he couldn't see that he, he wasn't able to do it, you know. Or not accepting that he could, he couldn't do things."

Leon's mother

It could be argued however that Leon simply had the same desires as other pupils and that his enthusiasm could have been nurtured with some adaptations to reduce the barriers for him. Possibly what we are seeing is Leon's mothers fears; fears which Mayall (2002) argues are completely normal for parents.

Unlike many of the young people Zack (11) was more open regarding his CP. His mother described an activity during an English lesson at secondary school.

"One of the first weeks in English, they had to do a talk about themselves and their hobbies and things, so Zack decided to tell everybody all about it. He took an old splint in and they had a look at that."

Zack's mother

It is interesting that Zack, unlike any of the other young people, chose to focus on his CP when presenting a talk about himself. He could have done this to avoid the questions other young people had faced, or alternatively it could be that Zack had accepted his impairment as being part of him, and did not feel the need to hide it. In

work carried out by Watson (2002) it was found that although most disabled people do not incorporate impairment into their identity, a small number of them do. Lewis et al (2007) also noted that for some young people they feel empowered by accepting the disabled label. What is evident here is what Allan (1999) defines as transgression. Whilst some young people moved away from the disabled label others moved towards it.

Some parents had a positive outlook like their children. They felt there was a definite need for the school to adapt and remove the attitudinal barriers which stopped their children attending. There was also a strong sense that others within the school needed to be educated about CP and disability in general.

“I mean they call him spastic and all this carry on right, and you know, it is hurtful for him. But what annoys me about, about it is that see the kids that are doing this, they don’t even know what’s wrong with Craig...And I just think that if the kids were better educated. If the kids in the class, in the school were better educated to...I mean exactly what the illness is , you know, and, you know, and the limitations of the illness...”

Craig’s mother

“Just things like when they, when the rest of the class has been having a test, and it’s a test where she reads out and they’ve for to write down the answer. He really needs to be in a separate room for that. So it’s just a case of, like today he stayed behind...He’s, he’s now done this test a good week after the rest, which is a bit of an unfair advantage, because its gone out of his head then....but he did OK, didn’t you? But apart from that, nothing major. I think it’s just them getting to know him...and um, realising that he needs to do what everyone else does.”

William’s mother

Thus many of the young people felt that they did not want to draw attention to their impairment, and wanted to be considered the same as the other pupils.

In this section there is evidence of conflict experienced by the young people. On the one had they spoke about not wanting others to know about their CP. They do not want to be, what Goffman (1968) would term ‘stigmatised’ but to be seen as normal. Other writers such as Watson (2003) stress how disabled people try to move away

from the media image of helplessness. However, on the other hand many also wanted the school to be able to address and remove barriers.

This shows the complexity of this issue for the young people and the internal conflict that they must be experiencing. It would also suggest that at this time the young people are in a process of establishing who they are and possibly are yet to establish how to deal positively with impairment and what language to use. As previously discussed, Connors and Stalker (2007) note that a lack of positive language may be a significant barrier to young people in expressing their views of impairment, in chapter 7 it was noted that there was a need for spaces to be created to support young people to have these discussions.

Establishing the right level of support for young people is difficult to achieve. One way possibly to get this balance right is to be led by the young person. Writers such as Kelly (2005) have found that young people want to be consulted regarding issues which directly impact on them. Within the remit of the ASL act it is necessary to involve young people in decisions, and from this work there is support that this is one way forward.

8.6 "I would say to ask questions."¹⁸ – Lessons learnt

As a final reflection on their transitional experience, at the end of the interview all of the young people were asked what advice they would give to another young person with CP going into secondary school.

When thinking about the advice they would give, all of the young people thought back to the concerns they had had. For many the most important thing was to know that it was alright to ask for help at secondary school.

"I just tell them who tae go tae if they are needing help wae anything. Whatever, just help whenever they need it."

Darren (15)

¹⁸ Steven's mother

“Um...um...that’s quite hard...I don’t know. [after question broken down] Not to worry and to go to your pastoral care teacher. And other teachers for help going around the school.”

Ian (11)

“Em, I might say to her that, em, it will be scary at first, but then if you are really worried, tell a parent or friend. And, like, just...but, when you get used to it you’ll like it.”

Kerry (12)

Gaining insight and experience of secondary school was also important.

“Go to the induction days. Get to go for a couple of days before move up.”

Elliot (12)

“It’s really good and...don’t be afraid to ask questions. And...just enjoy it.”

Helen (15)

Craig (14) had experience of name calling at secondary school, but like some of the other young people he would tell other young people with CP going to secondary school not to believe the rumours.

“[Don’t] believe the rumours, they are only false and that....Aye don’t, don’t be afraid to ask for help and if you are getting bullied don’t be afraid to ask for help either cause you might feel like if you are getting bullied. Like I know what it feels like to be bullied and that. And I know how I felt like, I didn’t want to tell a member of staff cause then like people would see me as a grass. But like you are doing what’s best for you.”

Craig (14)

Parents were also asked for their advice to another parent of a child with CP who was going into secondary school. Again, across the levels of severity and school type, all gave similar advice, as did parents in both the pre ASL and post ASL groups.

Most parents recommend being informed about the school. This involved asking questions, visiting and having a contact person at the school.

“To ask and you have the right to get an answer. So, you know, I would say to ask questions. And ask....and even for parents who find it really really difficult to assert themselves or maybe even ask questions about things. If, if you find it difficult to ask then write it down and put it intae the school”

Steven’s mother

“Just ask questions. If you don’t know something, just go and ask because, you know, they have a responsibility to let you know what’s happening and how it’s all gonna go.”

Kerry’s mother

“To go up and have a look and see what they think themselves”

Peter’s mother

Many parents felt that they needed to be informed about the transition and the secondary school, and that they also needed to inform their child.

“I think the important thing is that children see the school as much as it’s possible to, and it’s all positive things that you show them, particularly knowing who... Things that Elliot wanted to know, which would have helped, like ‘Who will be my SLA?’ That would have been quite helpful if he’d known that... So, you know, I wanted to know that for him before he went but he didn’t actually fully know all the classes and I think that was a downside, you know?”

Elliot’s mother

“Definitely see if you can get more visits into the school. I don’t think... what is it, two or three days they go in for? - I wouldn’t say that was enough. I would say they need more. The more you can get your child familiarised with it, the better. And talk to the staff if there’s anything worrying you.”

Zack’s mother

Parents also felt that there was an element of *“if you don’t ask you don’t get”* (Craig’s mother), or that *“the ones that shout loudest get”* (Leon’s mother). Similar findings were earlier made by Darrah et al (2002) where parents used terms such as *“fight”* when talking about accessing services. Thus for many parents the process was seen as a battle to achieve the input their child required.

“My advice to someone would be... just to be proactive and to shout a bit. Because if we hadn't done that, we wouldn't have a Co-ordinated Support Plan and he would be at a different school and so, I think, that would be the advice I would give.”

Freddie's mother

“I don't know, I find the whole thing - it wears you down sometimes, constantly being the bad guy and constantly fighting, but it's nice to have... if you find someone who'll fight your corner, but it's not very often it's the school...do your homework and find out what you should be getting.”

Harry's mother

Parents of young people with mild CP recommended that the parents should ensure the school is aware of their needs so they are not overlooked. For those with more severe CP an important piece of advice was to start the process of looking, visiting, and meeting with the school early, in particular if adaptations would be needed.

“Prepare for it as early as you possibly can [laughs] because especially if you are going to need physical adaptations to building cause that's going to take forever”.

Nathan's mother

“I think, a few things that we did at the end of primary school was, at the end of primary 6, when things are really quiet, before you even considered moving to primary 7 – that's when we went round all the high schools. And it was a good time to do it because the schools are winding down for the summer and it was months before you had to put in place any sort of placement requests or anything.”

Harry's mother

“I would say that if the primary school don't approach you at the beginning of the last year of primary, start the process. Because it has to be started to think about it a year before they go, it's too late, if their starting, if they've not done anything by the end of the Easter term it will be a disaster.”

William's mother

Finally, being open to change was advised by some parents of young people with both mild and more severe CP.

“When people suggest things not to say ‘no’.. to consider them because, you know, what, what you maybe say no for initially is because you are anxious about something”

Rebecca’s mother

Thus the recommendations parents make echo the literature, and work such as Anderson et al (2000) on the need for planning and Galton et al (2000) on the positive benefits of transitional activities.

When asked to reflect and draw out the key issues to the transition the need for support was consistently reinforced from both the young people and parents. This is an issue which must be highlighted to service providers and improved on in the future.

From the parents there was also the message that as a parent of a disabled child there was the need to fight services. It would appear that there was a lack of trust in services as discussed in chapter 6.

The young people in the post ASL group found it very difficult to answer the question regarding the advice they would give another young person. Most of them took some time, commenting that it was a hard question to answer. This was possibly due to their age, as the young people found it difficult to place themselves in the situation, or as Connors and Stalker (2007) note, a lack of language.

In most cases the question was broken down for the young person, as recommended by other researchers working with disabled young people (Stalker and Connors, 2003).

However, once this was done, many of the young people came up with similar concepts to those in the Pre ASL group. There was no difference between the types of advice given with regards to the severity of the young person’s CP or the type of school they attended.

8.7 Chapter Summary

At the beginning of the chapter it was outlined that parents' and young peoples' views of the transition process would be obtained, along with the impact of the transition on the young people. The key findings of this chapter are:

- The ASL act has had little impact on the transition.
- That social context has a major impact on the young people's experiences.
- Specialised training of mainstream school staff would be advantageous.

ASL act: In this chapter, and also in earlier chapters, there is evidence that the ASL act is not being fully implemented. Service provision is found to be variable across Scotland, parents and young people are not consulted, and contact people are not being allocated. Some parents in the post ASL group were more likely to receive an input from services out with education during the transition, but this was not consistent for all families. Not fulfilling the aims of the ASL act has led to the opportunity to build partnerships between parents, young people and services being missed. Such partnerships' can help support parents and young people through difficult events such as transitions, and contribute towards a more positive future working practice.

It is argued therefore that the act does not impact on this transition. In order for the act to be successful in achieving the aims it set out, there must be an improvement in information sharing and consultation with families.

Social context: In this chapter it is demonstrated that when reflecting on the transition, a number of the young people encounter property and attitudinal barriers, despite policy being in place to remove such barriers. The change in the social context of their schooling environment resulted in the young people experiencing impairment effects. Some attempts to remove barriers such as the allocation of assistants, or attendance at the support base, resulted in the young person feeling identifiably different to their peers. Families would benefit from the allocation of a contact person to discuss such contextual issues with.

Although neither parents nor young people expressed knowledge of the social model of disability, they both highlighted the need to remove both property and attitudinal barriers. This work concludes that for these parents and young people barriers are more than just physical obstacles that can be removed or fixed, as implied through a more medical discourse. Future efforts need to work towards removing both attitude and property barriers as put forward in chapters 6 and 7.

Training: In this chapter there is evidence that some young people find strength in identifying with other disabled young people, whilst others choose to move away from a disabled identity. It is clear that not all of the young people would be happy to identify with the social model perspective of a disabled 'collective' despite speaking in social model language about the removal of barriers as seen in chapter 7.

Throughout this work there is evidence of the dominance of the medical model, with even the young people and their parents adopting medicalised language to discuss certain aspects of impairment. In many cases the language used reflected the input health care professionals have had in the families life, often from an early age. Parents frequently discussed meeting multiple services, such as paediatricians, physiotherapists and occupational therapists. In several instances parents made reference to being referred to a specific medical service in response to a problem that had arisen. For these families discussing impairment in a medical way was the norm, and they had little or no experience of using more positive language. From the interviews it was possible to see how for most families discussing impairment in a medical way was mostly due to a lack of positive language as evidence from the transcripts show parents using a more social approach when discussing issues such as, accessibility or inclusion.

Therefore although parents and young people had no knowledge of theoretical models of disability, they use aspects of both models when discussing their lived experience. This demonstrates the importance of not adhering to a single model when conducting research, which would have prevented this work from presenting the whole picture.

Although parents and young people adopted medical language when school staff adopted medicalised attitudes this could result in the young person's impairments being highlighted. Such actions move away from the young person's sense of a 'normal' identity being achieved. It is therefore argued that in some cases mainstream school staff would benefit from specialised training to recognise and understand the impact impairment has on learning.

A final contribution to the central argument of this thesis is made in this chapter. It is argued that the goals of the ASL act have not been achieved, and that some attempts to remove barriers for young people impacts negatively on their sense of self. To support young people's sense of a 'normal' identity it would be advantageous for school staff to undergo specialised training.

What can be taken forward from these findings will now be discussed in the following chapter.

Chapter 9

Evaluating the experience of children with cerebral palsy and their parents in the transition from primary school to secondary school - Conclusion

9.1 Introduction

This chapter presents the conclusions of this thesis, addressing each research questions in turn.

A review of the methods used is also included which demonstrates the way in which the work was participatory. An overall evaluation of the project and recommendations for future work leading from this study are also presented. The final section presents my own reflection of the research process, and the journey I made as a researcher.

In response to the question “9.2 *What impact has the ASL act had on this transition?*” the findings from the four analysis chapters are drawn together to conclude that the act has had little impact on this transition. The next section “9.3 *What kind of transitional experiences do young people with CP and their parents have, and are their needs being met?*” puts forward that overall both young people and their parents report positive experiences of the transition, even through in some cases their needs were not met.

The role of the young person is considered in the question “9.4 *Does the ASL act’s call for young people to be involved in service planning have an influence on transition?*” It is demonstrated that efforts need to be made to improve the involvement of young people in this transition. Evidence is again put forward from all analysis chapters to answer the question “9.5 *Do young people and their parents adopt, or are they influenced by models of disability?*” this research illustrates that many parents and young people use both medical and social language when discussing impairment.

The final research question “9.6 *Does the social model aspect of the ASL (removal of barriers) help combat discrimination?*” concludes that young people continue to

experience both physical and attitudinal barriers at secondary school, which results in some parents choosing a special school for their child.

The methods section shows how a participatory approach, allowed the true experience of the young people and parents to be heard. Thus from this data it is possible to make future recommendations based on their reflective experiences.

The chapter then moves on to evaluate the project, to make recommendations for future work, and to present reflection from the research. The evaluation section considers both what the project has achieved, and also what could have been improved. This is followed by suggestions for future investigations derived from this project. In the reflection section the researchers journey is explored.

The project focused on hearing first hand the experiences of the transition from primary to secondary school, from young people and their parents. They were provided the space to share their personal accounts, and to say as little or as much as they felt necessary. These accounts led to the answering of the research questions

9.2 What impact has the ASL act had on this transition?

In chapter 3 the literature on the ASL act was discussed. It was hoped this act would improve the transitional experiences and reduce the variability of services. Through this study, it is evident that there is no significant difference between the experiences of those making the transition before the implementation of the act compared with those moving after it and that service provision remains variable.

The act was passed in 2004 and came in to effect in 2005, thus 2 years had elapsed since its implementation. It was envisaged that this would give sufficient time for the act to have made a change. From this project it is evident that it has not.

When parents were asked about the act before and after the transition, they appeared to be confused about it. In both cases, in the parents' opinion, the act has had no impact on their experience or that of their children.

Under the act, parents are given the right to have a contact person. As demonstrated throughout this project this was not a service received by all parents, but it was a service valued and wanted by parents. This act also states that the views of young people are to be taken into account. Again this research shows very few of the young people were consulted directly to obtain their opinions. Thus again key aspects of the act are not being implemented.

9.3 What kind of transitional experiences do young people with CP and their parents have, and are their needs being met?

From reviewing the literature pertaining to this transition, it was established that the views of disabled people and their parents were missing. In responding to this research question this work has contributed new knowledge to the field.

All of the participants reported that they felt the transition had been a positive experience. This was despite many of them experiencing problems along the way. For these families it was how such problems were overcome and addressed which impacted on their final evaluation.

The literature in chapter 3 clearly demonstrates that barriers are an issue to disabled young people in accessing mainstream schools. Young people in this work encountered physical barriers, and also attitudinal barriers, when trying to access these schools.

To some young people there continue to be barriers to accessing mainstream schools, and also barriers due to poorly informed staff. However, barriers were not experienced by all young people. Fewer barriers were encountered by young people moving to a school with previous experience of including disabled pupils. Those young people moving into special school also encountered fewer barriers.

Parents want to be able to have a choice of secondary school for their child. Many felt strongly about accessing the local mainstream secondary school but this was not always possible. The choice parents made was highly influenced by their own personal history.

Some parents chose special education for their children. For these parents having their child fully included in school was preferable to integration within a mainstream school.

In contrast to the literature presented in chapter 3, bullying was not the main concern of the young people. Both parents and young people held concerns which were related to social, mobility or structural issues. For the young people their concerns centred on aspects that they knew were 'real', such as negotiating stairs or carrying a heavy school bag, and not hypothetical issues such as bullying which might or might not occur.

Parents dealt with such concerns by drawing on past experience. Therefore it is important that early transitions are successful as their experiences of them will be drawn on during future transitions.

Many parents felt dissatisfied with services at this time and continued to feel that there was a need for them to fight for the right services. Feelings of dissatisfaction came about when parents felt they had been neglected. For example, following the induction days parents did not receive any feedback and were depending on their children to recall accurate accounts.

Also important to families was input from services who knew the young person. Parents in particular felt angry at professionals having an input into decisions regarding secondary school if these professionals had not previously met their child.

9.4 Does the ASL act's call for young people to be involved in service planning have an influence on transition?

It became apparent through talking with the young people that many of them are not consulted by services regarding their schooling. This is a disappointment and is also in breach of the UN Convention on the Rights of the Child (1989).

In the early stages of the transition most of the information went to parents, and the young people were somewhat neglected. With the induction days, there was a shift

with information provision going to the young people .The young people appreciated this and it resulted in them feeling more independent.

The ASL act has failed to develop spaces for young people to be involved in making decisions and to share power with their parents and services.

9.5 Do young people and their parents adopt, or are they influenced by models of disability?

Although parents and young people would not have been expected to have a knowledge of models of disability, both used such discourse in reference to impairments.

Parents often used medical discourse to explain why their child required support. However, their concerns regarding support were often coming from a more social model perspective and their real experiences of working with service providers.

A major part of this transitional experience for the young people was the development of their personal identity. Following the induction days they began to disclose issues relating to their identity. During this time young people begin to notice how their peers might be seeing them, and they began to choose not to be identified as 'disabled'. Many of the young people saw themselves as another 'normal' pupil in the school, and some did not appreciate anything which made them stand out, such as the allocation of assistants.

However, there was variability amongst the young people with some identifying with a disabled identity and gaining strength from this, whilst others chose to move away (transgress) from such an identity. The latter group felt they did not want to focus on their impairment.

9.6 Does the social model aspect of the ASL (removal of barriers) help combat discrimination?

As noted earlier, the literature in chapter 3 highlights the barriers young people encounter when attending mainstream school. Act's such as the ASL should have improved this situation.

This work found that within the mainstream setting young people encountered both property barriers, such as a lack of access, as well as attitudinal barriers, such as a poor understanding of impairment by teachers. Such restrictions demonstrate that the social context can result in disabled people experiencing impairment effects, and would imply that, at these schools, inclusion is not occurring. As a result of such barriers some parents elect to send their child to a special school.

Through this experience disabled young people encounter a language of impairment from their parents and services providers. Such experiences demonstrate that as yet the ASL has not successfully removed barriers.

It is disappointing to find such barriers in place for disabled young people wanting to go to mainstream school. Policy such as the ASL and DSPERA should have resulted in the removal of such barriers if implemented correctly.

9.7 The argument made by this thesis

This thesis argues that the aims of the ASL act have not been fulfilled and that as a result the opportunity for services, parents and young people to work in partnership has been lost. It is important that services create spaces to allow processes of partnership to be developed between them, parents and young people. In some cases working with groups of parents to enable local support networks to develop might be advantageous.

There needs to be improved transitional information for both parents and young people which is accessible to all. This would result in parents being able to carry out their desired role as responsible parents. Such information would also allow parents to make informed choices regarding schools. However, if a real choice is to be had, all schools need to be fully accessible.

Young people often miss out on opportunities for dialogue due to the homogenous views schools have of disabled young people and the assumptions they make. This work argues that the value young people placed on the independence experienced

at secondary school demonstrates that they are able to make choices but need the opportunities to do so.

Throughout this work, despite no knowledge of the social model of disability, both parents and young people speak about the need to remove property and attitudinal barriers. This work therefore concludes that effort needs to be put into the removal of attitudinal barriers as well as property barriers. In some instances staff at mainstream schools might also benefit from specialised training to understand the implication of impairment on learning.

Finally, this work argues that, although many young people speak in social model language about removing barriers, not all young people would agree that they identify with a disabled 'collective'. This work concludes that when working with young people it is essential to see them as individuals, and not project assumptions onto them.

9.8 Methods

This thesis has drawn a number of conclusions and made recommendations for the future based on the data collected. The aim was to make the voices of young people with CP and their parents heard and to use these voices to form recommendations. Adopting the methods that it has resulted in the data generated being deemed credible.

This project crossed between the fields of childhood and disability studies, thus the methodology was an amalgamation of these two fields. From both of these fields the message is that individuals need to be consulted directly, and here both the young people and parents were given this opportunity.

From disability studies, participatory and emancipatory research has evolved. This work justified being participatory, and thus consulted with the participants to generate the data. Although in reference to Hart's (1992) ladder of participation the top levels were not achieved, this research was well within the participation range and shared decisions with the young people despite the research being adult initiated.

A single model of disability was not adhered to. In order to represent accurately the lives of disabled people, the work needed to incorporate the essence of both. The medical model fails to acknowledge the impact of the environment on the lives of disabled people. Whilst the social model, although advocating the rights of disabled people and the need for society to rethink its attitudes, does not mention the role impairment plays on the lives of disabled people.

The young people were diverse social actors and thus their lives are more complex than either of these models proposes. For many of these young people there was a need to acknowledge both the impact of impairment and the need for society to represent disabled peoples true experiences. This realisation was adopted by the project and taken forward to the data collection and analysis phases. It is also the view of other researchers in the field, such as Shakespeare and Watson (1998).

The diversity of disabled young people was recognised, and the methods adapted accordingly. Researchers who view disabled children as a uniform group has been highlighted as a problem of earlier research (Lewis and Kellett, 2004). Shakespeare and Watson (1998) also criticised previous research for being primarily non disabled people discussing disability, adults discussing children. This study ensured that these people were allowed to speak for themselves, and discuss the issues that they saw as issues to them.

Individual interviews were adopted to give the participants the space to express their voices. The final part of the methodology was to disseminate the conclusions, which again was part of being participatory. Through disseminating to the young people directly it was demonstrated to them that they had been listened to, and their views taken into account.

9.9 Evaluation

This work set out to ask young people and their parents about the transition from primary to secondary, and the methods adopted have allowed this to be done.

In evaluating the study there are a number of points to be made, highlighting the success of the investigation and its limitations.

Contribution to knowledge: This research has made a number of contributions to our understanding of this transition.

- *The voices of disabled young people:* Previous studies on this transition have focused on the experiences of non disabled pupils. This work has allowed disabled young people to tell their story. For these young people there are a number of issues similar to their non disabled peers. However, these young people have concerns regarding mobility issues, deal with issues surrounding identity and perceptions of impairment, and may also encounter barriers to accessing their local mainstream schools.
- *The voices of parents:* Again the experiences of parents were not widely reported in the literature. From this study the preparation and time required from parents to assist the transition can be seen. They share the mobility concerns of their children and often act as a liaison between services.
- *Choice of schools:* This project provides an insight into how parents go about choosing a secondary school, which has not been extensively documented in the literature. For many parents their child remaining within the community was key, others valued having the option to choose special schooling. All parents considered accessibility, travel to school, and inclusion at the school. Several parents made a final decision based on the feeling they got from a school. It was concluded that the choices parents made were heavily influenced by their own personal histories.
- *Coping:* Much of the literature within this field identifies areas young people are concerned with. This project also identified these, along with areas parents were worried about. The question was then asked as to how such concerns are dealt with. From the parents it was established that coping came from the ability to draw on past transitional experiences, good or bad, and recall what was learnt at

these times. The young people also seemed to do this, through recalling events at primary school.

Comparing groups

- *Parents and young people:* The literature such as Mishna et al (2004) and Sloper and Lightfoot (2003) argues that parents and young people frequently have different views, thus consultation directly with young people is important. The views of parents and young people were listened to, and comparisons drawn. It was found that parents and young people in this study had similar views, and tended to report very similar thoughts and feelings. One difference which did emerge was that parents were worried about the increased number of teachers at secondary schools, whilst young people looked forward to meeting these new teachers.

These findings were found within both the pre and post ASL groups. Although parents and young people were interviewed together in the pre ASL group, this did not seem to influence the findings, as the young people were happy to disagree with their parents regarding minor details. What this finding does establish, similar to the work that of Zeedyk et al (2003), is that parents are overall in tune with their children. Although they may disagree on some smaller issues, generally they report similar views.

Although parents and young people agreed on the major issues, what speaking to the young people allowed was the realisation that there was more to their experience than moving from one school to another. Without talking to them directly the identity issues, and those pertaining to fitting in would not have been discussed.

- *Mainstream and special school:* This study included young people attending both mainstream and special schools. With regards to the transition, those in special schools tended to have fewer problems, mainly due to remaining within the same school building. Reports from parents also noted that teachers at special schools knew the young people very well which aided the transition. Many young people at mainstream schools felt that teachers did not know who they were.

- *Young people less visible CP and young people with more visible CP:* All young people on the CPRS were invited to participate in this research, thus the sample was made up from young people with different levels of CP.

For those with more visible CP there were a number of barriers to them accessing mainstream schools. Many of them were required to choose alternative mainstream schools other than the local community secondary they originally selected.

Many had feelings of wanting to move away from the 'disability' label. This was true of both those with less visible CP and more visible CP, although it was more frequently discussed by those in the former group. These young people also faced the dilemma of whether to disclose their CP to peers and teachers, or whether to hide it. Young people with more visible CP were more likely to be wheelchair users, and thus felt they could not hide their impairment from others. These young people were also more likely to be in special schools where this was not such an issue.

Methods

- *Merits of multiple interviews:* Single interviews were carried out with the pre ASL group and multiple interviews with the post ASL group. Being able to compare both methods of working led to the realisation that there were advantages to multiple interviews. The post ASL group were far more relaxed by the second interview, and had developed a relationship with me, which made the interview process more fluid. Single interviews were more appropriate with the pre ASL group, as the event had passed (Bricher, 1999). However, having seen the affects of multiple meetings, an introductory meeting would be advantageous for future work with young people.
- *Inclusion in planning:* In preparing to carry out this research it was envisaged that there would be some consultation with disabled young people regarding the planning of the study. In particular it was hoped that a focus group of young people would assess the information sheet to ensure informed consent could be

achieved. However, once the project started it transpired that this would not be possible, primarily due to time constraints. Eventually parents of disabled young people working for a charity assessed the information. Consulting with young people during the planning phase would have been beneficial, as it would have ensured that the materials and methods were user friendly. Future work should incorporate the time and resources to ensure this occurs.

- *Validation methods:* Within this work there was an attempt to incorporate further validation of the findings through a questionnaire. In this project the response rate was low, and as a result the data generated did not significantly contribute to the work. It would be advantageous for future work to repeat this exercise on a larger scale and to further investigate the views of parents and young people. A questionnaire would allow for larger numbers of families to be involved in the work. Therefore issues such as the area families live in, socioeconomic status and the role these play in the transition can be addressed.
- *Researcher affects:* As a young non disabled female researcher there is a question as to whether my characteristics impacted on the data. It is possible that the young people would have disclosed more to a disabled researcher, who they may have felt could empathise with them. Also the young males, who made up the majority of the sample, may have spoken more openly to a male researcher.

While these issues are possible, I approached the interviews as openly as possible, and took many steps to ensure the young people felt comfortable speaking to me. With the young people forming a highly diverse group, it would be difficult for any one individual to be the ideal researcher to talk to all of them. Where the characteristics of one researcher would be appropriate for one participant, they may not for another. Through adopting a non judgmental participatory approach, I feel that all the young people were given the opportunity to speak.

9.10 Future work

This project aimed to look at the accounts of young people with cerebral palsy during the transition into secondary school, and also the experiences of their parents at this time. This it succeeded in doing. However, from this project, it is possible to see future research questions which would be interesting to investigate.

The views of other disabled young people: This study is one of the first to directly consult with disabled young people regarding their experiences. It can be established that, although many of the issues pertaining to the transition are in line with non disabled young people, there are also differences. Representing the voices of young people with CP is only one small part of representing disabled young people. Future work should seek to increase our knowledge of the experiences of young people with a range of impairments, and illustrate how collectively young people can be disabled when attempting to access schools.

Other transitional experiences: It was established in this research that parents in particular use previous transitional experiences to cope with current transitions. Many of the parents in this project commented that they were now thinking about the transition out of school. There is scope for a future project to apply a similar methodology, to learn how this next transition is dealt with.

The school experience: From looking at the transition it emerged that these young people were dealing with issues of identity and fitting in at school. It would be interesting to further consult with disabled young people and investigate these issues. Current policy and school legislation can also be explored to establish whether it is assisting young people, or whether it could be improved.

Addressing mobility concerns: Within this project the young people spoke about the initiatives which have been implemented by secondary schools to deal with bullying. In many ways it appears that such initiatives have been successful. Investigating ways in which mobility concerns could be addressed, and developing a program which schools could adopt would be a beneficial future project to undertake.

Fighting for access to services: Many of the parents made reference to fighting to access services for their children. This is inline with earlier work published by Darrah et al (2002). Through consultation with parents and services, further work should investigate this issue and attempt to establish practice which could move this agenda forward.

Attitudes towards special schools: The parents of young people attending special schools were very positive about them, and the young people themselves were happy at these schools. However, legislation is moving towards emphasising education within mainstream schools for all children. It would be interesting for a future project to consult with young people and parents regarding their views of special schooling. Families accessing such schools, and also those who were not could be consulted and their views compared.

Addressing the need to be visible and invisible: An interesting concept emerging from the data is the young persons desire to be visible, wanting teachers and assistants to be aware of their needs, whilst also being invisible, wanting to be treated the same as other pupils. This issue should be investigated further to establish whether it is possible to achieve a balance between these two conflicting desires.

Applying the methodology: This project demonstrated that working with disabled young people can generate rich data, and also that these young people want to participate in research. The methods used here can be adopted in the future when consulting with young people, in order to gain an insight in to their worlds. As discussed above, one area of interest is their experiences of identity within mainstream schools. However, the methods could be applied to any issue, preferably ones that the young people themselves identify.

9.11 Reflection

Through conducting this study my own perception of disability research has changed. Having read the literature within the field, and decided upon the methods, I felt that there was a need for a mixed model approach to represent disability.

However, on reflection part of me felt that this would be a model weighted heavily on the impact of impairment compared to the environment.

Having experienced the data collection process, and having listened to the young peoples voices, I realised that the impact of the environment plays a dramatic part on disabled people's lives. Through hearing the experiences of the young people, some with mild CP, some with more impacting CP, common themes emerged. These young people wanted to live their lives in the same way as their peers. However, the barriers from society constantly reinforced their impairment, and their school experiences were dramatically shaped by society and the environment.

On writing this chapter I came across some notes I had made at the start of the project. These notes were made following a meeting with a parent at one of the charitable organisations. I had listed four things that I thought would be included in the outcomes of this research;

1. There is little choice of schools.
2. Limited planning and support.
3. Many problems sorted out as and when.
4. The ASL will possibly improve planning.

From this list I can say that some of these issues are true, although not in the way I had originally envisaged.

It is true that there is a limited choice of schools for some families. However, in many cases this was irrelevant as they wanted to attend the local school. Other parents wanted to choose a special school and were finding that they were slowly being merged into mainstream. Thus, choices were limited, often as a result of parents' and young peoples' educational preferences.

The planning and support available to families was variable between areas and limited for some. What I did not envisage was that many families did not just want support, but wanted it from professionals who knew their child.

In many cases problems were sorted out as and when. Although this was not ideal, parents did not seem to be too concerned; they simply wanted the problems to be resolved.

Looking back at this list I realise that I had held a very black and white picture of the transition. Having met the actual people involved, I can now see how the vast diversity of the individuals brings in several shades of grey.

I also note that before starting the research process I saw services as key to the transition. Although they do play a role, this transition was so much more of a personal journey for the young people, with issues of concerns, identity, and fitting in, at the forefront of their minds.

Prior to commencing the study I read the literature, and spoke to parents of disabled children, and I attempted to put all the theory into practice when carrying out my first interview. Throughout the research process I became more confident, and found that applying the theory became second nature. What was a surprise was the experiences recounted by the young people regarding teachers and learning assistants, who appeared to have very little insight into working with disabled people. Having prepared in depth to conduct this research project, I feel it would be beneficial to these individuals, to undergo similar preparation and to build their awareness of working with disabled people.

The main thing that will stay with me is the enjoyment of talking to the young people, with their vibrancy and energy, a true contrast to the depressing images portrayed in the media. Meeting and talking to them made it possible for me to see them as diverse social actors and to approach the data with this in mind.

9.12 Chapter summary

In conclusion the goal for these young people is to achieve an uninterrupted transition as discussed in chapter 3. It is possible to achieve this; however a number of the issues discussed in this thesis need first to be addressed, and the barriers to such a transition removed.

It can be established that the research questions have been answered. It was possible to give authentic accounts in response to these questions due to the methods adopted, which was an amalgamation of those used in research with children and disabled people.

In reply to the type of transition young people and their parents have, it is demonstrated that generally if problems are dealt with, the secondary school show an awareness of how to work with disabled pupils, and the young people are happy, the transition is deemed a success.

Throughout their experience many young people do encounter barriers, primarily to accessing mainstream schools. Similar to non disabled young people, these young people have a number of concerns prior to making the transition, as do their parents. It was revealed that these concerns are primarily social, structural and/or mobility related, and not bullying as much of the literature suggests. It is possible that the young people were concerned about issues that they felt were real rather than issues which were hypothetical. Alternatively bullying might not be a concern due to the initiatives implemented by secondary schools to reduce it and concerns about it. If the latter is true there is scope to address mobility issues in the same way.

This transitional experience also leads to the young people experiencing a development in their personal identity. Many young people on encountering the increased number of pupils in secondary school begin to think about how others see them and how they want to be perceived.

Questioning whether the needs of parents and young people are met throughout this transition, established that the support given by services is variable. Unfortunately as with earlier literature, many of these parents still feel that there is a need for them to fight to get access to services for their child. A key aspect to successfully meeting their needs is providing the family with a contact person. This is also one of the rights families have under the ASL. Hopefully in time this will become standard practice.

From this work it is established that the ASL act has had little impact on this transition. Having the pre and post ASL groups allowed for comparisons to be made,

and no significant differences were found. When parents were consulted directly about the act they were generally negative regarding the impact it has had.

This chapter evaluates and reflects on the project. In setting out to gain an insight into the transitional experiences of disabled young people and their parents, the research methods adopted have allowed this to occur. The work has generated new knowledge, contributed further to previous knowledge, and also concurred with literature already published. Through this research t possibilities for future investigations were generated and it was demonstrated that participatory methods with disabled young people can be successful.

On reflection I, as a researcher, can establish that conducting this research has given me the opportunity to gain experiences, and to have learnt from the young people.

The aim was to represent the experiences of young people and their parents during the transition from primary to secondary school. In this work their voices have been heard.

References

- Abberley, P. (2001). "Handicapped by numbers: A critique of the OPCS disability surveys." *Occasional papers in sociology*, 9.
- Agar, M. (1996). *The professional stranger*. San Diego: Academic Press.
- Ainscow, M., Booth, T., & Dyson, A. (1999). Inclusion and exclusion in schools: Listening to some hidden voices. In K. Ballard (Ed.), *Inclusive Education: International voices on Disability and Justice*. London: Falmer Press.
- Ajzen, I. (2001). Nature and operation of attitudes. *Annual Review of Psychology*, 52, 27-58.
- Alderson, P., & Goodey, C. (1996). Research with disabled children: How useful is child-centred ethics? *Children and Society*, 10(2), 106-116.
- Allan, J. (1999). *Actively seeking inclusion: Pupils with special needs in mainstream schools*. London: Falmer Press.
- Anderson, L., Jacobs, J., Schramm, S., & Splittgerber, F. (2000). School transitions: Beginning of the end or a new beginning? *International Journal of Educational Research*, 33, 325-339.
- Armstrong, D., & Galloway, D. (1996). How children with emotional and behavioural difficulties view professionals. In R. Davies & D. Galloway (Eds.), *Listening to children in education*. London David Fulton Publishers Ltd.
- Arnstein, S. (1969) A ladder of citizen participation. *Journal of the American Institute of Planners* 35 (4):216-224.
- Aston, J., Dewson, S., Loukas, G., & Dyson, A. (2005). *Post-16 transitions: a longitudinal study of young people with special educational needs (Wave three) (DfES Research Report RB655)*. London: DfES.

Backe-Hansen, E. (2002). Young people between home and school. In R. Edwards (Ed.), *Children, home and school: Regulation, autonomy or connection?* London: RoutledgeFalmer

Baker, J., & Gaden, G. (1992). Integration and equality. In G. Fairbairn & S. Fairbairn (Eds.), *Integrating special children: Some ethical issues*. Aldershot: Avebury.

Baker, K., & Donnelly, M. (2001). The social experiences of children with disability and the influence of environment: A framework for intervention. *Disability & Society*, 16(1), 71-85.

Bakheit, A., Bower, E., Cosgroves, A., Fox, M., Morton, R., Phillips, S., Scrutton, D., Shubb V., & Yude C. (2001). Opinion statement on the minimal acceptable standards of healthcare in cerebral palsy. *Disability and Rehabilitation*, 23(13), 578-582.

Bamford, D., Griffiths, H., & Kernohan, G. (1997). Research note: on patient satisfaction in cerebral palsy care. *British Journal of Social Work*, 27(4), 605-614.

Barnes, C. (1998). The social model of disability: A sociological phenomenon ignored by sociologists? In T. Shakespeare (Ed.), *The Disability Reader*. London: Continuum.

Bast, J., & Walberg, H. (2004). Can parents choose the best schools for their children? *Economics of Education Review*, 23, 431-440.

Bastiani, J. (1986). Going up to the big school: Parents experience of the transition from primary to secondary schooling. In M. Youngman (Ed.), *Mid-schooling transfer: Problems and proposals*. Windsor: NFER – Nelson Publishing Company Ltd.

Beresford, B. (1997). *Personal Accounts: Involving disabled children in research*. London: The Stationary Office.

Beresford, B. (1994). Resources and strategies: How parents cope with the care of a disabled child. *Journal of Child Psychology and Psychiatry* 35(1), 171-209.

Berndt, T., & Mekos, D. (1995). Adolescents' perceptions of the stressful and desirable aspects of the transition to junior high school. *Journal of Research on Adolescence*, 5(1), 123-142.

Boland, M., Daly, L., & Staines, A. (2007). Methodological issues in inclusive intellectual disability research: A health promotion needs assessment of people attending Irish disability services. *Journal of Applied Research in Intellectual Disabilities*.

Bonner, K. (1998). *Power and parenting: A hermeneutic of the human condition*. Hampshire, MacMillan Press LTD.

Bowe, R., Gerwitz, S., & Ball, S. (1994). Capture by discourse? Issues and concerns in researching 'parental choice'. *British Journal of Sociology of Education*, 15(1), 63-78.

Boyden, J, and J Ennew. (1997). *Children in focus: A manual for participatory research with children*. Stockholm: Radda Barnen.

Brammer, L. (1992). Coping with life transitions. *International Journal for the Advancement of Counselling* 15:239-253.

Bricher, G. (1999). Children and qualitative research methods: A review of the literature related to interview and interpretive process. *Nurse Researcher*, 6(4), 65-77.

Broome, M. (1999). Consent (Assent) for research with pediatric patients. *Seminars in Oncology Nursing*, 15(2), 96-103.

Brykczynska, G. (1989). Ethical considerations in paediatric nursing research. In G. Brykczynska (Ed.), *Ethics in paediatric nursing*. London: Chapman & Hall.

Burger, J. (1985). Desire for control and achievement-related behaviours. *Journal of Personality and social psychology*, 48(6), 1520-1533.

Cavet, J., & Sloper, P. (2004). The participation of children and young people in decisions about UK service development. *Child: Care, Health, and Development*, 30, 613-621.

Chappell, A. (2000). Emergence of participatory methodology in learning difficulty research: Understanding the context. *British Journal of Learning Disabilities*, 28, 38-43.

Charlton, T. (1996). Listening to pupils in classrooms and schools. In R. Davies & D. Galloway (Eds.), *Listening to children in education*. London: David Fulton Publishers Ltd.

Christensen, P. H. (2004). Children's participation in ethnographic research: Issues of power and representation. *Children and Society*, 18, 165-176.

Connors, C., & Stalker, K. (2003). *The views and experiences of disabled children and their siblings: A positive outlook*. London: Jessica Kingsley Publishers Ltd.

Connors, C., & Stalker, K. (2007). Children's experiences of disability: pointers to a social model of childhood disability. *Disability & Society*, 22(1), 19-33.

Convention on the Rights of the Child, UN General Assembly, 1989

COREC. (2003). *Ethical issues in research in children: COREC UK Guidance*: COREC

Corker, M. and T. Shakespeare (2002). *Disability/Postmodernity - Embodying disability theory*. London, Continuum.

Cornwall, A, and R Jewkes. (1995). What is participatory research? *Social Science and Medicine* 41 (12):1667-1676.

Costley, D. (2000). Collecting the views of young people with moderate learning difficulties. In A. Lewis & G. Lindsay (Eds.), *Researching children's perspectives*. Buckingham: Open University Press.

Cree, V., Kay, H., & Tisdall, K. (2002). Research with children: sharing the dilemmas. *Child and Family Social Work, 7*(1), 47-56.

Crow, L. (1995). Including all of our lives: Renewing the social model of disability. In *Exploring the divide*, edited by C. Barnes and G. Mercer. Leeds: The Disability Press.

Cutrona, C, and J Suhr. (1990). The transition to parenthood and the importance of social support. In *On the move: The psychology of change and transition.*, edited by S. Fisher and C. Cooper. Chichester: John Wiley and Sons.

Daly, K. (1992). The fit between qualitative research and characteristics of families. In *Qualitative methods in family research*, edited by J. Gilgun, K. Daly and G. Handel. London: Sage Publications.

Darrah, J., Magil-Evans, J., & Adkins, R. (2002). How well are we doing? Families of adolescents or young adults with cerebral palsy share their perceptions of service delivery. *Disability and Rehabilitation, 24*(10), 542-549.

Davis, J. (1998). Understanding the meaning of children: A reflexive process. *Children and Society, 12*, 325-335.

Davis, J. (2000). Disability studies as ethnographic research and text: Research strategies and roles for promoting social change? *Disability & Society, 15*(2), 191-206.

Davis, J., & Edwards, R. (2004). Setting the agenda: Social inclusion, children and young people. *Children and Society, 18*(2), 97-105.

Davis, J., & Watson, N. (2001). Where are the children's experiences? Analysing social and cultural exclusion in 'special' and 'mainstream' schools. *Disability & Society*, 16(5), 671-687.

Day, J. (1996). School friendship groups and their impact on learning. *Education 3-13*, 24, 51-58.

Delamont, S., & Galton, M. (1986). *Inside the secondary classroom*: Routledge and Kegan Paul.

Detheridge, T. (2000). Research involving children with severe learning difficulties. In A. Lewis & G. Lindsay (Eds.), *Researching children's perspectives*. Buckingham: Open University Press.

Disability Discrimination Act 1995

Dixon-Wood, M., Young, B., & Heney, D. (1999). Partnership with children. *British Medical Journal*, 319, 778-780.

Doland, P. (2006). Assessment, intervention and self-appraisal tool for family support. In Doland, P., Canavan, J., Pinjerton, J. (Eds). *Family support as reflective practice*. London: Jessica Kingsley.

Dyson, L. (1991). Families of young children with handicaps: Parental stress and family functioning. *American Journal on Mental Retardation*, 95(6), 623-629.

Dyson, L. (1997). Fathers and mothers of school-age children with developmental disabilities: Parental stress, family functioning and social support. *American Journal on Mental Retardation*, 102(3), 267-279.

Echols, F., & Willms, J. (1995). Reasons for school choice in Scotland. *Journal of Education Policy*, 10(2), 143-156.

Evans, J. & Lunt, I. (2002). Inclusive education: Are there limits? *European Journal of Special Needs Education, 17*(1), 1-14.

Farrell, P., Dyson, A., Polat, F., Hutcheson, G., & Gallannaugh, F. (2007). SEN inclusion and pupil achievement. *Journal of Research in Special Educational Needs, 7*(3), 172-178.

Farrell, P. (2001). Special education in the last twenty years. *British Journal of Special Education, 28*(1), 3-10.

Farrell, S., Aubry, T., & Coulombe, D. (2004). Neighbourhoods and neighbours: Do they contribute to personal well-being? *Journal of Community Psychology, 32*(1), 9-25.

Fisher, A., & Sonn, C. (1999). Aspiration to community: Community responses to rejection. *Journal of Community Psychology, 27*(6), 715-725.

Foucault, M. (1980). *Power/Knowledge: Selected interviews and other writing 1972-1977*. Brighton, The Harvester Press.

Franklin, A., & Sloper, P. (2008). Supporting the participation of disabled children and young people in decision-making. *Children and Society, early internet*.

French, S. (1993). Can you see the rainbow? The roots of denial. In J. Swain, V. Finkelstein, S. French & M. Oliver (Eds.), *Disabling Barriers - Enabling Environments*: Sage Publications.

French, S. (1993). What's so great about independence? In J. Swain, V. Finkelstein, S. French & M. Oliver (Eds.), *Disabling Barriers - Enabling Environments*: Sage Publications.

French, S., & Swain, J. (1997). Changing Disability Research: Participatory and Emancipatory research with disabled people. *Physiotherapy, 83*(1), 26-32.

Galton, M., Morrison, I., & Pell, T. (2000). Transfer and transition in English schools: Reviewing the evidence. *International Journal of Educational Research*, 33, 341-363.

Galton, M., & Willcocks, J. (1983). *Moving from the primary classroom*. London: Routledge & Kegan Paul.

Garth, B., & Aroni, R. (2003). 'I value what you have to say'. Seeking the perspectives of children with disability, not just their parents. *Disability and Society*, 18(5), 561-576.

General Register Office for Scotland Census 2001

Goffman, E. (1968). *Stigma: Notes on the management of spoiled identity*. London: Penguin Books.

Goodley, D., & Moore, M. (2000). Doing disability research: Activist lives and the academy. *Disability & Society*, 15(6), 861-882.

Graham, C., & Hill, M. (2003). Negotiating the transition to secondary school. *Spotlight*, 89, 3-6.

Greco, V., & Sloper, P. (2004). Care co-ordination and key worker schemes for disabled children: results of a UK-wide survey. *Child: Care, Health, and Development*, 30, 13-20.

Gururaj, A., Sztrihá, L., & al, e. (2003). Epilepsy in children with cerebral palsy. *Seizure*, 12, 110-114.

Guzzetta, A., Mercuri, E., & al, e. (2001). Visual disorders in children with brain lesions: 2. Visual impairment associated with cerebral palsy. *European Journal of Paediatric Neurology*, 5, 115-119.

Hanline, M. (1991). Transitions and critical events in the family life cycle: Implications for providing support to families of children with disabilities. *Psychology in the Schools*, 28, 53-59.

Harden, J., Scott, S., Backett-Milburn, K., & Jackson, S. (2000). Can't talk, won't talk? Methodological issues in researching children. *Sociological Research Online*, 5(2), Available from: <http://www.socresonline.org.uk/5/2/harden.html> [Accessed 17/01/2008]

Harris, J. (2003). Time to make up your mind: Why choosing is difficult. *British Journal of Learning Disabilities*, 31, 3-8.

Hart, R. (1997). *Children's participation: The theory and practice of involving young citizens in community development and environmental care*. London: Earthscan.

Hart, R. (1992). *Children's participation: From tokenism to citizenship*. Florence: Unicef, United Nations Children's Fund.

Haylock, C., Johnson, M., & Harpin, V. (1993). Parents' views of community care for children with motor disabilities. *Child: Care, Health, and Development*, 19(3), 209-220.

Hill, M. (2006). Children's voices on ways of having a voice - Children's and young people's perspectives on methods used in research and consultation. *Childhood*, 13(1), 69-89.

Hill, M., Davis, J., Prout, A., & Tisdall, K. (2004). Moving the participation agenda forward. *Children and Society*, 18, 77-96.

Hill, M., Laybourn, A., & Borland, M. (1996). Engaging with primary-aged children about their emotions and well-being: Methodological considerations. *Children and Society*, 10(2), 129-144.

Hirst, M., & Baldwin, S. (1994). *Unequal Opportunities: Growing up disabled*. Social Policy Research Unit.

HMIE. (2005). *Improving Scottish Education - a report by HMIE on inspection and review 2002-2005*. Edinburgh: HMIE.

Hood, S., Kelley, P., & Mayall, B. (1996). Children as research subjects: A risky enterprise. *Children and Society*, 10(2), 117-128.

International Classification of Disease (ICD) (1994). Diseases of the nervous system (G00-G99).

Ireland, L., & Holloway, I. (1996). Qualitative health research with children. *Children and Society*, 10(2), 155-164.

Iyengar, S., & Lepper, M. (1999). Rethinking the value of choice: A cultural perspective on intrinsic motivation. *Journal of personality and social psychology*, 76(3), 349-366.

James, A., Jenks, C., & Prout, A. (1998). *Theorizing Childhood*. Cambridge: Polity Press.

Jelliffe-Pawlowski, L., G. Shaw, & Harri, J. (2003). Risk of mental retardation among children born with birth defects. *Archives of Pediatrics and Adolescent Medicine*, 157, 545-550.

Jennings, K., & Hargreaves, D. (1981). Children's attitudes to secondary school transfer. *Educational Studies*, 7(1), 35-39.

Joseph Rowntree Foundation (2001) Consulting with disabled children and young people. Joseph Rowntree Foundation, York.

Keller, D., & Honig, A. (2004). Maternal and paternal stress in families with school-aged children with disabilities. *American Journal of Orthopsychiatry*, 74(3), 337-348.

Kelly, B. (2005). 'Chocolate...makes you autism': Impairment, disability and childhood identities. *Disability and Society*, 20(3), 261-275.

Kelly, N., & Norwich, B. (2004). Pupils' perceptions of self and labels: moderate learning difficulties in mainstream and special schools. *British Journal of Educational Psychology*, 74(3), 411-435.

Kelso, T., French, D., & Fernandez, M. (2005). Stress and coping in primary caregivers of children with disability: A qualitative study using the Lazarus and Folkman Process Model of Coping. *Journal of Research in Special Educational Needs*, 5 (1) 3-10.

Kenworthy, J., & Whittaker, J. (2000). Anything to declare? The struggle for inclusive education and children's rights. *Disability & Society*, 15(2), 219-231.

Kerr, S., & McIntosh, J. (2000). Coping when a child has a disability: Exploring the impact of parent-to-parent support. *Child: Care, Health and Development*, 26(4), 309-321

King, S., Teplicky, R., King, G., & Rosenbaum, P. (2004). Family-centred service for children with cerebral palsy and their families: A review of the literature. *Seminars in Pediatric Neurology*, 11(1), 78-86.

Koocher, G., & Keith-Spiegel, P. (1994). Scientific issues in psychosocial and educational research with children. In M. Grodin & L. Glantz (Eds.), *Children as research subjects*. Oxford: Oxford University Press.

Kvalsund, R. (2000). The transition from primary to secondary level in smaller and larger rural schools in Norway: Comparing differences in contact and social meaning. *International Journal of Educational Research*, 33, 410-423.

Lewis, R. (2008). Recruiting parents and children into a research project: A qualitative exploration of families decision-making processes. *International Journal of Social Research Methodology* iFirst Article:1-14.

Lewis, A., Davison, I., Ellins, J., Niblett, L., Parsons, S., Robertson, C., & Sharpe, J. (2007). The experiences of disabled pupils and their families. *British Journal of Special Education*, 34(4), 189-195.

Lewis, A., & Porter, J. (2004). Interviewing children and young people with learning disabilities: Guidelines for researchers and multi-professional practice. *British Journal of Learning Disabilities*, 32(191-197).

Lewis, V., & Kellett, M. (2004). Disability. In S. Fraser, V. Lewis, S. Ding, M. Kellett & C. Robinson (Eds.), *Doing Research with Children and young people* (pp. 191-205): Sage Publications.

Lightfoot, J., Wright, S., & Sloper, P. (1999). Supporting pupils in mainstream school with an illness or disability: Young people's views. *Child: Care, Health, and Development*, 25(4), 267-283.

Lincoln, Y., & Guba, E. (1985). *Naturalistic Inquiry*. London: Sage Publications.

Llewellyn, A., & Hogan, K. (2000). The use and abuse of models of disability. *Disability & Society*, 15(1), 157-165.

Lloyd-Smith, M., & Tarr, J. (2000). Researching children's perspectives: A sociological dimension. In A. Lewis & G. Lindsay (Eds.), *Researching children's perspectives*. Buckingham: Open University Press.

Lucey, H., & Reay, D. (2000). Identities in Transition: Anxiety and excitement in the move to secondary school. *Oxford Review of Education*, 26(2), 191-205.

Mackie, P., Jessen, E., & Jarvis, S. (1998). The lifestyle assessment questionnaire: An instrument to measure the impact of disability on the lives of children with cerebral palsy and their families. *Child: Care, Health, and Development*, 24(6), 473.

Mahon, A., Glendinning, C., Clarke, K., & Craig, G. (1996). Researching children: Methods and Ethics. *Children and Society*, 10(2), 145-154.

Mandler, G. (1990). Interruption (Discrepancy) Theory: Review and extensions. In *On the move: The psychology of change and transition*, edited by S. Fisher and C. Cooper. Chichester: John Wiley and Sons.

Maras, P., & Brown, R. (2000). Effects of different forms of school contact on children's attitudes towards disabled and non-disabled peers. *British Journal of Educational Psychology*, 70(3), 337-351.

Masson, J. (2004). The legal context. In S. Fraser, V. Lewis, S. Ding, M. Kellett & C. Robinson (Eds.), *Doing Research with children and young people* (pp. 43-58). London: Sage Publications.

Mauthner, M. (1997). Methodological aspects of collecting data from children: Lessons from three research projects. *Children and Society*, 11, 16-28.

Maxwell, T. (2006). Researching into some primary schools children's views about school: Using personal construct psychology in practice with children on the special needs register. *Pastoral Care*, March, 20-26.

Mayall, B. (2000) *Towards a Sociology for childhood; thinking from children's lives*. Buckingham: Open University Press.

McDermott, S., Coker, A., & al., e. (1996). A population-based analysis of behaviour problems in children with cerebral palsy. *Journal of Pediatric Psychiatry*, 21, 447-463.

McLean, S, and C Williamson. (2007). *Impairment and Disability; Law and ethics at the beginning and end of life*. Abingdon: Routledge-Cavendish.

McNeish, D. (1999). Promoting participation for children and young people: Some key questions for health and social welfare organisations. *Journal of Social Work Practice*, 13(2), 191-203.

Middleton, L. (1998). Services for disabled children: Integrating the perspective of social workers. *Child and Family Social Work*, 3, 239-246.

Middleton, L. (1999). *Disabled Children: Challenging social exclusion*. Oxford: Blackwell Science.

Miller, J., Colligan, J., & Colver, A. (2003). A qualitative study, using focused interviews, of the information needs of families whose children's names are on a cerebral palsy register. *Child: Care, Health, and Development*, 29(6), 465-471.

Mishna, M., Antle, B., & Regehr, C. (2004). Tapping the perspectives of children. *Qualitative Social Work*, 3(4), 449-468.

Mitchell, W., & Sloper, P. (2001). Quality in services for disabled children and their families: What can theory, policy and research on children's and parent's views tell us? *Children and Society*(15), 237-252.

Mollard, C. (2003). *Why it's worth it: Inclusive education in Scotland - a parents' perspective*: Enquire.

Moore, M., S. Beazley, & Muelzer, J. (1998). *Researching disability issues*. Buckingham, Open University Press.

Morris, J. (2002). *Foundations: Moving into adulthood*. York: Joseph Rowntree Foundation.

Morris, J. (2003). Including all children: Finding out about the experiences of children with communication and/or cognitive impairments. *Children and Society*, 17, 337-348.

Morrow, V. (2001). "It's cool,...'cos you can't give us detention and things, can you?!" :Reflections on research with children. In *Time to listen to children: A handbook for students, professionals and parents*, edited by B. Carolin and P. Milner. London: Routledge.

Morrow, V., & Richards, M. (1996). The ethics of social research with children: An overview. *Children and Society, 10*, 90-105.

Moss, P., & Petrie, P. (2002). *From children's services to children's spaces*. London: Routledge.

Motion, S., Northstone, K., Edmond, A., Stucke, & S., Golding, J. (2002). Early feeding problems in children with cerebral palsy: weight and neurodevelopmental outcomes. *Developmental Medicine and Child Neurology, 44*, 40-43.

Murphy, S. (1992). Using multiple forms of family data: Identifying pattern and meaning in sibling-infant relationships. In *Qualitative methods in family research*, edited by J. Gilgun, K. Daly and G. Handel. London: Sage Publications.

Mutch, L. (1992). Cerebral palsy epidemiology: Where are we now and where are we going? *Developmental Medicine and Child Neurology, 34*, 547-555.

Nadeau, L., & Tessier, R. (2006). Social adjustment of children with cerebral palsy in mainstream classes: Peer perception. *Developmental Medicine and Child Neurology, 48*, 331-336.

Nisbet, J., & Entwistle, N. (1969). *The transition to secondary education*. London: University of London Press Ltd.

Ofsted. (2003). *Special Educational Needs in mainstream*.

Ofsted. (2004). *Special Educational Needs and disability: Towards inclusive schools*.

O'Kane, C. (2002). The development of participatory techniques. In P. Christensen & A. James (Eds.), *Research with Children: Perspectives and Practices*. London: Falmer Press.

Oliver, M. (1992). Changing the social relations of research production? *Disability, Handicap & Society*, 7(2), 101-114.

Oliver, M. (1996). *Understanding Disability: From Theory to Practice* (Vol. MacMillan Press Ltd). Basigstoke.

Oliver, M. (2004). If I had a hammer: The social model in action. In J. Swain, S. French, C. Barnes & C. Thomas (Eds.), *Disabling Barriers - Enabling Environments* (Second ed.). London: Sage Publications.

Pain, H. (1999). Coping with a child with disabilities from the parents' perspective: the function of information. *Child: Care, Health, and Development*, 25(4), 299-312.

Pellegrini, A., & Blatchford, P. (2000). *The child at school: Interactions with peers and teachers*: Arnold (a member of the Hodder Headline Group).

Pratt, S., & George, R. (2004). Transferring friendships: Girls' and boys' friendships in the transition from primary to secondary school. *Children and Society*, 19, 16-25.

Prezza, M., Amici, M., Roberti, T., & Tedeschi, G. (2001). Sense of community referred to the whole town: Its relations with neighbouring, loneliness, life satisfaction, and area of residence. *Journal of Community Psychology*, 29(1), 29-52.

Priestley, M. (1999). Discourse and identity: Disabled children in mainstream high schools. In M. Corker & S. French (Eds.), *Disability Discourse*. Buckingham: Open University Press.

Priestley, M. (1997). *Who's research? A personal audit*. Leeds: The Disability Press.

Prigg, A. (2002). Experiences and perceived roles of occupational therapists working with children with special learning needs during transition to school: A pilot study. *Australian Occupational Therapy Journal*, 49, 100-111.

Prout, A., & James, A. (1997). A new paradigm for the sociology of childhood? Provenance, promise, and problems. In A. James & A. Prout (Eds.), *Constructing and reconstructing childhood*. London: Routledge Falmer.

Punch, S. (2002). Interviewing strategies with young people: The 'secret box', stimulus material and task-based activities. *Children and Society*, 16, 45-56.

Rabiee, P., Sloper, P., & Beresford, B. (2005). Doing research with children and young people who do not use speech for communication. *Children and Society*, 19, 385-396.

Rassool, N. (2004). Flexible identities. In V. Lewis, M. Kellet, S. Fraser, S. Ding & C. Robinson (Eds.), *The reality of research with children and young people*. London: Sage.

Reiss, J., Gibson, R., & Walker, L. (2005). Health care transitions: Youth, family and provider perspectives. *Pediatrics*, 115(1), 112-120.

Ribbens McCarthy, J. J Holland, and V Gillies, V. (2003). Multiple perspectives on the 'family' lives of young people: Methodological and theoretical issues in case study research. *International Journal of Social Research Methodology* 6 (1):1-23.

Robson, C. (1993). Approaches to Social Research. In *Real World Research*. Oxford: Blackwell Publishing.

Roker, D, and J Shepherd. (2007). Supporting children and parents during the transition to secondary school: A UK wide review. In *Working with parents of young people: Research, policy and practice*, edited by D. Roker and J. Coleman. London: Jessica Kingsley Publishers.

Ross, D., & Ross, S. (1984). The importance of type of question, psychological climate and subject set in interviewing children about pain. *Pain*, 19(1), 71-79.

Ross, N., Hill, M., & Shelton, A. (2006). *White children's perspectives on inter-ethnic relations following the move from primary to secondary school*. Glasgow: Glasgow Centre for the Child & Society, Glasgow University.

Royal College of Paediatrics and Child health (RCPCH) (2003) Health for All Children (Hall 4) Scottish Executive

Russell, P. (1996). Listening to children with special educational needs. In R. Davies & D. Galloway (Eds.), *Listening to children in education*. London: David Fulton Publishers Ltd.

Russell, P. (2003). 'Access and achievement or social exclusion?' Are the Government's policies working for disabled children and their families? *Children and Society*, 17, 215-225.

Sanders, D., White, G., Burge, B., Sharp, C., Eames, A., McEune, R., & Grayson, H. (2005). *A study of the transition from the foundation stage of key stage 1 (DfES Research Report SSU/2005/FR/013)*. London: DfES.

Sandstrom, K. (2007). The lived body - experiences from adults with cerebral palsy. *Clinical Rehabilitation*, 21, 432-441.

Sarantakos, S. (2005). Research Planning. In *Social Research*. Basingstoke: Palgrave MacMillan.

Schaffer, H. R. (1996). *Social Development*: Blackwell Publishers.

Schagen, S., & Kerr, D. (1999). *Bridging the gap? The national curriculum and progression from primary to secondary school*. Slough: National Foundation for Education Research.

Scottish Executive (2001), 'For Scotland's Children Report'

Scottish Executive (1999), 'Implementing Inclusiveness, Realising Potential'

Scottish Parliament (2004), Education (Additional Support for Learning) (Scotland) Act 2004

Scottish Parliament (2002), Education (Disability Strategies and Pupils' Educational Records) (Scotland) Act 2002

Scottish Parliament (2000), Education (Standards in Scotland's Schools Etc.) Act 2000

Scott, J. (2000). Children as respondents. The challenge for quantitative methods. In P. Christensen & A. James (Eds.), *Research with children: Perspectives and Practices*. London: Falmer Press.

SCPE. (2000). Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. *Developmental Medicine and Child Neurology*, 42(12), 816-824.

Shafir, E, I Simonson, and A Tversky. (1994). Reason-based Choice. In *Reasoning and decision making*, edited by P. Johnson-Laird and E. Shafir. Cambridge: Blackwell.

Shakespeare, T. (2006). *Disability rights and wrongs*. London: Routledge.

Shakespeare, T. (1997). Defending the Social Model. In L. Barton & M. Oliver (Eds.), *Disability Studies: Past, present and future*. Leeds: The Disability Press.

Shakespeare, T., & Watson, N. (1998). Theoretical perspectives on research with disabled children. In C. Robinson & K. Stalker (Eds.), *Growing up with Disability*. London: Jessica Kingsley Publishers Ltd.

Shakespeare, T., & Watson, N. (2002). The social model of disability: An outdated ideology? *Research in Social Science and Disability*, 2, 9-28.

Shaw, L. (1998). Children's experiences of school. In C. Robinson & K. Stalker (Eds.), *Growing up with disability*: Jessica Kingsley Publishers.

Shields, N., Loy, Y., Murdoch, A., Taylor, N., & Dodd, K. (2007). Self-concept of children with cerebral palsy compared with that of children without impairment. *Developmental Medicine and Child Neurology*, 49, 350-354.

Shier, H. (2001). Pathway to participation: Openings, opportunities and obligations. *Children and Society*, 15(2), 107-117.

Simmons, R., & Blyth, D. (1987). *Moving into adolescence: The impact of pubertal change and school context*. New York: Aldine de Gruyter.

Sinclair, R. (2000). *Young People's Participation: Quality Protects Research Briefing No 3*: Department of Health, research in practice, making research count.

Sinclair, R. (2002). *The education of children in need: a research overview*. Totness: Research in practice.

Sinclair, R. (2004). Participation in practice: Making it meaningful, effective and sustainable. *Children and Society*, 18, 106-118.

Sinclair-Taylor, A. (1995). 'Less better than the rest' :Perceptions of integration in a multi-ethnic special needs unit. *Educational Review*, 47(3), 263-274.

Skar, L. (2003). Peer and adult relationships of adolescents with disabilities. *Journal of Adolescence*, 26, 635-649.

Sloper, P. (1999). Models of service support for parents of disabled children. What do we know? What do we need to know. *Child: Care, Health, and Development*, 25(2), 85-99.

Sloper, P., & Lightfoot, J. (2003). Involving disabled and chronically ill children and young people in health service development. *Child: Care, Health, and Development*, 29, 15-20.

Sloper, P., & Turner, S. (1992). Service needs of families of children with severe physical disability. *Child: Care, Health, and Development*, 18(5), 259-282.

Smiley, E., Cooper, S., Miller, S., Robertson, P., & Simpson, N. (2002). Specialist health services for people with intellectual disability in Scotland. *Journal of Intellectual Disability Research*, 46(8), 585-593.

Stalker, K., & Connors, C. (2003). Communicating with disabled children. *Adoption and Fostering Journal*, 27(1), 26-35.

Stone, E., & Priestley, M. (1996). Parasites, pawns and partners: disability research and the role of non-disabled researchers. *British Journal of Sociology*, 47, 699-716.

Stradling, R., & MacNeil, M. (2000). *Moving on -The emotional well-being of young people in transition from primary to secondary school*: Highland Health Board.

Strauss, A., & Corbin, J. (1998). *Basics of Qualitative Research* (Second Ed.). London: Sage Publications Ltd.

Stryker, S., & Burke, P. (2000). The past, present and future of an identity theory. *Social Psychology Quarterly*, 63(4), 284-297.

Swain, J, and S French. (2000). Towards an affirmation model of disability. *Disability and Society* 15 (4):569-582.

Summerfield, M. (1986). Academic performance after transfer. In M. Youngman (Ed.), *Mid-schooling transfer: Problems and proposals*. Windsor: NFER- Nelson Publishing Company Ltd.

Thomas, N., & O'Kane, C. (2000). Discovering what children think: Connections between research and practice. *British Journal of Social Work*, 30(6), 819-836.

Thomas, C. (1999). *Female forms: Experiencing and understanding disability*. Buckingham: Open University Press.

Thomas, C., & Beckford, V. (1999). *Adopted children speaking*. London: BAAF

Thomas, N, and C O'Kane. (1998). The ethics of participatory research with children. *Children and Society* 12:336-348.

Tisdall, E., & Davis, H. (2004). Making a difference? Bringing children's and young people's views into policy-making. *Children and Society*, 18, 131-142.

The Union of the Physically Impaired Against Segregation, & The disability Alliance (1975). *Fundamental Principles of Disability*. London.

V. I. Scotland (2003). *Vision Impairment Scotland: A new system of notification of childhood visual impairment and the information it has provided on services for Scottish children*.

Ward, L. (1997). *Seen and Heard: Involving disabled young people in research and development projects*: Joseph Rowntree Foundation.

Watson, N. (2002). Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person: Identity and disability. *Disability & Society*, 17(5), 509-527.

Watson, N. (2003). Daily denials: The routinisation of oppression and resistance. In S. Riddell & N. Watson (Eds.), *Disability, culture and identity*. Essex: Pearson Education Limited.

Watson, N., Shakespeare, T., Cunningham-Burley, S., & Barnes, C. (2000). *Life as a disabled child: A qualitative study of young people's experience and perspectives* (Final Report): ESRC Research Programme Children 5-16: Growing into the twenty-first century.

Warin, J, Y Soloman, and C Lewis. (2007). Swapping stories, Comparing plots: Triangulating individual narratives within families. *International Journal of Social Research Methodology* 10 (2):121-134.

Weithorn, L., & Campbell, S. (1982). The Competency of children and adolescents to make informed treatment decisions. *Child Development*, 53, 1589-1598.

Weller, S. (2007). 'Sticking with your mates?' Children's friendship trajectories during the transition from primary to secondary school. *Children and Society*, 21, 339-351.

Whitehurst, T. (2006). Liberating silent voices - perspectives of children with profound & complex learning needs on inclusion. *British Journal of Learning Disabilities, Online Early*.

Woolfson, R., Harker, M., Lowe, D., Sheilds, M., & Mackintosh, H. (2007). Consulting with children and young people who have disabilities: Views of accessibility to education. *British Journal of Special Education*, 34(1), 40-49.

Worsley, M. (1986). Parental reactions to an induction programme. In M. Youngman (Ed.), *Mid-schooling transfer: Problems and proposals*. Windsor: NFER- Nelson Publishing Company Ltd.

Yude, C., & Goodman, R. (1999). Peer problems of 9-to-11-year-old children with hemiplegia in mainstream schools. Can these be predictive? *Developmental Medicine and Child Neurology*, 41, 4-8.

Yude, C., Goodman, R., & McConachie, H. (1998). Peer problems of children with hemiplegia in mainstream primary schools. *Journal of Child Psychology and Psychiatry*, 39(4), 533-541.

Zarb, G. (1992). On the road to Damascus: first steps towards changing the relations of disability research production. *Disability, Handicap & Society*, 7(2), 125-138.

Zeedyk, M., Gallacher, J., Henderson, M., Hope, G., Husband, B., & Lindsay, K. (2003). Negotiating the transition from primary to secondary school. *School Psychology International*, 24, 67-79.

Appendix 1:
Ethical approval letter

Appendix 2:
Parental letter of invitation

Name
Address
Address
Address
Post Code

Date

Dear name


Many parents of children with cerebral palsy tell us that making the move into secondary school is a complicated time for both the child and the parents. For this reason we, at the CPRS, have received funding to carry out research into the experiences of children and their parents at this transition time.

What we would like you to do is to take part in a one to one discussion about when [insert child name] moved into secondary school, and how you found the experience.

If at all possible we would also really like to talk to [insert child name] as we feel it is important that we hear about things from the point of view of the young people themselves.

We know that not everyone will be able to take part in an individual discussion with us. If you are unable to take part in one, we would like to offer you the opportunity to be involved with the research by telling us whether you agree or disagree with what we find through a short postal questionnaire in the autumn.

We understand that for some of you it may be stressful to remember this time, but we hope that by hearing your experiences we will be able to find out about what is currently working, and what is not working, then we can make recommendations for improvements in the future.

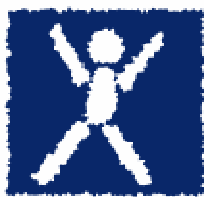
 We have included an information sheets for you, which tells you more about the research and how you and your child could be involved. These aims to answer any questions you may have, but if you would like to talk to us about any part of the research please contact Abbi Green on the details at the bottom of the information sheet.

We look forward to hearing from you

Abbi Green
Health Services Researcher

Taking part in this research is completely voluntary, and your decision to participate or not to participate will not affect your child's registration with the CPRS in any way.

Appendix 3:
Parents information sheets



Cerebral Palsy Register for Scotland

A joint project between Napier University and NHS Scotland

Moving schools project

Information about the study

Title

The title of the study is: "Evaluating the experience of children with cerebral palsy and their parents in the transition from primary to secondary school."

What this means

We want to find out about moving into secondary school (mainstream and special schools). We are interested in the services and information you received at this time, and the services and/or information you would have liked to have received.

Funding

The study is funded by a grant from the charity Cerebra.

Duration

We expect the study to take 2 years from start to finish. This means that in early 2008 we will be able to let you know what we've found.

Contacting you

When you agreed to participate with the CPRS you said it was ok for us to contact you about other research in the future. This **does not** mean that you have to take part in this study; the decision is up to you. Please read this information and then decide if you would like to be involved or not. Whatever you decide, it will not affect your relationship with the CPRS in any way.

Talking to someone

If you would like to discuss this study with somebody not directly involved, then please contact Sharon Dunlop, SNIP, Royal Hospital for Sick Children, Edinburgh (0131 536 0583).

Possible questions you may have

Why are you doing the research?

Comments made by parents and individuals working in this area have suggested that moving into secondary school can be a difficult time for some families, however there has been little work done to investigate how things can be improved. We also want to see if the new act introduced by the Scottish Parliament (Education (Additional Support for Learning) (Scotland) Act, 2004) which is meant to help this transition, has made a difference.

This research will also be submitted as part of an educational qualification (PhD) by the researcher, Abbi Green.

What do you want to do?

We want to know about the experiences of moving into secondary school from the people who actually go through it. This means talking to parents/carers and where possible children and young people. What we would like to do is to have a discussion with you about your experience, and if

possible talk to your son/daughter as well. Not everyone will be able to take part in a discussion, and so to include the views of as many people as possible, we would like to send those people who don't take part in a discussion a short postal questionnaire, to see if they agree with what other people have told us.

What will the research involve?

A researcher from the CPRS will meet you at a time and location you choose. This can be your home, a home of a relative or friend, or a public place. We would like to hear about your experience at 3 points during the move; after the Easter holidays, at the end of the summer term, and at the start of term in secondary school. The discussions will be recorded (sound only), and the researcher will take some notes. Each discussion should last around one hour. If your child is participating, we will talk to them on the same day if possible, again they can either talk to us alone, with yourself, or with somebody else they choose.

If you are not taking part in a discussion we would like to send you one short postal questionnaire once the discussions are complete.

What will you ask about?

We will talk to you about the things that are happening relating to the transition at each time. We would like to hear about what things worked for you, and what things need to be improved. We would also like to know where you found information and what information was helpful to you, was there any information you would have liked to have had but couldn't find?

Will my information be confidential?

When we write up the findings of this research we will not use your name, or any other information that would make it possible for others to identify you. In the reports we may wish to use direct quotes from yourself; however we will not identify them as being your quotes and will only refer to you by a fake name.

How long will you keep the information for?

In line with current research governance, all information from this research will be securely stored for 5 years. After this time it will be destroyed.

Why do we need this research?

From this work we will be able to say what services families with a child with cerebral palsy (CP) find useful, the times when they feel they most need services, and any problems that exist for families to have access to these services. By identifying these things we can make recommendations as to the type of service provision should be offered to families.

Who will have access to the findings?

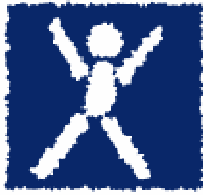
We will make all our findings and suggestions available to the people who are involved in the planning of care for children with CP, and hope that they will incorporate it into their work.

We will also publish our findings in the CPRS newsletter, and on the website. This will allow all parents/carers of children with CP to see our findings.

An article will also be written to be published in an academic journal. Although the actual publication may take some time, this will allow individuals involved in care from around the world to see our findings. Finally the work will be written up and submitted as a postgraduate project to Napier University.

<p style="text-align: center;"><u>Moving schools project Contact:</u> Abbi Green Health Services Researcher Cerebral Palsy Register for Scotland Merchiston Campus, Napier University Edinburgh, EH10 5DT</p> <p style="text-align: center;">0131 455 2454 a.green@napier.ac.uk</p>

Appendix 4:
Parental response form



Cerebral Palsy Register for Scotland

A joint project between Napier University and NHS Scotland

Moving schools project

Please complete this form and return it, in the envelope provided, to the CPRS.

Would you be happy to take part in a discussion with us?

Yes

No

Preferred method of contact to set up discussion:

Post

or

Phone

or

e-mail

(Please enter phone number)

(Please enter e-mail address)

Would you be happy to make comments about what we find at a later date?

Yes

No

Do you think your child would be happy to take part in a discussion with us?

(we can discuss this in more detail when we contact you)

Yes

No

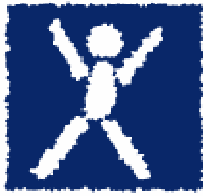
Your Name _____

Your Child's Name _____

Please use this space for any other information, or further details about how we should or should not contact you (e.g. preferred time of day)

Thank You

Appendix 5:
Young people's information sheet



Cerebral Palsy Register *for* Scotland

A joint project between Napier University and NHS Scotland

Moving schools project

The Cerebral Palsy Register for Scotland (CPRS) wants to find out about your move into secondary school. The rest of this sheet tells you more about what we're doing, and what we would want you to do if you decide to take part.

If you have any questions you can get in touch with me, or if you would like to talk to someone outside of the CPRS you can talk to somebody at **SNIP**. We can also send you this information in a bigger print, or in another language if you would like.

Thank you

Abbi Green
Health Services Researcher



SNIP
14 Rillbank Terrace,
Edinburgh EH9 1LN
Telephone : 0131 536 0583
Email : snip@btinternet.com

Information about the work

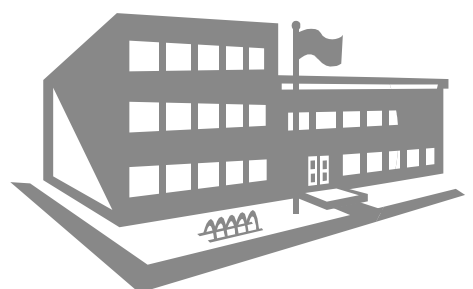
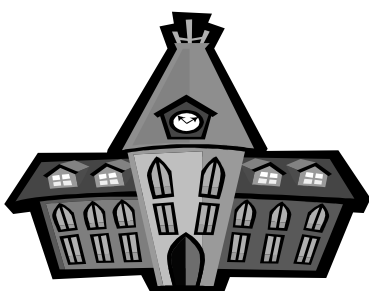
I work at Napier University in Edinburgh, and I'm, part of the Cerebral Palsy Register for Scotland (CPRS) team.

At the CPRS we look into, and find out more about what it's like to have cerebral palsy. This time we want to find out more about moving into secondary school.

We need to talk to lots of young people with cerebral palsy in Scotland about this move. We want to hear about what happens to you as you make the move. What are the good, and/or bad points about the move, what things you would change and what things should stay the same.

By talking to young people about how they found the move into secondary school, we can work out what things work well, and what things need to change.

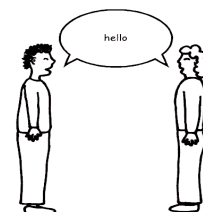
We then hope that at the end of the project, what we find can help change things for other young people with cerebral palsy when they make the move into secondary school.



Questions you might like to ask us

What do you want to do?

We want to come and talk to you to hear about what you think about your move into secondary school, and what you think would help other young people with cerebral palsy going through this move. We'll also talk to your parent(s)/carer(s) about this move at a different time.



What will I have to do?

We will meet you at your house, or somewhere else you choose, and talk about moving into secondary school. We'll ask you some questions and you can tell us what you think. When we talk we will record it onto tape so we can listen back to make sure we've got everything you've said. We would like to talk to you 3 times; after the Easter holidays, at the end of term in primary school, and at the start of term in secondary school.

What sort of questions will you ask?

We'll ask you about things like, who's been helping you through the move to secondary school, how you found out the things you want to know, and was there anything you wanted to happen that didn't.

What if I don't know the answer?

We want to hear about what you think, so there's no right or wrong answer. If we ask you about something you don't know about, just say and we'll move onto the next question.



Will other people know what I've said?

No, we will never use your name when we write about what we've found. We'll use the things you've said, but will never say it was you who said it.

Who will see what you find?

We will put our findings in our CPRS newsletter, and also on our website. We will also write a report for the people who plan the move into secondary school so they can see what things are working well and what things need to change.

What if I change my mind?

It's OK for you to change your mind. At any time when we're talking you can say you want to stop and we will.



About Me



Hi, my name's Abbi Green, I'm part of the CPRS team, and I'll be the person who comes to talk to you about moving into secondary school.

If you have any questions you would like to ask me you can get in touch with me by:



e-mail: a.green@napier.ac.uk



Phone: 0131 455 2454



Post: Cerebral Palsy Register for Scotland

Napier University

Edinburgh

Thank You!

Version number 5, 17/05/2006

Appendix 6:
Table of participants

Participants

Name	Age	Participated	ASL Group	Participating Parent	Area	Ethnicity	LAQ Score	Secondary School	Other
Andrew	16	Yes	Pre	Father	East	White	Mild	Mainstream	
Ben	15	Yes	Pre	Mother & Father	West	White	Moderate	Special	Wheelchair user
Craig	14	Yes	Pre	Mother	West	White	Mild	Mainstream	
Darren	15	Yes	Pre	Mother	East	White	Moderate	Mainstream	Wheelchair user
Ellie	14	Yes	Pre	Mother	East	White	Moderate	Mainstream	Wheelchair user
Elliot	12	Yes	Post	Mother	East	White	Moderate	Mainstream	Occasional wheelchair user
Freddie	12	Yes	Post	Mother	East	White	Mild	Special	
Gareth	16	Yes	Pre	Mother	South	White	Mild	Mainstream	Father participated for part of the interview
Harry	11	Yes	Post	Mother	West	White	Mild	Mainstream	
Helen	15	Yes	Pre	Mother	South	White	Mild	Mainstream	
Ian	11	Yes	Post	Mother	North	White	Mild	Mainstream	
John	15	Yes	Pre	Mother	East	White	Mild	Mainstream	
Kerry	12	Yes	Post	Mother	East	White	Mild	Mainstream	
Kyle	11	Yes	Post	Mother	North	White	Mild	Mainstream	
Leon	16	No	Pre	Mother	North	White	Moderate	Mainstream	
Matthew	14	Yes	Pre	Mother	East	White	Mild	Mainstream	
Nathan	14	Yes	Pre	Mother	North	White	Moderate	Mainstream	Wheelchair user
Olivia	12	Yes	Post	Father	East	White	Severe	Special	Wheelchair user, non verbal communication
Peter	15	Yes	Pre	Mother & Father	West	White	Moderate	Special	Wheelchair user
Rebecca	14	No	Pre	Mother	South	White	Severe	Mainstream	Wheelchair user
Steven	14	Yes	Pre	Mother	West	White	Moderate	Special	Wheelchair user, non verbal communication
Toby	14	No	Pre	Mother	South	White	Severe	Mainstream	Wheelchair user
Victoria	15	No	Pre	Mother	West	White	Severe	Special	Wheelchair user
William	11	Yes	Post	Mother	South	White	Moderate	Mainstream	
Zack	11	Yes	Post	Mother	West	White	Mild	Mainstream	

Appendix 7:
Example of an interview schedule

Schedule

Reference: C0 / / &

Introduction		
Consent	Answer Fully	No write or wrong answers
Recording & notes	Stopping	
Background		
Primary School		Type
Secondary school		Type
Help at school from:		Involved in care:

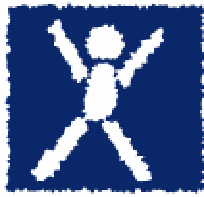
Parent	Young Person
School & decision	
<ul style="list-style-type: none">▪ How decide on school▪ Who aided/supported▪ Influence of primary▪ Happy with choice	<ul style="list-style-type: none">▪ Happy with choice▪ Involved in decision – anyone talk to you?▪ How different to primary▪ General view of school

Transition	
<ul style="list-style-type: none">▪ Preparation▪ Procedure involved – assessment?▪ Role of the school▪ Overall how did it go?▪ Any concerns	<ul style="list-style-type: none">▪ How did you feel about the move?▪ How were they dealt with▪ Any induction process?

Services & Information	
<ul style="list-style-type: none">▪ What support was there – support groups?▪ What support did you want/need/expected▪ Was there interagency working▪ What information was available? – Type, where found, quality	<ul style="list-style-type: none">▪ Did they have support networks – who?▪ Provided with information? How good

Summary	
What advice would you give other parents?	What advice would you give to another YP?

Appendix 8:
Parental consent form



Cerebral Palsy Register for Scotland

A joint project between Napier University and NHS Scotland

Moving Schools Project: Consent Form

Please read the following statements carefully:

1. I agree to participate in a discussion about my child's move into secondary school with Abbi Green.
2. I agree that this discussion can be recorded.
3. I agree that Abbi Green may use quotes from this discussion in written work she produces. However these quotes will be anonymous and I will not be identifiable as the source of the quote.

Signature: _____	Date: _____
-------------------------	--------------------

Name: «MothersFirstName» «MothersSurname»

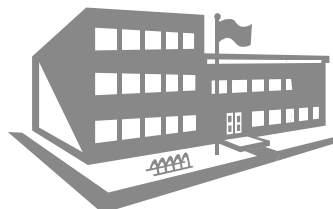
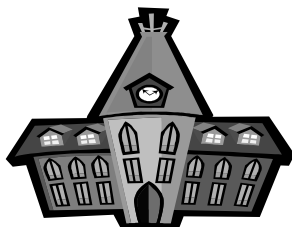
Address: «CurrentAddress1»
«CurrentAddress2»
«CurrentAddress3»
«CurrentPostCode»

Interview Details:

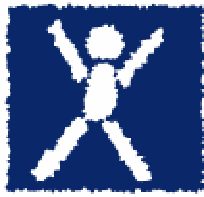
Location:

Date:

Time:



Appendix 9:
Young peoples consent form



Cerebral Palsy Register *for* Scotland

A joint project between Napier University and NHS Scotland

Moving Schools Project: Young Person's Consent

Please read the following statements carefully:

4. I will talk to Abbi Green about when I moved to secondary school.
5. Abbi can record what we talk about.
6. Abbi can use the things I've said when she writes about moving to secondary school, but she will not say I said them.

Signature: _____	Date: _____
-------------------------	--------------------

Signed on behalf of «FirstName» by: _____

Name: «FirstName» «Surname»

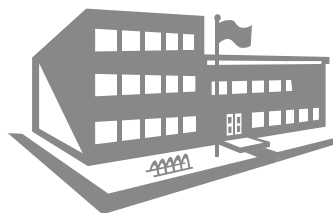
Address: «CurrentAddress1»
«CurrentAddress2»
«CurrentAddress3»
«CurrentPostCode»

Interview Details:

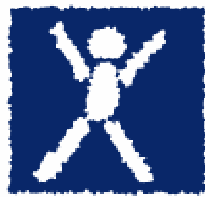
Location:

Date:

Time:



Appendix 10:
Pre ASL parental dissemination report



Cerebral Palsy Register *for* Scotland

A joint project between Napier University and NHS Scotland

Moving Schools Project Report to Parents

16 parents participated in the project, mainly from central or south Scotland, with some families also from Tayside. 11 young people also took part, all between 14 to 16 years old, with varying levels of cerebral palsy (CP).

Through the project we heard many interesting experiences and points of view, some of which were common to a lot of the families, and others were individual to you. In this report the main common points from the discussions have been brought together.

**Pseudonyms have been given to all participants.*

Choosing a Secondary School

Most parents felt that they did have a choice of secondary school. However in some areas there was no choice available or the accessibility needs of the young person resulted in a more limited choice.

Parents made several points over what was important when choosing a school:

- *Local School* → Going to the local school meant being part of the community to parents. This also reduced the distance travelled, and parents felt it was easier to deal with any problems if the school was close to hand.

“But I think that was our view very strongly was he lives in this community, this is where he’s going to school. And we didn’t want him to be taken away six miles away. Who was going to be his friends, you know, when he then goes out at the weekend?”

Parent to Nathan (14yrs)

- *Friends and Family* → Going to the same school as friends and/or family was also important, particularly to the young people.

“Ellie said her biggest concern about not going to [local secondary school] was all her friends were going there.”

Parent to Ellie (14yrs)

- *Accessible* → This was important when the young person’s CP impacted significantly on their mobility, particularly for

Worries before the transition

Many parents had some concerns about their child going to secondary school, although some parents didn't think that their worries were any different to parents of children without CP. Other parents felt less concerned if they'd had other children make the transition before.

“Aye it's just the same things that you always worry about. Because kids will be kids.”

**Parent to Andrew
(16yrs)**

Concerns parents did have included;

- Size of the school → Parents were worried about how their child would orientate themselves, manage all the additional walking, or navigating and using the lifts. Parents also worried about how their child would move between classrooms in particular with the increased number of children.

“You know, there was concerns then about him carrying the school bag and the number of stairs and moving from class to class rather than being in one class.”

Parent to Matthew (14yrs

)

- Teachers → Parents worried about new teachers getting to know their child and their needs. Parents of children with mild CP were particularly concerned as their child's CP was maybe less obvious to teachers.

“Well I think really your main worry is that they are going from somewhere that they are comfortable. Everybody knows them really well. And like you are so, you are happy that the people that are working with her know her inside out. And I think for a child that can't speak and can't move themselves around...to have the sort of confidence in the people that are with you. knowing what you want. you know. And

The transition

Most parents reported that their child had had an overall good transitional experience. Bad experiences occurred for some parents when staff at either the primary or secondary school had let them down.

The primary school, parents, and the secondary school all played a role in a successful transition. The primary school was often responsible for starting the transition process, passing on information to the secondary school, and also preparing the young person. Parents played an important role in the transition process through attending meetings and school visits. Often it was parents who challenged the schools over access for their child. Parents also used their experiences of other transitions, such as the transition into primary school, to help them deal with this one.

In preparation for the transition the secondary schools all held induction days, and some of the schools initiated visits for secondary staff to the primary school.

Visits usually involved a teacher or current pupils giving a talk about secondary school at the primary, and then answering any questions the pupils might have. These sessions often focused on dispelling myths and the young people appreciated and found this helpful. However these sessions tended to be general, and did not include elements related to additional needs.

Some of the young people also received an individual visit from secondary staff, usually someone from the learning support unit, who visited them to get to know their individual needs. This was a common occurrence for young people with more severely impacting CP.

“And the [secondary school] teacher came down to Patrick’s school as well.... So that she knew everybody before, you know, two or three of them knew the ones that was coming up to them.”

Parent to Patrick (15yrs)

All of the young people had some experience of induction days. They had either spent a few days at secondary school following their forthcoming timetable, or took part in special activities. Even if the young person was not making a physical change of school, they had induction days, spending time in the new secondary area within their current school.

All of the young people thought the experience was positive, and had helped them to get used to secondary school.

Some schools held additional days or clubs for those young people who required additional time to adapt to secondary school.

Some of the young people with milder CP told us that they had little opportunity during the induction days to be shown things such as lifts or special units, which might have been helpful.

“Fun, probably the funnest days at school cause it was just a bit of fun trying out things in each subject and you get like shown round by all the sixth years.”

Matthew (14yrs)

“yeah the classes was kind of helpful because then you know what classes are going to be like.”

Ellie (14yrs)

Most schools had worked hard to make the induction day a good experience, although some young people did encounter problems such as the school being unprepared for them, and teachers not being welcoming. Other events were out of the schools hand such as having to hold an induction event at another school, and the school burning down!

First experiences of Secondary School

The majority of parents felt that secondary schools had dealt with this transition well, and had in many cases, made adaptations to help the young person. These included the installation of lifts and ramps, allowing the young person to leave class early, and ensuring that they had a locker for their books and bag.

Many families found that the secondary school was more experienced in dealing with young people with additional needs, and the support provided was more flexible allowing the young people themselves to choose the level of help they required, which promoted independence.

“Whereas the high school was quite experienced from that point of view. And they have been good at differentiating the curriculum and in fact he was much more involved in classes there than he was in primary.”

**Parent to Nathan
(14yrs)**

“Whereas at secondary there’s more like Helen. There’s people that are better than Helen, there’s people that are worse than Helen. And Helen helps people now”

Parent to Helen (15 yrs)

Teachers at secondary school had been a source of support to many of the young people and parents; in particular most of the young people found the guidance teacher to be helpful.

However not all secondary schools performed well. Some problems we were told about included generally poor access, unprepared classrooms, and teachers with little understanding of CP, in particular when the CP was mild.

“The teachers who were involved in Craig’s immediate care like say his guidance teacher, the head of lower school, the headmistress....she would know. But the rest, no I don’t think they were even, you know, remotely interested. It was just, we’ve got all these pupils we need to get on with this.”

**Parent to Craig
(14yrs)**

Some of the young people attended Special Schools which were schools for children from 4 years old through to 18 years old. Parents with experience of special schools felt that being in a special school had helped their child cope with the transition. The school and staff were familiar to them, even though they were moving to a different part of the school.

“So he was familiar already. I think it would have been much more difficult if he was going to a different school.”

**Parent to Steven
(14yrs)**

Information

Nearly all parents received a school prospectus which gave general information about the school. In some of the prospectuses the school had included additional information about learning support, which parents found helpful.

In some areas parents would have liked some general information on transition, and what things to think about when you have a child with CP.

“And I suppose it would have been useful perhaps if, you know, in amongst all the booklets if you were given something that said if you need help with...going to the toilet or if you need help in the class with doing your school work there will be somebody to help you.”

Parent to Ellie (14yrs)

Parents obtained the majority of information they required verbally, and felt that this was necessary as each child's case was individual.

“The only thing that we did get was the, I think it's called the prospectus, that comes out when you know that the child is going to that school. That was really all...It was general information. The information that we needed to know was found out through the meetings before and the visits.”

Parent to James (16yrs)

Support

Depending on the area they lived in, some parents felt fully supported with access to someone they could call at any time with questions. Other parents felt as though they had been left alone during this time.

“No I think like all these people really put themselves out to make it work. And I don't think there was really any need for anybody else.”

**Parent to Rebecca
(14yrs)**

“I think we felt kind of on our own for quite a while, you know. Nobody was, we expected that people could come to us and say ‘right the ball's going to start rolling and, you know, we'll have to do this, we'll have to do that’. But nobody ever did, you know.”

Parent to Luke (16yrs)

Amongst the parents of young people with mild CP who would have liked additional support, the consensus was that it would be helpful to have someone who could tell teachers about CP, and possibly talk to the fellow pupils about it as well. They hoped that this would then lead to a reduction in name calling amongst the pupils, and improve the understanding amongst teachers.

Parents of young people with moderate to severe CP, who wanted to attend the local secondary school felt it was important to speed up the process of assessment, many of these families were

told too late that it was not possible to adapt the local school, and had often missed the induction days at other schools as a result.

Also some parents, particularly those asking for improved access, felt that it would be good to have support at meetings from some one who understood all the jargon.

Services

The majority of parents felt that although services (e.g. health, education, social) provided advice, it was primarily their choice which secondary school their child should attend. A number of services did provide advice on the transition, in some cases even when they were not actively involved in the young persons care at that time. Other services were brought in for additional support during the transition period.

“Everything was in place for him. He’s, andyou know, when he started high school his occupational therapist and his physio had a meeting with the school. And he had went up and made sure that everything was going to be in place.”

Parent to Craig (14yrs)

A major role adopted by one person from an individual service was that of transition lead (or key worker). This mainly involved liaising between different services and the parents, and also answering any problems. This role was vital to interagency working which was key to a successful transition. Many different professionals took on this role depending on the region, including educational psychologist, occupational therapists, head of learning support at the secondary school, or the primary class teachers.

“Yeah, it was great, everybody was round the one table telling, you know, everybody had to have their piece in.”

Parent to Craig (14yrs)

Some parents had to take on this role themselves, and found it very difficult to do. These parents would have appreciated someone from one of the services taking on this role for them.

“But again there was just no kind of liaison or anything with teachers.”

**Parent to Matthew
(14yrs)**

The local council stood out as a service parents felt poorly supported by. Many parents felt that the council was reluctant to invest money in this area, and were responsible for putting barriers in the way of their children.

“If they are around and they are available the council should be helping. If the Building is not fully accessible to wheelchair users they should change it. I mean there is the disability discrimination act. They should have done something about it.”

Parent to Thomas (14yrs)

Advice

The key pieces of advice parents would give to other parents of a child with CP included;

- Contact person → Parents felt it was important to ask as many questions as possible, and to have someone who could answer your concerns. Many parents stated that if you don't ask you don't get.

“I think if you got a named person at the school you can get hold of that's helpful.”

Parent to James(16yrs)

- Visit the school → Parents felt it was necessary to visit the school in person to identify any problems, and to see how the school works, in particular how they involve pupils with additional needs. Also this helped establish a contact person, and ensured that the school knew who you were and that your child was coming.

“I would definitely tell parents to go up and have a look and see what they think themselves.”

Parent to Patrick (15yrs)

- Preparation → It was important to start the whole process early, and also to establish exactly what it was that you wanted from the school.

“Before they even think about what school their child is going to or...what school the child is in or anything like that, I think probably sit down and actually like think what do we want from secondary school for our child.”

Parent to Victoria (15yrs)

- Work with what's on offer → Parents warned other parents not to discount things straight away, and to be prepared to work with services which are available. However they also stressed that it was important not to let people walk over you.

“You've got to be open to change and things.”

Parent to Gareth (16yrs)

“And not let anybody kind of try and sway you to something else just because it suits them better.”

Parent to Luke (16yrs)

Conclusion

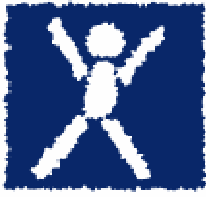
Through this project parents, and also young people, have provided a varied insight into the transition into secondary school for children with CP. Both the positive and negative aspects have been highlighted, and recommendations on what could change have been made.

Because we were only able to talk to 16 parents in depth about their experiences, we now want to see if the other parents on the register, with children of the same age, agree with the key points we have established. This will then allow us to put forward this information as representing experiences of parents in this position throughout Scotland.

Following this the next step is to see if anything has changed over the last 2 to 4 years since these young people made the transition. We know that the Additional Support for Learning Act has been introduced; has this lead to any changes? We will find this information out by carrying out more discussions with parents and young people who will be making the transition in 2007.

We will keep you updated with our progress through the newsletter and on the website.

Appendix 11:
Pre ASL young peoples dissemination report



Cerebral Palsy Register *for* Scotland

A joint project between Napier University and NHS Scotland

Moving Schools Project Report to young people

This report brings together the things you told us about moving to secondary school. 11 of you took part in the project, and you were all between 14 and 16 years old, with different levels of cerebral palsy (CP).

Some of you had similar experiences, whilst others had very different ones. In this report are the main points and the common things you said. This report talks about "you", this is used to mean most of the young people we spoke to.

All of you have been given a different name in this report so nobody knows who said what.

Which school?

When it came to choosing a secondary school nearly all of you said that you wanted to go to the same school as your friends. Usually this was the local school. When things like access stopped you going to that school you were disappointed.

Interviewer: So were you disappointed at all that you couldn't go to your local school?

Darren: A bit aye...Aye, well that's where all my family went and it was like where all, everybody from [primary school] went. I was the only one that went from [primary school] tae [secondary school].

Darren (16yrs)

Your worries

Before you went to secondary school there was some things you worried about. These included things like finding you way around, and the rumours about being bullying being true.

Matthew: I was excited but nervous cause it's much bigger and there's a lot more walking round and stuff.

Matthew (14yrs)

Andrew: So I was, in the back of my mind you always think in case something happens. But nothing

did happen so it was alright...Like somebody comes along and bullies you.

Andrew (16yrs)

Advice

We asked you what advice you would give to another young person with CP going into secondary school. This is what you said;

- Don't believe the rumours
- It's different to primary school

Ellie: Yes it's different and you are more grown up.

Ellie (14yrs)

- Just enjoy it
- It's not as bad as you might think

Helen: It's really good and...don't be afraid to ask questions...And...just enjoy it

Helen (15yrs)

- Don't be afraid to ask for help
- If you do get bullied tell someone.

Darren: Just tell them who tae go tae if they are needing help wae anything. Whatever, just help whenever they need it.

Darren (16yrs)

Craig: Like primary seven is like first year coming up, don't believe the rumours, they are only false and that.....Aye don't, don't be afraid to ask for help

and if you are getting bullied don't be afraid to ask for help either cause you might feel like if you are getting bullied. Like I know what it feels like to be bullied and that. And I know how I felt like, I didn't want to tell a member of staff cause then like people would see me as a grass. But like you are doing what's best for you.

Craig (14yrs)

Information

Only a few of you received written information about secondary school. Those who got this information did find it helpful. Some of you read your school prospectus, but found that it didn't really tell you what you wanted to know. Most of the things you wanted to know you found out through your induction days, or when teachers from secondary school visited you.

Craig: Well we got a booklet like something like what the school is about and all the teachers that are in the school and like what subject is this, and what subject is that. And it was just like normal basic stuff like when you go up to high school like what pupils want to know about...It was written for like P6 or the first years coming up and that...It was helpful like knowing what teachers names were and what to do in this subject and what to do in this subject, and what to do in this subject, and where to go and stuff.

Craig (16yrs)

Support

The main people who helped you, and answered your questions when you were making the move were your parents, primary school

class teacher, or some of the teachers at secondary school, especially your guidance teacher.

James: I just asked my mum and found out that way

James (16yrs)

Andrew: I could ask the teachers cause they do, they do have a little inking. But I don't know if they know a lot.

Andrew (16yrs)

The transition

Most of you said that overall you thought your move into secondary school had gone well. Although some of you did have some problems with getting around or with individual teachers.

Ellie: very well, it went really well. Cause I would like say to people , they would be like 'how was your move to high school?' And I would be like ' it was much better than primary school'.

Ellie (14yrs)

To help you with the move some teachers visited you at primary school, and the secondary school held induction days. These days usually involved you going to secondary school for a few days and either doing special activities or attending classes.

You all thought this was a helpful way for you to find out about what secondary school was like, and to find out what was true and what wasn't.

Andrew: Oh yeah, I had a couple of boys, no a boy and a girl... came in to speak to us and we asked them all the questions and they just told us the basics of the school and

stuff...How long periods lasted, how long you get for lunch and stuff like that...Cause that's the kind of stuff you are interested in.

Andrew (16yrs)

James: It helped a lot just to get used to it.

James (16yrs)

Ellie: yeah the classes was kind of helpful because then you know what classes are going to be like.

Ellie (14yrs)

Some of you mentioned that on these induction days there wasn't really any time for you to find out about things that might be helpful to you because of your CP, things like how to work the lift. This was something that could be added in the future.

Being at secondary school

Most of you preferred secondary school to primary school, you felt that the teachers treated you more like a grown up and that you had more of a say over what help you used.

Craig: I was excited and I really liked getting away from all the babies, like getting away from baby school and that.

Craig (14yrs)

Ben: I love it

Ben (15yrs)

A lot of the secondary schools made changes to try and help you, they did things like put in lifts and ramps, let you leave class early, and made sure you had a locker.

Some of you made use of the Learning Support Units within your schools, and liked the support it gave you. Most of you could pop in and out of there as and when you needed to.

Having new teachers at secondary school was something most of you were looking forward to, and you found your guidance teachers were quite good at helping you to settle in.

Interviewer: Do you remember what, what sort of things were you looking forward to?

Helen: Making new friends and seeing all the different teachers.

Helen (15yrs)

Some of you with milder CP found that the teachers in secondary school sometimes didn't know that you had CP, and it was up to you or your parents to tell them. It was important to you that they didn't treat you any differently, so sometimes you chose not to tell them unless there was a problem.

Matthew: Well it's okay sometimes if they are aware, but I don't want them to treat me differently....But most of them don't know and didn't have a clue.

Matthew (14yrs)

Friends

Your friends at school were very important to you. As we said before, you wanted to go to secondary school with them, and it also

made it easier for you to settle in if there was some of your friends (or someone you knew) in registration or other classes.

Andrew: But it was good cause I always, I always had somebody to talk to cause there was a guy there from my regi class, from primary school. So I already knew somebody. So I wasn't on my own at any time.

Andrew (16yrs)

It was important to most of you that you did the same things as your friends, and weren't treated any different. For some of you, you decided that you didn't need some of the help put in place by the secondary school before you arrived, as you preferred to do things in the same way as everyone else.

Conclusion

You told us a lot of interesting things about when you moved to secondary school. It was really good to hear about what you thought of the move straight from you, and not just what your parents thought.

We're going to take these main points you've made and ask other young people with CP, who are the same age as you, if they think that as well. This will mean that we can then use this information to show what young people with CP all over Scotland think about the move into secondary school.



Cerebral Palsy Register for Scotland

Napier University

Edinburgh


Appendix 12:
Examples of dissemination articles from the CPRS
newsletter and website

Quick Update - Windows Internet Explorer

http://www2.napier.ac.uk/cprs/update.htm

File Edit View Favorites Tools Help


Quick Update



Cerebral Palsy Register for Scotland

A joint project between Napier University and NHS Scotland

- Home
- About us
- Information
- Newsletters & Articles
- Links
- Contact us



- [Register](#)
- [Contact us](#)
- [Site map](#)

Cerebral Palsy Register for Scotland

Quick Update

- Over 500 children are registered on the CPRS from all over Scotland, and of all ages.
- Health boards across Scotland are working with the CPRS to ensure that the register represents children with CP throughout Scotland.
- Over 70% of the parents/carers contacted to complete the questionnaire about daily living have done so, which has provided us with some very interesting information.
- **Research:** The CPRS is due to complete a project looking at the transition from primary to secondary education from the point of view of young people with CP and their parents. Researchers met with families and spoke to both the parents and young people to hear their experiences. We hope to report on our findings towards the end of 2008.
- **Research:** The CPRS is working with registers across Europe as part of the Surveillance of Cerebral Palsy in Europe collaboration. This group aims to further investigate all aspects of CP and to improve what is known about the condition.

[Back](#)

Done Local intranet 100% 11:00

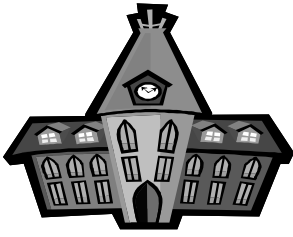
start

Inbox - Microsoft ...

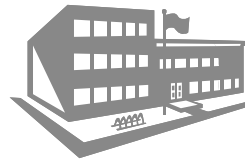
H:\PhD\Draft writ...

Method & method...

Quick Update - Wi...




Moving school's project



As we reported in our last newsletter the 'Moving School's Project' has started and we had spoken to 16 families about their experience of moving to secondary school.

We have started to look at what the parents and young people have told us. Here are some of the main points we've found so far from the **parents**;

- **Choosing a school** : Parents felt it was important that their child went to secondary school with their friends, and that they could attend the local secondary school. Accessibility was the main reason why some of the young people could not go to the local secondary school.
- **Concerns:** Prior to starting at secondary schools some parents reported being concerned about how their child would cope with the size of the new school, bullying, and access. Some of the parents drew on past transition experiences (e.g. the transition into primary school) to help them with this transition.
- **Help & Support:** parents involved in the project had very different experiences of the services and support available to them. It seems as though their experience was dependant upon where they lived. It was clear that those parents who had somebody to take charge of the transition (e.g. a key worker, or liaison) generally had a more positive experience than those without one. The school prospectus was the main information given to parents, which many found was too general.
- **Advice:** Advice parents would give other parents in a similar situation is to start the process early, to visit the schools in person and identify any problems, and to ask as many questions as possible, ideally to a named contact person. Parents were of the view that if you don't ask, you don't get.

 The main points raised by the **young people** include;

- **Friends:** Friends were very important to all the young people, they felt strongly about going to the same secondary school as their friends, and at school they didn't want to be seen as being different to their friends. Sometimes this influenced what support they used.
- **Preparing for secondary school:** The induction days and visits by secondary staff to primary schools were really helpful and enjoyable for the young people. They said it helped them to know what to expect, and also to dispel some of the myths about secondary school.
- **Help & Support:** The young people relied mainly on their parents, or guidance teachers for support during this time.
- **Worries:** Like parents the young people worried about getting lost, getting around, and bullying at secondary school.

Next step

This group of families told us some really interesting things about moving to secondary school. But it's also raised some questions that we would like to look into further.

What we want to find out:

- Are these main issues common to other families of a child with CP?
- Do parents get different support and help dependant on where they live?
- Do parents and young people with mild CP have different experiences to those with more severe CP?

How we will answer these questions?

To answer these questions we need a bigger group of parents to tell us their experiences, and whether they've had similar or different experiences to what we've already been told.

A questionnaire based on the main issues raised is the most effective way to answer these questions. If your son/daughter is between 14 – 16 years old you should have received this questionnaire. Completing it is completely voluntary, however we would really like to hear as many views as possible. If you have not received the questionnaire but would like to please contact us.

What about the young people?

In the same way that we have information parents have given us, we have questions about what the young people told us, and we would like to see if other young people with CP agree or disagree with these points. We've also written a questionnaire for other young people to complete. We know that not all young people will be able to fill in a questionnaire, but we would like to give as many young people as possible the chance to do so.

After this we would like to talk to some families who are making the move in 2007.

The "Moving schools" Project

The 'Moving schools' project which the CPRS has been carrying out for the last 3 years is now finished. In total 48 families contributed information to the project, 25 through interviews and 23 through a questionnaire. These families represented young people with CP from across Scotland, with all levels of CP, and those attending both mainstream and special schools.

The project has yielded huge amounts of interesting information, and in this article some of the main points are brought together.

The Additional Support for Learning Act (ASL) has had little impact on the transition.

The ASL is an act brought in in 2005 which aimed to improve the educational experiences of all young people with additional needs, including transitions. The act also introduced co-ordinated support plans (CSP) which is a written plan outlining the care and support the young person will receive.

The project compared the experiences of young people making the move before and after the act and found very little difference between their experiences.

Many parents felt that the Act had not brought about any change for them. Other parents were unsure of what the Act meant for them.

"He hasn't got one of those at the moment [CSP]. We're not sure if he should or not" - Mother

Feeling the need to fight for services

When talking about the transition many parents reported feeling that they had to fight to get support from services for their child.

"It wears you down sometimes, constantly being the bad guy and constantly fighting, but it's nice to have... if you find someone who'll fight your corner, but it's not very often it's the school" - Mother



Parents and young people want choice!

When choosing a secondary school families want to be able to access all schools. In particular families felt very strongly about attending their local secondary school. They felt that this would help the young person become part of the community.

Some parents felt that their child would benefit from special schooling, and they wanted to be free to choose this option. Many parents felt unhappy that many special schools were closing and merging with mainstream schools.

"When they say integration and inclusion, are they going to be in mainstream classes or in a unit by themselves?" - Father

Worrying about mobility issues

Before moving to secondary school most of the young people reported that they were worried about things linked to moving around the school, such as the stairs, lots of people, or carrying their bag all day. Their parents were also worried about these things.

“I think I would use my wheelchair more than I would walk...Because at primary school, like the one I’m in now, I walk with crutches, but I don’t walk with my crutches at, at high, I probably won’t walk with my crutches at high school that much.” – Elliot (12)

Most of the earlier work looking at this move into secondary school says that young people worry about bullying. So this shows that for young people with CP they may have different worries. Knowing this can help schools prepare to address these issues.

Teachers, assistants and pupils at mainstream don’t understand.

Young people moving into mainstream schools found that many teachers, assistants, or other pupils didn’t understand about CP. As a result some of the young people experienced negative comments about their impairment. Many of the young people and their parents felt that it would be useful to educate staff and pupils about what having CP means, and how it can impact on learning.

“But most of them [teachers] didn’t know and didn’t have a clue...and my parents had to go and speak to them and stuff. Cause they didn’t really understand...” – Matthew (14)

Although some teachers and assistants didn’t understand there were also many of them who were very supportive of the young people.



To be informed

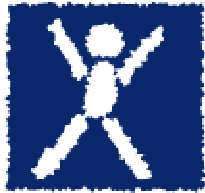
Throughout this work it was clear that both parents and young people wanted to be informed. They wanted written information, and went about collecting verbal information. All of the parents felt it was an advantage to have access to a contact person at the school who they could ask questions. Without such a person many families were left unsure who to contact and without answers to questions.

What’s happening now?

Although the project has finished this isn’t the end of the work. A report outlining the main issues the work found, and how things can be improved has been written, and that report will be sent to the child health commissioners, and also other professionals working with children with CP. This report will also be made available on line soon.

To reach an even wider group of professionals’ articles will be written for academic journals and submitted for publications. An update of our progress will be included in the next newsletter.

Appendix 13:
Post ASL parental dissemination report



Cerebral Palsy Register *for* Scotland

A joint project between Napier University and NHS Scotland

Moving Schools Project Report to Parents

In total 25 families took part in the project from all over Scotland. Families were involved as part of one of two groups; a group where the young person made the transition before the Additional Support for Learning Act, and a group where the young person was making the transition under this Act. This report concentrates on the group making the transition under the Act which came into force in 2005.

All families in this group included a young person aged between 11 – 12 years old, with varying levels of cerebral palsy (CP).

Through the project we heard many interesting experiences and points of view, some of which were common to a lot of the families, and others were individual to you. In this report the main points from the discussions have been brought together.

Pseudonyms have been given to all participants.

Before the move

Before moving to secondary school many parents were involved in a process of choosing a secondary school, and then meeting with members of the local authority to discuss the move. In many cases parents felt that they had to do this much earlier than they would have done if their child did not have CP.

“Well, we, I think, broached the subject first because we wanted to make sure that the high school were aware of Kerry’s needs and that she was coming up.”

Kerry’s Mother

There seemed to be two important factors that influenced which school parents choose for their child;

- The local school → Many felt that it was important that their child went to the local school with children they knew from primary school. Parents felt having CP shouldn’t exclude them from doing this.

“Well, I attended that high school, my brother went to it, my eldest...he went to it and all Kyle’s pals are going up there...And if he couldn’t cope, at the end of the day, then I’ll think again, but I would rather he had the chance”

Kyle’s mother

- The school ethos → Some parents felt that the local school wasn’t the best option due to the way it provided for young people with additional needs. Some parents chose a special school or mainstream with a good unit.

“At least in Olivia’s class everyone’s sort of... they’re all different but they’ve all got a serious problem. So okay, Olivia doesn’t talk and some else has to be tube fed – they’re all in there, it’s much of a much-ness. In fact, there isn’t any child in the school that sticks out. And it’s nice to be like everyone else.”

Olivia’s father

“Secondary was coming up... We looked at various options and decided that we wanted something with a more special needs element in it. So [chosen school] has got a unit on the side of it, so that’s what we chose for Elliot.”

Worries before the transition

Many parents had some concerns about their child going to secondary school, although some parents didn't think that their worries were any different to parents of children without CP. However some were linked to CP. Parents whose children were in a special through school had fewer worries as they felt that the teachers knew them and their child well.

Concerns parents did have included;

- Size of the school → Some parents were worried about how their child would orientate themselves, manage all the additional walking, or navigating and use the lifts. Parents also worried about how their child would move between classrooms in particular with the increased number of children.

"It's the sheer mass of people on the staircases that worries me about her moving around."

Kerry's mother

- Teachers → Some parents worried about new teachers getting to know their child and their needs. Parents of children with mild CP were particularly concerned as their

These worries were very similar to those the parents from the earlier group.

The induction process

The primary school, parents, and the secondary school all played a role in a successful transition. The primary school was often responsible for starting the process, passing on information to the secondary school, and also preparing the young person. Parents played an important role through attending meetings and school visits.

In preparation for the transition the secondary schools all held induction days, and some of the schools initiated visits for secondary staff to the primary school.

Visits usually involved a teacher or current pupils giving a talk about secondary school at the primary, and then answering any questions the pupils might have. These sessions often focused

on dispelling myths and the young people appreciated and found this helpful. However these sessions tended to be general, and did not include elements related to additional needs.

“We’ve had like the teachers down and they talked to us. They just talked to us and said like, um...you get like brand new things up there, and then the schools going to be changed when you get up, up inside the school. ‘Cos like classes change a lot, different classes every...like moving, different areas.”

Kyle

All of the young people had some experience of induction days. Even if the young person was not making a physical change of school, they had induction days, spending time in the new secondary area within their current school. All of the young people thought the experience was positive, and had helped them to get used to secondary school.

Abbi: “Was the induction days helpful?”

William: “Yes, definitely, because it gave you an idea of where everything was and things like that.”

Some schools held additional days for young people who required additional time to adapt to secondary school.

“Yeah, it was what we call an ‘enhanced induction’, and yeah it was good. Better than just two days, you know, that a lot of other kids had. It was good.”

“He also had about three or four days right up, didn’t you? Rehabilitation, through the social worker took him in the week before so he could get a real feel for the place.”

Many of the families found that the induction days highlighted some of the problems they thought might arise when the young person made the move, such as difficulty moving from class to class. Identifying the potential problems at this stage meant schools worked to solve these problems over the summer holidays, and many young people found that changes had been made by the start of term.

Example

Kerry was making the transition into a mainstream secondary school. She has some mobility issues, although she walks without any aids.

Her mother said: **“I mean basically it [the induction] just reinforced the problems that I thought there would be about the stairs, and she said she kept getting pushed out the way and like, everybody kept on overtaking her, which I thought probably would happen.”**

First experiences of Secondary School

The majority of parents felt that secondary schools had dealt with this transition well, and had in many cases, made adaptations to help the young person. These included providing lift passes and allowing the young person to leave class early to avoid crowded corridors, many of the young people in mainstream schools appreciated this as they often found the crowds difficult to negotiate.

“He gets to leave about five minutes before the bell so he can get...[to the next class]. He gets to use the lift as well so it saves him to walk up and down.”

Kyle’s mother

Teachers at secondary school had been a source of support to many of the young people and parents; in particular most of the young people found the guidance teacher to be helpful. However, some families felt that teachers had little understanding of CP, which caused problems such as not using specialised equipment in the classroom.

“His OT has been really good. She’s got everything he’s needed...The school didn’t use them [equipment] until we asked them...it depends on the individual teacher and what the subject is.”

“PE was another issue because they were doing rugby training at the beginning and Zack felt he couldn’t join in with a lot of it, he was kinda left to his own devices, instead of the teacher giving him a ball or something to do, a specific thing.”

Many of the young people in mainstream schools also had assistants with them at some point during the day. Generally this help was well thought of, with young people naming assistants as someone they could talk to about problems. However, in some circumstances the assistants were preventing the young people from becoming truly independent.

“I know he feels that his independence is compromised because they want to push him, whereas he wants to do it himself...I think if you don’t come across it yourself, you don’t know very much about the condition. So I think, they sort of ‘I’ll help you, poor you.’ They [the assistants] are really nice to him but, I think sometimes he feels it can be a bit suffocating.”

“Her learning assistants seem to be very supportive of her. She comes back and tells me about wee conversations that they’ve had and stuff like that. So she seems to be able to ask them things.”

Some of the young people attended special education schools Parents with experience of special schools felt that being in a special school had helped their child cope with the transition. They knew the school and staff, and even though they were moving to a different part of the school and having new experiences there were aspects of familiarity.

Information

Nearly all parents received a school prospectus which gave general information about the school. In some of the prospectuses the school had included additional information about learning support, which parents found helpful. However, some parents felt that there was a need for more detailed information before the transition; such as information about what schools were available and more information about services within schools.

“It would be very useful if it was also compacted! ‘These are all the independent schools and these are all the schools for special needs, these are all the schools that have units’, and, you know...”

Elliot’s mother

A lot of the information that the young people relied on came from parents, and many of the young people named their parents as their main information source. This highlights how important it is that parents have the right information. If young people rely on their parents to answer their questions parents need to have the information to be able to do this.

Some parents felt that there was a need for them to be proactive and to go out and find the information that they needed themselves.

“I mean, I’m quite able to go and find it out myself and I wouldn’t be shy doing it, but I don’t know how it would be if you were maybe more inclined to sort of sit back and just let it happen.”

William’s mother

Support

Depending on the area they lived in, some parents felt fully supported with access to someone they could call at any time with questions. Other parents felt as though they had been left alone during this time.

“So from that point of view at least, from this class and these teachers, the communication with us, we feel, is very complete.”

Olivia’s father

“Nobody’s been in touch...nobody really spoke to me about it. Because I filled in the form but they never got back to me.”

Ian’s mother

For most parents it was the primary school who acted as the main source of support, although other services such as physiotherapy and OT were involved with some of the young people. Many of the young people regained an input from services because of the transition.

“OT’s a bone of contention because we should get it, but he doesn’t...he did recently because he’s moving to high school, so we insisted that they have to go to the high school, so they came out then.”

Harry’s mother

Many parents felt that they would go to the primary school first with any questions that they had. Secondary schools were less likely to be contacted as families saw them as being very busy. However, once the move had taken place most parents felt that they would contact the secondary school directly if they had a school problem.

Overall parents felt that different services did work together, with schools taking the advice of physiotherapists or OT’s. Although some parents felt that the school sometimes needed to be chased up on some of these things.

Advice

The key pieces of advice parents would give to other parents of a child with CP going into secondary school included;

- Ask questions → Parents felt it was important to ask as many questions as possible, and to have someone who could answer your concerns.

“Just ask questions. If you don’t know something just go and ask because you know, they have a responsibility to let you know what’s happening and how it’s all gonna go.”

Kerry’s mother

- Visit the school → Parents felt it was necessary to visit the school in person to identify any problems, and to see how the school works, in particular how they involve pupils with additional needs.

“Definitely see if you can get more visits into the school. I don’t think...what is it two or three days they go for? I wouldn’t say that was enough. I would say they need more. The more you can get your child familiarised with it the better. And talk to the staff if there’s anything worrying you.”

Zack’s mother
“

- Preparation → It was important to start the whole transitional process early.

“I would say that if the primary school don’t approach you at the beginning of the last year of primary, start the process. Because it has to be started to think about it a year before they go, it’s too late if their starting, if they’ve not done anything by the end of the Easter term, it will be a disaster.”

William’s mother

- Stand up for what your child needs → Parents felt that it was important to be proactive and to ‘fight’ for what their children needed. Sometimes this involved finding out information and standing their ground.

“My advice to someone would be...just to be proactive and to shout a bit. Because if we hadn’t done that, we wouldn’t have a co-ordinated support plan and he would be at a different school and so, I think that would be the advice I would give.”

Freddie’s mother

“I don’t know, I find the whole thing – it wears you down sometimes, constantly being the bad guy and constantly fighting, but it’s nice to have...if you can find someone who’ll fight your corner, but it’s not very often it’s the school...do your homework and find out what you should be getting.”

Harry’s mother

Additional Support for Learning Act

The Additional Support for Learning Act came in in 2005, with the aim to improve school experiences for children with additional needs, most young people with CP would be considered as having additional needs. Co-ordinated Support Plan’s (CSP) are part of this Act and they replace the Record of Needs.

Some families were unsure of the Act and what it meant to them.

Generally families felt that the Additional Support for Learning Act had made no difference to their child’s experience of school or the transition. From this project there were very few differences between what families before the Act told us and what families making the transition after the Act told us.

“[It’s made] no material difference to Olivia’s education.”

Olivia’s father

The majority of families in this group had previously had a ‘Record of Needs’ although only some of the young people had a CSP. Some young people were waiting to be assessed for a CSP; some had been told that they did not qualify for one. Some families had been told that they would not get a CSP despite the young person having a number of additional needs; most of these families had appealed and now had a CSP in place.

“It hasn’t really affected Elliot yet, but he needs to be assessed for a CSP, so I suppose that’ll be when we find out.”

Elliot’s mother

“They can’t send a child with his level of disability with no plan at all. It’s ridiculous.”

William’s mother

If you would like to know more about the Additional Support for Learning Act or if you have any questions about it a good group to contact is ‘Enquire’.

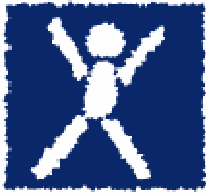
Helpline: 0845 123 2303, Website: www.enquire.org.uk/pcp/helpline.php, E-mail: info@enquire.org.uk

Conclusion

All of the families in this group felt that the transition had been a good experience. Although a few families had faced some problems it was how well the school had solved these that resulted in the overall impression of the transition. Through this project parents and young people have provided a varied insight into the transition into secondary school. Both the positive and negative aspects have been highlighted, and recommendations on what could change have been made.

There was little difference between the two groups that we talked to, and most parents felt that the Additional Support for Learning Act had made no difference to their children. It would seem that the most important things to a good transition are to have someone to take the lead on the transition, for therapists, schools and parents to work together, and for the school to be prepared to adapt to the needs of young people.

Appendix 14:
Post ASL young peoples dissemination report



Cerebral Palsy Register *for* Scotland

A joint project between Napier University and NHS Scotland

Moving Schools Project Report to young people

This report brings together the things you told us about moving to secondary school. 20 young people took part in the project all together. We talked to older children who'd moved to secondary school 2 or 3 years ago and we talked to children making the move in 2007.

In this part of the project you were all making the move in 2007, and you were all between 11 and 12 years old, with different levels of cerebral palsy (CP).

Some of you had similar experiences, whilst others had very different ones. In this report are the main points and some of the things you said. This report talks about "you", this is used to mean most of the young people we spoke to.

All of you have been given a different name in this report so nobody knows who said what.

Before you went?

Before you went to secondary school most of you knew that your parents had been busy sorting out which secondary school you would be going to. Most of you were going to your local secondary school with the children you knew from primary school.

A lot of you had an idea of what secondary school would be like from things you'd heard from brothers and sisters, or from going up to the secondary school for other reasons - like playing football.

"[Secondary school's] more faster, having to change about, changing about."

Kyle

"You get loads of...um teachers...you get to go to like up shops at lunch time and things...um there's football...er there's football teams my brother tells me...um...you sort of like, help primary school children like do sports and things if they come over to like the

Ian

Most of you had some questions that you wanted answered before you went, like who was going to be in your class and who was going to be your assistants if you had them.

Your worries

Most of you said that you had no big worries about secondary school. The things you had small worries about were things like getting lost, and lots of people being in the corridors when you were trying to get to classes. Some of you were also a bit worried about things like the stairs and all the walking being hard work.

"People pushing to get into the class."

Harry

"You only get one class in primary school and in secondary you've got hundreds, so worried about

Zack

New subjects and lots more homework was also on your mind. Even though you had some of these smaller worries a lot of you were looking forward to moving to secondary school.

"Well, I feel great, great...because [secondary school] is better than [primary school]"

Freddie



"It's more exciting than primary school. Because it's a lot bigger."

Kerry

A lot of you had some help during the day from an assistant whilst at secondary school. You thought this was good as it helped you with moving around the school, or to keep up with lessons. Sometimes you felt that you had a little bit too much help and that you would like to try and do things by yourself.

"I think it's good that their [assistants] writing for me, but I'd like to find a way that I can do it. Or find a way I could try, on a computer or something...like teach

Elliot

Some of you felt that you would have liked to have been more involved in meetings where things about secondary school were decided. Only a couple of you were asked by services (like Social Work, or OT) about your views before the move.

"A bit more involved...it's all going to my Mum, and I say 'what happened?!'"

William



Information

Not many of you had any written information about secondary school, although some of you had a school prospectus. Most of you found out the things you wanted to know verbally from your parents, on the induction days, or from teachers.

"Well, last night my Mum told me a lot about it."

Freddie

Support

The main people who helped you, and answered your questions when you were making the move were your parents, primary school class teacher, or your assistants. All of you could give me a name of somebody that you could ask a question to.

"I would talk to Mrs McGregor, because that's what she says."

Kyle



Induction

To help you with the move some teachers visited you at primary school, and the secondary school held induction days. These days usually involved you going to secondary school for a few days and either doing special activities or attending classes.

You all thought this was a helpful way for you to find out about what secondary school was like, to find your way around, and to find out what was true and what wasn't.

"[It helps you to know] your class and the people around you."

Ian



"Because it gets you used to the, the school. Rather than just not, not wanting to go there. Or even over the summer, I don't think that, I'm just saying it, but you could...you could um, go through the summer holidays trying

Elliot

Some of you mentioned that on these induction days there wasn't really any time for you to find out about things that might be helpful to you because of your CP, things like how to work the lift. This was something that could be added in the future.

A few of you had extra induction days added on, or got to go back to the secondary school at another time. This was a good thing as it

helped you get used to the school building, the lessons, and the teachers.

Being at secondary school

Most of you preferred secondary school to primary school, you felt that the teachers treated you more like a grown up and that you had more of a say over what help you used.

"Good...better than primary because I've got different teachers...well, nice teachers, more than primary, well...their nicer than I thought they would be."

Harry

A lot of the secondary schools made changes to try and help you; they did things like, let you leave class early, and gave you a lift pass. Although these things were available to you, some of you chose only to use them if you needed to.

"If my next class is like down or up the stairs I will have to leave a bit earlier...and that's also good about leaving early you don't get caught in the crowd "



William

Some of you made use of the Learning Support Units within your schools, and liked the support it gave you. Most of you could pop in and out of there as and when you needed to.

Some of you were in a special school which had smaller classes. When you moved into the secondary part of the school you got to do different lessons, and move classes, which you enjoyed.

"Do you like Senior Base?"

Abbi:

"Yes"

Olivia:

"Do you like Senior Base better than the Base?"

Abbi:

"Yes"

Olivia:

"Is Senior Base good or very good?"

Abbi:

"It's good"

Olivia:



"I go to the lunch club...it's just like em, well if you want you can go to the lunch club. It's like puzzles and games and playing the computer."

Advice

We asked you what advice you would give to another young person with CP going into secondary school. This is what you said;

- Don't worry about it → Many of you felt that secondary school wasn't too scary once you had started and got used to it.

"I might say to her that, em, it will be scary at first, but then if you are really worried tell a parent or friend. And like, just...but when you get used to it you'll like it."

Kerry

- Ask for help → A lot of you thought it was important to not be scared to ask for help when you're new at secondary school.

"Not to worry and to go to your pastoral care teacher, and other teachers for help going around the school."

Ian

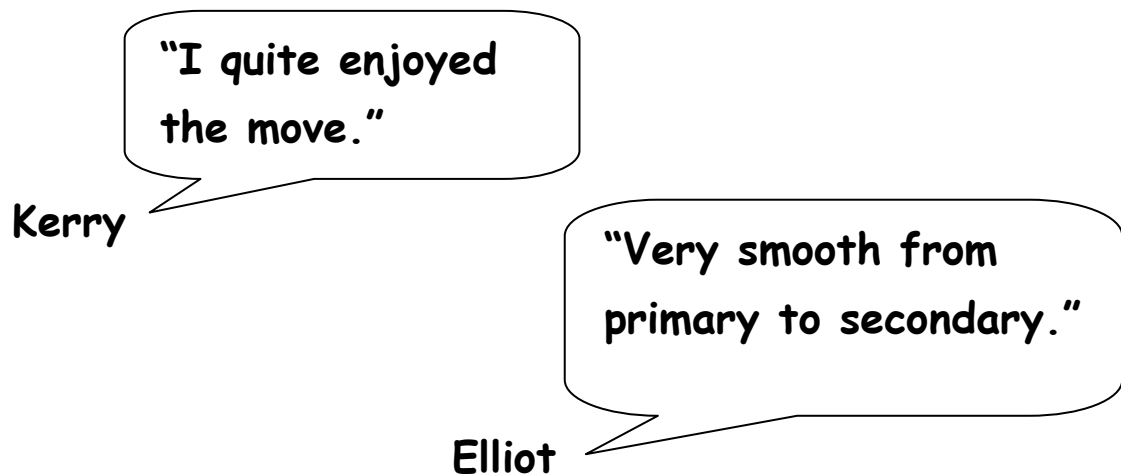
- Go to the induction days → Nearly all of you thought that the induction day was helpful to you in getting ready for secondary school, and you wanted new people to have that chance too.

"Go to the induction days. Get to go for a couple of days before you move up."

Elliot

Conclusion

Overall most of you said that overall you thought your move into secondary school had gone well. Although some of you did have some problems with getting around or with individual teachers, you didn't think this had been bad enough to spoil your move into secondary school.



You told us a lot of interesting things about when you moved to secondary school. It was really good to hear about what you thought of the move straight from you, and not just what your parents thought.

We're going to take these main points you've made and ask other young people with CP, who are the same age as you, if they think that as well. This will mean that we can then use this information to show what young people with CP all over Scotland think about the move into secondary school.



Cerebral Palsy Register for Scotland

Napier University

Edinburgh



0131 455 2454



a.green@napier.ac.uk

Thank You!

Version 1: 9th June 2008