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UNIVERSITY OF SOUTHAMPTON

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES

SCHOOL OF HEALTH SCIENCES

**THE PHYSICAL MANAGEMENT OF CHILDREN WITH CEREBRAL PALSY
ATTENDING MAINSTREAM PRIMARY SCHOOL**

by

Sarah Crombie

Thesis for the degree of Doctor of Philosophy

June 2010

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

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When children with cerebral palsy attend a mainstream school, their physical functioning may impact on day-to-day school activities and on their active participation. The Special Educational Needs Code of Practice (DfES 2001b) advocates a multi-agency approach to enable children with SEN to be included within the mainstream school system. Physiotherapists often work with school staff to manage the child's physical needs within this environment and to deliver therapeutic interventions. Despite numerous government policies endorsing the inclusion of children with SEN within mainstream school, there has been little research into the detail of how this might be achieved for children with physical impairments.

This qualitative study explores the physical management of children with cerebral palsy within mainstream school. In the first phase I conducted focus groups and semi-structured interviews exploring the views and experiences of parents of children with cerebral palsy, physiotherapists and school staff regarding the management of the child's physiotherapy needs. The second phase utilised a case study approach to generate in-depth contextual knowledge of the issues faced when managing the child's physical needs by exploring individual cases within three mainstream schools using observation, interviews and documents. Thematic analysis was used to analyse these data.

Three main themes emerged from the findings of the study: how therapy and education services work together; the delicate balance to achieving participation; and how views of difference impact on the child's management. I found that the way physical impairments were viewed within the current SEN framework, inhibited a holistic view of the child with physical impairments. It impacted on collaborative practice between agencies affecting how the child's needs were met. I conclude that a more interactional model of viewing disability is required to ensure that the child's needs are considered within the context of not only school but the child's life as a whole.

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Declaration of authorship

I, Sarah Crombie declare that the thesis entitled ‘The physical management of children with cerebral palsy attending mainstream primary school’ and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

- this work was done wholly or mainly while in candidature for a research degree at this University;
- where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- where I have consulted the published work of others, this is always clearly attributed;
- where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- none of this work has been published before submission.

Signed:

Date:.....

Acknowledgements

I would like to thank the following for their contribution to this work:

All participants and schools involved in this study

My supervisors: Professor Ann Ashburn, Dr. Rose Wiles, Professor Melanie Nind

Physiotherapy Research Foundation

Association of Paediatric Chartered Physiotherapists

Nancie Finnie Charitable Trust and Jenx Ltd.

Abbreviations used

GMFCS	Gross Motor Function Classification System
ICF	International Classification of Functioning, Disability and Health
IEP	Individual Education Plan
LSA	Learning Support Assistant
NTA	Non-teaching Assistant
NSF	National Service Framework
OT	Occupational Therapist
PE	Physical Education
SALT	Speech and Language Therapist
SEN	Special Educational Needs
SENCo	Special Educational Needs Co-ordinator
SSU	Special Support Unit
TA	Teaching Assistant

Chapter 1: Introduction

Over the past two decades, the ethos of inclusive education has become firmly embedded within the UK education system. Most children with ‘special educational needs’ (SEN) such as children with cerebral palsy, now attend a mainstream school (Audit Commission 2002) and have an increased right to do so (DfES 2001b). Cerebral palsy is however, a low incidence condition (SCPE 2000) and consequently many school staff may never have had the experience of managing these children in their school. The SEN Code of Practice (DfES 2001b) advocates that schools should work in partnership with other agencies to identify and address the child’s SEN. For the child with cerebral palsy, schools may need advice and support from specialist therapy staff to learn the necessary skills to manage the child’s different needs within the school environment.

Paediatric physiotherapists are involved with children with cerebral palsy from a young age, often throughout their preschool years and much of their school life (Parkes *et al.* 2004). With the increasing emphasis on inclusion and participation in school and community life, the physiotherapist’s role has evolved to provide not only physical interventions impacting on impairments, but strategies to influence the child’s activity limitations and participation (Palisano *et al.* 2004; APCP 2009). Health service and other government policies (e.g. National Service Framework for Children and Young People (DoH 2004); Aiming High for Disabled Children (DfES 2007)) endorse partnership working to develop a more child-centred, holistic approach to the management of childhood disability. For the child with cerebral palsy, the physiotherapist should therefore work not only with the child, but with all those involved with them to promote their inclusion and meet their physical needs within differing environments.

As a paediatric physiotherapist working with children with cerebral palsy in mainstream schools, I embarked on this study as I was concerned about the lack of research evidence to guide my clinical practice. Although there were national policies and broad professional guidance (APCP 2009), there was little empirical evidence to guide the detail of practice: effectiveness of direct therapy interventions or school based therapy carried out by school staff; the consultative role of the physiotherapist and importantly

children's views on therapeutic input in school. I experienced differing practices in schools possibly as Llewellyn (2000) proposes, due to different interpretations of policy, availability of physiotherapy resources or individual needs of the child and family.

The aim of this study was to explore the physical management of the child with cerebral palsy within mainstream primary school. I wanted to understand the everyday issues relating to managing the child with a physical impairment within this environment and to explore the role of the physiotherapist in this setting. Before any model of inter-agency practice or physiotherapy intervention in school can be evaluated, I considered it necessary to gain a greater understanding of these issues.

This thesis begins at Chapter two with a literature review of the issues relating to inclusive education, the physical management of the child with cerebral palsy in school and inter-agency practice. Chapter three presents the initial phase of this study: the aims, methodology and methods utilised, followed by the findings from this phase. Chapter four explains the research aims and methods of the main study. Chapters five, six and seven, present the findings from this second phase. I discuss the findings from the whole study in Chapter eight with my conclusions and implications for practice, policy and further research.

Chapter 2: Literature review

In this chapter I firstly discuss the literature on inclusive education to provide the educational context influencing the management of children with cerebral palsy in mainstream school. I continue by discussing current physiotherapy interventions for this group of children relevant to the school environment, different models of therapy provision and collaborative working. I identify gaps in the literature relating to the management of the child's physical needs within the UK mainstream school system.

2.1 Inclusive education

2.1.1 Policy and legislation

To understand the issues surrounding inclusive education, it is important to have knowledge of how policy and legislation have changed and influenced views and practices over the past half a century (Clough 2000). Over this period there has been a radical change in England in how children with disabilities are viewed, not only within the education system but within the wider social context.

Children with SEN have not always had the opportunity or right to be educated within the mainstream school system. It was not until the Education Act of 1970 that all children irrespective of their disability had the right to education per se, with responsibility shifting from Health to Education services. This paved the way for improved educational opportunities and for the possibility of transfer into a more inclusive education system (Thomas and Vaughan 2004).

The Warnock Report (DES 1978) and 1981 Education Act established the principle of a mainstream education for children with SEN. These marked an important change in viewing children with SEN not through their diagnosis and perceived disability, but through their individual needs by the consequent introduction of formal assessment and statementing procedures (Clough 2000). How these procedures are used to construct special education today remains a controversial aspect of the education system (Topping and Maloney 2005).

Over the past two decades, educational policy has been largely influenced by broader changes in thinking on the education of children with disability emerging primarily

from the human rights perspective. The UN Convention on the Rights Of The Child (UN 1989), the Salamanca Statement (UNESCO 1994) and its accompanying Framework for Action spelled out the rights of disabled children to be educated within the mainstream to achieve maximum social integration, individual development and importantly, their rights not be excluded or discriminated against. The UK government has endorsed such rights with the Special Educational Needs Disability Act (2001) and policies such as 'Every Child Matters' (DfES 2004a), 'Removing Barriers to Achievement (DfES 2004b), and Aiming High for Disabled Children (DfES 2007).

Despite this positive outlook within policy towards inclusion, how this works in practice remains controversial. Allan (2008 p.3) reflects that 'inclusion appears to be in something of a sorry state' and even Warnock (2005) appears to have changed her mind arguing strongly that the move towards inclusion was a big mistake. Although much of the criticism relates to the inclusion of children with emotional or behavioural difficulties, concerns remain as to whether a mainstream environment can adequately provide for all children's needs and whether teachers have the necessary skills (Dockrell and Lindsay 2001). Some have reservations about full inclusion, where the goal is for all children with SEN to be educated in mainstream classes (e.g. Hornby 2002).

2.1.2 What is 'inclusive education'?

Firstly it is important to consider what is meant by inclusive education. This concept is contentious, with different definitions and conceptualisations perhaps reflecting that 'inclusion is not a single movement' but 'made up of many strong currents of belief, many different local struggles and a myriad forms of practice' (Clough 2000 p.6). For many, the belief is that inclusion in education is integral to the wider social inclusion agenda and is about a comprehensive education for all, equality and collective belonging (Thomas and Loxley 2001). Booth *et al.* (1997) make it clear that inclusion constitutes two processes: increasing pupils' participation within the culture and curricula of mainstream schools and decreasing exclusionary pressures. For Barton (1997), inclusive education is about responding to diversity and celebrating difference.

Many inclusionists (e.g. Ainscow 1997) emphasise inclusion as being a process, rather than a specific ideology or set of practices. This process involves whole school reorganisation of the curriculum and organisation. It is important therefore to have an understanding of different ways of conceptualising and interpreting inclusion to

understand how this might influence the detail of practice for children with cerebral palsy. I discuss these ideas from different perspectives such as human rights, constructions of difference and need, access within education, models of disability and pupil's views.

2.1.3 Conceptualising inclusion

An important concept in inclusive education is that of the rights of the child to equal education without discrimination within the mainstream setting. Those who strongly support inclusion from this perspective (e.g. Oliver 1996), consider any segregation to be a denial of the child's basic human rights. Everyone should have equality of education regardless of background, gender, ethnicity, disability or sexuality; inclusion is therefore not just about SEN, but about society's views on the inclusion of all minority or oppressed groups.

A group arguing for what they call 'responsible inclusion' (Hornby 2002, p.12) consider there are children for whom this approach provides no benefit and could potentially be harmed. From this perspective children's human rights means an appropriate education which in some cases may override the right to be educated in the mainstream. For some children it may be that as Lindsay (2003) argues, provision may be 'inclusive' but not meet the child's needs, with practice being driven from a human rights perspective rather than by evidence of efficacy.

There is little disagreement that inclusion should mean more than the equal opportunity for a child to be present in a mainstream school. Being present in a mainstream school as described in the Warnock Report (DES, 1978) as locational integration, was about how to join the mainstream, adapt and fit in. Most modern usage of the term 'inclusion' stresses the importance of going beyond placement to active participation of the child in all areas of school life, for example 'inclusion refers to the opportunity for persons with a disability to participate fully in all of the educational, employment, consumer, recreational, community, and domestic activities that typify everyday society' (Inclusion International 1996). This stress on participation implies active involvement and choice and not just a role as passive recipient of resources that are made available to them.

Another important argument influencing inclusive education is how 'difference' is constructed and thus managed. Tomlinson (1982) has highlighted that when a pupil is thought of as 'special', they are firstly given a label or identity recognising them as different from others, and secondly a set of interventions to reinforce this state of difference (to manage their 'special educational needs'); whether this label is given to them is dependent on the more powerful person's perception of difference and conceptions of normality. Foucault (1991) describes difference as being perceived as permissible, but only within a specified region of tolerance. Outside of this region is behaviour or a state of difference which is recognised as being abnormal and may therefore constitute the child as having a special need. Thomas and Loxley (2001) write that there are no universal markers to identify SEN and teachers in one school may identify 'need' differently from those in another, dependent on their local experience. Being considered to have SEN may therefore largely depend on which school the child attends, how they are assessed for this need and subsequent educational treatment (Roaf and Bines 1989). How a child's need is constructed may therefore depend on the current knowledge and conception of good practice. 'Needs' themselves do not define teaching practices or the extent of special provision and are therefore open to unequal practices (Thomas and Loxley 2001).

Equality of opportunity has been favoured by many as a better approach to the concept of meeting needs. Roaf and Bines (1989) argue that this focuses on the system rather than on the individual and as it involves equality it raises issues of discrimination and disadvantage. For the child with cerebral palsy, this means providing equality of opportunity in all aspects of school and may mean the need for positive discrimination and provision. Their needs may not just require structural changes in the environment to provide opportunity, but compensatory measures. 'When different resources, teaching and provision are required, this raises a central area of confusion for teachers for whom a 'difference blind' or 'normalization' approach is more familiar than the 'social justice' perspective to equality concerned with realization of potential' (Roaf and Bines 1989 p.20).

Equality of opportunity implies equal access to the curriculum and all school environments. From this perspective schools may need to undergo radical reform of their pedagogy and curriculum to include pupils with SEN (Mittler 2000). If not, as

O'Brien (2002) argues, schools may describe themselves as being inclusive as they have created suitable adapted environments, but are not necessarily learning inclusive. The child may therefore be at risk of isolation if teaching approaches and curriculum fail to recognise their individuality (Rose and Howley 2002). Hornby (2002) argues that some children need a curriculum appropriate for them and not one designed to fit the general mainstream population. Children with physical impairments for example, may require adaptations to the general class curriculum or additions to the curriculum.

Teachers therefore need to feel confident in their teaching practice and competent to meet the diverse needs of pupils. Teacher training has however, been criticised as being inadequate to meet this need (Golder *et al.* 2005), although there has been little research into meeting a child's physical needs within the classroom. Croll and Moses (2000) found in their research that teachers felt unable to meet the needs of all pupils, but were less concerned over children with physical impairments compared to those with other SEN. Others however, argue that there is a 'loosening of faith in the supposed benefits of special pedagogy' and a shifting of resources from special to the mainstream system could alter this view (Thomas and Loxley 2001 p.107).

2.1.4 Models of disability

How a child's 'disability' is viewed may influence their inclusion and management in school. Oliver (1996) argues that disability as a category can only be understood within a framework which is culturally produced and socially constructed. Disability therefore cannot be abstracted from the social world which produces it. This contrasts with the individual or medical model, which locates the problem firmly within the individual stemming from their functional limitations or deficits (Oliver 1996). Disability rights groups have viewed this individual model as a means of control by professionals as well as an excuse not to include people with disabilities in mainstream society. Management of the child they argue was focussed on fixing or altering the impairments or deficits with no assumption that the school needed to change its environment or teaching to accommodate a child with different needs.

The social model of disability has been used to counter the medical model; disability is viewed as socially constructed and society and its institutions, such as schools, as oppressive, discriminatory and disabling (Oliver 1996). It shifts attention away from the individual's deficits to the way in which society includes or excludes them: 'the

experience of disabled people is dependent on social context, and differs in different cultures and at different times' (Shakespeare 2006 p.29). It therefore focuses on the removal or elimination of disabling barriers. This model has influenced the Special Educational Needs and Disability Act (2001) 'to prohibit all schools from discriminating against disabled children' (DfES 2001b p.v) and to create school environments free from barriers.

More recently disability theorists have become concerned about the simplistic solutions offered within this approach (e.g. Morris 1991). As Shakespeare (2006 p.62) argues 'a theory which addresses only external barriers is an incomplete response to the challenge of disability'. He advocates an interactional approach taking into account different levels of experience and factors affecting the individual. Improving a person's quality of life may include barrier removal and attitudinal change, but also medical intervention and therapy.

One of the main criticisms of the social model is the denial of the importance of impairment. As Corker and French (1999) argue, impairment can cause pain or discomfort and thus the individual's experience cannot be separated from the social context. French (1993) writes that as a person with a visual impairment, no amount of barrier removal or social change would entirely remove her problem of visual impairment. For Shakespeare (2006 p.43), 'disabling barriers make impairment more difficult, but even in the absence of barriers impairment can be problematic'. He argues that there is a need for some engagement with medical responses to impairment and whether treatments are effective. If there is an interest in a person's quality of life then this should include minimising the impact of the impairment and impairment complications. This is particularly pertinent for a child where growth and maturation may impact on their impairment and the potential to develop or maintain functional skills.

Although many may wish to abandon the social model, writers such as Thomas (2004) have proposed instead a social relational perspective to understanding disability. She argues that disability may be viewed as oppressive, social reactions towards people with impairments, but that there is equally no need to deny that impairments may still cause some restrictions to activity or that disability and impairment effects may interact to cause activity limitations. The social model of disability is thus important to ensure

equal opportunities and access for the child at school, but acknowledgement of their impairment may be crucial to enable this and to address their individual physical needs.

2.1.5 Pupils' views

Listening to the views and experiences of children and young people has increasingly become recognised as important and necessary within health and education (Alderson 1995; Curtin and Clarke 2005). Although some studies have explored how children and young people view inclusion, as Allan (2008), argues knowledge is limited regarding what inclusion looks like and feels like from their perspective.

Attitudes towards disability or impairment have been voiced by children to be a barrier to inclusion. In Pivic *et al.*'s (2002) study, children with mobility limitations faced instances of isolation, physical or emotional bullying impacting on their inclusion. They reported lack of understanding by teachers and support staff regarding their physical capabilities and difficulties. Allan (2005) found that attitudes need not be blatantly negative, but more subtle and caused by an individual being unable to deal with a child's impairment. Children in Allan's study found that teachers more than other pupils misunderstood their impairment, made an unnecessary fuss about a given situation or dealt differently with the child with a disability compared to another child in the class.

A few studies have found that children report that difficulties with access are a barrier to inclusion (Pivic *et al.* 2002; Kenny *et al.* 2005). Children have described access difficulties within classrooms and other physical spaces in school, creating difficulties with independence and affecting social relationships with peers (Hemmingsson and Borrell 2002).

In a study of children with SEN, Allan (1999) found that inclusion and exclusion were moveable processes whereby the child could feel included in one moment and excluded in the next. She concluded that there is a conflict between children's 'desires' such as to be treated normally and teachers' wishes to meet what they consider to be the child's needs. De Schauwer *et al.* (2009) in their study with children with cerebral palsy concurred with Allan that children move between two worlds: being a child with a disability and an ordinary child in the class. The children in their study stressed that their difference and difficulties were part of who they were and reflected that although

they enjoyed friends and school in similar ways to others, their difference became relevant at certain times and in particular contexts. The reactions of their peers affected how they felt about their difference and their sense of belonging was positively affected by participating in activities alongside their peers.

The literature is sparse regarding children's views of how their physical needs are addressed in school. A study by Lightfoot *et al.* (1999) interviewed secondary school children with a chronic illness or physical disability and found that they acknowledged the role visiting health professionals played in maximising their participation in school life. This was mainly with respect to timetabling as they valued the efforts made in ensuring their schooling was disrupted as little as possible and highlighted the importance of accessing pupil's views when timetabling therapy so they had a say in what they might miss in school. Schools needed to have appropriate access facilities and equipment to ensure participation, although this was not always the case. Strategies such as leaving class early or asking other pupils to carry their bags were considered to facilitate potential mobility problems. When PE classes were difficult, pupils wanted teachers to adapt the activity or find constructive alternatives for them such as physiotherapy or other class work. The pupils' views point to the importance of consultation with pupils about the kinds of support they need and that therapy needs to be viewed within a holistic view of the pupil's life at school.

This section has discussed how different perspectives on 'inclusion' might influence the experience and management of the child with cerebral palsy. It highlights important issues such as equal opportunities, active participation and the child's sense of belonging. For children with physical impairments, there is limited knowledge however, of how their needs are viewed and managed within the framework of inclusive education, how therapy may be integrated within school particularly for the younger primary school child or how equipment might hinder or facilitate their inclusion. The following section addresses therapeutic perspectives on the physical management of the child within the school environment, different models of therapy provision and issues in collaborative practice.

2.2 Physical management of the child with cerebral palsy

The International Classification of Functioning, Disability and Health (WHO 2001) has increasingly been used as a means of viewing health interventions. According to the ICF definitions, impairments are deviations or losses to body function or structure, activity limitations are difficulties in executing tasks or actions, and participation restrictions are problems with involvement in life situations. For the school-aged child with cerebral palsy their functioning and disability may therefore be considered as a dynamic interaction between their health condition (cerebral palsy) and contextual factors such as the environment (e.g. school). Interventions may be targeted towards one or more areas of the ICF such as their body structures or function, activity limitations or participation in school life.

Cerebral palsy is an umbrella term for a heterogeneous group of conditions both in terms of aetiology and in type and severity of impairment. It originates in childhood, but is a life-long condition affecting 2-3 children per 1000 live births (SCPE 2000). Bax *et al.* (2005) describe cerebral palsy as:

‘a group of disorders of the development of movement and posture, causing activity limitation that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder’.

This definition describes the child as demonstrating abnormal motor behaviour affecting their functional motor abilities as detailed in the Gross Motor Function Classification System (Palisano *et al.* 1997). This classification system groups children with cerebral palsy into one of five levels depending on their functional mobility or activity limitation. Classification at level I would indicate that a child has reduced balance, speed and co-ordination skills, but can walk indoors and outdoors. At level V, the child has physical impairments restricting voluntary movements with no means of independent mobility. Bax *et al.*'s definition of cerebral palsy also includes additional impairments to the motor disorder such as seizures, hearing and visual impairments, cognitive and attention deficits and behaviour and emotional difficulties, necessitating a multi-professional approach to the child's management.

2.2.1 Physiotherapy management

The heterogeneous nature of cerebral palsy presents many methodological difficulties for research into the effectiveness of physiotherapy interventions and how the results are applied to clinical practice. Interventions targeted at the young pre-school child may not necessarily be appropriate in the environment of a mainstream school.

Consequently as found by Antilla *et al.* (2008) in their systematic review of physical therapy interventions for children with cerebral palsy, there is mostly limited evidence to support interventions. They describe many methodological difficulties such as controlling for environmental or personal factors which may impact on outcomes. As physiotherapy has such an established role in the management of these children, control groups with children not receiving therapy are not usually used for ethical reasons (Siebes *et al.* 2002). Results therefore only represent the additional value of the intervention under study. Sample sizes are usually small (King *et al.* 1999) affecting the statistical significance of results. As cerebral palsy affects children during their years of growth and development, Siebes *et al.* argue that it would be more realistic to expect long-term rather than short-term results, but most studies measure the latter. Another significant problem reported is the lack of sensitivity of instruments to measure change (Fetters and Klusik 1996) as although children may have made important changes, they may not be sufficiently detected.

An important difficulty in measuring the effectiveness of physiotherapy for this group of children is the lack of clinical guidelines for management. As Mayston (2004) points out, the complex nature of cerebral palsy means that physiotherapy may encompass a variety of techniques, approaches and skills to meet the child's changing physical needs. What constitutes 'physiotherapy' for one child may differ for another. Many studies on physiotherapy do not detail the techniques used. Guidance for physiotherapists working with children within schools is generally broad, emphasising their role in the child's 'physical well-being' and 'providing advice to maximise the opportunities for the child or young person within their educational provision' (APCP 2009 p.14). Although Parkes *et al.* (2004) found that 94% of school-age children with cerebral palsy in their study received physiotherapy, there is as yet very little research exploring the role of the physiotherapist within the UK school system and the effectiveness of school-based interventions. For the purpose of this literature review, I will discuss only physiotherapy interventions relevant within the school setting.

Most research on physiotherapy for the school-age child has focused on specific interventions aimed at the impairment level or activity limitation, rather than the impact on the child's inclusion or participation. Muscle weakness is considered to be an important aspect of motor control and has been found to affect children with cerebral palsy (Wiley and Damiano 1998). Even highly ambulant children with spastic diplegia or hemiplegia have been found to be weaker than normal in the affected muscles in their lower limbs. In recent years therefore, muscle strength training programmes have been advocated as one approach to maximising function for children with cerebral palsy, often being carried out in schools as part of the child's physical programme. Research into the effects of these programmes have focussed on ambulant children targeting specific muscle groups of the lower limbs, to improve walking ability and posture in standing and walking (Morton *et al.* 2005; Eek *et al.* 2008). A systematic review by Dodd *et al.* (2002) found evidence that at an impairment level, these programmes improve specific muscle strength, but as environmental factors were not measured, it is unclear whether this affected the child's ability to perform activities or to positively affect their participation. A more recent review by Antilla *et al.* (2008) concluded that there is conflicting evidence for the effectiveness of strength training on gross motor function. When strength training has been used however, as part of a more comprehensive therapy programme incorporating cardiovascular training and PE at school, benefits on functional ability have been found (Andrew *et al.* 2004).

Damiano *et al.* (2002) have stressed the importance of exercise as an adjunct to strength training. This would have benefits not only for the muscles but on the child's cardiovascular system. Participation in physical activities within school and in extra-curricular activities would be an obvious means of promoting this. The physical benefits of participation within school, has as yet not been explored.

Reducing musculoskeletal impairments to prevent deformity and improve function is often described as a main therapeutic aim (Damiano 2004) and impact on the child in school. Strategies to implement this might include spasticity reduction using botulinum toxin injections (Heinen *et al.* 2006), serial casting to lengthen muscles, or the use of orthotics to improve gait (Olney and Wright 2000). Although there is some evidence for the effectiveness of these interventions, the intensity or type of physiotherapy

required alongside these interventions has not been fully evaluated (e.g. following botulinum toxin injections APCP 2009).

Therapy strategies often involve the principles of motor learning and motor control to improve gross motor skills. Larin (1992) found that therapists treating children with cerebral palsy implemented most of the recognised strategies for motor learning and teaching. These involved providing appropriate stimulation, keeping the child active, emphasising mobility over stability activities, providing feed-forward instructions and taking breaks when necessary. Motor learning has been described as a set of processes associated with practice that lead to permanent changes on motor performance which can be transferred to other settings or tasks (Schmidt and Lee 1999). Practicing motor skills in a variety of situations thereby providing repetition of skills and different movement opportunities, is viewed as important for motor learning (Mayston 2007).

The school environment could therefore be viewed as an ideal opportunity to promote motor learning on a regular basis if built into functional daily activities. Thorpe *et al.* (2002) in their study of motor skill learning concluded that children with cerebral palsy benefitted greatly from practice of motor tasks. Experience of movement appears to be important in shaping the function of the nervous system in these early years of a child's development (Hadders-Algra *et al.* 1996; Hadders-Algra 2001). Movement skills should therefore be practiced within the environment where the skill is needed, yet physiotherapy is often carried out in an isolated setting. Children have been found to perform concrete perceptual motor tasks much more readily than abstract ones, even if the same movements are involved (Van der Weel *et al.* 1991) possibly due to information from the environment directing the task. Other opportunities to practice motor skills may be through the use of postural management equipment such as a standing frame for upper body control, hydrotherapy or swimming. A review of the use of postural management equipment in special schools concluded that good practice involved equipment being viewed as an integral part of the child's day rather than as a separate programme (Dabbs *et al.* 2004).

For children at GMFCS levels III-V, a postural management programme is often advocated to integrate the use of specialised equipment with therapy (Pountney 2007). Within school, this might include equipment such as a standing support or specialist seat, the use of orthotics and exercise programmes (Gericke 2006). Postural

management equipment is used to promote the experience of ‘normal’ movement, acquisition of motor skills and function. It also aims to prevent musculoskeletal deformities, and a study by Pountney *et al.* (2009) found that a 24 hour postural management approach significantly reduced hip subluxation. A recent evaluation of the evidence for the use of standing supports by Bush *et al.* (2009) however, found inconclusive evidence for its proposed benefits on bone mineral density, hip development or muscle length. How postural management equipment is used within mainstream schools and its benefit on the child’s physical functioning and participation require further study.

As children with cerebral palsy with low activity levels have been found to be most restricted in participation (Schenker *et al.* 2006), mobility aids such as walkers, tricycles, and wheelchairs are often used within school to promote further activity, independence and participation. When ambulation is difficult or inefficient, augmentative mobility such as manual or powered wheelchairs and adapted tricycles enable children to explore their environment and acquire spatial concepts (Butler 1991). How this equipment is used within the mainstream school system and the barriers to its use has not been fully explored.

There has been little research into ‘hands-on’ physiotherapy at school, particularly when undertaken by school staff. Neurodevelopmental therapy for example, may be taught to parents or school staff to incorporate techniques into everyday life, but research has focussed on evaluating therapy carried out by therapists (Tsorlaks *et al.* 2004). Likewise studies into the intensity of physiotherapy e.g. Bower *et al.* (2001) have used therapists rather than school staff undertaking therapy.

2.2.2 Models of therapy provision in schools

The Disabled Child Standard of the NSF for Children, Young People and Maternity Services cites the therapist’s role as educating and supporting school staff in building therapy throughout the child’s daily routine (DoH 2004). How this may be achieved however, has yet to be fully evaluated. Different models of therapy provision have been identified ranging from individual therapy with the child outside of the classroom, working with the child within the class, through to indirect therapy through collaboration with the class teacher (McWilliam 1995).

Individual input by a therapist is viewed as a necessary component of physiotherapy intervention in school for instances where a child is learning new skills, an orthotic appliance has to be fitted or when therapy needs to be more intensive and focused, such as for muscle strengthening or specific skill acquisition (Kaminker *et al.* 2004). Most therapists however, do not consider that one model of therapy fits all aspects of the child's management (Effgen and Klepper 1994) and as Kaminker *et al.* (2004) found in their survey of therapists, children benefit from different models of therapy dependent on their needs.

Integration of therapy within the classroom enables the child to practice functional movements within a natural setting and elaborate on activities they have initiated. It provides repetition for the child, variation in different movement skills and generalisation of skills (Sekerak *et al.* 2003). This concurs with theories of motor learning that children benefit from regularly practicing functional movements. To practice movements, Sekerak *et al.* conclude that the class timetable needs to be planned with the child's activities in mind to allow flexibility as well as predictability of routines, especially for older children where the day is more structured. Intervention needs to be planned for when the child is in an optimal state for learning and not just fitted in when possible. The classroom environment is viewed as important for allowing mobility and other equipment to be used effectively. Therapists therefore need to be involved in planning the optimal utilization of space alongside teaching staff.

Despite theoretical agreement for this integration model, there is little evidence of its efficacy over other models of service delivery (Ott and Effgen 2000; Nolan *et al.* 2004). Outcomes have focused primarily on the child's physical abilities rather than on their participation, inclusion or impact on other areas of learning. Studies exploring this model (e.g. Hanft and Pilington 2000) have also used therapists whereas in the UK, TAs are often involved with the child's physical management in class.

Studies into integrating therapy into daily classroom activities are however informative: Sekerak *et al.* (2003) found that therapists described relationships between teachers, parents and therapists as critical markers of success, although how parents were involved was not evident. Teachers were considered the vital foundation for the success of this model and needed to learn effective ways of incorporating therapy into daily activities even when the physiotherapist was not there and develop a team approach to

the child's management. This study also identified limiting factors such as the cognitive ability of the child and their distractibility when integrating therapy.

The consultative model of therapy (Sandler 1997) is commonly used in the UK. With children spread over numerous schools, this model has been adopted to provide indirect cost-effective therapy (Dockrell *et al.* 2006). Sandler identifies training as an important factor in the ability of school staff to effectively implement therapy programmes, but as Mahon and Cusack (2002) found, appropriate training is largely unavailable. Good communication between school staff and therapists is vital for this model to be successful (York *et al.* 1990), but Mahon and Cusack found that the majority of teachers had no direct communication with physiotherapists. They did not report whether there was communication instead with TAs. This model has been mainly studied within SALT services, with concerns raised that highly skilled interventions may not be delivered by appropriately experienced professionals (Law *et al.* 2000; Dockrell *et al.* 2006) and parents perceiving this model to be adopted mainly for cost-cutting purposes rather than efficacy (Band *et al.* 2002). Dockrell *et al.* (2006) conclude that practice in schools must be based on an analysis of the child's needs and on negotiated intervention to provide both complementary and integrated delivery of support.

In the UK TAs are integral to the consultative approach to therapy as they work within the classroom to support children with SEN (DfES 2001b). Research into the working practice of TAs with children with physical impairments has focused however, on the effects on participation and learning, (e.g. Skar and Tamm 2001; Hemmingsson *et al.* 2003), rather than on the physical management of the child. As Robertson (2003 p.99) points out, 'the important role that teaching assistants have to play in developing inclusive practice as indirect providers of therapy services, needs to be appraised and monitored in the context of a clearer conception of what counts as good-quality therapy provision'.

2.3 Collaborative working

Collaborative working is advocated as best practice in meeting a child's complex needs (DfES 2001b). Despite theoretical agreement in the literature there has been little research evaluating how this may be achieved. As Lacey (2003) points out, in practice numerous factors hinder this including varying professional practices and time

constraints, communication, and weak commitment to joint working. She argues that school staff involved with the child need time to plan and discuss issues amongst themselves and with outside therapists, and to work side-by-side with therapists to gain skills and confidence. Lack of time however, was an important factor identified by teachers in a study by Mukherjee *et al.* (2000) on managing children with physical disability in school.

Parents of children with cerebral palsy and teachers have highlighted the importance of a person responsible for co-ordinating the child's needs in school, and parents often feel frustrated if there is no one responsible in the school to disseminate information about their child (Mukherjee *et al.* 2000; Datta *et al.* 2006). This is particularly a problem for children without a Statement of SEN where there is often no clear policy for responsibility (Asprey and Nash 2006). Although this responsibility would appear to be the natural role of the SENCo, as Mittler (2000) notes, this role includes increasing responsibilities which are difficult to fulfil. Robertson (2003) has proposed the development of a specialist teacher co-ordinator to ensure liaison, but others have raised concerns about the SENCo or a SEN teacher having responsibility for the child as it may create the impression that the child is not the responsibility of the class teacher and consequently expose the child to exclusionary processes (Mittler 2000; Evans and Hunt 2001).

Mukherjee *et al.* (2000; 2002) and Datta *et al.* (2006) have highlighted the value of information sharing between health professionals and school staff. Good written information helps teachers understand the child's difficulties and their capabilities. If teachers are well informed, pupils feel their difficulties are understood and feel supported when tired or in pain. Cavet (2000) and Mukherjee *et al.* (2000) found visibility of the condition affects staff awareness of the child's needs. Mukherjee *et al.* also found that teachers prefer information from health professionals rather than from parents possibly as they may not wish to look incompetent, believe that technical information can only come from professionals or not want to overburden parents. In another study, Mukherjee *et al.* (2002) found examples of good practice to include joint meetings between health and education staff and shared written information including the child.

Collaborative goal setting is viewed as a way of ensuring that physical goals are incorporated into everyday function in school. Studies investigating its effectiveness on motor skills in school using a consultative or direct therapy model have found positive outcomes for children. King *et al.* (1999) used collaborative goal setting to identify whether children attained their therapy goals within the school setting using a functionally-oriented and family-centred approach. They investigated indoor mobility either walking or in a wheelchair, transfers and functional gross motor skills necessary for participation in school life. Their service delivery model incorporated direct therapy, monitoring and collaborative consultation between therapists, teachers and parents. This family-centred approach involves families as key partners in the child's management at school (King *et al.* 2004). Functional outcomes have been described as the essential activities required in school which are directly related to the child's quality of life (Harris 1990). Rather than measuring a particular ability in isolation, functional outcomes measure the child's abilities in the context of the environment. King *et al.* (1999 p.25) 'speculate that collaborative consultation is a key feature of effective therapy intervention for children with special needs in schools' and that therapists in schools should focus on functional goals. How physical goals are incorporated into a child's Individual Education Plan however, has not yet been investigated.

2.4 Summary

In this chapter I have discussed the literature relating to the physical management of the child with cerebral palsy in mainstream primary school. I have discussed how different interpretations of 'inclusion' and views on disability may influence the child's experience in school, current knowledge of physiotherapy for the child relevant to the school environment, models of service delivery in school and important gaps in the literature. The current inclusion agenda in schools endorses collaborative working between health and education services, yet there has been little research within the UK education system. There needs to be a greater understanding of how a child's physical needs are currently met in school, the impact of their difficulties on inclusion and how agencies work together for the benefit of the child. This study aimed to address these issues.

Chapter 3. Phase one: Exploring the physiotherapy management of children with cerebral palsy in mainstream settings

In this chapter I explain and justify how I conducted the initial phase of this study. I explain the research aims, methodology, design, methods and analysis. I then discuss the findings from this initial phase.

3.1 Research aims and questions

In the initial phase of this study I aimed to explore the physiotherapy management of children with cerebral palsy in mainstream primary school. My interest was in how the physiotherapy needs of children with cerebral palsy were met both in and out of school and with issues relating to inter-agency practice. I wanted to explore the views of those involved with the child to gain an understanding of different perceptions and experiences in this area.

This study aimed to address the following research questions:

1. What are the experiences of parents of children with cerebral palsy, school staff and physiotherapists in the physiotherapy management of children with cerebral palsy at school?
2. What are the issues in meeting the child's physiotherapy needs within the school setting?
3. What role do physiotherapists, school staff and parents, perceive they have in the physiotherapy needs of the child?
4. What are the important issues around managing these children within primary school?

Children were not included in this first phase as the questions were broad and I felt that a more focussed approach would be needed with young children to gain in-depth understanding. As children's views were considered essential to this study, they formed an integral part of the main study.

3.2 Methodological approach

To address research questions where relatively little is known in the field as in this study, a qualitative approach is appropriate (Morse and Field 1995). The approach or strategy taken in any research is typically informed by beliefs about how the social world can be studied, by how the validity of this knowledge might be assessed and by a set of decisions about the research design (Pope and Mays 2000). This strategy needs to be explicit to understand the reasons for the use of particular methods for data collection, analysis of the findings, and the nature of my role in this research.

Any researcher needs to consider their personal beliefs about how knowledge is constructed and how the nature of the social world is viewed. In this research study I aimed to explore in depth, the issues involved in managing the physical needs of children with cerebral palsy within a mainstream school setting. From an interpretivist standpoint, rather than viewing there to be one 'truth' out there to explain events or actions, I wanted to explore multiple meanings and interpretations (Finlay and Ballinger 2006). As Crotty (1998 p.67) describes, the interpretivist approach is research 'looking for culturally derived and historically situated interpretations of the social life-world'. I wanted to explore multiple realities to develop an understanding and theory of how and why children's physical needs are managed in certain ways in school.

As an interpretivist researcher, I recognised that my identity and standpoint shaped the research process and findings in a fundamental way. My own social background, understandings, convictions and experiences influenced what I heard and observed in the field, how I collected and selected data, and interpreted it. I viewed knowledge that I gained from the field and from interviews to be co-produced between myself, the participants and our relationship. Another researcher may have unfolded a different story.

Whilst viewing the epistemology as interpretivist, there is also the consideration of ontology. Some researchers believe that there is a world 'out there' that can be accessed by the use of particular techniques and that phenomena are made up of essential structures that can be measured. This 'realist' position can be contrasted with the 'relativist' position which 'emphasises the diversity of interpretations that can be applied' (Finlay and Ballinger 2006 p.19). I viewed participants in my research to have

particular experience of their situation, which could be described and explained. Their knowledge and experience to them represented their reality. This reality however, would be influenced by the methods used to capture it and by their own perspectives of the phenomena as they see them. Their perspectives therefore reflected the research context, their culture, expectations, and prior experiences. This position lies somewhere within the realist-relativist continuum and is described by Pope and Mays (2000 p.93) as 'subtle realism'. It is a view of qualitative enquiry that accepts that there is an underlying single reality which can be explored, but acknowledges that all research involves subjective perception and that there may be different views or perceptions about what is happening. My role as the researcher was to explore aspects of the underlying reality perceived by different participants through different research methods. From the subtle realist position, I clearly need to account for the ways in which I chose to access information, including how the participants were chosen and recruited, the methods used for data collection, the process taken and my possible influences in this process.

3.3 Research design

The research design used in this study included:

1. Focus groups with parents of children with cerebral palsy and physiotherapists;
2. Semi-structured interviews with school staff.

3.3.1 Focus groups

Focus groups were chosen for data collection with parents and physiotherapists as they have been found to be useful in studies where little is known about the subject and the main aim of the study is exploratory (Kitzinger 2000). A focus group can be defined as a discussion based group interview, which is 'focused' (centred on a particular topic) and facilitated by a moderator (Sim and Snell 1996). This method is considered a useful means of enabling the exploration of beliefs, understandings and priorities related to illness and disability (Bowling 2002) and the understanding of complex issues involving many levels of feeling and experience (Carey 1994). It was anticipated that group dynamics would facilitate discussion and interaction between participants, encouraging 'participants to generate and explore their own questions and to develop their own analysis of common experiences' (Kitzinger 2000 p.21). Different attitudes

and priorities might be highlighted and facilitate ideas and experiences to be expressed that might not otherwise be voiced in an interview.

Focus groups with parents

Physiotherapy managers from two Health Trusts in the south of England were asked to identify all children with cerebral palsy fitting the inclusion criteria below:

1. Aged between 4 and 11 years;
2. Confirmed diagnosis of cerebral palsy;
3. Classified as Level II or above on the Gross Motor Function Classification System for children with cerebral palsy (Palisano *et al.* 1997);
4. Attending mainstream primary school;
5. Receiving physiotherapy in or out of school.

All parents with children fitting these criteria were invited to be included in this study. I aimed to gain as wide a range of views as possible to address the research questions. Although it was not possible to sample purposively (Silverman 2000) for variables such as parents with children of differing ages, at different schools and with different experiences, by including all parents this was more likely to be achieved.

Parents were sent an invitation letter (appendix 3.1). If they wished to participate, they were invited to attend a focus group at their local child development centre. Fifty-six invitation letters were sent to parents, and 16 parents replied.

Three focus groups were organised and conducted in one of the two child development centres. These venues were chosen as they were familiar to parents, had suitable rooms for the groups to convene, convenient access and parking facilities (Millward 1995). A topic guide was used based on the research questions to guide the conversations (appendix 3.2).

The groups were audio-taped and an observer took notes on non-verbal participant interactions. Each group lasted approximately one hour when discussions appeared to have come to an end.

Focus groups with physiotherapists

The physiotherapy managers from the two Trusts were asked to identify all their paediatric physiotherapists currently or in the previous year, managing children with cerebral palsy fitting the above inclusion criteria. I envisaged that within this sample physiotherapists would have a wide range of views and experiences with differing attitudes and approaches to disability and inclusion. Seventeen physiotherapists were identified as meeting the inclusion criteria and sent an invitation letter to participate (appendix 3.3). All 17 physiotherapists agreed to participate.

Two focus groups were arranged at two child development centres. A topic guide was used to guide the discussions (appendix 3.4). The groups were audio-taped and lasted approximately one hour.

3.3.2 Semi-structured interviews

Semi-structured interviews were chosen over the focus group method for school staff as they were geographically spread out and a group session was not practical. By conducting individual interviews I was able to gain the views of a wide range of staff working in different environments and with children in differing situations. School staff may have felt more comfortable on home ground and able to speak more specifically about the child in their school (Murphy *et al.* 1998). These interviews could therefore produce richer data than those generated in group situations (Morse and Field 1995). Semi-structured interviews are suitable for this type of exploratory study where the aim is to gain a detailed picture of participant's beliefs, perceptions and accounts (Smith 1995).

The physiotherapy managers from the two Trusts were asked to identify schools attended by the children fitting the inclusion criteria. By including all these schools, I aimed to access participants with a wide range of views from schools with differing policies and approaches to disability and inclusion. Letters were sent to the SENCo at the school and any TA directly involved with the child (appendix 3.5) inviting them to participate.

Thirty-one primary schools were identified. Some of the letters to the TAs were sent via their SENCo which possibly impacted on recruitment as letters may not have been passed on. Fifty-one letters were sent to school staff and 14 agreed to participate.

I used an interview schedule to give a general loose structure with open-ended questions defining the area to be explored (Pope and Mays 2000) (appendix 3.6). Participants were encouraged to talk freely around the questions and introduce their own interests and concerns. I viewed the participant as the 'expert', allowing them maximum opportunity to tell their story (Morse and Field 1995). By remaining 'flexible and sensitive to the specific dynamics of each interaction' (Mason 2002, p.64) I could take cues from the conversation to see which questions to ask next, rather than having a pre-scripted order of questions. I was therefore able to follow a line of questioning, which I may not have previously anticipated. I tried to convey that there were no right or wrong answers and that their views were paramount.

All participants chose to be interviewed at school except for one SENCo who chose her own home as she had recently retired. Each interview lasted between one and one-and-a-half hours when it was considered that the topics had been covered. All interviews were audio-taped.

3.3.3 My influence as a researcher

Reflexivity has been described as critical self-reflection (Finlay and Ballinger 2006) and sensitivity to the ways in which the research has been shaped by the researcher's prior assumptions and experiences (Pope and Mays 2000). This involves reflecting on my position as a researcher and my impact on the research process and considerations needed whilst conducting and analysing the study. As a physiotherapist working with children with cerebral palsy in schools, I had to acknowledge that my experiences, assumptions, beliefs and biases needed to be addressed during the research process. I viewed that any understanding I gained was influenced by my position: my culture, expectations and understandings of the world. My relationship and behaviour with the participants would have had an impact on their responses and therefore on the findings obtained. I viewed this research to have been co-produced between the participants, myself as the researcher and our relationship.

My introduction in the initial letter of invitation as a physiotherapist meant that I could be open with the participants about my background. From an ethical point of view, I considered this to be important so that participants would not perceive that I was concealing any hidden agenda from them. I wanted them to feel that I had a genuine interest in developing knowledge in this area, but in knowing that I came from a therapy background, would be approaching this research from this perspective. In some respects, I felt this gave me some credibility with participants in that they felt I had prior knowledge and understanding of the issues.

I understood however, that there could be difficulties in being viewed as a physiotherapist. Participants might have felt that I could be critical of their practice and perhaps alter what they might say. They might have assumed that I had certain knowledge and therefore not feel the need to relate relevant information to me. I endeavoured to present myself primarily as a researcher rather than a physiotherapist, not using any clinical jargon reinforcing my role or giving any opinions on situations.

I kept a field diary following all focus groups and interviews. For the focus groups this diary was used to record my impressions of the group dynamics, non verbal communications and how I felt my position as a researcher had influenced the nature of the conversations. This was similar following the interviews so that I could reflect on the process of the interview and my influence on the conversations.

3.4 Ethical considerations

Ethical approval was granted for this study (appendix 3.7). Ethical considerations were centred on confidentiality, data protection, child protection, possible undue stress and informed consent. Although it was not possible to guarantee confidentiality within the focus groups, all participants were asked to maintain confidentiality of the discussions within the sessions. Confidentiality of data collected meant that I did not use names of participants or identities of schools in any of the transcripts. Considerations were made for potential issues of child protection and the possibility of undue stress. Local health service and education policies were to be utilised in the event of these circumstances arising.

Informed consent was sought from all participants. Along with the letter of invitation, they were sent an information sheet detailing the research objectives and nature of their

involvement. Prior to the start of each focus group and interview, the research objectives and topics for discussion were explained. Each participant was then asked to sign a consent form.

Findings of this study have been fed back to all participants. Meetings were held at the two physiotherapy departments to give verbal presentations of the findings and to answer questions. This was not possible for the parent or school staff participants, so they were sent a written summary of the findings.

3.5 Data analysis

Each focus group and interview was transcribed verbatim. The focus groups with parents, with physiotherapists and the interviews with school staff were initially analysed separately. The findings from these three parts were then analysed together to develop common themes.

The first stage of data analysis involved familiarisation of the data. Transcripts were initially read in detail. Alongside reading the transcript, I listened to the tape recording, read my research diary notes and notes from the observer in the focus group (Ritchie and Spencer 1994).

In reading the transcripts, I started to code the data by reading the text in different ways: literally, interpretively and reflexively (Mason 1996). I developed codes by using words or phrases directly from the participants themselves, interpretively by reading beyond the data and constructing a version of what I considered the participants meant or understood, or reflexively by exploring my role in the process of data generation. In this first stage of coding, data were broken down, conceptualised and categorised. This allowed me to identify similar concepts or to group together similar incidences or issues.

Once the first transcript was coded, the data from the following transcripts were checked against these codes for 'fit'. If the match was poor then the codes were adjusted to represent clearly the meaning in the data. The developed codes were then used to 'frame' the data in the next transcript, whilst negative cases or data which did not 'fit' were also identified (Grbich 2003 p.234). Care was taken to ensure that the coding process accounted for all the data in a way that did not force them into

predetermined codes, but allowed for revision of previous coding and the addition of new codes.

Once I was satisfied that the coding process was comprehensive, the codes were then sorted into interpretive categories or themes (Mason 1996). This was achieved by looking for links between codes which appeared to be describing or explaining the same phenomenon. These codes were then grouped together into categories. I kept categories as broad as possible, whilst aiming to avoid any overlapping. Each category heading therefore consisted of a set of quotes taken directly from the transcripts, giving the range of views and experiences related to that category. The category included not only the typical views and experiences, but the range of views identified, including deviant cases. These deviant cases were important as they helped to provide an alternative view and perspective. It also put the data back together in new ways whilst searching for additional properties of each category and making connections between them (Strauss and Corbin 1990).

Each category or theme was examined in turn by using the raw data to explore more clearly what the theme was about. Comparisons were also made across themes. During this process, overarching themes emerged which linked together some of the more disparate categories. Some recurrent themes arose early on in data analysis as they emerged directly from responses to specific research questions. Other new themes emerged gradually over the course of data analysis as participants gave views which were unexpected or took the focus in a different direction. The development of these overarching themes was a cyclical process which involved exploring the connections between categories or themes and checking these against the transcripts and the context in which they arose. I aimed to produce both descriptions of the study findings and the formulation of explanations of the phenomena described. The table below gives examples of this process.

Table 3.1: Two examples of the development of codes, categories and themes

Quote	Coding	Category	Theme
‘He’s got a lycra armband that the previous school just weren’t interested in taking off and putting back on again because it was too much trouble’ (parent)	Time	Conflicting priorities	Knowledge
‘But somehow with a physical problem you feel that you could be doing damage if you’re not doing it right, whereas with speech it’s obviously something that isn’t critical...if you’re not doing it quite right.’ (SENCo)	Role of school staff	Competence	Responsibility

Trustworthiness of data analysis

In any research study it is important to demonstrate and justify how the research has been conducted and how the conclusions have been reached. Trustworthiness is dependent on the quality of the research process: my role in the research process; what questions were asked; the appropriateness of methods of sampling and data collection; and how data collection was conducted (Mason 1996). I have already discussed my philosophical assumptions and from this perspective, have had to account for the ways in which I have chosen to generate data, the weight I have attributed to the views of the participants and my influence in the research process. I have had to think about how and why my methodological strategy is a valid way of answering my research questions. The process of data analysis and the influences on it need to be transparent so that it is clear to others how the data were interpreted (Murphy *et al.* 1998).

The data analysis process always involves a strong element of individuality stemming from my background knowledge and individual experience as a researcher (Grbich

2003). The development of a coding system is therefore not an analytically neutral process (Mason 1996). Assumptions were made about the kinds of phenomena I wished to collect and those I chose to leave out. Judgements were made about the meaning and significance of the data and the appropriate code that was applied to it (Ritchie and Spencer 1994). It was influenced by my theoretical framework and how this was introduced into the focus groups and interviews via the topic guides.

Although the data analysis was as an individual process, by adopting a written system of coding, the process is visible for other researchers to see how the data were sorted and organised (Mays and Pope 1995). By using a numerical system attached to the quotes, they can be traced back to the original transcripts to reflect on context and meaning. Transcripts were read by my research supervisors to check the coding system and assumptions made from the data. How the data were then interpreted needed to be clear, particularly how links were made between codes and categories and how explanations for the phenomena have been reached.

3.6 Findings

From analysis of the data four main themes emerged:

1. Roles and responsibilities;
2. Knowledge and competence;
3. Attitudes of school staff;
4. Integration of physical goals within education.

These themes are considered in turn and illustrated with direct quotes from the transcripts referenced with a code. Participants from the parent groups are coded P1-P11: ages of their children ranged from five to eleven years, six girls and six boys; five attended a school with a special support unit (SSU). One parent had two boys with cerebral palsy.

Participants from the physiotherapy group are coded PT1-PT17. Participants coded PT7, PT8, and PT14 worked in schools with a SSU.

Participants from the schools are coded S1- S14: seven TAs and seven SENCOs. Six participants worked in a school with a SSU.

3.6.1 Theme 1: Roles and responsibilities

One of the key themes was the perception of the roles and responsibilities of those involved in the physical management of the child. Parents agreed that they had their part to play in promoting physical exercise and activity with their child, but as the child spent much of their day in school, schools needed to share this responsibility. Within school, all participants agreed that the TA was responsible for the practical management of the child's needs on a day-to-day basis with advice from the physiotherapist and little involvement of the class teacher.

Responsibility of parents

Many parents acknowledged the importance of physiotherapy exercises for their child's physical development, and encouraged these at home on a regular basis. Parents of younger children reported how they incorporated physiotherapy advice into functional

activities, or general physical play, to make it part of the child's day rather than doing separate activities.

'We do our own home exercises, we go out on the bikes, we go swimming, we stand up at the tables and the chairs...Ben is starting to sit on a little plinth now when I put his splints on in the morning, so he's sitting a bit better and we do little things throughout the day, but we don't really say: 'Right it's physio time.'
(P5)

Fatigue however, was an important barrier for many children: *'at primary level they're too tired necessarily to do physio after school'* (PT4).

Parents of older children seemed to encourage other physical activities more than physiotherapy exercises. It may be that it was easier to motivate their child with these activities than with physiotherapy, as they involved participation with others:

'We take her riding and she goes swimming so she does all the, you know, as much physical stuff as we can pack in other than doing actual physio.' (P3)

When children were either not compliant with their physiotherapy or other family demands took precedent, some parents talked about *'a feeling of guilt'* (P7) that they were not fulfilling their responsibilities. This was particularly the case for parents of children with milder cerebral palsy who did not have physiotherapy at school and therefore parents felt fully responsible for this.

Physiotherapists however, pointed out that the Statement of SEN was an important factor in how much responsibility parents took at home. They viewed that some parents considered this to be a *'kind of a golden egg'* (PT1) where responsibility for their child's physiotherapy could be handed over to the school and physiotherapist. Parents were in agreement that schools had a responsibility to carry out physiotherapy with their child, with concerns that this was not always the case due to other priorities.

School staff generally did not share physiotherapists' concerns over parental responsibility. They viewed the child's physiotherapy programme at school as their responsibility as they had allocated support time to undertake this. They were only concerned with the child's needs within school and any physiotherapy at home was perceived as a separate issue from school. There did not appear to be any joint sessions

involving parents, physiotherapists and school staff to discuss physiotherapy progress so that programmes could be shared.

Parental involvement with their child's physiotherapy appeared to affect the role the physiotherapist and teaching assistant took in school. If parents were perceived to do very little at home, then the emphasis on physiotherapy input was centred at school. Physiotherapists visited the child at school more frequently to ensure that the child was doing essential exercises.

'People do, do it at home and therefore you don't need to see those, you don't feel that you need to see that child so often and that might not be based on need as much as how much input and support they're getting from home.' (PT5)

Responsibilities of school staff

All participants concurred that TAs were a vital resource in enabling the child's physical needs to be addressed in school. There were differences, however, in the responsibilities of TAs between different schools depending on the needs of the child, type of school, and differing practice between schools. Some assistants provided full-time support for the child during the day, whilst others were only involved with the child for therapy. There were also variations in how support time was organised and the extent to which class teachers were involved in the management of the child's physical needs.

As TAs had been trained by the physiotherapist to undertake their role, they were viewed as the 'experts' in the school and other members of staff did not usually share their duties.

'Nobody else would sort of, the teacher wouldn't go near it [standing frame] or you know, the other TAs in the class wouldn't have anything to do with it.' (S2)

There were differences however, in whether participants viewed this responsibility to justly be the role of a relatively untrained person. School staff had mixed views on this issue. Those in schools with a SSU appeared more comfortable in their role perhaps due to more frequent contact with a physiotherapist, experience of managing children with physical difficulties and working as part of a team of TAs. Other schools reported

less visits from their physiotherapist, with usually only one TA being responsible for the child. They consequently were more concerned about the responsibility given to them.

'One thing I feel is quite hard on the schools these days is that the bulk of the work is being done by us and we're not trained....it's a huge responsibility.' (S3)

Some school staff were concerned about the possible damage they might do to the child. They felt that unlike other therapy programmes, physiotherapy had more potential for harm. They were therefore aware of the need for correct instructions and adequate support to undertake their responsibility.

'We're not the experts...very often I think, 'if I do such and such, is it going to damage the child's legs or whatever?' (S2)

TAs were the main members of staff to work with physiotherapists. Physiotherapy programmes were taught by the physiotherapist directly to the TA and physiotherapists gave them advice and guidance on managing the child within the school environment. Physiotherapists relied on TAs for information on the child's physical progress or signs of deterioration, as they were not with the child on a regular basis.

'We do expect quite a lot from the NTA's. We need them to be the front line to let us know whether there, when there are problems and feeling if joints are getting tighter and things like that, because they're the ones that are handling the child more regularly than we are.' (PT13)

For children with milder physical problems, the role of the TA differed as they were often only involved with the physiotherapy programme. If the child required support in class for other aspects of their education, another TA not involved with their physical needs might assist them. This meant that physiotherapy advice given to the TA was not readily incorporated into other areas of the child's schooling.

Some parents, whose children did not have any allocated support, were concerned that no-one took responsibility for their child's physical development. They felt that school staff were not concerned about the child's physical impairments if their difficulties did not overtly affect their education.

‘Throughout school I’m just worried that he’ll just be left to do it his way because he can do it his way, but it’s not the correct way we want him to do it, not the correct way we want him to sit, not the correct way we want him to do his shoes or eat or sit and walk.’ (P6)

When TAs were given sole responsibility for managing the child’s physiotherapy programme, they sometimes felt unsupported within the school. One TA described how she felt that other staff did not understand the child’s needs:

‘It’s quite difficult for other members of staff sometimes to kind of take it seriously, because they don’t understand the condition. They just see me with a child perhaps balancing on a wobble board.....thinking ‘oh what’s all that about? Wouldn’t matter if she didn’t do that’. They don’t really understand.’ (S7)

In schools where a number of TAs supported children with SEN, they felt more supported by their SENCo, physiotherapist and others performing a similar role. They often shared classroom support for children, but were responsible for the physiotherapy programme for only one child. Although TAs considered this sharing of roles to be beneficial for themselves and the child, it created a difficulty in communication for physiotherapists involved with the child. They might need to liaise with a different TA for the child’s programme to those involved in their daily management.

Communication of the child’s needs was an important issue. In schools with a SSU, the SENCo appeared to take the responsibility for communicating with parents. In other schools however, the TA appeared to take on this responsibility. This was difficult for them as there was no time allocated for this and they were not always in the same class as the child at the beginning or end of the day to talk to parents.

‘There isn’t any time in my timetable when I’m free to go off and make phone calls, so when do I do it? So then I do it in my own time and sooner or later that pales a bit really.’ (S7)

Some TAs therefore communicated instead through the physiotherapist.

TAs were also often responsible for communicating the child’s needs to other school staff. As they liaised regularly with the physiotherapist, they *‘would be the one that*

would be hearing it, seeing it and then would pass the information onto the SENCO and the class teacher' (S12). Time for communication was viewed as an important issue particularly as meetings were not arranged for this.

SENCOs appeared to have differing responsibilities: some were heavily involved in the co-ordination of the child's needs, whilst others seemed to have a more administrative role. Most TAs however, viewed the SENCO, rather than the class teacher, as the person in the school to approach for advice and support in managing the child.

Responsibility of the physiotherapist

Physiotherapists were considered the most knowledgeable professionals regarding the child's physical capabilities and therefore the most appropriate to advise on any physical difficulties the child might face in school. School staff expressed concerns when time limitations and staff shortages meant that they did not feel sufficiently supported by their physiotherapist.

The main emphasis on the role of the physiotherapist however, focused on providing therapy for the child in school or importantly, to teach a physiotherapy programme to TAs.

'(My role is) teaching the LSA how to do the physio and then going in and going through their programme, adjusting it where necessary, extending the programme, adding more exercises, that sort of real practical type role.' (PT2)

There appeared to be many factors affecting the balance between physiotherapy being carried out by the physiotherapist and a physiotherapy programme with a TA. For children in schools with a SSU, therapists were expected to undertake therapy with the child on a regular basis as well as train the TA. This may have been due to historical practice as well as the children being more severely impaired in these schools and perhaps requiring more expertise.

Practice in other schools differed, depending on the physiotherapist. A few therapists considered it their role to provide therapy within the school setting, but most did not feel they had the time. Many physiotherapists appeared to take a holistic view of the child's physical needs, balancing activities at home and at school, whilst others focused more on physiotherapy at school. They agreed however, that a child's individual and

family needs played an important part in determining their practice within the school and that this needed to be flexible.

'I don't think you can have a blanket thing for children in mainstream school, I think it's quite variable.' (PT5)

3.6.2 Theme 2: Knowledge and competence of school staff

The second theme emerging from the data was that of knowledge and competence of school staff to adequately manage the child's physical needs. Participants agreed that most school staff had little knowledge about cerebral palsy and how it affected the child. Parents were especially concerned that the class teacher, who was with their child all day, had little knowledge of their child's difficulties.

'I don't think the mainstream teachers and that have the knowledge of disabilities to know what to do anyway. I mean if I didn't have a child with a disability I wouldn't know what to do, I mean it's a learning process for me and you kind of send these children to mainstream with teachers who've never looked after disabled children because they're still quite a new thing in mainstream school and I don't think they know what they should be doing.' (P1)

There did not appear to be any specific support within the local education authority for schools to access advice in managing children with physical impairments. If a school required information or had specific problems in managing a child, they looked within their own staff for knowledge or to the visiting physiotherapist. Only one school had used the resources of a nearby school with a SSU to access training.

A few parents, especially those with more severely impaired children, were concerned about the lack of disability awareness in their child's school. They considered that this influenced their child's inclusion and schools needed training to develop their awareness.

'There are people that will go and give talks about, or disabled people who go and give talks to children and teachers, which I think is a good idea. I think they need educating.' (P3)

Parents of children attending a school with a SSU however, appeared happier that school staff had sufficient experience and knowledge. They were also less concerned about their child's inclusion and how their physical needs were managed.

Physiotherapists and school staff agreed that although whole staff training sessions might be a good idea, in reality these would not be prioritised as it only involved one child in the school. Most SENCos felt that training should focus on the TA rather than teaching staff as they were more directly involved with the child's physiotherapy.

TAs viewed their learning needs very differently. Some wanted to develop their understanding, whilst others appeared content just to follow instructions given to them. Physiotherapists agreed with this view and described how they needed to tailor their approach depending on the attitude of the TA in the school.

'some SSAs [special support assistants] want to know more, want to know exactly why they're doing it and others are quite happy to just have their list of exercises and to go through it...and don't want to know why they're doing it.'
(PT8)

Therapists were clear that there were limitations regarding the range of skills it was possible to teach a relatively untrained person. There appeared to be some frustration that due to their time constraints most of the child's physiotherapy was delivered through the TA and that they had limited skills.

'I think it's very difficult if you try to deliver a programme through a school or some SSA or whatever. They don't have the kind of background knowledge, so although you've talked about why stretches are important or why this position's important, because they don't have all this kind of innate knowledge that we just have, they don't always understand the underlying things....so I think that makes it difficult for physio sometimes to be effective in schools.' (PT1)

Parents were generally more confident in the abilities of TAs working in schools with a SSU compared to those in other mainstream schools. They felt that these assistants were more closely monitored by the physiotherapist and had experience of managing children with similar difficulties. Physiotherapists considered these TAs to *'probably work at a better level'* (PT8).

Transferring knowledge and advice from the therapy situation into daily functional activities within the school environment was an important consideration by therapists. They agreed that this was an important skill needed by the TA so that therapy could be incorporated into everyday school activities.

'Some NTAs you only have to explain it once and then they transfer what you've told them into lots of other situations in school...other NTAs will only carry out exactly what you say at that time and won't think beyond the therapy session.'
(PT13)

That their children received physiotherapy from an unqualified person as opposed to a physiotherapist was a concern for only a few parents. Many parents were more concerned about the personality of the TA and the relationship they developed with their child. They felt that when the child first started school, they required a TA who was kind and caring, but as they got older they needed someone who would allow their child to grow up and develop independence. For those parents whose children had several assistants working with them in one day, there was the possibility of comparison and parents seemed aware of the skills of different assistants.

Many TAs followed the child through their primary school years. Many parents regarded this continuity as an advantage, but for those who were not confident in the skills of that particular assistant, this was a problem.

'I mean Zoe very much built up a friend's role with this lady, which is fine to an extent, but then she started treating her like she was a niece or something like that. There were interactions going on between them that I don't think were appropriate for a school setting.' (P1)

3.6.3 Theme 3: Attitude of school staff

The third theme to emerge was the attitude of school staff towards children with physical impairments. Participants viewed that attitudes affected how the child's physical needs were met within school and their inclusion in school activities. Schools with a proactive attitude were more likely to address difficulties and access support.

'And it's attitude, it's like 'What does the child need?', 'Well where do we get it?', 'Right let's get it' and they're very proactive in it. Whereas we could have

got a completely different attitude where 'Oh, we've never had a physically disabled child with a hearing impairment, what do we have to do?', 'oh more work'. You know, it depends doesn't on, you know, who you're talking to.' (P5)

Some parents of children with milder cerebral palsy were concerned that school staff were not aware how the child's physical impairments might affect them in school. When they pointed out issues, they felt that school staff were not open to suggestions or unnecessarily complaining.

'But I do think they actually forget that she has got underlying difficulties and I also get the, (I may be paranoid here) but I sometimes think they think 'Oh this mother fusses too much she, she's too worried about her children.' (P7)

Physiotherapists agreed that attitudes varied widely. The majority of physiotherapists viewed the attitude of the SENCo to be instrumental to how the child's physical needs were managed. If the SENCo was involved with the child's needs and did not leave this responsibility to the TA, it was more likely that a collaborative approach would be taken. If not, physiotherapists often felt like visitors to the school seeing the child in isolation with little involvement with the child's day-to-day school life.

'I think that the schools where it works best, is where the SENCo actually has an inkling, you know, of the idea that we go in to advise them, to help them on what they need to do on a daily basis rather than, you know, 'oh it's the physio, yeah there's a corner down there' you know?' They don't even really want to see you when you've gone and finished or anything.' (PT1)

Physiotherapists agreed however, that they often did not give sufficient time for communication. Due to lack of time, they often only visited the school for brief periods and did not liaise with anyone other than the TA.

'In a lot of mainstream schools we kind of fly in, do what we need to do, have a quick chat and have to fly out to the next one.' (PT1)

Most SENCos however, did not share the physiotherapists' concerns about lack of communication as long as they visited regularly and liaised with the TA. SENCos working in schools with a SSU tended to have stronger relationships with their physiotherapists as they visited more regularly. Those with teaching commitments

agreed that it was difficult to find time for liaison. They were mostly concerned about the need to discuss issues such as budgeting for equipment or the use of TA time.

Attitudes to inclusion, in particular PE, were viewed to be important by parents and physiotherapists. A few parents of children with severe impairments felt that schools did their very best to include their child in all activities, even in after school clubs. This was especially so in schools with a SSU where they felt staff had more experience of including children with physical difficulties.

'He's doing, tonight after school he does a rounders and cricket club and he's probably the only one with a disability doing that club but he's really keen to join in, be a part of things. And I think the school will just accommodate him as much as they can.' (P11)

Other parents were concerned that PE activities were not always adapted sufficiently for their child to be able to join in. They felt that PE was important for the child to feel part of their class and to learn team and collaborative games. One parent explained how her child was excluded from class PE now that she was older and more difficult to physically manage.

'Although Zoe is accepted in a mainstream school, she's accepted as long as she fits into their system. Not 'Oh well ok we'll do, you know, basketball today or whatever and we'll try and adapt it a bit so Zoe can join in'. It's like 'Well if your TA can hold your hand and you can like hobble your way round then you can join in, but if you can't then you'll have to go and do something else', so she does physio instead.' (P1)

For children with milder difficulties, most parents felt that their children were included, but that some schools were better at adapting the curriculum. Those who were not happy that the school fully included their child felt that this was either due to lack of understanding or willingness to adapt sessions to include the child.

'It would be nice if the, if the school PE teacher could be more involved or if she wouldn't single her out and say 'you can't do this', 'you'd better not do that', perhaps it's fear.' (P7)

3.6.4 Theme 4: Integration of physical needs into education

The fourth theme to emerge was that of integrating the child's physical needs within education. Whether the child's physical needs were viewed as a separate health issue or as part of their general educational development was an important factor in how their needs were managed in school. It impacted on the involvement of other staff in the physical needs of the child, how physiotherapy fitted into the school day, and the integration of physical and educational goals.

Although the child's physical management was viewed as primarily the responsibility of the TA, many TAs agreed that it was important for the class teacher to have an understanding of the child's physical difficulties as *'they're the only people that are with that child every day'* (S3). This was the case for children in all schools as teachers were not viewed to be more knowledgeable in schools with a SSU compared to those without. TAs who took a more holistic view of the child's physical management were concerned that if teachers were not involved, therapy advice could not be incorporated into the child's day. If they were not in the classroom, there was no one to correct their posture or ensure that their physical abilities were encouraged. They also felt that as an assistant, it was sometimes difficult to give advice to a teacher.

'That's a difficult area for somebody like me to come into a classroom and say 'actually he needs to be facing the board because his physical problems are such that he can't transfer the information from the board and retain it and put it on paper, he particularly needs to be sitting up straight, he needs to be looking forward ...some people don't like somebody like me suggesting things like that.'
(S12)

School staff and physiotherapists agreed that if the child had a physiotherapy programme, this needed to be done outside of the classroom. In most schools, SENCos considered it their role to timetable therapy programmes into the curriculum usually in conjunction with the class teacher. They mostly tried to ensure that children did not miss out on the same lessons each week and therefore rotated the times the child came out of class. Otherwise they used times in the day such as assembly or PE when the child would not miss out on academic lessons. One SENCo pointed out the difficult decisions she had to make in balancing the child's physical needs with their education and inclusion: *'You have to kind of make priorities, don't you. Is it important that John*

and Ben do their driving practice or is it important that they're in class with the other children in a lesson?' (S4)

In classes where the TA worked within the class, they appeared to take more responsibility regarding when to withdraw the child. They considered the class' activities, trying to ensure that no important or favourite lessons were missed.

'I try to fit it around her now because I work in the same classroom... she doesn't really like missing things like English and so I try and take her out of lessons that she's probably not enjoying like PE or something and then use that time.' (S14)

One physiotherapist brought up the issue of involving the child in timetabling. She felt that if the child knew when a therapist was visiting, there was less of an issue to being withdrawn from class as the child was expecting it.

'I think the child prefers to hear about timetabling as well, the child doesn't want to be whipped out without any advanced warning.' (PT14)

Most school staff, however, did not consider withdrawal from class for this age group to be a problem. They felt that in primary school withdrawal from class was common practice and that there was no stigma attached to this.

'I mean here it's quite nice actually because they do seem to think there's something special about being taken out rather than there being a sort of stigma to it, which is nice.' (S14)

Integrating the use of standing supports into the classroom was highlighted as a difficult issue. School staff expressed how they could incorporate these within class for younger children as part of their play, but it was more difficult for the older child. Many considered that the child felt self conscious about using standing supports in class and if they needed hoisting, this was not practical in the classroom environment.

Physiotherapists indicated that some schools viewed specialist equipment like standing supports only as therapeutic tools and not as enablers for participation. This meant that equipment was not used in an integrated way, but only as part of a therapy programme.

Individual Education Plans (IEPs) could be viewed as a means of integrating therapy goals into education. SENCos however, had differing attitudes on this as most viewed therapy and education quite separately. Many viewed IEPs as a tick-box system for ensuring that physiotherapy was being carried out. One TA expressed how she wanted the IEP to help incorporate physical goals into the classroom situation, but felt that the teacher had other priorities.

‘I mean, I do have a concern about her left arm and I’d really like to see on there [the IEP] that while she’s writing in class that she actually puts that left hand on the table rather than holds it up here, but I’m not sure whether the class teacher would think: ‘Well, I’d rather she just was able to write something, never mind about worrying about her arm.’ (S7)

Most physiotherapists were not directly involved with IEPs, even though SENCos often used their written advice as guidance. There appeared to be a variation in how parents were involved; most parents were asked for comments at parent consultations, whilst others were sent the child’s IEP home by post. Only two schools mentioned that they asked the children for their own personal goals.

3.7 Conclusions

In this initial phase of my study I aimed to explore how the physiotherapy needs of the child with cerebral palsy are met within mainstream primary school. Having analysed the views and experiences of parents, school staff and physiotherapists across various contexts, I found many similar issues impacting on meeting the child’s needs. The impact of TAs being the primary person responsible for the child’s physical management at school meant that their needs were generally viewed and managed separately from their education, with little involvement of their class teacher.

I identified concerns regarding knowledge of school staff of the child’s physical needs and the impact of this on their inclusion. Physiotherapists worked primarily with TAs impacting on the understanding of others involved with the child such as the class teacher. The child’s physical needs were viewed as being met by providing a regular physiotherapy programme, with little emphasis on the barriers they might face with participation in school life or in their education. How children were included in school

was viewed as being dependent not only on staff's knowledge and understanding, but on their attitude and approach to disability.

Prior to this study, my aim had been to explore how the physiotherapy needs of the child with cerebral palsy are met in school. Findings from this first phase highlighted many complex issues of meeting their needs within the current education system. It identified the need to further explore not just how therapy 'fits' within an ethos of inclusive education, but how their physical impairments impacting on their function and inclusion, are managed throughout the school day. These issues were the focus of my main study.

Chapter 4. Phase Two: Methods

In this chapter I explain and justify how I conducted the second phase of my study. Firstly, I explain the research aims and questions, justify the use of case study as a research design, describe the recruitment process and data collection methods used. Secondly, I discuss the methodological and ethical issues raised, in particular those I faced in conducting a research study involving children. Lastly, I explain the approach and method I used in the analysis of the data collected.

4.1 Research aims and questions

The aim of this study was to explore how the physical needs of children with cerebral palsy are managed within the mainstream school environment. The specific questions I sought to address were:

1. What decisions are involved when promoting a child's physical needs within the primary mainstream school environment?
2. How do these decisions influence their inclusion in school activities?
3. What decisions need to be considered when integrating the use of specialised equipment in school, to promote a child's physical needs and their inclusion?
4. What issues influence how therapists and schools work collaboratively to promote the child's physical needs and inclusion?

4.2 Research design: Case study

To answer these research questions, I chose to use a case study approach. Case study is the study 'of a singularity conducted in depth in natural settings' (Bassey 1999, p.47). It enables an exploration of a phenomenon within real life contexts such as the school environment; the approach enables exploration of how different groups of people confront the specific problems and provides multiple perspectives on the same situation. Through case study the researcher aims to provide a rich, 'thick description' of a case, not only to describe the complexity of a situation, but to enable plausible interpretations of the data in terms of cultural norms, values and attitudes (Guba and Lincoln, 1981). It is important not only to describe the activities, but the context as activities may be

influenced by this (Stake 2005). Case study has been described as heuristic, meaning that it can 'bring about the discovery of new meaning, extend the reader's experience, or confirm what is known' (Merriam, 1988, p.13). I wanted to develop insights into how specific situations have arisen and why certain strategies succeed whilst others fail.

Various types of case study approach have been described. Yin (1993) for example, categorises case study into three forms: exploratory, explanatory or descriptive. Bassey (1999) uses three categories of case study: theory-seeking and theory-testing; story-telling and picture-drawing; and evaluative. The type of case study used in this research could be described as theory-seeking as it aimed to generate theory. It was exploratory in nature as there was a lack of theory in this field especially in the multi-agency management of children with disabilities. Case study has also been described by Stake (1995) as being either instrumental or intrinsic. In an intrinsic case study, the particular case itself is of prime importance. My study was an instrumental case study in that although the cases were themselves of interest, they played a supportive role in enabling the understanding of particular phenomenon. I had particular issues I wanted to explore and therefore cases were specifically chosen which would allow the greatest understanding of these issues.

The 'case' consisted of three case sites involving a child with cerebral palsy, their parents, the school, its staff and pupils, and therapy services visiting the school. I was interested in the child's physical management in school and therefore focussed on these issues within the case. Qualitative case study is characterised by 'researchers spending extended time on site, personally in contact with activities and operations of the case, reflecting, and revising descriptions and meanings of what is going on' (Stake 2005, p.450). There are no specific methods of data collection or analysis unique to case study, but I chose methods which I considered appropriate to answering the research questions: observation, informal discussions, interviews and use of documents (Bassey 1999). Observation allowed me to experience real-life situations and actions rather than relying solely on reported situations such as in interviews. I was able to observe the child throughout their school day to develop theories of how and why their physical needs were managed in certain ways. These I could explore further with informal discussions during the school week with the child and those involved with them. These discussions not only verified observations, but explored meanings and interpretations of

actions. More formal interviews helped to further explore these meanings from multiple perspectives. Documents were used to add detail to certain issues and background information necessary to understanding the context and factors affecting the child's management in school.

Generalising from case study

One of the main criticisms of the case study approach is that the findings are not viewed to be generalisable to a larger population. Many researchers from the qualitative tradition however, actively reject generalisability as a goal (e.g. Denzin and Lincoln 1994). Rather, the goal is to produce a coherent and revealing description of and perspective on a particular situation requiring detailed study of that situation. Shofield (2002) argues that qualitative researchers have to question seriously the internal validity of their work if other researchers reading their field notes feel the evidence does not support the way in which they have depicted the situation.

Other qualitative researchers have looked towards how their research might be more generalisable to a wider population. Guba and Lincoln (1981) for instance argue that the concept of 'fittingness' is appropriate in case study in that it looks at how the situation studied matches that of another situation. A logical consequence of this is that one needs to provide a substantial amount of information about the context and situations being studied so that judgements can be made about the conclusions reached and whether they are useful to study other situations. Others e.g. Bassey (1999) and Stake (2005) have argued similarly that by putting forward an empirical statement of what has been discovered regarding the participants studied, one may propose that this may be found in similar contexts.

In this case study I have provided detailed descriptions of the case sites so that others may be able to judge whether they are comparable to other situations. I have provided information about my theoretical stance and how I conducted the research. I chose school sites and situations which I considered to be typical in my experience of the phenomena being studied. As Gomm *et al.* (2000) argue, selecting cases using information about the dimensions of the larger population makes case study more relevant to the target population. In this way I was 'studying what is' (Shofield 2002) so that there would be a greater chance of others finding similar situations.

I also chose case sites where I wanted to ‘study what could be’ to study examples of exemplary practice. Shofield argues that rather than looking for one case to be wholly similar to another, one may be able to find certain aspects of situations which are similar or different and to what aspects of the findings these are connected. In studying three case sites several themes were found to be applicable across the cases and should therefore present more strength to the findings presented and to the ability to generalise to the larger population.

4.3 Choosing the case sites

Stake (2005) argues that cases should be chosen from those from which we have the most opportunity to learn. Purposive sampling was therefore used to ensure that the case sites represented the range of phenomena I wished to explore in this study (Silverman 2000). As I wanted to learn about the inclusion of children with physical impairments, I chose case sites where the school was identified as having an inclusive approach through their literature, information on their website or via the therapy services. I wanted to learn how working relationships between schools and therapy teams impacted on the management of the child, and how specialist equipment and therapy was integrated into the child’s life at school. I therefore chose case sites where these issues could potentially be explored and ‘good’ practice shared. I chose to use typical school situations so that others would easily find similar situations to compare them to.

There were also practical issues in choosing a case site. As Stake (2005) points out, a receptive environment where participants are willing to share their experiences with you allows more opportunities to learn than a more hostile environment. I therefore had to consider where there was genuine willingness from all parties to participate in the study.

The first case site was a large first and middle school with a SSU for children with physical impairments. The child in the case was a nine-year-old boy who was wheelchair dependent. There were 13 children in the unit, but he was the only wheelchair user in his class.

The second case site was a large primary school with four children with physical impairments. The child in the case was an eight-year-old boy who walked using a mobility aid. He was the only child with a physical impairment in his class.

The third case site was a small rural primary school with only one child in the school with a physical impairment. She was an eleven-year-old girl who was independently mobile without aids.

4.4 Recruitment

For each case site, participants recruited were: the child with cerebral palsy; their parents; school staff who had some responsibility for the child; physiotherapist; and OT.

A flow chart of the recruitment process is shown in appendix 4.1. To identify possible study participants, physiotherapy managers from two health Trusts were requested to identify children with cerebral palsy receiving physiotherapy fitting the following criteria:

- Diagnosis of cerebral palsy classified as level II or above on the GMFCS (Palisano *et al.* 1997);
- Attends mainstream primary school;
- Aged between 4 and 11 years;
- Physical needs requiring TA support in school;
- Physiotherapist visits the school at least once a term.

Children with cerebral palsy with a classification of level II or above on the GMFCS would have physical impairments impacting on their everyday school life. A child of level III to level V would use a wheelchair within school and require adaptations for access and specialist equipment within class. Therapy services should be involved with a child with physical needs requiring support from a TA (DfES 2001b). I chose primary school children as in my experience therapy input is mostly targeted in these younger years.

Three children fitting the inclusion criteria and in intrinsically interesting and diverse settings were identified and invited to participate in the study. A letter was sent to the child and their parents explaining the research aims and method of involvement (appendix 4.2). A child-friendly information leaflet (appendix 4.3) was included. This leaflet had previously been piloted with children at a mainstream primary school to test

for its understanding and clarity. I was concerned that parents might not be happy for their child to be involved in a study where they were not present and did not know me. This did not appear to be an issue perhaps as schools are considered a ‘safe’ environment. On agreeing to participate, I telephoned the parents to answer any questions they might have and offered a meeting, although only one parent requested this.

Letters were then sent to the child’s school inviting them to participate in the study (appendix 4.4): to the headteacher to ensure that they were willing for staff to be involved in the study and for official permission to visit the school; and to the SENCo as they have a management role with the child’s SEN (DfES 2001b).

On agreement to participate, I telephoned the headteacher to discuss the research study and implications for the staff, class and child. Further invitations were then sent to the child’s class teacher and any TAs involved in the management of the child. I was concerned that not all members of staff would agree to the study, but this did not occur. I telephoned the school and parents to arrange a suitable week for observation.

During the observation week I identified other school staff involved in the child’s physical management. To ensure that they were fully informed of my study and given the choice to participate, I discussed my study with each individual before asking them to sign a consent form. The following table details the participants involved in each of the case sites.

Table 4.1 Participants recruited to each case site

Case site	Type of school	Child	Details	School staff	Parent	Therapists
Case site 1	Mainstream school with SSU	Zac	9 years old GMFCS level V	Class teacher, three SSAs allocated to Zac, SSA from the unit, SENCo, teacher for SSU games, teachers (maths and supply)	Mother	Physiotherapist (PT) Occupational Therapist (OT)
Case site 2	Mainstream school	Sam	8 years old GMFCS level IV	Class teacher, allocated TA, class TA, class TA for playground supervision, ICT teacher, previous allocated TA, SENCo	Father	PT OT
Case site 3	Mainstream school.	Josie	11 years old GMFCS level II	Class teacher, allocated TA, head teacher/SENCo, TA for cooking, other teachers in school	Mother	PT OT

Physiotherapists and OTs who were working with the child were identified by their manager. They were sent a letter inviting them to participate (appendix 4.5) and on reply, I telephoned to discuss the study with them. I informed them when I would be visiting the school, requested to observe a therapy session if it coincided within that week and arranged an interview date with them.

4.5 Data collection methods

Data were collected via three different sources throughout this study: observation, interviews and documents. For each case site this included:

- five consecutive days of observation data;
- individual interviews with the child, parent, school staff and therapists;
- documents from school and therapy information relevant to the child's management in school.

I wanted to gain multiple perspectives on real life situations as they naturally arose and to explore explanations for these. I therefore combined methods to observe situations which might otherwise not be brought up if I had just conducted interviews, to follow up my observations on interesting situations by informal discussions and more formal questioning, and to use documentary material as evidence for practice and to support my analysis. The table below displays a summary of the types of data collected from the three case study sites.

Table 4.2 Overview of data collection methods used

Data collection method	No. of:	Case site 1	Case site 2	Case site 3
Observation (written up as field notes)	Days observed	5	5	5
	School staff observed	10	9	4
	Therapists observed	1	1	1
Interviews	Participants	8	7	7
Documents	Documents utilised	9	7	7

4.5.1 Observation

I wanted to actively observe how children's physical needs were managed in school: how school staff facilitated the child's inclusion in activities and the barriers to this; how specialised equipment was used to promote physical function; and how therapy advice and goals were integrated into life at school. Observational fieldwork enables the researcher to observe the dynamics of the interactions involved and to determine differences between what participants view should be done and what happens in reality. Patton (2002, p.262) argues that it allows the researcher to be 'open, discovery oriented, and inductive' by being on site and less reliant on prior conceptualisations of the setting. It also gives the opportunity to see things that may not otherwise be in people's awareness and therefore not necessarily brought up in an interview situation. I might also be able to observe situations which in an interview might be sensitive or difficult to talk about.

In using this method of data collection, my main concerns were how much of a participant I should be in the field, how to develop relationships in this role, how to focus my data and my effect as a researcher on the situations being observed. I now discuss how I conducted this observation week and my considerations and management of these issues.

In each case, the observation period was five consecutive days. By observing consecutive days rather than separate days, I considered that staff would feel more relaxed in my presence as the week progressed and I would be more likely to observe usual practice with the child. The week was chosen with the following considerations in mind:

- a) that it was a convenient week for the school to accommodate a visitor in the classroom;
- b) that it was a 'usual' or typical week for the child as far as possible e.g. no school trips, most lessons were the usual lessons, no changes of staff planned;
- c) that it was not at the beginning or end of term where there might be other factors affecting usual practice, such as a new member of staff or the child's fatigue affecting their usual function;

- d) that it was a week when there might be therapists visiting so that these sessions could be observed;
- e) that the child had no planned absences or recent unusual medical interventions.

The table below details the main participants involved during the observation week in each of the case sites. Being present in a classroom and within the school, meant that I was able to observe many children and adults during the day, but the table details the participants who had direct involvement with the child during the observation period.

Table 4.3 Participants involved in observation week

Case site	Participants
Case site 1	Child (Zac), class teacher, three SSAs allocated to Zac, SSA from the unit, SENCo, teacher for SSU games, teachers (maths and supply)
Case site 2	Child (Sam), class teacher, allocated TA, class TA, class TA for playground supervision, ICT teacher, previous TA, lunchtime supervisors, TA teaching one of the lessons, SENCo
Case site 3	Child (Josie), class teacher, allocated TA, head teacher/SENCo, TA for cooking, other teachers in school

During the observation week, I followed the child throughout their school day: in their classroom and in all school activities. As Patton (2002) argues, careful preparation is vital before entering into fieldwork. I therefore gave careful consideration to how I focused my observations: on interactions; behaviours and relationships between the child, their peers and members of staff; use of specialist equipment; and management of their physical needs. My observations were particularly focussed on the child and those involved with them, but I was also interested in the environment and ethos in which the child was functioning. I wanted to describe the setting, the people who were

participating in the activities I was observing as well as the activities that took place. The descriptions needed to be factual, accurate and thorough with enough detail to give context to my observations (Patton 2002).

I initially tried using a broad observation guide to capture events, interactions or situations which I could relate to my research questions. As I developed more insight into the case I refined this to write more freely about what I observed. I wanted to capture the detail of situations to make it easier to develop my thoughts at a later stage and keep field notes in context. I used these notes to later write detailed vignettes as examples of data to illustrate my findings. As Emerson *et al.* (2001 p.353) argue, 'field notes are a form of representation, that is, a way of reducing just-observed events, persons and places to written accounts'. As well as using my field notes to record events or situations as I saw them, I also used them to record my feelings and reactions, and to reflect on the meanings and significance of situations I observed (Mason 2002). The field notes also included data from informal discussions with participants and other children and staff at the school.

At the end of each day, I read my field notes and expanded on these to add more detail or more thoughts on the day's observations (Miles and Huberman 1984). I wrote down any developing theories or 'hunches', questions to ask the following day and further areas to focus observations.

How much of a participant I should be within the field was an important consideration. It can be argued that this should not be a 'once and for all decision', but that one should move between a variety of roles dependent on how it might shape the data (Mason 2002). For each situation I needed to make a judgement as to how much I could learn by being more of an observer or whether it would be more beneficial to be a participant observer. In the classroom I sat a short distance away from the child so that they would feel as least inhibited as possible by my presence, but near enough to hear their conversations and observe their actions and those around them. I wanted my presence in the classroom to have as little impact as possible on the usual interactions. After a short period of time, I felt that the children appeared not to notice that I was in the classroom. For the majority of the time, I was a non-participant observer in that I did not speak or choose to join in with any of the children's activities. I did not want to alter the usual classroom dynamics and assistance usually offered to the child. This was not difficult in

the classroom setting as the children were usually focussed on their activities and on the teacher. On a few occasions however, other children in the class approached me to ask for help with their work. I gave my help on these occasions, but as I did not want to be viewed as another 'teacher', I tried to direct the children to the classroom staff for assistance.

At other times such as at during break, I engaged in more participant observation involving not only watching, listening and reflecting, but used these times to engage the child and other children around me in conversation (Mayall 2000). I sometimes sat with the child whilst they had their lunch to use these opportunities to talk to them and other children around them. On other occasions when I wanted to observe their behaviour and those of others, I observed the child from a short distance away, whilst in the playground or in the hall for lunch. This gave me the opportunity to talk to other children in the school as well as staff supervising the children. I attempted to be near enough to hear conversations, but was aware that my presence might prevent or inhibit the child's natural activities. In cases two and three, I was invited into the staffroom, where I had opportunities for informal conversations with the staff.

During therapy sessions I was aware that school staff might view me as a 'knowledgeable' person to involve in the therapy session. As far as possible I tried to be an observer, but this was more difficult than in the classroom situation as the staff often tried to draw me into conversations or the child requested that I join in with their game. To ensure that they did not feel awkward in my presence, in these instances I participated in the activities. I attempted to behave as any other non-medical adult might do in these circumstances and did not offer any opinions or guidance on the activities even when asked. I did not want to reinforce my background as a therapist and tried to play 'the helpful adult' so that I could participate in the games and conversations if asked.

If the child went out of the class for any reason such as for a therapy session, to transfer into specialist equipment, or to work with a different member of staff, I followed to observe. These were usually good opportunities to talk to the child and the adult in an informal situation as we were walking along a corridor or waiting for a therapist to arrive. I was aware that the child or the adult might not be as open with me in front of each other, but I used these opportunities to discuss recent situations that had occurred.

Sometimes I had the opportunity to talk to the child alone, which helped me to gain more of a rapport and relationship with the child and to talk informally to them.

During the week I had numerous opportunities to have informal conversations with the child in the case, other children and members of staff to help clarify situations and meanings for me. I used break times or gaps between lessons to ask for explanations about situations I had observed. I decided to keep some of the more sensitive questions for the formal interview particularly where there might be disagreement.

4.5.2 Semi-structured interviews

Following the observation week, I arranged to interview the main participants involved in the management of the child. The aims of these interviews were to clarify meanings about the observations and actions observed during my week at the school and to ask additional questions I had not yet addressed.

All school staff and children chose to be interviewed at school, whilst the therapists chose their child development centre. Two parents chose to be interviewed at home, one at their child's school. All were interviewed individually except for the three TAs in case site one who chose to be interviewed together. As they had worked together for some time, they appeared comfortable to share different views with each other, although being with others may have inhibited some views being voiced.

All interviews except for two of the children's interviews were audio-taped. These were later transcribed verbatim. The other children's interviews were recorded as notes, with as many verbatim quotes as possible.

The following table details the participants who were interviewed in each of the three case sites.

Table 4.4 Participants interviewed

Case site 1	Case site 2	Case site 3
Zac (child)	Sam (child)	Josie (child)
Mother	Father	Mother
Class teacher	Class teacher	Class teacher
TA 1	TA	TA
TA2	SENCo	Head teacher/SENCo
TA3	Occupational therapist	Occupational therapist
SENCo	Physiotherapist	Physiotherapist
Occupational therapist		
Physiotherapist		

For all the adult participants, I conducted semi-structured interviews as described in Chapter 3.3.2. Prior to the interviews, I prepared an interview guide consisting of some general questions relating to the research objectives as well as specific questions relating to observations or actions I had seen (see appendix 4.6 for one example). I developed a different guide for each participant so that I could focus the interviews with particular issues in mind relevant to that person's experience (Mason 2002). As I had developed a relationship with most of the participants during the observation week, they appeared to be comfortable and seemingly open with me during the interviews. I left the more sensitive subjects and specific questions which they might find more difficult to answer until they appeared comfortable with the interview. I was aware however, that there were times where they opted to give public rather than private views or chose to say very little about an issue or particular situation.

At the end of each interview I wrote detailed memos to convey my overall impression of the interview (Mason 2002). This included a summary of the participant's responses,

particularly important themes, and my own interpretations and observations. I noted any usual behaviours or events that might influence the analysis.

4.5.3 Interviewing the children

Gaining the child's view about their own management in school was an important aim of this study. I was aware of the methodological challenges in interviewing children which I will discuss in section 4.6. During the observation week I spent much of my time with the child developing a relationship and used many informal opportunities throughout the week to ask them questions.

In addition to this, I spent some individual time with the child to further explore issues. I considered different methods of data collection such as drawings, use of play materials and other participatory techniques (O'Kane 2008). In each case I used a different method and style for gaining data as I had to take into account their confidence with me as an adult, communication style and ability, and level of understanding. I kept the interview short so that the child would not lose concentration and interest, but acknowledged that in doing so I may not be able to ask all of my questions. As I interviewed the child towards the end of the week's observation, I still had the opportunity to ask questions in a more informal setting.

The child in the first case, Zac, was particularly keen to communicate with me about his life in school. Due to his significant communication difficulties, I was initially concerned about how I would explore issues with him. This proved to be much less of a problem than anticipated however, as he was proficient at eye-pointing and used to this method of communicating 'yes' or 'no' to questions. The main problem was that this was a time consuming process and consequently quite tiring for him. I decided to use opportunities such as when he was waiting to be collected after school, break times or between lessons rather than a more formal interview session. In my field note book I wrote a section entitled 'Questions to ask Zac' and he knew that I added to this every day. When there was a spare moment he would often convey to me that he wanted me to ask him a question from my book.

For more abstract conversations, I used a combination of Zac's communication book where he had several diagrams with which to start conversations and my own drawings

to convey other ideas that were not in his book. He had a good sense of humour and I used this to encourage him to share his views (O’Kane 2008).

The child in the second case, Sam, was quite a reserved child compared to the other two children and was also the youngest of the three participants. He did not want to be interviewed alone, but agreed to talk to me alongside a friend. School staff organised for me to join Sam and his friend in the indoor lunchtime club. They felt that Sam would be more comfortable in this situation rather than in a more formal interview. Sam regularly played in this club if the weather was cold or wet and he viewed it as being ‘a treat’ to be indoors.

I joined the two boys at a table playing with a large castle and some play figures. I asked if they were happy for me to join them and to talk to Sam about school. They agreed. After some time playing, I asked if we could use the toys to talk about what happens in their school. They appeared willing to play this game. For example we talked about PE and what they were doing at the moment in their lessons and used the toys as props for my questions. They helped me to lay out the figures in the positions they had been in the previous PE class and enjoyed giving them all names. During this process I asked open questions such as ‘What is Sam doing now?’ or ‘Do you think Sam can join in with this one?’ In this way I was able to gain some idea of his views on participation and use of his equipment in school. It was a time consuming process however, and I therefore had to limit my questions to these subjects and used other informal times to ask him further questions.

The child in the third case, Josie, was the oldest child of the three cases and appeared confident and comfortable to be interviewed in a more adult fashion. She talked freely to me in the playground during the observation week and chose to be interviewed alone. As she was articulate and seemed comfortable to talk to me, I was able to use a more adult style interview schedule to ask questions and used real-life scenarios to discuss issues.

4.5.4 Documents

Documents were used to gather additional support or provide explanations for data from other sources. Written text can be ‘used alongside other forms of evidence so that particular biases of each can be understood and compared’ (Hodder 1994). As Patton

(2002 p.294) argues ‘documents prove valuable not only because of what can be learned directly from them but also as stimulus for paths of inquiry that can be pursued only through direct observation and interviewing’. I wanted to gain information on how the school viewed itself and how it was viewed by others, how information on the child was given and shared amongst staff, and the difference between written information and what occurred in practice. I viewed these documents as adding to the data gained from other methods, but had to give careful consideration to how I treated this data. As Atkinson and Coffey (2004 p.58) point out, documents are ‘social facts, in that they are produced, shared and used in socially constructed ways.’ I did not therefore treat these as firm evidence, recognising that they have been written for a particular audience and for a particular purpose. Patton (2002) points out the limitations of documents as being sometimes incomplete or inaccurate and variable in quality. School staff often did not know if particular written information existed, which gave an insight into the use of these within school.

For each case study site, I sought general school documents which would provide additional information on the context of the school. School web-sites, prospectus and Ofsted reports helped me to gain an understanding of the general characteristics of the school as well as an idea of the school’s general ethos towards learning and their attitude and approach to inclusion. Other documents such as school development plans gave insights into plans for developing the organisation or structure of the school possibly influencing the child’s inclusion. I was also interested in any letters which were sent home as evidence for how the school viewed parental involvement and general inclusion.

As well as general school documents, I sought specific documentation related to managing the child’s physical needs within school. These included documents such as the child’s Statement of SEN, IEP and other physical management plans within school. I also used any therapy programmes or advice given to the school.

From the individual therapists, I asked for any written advice, programmes or goals that they had given to the school regarding the child’s physical management. I wanted to compare this to those the school shared with me. From the therapy notes, I was able to gain information on the child’s physical functioning and GMFCS level and relevant medical information.

4.6 Methodological challenges

4.6.1 My position as a researcher

I have discussed the importance of reflexivity and the possible influences of my position as a researcher in section 3.3.3. In this phase of the study, there were some additional considerations.

Although school staff were aware of my background, I tried to promote them as the experts in this particular case with knowledge to share with me. When they explained problems or issues, I tried to show understanding without giving any opinions or advice on the situation. As I was present as an observer in the classroom everyday for a week I felt that they often forgot my position especially as the week progressed. I developed relationships with many of the participants and felt they became more relaxed and open about their practice and the difficulties they faced.

During the observation week, I used my field notes to reflect on any possible influences I was having on the data as a researcher. I wrote notes to check observations and reasons for actions if I considered that these might have been performed for my benefit. For instance when a child was offered the use of his walker during a literacy session to assist him to stand up and join in with the other children, I was unsure whether this was done to impress me. I later checked this by talking to the child and TA about whether this equipment was usually used.

With those participants with whom I was not able to develop a relationship prior to their interview, such as some of the non-classroom staff, parents and one or two therapists, I felt that my position as a physiotherapist was more prevalent. I was concerned that they might think I could be critical of their management of the child, influencing how they responded to questions asked of them. I confronted this issue by focusing on real life events that I had observed to encourage them to explore why they thought certain actions had been taken. In this way, I was not giving any opinions about practice, but encouraging them to explore meanings and explanations.

When talking to therapists, I was particularly aware that my position as a physiotherapist might influence our interactions. I tried to focus the conversations primarily around their views of how the child was managed in school rather than purely on their practice. Although I did gain information indirectly about this, I felt that this

approach was less threatening to them and in this way gained valuable data from their perspectives. I also had to take care that I was not making assumptions based on my experience and knowledge but to ask questions to clarify my observations and interpretations.

In this study I wanted to focus on the physical aspects of the child's life in school although I was witness to all of their school day. I was aware that coming from a therapy background, I had decided to focus on details that I considered important, but in doing so, might miss other crucial data or opportunities to ask questions which would throw light on the information I sought. I tried therefore to keep an open, questioning mind so as not to accept data just as I saw them, but to seek clarification from differing perspectives. I was also aware that in the analysis of the data, my own assumptions and experiences would have an influence in how I interpreted them.

4.6.2 Research involving children

One of the main challenges of this study was gaining the involvement of the child. As Kellett and Ding (2004 p.165) argue 'children are themselves the best source of information about matters that concern them'; they 'can and do provide reliable responses if questioned in a manner they can understand and about events that are meaningful to them'. Conducting research involving the child, rather than research on or about them, does however necessitate consideration of many methodological and ethical issues (O'Kane 2008). In particular, I was concerned with how to deal with inevitable power relations as an adult in a child's world and how to ensure that my research methods facilitated participation of the child. Ethical considerations were primarily concerned with informed consent and dissent, privacy and confidentiality.

The effect of power relations cannot be ignored when conducting research with children (Mayall 2008). Culturally there are generational issues between children and adults, which affect how children behave in the company of adults. In addition to this, school is a context where the adult-child power ratio is thought to be particularly acute (Robinson and Kellett 2004). As an adult in the classroom and in the playground, I had to consider how I could present myself in the 'least adult' role to facilitate engagement with the child in the case and with other children around them. Although I would be viewed as an adult, as O'Kane (2008, p.143) suggests, as a researcher I needed to find

ways of engaging with children ‘to build a relationship where respect, openness and a genuine intent to listen is evident’.

Break times were particularly important opportunities to develop relationships with children as they were able to approach me at their ease, introduce their own conversations or ask me questions. I tried to be sensitive enough to keep my distance from the child if they obviously wished to go off and play without disturbance. I used strategies such as sitting in a place where there were no other adults, but where the child was playing close by. Other children would often approach me for a chat or to ask me to join in their games. This sometimes brought the child in the case into direct conversations with me and as the week progressed, they appeared more comfortable to have these conversations either individually or alongside a friend. Mayall (2008) suggests that the issue of power cannot be fully diffused, but there are ways of limiting the effects. I tried to be viewed as an adult ‘friend’ (Mandell 1988) rather than as a teacher by not disciplining the children or becoming involved in arguments in the playground. I instead directed them to a member of staff to deal with these problems. Sometimes I asked the child if I could join them for lunch and sat with their group of friends to eat my packed lunch. This gave opportunities to ask about all aspects of their life at school in an informal situation. Although other children were around, this was an opportunity to talk about school from their perspective and to use the other children to facilitate conversations.

There are however, limitations to using techniques which are more responsive to participants. If participants are given more control over the focus and agenda of issues, then the field of investigation may be limited to the issues they choose to discuss or feel are significant (O’Kane 2008). Allowing children to be in control of conversations meant that they left when they felt they had finished or changed the subject to another conversation. It was sometimes frustrating when I had just managed to engage the child in an interesting dialogue and another child joined in and changed the focus.

There are many methodological considerations when using interviews as a research method with children such as where to hold the interview (Morrow and Richards 1996), whether children should be interviewed alone or with other children (Greene and Hill 2005), and how to facilitate constructing a meaningful account with children (Westcott and Littleton 2005). Power relations cannot be ignored and children often find it

difficult to disagree or say things they think might be unacceptable (Greene and Hill 2005). I tried to give the child some power by asking them where they would like to be interviewed and whether they would like anyone else with them. For one interview I used a tape recorder and placed the child in control so that she could switch it off if she so wished (O’Kane 2008).

4.7 Ethical issues

Ethical approval was granted for this study (appendix 4.7). A number of ethical issues were considered and these are explored below.

4.7.1 Informed consent

When considering ethical issues for children of this age group and for those who may have communication difficulties, I was concerned with two main issues: how to make the research aims and processes clear for the child’s level of understanding; and how to ensure that they felt ‘active’ as participants in this study. Much has been written about the ability of even young children to give consent as long as care is taken to explain the study in an appropriate way (Morrow and Richards 1996; Alderson 2004). When introducing this study to the families, along with information for the parents I included a child-friendly leaflet. I asked the parents to discuss the study with their child using this leaflet and checked in my initial telephone call whether the parent felt that their child was happy to be involved. As parents have to legally be asked for consent for their child of primary school age to participate in research, they are also naturally their gatekeepers (Masson 2004). I was aware of the possibility that parents might not fully explain the study to the child, or put pressure on them to agree to participate. I therefore had to consider ways of ensuring the child’s informed consent before I began data collection and dissent during this period in case they changed their minds.

On first meeting the child, I used the leaflet to explain the aims of the study once more and the nature of their involvement to confirm that they understood and were happy to give their consent. As an adult I was aware of the issue of power relations particularly in a school situation where children are expected to conform to adult requests. I therefore constantly checked the child’s responses to my presence and to questions I asked as an indicator of their willingness to participate (Alderson 2004). From time to

time, I consulted adults who knew the child well, to ask if they felt that the child was comfortable with my presence.

Although I was not directly observing the other children in the class, I considered whether I required consent from all the children for my presence in their classroom. Was it sufficient that the headteacher gave consent for me to be in the school and for me to talk to any child in the school? These are questions many others have debated (Alderson 2004). I was informed by the local education authority that I only required a letter of agreement from the headteacher. Prior to my visit, I asked the class teachers to talk to the children about the reasons for my visit and to ask the children to approach me if they had any questions. Sometimes children did approach me to ask why I was there, particularly in one case where the teacher did not appear to have given the children any explanation for my visit. When this occurred, I was as open and honest about my research as possible, so that any information they offered was given with this knowledge. I did not use any direct quotes from any child in my data, other than the child in the case.

Informed consent was equally important for the adult participants in this study. Care was taken in how they were recruited so that they would not feel persuaded to participate by their therapists, managers or by more senior staff at school. Each participant's consent was sought prior to any involvement and additionally prior to their interview. The study was explained both in written form and verbally allowing participants to ask questions. They were all asked to sign a written consent form and it was made clear that they could withdraw from the study at any time.

In addition to this, there was the issue of whether I required consent from any other staff member I spoke to in the school. Being a school environment, it was not possible to talk only to those I had directly asked for consent to participate in the study. Sometimes other staff would talk to me about the child to offer information or their opinion. In one of the cases the SALT not involved in the study was interested in talking to me about the child and giving me her opinions about his management. This was often useful data and provided a different perspective perhaps from the other participants who were directly involved. In these cases, I had to make a judgement about whether the data would be used and if so how I would gain consent. I asked the informant whether they

were happy for me to use their data in my research and if so, made sure that they were fully informed about the study and the consent process.

4.7.2 Data protection

All data collected were stored securely and personal data were kept separate from the transcripts. Pseudonyms were used for all participants and schools in the field notes, transcripts and reporting of all data. This aimed to keep the reports and direct quotes as anonymous as possible. In case study research however, detailed descriptions of the case add strength to issues such as validity and generalisability. This allows case sites and consequently participants to be more easily recognisable despite the use of pseudonyms. If a particular region of the country is given, then case sites may be more recognisable particularly if the site is an unusual facility such as a school with a particular unit. Giving these details needs to be weighed up against the need for detail to adequately describe the case.

Data from other children and staff in the school were only used if deemed important to the aims of the study and were not made identifiable to any particular person. No direct quotes were used from these informants.

4.7.3 Confidentiality

Confidentiality is an important ethical issue in any research study. As well as confidentiality of data, there were issues relating to working in a school environment where I was rarely alone during conversations. For instance, I did not want to talk about the child in front of them and sometimes had to prevent school staff from doing so. I also did not want to talk about the child in the case within earshot of other children. I sometimes had to tactfully suggest that we moved to a more private place for a conversation. I was at times party to conversations which were unrelated to my study, such as conversations in the staff room about other children or issues. I had to ensure that I kept these conversations confidential. I was particularly aware that some staff may not have known that I was a researcher and my reasons for being in the school.

Another issue I faced was whether to report data where there was criticism of another individual in the case and this could be recognisable. This was a difficult issue as these views were often important reasons why certain behaviours were observed. In these cases I had to decide whether it was crucial for these data to be included and if so,

reported these data as one perspective on a situation in an attempt to give a balanced viewpoint.

There were also issues over confidentiality of information within and between cases. I did not encounter any strong disagreements about practice, but staff did sometimes ask if others had reported similarly. In these cases I tried to give as little detail as possible so as to keep the conversations confidential. Instead I tried to give them examples of practice from my experience as useful comparisons for them. This was also a strategy I used if asked about other cases in my research and how their school practice compared.

4.7.4 Privacy and child protection

As with all research participants, I had to be aware that the child's right to privacy was respected. If a child appeared to be having a private conversation with either their friends or with members of staff, I made sure that I moved away from them to ensure their privacy. There were many situations where ethical decisions had to be made 'on the spot' and I had to decide how to act and behave as a researcher.

Child protection procedures were addressed using local education and health Trust policies.

4.8 Trustworthiness of data

I have discussed the importance of trustworthiness of data in section 3.5. In this phase of the study credibility can be demonstrated in a number of ways. I have already described the methods I followed in my fieldwork in detail. By spending a week in the field, I was able to focus on issues in some depth to discover whether they were relevant or not, avoid misleading ideas and to build the trust of those who could provide data (Bassey 1999). I was able to do member checks by asking questions of participants so that my understanding of what was going on could be clarified (Strauss and Corbin 1994). To demonstrate transferability I have endeavoured to provide 'thick' description in each of the case sites, by providing extensive details about the context, participants and situations so that there is enough information to have confidence in the findings. Dependability and confirmability (Lincoln and Guba 1985) can be demonstrated by explaining the systematic process I followed in data collection and providing an audit trail (see appendix 4.8 for an example of part of this) to show how I developed my thinking and provide evidence for how I reached the conclusions.

4.9 Data analysis

As recommended by Miles and Huberman (1994), I began data analysis from the early stages of data collection. For each case, during the observation period and whilst conducting the interviews, I continually revisited the data already collected to look for developing themes and to consider how I might explore these further. At the end of data collection of the first case, I undertook a further period of analysis to explore the important themes in this case. I then moved on to collect data from the second case with these themes in mind, but was also open to new themes emerging. This enabled themes to be further explored in the next case, for confirmation of importance or alternative explanation. I continued this process for the final case.

At the end of final data collection, I began a more detailed analysis of one case. During this time I returned to the literature, which eventually informed the structure of the analysis. I developed four overarching themes for the first case and considered using these as a structure for the next two cases. During the analysis of the next case however, I realised that there were other more important themes and therefore decided to only partly use this structure. The same applied to the third case. I will now describe my analysis under the headings of data reduction, data display, and conclusion drawing/verification (Miles and Huberman 1994).

Data reduction

Data reduction is usually viewed as ‘the process of selecting, focusing, simplifying, abstracting, and transforming the data that appear on written-up field notes or transcriptions’ (Miles and Huberman 1994 p.10). I began this process prior to data collection by deciding what data to collect in my observation field notes. I had already identified some a priori codes based on the findings from the first phase, my research questions for this phase, and from my conceptual framework. These loose codes were used during the first stage of coding to initially highlight areas for further analysis. For example, one of the important themes from the first phase was that of ‘responsibility’. This code was therefore assigned to all sentences, paragraphs or ‘chunks’ of data containing any information pertaining to this theme.

As well as looking for particular themes in the data, other themes emerged and I developed codes to identify these data. As my understanding of the case deepened and

with more data collected, many of these codes were reviewed and revised. Codes were often grouped together to create a larger category. Sometimes codes became too large and unwieldy and required sub-division to tease out the various components of the code. For example, ‘communication’ was an important issue identified, but as data pertaining to this issue occurred so frequently and I realised that there were many aspects to this issue, I developed separate codes to capture these different themes. I also checked for phrases repeatedly used by participants as ‘they often point to regularities in the setting’ (Miles and Huberman, 1994, p. 61). ‘Finding the balance’ for example was an ‘in vivo’ code which was articulated by different participants in the second case and pointed to a more interpretive theme of how participants viewed prioritising the child’s needs. All segments of data under these codes were then filed together for later retrieval.

Following this initial coding process, I re-visited the literature on the social model of disability and inclusive education. In doing so, I considered how these theoretical frameworks might structure my analysis. I started to connect theories in the literature with themes I had explored in my data. For example the issue of independence for the child in the second case had already emerged as an important theme. I then used theories relating to constructions of independence to build a framework for this overarching theme. I returned to the data to search for all examples relevant to these concepts. This process generated new codes which added to this framework. I compared data from different sources to show multiple perspectives, confirming explanations or offering alternatives. I explored each concept comparing different perspectives or observations of actions whilst also looking for negative cases. The following table illustrates examples of quotes from different sources.

Table 4.5 Example of multiple perspectives used in the code ‘Working by himself’ from the second case

Code	Quotes from transcripts/examples from field notes/documentation	Source
Working by himself	‘He can sit up, he can do the task himself, he can do the activity and the adult is free to sort of move away to a different group’	Interview, class teacher
	‘We don’t want someone perched by his side when he’s safe in the standing frame or in his chair’	Interview, father
	Interviewer: ‘Did you deliberately go with a different group so that he had to work by himself?’ TA: ‘Yes which I think is right. Because they do get so, so reliant’	Interview, TA
	Vignette of Sam doing art activity where he is left to work by himself, but has to wait for an adult to notice he requires help	Observation, field notes
	Supporting TA to ensure that Sam’s physical needs have been met before encouraging him to work independently with his peers in class	Documentation, IEP action plan

Throughout the data collection process and analysis, I used memo writing to explain the concepts as I saw them and how they might link to other concepts. During the observation week, I wrote notes of possible explanations for concepts and how I might explore these further. As Miles and Huberman (1994 p.72) write, memoing is a ‘sense making tool’ to tie together different pieces of data, ideas and relationships.

I also created numerous vignettes from observations during the observation week. These created 'a concrete, focused story' (Miles and Huberman, 1994 p.83), utilising real life situations to illustrate core issues or concepts. In doing so, it assisted the analysis process by integrating concepts found in the observation data with those in the written transcript data.

Data display

During and after the coding process, I used data display in the form of matrices and network maps to develop the analysis. I used these as visual aids to describe where data was derived from, links between different concepts and themes, as well as a method of exploring developing themes.

Matrices were used to display data in a table such as where sources of information were derived to look for frequency and to use as an audit trail of data source. An example is illustrated in appendix 4.8.

Network-like diagrams were used widely to help map concepts. They assisted in exploring explanations of a concept using different data sources, the relationships and links between these explanations and between this concept and others. They were particularly useful for viewing links between larger categories and relationships between them. These diagrams helped to theorise a logical chain of evidence and to eventually draw conclusions. Appendix 4.9 illustrates an example of a network map.

Conclusion drawing/verification

In any qualitative study, it is important to be able to demonstrate confidence in the findings reported. As well as ensuring rigour in the data collection methods as previously described, I used certain strategies to test hypotheses and to consider alternative explanations. Checking for representativeness can be one strategy to aid conclusion drawing and verification. By observing and interviewing all those involved with the child's management, I tried to obtain views from varying perspectives. During the observation week when actions were observed, I often asked participants for feedback or explanations for these actions to verify my explanation. I tried to visit the child during a week that was described by the school as the child's 'typical' week and I asked this question of different participants during the week and afterwards during

individual interviews. It was important that I wasn't observing behaviour that participants viewed to be unusual or atypical.

Triangulation of data was an important part of data analysis, which I did by including different data sources as well as different data methods. Appendix 4.10 illustrates the main codes used in case study three and the data sources.

I also used strategies such as following up surprises, using negative evidence and checking the meaning of outliers to verify my findings. For example in the second case, during the observation week I noticed that the TA very often sat on the opposite side of the room from the child, with a consequence on how he accessed support. I had to explore further to uncover reasons for her actions which were in contrast to the role portrayed to me in discussions.

Silverman (2005) suggests using the constant comparative method to test out a provisional hypothesis. As I began data analysis at the beginning of data collection, I was able to use small sets of data to start with to compare all the data fragments within each case and expand these as my data grew. For instance a hypothesis such as personal beliefs on difference guiding the use of specialist equipment with the child, meant that I trawled through all the data sets to look for instances where this hypothesis could be tested. It meant that I looked not only for confirming evidence, but also for alternative explanations.

I utilised theories of inclusive education and the social model of disability as a lens through which to analyse my data as well as keeping my research questions at the forefront. This enabled conclusions to be related to theory and backed up by evidence from the data. In this way I was able to explain the processes as I saw them.

In conclusion, this chapter has provided a rationale for the use of case study as an appropriate method, described the methods used in this study, methodological issues particularly those affecting research with children and data analysis. I have reflected on my role as a researcher and the possible influences of this on the research process. I now discuss the findings from the three case sites.

Chapter 5: Case study 1

Zac is pushed into the playground by his mother to wait for the morning bell. A few girls notice Zac has arrived and rush up to him, chatting excitedly. Immediately one of Zac's SSAs joins them and asks Zac if he has had a good weekend. His mother replies that Zac has had an excellent weekend and is keen to show the class something special he received from a party at his grandmas. Zac laughs in agreement. His mother gives him a quick kiss goodbye and the SSA pushes him in his wheelchair to the unit. The unit is bustling with children, staff and a couple of parents getting the children ready for the morning. Zac's SSA takes Zac's coat off and hangs it on his peg. She then wheels him into the main part of the school.

This morning after registration, Zac's class have Year 4 assembly and Zac is timetabled to go into his standing frame for this. As there is no time for registration with the rest of the class, he is pushed straight from the unit to the disabled toilet where his standing frame is kept. His SSA confidently lifts him from his wheelchair into this piece of equipment. She then pushes Zac into the hall in his standing frame to join the rest of his class. Although Zac is not given any choice as to whether he wants to go into his standing frame or not, he does this every day and appears happy to do so. By the time Zac has reached the hall, the assembly has started and his SSA places him at the back of his class, who are all sitting on the floor. She nudges the child nearest to him, pointing to Zac, as if to say 'look after him' and leaves to join the other staff sitting on a bench at the back of the hall. Some children in his year group are performing a song at the front of the hall. Zac watches intently making loud excited noises alongside the children's applause. (FN)

5.1 The context

The first case in this study was conducted in Norbury school, a large first and middle school situated on the outskirts of a large seaside town on the south coast of England. This was a voluntary controlled Church of England school for children aged four to twelve years with approximately 800 pupils. Most children were from white British families, with a small number of children from minority ethnic groups (Ofsted Report 2006). Nearly a quarter of the pupils were described by Ofsted as having SEN with the number increasing after Year 4 when there was a new intake of children from

neighbouring schools. As a church school, it was described by the report as having a 'caring ethos for those less fortunate'.

The school accommodated two SSUs; one for children with physical impairments (the PD unit) and the other for children with specific learning difficulties. The PD unit was led by Mrs Jones, the SENCo who had been at the school for two years. She described her role as being responsible for the management of six SSAs and 13 children with Statements of SEN within the unit. Her role was to be '*the specified named person responsible for making sure that everything that's in that legal statement is fulfilled*'; '*the link between parent and the class teacher*'; '*co-ordinating all the provision*'; making sure that '*the class teacher has the IEP and is supported with the planning*'; '*a sort of middle person between everyone trying to keep everything on track and on an even keel*' (SENCo, interview). Other children in the school with physical impairments without a Statement of SEN, e.g. a child with mild cerebral palsy, were the responsibility of the main school SENCo.

The unit was a single storey building situated on one side of the school, with a large ramp up to automatic doors. This door and the one which led into the main school were the only two automatic doors in the whole school. The School Improvement Plan detailed this as a priority for development. On the other side of the unit, there was a separate entrance, which could be used by parents or school transport to bring the unit children into school. The unit acted as a base for Mrs Jones and the SSAs, who gathered there at the beginning and end of each day for a chat and a cup of coffee. The therapists spent their time in the unit with the children and other individual programmes were undertaken there by the school staff. All pupils in the unit were part of a mainstream class where they spent the majority of their school day. Ofsted in 2006 described the children as being 'fully integrated into the school' and concluded that 'good attention was given to the children to address their individual special needs'.

The SSAs considered themselves to be part of a special support team who supported children from the PD unit within the school. They were allocated to support particular children and had duties shared only with other SSAs from the unit. Other TAs moved between different classes to support groups of children, but did not share any duties with the SSAs. If a child from the unit was off school, the allocated SSA would assist another SSA to work with the 'unit' children rather than support another child in the

class they were usually in. The SSAs were currently being encouraged to spend their lunch breaks in the main school staff room rather than in the unit, as part of the new policy to integrate all staff. Mrs Jones supervised all the children from the unit in the playground at break times.

Zac

Zac was a nine-year-old boy in Year 4. He was described as a content and happy child with a good sense of humour, a *'laid back'* boy (mother, interview) with an *'easy going personality'* (SENCo, interview). He told me he enjoyed all of school, in particular his playtimes. Zac's parents chose this school as they felt that staff in the unit could meet his complex needs. His mother considered that he had done *'incredibly well'* considering his difficulties: *'I know that he's happy...he's in a stimulating environment, he loves it, he loves the kids, he's spoken to every day by the other children, you know he's really interacting with them...and learning'* (mother, interview).

Zac had a diagnosis of cerebral palsy affecting his whole body (GMFCS, level V), with increased muscle tone throughout his body and severe dystonic movements. He had some control of his head, but very little voluntary control of other body movements, including the ability to articulate words for speech. He required extensive supportive seating to sit upright, but when in this equipment was able to maintain his head upright and use sideways head movements to touch a switch on the side of his headrest. Whilst in school, Zac sat in his powered chair for most of the day, except for when he used his standing support or had physiotherapy. He was usually pushed in this chair by his SSA, but was learning to use switches with one hand to manoeuvre the chair independently.

Zac was considered to have good comprehension, but difficulty in articulating words. When relaxed, he could say some words, but as this was difficult for him he used up and down eye movements as his main mode of communication at school. This enabled him to answer 'yes' or 'no' to questions asked of him. This method of communication had obvious limitations for his level of understanding and the SALTs were exploring other means of communication such as a communication aid and use of switches.

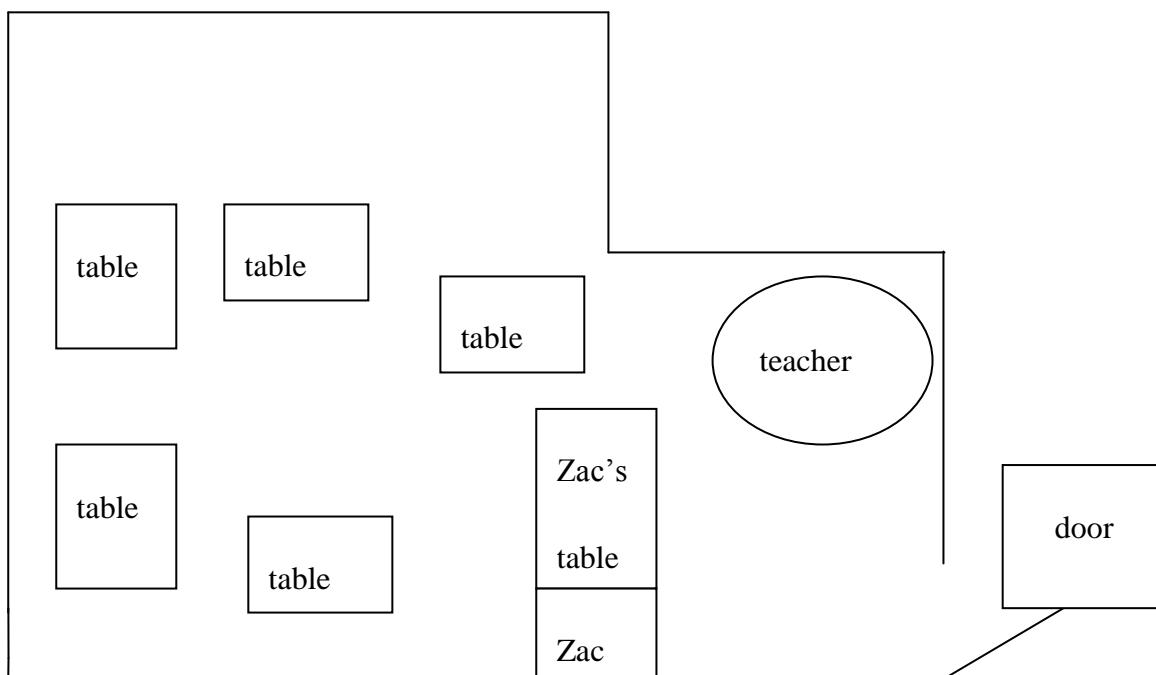
Zac lived approximately twenty minutes drive away from school with his parents and twin brother. His brother also had cerebral palsy, and attended a different mainstream school with specialist skills to address his particular additional difficulties. His mother

usually drove Zac to school by car, but one day a week he arrived by taxi and was collected by a carer after school.

Dolphin class

I visited this school towards the end of the autumn term. Zac was one of 32 pupils in Dolphin class and the only one with a physical impairment. The classroom (see Figure 6.1) was arranged so that the children sat at group tables decided upon by the class teacher (FN). Zac sat at the end of a table of six children to one side of the class teacher and by the open door to the classroom. This meant that anyone walking by was clearly visible to him and he spent much of his time looking out along the corridor. His teacher had decided on this position so that he had easy access in and out of the classroom: *‘I completely re-did it [the classroom], so that Zac could fit in and so that his support people would have room...because he has to get in and out’* (CT, interview).

Figure 6.1: Diagram of Dolphin class



During my observation week the children stayed at their group tables for most of the time. The children on Zac's table were described as being '*at a similar level to him*' (CT, interview). Although the children were arranged in groups, during my observation week they only worked as part of a group on two occasions. Most of the time, they worked independently in silence, unless answering a question from the teacher. The class teacher told me that she considered discipline important in this class and had to '*keep on top of it all the time*' (CT, FN). As she was also the Head of Year 4 and heavily involved with the school choir, the class were regularly taught by two other teachers to cover her extra duties. Zac therefore had four different teachers during the week.

At lunchtime, the children ate in the classroom at their tables. Surprisingly, they did not move to sit next to children at other tables, but sat at their usual set places. After lunch, the children went out into the playground.

I now discuss the findings from this case. Four main themes emerged from the findings (see Chapter 4.9 for the process of arriving at these themes):

- Constructing Zac's needs;
- A child from the PD unit: a separate child;
- Independence;
- Knowledge creation and exchange.

5.2 Theme 1: Constructing Zac's needs

Although Zac attended a mainstream school, his needs were constructed within the framework of a school with a special unit and with 'specialist' staff. He was viewed by all staff as a 'child from the unit' requiring specialist provision both within the mainstream environment and separate from it. Although a school with experience of children with physical impairments, Zac was considered to be a child with particularly challenging needs. With his complex physical and communication difficulties, his needs were constructed predominantly from a medical model perspective, with identified needs to be ameliorated with appropriate intervention. Within this framework, 'the surrounding environment and culture within which the impaired individuals are situated is regarded as unproblematic' (Swain *et al.* 2003 p.23). This construction of his needs meant that he was viewed as a 'special needs child' within his class, 'doing his own thing', the responsibility of the special needs team and not the class teacher.

A child needing specialist support

All agreed that Zac was at this school as he required experienced staff who could meet his complex needs: *'That's why we have [Zac] at this school, we have a special PD unit and they deal with that'* (CT, interview). As a child with SEN, Zac's needs were formally constructed by the local education authority detailing his specific needs to be met by the school. He had SSA support to enable him to 'access the curriculum' (Statement of SEN, doc), therapy on a regular basis by visiting therapists and therapy programmes undertaken by the SSAs and the SENCo. From the physical management point of view, although he spent much of his day in his powered wheelchair, he required regular help to be repositioned when he became uncomfortable, assistance with all transfers, to use the toilet, to eat his lunch, and to move from place to place. Despite his severe physical impairments, the SSAs appeared confident with these activities. Two of the SSAs (SSA1, SSA2) had been with Zac since he started in reception and the other one (SSA3), although new to Zac this year, had been working at the school with other children from the unit for many years.

Zac is in a literacy lesson and the children are all finishing off their story. Sheila (Zac's SSA1) is sitting next to him and whispers that they should tidy up their work now

and get ready to move to the next lesson in the ICT suite. She puts his work away and pushes Zac in his wheelchair, out of the classroom. The teacher does not look up or acknowledge that Zac is leaving. Sheila chatters away to Zac as they go along the corridor and into the disabled toilet. She confidently picks Zac up out of his chair and transfers him into his standing frame. Zac is not able to assist in this transfer, but she tells him what she is doing and reminds him to relax (as he apparently accidentally hit her last week with his involuntary movements). She positions Zac in his standing frame and when she has finished doing up all the straps, asks if he is comfortable. He moves his eyes upwards to reply 'yes' and Sheila positions the electric controller in front of him so that he can see it. She pushes the button to move the standing frame into an upright position, watching that Zac is happy with the movement. When he is upright, Sheila stores the controller away, takes off the brakes and pushes him out of the toilet, down the corridor towards the ICT suite. (FN)

Zac's management within the school was viewed predominantly from a medical model perspective with therapeutic input being carried out primarily within the unit. As he was regarded as a child with particularly complex difficulties, the school relied on the expertise of visiting therapists to advise them how to facilitate his access to learning, on his daily physical management, and on his communication skills. The school received advice from a physiotherapist, OT and two teams of SALTs. Although the therapists visited the unit on different days and at differing intervals, they all appeared to take a similar problem-solving approach to his management, working in close collaboration with the unit staff and as far as time allowed, with each other.

All the unit staff and Zac's mother agreed that the physiotherapist was pivotal in Zac's management, particularly as she was '*very accommodating*' (SSA3, interview) when it came to problem-solving difficult issues. They appeared to rely on her to give them '*quite a lot of input*' in all areas and would '*throw most things at her*' as it was usually '*[the physio] or no-one*' (SSA2, SSA3, interview) who was regularly available to help them. Zac was timetabled to see the physiotherapist every week. As one of the SSAs was always with him, this gave them regular opportunities to ask the physiotherapist any queries that had occurred during the previous week. The SSA was also required to carry out a physiotherapy programme with Zac at another time in the week. As the therapist who worked with Zac the most, the physiotherapist changed the emphasis of

her input depending on what was considered to be his priority needs, taking all views into account including those of Zac and his mother: *'I change according to really how his weekly programme is panning out and try to look for where the gaps are and try to help with the gaps rather than having my own agenda as such. And that can vary according to what's happening at home and at school'* (PT, interview). She appeared to have a good relationship with the staff, Zac and his mother. Although the physiotherapist did not do regular home visits, Zac's mother considered that they had a *'very good communication process'* and she could text her on her mobile phone if there was a problem and could *'drop by any week'* (mother, interview) to have a chat if issues cropped up.

This term Zac had a new OT who had started in the unit. She did not see Zac on a regular basis, but viewed her role as *'long term prevention of contractures'*, *'switch control'*, *'attention difficulties'* impacting on his learning, and developing his *'control'* over his life in school by aiding communication (OT, interview). She agreed that her role overlapped with both the physiotherapist and SALT. She had not as yet observed or worked with Zac within the classroom setting or visited him at home. His mother had not yet *'been informed'* that he had a new therapist (mother, interview).

As Zac's physical and communication difficulties impacted on his ability to access his learning environment, school staff relied on therapist's help in this. They agreed that *'it's very difficult to actually check how much he's understood'* (SENCo, interview) and worked collaboratively with the therapists to promote his learning in class: *'I liaise a lot with the speech therapist because we have had issues over Zac and his maths. It's not an area that he finds easy so again I'm taking advice, I'm making sure he's got the number lines, I'm making sure he's got the practical equipment to help him'* (SENCo, interview).

The SENCo co-ordinated all the advice and input from the different therapists. She shared information given to her from the therapists with the SSAs, who were with him in class and with Zac's teacher on a once-a-term basis. As Zac had a new teacher this year and the annual review meeting was held at the end of the school year, the class teacher had *'never met any of his therapists'* (CT, FN) and did not expect to do so until the annual review. Zac's needs were therefore constructed as complex needs to be dealt

with and managed by the special support team and therapists, separately from his educational needs.

A child needing friends

Social interaction was constructed as an important need for Zac in school, particularly as this was a challenge for him due to his communication difficulties. Other than at break times however, there was little opportunity for Zac to interact with children as most work in the classroom was conducted independently. Zac did not participate in class PE where there may have been more collaborative working between children. Continuous close proximity of an adult has been found to have unintended negative effects on pupils' engagement with others (Howes *et al.* 2003) and the LEA Audit of Inclusion had identified that SSAs needed to spread their support to others to allow more independence of the child. Zac however, was rarely alone without his SSA and when children approached him, they tended to talk to the SSA rather than to him (FN).

Break times provided the most opportunities for Zac to socialise without an adult at his side. Staff encouraged this social interaction by leaving him alone to operate his powered chair by himself. In these situations children talked more freely to him and involved him in their play. He clearly enjoyed this interaction and freedom.

Zac is out in the playground in his wheelchair. He is driving it himself using the button switches on his tray. He is surrounded by a small group of girls all laughing and skipping around him. They appear to be playing chase. Zac shows obvious enjoyment and chases the children in his wheelchair. A couple of boys come over and talk to Zac. They stay for a few minutes and then run off to play another game. One girl asks him what he would like to play, giving him two choices and holds up her hands. He eye points to the hand indicating arm wrestling. She holds his hand and plays a pretend game of arm wrestling with him. They laugh as he tries to join in and then another girl asks if she can have a turn. Zac is watched from the edge of the playground by the SENCo. He plays with the children without any adult involvement for the whole of break time. (FN)

Compared to this positive approach to encouraging social interaction in the playground, there was a different attitude towards the use of Zac's communication aid, the Advocate. This communication aid had been given to Zac by the SALT and was

identified as a target on his IEP to be used regularly: 'To use the Advocate this term with [the class teacher] and small groups within class' (IEP, doc). The Advocate was similar to a tape recorder whereby a person could record a message or a question from Zac so that this could be played back to the appropriate person. It aimed to give him the opportunity to instigate conversations rather than always being the recipient of questions.

It's Zac's communication aid so therefore it's for Zac to use how he feels he wants to use it really. And Zac used to like lots of messages going...we managed to get to school with 10 minutes in the playground and he would always in the car on the way to school, we'd chat about what he wants on the Advocate, what message to who, and we'd have time in the playground to find that person and play it. And that was his message for the day and he was happy'. (mother, interview)

Recently, the school start time had changed so that he did not have any time before school to use the Advocate. His mother still helped him to put in a message, but the use of this was reliant on school staff. They did not however, view it as facilitating social interaction and considered it caused 'so many problems because kids don't know what to do with it...well they stand there and they know it's Zac's mum [talking on the Advocate] so they look at us as if to say 'What are we supposed to say?' Ahhhh, horrible' (SSA1, interview). It appeared that this equipment caused them embarrassment and it was therefore not used. Zac was considered to be ambivalent about using it, but his mother was adamant that Zac wanted to use it: 'This is Zac's needs, it's not my needs, it's not [his teacher's] needs or anybody who's looking after Zac. It's not 'Oh I don't like my voice' or 'We haven't got time'. Let's get it sorted' (mother, interview).

Zac said that girls were his friends at school and his mother confirmed this. The SSAs felt that there were a number of girls who chose to be friends with Zac 'because they've gotten to know him over the years' (SSA1, interview). His mother was happy that Zac had chosen his own friends but was concerned that the school was trying to encourage him to make friends with boys: 'That's through his choice... would they tell another nine-year-old that was a boy around with girls to have more boy friends. They

wouldn't, would they? I think, why should you be worried if he's got girl friends? Good on him, he's happy' (mother, interview).

A child who is different

How individual staff viewed Zac's difference impacted on their attitudes towards him and how they constructed his needs in school. Some disabled commentators, such as Barnes (1996), have pointed out how stereotypes are often used within literature to depict disabled characters such as a 'plucky, tragic but brave hero' (Swain *et al.* 2003 p.23). Zac's class teacher appeared to hold this 'personal tragedy' (Oliver 1996) view towards him, feeling '*privileged*' (CT, interview) to have him in her class. She felt that he was a '*lovely boy*' who '*gives off such a good vibe that the children just want to get involved with him and they want to find out about him and they are intrigued by him*' (CT, interview). Her construction of Zac as a 'special' child meant that she often treated him differently from others in the class. Zac agreed that she never told him off and on one occasion when he laughed inappropriately, his teacher used different language towards him compared to the other children: '*Oh Zac's finding something funny, isn't he a pickle!*' (FN)

Despite the SSAs being used to children with physical impairments, they sometimes found it difficult to talk to other children about his difficulties. Sheila (SSA1) commented that she found it embarrassing when children asked her awkward questions about him: '*It was a bit awkward this year because the class he moved into had kids feeding in from other schools who had never seen Zac before. And they stood and watched and gawped, I mean really gawped at him and it got a bit embarrassing and I'd have to say 'Go and sit down now'*' (SSA1, interview). There had not been any discussions with the children in his class about Zac's difficulties except for an explanation of how he used eye pointing to communicate (FN). When Sheila (SSA1) had to move Zac for any reason she was very aware of making a scene. Rather than move Zac nearer the front of the class, she would choose not to: '*I think it makes a big scene, doesn't it. Clunk, crash, bang. So I tend to leave him there, when he's in, he's in, less hassle*' (SSA1, interview). In this way efforts were made to minimise his difference.

5.3 Theme 2: A child from the PD unit

By constructing Zac as a child with complex needs, managed by the staff from the unit, he was viewed as a child with separate needs from the rest of his peers in the class. Staff from the unit were responsible not only for his physical requirements throughout the school day, but for many other aspects of his learning. Although schools may describe themselves as being inclusive if they have created suitable adapted environments, this may not necessarily mean that they are inclusive in their teaching and learning environments (O'Brien 2002). This appeared to be the case for Zac as although he was taught mostly within the classroom, being viewed as the responsibility of the unit staff impacted on his learning, participation and inclusion as a member of his class.

The class teacher asks the children to get their spelling books out for a test. They should have revised their spellings over the weekend. Sheila, Zac's SSAI asks Zac whether he has done his homework and he lifts his eyes up to say 'yes'. She gets his spelling book out for him as well as an alphabet grid. The teacher reads out the spellings to the class whilst the children write them down in their books. As Zac cannot write, Sheila uses the alphabet grid to check that he knows his spellings. She moves her finger slowly down the left hand side of the grid and watches until Zac lifts his eyes up to say 'yes'. At this point she stops her finger moving down and starts to move it across the grid until Zac lifts his eyes up to tell her to stop at a letter. Sheila writes this letter down in his spelling book. They continue in this manner until he has finished his first word. They appear extremely proficient in this exercise and Zac appears to have learnt all his spellings. After the first five words, Sheila decides to check his more difficult spellings by giving him a choice of differently spelt versions of the same word and asks him choose the one spelt correctly. She says that for longer words, the grid process is too slow and they can't keep up with the class. They have not yet finished the test when the teacher tells the class to put their books away and get their history books out. Sheila laughs and says to Zac 'Oh we never have time to finish our tests!' The teacher does not acknowledge Zac in any way during this test or ask if he has finished, but continues on with the next lesson. (FN)

Responsibility for learning

Although Zac's teacher reported that she was '*responsible for the academic things*', she considered that '*they [the SSAs] are helping to enable him to access the curriculum*' (CT, interview). She acknowledged that the SSAs and the SENCo were responsible for differentiating his work as '*they understand very clearly what he does understand, when he doesn't understand*' (CT, interview). The SENCo agreed that this role was '*written in their job description, they know Zac, they know the way in which he works*' (SENCo, interview). She explained that in an ideal world the SSAs and herself would sit down with the class teacher and go over the lesson plans, but that this did not happen due to lack of time. The SSAs were only funded for school hours and the class teacher could not spare any time in the day to discuss lessons. This meant that '*most of the time that differentiation has to happen on the spot*' (SENCo, interview).

The SSAs felt that Zac's teacher could at times have given them more support with differentiation, especially if it was a lesson they knew little about or they had missed instructions due to being out of the classroom: '*It's worse when you come in and they say 'Right now get on with your work'. You think 'oh great, we've missed everything now'. But the teacher will then say to you 'oh dah, dah, dah, dah' and then they zip through it and you're thinking 'crikey give us a chance, we haven't actually learnt any of this before*' (SSA1, interview). The teacher usually presented the lesson to the class as a whole and relied on the SSA to help Zac with his work. His teacher viewed that he was able to '*basically access everything*' and if he couldn't, then the SSAs would make it '*his level*' (CT, interview). The SSAs rarely talked to the teachers to discuss how to present work to Zac as they felt '*it would be difficult to get a word in edgeways in a classroom*' (SSA3, interview), but decided by themselves how to differentiate the work. The teachers did not involve themselves in his work other than occasionally asking if he was 'OK'.

The class are learning about Henry VIII. They talked about his life in yesterday's lesson, but Fiona [SSA2] was not with Zac yesterday. The teacher asks the children to write down five questions they would like to ask Henry VIII if he were here today. Fiona is unsure where to start, but feels she knows something herself about the King to be able to help Zac. She does not ask the teacher for any feedback or help. She laughs and jokes with Zac that she was never really any good at history and that he needs to

come up with the questions himself. She knows this is difficult for him, so she starts by thinking of questions and asks if he would like her to write these suggestions down. He agrees with a few questions and she puts these down on his piece of paper. She runs out of questions to ask Zac and he appears to have lost interest in the task. She tidies his work away and says 'I'll let Karla [SSA3] finish this off tomorrow, she's better at things like this'. (FN)

In situations where there was whole class teaching, Zac was expected to listen and learn in the same manner as others. If the teacher wanted to confirm understanding she would ask the children a question. Zac had difficulties responding verbally to a question and the class teacher did not seem to give him any alternative strategies. Sometimes in smaller groups such as in his maths set, his teacher would notice that he wanted to answer as *'his face lights up'* (SSA1, interview). More often the SSA would notice this and lift Zac's arm up or put her own hand up for him, saying 'Zac knows the answer' and if chosen, tell the teacher Zac's answer. If however, she had to go through a range of yes/no questions to get to the right answer, it was often too late to answer the question as the class had moved on.

Although it was the SSAs and SENCo who knew how to promote Zac's learning, it was the class teacher who talked to his mother at parent evenings about his progress in class. She viewed his teacher to *'have a good handle on where he's coming from'* and to be *'on top of where his level is'* (mother, interview). She however, saw his teacher *'very, very little'* (mother, interview) except for parent evenings once a term and generally liaised instead with the SENCo. She viewed the SENCo as responsible for his overall learning as well as his physical needs and directed all questions to her via the home-school communication book: *'I just put it [the question] in the book now for the attention of [the SENCo]'* (mother, interview). She did not go directly to his teacher even if she was unclear about the homework set, but instead asked the SSAs. It was not always easy however, for the SENCo to know exactly what had been taught in the lessons and with three SSAs with Zac during the week, they were not in all lessons. When it came to homework for example, there did not appear to be any feedback to his mother regarding the best way to promote Zac's learning and the SSAs used different strategies themselves. Zac's mother reported that she used her own commonsense to do

most of his homework as *'they don't actually tell me how they do it'* (mother, interview).

As Zac was constructed as a child with particular needs to be managed by the special support team, the SENCo was considered to be ultimately responsible for ensuring that his needs were met within class. As she was not physically present in the classroom herself, she had to rely on regular verbal feedback from the SSAs as to how they were managing Zac on a daily basis. She expressed that she would have liked to monitor the work of the SSAs more closely in the classroom, but that the school did not consider this to be her role: *'In an ideal world I'd be going in doing lesson observations, but I don't get involved in lesson observations, the senior management team would do that'* (SENCo, interview).

Participation

Social, environmental and attitudinal barriers rather than lack of ability are often argued to be what disables people (Crow 2003). When Zac's mother was asked if she felt he was included in everything he could be in school considering his difficulties, she replied: *'That's a good question actually, I'd like to say a 100%, but I'm going to say 60%'* (mother, interview). Although Zac was expected to be present in most of his class' lessons, by managing him as a child with separate needs, there were many barriers to his participation within lessons.

Although it was agreed that Zac had particular needs which meant he had to frequently leave the classroom, his SSAs did everything they could *'to avoid his physical side getting in the way of his learning'* and tried *'to keep him in for the main part of the lessons, the important parts of the lessons for him'* (CT, interview). Zac clearly enjoyed school and disliked being out of the class if it could be helped (FN). He would encourage his SSA to hurry up when he was out of the classroom so that he could return as quickly as possible back to his lessons:

Zac has been in the unit with the physiotherapist for nearly half an hour. Today he has been taken out of his science lesson, as last week he missed literacy. The time of his physiotherapy sessions are changed periodically so that he does not miss out on the same lesson each week. Karla, his SSA has asked the teacher what the class will be doing in the lesson and she has brought the experiment with them to the unit. They are

to experiment which plasticine shape takes the longest to fall to the bottom of a tall cylinder full of water. Zac is enjoying this experiment very much and excitedly shouts instructions. His speech is more clearly audible today. Karla says that this is because he is in a quiet environment and relaxed. When the experiment is finished, Zac makes agitated noises and eye points to the clock on the wall. He says 'quickly, quickly' several times and Karla realises that he is missing his next lesson. She helps the therapist to put Zac back in his wheelchair and they rush back to the classroom. (FN)

For a child with different needs from the rest of his class, there was a tension between meeting his needs within the classroom in an effort to be 'inclusive' and allowing him time and space to concentrate on new or difficult skills. There were many instances where the SSAs were able to use different techniques, e.g. numeracy or alphabet grids, to facilitate his learning alongside his peers, but he required additional time for this. Large equipment such as his standing frame was used within the classroom, but lack of space sometimes prevented his full participation in class activities. Practising his switching skills to use his laptop was an emerging skill for him, and this was quite slow and required a great deal of concentration to be accurate. Out of the classroom he was able to concentrate and use his head switch quite accurately, but this meant that he was missing out on other class activities. Withdrawal for special input therefore had to be balanced with his other lessons. The SENCo was responsible for organising when he was withdrawn from class and tried to take him out of lessons in which he could least participate: *'Handwriting's not a crucial time for him so we look at when they're doing handwriting and when he can do his Clicker work, so he's not really missing key things but actually timetabling in some other things'* (SENCo, interview).

Even when Zac was present in the classroom for lessons, the teachers did not always know how to involve Zac or left this entirely to the responsibility of the SSA. If the children went to sit on the carpet at the front of the class, Zac was usually left in his place. As his SSA explained: *'if it's all doing things on the floor, you're then stuck, just watching'* (SSA3, interview). When the children left the class for assembly, he did not join the line, but usually waited until they had left the room and followed on behind. This also occurred if the children left the room to go and look at something outside. Zac was expected to follow, but often did not have time to join in the activity: *'By the time you've got him out there, they're on their way back in again'* (SSA2, interview).

Allan (1999) described ‘gatekeepers’ facilitating inclusion and exclusion of children with SEN. The SSAs acted as important gatekeepers to Zac’s inclusion. They needed to be responsive to his needs and quickly act upon them, e.g. if they felt he had a question he could answer they needed to quickly put up their hand, or be alert to situations where he clearly wanted to participate and required assistance to do so. They knew Zac well and often read the signs that he wanted to participate, but also sometimes sat back and watched whilst others joined in.

Sometimes it was difficult for the SSAs to actively promote Zac’s inclusion in a group situation where the teacher was leading the class. During whole class activities, there was little allowance for Zac who was often slower than others at completing the same task. One supply teacher had been more aware of Zac’s needs and altered the pace of the lesson: *‘She [the supply teacher] checked to see each time that I was ready to go on, whereas when they do the spelling test on Friday morning, Mrs Carter [the class teacher] never does, she just whacks through the spellings and I go ‘oh, oh, oh’ and as the words get more and more letters, it gets harder and harder to fit in’* (SSA3, interview). Even when Zac was able to keep up with the pace of the class, sometimes other barriers were created to his participation such as activities requiring mobility.

It is a numeracy lesson and Zac is in a group of ten children with a specialist maths teacher. His SSA tells me that she feels this group is quite easy for him, but the pace is slower so he can keep up. She uses a number grid so that Zac can eye point to the answers. They work quickly through the sums using the grid in much the same way as the alphabet grid. He appears to keep up with the group and finishes at the same time as the rest of the children. The teacher has moved herself around the room and helped children as necessary, but does not speak to Zac or his SSA. The teacher then says that she would like to play a game and asks the children to stand in a line at the back of the class. She says she will ask them some sums and if they know the answer, they must jump out of the line and answer it. Zac is not moved from his place possibly as the room is quite cluttered with furniture, but is not involved in the game in any alternative way. Zac however, appears to enjoy the game watching as the children jump around. Once or twice, his SSA asks him if he knows the answer and uses the grid with him to find out his answer. (FN)

PE lessons were not considered to be lessons where Zac was able to actively participate and he therefore went to the unit to undertake his physiotherapy programme or computer practice. His mother was unsure whether he joined in with PE or not and it appeared to be the decision of the SENCo whether Zac participated. His class teacher did not consider PE to be an option for Zac: *'Zac doesn't come to our PE lessons or our games mornings. He goes to the [unit] for those lessons and I think they have their own PD games on a Friday afternoon'* (CT, interview). When he was younger and easier to physically manage, he had joined in with PE such as dance and his walker had been brought in from home. The SENCo felt that for his participation *'it would depend on the PE programme'*, but issues such as manual handling were now a barrier: *'Things like that [dance] are getting quite difficult now because we're not supposed to be doing two person lifts and it's hoisting. If they're only in the PE lessons for half an hour, again it comes down to practicalities really'* (SEnCo, interview). Rather than joining in with his powered chair, separate, specialist PE for the unit children was considered more appropriate. Sometimes a volunteer PE leader would lead the lesson:

The children from the unit all gather in the hall. A PE leader is there today, who is herself a wheelchair user and is here to teach curling. They are soon going to compete in a regional competition with other special schools. Zac is given a plastic shoot to rest on his lap and handed a large, flat disc. He is helped to push the disc down the shoot and along the polished floor towards some numbered targets. Zac is extremely excited about this activity and in trying to control his movements becomes very hot and sweaty. He has achieved quite a high number and is clearly pleased with himself. He is pushed over to the whiteboard where all the numbers are being put up on the board. As the other children have their turn, Zac is responsible for adding up the numbers using his number grid to help him. (FN)

There were occasions however, when Zac participated in his own way, to the best of his ability. Even though he could not play the recorder as other children could for instance, Zac enjoyed participating and being part of the recorder club.

Zac has stayed after school for recorder club. There are about thirty children of all ages in the room preparing their music for the lesson. Zac has a recorder which is held to his lips by his carer and he is keenly waiting for the lesson to begin. The teacher explains what they are to play today and organises the children into ability groups. As

the children play their instruments Zac thrusts his arms about excitedly as he tries to blow into the recorder. He appears to be looking at the music and achieves a sound from the recorder from time to time. The music is quite loud and no one notices Zac's notes. The lesson lasts for about half an hour and Zac appears to concentrate all the way through, listening to the teacher and playing his recorder. He appears to be thoroughly enjoying this lesson. (FN)

5.4 Theme 3: Independence

Independence is usually considered to be a concept defining self-sufficiency: the ability to be able to do things by oneself without the help of others (Oliver 1996). As Zac had very little control over his body movements, he required assistance in most activities of daily living, he needed his SSA to either write for him or facilitate him to communicate and relay his thinking and ideas. With this notion of independence, Zac was extremely limited as there was little he was able to do without the help of others. However, as Oliver (1996) argues, we are all dependent on others for some aspects of our lives and with assistance Zac certainly could do some things for himself, e.g. use the computer to do his own work and drive his powered chair in the playground.

Another way of constructing independence is the control Zac had over his own life and the choices he was able to make for himself (Swain *et al.* 2003). In many respects, school staff encouraged this construction of independence for Zac, as they knew him well and facilitated him to make choices for himself. In other respects this did not appear to be the case and the personal beliefs of staff influenced whether Zac's 'voice' was heard or even sought.

Respecting Zac's 'voice'

Adopting what might be seen as a disability rights perspective (Oliver 1996), Zac's mother was adamant that Zac was '*a child first*' with '*something to say just as much as you or I*' (mother, interview). She felt that as Zac had such little control over most things that happened in his life, he should be facilitated to have some choice whenever possible. For example, when deciding what type of control to put onto his wheelchair, Zac chose a joystick to use at home instead of easier push buttons. His mother related that although he had very little chance of learning to use the joystick accurately, it was his choice to try and therefore he should be allowed to do so: '*Zac decided he wanted a*

joy stick, so who are we to say no you can't unless we give him the opportunity...he instigated it you know, he wanted a joystick.' (mother, interview)

Some school staff were conscious of Zac's mother's views on listening and respecting Zac's voice, although they did not fully share her 'rights' perspective. In many respects they gave Zac these opportunities, particularly where other children would naturally have some control, such as in their work in class. The SSAs would frequently ask him how he would like to go about his work or how he would like it presented: *'I would sort of like say, "Do you think you can do it on your own? How would you do this bit?" You know, to see if he can do it.'* (SSA3, interview). They were conscious that they could easily do Zac's work for him and tried to make sure that it was as much his own work as possible. Zac was usually quite clear about his opinions and protested if he felt they did not do as he wanted:

I did a story with him once...I can't say how much of it was my input really, it's difficult to draw a line on something like that...I remember he wanted a crocodile or an alligator and I couldn't understand and he had a very, very clear idea and I went through all the animals I could think of and he'd say 'no, no, no' and I was thinking it was something that didn't exist and in the end it was either a crocodile or an alligator and he'd got this very clear idea and he wasn't going to let me put anything else in, however hard I was trying to!
(SSA3, interview)

As far as his physical comfort was concerned, staff knew that this affected his work and ability to concentrate and were therefore conscious about asking him whether he was comfortable or required re-positioning:

Zac is sitting in the corridor in his powered chair at a table ready to do some computer practice. The SENCo is sitting next to him as she is going to be assisting him in his session to practice using a programme called Clicker. She asks him if he is comfortable in his chair and he lifts his eyes upwards to indicate 'yes'. She then positions his arm rests on the table and asks him if they are in the right position or if he would like her to move them. He agrees that they are in the right position and she proceeds to velcro his arms into the arm rests. This action enables Zac to use his head movements without involuntary movements from his arms. She starts up the computer programme, which

Zac accesses by using a switch placed on the side of his head rest. By moving his head to the left and touching the switch, he is able to control the cursor on the computer. Today he is learning about making lists using commas and bullet points. During the session, the SENCo periodically asks Zac if he is comfortable or something needs adjusting. (FN)

Zac's mother was concerned however, that he was not always asked his opinion and decisions were often made on his behalf. When I visited the school, Zac did use the standing frame in the classroom, but his mother related that she had had a battle to make sure that this happened:

Children in the past have been standing in the [unit] and [the physio] said well perhaps we could ask Zac if he wants to stand in the classroom. And of course, the classroom is very limited for space so it was 'Oh well, all the other children have chosen to go in the [unit] you know'. Well, can we ask Zac and see what he thinks? And when he was asked he said he'd like to have the standing frame in the classroom. (mother, interview).

If Zac's voice was to be respected, he needed his opinions listened to and acted upon if possible. All children in Zac's year group were encouraged to attend parent evenings and Zac's mother made sure that he was always present so that he could be part of any decision making. His teacher had asked him at the last parent evening what he would like to see changed and he had replied that he would like to use his laptop in the classroom more. His mother was unhappy that this practice had not been instigated:

I was told in Year 3 that he's got a new classroom, it's got a computer socket and he'll have his computer there rather than go over to the unit. Oh, there were three different excuses I was given...you know it's things like that they say 'oh it takes so long', but if they actually planned it, right this is what we've got this week, let's put the information that he needs on [the computer] and get him up and running (mother, interview).

The computer appeared to be used primarily in the unit or out in the corridor rather than in the classroom. This may have been because Zac was not quite ready to do so as he required more practice to produce sufficient output or that it took too much time to set up. The SENCo considered that he had better concentration when there were no

distractions. Unfortunately these views did not appear to have been communicated and Zac's mother felt that he was not being allowed this choice.

Zac's OT and SALT were planning to build in more opportunities for Zac to communicate his choices, rather than rely on his SSA to ask him. They were considering a card system so that he could readily eye point to the card showing that he needed something e.g. go to the toilet or that he didn't understand. In this way they were endeavouring to promote his self advocacy to ensure more control over his own life at school.

Beliefs

Although Zac's views were often respected and taken account of, in some aspects of his school life, the beliefs of individual staff members influenced how they allowed choice or control. Where a more medical model of disability predominated, Zac was not allowed choice as these aspects of his management were viewed as being '*good for him*' (SSA1, interview). An example of this was the use of the standing frame, which although Zac expressed he disliked, was viewed as an important aspect of his management to '*stretch out his hamstrings*' (SSA1, FN), and not end up '*stuck in a sitting position*' (SSA1, interview). When his standing frame was sent home in the holidays, his SSAs felt he was given too much choice about using it and usually chose to use his walker:

'He took the stand home with him in the holidays and it spent it's time six weeks outside with a tarpaulin tied round it because he didn't want to go in his stand, he wanted to go in his walker and that's because he's just being lazy, he doesn't like it, it's uncomfortable' (SSA1, interview).

In school they did not give him a choice about going in his standing frame and they decided when it would be the best time to do this: '*From my point of view I always say 'We are going to stand'' (yeah) [all SSAs agree], because I know if he had an option he wouldn't*' (SSA1, interview). They did however, acknowledge that if Zac was having '*a really bad spasm day his legs are sort of flexed in the stander so it must be really uncomfortable*' (SSA3, interview) and would then take him out.

How school staff viewed Zac as a boy with a right to choices, impacted on their actions with him. Karla, (SSA3) for example was described as someone who ‘*treated him as Zac rather than as a disabled boy*’ (mother, interview) and was observed to offer Zac more choices which were then acted upon, compared to the other two SSAs. She knew that Zac did not like to miss out on class activities and therefore when he came out of lessons for his physiotherapy, she made sure that she had the class work with her to do during the session. When the other children were sitting down on the carpet near the teacher, she would ask Zac if he would like to move nearer the group rather than stay at his desk.

Fiona’s beliefs (SSA2) led her to manage Zac in different ways. Rather than eye pointing for communication, she felt that Zac wanted to speak and so spent time trying to listen to him. She viewed that he wanted to hold a pen and try to write, and so sometimes used opportunities to do this. When the class were asked to draw a poster for anti-bullying week for example, she tried to help Zac to draw by holding a pencil in his hand, but the effort of this made him extremely tense.

In contrast to this, Karla (SSA2) approached this task by taking Zac to use a computer to see if they could find some appropriate pictures from the internet.

Zac’s class are finishing off their anti-bullying poster today. Karla suggests to Zac that they could use the internet to find some pictures rather than drawing the poster. Zac agrees and they leave the class to go and find a spare computer. She positions Zac in front of the computer and finds some pictures that may find helpful. She asks Zac which ones he would like to use and then prints these off. When they get back into the classroom, the children are still working on their posters. Karla cuts out the pictures and asks Zac where he would like to position the pictures. She puts some glue on the pictures and helps Zac by holding his hand to place the pictures on his poster. They just finish the poster when the teacher asks the class to tidy up and hand in their posters.
(FN)

Use of peers

As Zac had constant support from his SSA, there appeared to be little need for his peers to assist him and other children were rarely asked by adults to help him, other than to open doors. On one occasion however, when the class worked in the ICT room, Zac’s

SSA made a conscious effort to leave him to work more collaboratively with other children:

Zac is in the ICT room in his standing support. The children are milling around getting themselves into small groups. A girl immediately comes up to him and says 'Hello, we're working together again'. She asks Zac whether another girl can join them today, to which Zac agrees. The SSA stands nearby, but allows them to make their own decisions about who to work with. The three of them then move over to a computer, the two girls sit down and Zac is positioned by his SSA between them in his standing support. He appears interested and enthusiastic about the task set for them. Zac's SSA leaves to watch others in the class.

The girls initially involve Zac by asking his opinions and where to click the mouse on the screen. They naturally include him in their discussions and act on Zac's decisions. As they continue to work however, the girls became absorbed in their task and the pace quickens. The teacher is encouraging the class to hurry up and finish. The girls take it in turns to use the mouse and therefore take charge of the decisions, but as Zac is not able to use a mouse, he cannot take a turn. As the girls work without him, he looks around the classroom. (FN)

5.5 Theme 4: Knowledge and information sharing

By viewing Zac as a child managed by the special support team, knowledge and information regarding his needs was predominantly kept within this team. In doing so, Zac's physical needs were managed by experienced and knowledgeable staff, but it impacted on how other staff might be involved in Zac's development and learning. It impacted on how priorities and goals were set and influenced Zac's inclusion and experience in school.

Knowledge held within the 'team'

One of the strengths of having a team of staff from the unit to support Zac within school was that '*that team between them [had] got quite a good length and depth of experience*' (PT, interview) and as his mother commented positively, that she '*was staggered by how he's [physically] managed in school*' (mother, interview). The SSAs had had experience of supporting other children with physical impairments and

appeared confident in most aspects of managing Zac's physical needs. If they were uncertain about anything, they would readily ask one of the other SSAs, SENCo or therapists for their advice: *'If they thought there was a problem with anything, they [the SSAs] would say 'It doesn't look quite right' (PT, interview).* Although the SENCo had only been at the school for two years the therapists felt confident in her *'understanding and experience of what you're trying to convey'* (OT, interview). They felt that she understood Zac's needs extremely well and would support them in the training and advice they were giving to the SSAs.

Although the team were considered by others to be experienced, they agreed that they had not had any formal training, having *'learnt on the job'* and as Zac had quite complex needs, had *'made it up to start with as we went along'* (SSA1, SSA2, interview). Despite this, they appeared to be confident in their abilities and felt supported by being part of a team. With Zac's difficulties, they agreed that it was often trial and error before the most appropriate or successful strategies were developed for him. For example after their school manual handling training, they felt they had to adapt the advice to suit Zac's particular needs: *'When we've done manual handling, it's always for children that are just sitting, never for one like him. So you sort of think 'great' you know and that's why we adapt and change things around to suit us basically'* (SSA1, interview).

The therapists who visited the unit were considered to be an essential part of the 'special support' required to meet Zac's needs. Good working relationships have been identified as key factors in successful multi-agency practice (Atkinson *et al.* 2001) and this appeared to be the case at this school. The physiotherapist worked most closely with the SSAs, training them in the use of equipment and collaboratively problem solving situations as the need arose. She felt that she did not need to monitor them closely as they were competent in most areas of his management and would always approach her if they had any problems: *'I think the three that work with Zac are generally pretty straight forward in coming and saying 'I don't know how to do this' (PT, interview).* If a piece of equipment was new as his standing frame had been at the beginning of this year, she would go through the appropriate training, but otherwise only went through exercises with them or checked how they used equipment once a year. Although the physiotherapist only regularly saw one of the SSAs, they were all viewed to have

sufficient experience such that they could pass on information to each other, particularly if it was not something new to them:

‘If it was something straightforward and they [SSA] say ‘that’s OK we can, we can do that, I know exactly what you mean’, or it’s something we’ve done before but we’re changing the programme round, she’ll relay that kind of information back to them. But if we want to try to do something in a different way that we’ve not done before I’d probably get the person who’s going to do it to come and work with me for the first time and we’d do it together and see how it was going to work’ (PT, interview).

Information sharing

Knowledge created within the special support team was not readily shared with other staff outside of this team as Zac was considered to be only their responsibility. The team viewed themselves and were viewed by other staff as the ‘experts’ in Zac’s management. In this way, they did not actively empower others to understand or be involved in his needs: *‘she [the class teacher] would leave that to me because the Clicker is quite a specialist area’ (SENCo, interview).* If for example, assistance was required to move Zac or transfer him into another piece of equipment, the SSA would ask for another SSA from the unit to help rather than one of the staff in the classroom. If the SSA had to go out of the classroom for any reason, no one else was expected to assist him. This meant that other staff did not develop any experience with Zac even on an assistance level and promoted the view of Zac as a ‘special child’ who required ‘specialist management’.

The class are having an art lesson and have been asked to draw a poster. Considering Zac’s lack of fine motor skills, his SSA is thinking about how he can best do this task. She decides to find some materials for him from the art cupboard and leaves the room. She does not tell the teacher where she is going or how long she will be. The teacher is moving around the room checking how the children are working, making suggestions or complimenting them on their posters. She does not approach Zac, but leaves him alone sitting at his table watching the others working. The SSA returns after 10 minutes with a bag of materials for Zac and sits down to discuss how he might like to make his poster. (FN)

Although Zac's therapists visited the school regularly, they worked directly with the unit staff, rather than with his teachers and relied instead on the SENCo to relate any information about Zac and *'pull everyone's advice together'* (SENCo, interview). The SENCo met with the class teacher once a term to discuss Zac's progress and pass on any new information. At other times of the term, she would give the teacher any new written information from the therapists, but agreed that this would probably not be read until their next meeting: *'As soon as the report comes in it will be put in her pigeon hole, but chances are it would not get looked at'* (SENCo, interview). Zac's teacher therefore appeared to rely solely on the SENCo to give her the information verbally that she felt she required. At Zac's annual review meeting, where all those involved with Zac met once a year, the SENCo commented that this was the one opportunity the class teacher had to *'hear everybody'* (SENCo, interview).

Most information sharing within the special support team was conducted in an informal fashion as and when the staff considered it necessary. It was agreed that verbal communication was the most useful means of exchanging information between them, particularly as the therapists visited regularly. The only written programme was from the physiotherapist. Generally if a therapist had been working with Zac and wanted to pass some information on, this would most likely be done verbally at an appropriate time e.g. where to position his switch or checking whether he would be more accurate using a chin switch. The SENCo and SSAs met each other most days for informal exchanges of information: *'It's learning from each other, it's all that informal chat, informal chat at 8 o'clock in the morning and again after school 'How do you do this?' and 'Shall we try this differently?''* (SENCo, interview).

Although information was readily shared amongst the special support team and between therapists, there appeared to be a reluctance to share information regularly with Zac's parents. His mother felt that she often received a *'negative response'* if she asked questions. It may be that as critics of professionalism (e.g. French and Swain 2001) argue, professionals are often the ones to decide on the needs of a disabled person and how these might be met, rather than the disabled person themselves. His mother felt that the staff's response to her asking questions was: *'What are you asking questions for? We've got everything under control'* (mother, interview). The SSAs agreed that the communication book between themselves and Zac's parents was rarely used,

possibly as they were concerned that any information might be used as criticism against them (FN).

Setting goals

Although all agreed that verbal communication was a valuable means of sharing information, with numerous sources of advice there was the possibility that not all information was shared. As the OT pointed out, this impacted on any collaborative approach towards balancing priorities and agreeing goals for Zac (FN). The physiotherapist agreed that there were many areas where input could be targeted for Zac and that priorities needed to be set. With the special support team being viewed as responsible for Zac's learning and development in school, it appeared that the SENCo primarily made these decisions, based on her knowledge and the information shared with her.

The IEP process did not appear to be a useful tool for joint goal setting. The school had a policy of only writing three targets, which for Zac included use of the Clicker computer programme, use of maths visual aids to help his numeracy and encouraging communication by speech and use of the Advocate. The IEP process appeared to be a meeting once a term conducted by the class teacher and the SENCo. This was considered by the SENCo to be a valuable meeting to discuss Zac's progress and to share information with the class teacher, but that the target setting part was not that useful: *'I actually think the piece of paper at the end of the day we take away is irrelevant, it's actually that meeting that is crucial'* (SENCo, interview).

The SSAs seemed unaware of these targets. They commented that it was *'great on paper'* (SSA1, interview), but not referred to: *'Confused me looking at it. You think 'Oh my goodness I should have been working on this all term! What have I been doing?''* (SSA3, interview). It appeared also that neither Zac nor his parents were involved in setting these targets.

5.6 Conclusion

In this case, Zac was constructed as a child with complex difficulties requiring 'specialist' support from the PD unit team. This meant that whilst Zac was in a mainstream class, he was viewed as a child who had quite separate and different needs

from others. Although in many ways his SSAs tried to facilitate his participation within the class, there were many barriers to this. With little knowledge sharing outside of the special support team, other staff were not confident to manage his needs within the curriculum or facilitate his active participation. Therapy staff worked collaboratively with the team in the unit, but there was little contact with staff within the classroom or other areas of the school. How Zac's own views were considered depended on factors such as personal views on disability. I now continue with the second case in this study.

Chapter 6: Case study 2

I arrive in October, five weeks into the start of a new school year. I am here to observe Sam, an eight-year-old boy who has just started in Year 3 with a new class teacher and TA. The school secretary takes me to the classroom and I am introduced to them. The teacher tells me that she has been expecting me, but had not been given a date for my arrival. Although surprised to see me here today, she appears quite comfortable. She tells me to feel free to sit anywhere as the children are used to visitors and will be happy to talk to me. I choose to sit at one of the children's tables near the back of the class where I am not too conspicuous, but within earshot of Sam's table. Shortly, the teacher starts class registration and when she has finished, turns to introduce me to the class. She tells the children that I am a visitor, here for the week to observe how well everyone in Oyster class works. (FN)

My first impression of St. Agnes' school was that of openness and friendliness. The school advertised itself as a friendly, welcoming and inclusive school and this was certainly evident in the way I was welcomed into the school by all staff and children I met. There appeared to be much respect for pupils' views and opinions, partnerships with parents and outside agencies. In the hall, surveys were displayed on how to improve the school grounds or make lessons more enjoyable. Posters advertised the parent support group who organised regular social and fund-raising activities and parents were observed helping with reading and after school clubs. Both the therapists I talked to found the school staff friendly, approachable, 'easy to work with' and 'good at including as much as they can' (PT, interview).

The school prospectus advertised that it 'welcomes differences' and viewed all children with SEN as a shared responsibility, aiming to provide equal opportunities for all. I arrived at the start of 'Caring' week where I witnessed assemblies with children discussing how they had cared for others. Posters in the hall and corridors displayed children's work with examples of how they had helped and worked with others. Within Oyster class I observed much celebration of children's achievement at all levels. For example, every Friday one child was celebrated by the teacher and became 'Child of the Week'. The teacher asked the other children to tell her why they thought the child was

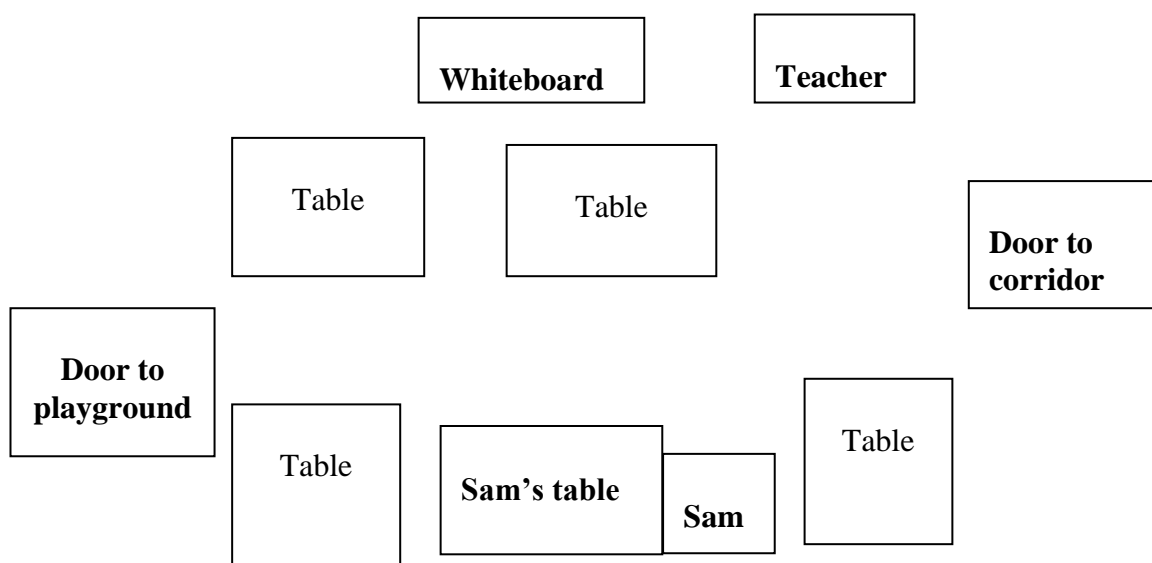
‘special’ and their comments alongside the child’s picture were displayed outside the classroom door for all to see.

6.1 The context

St. Agnes’ school was a large primary school for over 400 children aged four to eleven years on the outskirts of a seaside town in the south of England. Being built in the late 1990s, it was a relatively modern school with single access throughout facilitating physical access to all areas for wheelchair users. There were separate playgrounds for the lower and upper school and a large shared grassed area. The upper school playground had several outdoor games tables, climbing apparatus and a shed containing outdoor games such as hoops and balls. All the classrooms had direct access onto the playground where parents gathered to drop off and collect their children.

Oyster class was one of two Year 3 classes with 30 children, taught by Miss Cartwright, their class teacher and supported by two TAs. One of the TAs worked in the mornings with groups of children within the classroom. The other, Mrs Pope, supported Sam the child in this case, for most of the 30 hours per week allocated to him through his Statement of SEN. The children were organised into group tables and Sam sat at a table near the front, where he had easy access to the corridor and the playground (see Figure 6.1).

Figure 6.1: Diagram of Oyster class



Sam

Sam was the only child in Oyster class with a physical impairment although there were three other children within the school, one of whom was also a wheelchair user. Sam had been at the school since he started in reception. He was described as a '*happy*' boy, '*easy going, open, with a good sense of humour*' and academically '*an able boy, particularly in maths*' (CT, interview). When children were around him he was chatty and sociable, but his restricted mobility within the classroom meant that he could not move to talk to children far away and was therefore dependent on children approaching him.

Sam told me that his best friend was Charlotte and he was observed spending most playtimes with her and other girls. She often chose to be his partner, readily helped him when she noticed he needed help and sat with him at lunchtimes. All staff described Sam positively as a '*lovely member of the class*' (CT, interview) who participated in everything he could. He told me that he enjoyed school and particularly liked his maths lessons and playtimes.

Sam had a diagnosis of cerebral palsy, diplegia (GMFCS, level IV). As his sitting balance was limited, he spent most of his time when in the classroom in his supportive

chair, which enabled him to sit safely and independently at a table with other children. This chair did not have wheels however, so if he needed to move to another table, he was pushed in it by his TA.

Sam could not stand without support and often used a standing frame in the classroom. In this frame he was supported from the waist downwards so that he could stand independently yet move the upper part of his body. It had a tray so that he could work whilst in this position. Sam needed assistance with transfers into all of his equipment. Once placed in his walker however, he was able to walk independently both indoors and outdoors. He had a self-propelled wheelchair, but was usually pushed in this by staff or other pupils. In his powered wheelchair however, he could drive himself without assistance around all areas of the school.

Sam lived with his sister and both parents about a five-minute drive away from the school. His twin sister also had cerebral palsy, but was more physically mobile and able to walk without the use of aids. His physiotherapist reported that *'it was really important [for their parents] that they [the children] actually went to the local school'* (PT, interview). Sam's father agreed that they had not particularly looked at other 'special' schools as they wanted them to attend their local school. Sam's father described himself as *'the main carer'* (father, interview) and he attended school meetings, liaised with the therapists and was responsible for the children's physiotherapy at home. He brought them to school and collected them each day.

I now discuss the four main themes emerging from the data:

- Constructing Sam's 'needs';
- Compromise;
- Independence;
- Knowledge creation and knowledge exchange.

6.2 Theme 1: Constructing Sam's 'needs'

Proponents of the social model of disability (Barnes 1996; Oliver 1996) argue that the concept of needs is socially constructed in that 'what comes to be identified as a need depends greatly on social organisation, power and ideology' (Marks 1999). Assessing for a child's 'special need' within the constructs of the school organisation and the ideologies held by those within it, cannot therefore be viewed as an objective, value-free process. Sam's 'special needs' were constructed firstly at an organisational level through his Statement of SEN, but importantly at a operational level by those who were involved with him on a day-to-day basis. Personal values and beliefs on difference and inclusion influenced the management of his 'needs' and Sam's experience within the school.

Special educational need

The process of labelling a child as having a 'special educational need' could be argued as primarily an essentialist view of disability, where once the problems have been identified, appropriate medical or educational provision can be made (Marks 1999). Physical impairments were identified by all those interviewed as Sam's main 'needs', with other 'needs' such as independence, self-esteem and social development viewed as a consequence of this: *'Without his physical disability I don't think he'd be on an IEP'* (CT, interview).

This essentialist view of disability was reinforced by Sam's Statement of SEN specifying the need to follow a physiotherapy programme within school. His parents felt it was *'so important'* for Sam to have physiotherapy within school time even though they reported that he *'had physio sort of three or four times a week'* at home (father, interview). They did not follow exactly the same programme that was carried out at school, but viewed physiotherapy as part of natural play: *'Sometimes he's not even noticing he's doing it you know being involved within the rough and tumble. And you can be holding his foot in a certain position and stretching, making it almost fun without him realising'* (father, interview). They were vigilant in ensuring that Sam's programme was carried out at school and would readily talk to school staff if they felt this had not been carried out: *'They've had a few staffing problems and he's not been getting his physio so that's something I want to chase up'* (father, interview). It seemed

that his parents viewed physiotherapy at home as a separate issue and rarely involved therapists in this: *'I don't have a lot of involvement at home and that's more really through parents' choice than from me'* (PT, interview).

It appeared that some aspects of his physical 'needs' were negotiated to either be carried out at school or at home presenting a more collaborative approach to meeting his needs. For example, when he was younger he had used a floor seat to stretch out his legs whilst sitting on the floor with the other children. Due to increased manual handling risks now that he was heavier as well as more table-based activity, it had been decided that this aspect of his programme would be done at home: *'we used to have it [floor seat] in school, but they [school staff] found it increasingly difficult to have him on the floor, when all the other kids are up here'* (father, interview). His standing frame was kept at school during term time and went home only in the holidays. Sam had a specialist trike which he used to *'cycle up and down the road outside the house'* (Sam, FN) but this did not come into school. School staff had not considered its use within this environment perhaps as Sam was mobile in his walker in the playground and did not require an alternative form of mobility.

Difference

How Sam's 'difference' was viewed influenced whether his needs were thought of as his individual 'special educational need' or as part of the diversity of needs within the class. In some respects his needs were viewed as too 'different' to be integrated into the curriculum and were therefore managed separately. As school staff had little experience of children with physical impairments, they felt most confident to follow a fairly prescriptive programme designed by the physiotherapist: *'We are very much led by what the experts say with physical needs. If they say you have to do this, this and this, well that's what we'll do'* (SENCo, interview). Sam had a programme of exercises to be undertaken three times a week with the support of his TA:

Sam is walking in his walking frame down the corridor to the medical room. We enter the room where there is a hoist, a desk and a plinth. The TA takes Sam's splints and shoes off and Sam gets down onto his knees on the carpet. The first activity is a game where Sam has to throw beanbags into a box whilst balancing on his knees. This is followed by a crawling game, some tummy exercises and an activity where Sam lies on

his back and lifts his bottom up, counting to five. The TA suddenly realises that it is already 9.30am and tells him this is all they have time for today. She puts his splints and shoes back on and we hurry back to the classroom as quickly as possible. (FN)

Using his standing frame was similarly viewed as a need 'prescribed' to be used twice a day, but rather than being withdrawn from the classroom, this was undertaken alongside other activities. The physiotherapist had taught Sam's TA how to position Sam correctly in this and advised the school how often he should stand: *'The teacher will look at all the things he's got on his programme and work out how to fit it in, but they often want advice from me, obviously about how many times do they need to fit this in'* (PT, interview).

Sam's father was clear about the purpose of this equipment that it was *'great for his bone growth ...the more pressure you're putting on his bones the denser they get so he's got more chance of you know keeping himself straighter. And he says he can control himself better because he's more secure: his feet are secure, his hips are secure, he can then do cutting with scissors so much better than if he's sort of slumped in a chair'* (father, interview). Sam's TA and teacher were also aware that Sam might have more control over his fine motor skills when in his standing frame, but although this may have been discussed at a meeting, it was not written down on any therapy programme or advice regarding Sam. It appeared that despite this awareness, Sam's standing frame was not thought of as a means of improving his academic performance, but primarily as a therapy tool. They did not consider how it might be integrated into other school activities or how it might potentially exclude Sam from other aspects of learning:

Miss Cartwright is talking to the children who are sitting on the carpet in front of her. Sam is sitting in his chair at his table a few metres behind the other children. Miss Cartwright is telling them about their next activity which is to be a story book they will be compiling over the next few days. Whilst she is speaking, Mrs Pope, Sam's TA, goes out of the classroom and fetches Sam's standing frame. She transfers him into it whilst the other children go back to their group tables and start their work. A few minutes later Sam is ready to start his work. Mrs Pope takes his writing book to him and then leaves him whilst she joins another group. All the other children are sitting in groups at their tables whilst Sam is standing in his frame in a space in the middle of the

classroom. The children talk quietly to each other and discuss their stories, whilst Sam silently gets on with his work. (FN)

In contrast to this construction of ‘need’ for specialist input for his physical impairments, Sam’s fine motor difficulties were viewed instead as part of the continuum of difference seen within the class. Although he had an OT programme to develop his fine motor skills, the teacher considered that these strategies could be managed within the class: *‘We haven’t been currently carrying that out [OT programme]. But that will be the handwriting group that we’re doing which will start off as fine motor skills...but that would be done within a group rather than him just being singled out one to one’* (CT, interview). It appeared that when difficulties were perceived to be within the boundaries of normal development, the teacher did not view this as a ‘special need’ but as a need shared with other children and dealt with by differentiation of the curriculum.

There may be presumptions when conceiving a child’s difficulties as purely a variation of the norm that with practice and maturation, the skill will develop. Speed of writing was identified as a difficulty by all those involved with Sam. Children with neurological problems have been found to devote more time and energy to writing legibly (Berninger and Rutberg 1992) and as his teacher acknowledged: *‘he’s probably more capable than he’s able to show through his writing, because that probably holds him up and the speed at which he records things’* (CT, interview). Sam had a laptop to use at school, but this had not been used so far that year. His teacher felt that as he was *‘keeping up’* (CT, FN) by writing, and had not yet considered using the laptop in class. She seemed unclear as to how to manage the development of his handwriting alongside the need to develop his keyboard skills. She had not considered the benefit of developing his keyboard skills beyond that of other children in his class or the use of this to replace some of his handwriting work. Her concern for how this might make him ‘different’ from the other children was prevalent and she felt that if he were to need a laptop, she would *‘make sure that it wasn’t just him on the computer’* (CT, interview). The OT had organised for Sam to have a course of one-to-one tuition to develop his keyboard skills and was clear that in the future this would be his main means of output. His father agreed that *‘he’s never going to be able to write at a certain speed’* (father, interview). It seemed however, that all felt that as long as Sam was ‘keeping up’ then he should continue handwriting. He appeared to work well independently in his writing

group for much of the time, but the vignette below illustrates that this was not always the case:

Sam is in a small group of six children sitting around a table. They have been placed in ability groups, all doing different writing activities. Sam's group have been asked to read a book and write out important facts from it. Some of the children get on quickly with the task working in pairs. Sam seems completely lost at this point as the girl sitting next to him has chosen to work by herself. He tells me he needs a teacher to help as he can't write quickly enough. His TA hears him and comes over to see what is happening. She asks the girl sitting next to him to write for him and goes back to the table she is supervising. The girl does not take any notice and carries on working by herself. Sam is left doing little work in this session. (FN)

It may be that as other children in the class were still developing writing skills, Sam's skills could be developed in similar ways. There was little recognition however, that Sam's difficulties in writing as a child with cerebral palsy might be different from another child requiring extra support.

Need for/right to inclusion

Inclusion in school is viewed by disability activists not only as a 'need' but as a 'right' (Oliver 1996). The opportunity for active participation and for Sam to have a sense of belonging was considered to be of paramount importance by his teacher and TA. Sam was viewed as an important member of the class and expected to be part of all activities, doing 'what he can do, what he's physically able to do' (CT, interview).

It was naturally considered that Sam would participate in any activity the class was doing, that he would join in as best he could e.g. for PE, and for the most part be doing 'the same' as other children in the class. In whole class teaching situations, the teacher often noticed if his chair was facing the wrong way to the rest of the class and hurried to turn it round so that Sam would feel more part of the class. She made sure that Sam used his equipment such as his walker to do activities requiring him to stand up for periods of time e.g. dance. If it was not possible for him to do a certain physical activity, she gave him an alternative to ensure that he could actively participate and achieve the goal of the lesson:

The teacher sits at the front of the class facing the children who sit on the floor in front of her. Sam is sitting at the back of the group in his classroom chair. It is a maths lesson and the teacher is explaining a game where when they know the answer to the sum, they have to stand up. She realises that Sam is not able to do this and tells him that when he knows the answer he should raise both his arms instead. He happily joins in the game with the other children raising his arms when he knows the answer. (FN)

Whilst some physical barriers to Sam's participation were readily taken account of and strategies used to overcome them, others often went unnoticed. Particular classroom practices such as sitting on the floor at the front of the class to listen to the teacher were a potential barrier to participation for a child unable to do so. His teacher tried her best to ensure that he felt part of the group by asking him questions if she felt he was not joining in. Due to his immobility however, whilst other children could come to the front of the group to present topics or answer questions, Sam could never do so and his teacher did not appear to offer him any alternative to this. When the children were asked to choose a partner, they could move around the class and make their choice, whilst Sam generally had to go with whoever was left unless his main friend decided to choose him that day. They appeared to rely on his main girl friend choosing him as her partner and if not, another child was then persuaded to join him.

In some areas of the curriculum despite his physical impairments, his 'need' for, or right to inclusion in the form of participation predominated over any need for physical development. Sam was always included in PE classes even when he could only partially participate in the activities. In contrast to Zac, Sam's teacher felt that he should always be involved and '*join in as much as possible*' (CT, interview). The physiotherapist had not been involved this year as she had done in the past, in advising on participation in PE, and this was not a consideration of Sam's current teacher who had received advice from a PE inclusion advisor instead. The emphasis in the PE lesson was therefore entirely on inclusion in terms of participation, rather than physical development. Any advice given to the TA by the physiotherapist on developing Sam's motor skills was not passed on to use in this setting and the teacher did not '*know the ins and outs of his exercises*' (CT, interview). His TA and physiotherapist held different views from his teacher in that although they were keen for Sam to participate as much as he could, they felt that sometimes due to his physical limitations, one might '*exclude*

him more by trying to include' (TA, interview). His physiotherapist agreed that 'it depended on what PE activities they're doing. There have been times when we've agreed [in previous years] OK that it really is difficult for him to join in with that, therefore maybe it would be more productive for him to do some one-to-one' (PT, interview). It seems that without a greater understanding of a child's physical abilities and the ways in which these may be maintained or promoted, it is difficult to integrate the development of these skills into the curriculum.

6.3 Theme 2: Compromise

Alongside this rights vision of inclusion that Sam would participate in everything possible, there co-existed a more medical model of disability emphasising the necessity to meet Sam's 'special needs' within school. All those involved with him were also influenced by their personal beliefs of what they viewed as priorities for Sam. How Sam's needs were met was therefore influenced by this conflict of priorities leading to tensions and often a level of compromise was necessary.

'Fitting it in'

Sam's physiotherapist understood that there were many competing priorities to meeting Sam's physical needs. She therefore made decisions on the content and frequency of Sam's physical programme based on what she felt was achieved at home and how much she viewed could be practically managed by the school: *'We usually have kind of sat down together, you know myself and the staff and really worked it out, because just getting the balance of how many times ideally I'd like them to do it and how many times is realistic' (PT, interview). She would give them advice on how often she considered it best to undertake certain activities and then leave it up to the school staff to decide on how to fit these into the timetable: 'I've given them advice on you know, how often he should use things, what kind of activities he could do while he's in a piece of equipment, what things he maybe needs to practise more, and then they'll take that information and actually build it into his day...I've actually always encouraged them to stay quite in control of how they arrange things'. This guidance enabled the staff to follow a fairly prescriptive programme to plan into Sam's school week, but which could be altered depending on other priorities in the class.*

Timetabling activities into the structure of the school day was the strategy used to try to ensure that Sam's physical activities were carried out. It was planned for Sam to undertake his physiotherapy programme first thing in the morning, go out to play using his walker, to use his powered chair every week to go down to the ICT suite and into the hall for assembly. If timetabling went according to plan, then his physical needs appeared to be fit in smoothly into the class activities:

Sam is assisted to transfer into his powered chair ready for assembly. His teacher asks him to lead the way and he does so independently. His TA does not follow, but waits until all the children have left the room. He is able to push the doors in the corridor open by himself or is helped by one of the children and leads his class into the hall. All the children including Sam line up in their year group ready for assembly. (FN)

Planning for Sam's needs however, required regular liaison between the teacher and TA. In the mornings, for example they might have a conversation about when would be the best time in the day for Sam to go into his standing frame: 'Chloe [TA] and I at the beginning of the day or throughout the day will say: 'Well thinking about this morning in maths today, it'll be really good if he was in his standing frame' (CT, interview). They had decided that it was not practical to have a set time for this to happen during the day as the class activities were different from day to day. The intention was to plan this together on a daily basis, but with a busy curriculum his TA acknowledged that 'it doesn't always happen' (TA, interview). During my observation week, Sam used his standing frame only three times when it was planned to be used once or twice a day.

Timetabling also meant that Sam would miss out on as little as possible. His teacher decided to timetable his physiotherapy programme in 'morning activities' time, which was used for catching up so that he would miss the least amount of 'proper' lesson time: 'Compared to the other activities in the lessons they have throughout the day, I think that's the best time for Sam to be out of class...he does miss out on that warm up at the beginning of the day and talking to people in his group and things...so it is a bit of a balancing act...so that he doesn't miss out on the proper lessons' (CT, interview). Compared to this focus on inclusion, Sam's TA was more concerned that his exercises were done at a time when he would be least tired. Sam himself liked doing physiotherapy in the morning as it 'made him feel better for the day' (Sam, FN) and agreed he didn't miss out on much.

Inevitably Sam would sometimes miss out on activities due to the time taken to undertake certain aspects of his physical management. His TA tried to think ahead whenever possible to ensure Sam was ready to join in with activities at the same time as other children and therefore not miss out: *'I try and make sure I've got him ready when the other kids go out so that he's not behind and waiting and missing part of his play'* (TA, interview). As she knew the timetable, she would organise his equipment so that he could quickly be transferred into it and be ready for the next activity:

The next lesson is library time. The library is at the other end of the school and Sam usually goes there in his powered chair. Whilst the children are finishing off their work, his TA goes out of the classroom and prepares the powered chair for use. She brings in Sam's walker and when the class have finished their work, she helps Sam to transfer into his walker. He then walks out of the classroom to his powered chair and transfers into this. By the time he is ready to move forward, the other children are just coming out of the classroom and walk in a line down the corridor. Sam joins them in his chair to make their way to the library. (FN)

As it did take time to transfer Sam into his equipment, staff sometimes chose not to do so if they felt he would miss out on activities. They acknowledged for example, that Sam should have as many opportunities as possible to use his powered chair to practice manoeuvring it, but as it was stored outside the classroom and it took time to transfer him into it, they rarely used it: *'I mean it's only had limited use in school'* (CT, interview). It seemed quicker to transfer him into his manual chair which could be more easily wheeled into the classroom and push him in this to another part of the school.

It was not always possible though to avoid missing out on activities as inevitably situations arose where Sam had to be out of the class: to go to the toilet, change his clothes or undertake his physiotherapy exercises. By the time Sam was ready to join his class, sometimes he had missed important parts of the lesson.

Oyster class have PE this afternoon and the children are changing into their PE kit in the classroom. The teacher tells them to hurry up as they need to get out into the playground as soon as possible. Sam's TA transfers him into his manual chair and pushes him out of the classroom towards the disabled toilet at the other end of the corridor. He appears back in the room ten minutes later dressed and ready for PE. He

has had to use the toilet and get changed. Everyone else is already out on the playground and practising ball skills. Sam has one or two goes before the teacher blows her whistle and asks the children to stop playing. Sam has missed the warm up and ball skill part of the lesson where he is most able to participate. They then practice shooting goals into a net which is difficult for Sam to do from his chair. (FN)

Staffing issues

Staffing issues impacted on the ability of the school to undertake Sam's physical programme. Mrs Pope was the only TA this year trained by the physiotherapist and she was regarded as the 'expert' in this aspect of his management at school. Rather than the teacher, she was the person who liaised directly with the physiotherapist: *'I know she's sort of expert in that field and the physio tends to talk to her about the exercises rather than with me...I've sort of left her in charge of that'* (CT, interview). This meant therefore, that if Mrs Pope was off sick, some aspects of Sam's management were unknown to the class staff. When her absence was planned, Sam's TA from his previous year covered the support role, but for unplanned absence, other TA's or lunchtime supervisors, who had not been trained in managing Sam's physical needs were used for cover. This meant that during these periods, Sam was unable to use his standing frame or undertake his exercises as there was no one to assist him. As Sam's father pointed out, *'You can't help staff shortages but I would have pulled out one of the TAs in Key Stage 1 that have had Sam before...he's got three or four people in Year 1 who've worked with him that maybe wouldn't hurt swapping for two hours'* (father, interview).

Another concern raised by Sam's father was the school practice of a yearly change in staff. The school had tried to maintain some continuity for Sam in Key Stage 1 by allowing his previous TA to stay with him for two years. Now that Sam had just moved into Key Stage 2, he had both a new class teacher and TA. His father was concerned about this change for him as he felt that every year for the first term, there was a learning period before staff became proficient in his management: *'It's just getting to know the staff again, you find the first few weeks, months just a bit of a learning curve for everybody'* (father, interview).

Although the teacher worked at times with the whole class without a TA, there were times when the lack of support impacted on Sam's ability to fully participate. This was especially the case when Sam required adequate fine motor skills to participate in an activity. Without sufficient support either from his peers or from an adult he would be left unable to participate or would be given an alternative activity even though he could do the same as other children if support was available.

The class are having a maths lesson and the teacher asks the children to divide into pairs to do a task. Mrs Pope has had to have a day off today and there is no cover for this lesson. Sam and his partner are given a peg board with several thin elastic bands. The teacher explains how the children can demonstrate shapes by using the elastic bands and asks them to try to use the bands to make all the shapes on a worksheet she has given them. Sam knows what he'd like to make and asks his partner to help him to use the peg board and elastic bands. He finds it difficult to stretch the bands and they fly off across the room. His partner becomes frustrated with him and takes the board out of his hands. Sam does not object but tries to join in with his partner trying to make the shape. His partner ignores Sam and works by himself making the shapes. Sam sits and watches what he is doing.'(FN)

In a lesson such as the above, Sam required support either towards achieving the maths task or towards practising his fine motor skills. This example illustrates how he had little time or opportunity to practice fine motor skills as he was encouraged to work independently wherever possible and needed to keep up with the pace of the class.

Classroom practice

It has been proposed that schools often need to change elements of pedagogy or teaching practice to enable inclusion to be realised (Mittler 2000; O'Brien 2002). 'Carpet time', was an integral part of many lessons throughout the school day in Oyster class. The teacher asked the children to sit in front of her on the floor for registration twice a day, at the beginning of most lessons where she wanted to talk to the class as a whole, and for other lessons where there was whole class teaching. As it was difficult for Sam to get on and off the floor, he usually sat in his special chair at his table away from the main group. His teacher was aware that he was a distance away and frequently asked him if he could hear or had understood something. He was however, never

moved nearer the group, possibly due to the chair not being on wheels, although he was regularly pushed by his TA when the children changed group tables. His chair had never had wheels and this was being looked into being ordered by the SENCo. It may be that moving tables was viewed as a necessity, but that moving him nearer the group for five minutes of carpet time, was not viewed as such. He rarely used his wheelchair within the classroom, but on the two occasions observed when he did do so, he was encouraged to sit more within the group rather than at his usual place at the back.

Children worked in different groups depending on the lesson. This practice meant that there was significant movement around the classroom throughout the day, with an emphasis on hurrying to move tables and start work as soon as possible. Sam was always pushed in his classroom chair to a different table by staff, rather than using his walker to move by himself. This may have been due to the concern about space or the time it would take to do so. By moving tables frequently, staff had to remember any equipment he needed such as his slanted table top to facilitate writing. Other children carried their own pencil cases to the next table and could walk over to their personal drawers for anything else they might need. This practice meant that if Sam needed anything from his drawer, he would usually wait until he had the attention of his TA, rather than ask another child. Moving groups may have made it more difficult for him to develop relationships where he felt able to ask his peers for assistance.

The pace of the class was also an important factor influencing Sam's participation: children were often given strict time limits for an activity and reminded when time was running out. For a child whose movements were slower than other children's, Sam was at a disadvantage when speed of working was an issue, particularly if there was not enough support available:

The teacher tells the class that they are to finish off the story books they have been working on all week. The children have been writing and drawing sequences of a story on separate pieces of paper and it is now time to stick these into their books. She says that they are not to stick them in unless they have completed their entire story, and then to ask an adult to stick them in as they are going out on display for parent's evening. She tells them that they have 20 minutes and the children get on with the task. Sam sits at his table and quietly gets on with drawing animals to illustrate his story. His TA is not at school today and the class TA is in the classroom. She sits at a table and the

children come over to her when they are ready to stick their work into their books. The teacher reminds them when they have only ten minutes left to finish their work and then finally tells them that time has run out, to bring their books to her and to tidy up their tables. Sam is only just finishing his second drawing and there are still loose bits of paper in front of him. He is concerned that he has not stuck any parts of his story into his book. The TA comes over to him, tidies up his work and takes it to the class teacher. (FN)

6.4 Theme 3: Independence

Independence has been defined as a socially constructed concept based on an individualist model of autonomy in Western societies (Priestley 2003). It is usually thought of in the narrow sense of physical self-sufficiency, meaning the ability we have to do things for ourselves without the help of others. It has been argued however, that in reality no one is entirely independent of the need for assistance, but instead we live in a state of interdependence (Oliver 1996). All children in the class needed some help from an adult at times, and therefore the amount of help Sam required may be viewed as just different by degree. Another way of defining independence preferred by disability theorists is the way we are able to have control over our own lives whether or not we require assistance to do so (Swain *et al.* 2003). The concept of independence for Sam was constructed primarily in terms of self-sufficiency, and expressed in both Sam's Statement of SEN and current IEP: Sam should '*continue to develop self-esteem and independence skills*'; '*work independently with his peers in his class*' and '*move with increased independence around the school*'. Staff were aware that Sam's physical impairments impacted on his ability to control aspects of his school life e.g. who to sit next to at lunchtime, which activity to choose for Golden Time, and whenever possible provided opportunities for Sam to have the same choices as other children had and a degree of control over how his physical needs were managed.

Working without an adult

Working without an adult was an important construction of independence for Sam. It had been discussed at the planning meeting that he should develop more independence from his TA and that he did not need '*someone perched by his side when he's safe in the standing frame or in his chair and he's doing part of the curriculum...almost doing*

the work for you' (father, interview). All agreed that he just needed to be '*set up physically so that he's at his table or in the right equipment...and the adult is free to sort of move away to a different group*' (CT, interview). His TA was usually responsible for organising Sam so that he was able to work on his own without her help alongside the other children at his table. He was encouraged to work by himself for most of the time other children in the class were expected to do so and for much of this, he was happy to work alone and conscientiously got on with the tasks set.

Sam sits at a table with five other children. His teacher tells me that they are in ability groups for this writing activity. He has an angled worktop to place his work on, which has been given to him by the OT to improve his posture and handwriting. His TA checks that he is comfortable and has all he needs for the activity, e.g. pens and activity sheet, and then goes over to the other side of the room to work with another group in the class. Sam and the other children on his table work quietly by themselves to complete the writing task. (FN)

There were times however, when he appeared to be disadvantaged by this construction of 'independence'. As Swain *et al.* (2003) argue, we are all dependent on other people for at least some of our needs, whether physical, emotional or social. Due to Sam's limited mobility, unlike other children he was not able to fetch the book he needed if the TA had forgotten to take it out of his drawer, or walk over to the teacher to ask for help. There were instances where Sam sat waiting patiently for a significant period of time, before an adult noticed he needed help:

Sam is sitting with the usual group of children at his table. They are all doing an art activity making African masks. The children are cutting out shapes to stick onto their masks. The TA has left the room to do some photocopying. Sam cannot use ordinary scissors and waits for five minutes until his teacher notices that he is not working. She comes over to him to ask him what his problem is, and suddenly remembers that she had decided that he would draw his mask instead of cutting out shapes as this is difficult for him. She goes and collects his picture for him from his drawer. He picks up the colouring pencils and happily gets on with his work. (FN)

In conjunction with this view that Sam should be developing independence in his class work, his TA had particular concerns regarding her own role with him. She felt that she

had learned from past experience with another child, that *'if you're right beside them they don't learn for themselves'* and didn't want Sam to be *'stuck like glue'* to her (TA, interview). She had not chosen to be Sam's TA, but had been asked by the headteacher to fulfil this role due to her previous experience with another child with a physical impairment. She was not paid any more to perform these *'caring'* aspects of her role and would have preferred to remain a general classroom TA (TA, interview). She agreed that as there was no job description for this role, she was trying to develop it as that of facilitator rather than close supporter of Sam, so that she could be free for most of the time to work with the other children: *'I don't want to be seen as Sam's TA, because I don't think that's just what my job is. Sure I'll do that as part of my job, but I'm not there for Sam and Sam alone. That's the way I see it.'* (TA, interview). Her views on Sam's need for developing independence and of her role to be independent from him, affected how much dependence she allowed from Sam. She accepted that she should undertake the *'caring'* aspects of her role, e.g. taking him to the toilet, helping him to change for PE or transferring into different pieces of equipment, but otherwise would treat him as any other child.

Sam's TA understood that he required assistance with some aspects of his class work such as cutting and was usually ready to help him with these activities. At other times she waited for Sam to ask her for help when he needed it rather than relying on her to anticipate that he required it: *'getting Sam to ask for help when he's needed it rather than me doing it automatically, again him using his voice and telling me yes, I'd like some help please'* (TA, interview). As Sam had difficulties with voice projection and she was often on the other side of the classroom, it was difficult for him to easily gain her attention. There did not appear to be any other system for asking for help and he was not observed to raise his hand or ask another child to go for help for him.

Use of peers for support within the classroom can be viewed as part of the spectrum of the natural interdependence we all have on others (Oliver 1996). Children sat and worked in small groups and often asked each other if they did not understand or needed help from others in the group. For much of the time, the children appeared to view Sam as just another member of the class and Sam talked easily to them when at his table. There were times when they noticed that he needed something and would offer to fetch it from his drawer or from the other side of the room. Occasionally the teacher might

ask one of the children to do something for Sam. On one occasion, when another child needed help at his table he was observed to offer his help to them. It appeared that if there was no adult around he was more likely to ask a child for their help.

Everyone is writing their names up on a chart on the classroom wall to choose which activity they'd like to do for 'Golden Time'. Sam's TA is not in the classroom at the moment and his teacher asks his friend, Charlotte, to write his name against the activity he chooses. Charlotte is busy writing her own name and then rushes out to play before she has a chance to help Sam. Sam is standing by the chart in his walker, but can't reach down to write his name. Another boy is now crouched down on the floor and writing his name on the chart as it is quite low down. Sam asks him to write his name down in the column to do art and the boy does this for him. Sam then walks out to the playground for break. (FN)

It was rare however, for Sam to ask other children for their help, perhaps as he was used to adults undertaking this role. Although staff expressed that they aimed to encourage peer support, this was rarely observed. There was no buddy system within the class and the children appeared unused to noticing that he required help.

Sam's lack of mobility, together with lack of assertive communication and a lack of effective natural supports, at times made it difficult for him to work independently from an adult within group work. The other children could move around the table to choose their partner to work with or change partners if they had differences of opinion. Sam had to work with whoever chose to work with him or whoever was sitting next to him. Generally the children did not treat him any differently from anyone else and seemed happy to work with him. It was more difficult if the group work allowed the children to physically move around as this obviously placed Sam at a disadvantage.

Sam's TA pushes him in his classroom chair into a small room adjacent to the classroom. The other children from his table follow. The science lesson involves exploring prisms and shapes from a box which is placed in the middle of the table. Sam is positioned at the table by his TA who then leaves him with the others to get on with their task. The other children do not sit down but take the shapes out of the box and start to move them up against the window. Sam cannot reach the box. A girl near him takes a shape out of the box and holds it up to the light. Sam asks her for it and she

gives it to him. He holds it up to the light, moving it around. The girl goes to get another shape and starts a conversation with another child, forgetting Sam. Three boys in the group have decided to sit under the table to see how these shapes look in a darker environment. Soon all the children are discussing the shapes and moving them towards the light or under the table, whilst Sam sits in his chair holding his one shape. His TA comes into the room and says to the children: 'Think about others in the group. How can Sam learn best?' She then leaves the room and the children continue as before.
(FN)

Independent mobility

Another means of constructing independence for Sam was through mobility: the ability to move from one place to another on his own as he did in his walker or his powered chair. Before Sam started in her class, his teacher had thought about access issues and tried to make the room as accessible as possible for him: *'A big issue for me was sorting out a classroom so that he could manoeuvre around with as much access as possible'*. Despite this she felt *'it was tricky for him to get around in his Kaye walker, around to all areas of the classroom'* (CT, interview) and he therefore rarely walked within the classroom. His OT felt that she had given staff advice on lowering his peg so that he could hang his coat up and making sure that he had an accessible drawer, but Sam was not expected to do either of these things himself and was not observed to do so.

Sam was encouraged however, to use his powered chair to manoeuvre himself from one area of the school to another and when in this could move at the same speed as other children walked. It appeared however, that unless it was timetabled to be used, there was not enough time allocated to use it or its use was not considered. Conflicting opinions regarding his driving skills may have been a factor in deciding whether he was offered the use of this form of mobility. His father viewed that he was able to *'drive it perfectly well'* and to be *'very capable as he's had one indoors since he was two and a half'* (TA, interview). His TA on the other hand expressed that he was a *'terrible driver'* and needed more practice, although he was observed to manoeuvre the chair adequately in both large and small spaces.

Environmental barriers are considered by proponents of the social model of disability to be one of the main causes of disability (Oliver 1996). Certainly there were barriers to

the use of the powered chair within the classroom situation. Although the room was quite large, it was considered too crowded to be used in this environment. He did however, use it every week in the library where the space was considerably smaller. Another important factor preventing the use of the chair in the classroom was that it was too high to work at the class tables and he would have had to sit at a separate table to use this. Similarly, the same reason was given for its lack of use at lunchtime in the hall as *'it won't fit under the table'* (TA, interview).

The powered chair appeared to be thought of as solely a means of mobility to travel longer distances rather than as a mobility aid to facilitate other activities. His physiotherapist for instance, had suggested the use of this chair to enable Sam to participate more actively in PE: *'If all the children are up on their feet moving around, then actually he could join in...in his powered chair'* (PT, interview). His teacher however had only considered the use of the manual chair pushed by his TA when the other children were running around in outdoor PE lessons.

Choice and control

Having control over one's life is viewed as an important element of independence. Even though all children have to comply with the timetable or classroom practices, they do have choices over other aspects of their life in school such as choosing who to play with or sit next to at lunch times. Staff respected Sam's views and tried to give him some autonomy when opportunities arose e.g. whether he wanted to sit in his manual or classroom chair or use the powered chair for playtimes. In reality however, most of the time his timetable was mapped out for him and he stood in his standing frame when it was 'best' for him, or used his powered chair when it was planned for him to do so: *'I mean it is on his IEP to choose on certain occasions... because he doesn't always know exactly what we're going to be doing whereas obviously I plan the activities and I think that's a good time for him to be using that [the standing frame]'* (CT, interview).

Other factors impacted on allowing Sam the same choice as other children had. As he was reliant on adult assistance for some activities such as toileting, this was dictated by staff availability. Usually Sam was allowed along with the other children to leave the room to go to the toilet whenever necessary. However, as his TA was responsible for the daily lunch club, she had to leave the class at a certain time for an early lunch break.

This meant that Sam had to be taken at this time to the toilet before she went off to lunch, irrespective of whether he required it.

At other times of the day when all children were freer to make their own choices, Sam was also given these opportunities. His teacher reported that she felt he was *'becoming more independent about who he chooses to play with ...whereas at the beginning he needed a prompt to 'Who are you going to sit with today? Or who are you going to play with?'* (CT, interview). There appeared to be a difference in how proactive he was in making his own decisions dependent on how independently mobile he was. When in his walker, Sam actively moved towards children to ask them to play with him in the playground and had the required mobility to 'run around' and play with them. In his powered chair he would move swiftly into the hall and decide where to place himself within the line of children. This was in contrast to other situations where he was placed outdoors in his manual or classroom chair for outdoor lunch and had to be asked where he would like to sit, and appeared to be more passive and accepting of choices made for him. If the children moved away from him, he waited until an adult came to ask him what he would like to do.

School staff considered Sam to be a *'very amenable'* child who's *'not complained once about any of it [his physical management]'* (TA, interview). Although his TA described him as *'very outspoken... says what he thinks... a very mature young man'* (TA, interview), this self-confidence was not obvious. Sam's father felt that Sam found it difficult to *'have an opinion'*, particularly around people unfamiliar to him. He knew that Sam was not comfortable when different staff were responsible for his personal care as was demonstrated during my observation week, when he came in wet from the playground: *'he will not ask strangers to go to the toilet. Like yesterday I said to him 'Who took you to the toilet? I didn't go ... 'cos I didn't know the person'. I said: 'Did you need to go?' 'Yeah''* (father, interview).

6.5 Theme 4: Knowledge creation and knowledge exchange

'Sam was probably one of the first people for the whole school' (CT, interview) to be a wheelchair user and therefore managing his needs was a first time experience for most of the staff involved with him. Sam's teacher had previously worked as a TA in a senior school with children with physical disabilities, but viewed her role now as a

teacher to be very different: *'I have worked previously as a TA with children with physical disabilities...I think it's very different doing that and being sort of one-to-one, to being a class teacher with a class of thirty'* (CT, interview). Sam's TA had never supported a child with cerebral palsy before although had previously worked with another child who was a wheelchair user. This 'personal knowledge' based on previous experience was thus combined with 'new knowledge' that was being gained from learning to manage Sam's specific needs. Staff used this knowledge and shared it with others, influenced by their own beliefs of inclusion and disability.

Knowledge on a need-to-know basis

Learning only that which was considered necessary to manage this particular child was an important factor in how new knowledge was sought and then shared amongst staff. None of the staff involved with Sam had attended any courses or formal training relevant to meeting his physical needs and did not feel that this was particularly necessary. They relied instead, on visiting 'experts' such as the physiotherapist, OT and more recently a PE inclusion advisor to provide specific training and advice to manage Sam's needs in school. As well as the formal Annual Review meeting to discuss the provision in Sam's Statement of SEN, a planning meeting was also arranged at the end of the school year to discuss issues for staff in the following year. The relevant staff and Sam's father discussed practical issues in this meeting, although neither therapist had direct input into this: *'About June time I come in for about an hour and a half, a couple of hours and sit around a table with his existing teacher, and a carer and then who he's going to have for the following year, discuss issues, physio, seating arrangements, where he should sit, how he toilets, you know every aspect'* (father, interview). Sam's father was viewed as a crucial part of the knowledge creation process for the new staff as it was felt he naturally knew most about his son. This view of him as an 'expert' continued through the year as he was often the one asked to check equipment if the physiotherapist was not due to visit for a while. The physiotherapist was concerned that she was not always consulted on this when she had responsibilities for the equipment from a health and safety perspective: *'Dad will often go into school to alter bits of equipment, which I have to try and keep on top of and keep an eye on. I think as far as Dad's concerned it's his son, he's familiar with the equipment, why shouldn't he go and adjust it slightly. I often have to try and say to the staff 'You do*

need me to come in and check that that's been done properly and that's the right height' (PT, interview).

Sam's physical needs were viewed primarily within a medical model of disability, with responsibility for his exercise programme and therapeutic equipment delegated to his TA. The physiotherapist therefore spent most of her time with her and had not spent any time with his teacher this year as yet, although she felt that she had '*made herself available*' if his teacher wished to speak to her. Sam's teacher confirmed that she did not feel that she needed to speak directly to the physiotherapist when she visited as she was there primarily to discuss his physical programme: '*The physio tends to talk to her [TA] about the exercises rather than with me...I've sort of left her in charge of that*' (CT, interview). The following vignette illustrates how the physiotherapist was involved not only in Sam's exercise programme, but in other aspects of his physical management:

Helen, Sam's physiotherapist, sits in the corridor outside the classroom with Chloe, his TA. Helen is here to check that Chloe is happy with the therapy programme she gave her two weeks ago. Chloe asks for clarification on some of the exercises, but appears happy to do all that is asked of her. She says how pleased she is to have such clearly written instructions. After their short discussion, she fetches Sam from the classroom. Chloe brings out a small wedge which she thinks has been loaned to them by the OT, to put into his classroom chair. Helen does not appear to know anything about this, but puts it into his chair and asks Sam to try it out for comfort, checking his position in it. They decide that it must have been ordered by the OT to improve Sam's posture in his chair as he does slump over sometimes when working at his table. They all agree to give it a go. They talk about Sam's standing frame and discuss whether Sam writes better when he is standing or in his classroom chair. Chloe decides that she will photocopy his work in the two positions and show it to Helen the next time she is in.

They discuss the use of Sam's powered chair. Chloe thinks that Sam needs more driving practice as he ran over a child's foot this morning in the library. She says that he is only using it to drive to ICT and assembly at the moment. Helen agrees that it is a good idea for him to have more practice as he will become more dependent on his wheelchair as he grows up. Chloe feels that Sam's parents may have a different view and want him to use his walker in the playground. She thinks however, that one

playtime per week he could use his powered chair when she is on duty to keep an eye on him. Sam agrees to this. (FN)

It was clear that the physiotherapist's role with Sam included 'monitoring', 'changing his programme', and 'making sure they're happy with all of his equipment and his exercises' (PT, interview). The physiotherapist however, also viewed her role as 'educating staff', 'advising them on their timetabling', and on 'inclusion' (PT, interview). In reality though, as she only met with the TA and not with the class teacher, her influence was limited to aspects of Sam's management where the TA had direct control, e.g. his exercise programme, and relied on the TA being able to disseminate information. Sam's TA would naturally raise issues with the teacher which she considered important, e.g. use of the powered chair, thereby indirectly influencing the knowledge or advice gained by the teacher.

Sam's teacher viewed aspects of his management not linked directly to physiotherapy, from a social inclusion perspective. She was keen that there would not be any barriers to participation for Sam, and in this respect was interested in learning about Sam's physical requirements and advice given from the physiotherapist. She specifically asked for feedback from the TA following the physiotherapist's visit to learn about any changes or recommendations that had been discussed. Although she had not had any direct training from the physiotherapist, with her background as a TA with children with physical impairments, she appeared confident to manage some aspects of Sam's needs such as assisting with transfers from chair to walker and readily suggested using the walker when she felt he needed to stand up to participate:

The children are all sitting on the carpet in front of the class teacher to listen to a story. Sam is in his powered chair at the back of the group. The teacher asks the children to act out the story with facial and body expressions. She then tells the children to stand up so that they can pretend they are running against the wind. She notices that Sam is in his chair and asks the TA to transfer him into his walker so that he can join in. Once standing in his walker, Sam eagerly joins in with the story, making gestures and laughing. (FN)

Knowing what you don't know

Sam's management was influenced by school staff's knowledge of the therapists' roles as well as their beliefs on how his difficulties should be managed. During the school year, they needed to identify relevant issues as they arose and decide whether the therapists had any advice or intervention to offer. As the physiotherapist put it, she only got as '*involved as the staff kind of want me to really*' (PT, interview). Similarly the OT who worked on a '*consultation model*', relied on the school to contact her with any problems they perceived to be within the remit of her role.

If Sam's difficulties impacted on his participation or function, this had to be firstly recognised by the school staff and secondly identified as an issue which would benefit from a therapist's advice. Last year for example, Sam had participated in class swimming lessons at the local pool with the support of his previous TA. He had to stop attending however, after a few sessions as he became uncomfortable in the water. The school had not sought advice from the physiotherapist despite her regular visits and knowledge of Sam's physical abilities. The physiotherapist felt that she could have offered them advice, but as this was not their understanding of her role, they had not thought of asking her: '*They didn't involve me at all last time. They obviously had someone in the water with him, but quite what that person was doing I don't know. I would think supporting him and you know not really knowing. I guess not really knowing what to do with him*' (PT, interview). It may be that swimming for Sam was considered purely a matter of participation and therefore from a school point of view, the responsibility of the class teacher. Similarly, in PE lessons, with only a little knowledge of Sam's impairment there was no possibility of combining his physical goals into the curriculum. The importance of acknowledging impairment in disability has been highlighted by critics of the social model (Crow 1996).

A similar case could be argued for how the role of the OT was perceived at the school: her input being viewed only in terms of a medical model of intervention solely for fine motor skills, whereas the OT considered her role extending to that of developing independence and self-help skills such as toileting and dressing. As school staff were unclear of her role, it would be difficult for a '*consultation model*' to be effective as it relied on staff identifying areas in which the OT might be able to advise e.g. transferring from hand writing to the use of a laptop or facilitating independent toileting. These two

examples were issues expressed by school staff where OT advice was not currently being sought.

Sharing knowledge

As the main person receiving advice and training from therapists, it was important that knowledge given to Sam's TA was communicated to other members of staff involved in his management. She often met with the class teacher first thing in the morning or on an ad hoc basis during the day when a free moment occurred: *'They don't give you any allotted time to sit down and discuss anything, so that's a problem...that's why I come in early for that reason...but then there's a lot of good will on my part for this job'* (TA, interview). Current issues were therefore discussed on a problem-solving basis as they arose, but there did not appear to be a forum to have a more in-depth discussion of Sam's management. His teacher was planning however, to involve the TA in reviewing Sam's IEP and to use that time to talk about Sam: *'I suppose I'll book a time, say like assembly time to sit down and talk about how he's getting on and I'd expect her [TA] to review some of the targets'* (CT, interview).

Both the class teacher and the TA took the responsibility of cascading necessary information about Sam's management to others. This generally occurred on an informal basis *'with other adults in the school, in passing in the corridor and things. And people are familiar because he's been here since reception, it's just obviously when people have more contact like his midday meals, that you make time to talk things through with them at the beginning of term and talk them through what needs to be done'* (CT, interview). His teacher reported that she was responsible for cascading information to the lunchtime supervisors such as taking Sam to the toilet or using his equipment. Their knowledge was therefore dependent on the level of his teacher's knowledge. Although Sam's class had one regular lunchtime supervisor who knew Sam well, others were often involved with him. Without knowledge of his physical needs, they would sometimes use their own judgements to decide which equipment to use with Sam: *'He was going in his manual chair quite a bit when they were playing out on the field, because his frame's not very steady on an uneven surface...and he was being plonked in his chair and left there whereas he should really be using his powered chair'* (father, interview).

By training only one TA to manage Sam's physical needs, the school did not prepare for any absence. As Sam's father pointed out when the TA was absent during my observation week: *'I think they're having to use the assistant from the class you know, which is OK but then they've no idea about cerebral palsy, and how to lift, they've not been shown how to lift Sam and how his muscles work or anything'* (father, interview). Sam's physical management was therefore influenced by the cascaded knowledge of those who were responsible for him.

Sharing goals

IEPs have been viewed as a useful means of communication, allowing a sharing of practice, directing staff towards shared goals (Tod 2002) and an important feature of inclusive education (Giangreco 1997). Sam's IEP appeared to be a collaborative process: prepared by his class teacher with his parents and the physiotherapist being asked for their comments. There was however, no evidence of any direct input from Sam although he was often asked for his opinions informally and his views may therefore have been taken into consideration in this way. At the time of my visit, half way through the first term of the year, Sam's IEP was a document known to his class teacher and his TA seemed unaware of specific targets.

Despite a seemingly collaborative process to identify and share Sam's goals via the annual planning meeting and his IEP, Sam's father pointed out, *'it never seems quite that easy'* (father, interview). The importance that was placed on particular goals was influenced by perceptions of Sam's need. His teacher for instance, with her strong beliefs on social inclusion and participation, prioritised these goals over others. Sam's TA on the other hand, viewed independence as Sam's most important goal and had personal goals for him that had not been identified on his IEP.

With limited knowledge and experience of children with cerebral palsy, staff were influenced by their own beliefs on disability. It was difficult for staff to predict how Sam might function in the future and therefore work towards realistic long-term goals. The class teacher for example was proposing that Sam might become more proficient in his manual chair so that he could participate in games such as wheelchair basketball: *'He's generally pushed in his manual chair, but again that could be something to be working on as he gets stronger to use his own wheelchair to go short distances*

around.' (CT, interview). She had not considered the '*fatigue*' expressed by the physiotherapist and his father that Sam had when manoeuvring his manual chair, hence the reason for Sam to become more reliant on his powered chair as he became heavier and less able to walk. His TA expressed her view of Sam becoming more proficient in using scissors that with perseverance, he would eventually succeed: *'I see it as a challenge now, so I'll make sure I can get him cutting with his scissors. Some of it is confidence, isn't it and 'yes, you can do it!'*' (TA, interview).

6.6 Conclusion

In this case, Sam was constructed as a child, who although had 'special' needs requiring different or separate provision, was fully embraced as a member of his class with rights to full participation. The school had an inclusive ethos whereby Sam was expected to participate in all class activities and provision was made for him to have support and a range of specialist equipment to facilitate this. His class teacher and TA worked collaboratively to meet his needs within class, yet there were many conflicts in how to balance Sam's individual needs alongside that of participation and inclusion. Day-to-day decisions as to the use of equipment or how staff provided support, impacted on his participation and learning. As an immobile child within an active and mobile classroom, he faced many subtle barriers to his learning, social interaction and independence. Staff were supported by therapy services to manage Sam's 'special' needs, but his physical difficulties impacted on many areas of school life where therapists were not involved. I now discuss the findings from the third case.

Chapter 7: Case study 3

The class are getting ready for a lesson on maypole dancing. I am told they will be performing at the village fair in two weeks time. Josie tells me that she really enjoys maypole dancing and will be performing at the fair as she did last year. She comments that some of the dances are rather fast for her and she finds it difficult sometimes to keep up with the music, but that she can do many of the dances. Josie gets herself undressed, but has some difficulties with the buckles on her shoes as they are quite new and the leather is stiff. She says out loud 'I can't get my shoes off', but no one appears to take any notice as they are hurrying to get themselves undressed. There are no adults within earshot. Eventually, she manages to undo her buckles and tidies her clothes as the others have done. One girl appears to notice that Josie is being rather slow, waits behind until she is ready and they walk to the hall together.

For the first dance, the teacher asks Josie to sit out as the music is quite fast. Josie seems accepting of this decision and sits on the side. The other children perform the dance, skipping around the maypole and Josie watches with interest. For the next dance, the teacher asks one of the children to change places with Josie so that she can now join in. Josie happily takes her place. The teacher has made sure that Josie is positioned in the inner ring of the two circles so that she does not have to move as fast as the others have to in the outer circle. Josie eagerly dances the next dance, more by running than skipping, but manages to keep to time and with the pace of the dance. Throughout the session, the teacher asks different children to change places with Josie dependent on whether she feels Josie can manage the dance. (FN)

7.1 The context

The third case in this study was undertaken at Loxwood Primary School where Josie, an eleven-year-old girl was in her final school year. Compared to the other two schools in this study, this was a small school with only approximately 70 pupils aged between four and eleven years, situated in a rural village in the south of England. The school was a single storey building enabling wheelchair access to all areas with ramps to the large outdoor playground and field. There were only three classes in the school consisting of children from two or three year groups within the same class. For these classes, there were six teachers, one of whom was a specialist teacher for children with SEN and five

TAs. The headteacher held a dual role of headteacher and SENCo. Being a small school, the staff and children appeared to know each other well and there were many siblings and cousins within the school and within each class. Each term the headteacher had a meeting with each of the class teachers to discuss not only the children with SEN in their class, but every child's individual progress.

The school was a Church of England school attended by many of the children from the village, but also by a significant number from outside of the immediate catchment area. Most children were from white British families, but several minority ethnic groups were represented in small numbers. A quarter of the children were reported to have SEN, mostly of moderate learning difficulties (Ofsted 2005).

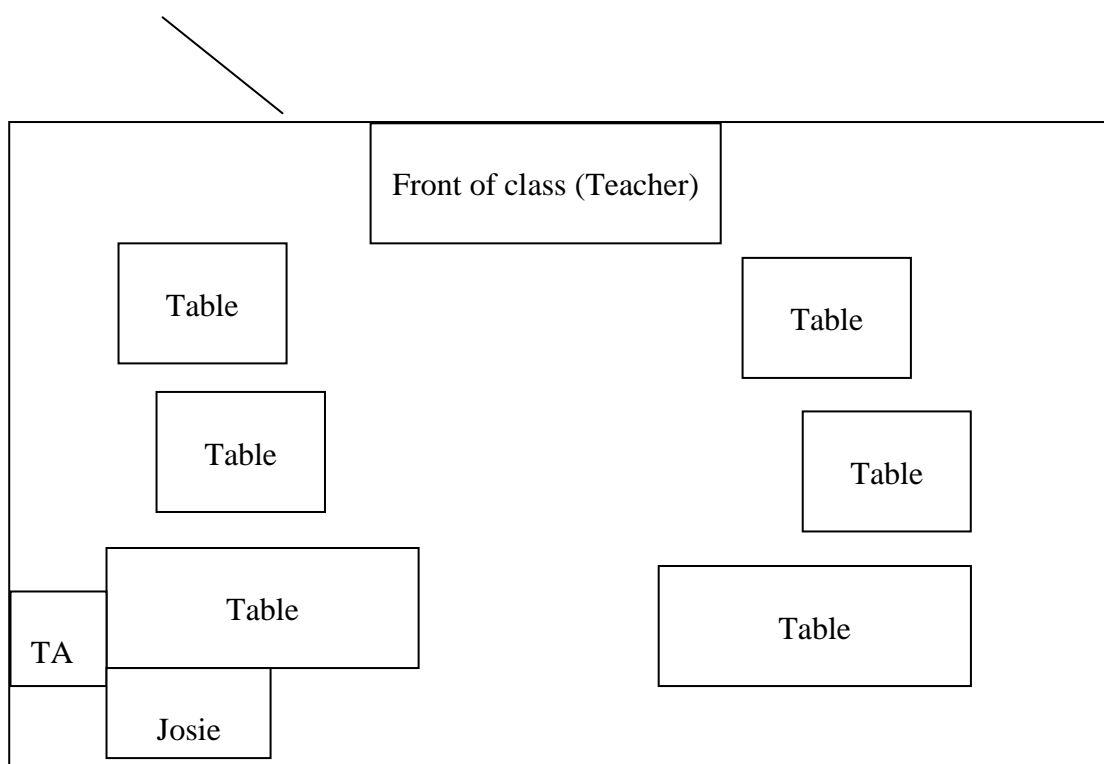
The school was reported to display a strong Christian ethos of respecting and valuing others, offering good support to those who were vulnerable or with special learning difficulties. Children's views were said to 'really matter' and be valued. The children were reported as being caring about others in an exemplary way. The headteacher described the school as '*very family*' and that '*everybody knows everybody so very well*', making it easy to be caring towards those who needed it: '*[the school's] like a big extended family really, so if you've got someone in your family who needs support for one thing or the other, well you just do it, don't you*' (HT, interview). There was evidence of parental involvement in the school, such as a parent running a cake decorating group with the younger children and parents assisting with school repairs.

Josie was in Class 3, the class in the school for older children from Years 5 and 6. This class consisted of 22 children (seven boys and 15 girls) with Mrs Dawson as their class teacher. She taught the class for all lessons apart from one planning afternoon per week, when she was relieved by a regular supply teacher. If she was absent for any other reason, the class were usually taught by the SEN teacher. The classroom was arranged into small group tables, so that the children all faced the teacher at the front of the class. Mrs Dawson reported that she made decisions on where the children should sit at the beginning of the school year, dependent on their ability to work with the other children at their table and on their level of ability. One of the tables at the front of the classroom was for the 'more able' children (CT, FN). Josie sat on a table at the back of the class with three other children. Susan, her allocated TA sat to one side of her at this table (see Figure 8.1). Her teacher commented that she had chosen these three children to share a

table with Josie, as they were the less able children in the class who would also benefit from Susan being there to provide extra support. Similar to the last case, the children did not stay at their set tables for all lessons, but often moved tables within the classroom for different group activities. Mrs Dawson reported that for many activities, she chose children who could work well together as a group rather than children of similar ability always working together.

Figure 7.1: Diagram of Class 3

Door into class



On the walls of the classroom were displays of the children's work on Victorians and an art project. One wall displayed charts for class duties such as ringing the school bell and closing the school gate at the start and end of school, or being the playtime buddy who looked out for children who needed help at playtimes. This was a child in Year 5 or 6 who wore a sash at break time so that the other children would know whom to approach if they had any problems. As in the other two schools there were agreements displayed regarding class conduct, but this class displayed written guidance on what a child should do if they felt they were being bullied.

Josie had been at Loxwood school since she started in reception and there were plans underway for her transfer to the local secondary school the following year. She was the only child in the school with cerebral palsy and the first experience of a child with a physical impairment for most of the staff. Josie's mother '*was so pleased with it [the school]*' (mother, interview). Josie's cousin was also in Class 3 and another cousin was in the class below.

Josie had a diagnosis of cerebral palsy, diplegia (GMFCS, level II). She could walk independently without any walking aids, but tended to walk up on her toes especially on one side. This affected her balance when on her feet and stamina for walking for any length of time. More recently, this had begun to deteriorate and there was talk about possible surgery to improve her gait. Although she could walk independently and even run short distances, she tired easily. This was observed when she was playing outdoor games, during PE and at break times when she frequently sat down for a rest. At least a couple of times a year, Josie had plaster casts put on her lower legs to stretch out her muscles and try to improve her walking: '*Afterwards it usually makes her walk with her feet flatter*' (TA, FN). At these times she used a walker when walking outdoors for safety purposes as otherwise '*children might bang into me*' (Josie, FN). She did not usually use her wheelchair in school, but did so for school outings such as when everyone else walked to the village church or for school trips.

Josie was able to sit on the ordinary school chairs, but had been bought a more supportive chair to use in the classroom to encourage a more upright posture. She could sit on the floor alongside the other children for assembly or for circle time in the classroom, but her physiotherapist felt that she was starting to find this more difficult. For this reason, when her legs were put into plasters, she sat on a chair rather than on the floor.

Josie had a Statement of SEN specifying individual support for 22 hours per week primarily to support her physical needs. Her TA was allocated to work with her in the classroom every morning and Josie went out of the class for an hour every week to work with the specialist SEN teacher. Susan had started working with Josie as her assistant at nursery school and then moved with her to primary school. In the past she had looked after Josie and her sister after school when her mother was at work: '*Susan used to have them because my working hours were a bit different...so we'd sort of got a*

nice relationship between the two families' (mother, interview). Nowadays, Josie was picked up by her aunt after school, and Susan reported that she hardly met Josie's mother except occasionally at the supermarket. Susan was considering moving with Josie to her new secondary school, as both Josie and her mother were particularly keen for this to happen.

Three main themes emerged from analysis of the data:

- Constructing Josie's needs;
- Responsibility for Josie's needs;
- Growing up with a 'disability'.

7.2 Theme 1: Constructing Josie's needs

'An inclusive place'

Josie's needs were constructed within an overall ethos of inclusion and a positive approach to supporting diversity. These attitudes and values influenced how her needs were viewed and managed by all of the school staff. As Roaf and Bines (1989) argue 'needs' in themselves do not necessarily define special provision and how this should be provided, but very much depends on the school's culture of good practice. Loxwood school was described by the headteacher as an '*inclusive place*', with '*values and attitudes which expect Josie to take part in everything to the best of her ability and with the best of our support...we strive to the best of our abilities to minimise those barriers for all our children*' (HT, interview). She viewed that '*good educational practice should be inclusive in the broadest sense*' not only within the classroom, but for all aspects of the child's school life and considered it to be her role to promote this inclusive ethos: '*The role as headteacher is to set the ethos of the school*' (HT, interview).

Booth and Ainscow (2002) purport the importance of an inclusive culture, for equal opportunities to overcome barriers to participation, and to support diversity. There were many examples where this inclusive culture was evident. For example, the annual residential trip was being moved this year from a centre 20 miles away to a nearer one, as the school felt the distance and overnight stay excluded some children from the trip.

Enjoyable tasks such as ringing the school bell at the start and end of the school day were organised on a rota basis rather than as a reward for good behaviour. Josie's mother commented that Josie had *'just had a fantastic school life there...they have handled Josie as every other pupil in the school, and they put obviously things in place to help Josie, to try to make it easier for her'* (mother, interview).

The school had a more open approach to diversity compared to the other two schools. I observed a circle time session where the children discussed differences between themselves and what it meant for the individual person. In contrast to the other two cases where the children were not told the reason for my visit, when I arrived at this school, I was introduced to the class as a visitor who was interested in children with cerebral palsy such as Josie.

The school appeared to openly discuss issues and problems with the children on a regular basis. On one occasion during the observation week, when there were problems in the playground between children, Josie's teacher talked to the class, hearing the individual children's views and helped them to come to a solution. When a child with diabetes moved to the school last year, the teacher had talked openly to all the children regarding her difficulties and reasons for extra precautions: *'When Helen came with her diabetes and she was brand new to the class, I had to explain why she had to do things...why she was allowed to eat a biscuit...and now they don't really blink an eyelid about Helen and her thing, but they did when she first came a bit'* (CT, interview).

Although they had not had a similar discussion about Josie as she had been at the school since she was very young, her teacher felt this would be important if anything new happened for Josie. For example, when Josie had to start wearing a lycra suit under her clothes to try to improve her posture, her teacher had talked to the other children about why she needed to wear this: *'She had a blue suit which is made from NASA. She got changed into it and her teacher had them all in the hall, Year 6 and 5s and explained about her blue suit and something that was going to help her and that. So they do explain with any child who's got a problem'* (TA, interview).

From a disability rights perspective, the headteacher had *'championed just to get anything possible for Josie'* (mother, interview). Her attitude was that *'we [the school] must do our best to remove those barriers if it is within our capacity to do so'* (HT, interview) and had ensured that any equipment Josie required was provided for her, that

she had adequate access to all areas of the school and that funding was sought annually through her Statement to provide additional hours for her. She viewed the extra support hours as Josie's 'right': *'I don't see there's any negotiation necessary. It's quite obvious that Josie needs a level of support and that level of support's appropriate for her'* (HT, interview). For Josie's new secondary school, she had advocated many adaptations for her to ensure that she had full access to the curriculum and areas of the school, considering that this *'had to happen for Josie'* (HT, interview). When she had started her post as headteacher at this school, she had fought to ensure that ramps and a disabled toilet were put in place, despite difficulties with funding: *'[the difficulty] was purely down to County and their hold ups, it took just about 18 months. And it ended up with the headteacher saying: 'Right, we're going to take this to the papers' and then the ramps were put in two weeks later'* (mother, interview). The headteacher had *'just phoned up and said 'Look we've got a child here already and we've got an accessibility plan, but we don't have ramps, we don't have a disabled toilet. Where's the money going to come from?'* Actually there were pots of money for things. Now because I'm proactive we were able to access those pots of money and the job was able to be done' (HT, interview). She viewed that children should not have to worry about how their needs were met, but that they should be met without the child perceiving *'any kaffuffle or problem or worry'* (HT, interview).

Accessing the curriculum

Accessing the curriculum in terms of providing equal opportunities for Josie to learn and participate, were important constructions of Josie's needs within the school. All agreed that Josie had primarily physical needs both gross and fine motor, as stated in her Statement of SEN. This document stated that she should be facilitated to have *'access to the curriculum by taking into account the effects of her physical difficulties'*, *'to continue to develop her motor skills'* and to *'maintain her confidence and self-esteem'* (SEN Statement, doc). Within the classroom, Josie was viewed as requiring support primarily with her fine motor skills:

'Her understanding of things is slightly lower than average, but not desperately poor academically and so she holds her own within the class, in the poor group if you were to split them into top, middle and bottom. So she doesn't need extra help as in academic work. Obviously where Susan helps her out is that if you're drawing tables and things

you can just kind of help her with the physical side of it, more to do with the motor. I mean she'll also act as a very good TA as well in explaining. So I've gone through it in a board and if Josie's not sure, she'll kind of help her re-learn it and go over it, so she'll use herself like that as well. But she very much helps Josie with anything physical about that piece of paper' (CT, interview).

Josie felt that it was her speed of writing that was her main problem: *'I'm really, really slow with handwriting. It takes me forever to write a story or anything'* (Josie, interview) and her teacher described the quality of her writing as *'like that of a six-year-old'* (CT, FN). In the mornings when Susan was in the classroom, she would sit to one side of Josie and assist her whenever she felt it necessary:

The class are having a maths lesson. Susan is sitting next to Josie and as the teacher explains the work to the whole class, Susan repeats the instructions to Josie. She then draws lines for her and places her book in front of her. Josie gets down to work, writing her answers using an ordinary pencil. When she needs to use a ruler, she asks Susan for help. Her writing is large and appears laborious. Sometimes Susan whispers to her, prompting her with her work. At times other children on the table ask Susan for help too. The teacher walks around the classroom helping those who ask for help, but she does not help anyone on Josie's table. (FN)

The OT agreed that Josie required assistance with her fine motor skills, but that greater keyboard skills would improve independence in this area in the future: *'She can't keep up with the written work. She has to have her TA to scribe for her. So if she's going to become more independent in that way then she's going to need to use her laptop more... I don't think the laptop is used a great deal at the moment, but I can foresee that it will be needed in the future, so it's good for her to work on those skills'* (OT, interview). It was on her IEP to *'improve touch typing skills'* (IEP, doc), but this was not readily voiced by school staff. It seemed that Josie's fine motor needs were constructed from the point of view of accessing the curriculum, rather than developing independence. As Josie was accessing the curriculum by Susan scribing for her, they did not place any particular need at present to further develop her keyboard skills. In the past Josie had had extra sessions to try to develop her keyboard skills, but this year all agreed that the laptop had not been used at school.

Apart from her fine motor skills, Josie considered that her *'hand eye co-ordination's not very good'* making games such as hockey difficult for her and that she couldn't *'do running very well'* (Josie, interview). This impacted on her ability to fully participate with some physical activities in school. Her physiotherapist commented that although she was quite physically able in many ways, her difficulties did affect her at school, in particular her *'health and safety in PE'*, *'some balance issues if she's being asked to do something in standing'*, *'accessing the outside because she needs rails and things, up and down steps, she can't really do steps, she needs a rail'* and *'school trips'* (PT, interview). She was concerned that her walking ability had deteriorated as she was getting older and that she was finding physical skills more of a challenge.

Josie's TA agreed that *'she's finding things harder like the PE'* (TA, interview). Josie often required assistance to perform some activities: *'When I walk along a bench, she [Susan] just holds my hand and I walk across like this'* (Josie, interview). Susan would help her to join in wherever possible and do the same as the others, but knew Josie's limitations and her own limitations as far as health and safety was concerned. If she felt Josie was unable to perform an activity, she would suggest doing some physiotherapy instead:

'I mean if they do their warm ups, their stretches and things I will help her, because if they've got to go on one leg, because of her balance, so she'll join in, I'll help her with that. If they've got the climbing stuff out obviously she can't now sort of climb because she's getting heavier and it's not for me to support her...if it's something she really can't do then I'll do some physio with her. A lot of it she tries, some of it she wants to do, but I'll say 'well I can't do it because I don't want to put my back out' (TA, interview).

As Josie's TA only worked in the mornings, her teacher usually planned for PE classes then so that Josie could be supported. Susan felt that Josie missed her if her PE was changed to an afternoon: *'Sometimes she'll say 'I wish you were there in the afternoon', if they had PE or something'* (TA, interview).

A holistic approach to physical needs

School staff were clear that physical development was as important an aspect of Josie's overall development as other areas of her education. The headteacher reported that the

TA's role was to support Josie not only in *'her learning, but also in her physical progress, in her physiotherapy'* (HT, interview). There was a strong belief that physiotherapy was an important aspect of Josie's overall development and therefore something to be done as much as necessary and prioritised over other less important aspects of her school life: *'Physio's more important to Josie than her listening to a song'* (referring to part of assembly) (CT, interview). She viewed that physiotherapy was necessary *'from a movement and mobility type thing'* to maintain Josie's walking ability and argued that *'if hand on heart we could say that we had done it every day as much as you do that, then at least we felt that we had helped Josie as much as we could do with regards her mobility'* (CT, interview). Josie appeared to accept that physiotherapy at school was *'something that I have to do'* (Josie, interview). Her class teacher agreed that Josie accepted her need for physiotherapy, although was not always keen to do it: *'Anytime she gets grumpy is when I make her do her physio and if it means that because of what the lesson is, Susan couldn't sit there and do it at the same time...sometimes she hopes that I haven't remembered'* (CT, interview).

Josie had a physiotherapy programme of exercises provided by the physiotherapist, which she did most days with her TA. From a medical model perspective this programme of stretches and strengthening exercises, was viewed as meeting her need to keep muscle flexibility and strength. Susan commented that she was *'not trained to be a physio or anything'* and therefore would not *'do it as hard [as the physiotherapist would do] as I don't want to do any damage or anything. So it's just to keep her movements really, so she doesn't stiffen up'* (TA, interview). Unlike Sam and Zac who always did their exercises separately out of the classroom, Josie often did her exercises within the classroom alongside her lesson. In this way, it was viewed that she would miss as little lesson time as necessary.

The second session of the morning is music. The class teacher tells Susan that she can do Josie's physiotherapy with her in the classroom whilst everyone has their music lesson. The class are to sing along and clap to a tape of various jazz rhythms. Susan sits opposite Josie and starts to stretch out her ankles and feet. Josie joins in with the singing. After a little while, Susan asks Josie to kneel up at the table so that she can practice balancing in this position. Susan occasionally reminds her that she needs to kneel up straighter or adjusts the position of her legs. Josie carries on with her

physiotherapy activities throughout the music lesson joining in with the singing. None of the children appear to notice that Josie is doing something unusual or different. (FN)

As well as undertaking her physiotherapy, the school had actively sought a one week swimming programme for Josie to do this term. This was separate from school swimming and had been found by the headteacher as a course to boost children's swimming abilities.

Specialist equipment such as Josie's supportive chair was readily used and integrated into the classroom and school. Although Josie was able to sit on the ordinary school chairs, the physiotherapist had recommended a supportive chair for her to encourage a more upright posture. Josie agreed that *'it [her chair] makes me sit up straight'* (Josie, interview), that she often slumped forward when sitting on an ordinary chair and *'then I do get backache'* (Josie, interview). Josie was encouraged by school staff to sit on her chair whilst at her table as they considered that it was *'very difficult for Josie to sit unsupported'* (HT, interview), although it was not always moved to a different table if Josie moved tables. Although all agreed that sitting in this chair was beneficial for her, there appeared to be a balance between whether to make her move it every time she moved places, or just allowing her to 'fit in'. When they perceived a more definite need for Josie to sit on a chair such as when she had her plasters on and could not physically sit on the floor, then the chair was used. Her teacher made sure that one of the children pushed it into the hall for her to use during assembly or at circle time when others were sitting on the floor (FN).

Participation

Participation was an important construction of what was considered to be Josie's needs. As for any child in the school, it was an expectation that she would participate in all school activities. Despite her physical limitations, she was expected to participate in activities such as PE, swimming and outdoor games even if it meant that they had to be modified or that sometimes she required assistance to participate. For much of the time she could do *'exactly the same as everybody else, but sometimes you have to tweak it slightly so that in a PE lesson she doesn't do exactly what we're all doing'* (CT, interview). Her teacher explained how *'when they did the cycling proficiency last week, she brought in her special bike so she was still able to join in. It might not have been a*

bike like everybody else's, a tricycle low down thing, but she joined in' (CT, interview). When the class went swimming, Josie's TA assisted her in the water, so that she was able to participate along with others in her class: *'Susan came and got in the water with her, while we only did that for Josie because of her need. She wouldn't have got in the water for somebody else who couldn't swim'* (CT, interview). Josie's own expectation was that she would be part of all activities and as her mother said: *'I'd be mortified if somebody said 'oh I don't think you can do that. I think Josie would be even more so'* (mother, interview).

The class are having a PE lesson outside in the playground with the whole school today. The older children are to help the younger children with the activities. The children are divided into small groups of children from reception through to Year 6. For the first activity, a rope ladder is laid on the ground and an older child shows the others how to step between the spaces and reach the other end of the ladder as quickly as possible. He then helps a child from reception to do the same holding his hand and guiding him along the ladder. This continues with the older children helping the younger ones as necessary. When it is Josie's turn, she does her best to step between the spaces, but frequently steps outside of them and misses some of the spaces out altogether. Unlike the other Year 6 children, she does not assist the younger children, but concentrates on performing the activity herself. The next activity involves walking along a beam. Josie cannot do this so her teacher suggests that she carries on practising stepping in and out of the rungs of the ladder. She happily does this on her own, whilst the others practice walking along a beam. (FN)

Although Josie could participate in many activities, she did have limitations. In PE as illustrated above, if the class were doing an activity that Josie could not do, then she would either be given an alternative similar activity or use that time instead to do her physiotherapy exercises. For school trips, her teacher pointed out that participation was sometimes a problem as although all children were *'more than welcome'*, on the practical side for some children, *'someone will need to come to be their person'* (CT, interview). As Susan was only funded to support Josie for five mornings a week, on a recent residential trip Josie's mother stayed the week to provide the extra support for her when necessary: *'Mum didn't stay with Josie the whole time as sometimes we didn't need her, so she could go off and do her own thing'* (CT, interview). She was needed to

offer Josie an alternative activity when she was not able to participate: *'Like the four mile hike, she couldn't possibly do, nor could the other two, so the three mums took their children all off together somewhere'* (CT, interview). In this way, Josie was able to participate in all the physical activities she could.

It seemed important to the school that Josie was given the same opportunity as others without *'wrapping her up in cotton wool'* (HT, interview). It was accepted that a certain degree of risk was inevitable if Josie was to fully participate, as it was for all children: *'And sometimes she does fall and hurt herself, but then all children sometimes fall and hurt themselves. Whilst you minimise the risk, there's got to be a certain element of that.'* (HT, interview).

7.3 Theme 2: Responsibility for meeting Josie's needs

By constructing Josie's needs within an ethos of inclusion, it required a more collaborative approach to meeting her needs within school. Unlike the other two cases where the children's physical needs were primarily the responsibility of the TAs, Josie's needs were viewed more as a collective responsibility. Her mother stated that she could talk to different members of staff about Josie, depending on who was available as *'they all know everything anyway'* (mother, interview). This view of collective responsibility for meeting her needs affected how her needs were planned for, communicated and delivered.

Planning for her needs

Although Josie's TA had the responsibility of undertaking her physiotherapy exercise programme, her teacher considered it her responsibility to ensure that this programme was carried out daily. It was not routinely timetabled into the week, as it was for the other two cases, but fitted in whenever the teacher felt it least disrupted Josie's lessons. At some point during the day, she would decide that it was the best time for Josie to do her physiotherapy and whether this was to be done alongside her lessons or separately out of the classroom: *'I might have to think about Josie a bit in my timetabling...Susan would just fit in and I might say to her 'I think you could do the physio now'. But it won't be the same time each day so Susan's good at slotting in. And if I've missed it, she might say 'Did you want me to do it at some point?'* (CT, interview). This sense of responsibility is illustrated in the vignette below:

Mrs Dawson asks the children to get into their reading activity groups. The children arrange themselves into the different groups and Mrs Dawson suggests that Josie's group go out into the cloakroom area so that they can do their work there whilst Josie does her physiotherapy exercises. The group go out of the classroom and sit on the floor ready to discuss the story they have been given. Susan follows the group out and sits next to Josie. The children start the discussion amongst themselves without taking much notice of Susan, who is helping Josie to sit with her back against the wall and puts on her leg gaiters. Once Josie is settled, Susan sits to one side and listens to the children discussing the story. Josie joins in with her ideas. Now and again the other children turn to Susan and ask for her help, but she only gives them one idea before encouraging them to carry on by themselves. (FN)

Josie's teacher was aware that sometimes Josie had to miss something in the day to fit in her physiotherapy, so planned for this to be undertaken either within a lesson as in the vignette above or at a time where she felt she would not miss too much, such as assembly: *'The week you were here it was very much DT [design and technology] time. If they were spending all morning doing this making, Josie really should be part of that so therefore she could do it [her physiotherapy] at assembly time. But officially she shouldn't miss assembly, but for her to get the best out of a session and the lesson, it makes sense for her to miss assembly'* (CT, interview). Her teacher therefore balanced what she considered to be Josie's priorities to make decisions as to which activities or lessons were more important for her. She related that although Josie enjoyed doing class duties, she sometimes had to limit these to fit in her physiotherapy programme: *'When its assembly duty I only let her do it for a week...I let her do it, but not so that it takes precedent over her physio'* (CT, interview). Her belief of Josie's need for physiotherapy had to be therefore balanced with her construction of inclusion: the need for her participation and equal rights as a member of the class.

Josie's teacher agreed that she didn't *'really understand much about cerebral palsy'* (CT, interview). She felt that she only needed enough knowledge of any child's condition so that she could plan for their needs within the class: *'I could perhaps find out more, but I suppose I just deal with what I need to know...I suppose I can't hold everything and you kind of deal with what you need to do so that they can be part of the class and cope'* (CT, interview). This meant that the TA was given the responsibility of

liaising with Josie's physiotherapist regarding her programme and what was involved within this. When her teacher therefore asked Susan to do Josie's physiotherapy with her, Susan was the one to decide which activities to choose from the programme. For instance, if Josie was discussing a story such as in the previous vignette, then Susan might choose an activity such as stretching using the leg gaiters, where Josie could be relatively passive and concentrate on the discussion. If she took her out of the classroom on her own, she would more than likely choose a more active exercise where Josie needed to concentrate on the physical activity. Josie agreed that she found it difficult to concentrate on any physical exercise at the same time as concentrating on her lesson: '*Mrs Payton [TA] says something to me and I miss what Mrs Dawson is saying*' (Josie, interview). By trying to ensure that this programme could be fitted in alongside Josie's lessons, Susan tried to choose appropriate activities. As much of Josie's programme involved either strengthening or balance exercises, it meant that these either had to be done within the class where Josie found it difficult to combine the two, or more passive activities were done instead. The physiotherapist did not appear to give Susan any clear guidance as to frequency or importance of any particular activities so she made her decisions based on which activity best fitted in.

Apart from regularly fitting in a physiotherapy programme, her teacher also took responsibility for trying to minimise the impact of Josie's physical needs on other areas of her participation. For example, Josie often had hospital appointments for which she had to miss school and her teacher tried to plan for her to miss as little as possible.

It is early morning and the class teacher talks through the timetable for the day with the whole class. She tells them that a small group of children will take it in turns to go out for cooking lessons with another TA. The teacher suggests that Josie is in one of the cooking groups today rather than tomorrow. She has been told by the physiotherapist that Josie is having her legs put into plaster tomorrow, which means that she will find it more difficult to stand up and walk around in the kitchen.

Josie's group of children make their way to the kitchen with Susan following on behind. Another TA is waiting for them in the kitchen and appears to be in charge of this activity. She appears to know Josie well and treats her as she does the other children, alternating tasks so that all the children participate in different activities. Josie is

capable of performing all the activities and Susan stays in the background observing for the whole session. (FN)

Communication

Communication was an important factor in how the school could plan for and meet Josie's needs. This involved communication not only between the staff at school, but with outside therapists, other agencies and importantly, Josie's mother. Within school, although the class teacher and TA took most responsibility for meeting Josie's needs, the headteacher and SEN teacher were also involved. As a small school, they considered that they often had opportunities to talk to each other: *'It's worked here because we're a small school, we talk to each other'* (CT, interview). Josie spent one hour per week with the SEN teacher to do some individual work with her. The school had decided to use the extra funding provided by her Statement to allocate her this hour: *'Because of her thing [her Statement], there's a dedicated hour. And I think we could have had an hour of Mary [SEN teacher] or so many hours of a TA, so we thought we'd have an hour of Mary so that there's another kind of drop in point where somebody different can kind of pick up things as and when they need to be really'* (CT, interview). This session seemed to be predominantly to boost her academic work rather than for any involvement in therapy programmes: *'Mary doesn't have anything to do with the physical side apart for say touch typing'* (CT, interview). Her teacher and SEN teacher appeared to decide together what extra work was best for Josie and as it was a small school, would frequently find the opportunity to liaise informally in the staff room or in a corridor. Setting IEP targets for her was also more of an informal process:

'I think if we were a bigger school we'd probably have to have a meeting to sit down and do it [IEP] together and make it more official, but I think as we're so small. And also we have, which probably helps, a day a term where we sit down with Claire [headteacher], Mary [SEN teacher] and myself and we go through every child in my class...and in this meeting out come the SEN files so if you're an SEN child you'll say 'oh she's fine or we need to watch her, she might be on your list at some point'. Get to Josie and out comes her file and I'd say 'oh when she does such and such she really finds it difficult'. So we might decide to put that on the next IEP as something extra to focus on. So that's the more

formal conversation about Josie of which Claire is in on as well so we all know what's going on' (CT, interview).

Communication between Josie's teacher and TA was also of an informal nature, rather than having a regular time for liaison. Although Susan was in the class every morning, the teacher found it difficult to talk to her about Josie, without having to talk in front of other children. As Susan had other duties in the school however, she found other opportunities to talk to her: *'On a Monday she's [Susan] on playground duty so we'll have a chat then'* (CT, interview). She also felt that Susan was a competent TA and knew Josie extremely well. She felt confident that Susan would approach her if she had any concerns and trusted her to do so: *'Basically Susan kind of gets on with it. I think because she's worked with me for two years, she kind of knows...Susan will come to me and say she found that really actually quite hard, but it's more of an 'as and when' opposed to a meeting'* (CT, interview). Susan agreed that she would ask if she had any concerns: *'If I've got any problems I will say anyway to her teacher'* (TA, interview). An important factor for liaison was time and as Susan only worked in the mornings, all her hours were allocated to lesson time. Josie's teacher felt that she could not expect Susan to come in early or stay late just to have a meeting about Josie.

For the school to manage Josie's physical needs, they required advice from visiting therapists. As the only formal meeting in the year was the annual review, when the therapists visited at other times, there required an alternative means by which information and knowledge was shared. Josie's physiotherapy programme was viewed as entirely the responsibility of the TA: *'Nobody else does the physio...if Susan's off, apart from making sure she can cope with the work, that's what I'd do for all children who couldn't cope academically, nothing else kind of happens'* (CT, interview). This meant that when the physiotherapist visited, she only met with Susan and Josie. They would discuss the programme to review any changes as well as discuss other aspects of Josie's physical management. As Susan was the only one involved with the programme, she did not necessarily discuss any changes to the detail of it with the class teacher.

As the person responsible for Josie's overall progress, Josie's teacher felt that she had little communication with the physiotherapist. Although she understood that the physiotherapist needed to liaise directly with Susan about Josie's exercises, she felt that

she would have liked more opportunity to talk to the physiotherapist herself about her general progress. She felt that *'Ann [the physiotherapist] kind of by-passes me. Ann never speaks to me, she always goes to Susan'* and wanted to know if there was anything special *'Ann wanted me to do with her'* (CT, interview). She felt that *'the problem comes when a parent then comes and says 'So what's happening with whatever?' That's perhaps been mentioned to Susan and you're going, 'I don't know, what's that then?' I think it might be because again over time that Ann knows Susan so well from the few meetings they have a year, that she feels she can perhaps talk to her, whereas I'm just a person who's in the classroom and maybe she feels like I've got 30 others, so speaks to Susan who's kind of there.'* (CT, interview).

It appeared to be the same scenario with the OT whom the teacher did not know at all and did not know whether there was any advice she should know about: *'I mean they [OT] kind of drop in once a year...I couldn't tell you who she was or what she told me to do 'cos they seem to come like ships in the night and out again'* (CT, interview). She particularly felt that she needed feedback not only in Josie's progress, but as to how much she needed to prioritise Josie's physiotherapy over other aspects of her education: *'I suppose it's more of a feedback thing. If she [the physio] came and said' the physio work's been really helpful, her having half an hour every day to do it', then I would know it's worth persevering to do. Or if she was to say 'she's really stiff at the moment if there's any chance you could do more', that'd be helpful'* (CT, interview). She considered that Susan might feel awkward telling her that the physiotherapist had suggested they do more physiotherapy in school: *'I think Susan would feel, crikey how can I tell Karen [teacher] that despite all that, it's still not enough and we're needing to do more'* (CT, interview). By having the responsibility of Josie's physiotherapy programme, she wanted to ensure that they were 'doing things right' (FN) and not just following the programme regardless. Without any regular conversations with the therapists, there was no opportunity for her to discuss any concerns or views regarding long term goals for Josie except at the formal annual review meeting.

Both therapists agreed that this was *'a good school'* (PT, interview) that took the responsibility of meeting Josie's physical needs. They agreed however, that they did not have sufficient time to spend there to provide more support for the staff: *'In an ideal world I would like to be able to go back and review several times a year, but I'm afraid*

it's the reality of it isn't it really, the reality of caseload numbers and time' (OT, interview). It seemed therefore that when they visited, time was of the essence and they had to focus on the reason for their visit, e.g. reviewing the programme or re-assessment, rather than general liaison. They commented that although they did not regularly see Josie's teacher, they were always open for advice and left it up to her to approach them when they visited: *'They know I'm in school so if they want to nab me they do'* (PT, interview). As class teachers change every year, there was also the view that limited time was best spent with Susan who carried on with Josie through the school.

The OT visited only once a year to assess Josie in preparation for her annual review and to give any recommendations as necessary. Although Susan used to be in the assessment session, Josie had more recently been meeting the OT by herself: *'The last couple of times she's [Josie] actually come in on her own. I'll say 'Do you need me or does Josie want me?' I mean they'll come and get me if they need me, but no mainly Josie does it on her own, speaks to her [OT], any problems'* (TA, interview). The OT would write her findings in a report, but did not attend the annual review meeting. Although she sometimes saw the physiotherapist at the child development centre, others involved with Josie did not know who she was and that she was involved in Josie's transition to secondary school: *'I couldn't even tell you who Josie's OT is'* (mother, interview). The OT had in fact visited the new school to assess the environment and to make recommendations: *'I've also been in to see her new SENCo at her secondary school and we've sort of talked through the environmental changes'* (OT, interview). Without a meeting once a year at the annual review, there was no opportunity to discuss any advice or recommendations given to them. For example, even though the OT had recommended that Josie develop her keyboard skills for the future, it was difficult for school staff to know when to change from writing to the use of a keyboard. As Josie was a child with a difficulty they had not encountered before, it seemed that they had used their personal judgements to decide to continue with Susan as her scribe.

All agreed that communicating with Josie's mother was a challenge, sometimes making it difficult to plan for her needs. It was difficult to talk to her on the telephone and she rarely came into school: *'I don't really see her at all unless she's coming in to tell me something'* (CT, interview). The school often only knew if Josie was going to miss

school on the day of an appointment: *'She'll [mother] come and tell you on the day. I mean Josie might say 'I'm going into plaster' and Susan might go 'No one's said you are'. Then you find on the day 'she's going in early today as she's having her legs in plaster'. That's how we kind of hear things'* (CT, interview). The school therefore, had to have a flexible approach towards meeting Josie's needs and tried to be as accommodating as possible. They were flexible in allowing her to leave class to see the therapists whenever they were asked. They understood that the therapists often found it difficult to communicate with Josie's mother. The physiotherapist felt that it was difficult to have a collaborative approach towards meeting Josie's needs due to this paucity of communication. This was particularly a problem as she attended a tertiary centre in London for specialist advice where she would be given advice regarding exercises or orthotics to wear, but this was not communicated: *'I think [the London centre] has been giving mum programmes, and she's got an Upi suit, she's got toe-off splints and they haven't been coming into school'* (PT, interview). Josie's mother appeared to have a good relationship with Susan as she had known her for many years, and if the school wanted to contact Josie's mother, they felt Susan was the most effective person to do this: *'If we need the wheelchair she'd [Susan] ring mum when she got home or at the weekend to say 'Can you bring it in?' ...when Susan rings up and says 'Can I have the wheelchair? She [mother] just conforms. I mean she would do it if I ask, but it's better coming from Susan'* (CT, interview).

One of the factors influencing the belief that Josie should undertake her physiotherapy programme regularly in school was that the school staff and the physiotherapist did not consider that much physiotherapy was done at home: *'It doesn't happen at home'* (CT, interview). Josie agreed that she did her physiotherapy at school: *'most of them [exercises] I do at school'* and she considered Susan's role with her to be primarily to do exercises with her: *'The one reason why Mrs Payton is there is basically to do my exercises with me'* (Josie, interview). Josie's mother agreed that she did leave the responsibility of Josie's physiotherapy programme to the school, but that she did encourage other aspects of her physical development: she took her to judo club and encouraged her to use her night splints. Although the physiotherapist appeared frustrated that Josie's mother did not always do physiotherapy with Josie, she agreed that *'mum's gone out and got a trike thing for Josie, she's gone off and got a sporty wheelchair and things like that, she was going swimming'* (PT, interview). Josie's

mother appeared to want to balance her therapy with her home life, especially as Josie was often very tired after school and difficult to motivate to do exercises: *‘It’s hard to find the balance...we’ll do her physio...make her wear her night splints...you know, you can’t let this just encompass you so that you are just a disabled child, it’s unfair, because that’s not how it should be at all’* (mother, interview).

Perhaps as communication with those outside of school was a challenge, IEP targets were generally set amongst the school staff. It was considered that Josie’s mother would probably not be able to spare the time for a meeting: *‘If it was like the annual review she’d come, but if it was just a meeting in school time about the IEP, she’d say that’s OK, it’s fine.’* (CT, interview). Josie’s mother agreed that she had sufficient confidence in the school and didn’t really need to go in for anything extra other than the annual review.

7.4 Theme 3: Growing up with a ‘disability’

Josie had been at this school since she started in the reception class and all agreed that her needs had evolved and changed over the years she had been there. She was a child who could walk independently, but was finding this more tiring as she was getting older. Being a *‘determined child’* (TA, FN) who would participate in most activities in school, it was felt that it was not always easy for her to accept her limitations, that different activities or equipment might be beneficial to her in the long term, e.g. use of an angled worktop, and that she could not always do the same as others: *‘Sometimes you have to say ‘Josie, you can’t do this’, because otherwise she’ll do it, and ‘No, we can’t have you jumping off thank you’* (CT, interview). They felt that this awareness of difference was becoming more apparent as she was getting older.

Although Josie was considered to be largely independent as she could do most things for herself, she did require assistance with many fine motor tasks. School staff considered that her physical limitations sometimes affected her independence in other areas and this was a concern as she was shortly to be moving onto secondary school.

Being ‘different’ in a mainstream school

Unlike Zac and Sam, Josie’s physical difficulties were such that she was able to participate and perform many activities similarly to the other children in her class: *‘she*

doesn't get treated that much differently to the others' (CT, interview). Her teacher described her as a 'gutsy' type of girl, who was willing to give things a go and enjoyed physical challenges (CT, interview). For example last year's school trip involved quite challenging outdoor activities such as abseiling, which Josie had been quite happy to try: *'she did the abseiling, she went up and did it all and she was really proud of herself'* (CT, interview).

Sometimes however, Josie did have to be treated differently from other children, such as using specialist equipment or doing her physiotherapy. As well as her supportive chair, she had an angled desk top to promote a more upright posture when she was writing, and foot splints and a lycra suit to try to improve her gait and posture. School staff appeared supportive and encouraging in the integration of such equipment into the classroom, but apart from the chair, the other equipment was not used. It was felt that Josie did not want to look different if at all possible: *'If I'm not there she'll sit in the normal chair. I don't know why 'cos it's really comfortable actually to sit on, isn't it. I think it's all part of being the same as everybody else probably'* (TA, interview). The physiotherapist considered that Josie had chosen not to wear her lycra suit *'because she felt different'* and that her splints were being deliberately left at home so that she did not have to wear them: *'She's got toe-off splints and they haven't been coming into school'* (PT, interview). She also had glasses which her TA commented were rarely worn.

As her headteacher reflected *'if you're a child like Josie, you don't like a great deal of obviousness'* (HT, interview). School staff therefore tried to balance her physical needs with her need not to stand out from others. They approached her management by making *'as little fuss as possible'* (HT, interview). For example when Josie returned to school with plasters on her legs, her activities continued as usual with allowances made for her reduced balance and safety when walking:

Josie wheels herself back into the classroom after having been to the hospital. She has plasters on her legs and the plaster is not yet dry. She has been told not to put any weight on her legs until they are dry in about an hour's time. Mrs Dawson helps her to manoeuvre her wheelchair to her table. The class are in the middle of a lesson and no one seems to take much notice of Josie. Mrs Dawson notices that the table is now too low for Josie as she is in her wheelchair, but asks her if she can work on her lap for the next twenty minutes until the end of the lesson. Josie agrees.

The next day when Josie returns to school, she is walking in her plasters. When the class go into the hall for a maypole dancing lesson, Josie follows along with Susan. Mrs Dawson suggests that Josie does her physiotherapy on a mat today, to which Josie reluctantly agrees. Susan gets a mat out for her and they do some exercises together on the floor watching the others dance. After a little while, Mrs Dawson asks if Josie would like to join in a dance. Josie happily gets up and walks over to the maypole. Mrs Dawson holds her hand while she walks swiftly in and out of the ribbons keeping up with the dance as much as she is able. (FN)

Despite this view that Josie did not wish to look different, Josie sometimes had other reasons for her actions. She agreed that she did not always use her supportive chair, but that this was largely due to the effort of moving it if she moved tables: *'Say like I'm doing art and I move to a different table, there's no point in me moving my chair, 'cos I've got to move it from there to there to there. So I just leave it there and sit on a normal chair'* (Josie, interview). Josie's teacher commented that Josie did not always show self-awareness of her difference: *'sometimes you have to kind of almost remind her she has a disability'* (CT, interview). For example, she explained that despite Josie's obvious difficulties in running, she had still expected to be included in the more competitive part of sports day such as the finals running race: *'Interestingly Josie did say 'Which race am I in?'... and I said 'It's just the finals Josie'. And the reason we had done it like that is that we kind of feel they get more self conscious the older they get. Now Josie is more than happy to be last by five miles in a class lesson, but I feel that it's wrong for her or anybody else who's the slowest, to be in the final with all the parents there watching. But I was not really surprised but intrigued that Josie either hadn't thought about that side of sports day, but was quite happy to do it and I think she probably would have been, as she quite enjoys that kind of thing'* (CT, interview). As she enjoyed physical activities, she did not seem to worry about participating in organised games, and often did tag rugby or cricket after school.

As far as her physical limitations were concerned, Josie did appear to be very much aware of her changing needs: *'She's also been getting aware that I'm very different and things are not going to get better and how's that all feeling'* (PT, interview). Josie explained that she was often extremely tired after school and that sometimes she would *'just zonk out on the sofa and just fall asleep...I don't have dinner sometimes'* (Josie,

interview). All agreed that her walking was *'going downhill'* (PT, interview) and her mother reported that *'sometimes if she's had a really active day, she'll come home and she'll be asleep by 5 o'clock and there's no waking her up'* (mother, interview). Josie was therefore choosing more often to use a wheelchair out of school when she had longer distances to walk: *'If we go into town or even go sort of shopping round the supermarket now, she'll tend to say I cannot walk that distance. Can I have my chair? And sort of choosing to now, even though I think in her heart of hearts, wouldn't want to use the chair at all, she's now realising her own abilities'* (mother, interview). There were concerns about how she would cope at secondary school due to the distances between classrooms, but Josie had made the decision to use her wheelchair in her new school: *'When I move from class to class, I'll wheel myself'* (Josie, interview). Her mother commented that sometimes Josie did get frustrated about her limitations saying things like *'Why don't my legs work properly, it's not fair'*, but that this did not last too long and on the whole, she was *'very accepting about things in that way'* (mother, interview).

Together with increasing awareness of her difficulties, Josie was becoming more self-conscious about doing anything different from other children. For example, she had always done her physiotherapy exercises within the classroom and school staff considered that she accepted that this was necessary for her: *'I think Josie doesn't like to be different, she accepts that she is, and to a point will do things like the physio when you're reading a book or I'm talking to them all. She'll sit and do her physio on the floor and the kids don't bat an eyelid'* (CT, interview). Although the school tried to incorporate her physiotherapy into her daily school life, and for it not to be looked upon as anything special or different, Josie did not feel the same way. She would have preferred to go out of the classroom for her physiotherapy as *'they [the other children] like keep on looking at me'* (Josie, interview).

In contrast to this self-consciousness regarding her physiotherapy, Josie appeared to enjoy the attention she received when being in school with plaster casts on her legs, despite her reduced mobility and need for special equipment. In the morning when she was due to have her plasters put on, she talked eagerly about it to others in her class. This was despite the fact that everyone agreed that she usually only managed to keep the plasters on for a few days, when they were planned to be on for a couple of weeks.

When she returned to school with the plasters on, this was the main topic of conversation for her with her peers, particularly as one other girl had broken her arm and also had a plaster on:

Josie is going to the hospital this lunchtime to have her feet in plasters. She spends most of the morning break talking to a girl in her class about it as she has her arm in plaster having broken it last week. Susan says that Josie seems to like the attention she gets when she first goes into plasters, but soon grows tired of having them on and asks to have them removed.

Josie arrives back after lunch in her wheelchair. At afternoon break, some of the children are curious about what has happened to her and ask her questions about how long she will have to be in her wheelchair and the plasters. She appears to be enjoying the attention and they go on to talk about secondary school and how she will use her wheelchair there more. She seems pleased that the new school are making a lot of alterations for her as she will sometimes be in her wheelchair.

The next day, when it is break time, Susan gets the walker and wheelchair out for Josie to choose which she would like to use in the playground. Josie chooses her walker and quickly walks out into the playground. In contrast to other days, when she has gone over to the trim trail and played with younger children, she instead shouts in a loud voice 'Does anyone want to sign my plasters?' Immediately a group of children come over and crowd round her eager to write on her plasters. Josie seems very confident and chatty today. As soon as they have finished writing, they run off to return to their game, leaving Josie by herself (FN).

Her TA had started to notice that as she was getting older, her physical limitations were affecting other aspects of school life: 'different things maybe friends, playing that sort of thing' (TA, interview). At break times, she commented that although the children were usually open to anyone joining in with group games, sometimes Josie's view of her own physical difficulties would prevent her from joining in:

'Sometimes she'll hold back, sometimes I say to her, she's clinging to me and I'll say: 'Look they've got the rounders or cricket. Why don't you...? Oh I can't do that'. 'Oh you can Josie come on, would you like to play?' And sometimes she'll say 'Yes I would' and I'll take her over and then that's it you know, I'll move away and she's quite happy

to play. Sometimes she does hold back and I think she wonders if the others don't want her to join in, but I mean they're pretty good, they normally let her join in anything (TA, interview).

School staff were concerned that she might find participation at break times more difficult when she moved to secondary school: *'when she gets to senior school, she'll notice it probably more there. Unless she's got a very, very special friend that's with her mainly all the time, I think she'll find that quite hard'* (TA, interview). Instead of being with her peer group, Josie often played with the younger children in the school. Her TA felt that this was because she could not keep up if they were doing any games involving running and was also less mature than many of her peers. She was not observed to chat to her peers during play times and did not seem to have any friends she regularly played with. Her teacher agreed that Josie was *'friends with everyone'* and Josie herself said that she did not have any special friends (FN). Her TA thought she liked to *'mother'* the younger children and being a small school, meant that older children quite often played with younger children anyway: *'But then some of the Year 6s you'll see play with the little ones a lot anyway, which is nice to see actually'* (TA, interview). The following vignette is an example of one lunchtime break:

It is lunchtime and as the weather is fine, all the children are out in the playground or on the field. A group of Year 5 and 6 children are playing cricket at one end of the field, whilst others of their age group are sitting on the benches chatting. Josie is on the trim trail in the playground. She tells me she doesn't want to play cricket as last time she was told to sit out for no reason. Instead she happily plays with three children from reception and Year 1, chatting and doing head-over-heels over the bars. They say they're not really allowed to do these, but no one usually tells them off. They tell me they often play with Josie on the trim trail. After a while, Helen the girl in her class with diabetes, comes over to Josie and asks if she would like to have a running race. Josie eagerly agrees and Helen gives her a head start before chasing after her. They run a few races before the bell rings. (FN)

Josie's teacher agreed that Josie might find secondary school a difficult change and was particularly concerned that she had chosen to move on to the local secondary school rather than another school with a unit for children with physical difficulties. She felt that Josie would need peers as she was growing up who could understand her different

physical needs with whom she could confide: *'I think it's the wrong place for her [the local school]. I think it's a great shame she didn't look at Altern school [school with unit]. I mean like the physio's obviously very important for Josie...and I can't see how they're going to fit that in...My other concern is I think the gap between Josie and her peers could widen socially. And if there was somebody else in a similar position to her, as least they could chat about getting boys, doing this, whatever it might be, however they might perceive it. My concern is that she isn't going to get that'* (CT, interview).

Independence

As for Sam, independence was constructed for Josie primarily in terms of self-sufficiency: what she was able to do for herself. Compared to the other cases, she was a relatively physically able child who rarely required assistance with activities such as walking or self help skills and more with fine motor skills such as writing and activities requiring balance. Maintaining this level of ability to do things for herself with as little assistance as possible, appeared to be an important goal particularly with her increasing fatigue and future additional demands of secondary school.

Josie's TA described her supporting role as *'just being there for her when she needs help, her asking or me seeing her body language'* (TA, interview). She explained that when she was younger she naturally had to do more for her, but now she was *'standing back'* more and waiting for Josie to ask for help when she needed it: *'she's got more confident and growing up and that, lots of things she'd like to do herself, but she will ask for help if she needs it'* (TA, interview). This was observed in class where Josie would ask for Susan's assistance for activities such as writing, drawing or whenever she required more skilled or prolonged fine motor work: *'She'll do a certain amount of writing and then when she starts going like this with her hand because they're tired, I'll say 'Would you like me to write some?' and I'll write bits or anything copied off the board and sort of keeping up if I know she's slowing down. I'll sort of just put the odd bits in for her, but she likes to try and do as much as she can by herself'* (TA, interview). Susan would either work with her individually or join Josie if she was part of a group. The following vignette describes how Susan had to balance the need to help Josie with her fine motor skills at the same time as not interfering in the collaborative work of the group:

The first lesson of the day is DT. The children know which groups they are in and organise themselves to sit in these groups. Josie moves to a different table and sits down on an ordinary chair next to a girl. Susan positions herself next to her. Neither considers moving her special chair to this table. The session involves the group working together to produce a vehicle from a plan they discussed last week. Susan, Josie and the girl sitting next to her start looking at the plans whilst the other two girls ignore them and chat. Susan does not try to bring the other girls into their discussions, but instead helps Josie as she is trying to saw a piece of wood. Suddenly one of the other two girls turns to them and says 'You're not letting us do anything'. She tells them she has thought of an idea about how to construct the wheels. All four children then discuss this idea and agree who will make the wheels.

The children agree that Josie's task is to cut up triangles of card. Susan helps her to do this using her special pair of scissors. Now and again other children in the group also ask for assistance from Susan. Josie appears to participate as much as the other children in the group discussions, offering her ideas which are discussed alongside those of others. Susan tells me that Josie needs to be in a group where there is not a dominant character as otherwise she will just sit back. Susan feels that this group of children are not worrying too much that her pieces of card are not very accurately cut, but others in the class would have made more of a fuss about this. When the vehicle is finished, the teacher asks each group to bring their vehicle over for her to have a look at. Josie eagerly says 'Me, me' and the other children nod in agreement that she can have this job. Josie picks up the vehicle and takes it over to the teacher. (FN)

Unlike Zac's TAs, who were viewed as being there exclusively for Zac, Susan was viewed as a TA who could assist anyone in the class: '*So although Josie knows she's here for her, the other children know she's here for Josie in the morning, but she's not seen as just Josie's helper or TA*' (CT, interview). As well as assisting Josie, Susan occasionally did jobs for the teacher if asked or helped other children in the class: '*Sometimes I do help [others] and sometimes I go off with another child or something depending on what they're doing*' (TA, interview). Unlike Sam's TA however, who moved away from Sam when she felt she was not needed, Susan usually stayed at Josie's side, thereby only helping those nearest her and only when they asked.

Susan considered an important aspect of her role was to encourage Josie to develop her self-confidence to attempt difficult tasks or to join in if she was hesitant: *'Like if we're going to draw a person or something, I'll say 'You do this bit first, copy what I'm doing'. And she'll do it and then gradually and she'll look at the picture and I've said 'You said you couldn't do that Josie'. 'Oh I can, can't I?' And I've said 'Don't give up'. It's actually just sort of showing her and helping her I suppose not to give up'* (TA, interview).

As Susan was not with Josie in the afternoons however, she then had to *'just get on with it'* (Josie, interview). She felt that she did have to then *'try harder'*, but also sometimes did *'struggle quite a lot'* (Josie, interview). Her teacher however, did not consider the afternoons to be a problem as she tried to timetable lessons where Josie would require more physical assistance into the mornings. By Susan not being there however, other children were often asked to assist Josie if necessary. Josie agreed that other children did sometimes help her, but *'only if they finish, before I finish'* (Josie, interview). It seemed that either the teacher came over to help or she asked one of the children to help: *'In the afternoon I [class teacher] would possibly go and sit next to her or get someone to do something for her so if they were writing up their homework and Josie could not keep up with the speed of that, then I'd say to Tara [a pupil] 'Oh can you just write Josie's out for her'* (CT, interview).

Josie was perceived as a *'determined'* character (HT, interview), who wanted to do things for herself and only asked for help if absolutely necessary. Consequently the other children did not *'mother'* her, particularly as she was not a child who would *'play on'* being dependent (CT, interview). Therefore if Josie required help, unless the children were asked, they did not usually offer it. Even Susan commented that she relied on Josie's body language where *'her head goes down'* (TA, interview) to realise that Josie required help. As Josie often had the support of Susan, the children were not usually aware if Josie required help with class work. She rarely asked one of the children to help her, but waited for the teacher to notice she required help.

As has been previously discussed, Josie's main form of output was by Susan scribing for her. Without her there, Josie could not always rely on other children to write for her as they had their own work to do. By using the computer however, she was able to produce work by herself and it was agreed that this was to be her future means of

output. She rarely used the computer in the classroom, but when she did so, she produced work with very little assistance:

It is after lunch and the class are going to write up their DT projects. The children get their books and pens out to do this at their desks. Mrs Dawson asks Josie whether she'd like to use the computer in the classroom rather than write her work. Josie agrees to use the computer and Mrs Dawson switches it on for her. Josie sits down at the computer and slowly and methodically starts to type her work. She works quietly by herself to finish her piece. When she tries to print the document, the printer does not seem to be working. Mrs Dawson notices and sends another child who has already finished her work, to go and help Josie. She cannot make the printer work either, so Mrs Dawson goes over to help. Despite this problem with the printer, Josie manages to finish at the same time as many others complete their written work. (FN)

Using a different construction of independence as has been discussed in the previous cases, school staff tried to promote Josie's sense of control, by allowing her as much choice as other children had at school. If Susan thought that she was not able to do PE for any reason, she would give Josie the choice to stay doing some sort of PE or do her physiotherapy exercises instead. Josie's teacher considered that Josie would not accept any special or different treatment unless she felt this was necessary: *'I think Josie would fight anything where she kind of thought there really wasn't a need or doesn't see a need'* (CT, interview).

At home, Josie's mother appeared to offer her a great deal of choice over whether she accepted any specialist equipment or medical interventions: *'She's getting to that age now where I have to start letting her make informed choices'* (mother, interview). For example, she had the same supportive chair at home as at school, but she agreed that Josie never wanted to use it at home. Josie had been given special insoles, but these were not worn as *'she didn't like them'* (PT, interview). The physiotherapist felt that now that Josie was getting older, she was the one she had to convince to have another try with splinting or to do her exercises, as Josie was very much in control of what happened at home: *'I'm trying to work through Josie more now'* (PT, interview).

7.5 Conclusion

In this case, Josie was constructed as a child whose difficulties were viewed within a whole school ethos of inclusion. She was viewed as a child with equal rights to learn and participate in all school activities and to be a full and active member of her class. Participation was a key goal for her even if she required adaptations or had to perform activities differently. Where her difficulties affected her participation, she usually had support and this case highlighted how support may either positively or adversely affect a child's participation and independence.

Josie was also constructed as a child with different, additional needs requiring specialist provision to be fitted into her school curriculum. Although her teacher planned when to meet these needs, it was her TA who liaised with outside agencies, her new school and with her mother regarding her additional needs. Communication was therefore vital to share her skills and knowledge, which was facilitated by Loxwood being a small school. This case highlighted important issues for Josie, a child living with physical impairments amongst able bodied peers: how she viewed her difference and how sensitive support facilitated participation, learning and independence.

Chapter 8: Discussion

In this chapter I argue for a more holistic approach to the management of the physical needs of a child with cerebral palsy within the mainstream school system. The most important finding to emerge from this research was that how the child's physical impairments were viewed within the policy contexts of SEN impacted on how their needs were addressed within school and on inter-agency practice. It influenced the extent to which, and the ways in which the child was facilitated to participate as an active member of their class with equal opportunities and rights to access the full curriculum, environment and activities within school. It impacted on how the child with a physical 'disability' was viewed and how much choice and autonomy they were given regarding their physical management within school.

When I initially embarked on this study as a paediatric physiotherapist working with children with cerebral palsy, I was interested in exploring the issues around inter-agency working and the delivery of therapeutic input within the school setting. I was concerned that TAs were taking on the responsibility of therapeutic programmes in school with little training and supervision. I aimed to explore these issues and evaluate an intervention programme. In the first phase of this study I conducted focus groups and interviews with parents of children with cerebral palsy, school staff and physiotherapists to gain an understanding of their views of these issues. The findings from this initial phase reinforced some of my own concerns, but importantly indicated different ideas, difficulties and priorities I had not fully considered. In particular, participation of the child in all areas of school life, communication of their difficulties, and responsibility for their physical needs were important issues raised. This initial study changed my focus from how and where therapy was delivered to a wider one, of understanding how the child's physical needs were managed on a daily basis within the context of an inclusive education system.

The second, larger phase of this study utilised a case study approach to gain an in-depth understanding of the issues relating to the management of a child with physical needs. In discussing these case studies, I identified many tensions in balancing the additional needs of individual children within the mainstream educational environment. As Norwich (2008) argues, these tensions create 'dilemmas' for those making decisions as

to how to manage the child's individual needs when each option has benefits and risks. There were often competing goals of meeting the child's physical needs at the same time as ensuring their participation in activities; or enabling the child to function 'differently' whilst also striving for them to 'be the same' whenever possible.

Some of the themes which emerged from this study were particular to one case, but many were common across all cases. In this chapter I discuss three important themes from the findings of all the cases. In the first theme 'Working together' I argue that how the child's physical needs were viewed within different policy frameworks, impacted on a holistic view of the child; as a child with a disability requiring management of their physical needs both in and out of school. I discuss the effect of this view on collaborative working between schools and therapy services. In the second theme 'Achieving the goal of participation' I discuss how decisions influencing the child's participation were made regularly throughout the school day and the tensions between meeting the child's individual needs whilst facilitating their participation. The third theme 'Being the same: being different' argues that for a more holistic approach to meeting the child's physical needs, their views need to be sought and taken into account when decisions are made regarding their physical management. Within this I discuss how an adult's view of difference influences the child's participation and how their needs are met. Following this discussion I continue by outlining the study limitations and the implications of the study for practice, policy and further research.

8.1 Theme one: Working together

Children with cerebral palsy often have physical impairments which impact on their function and ability to fully participate in activities within the school environment. Inclusive education legislation and policies (e.g. SENDA (2001); Removing Barriers to Achievement (DfES 2004b)) advocate that all pupils have equal opportunities and rights to access the full curriculum, environment and activities within schools. Disability politics has changed the way people with disabilities are viewed in society (Shakespeare 2006) and attending a mainstream school is not just about being integrated with able-bodied peers but being included in everyday school life. SEN policies promote multi-agency practice to enable inclusion of the child and to provide specialist or additional provision if necessary whilst the child is at school (DfES 2001b). Health policies (e.g. National Service Framework for Children and Young People (DoH 2004)) reinforce this

inclusion agenda by encouraging the provision of services out of more traditional health settings into environments such as schools to promote participation and the integration of therapy into the child's daily life. In this study I found that the way the child's physical needs were viewed within these policy frameworks influenced their physical management within the school context and discouraged children being managed in a holistic way.

Defining 'physical needs': are they 'special educational needs'?

One of the pivotal aspects of how each child's physical needs were managed at school was whether their physical impairments were viewed as a 'special educational need'. The SEN Code of Practice (DfES 2001b p.6) defines SEN as '*a learning difficulty which calls for special educational provision*'. It describes a learning difficulty as '*a disability which prevents or hinders [the child] from making use of educational facilities of a kind generally provided for children of the same age*'. Special educational provision is defined as '*educational provision which is additional to, or otherwise different from, the educational provision made generally for children of their age in schools*'. As Lightfoot *et al.* (2001) found in their study on children with complex health needs and physical disabilities in mainstream schools, physical impairments may not always be considered to be a 'learning difficulty' and thus a source of confusion for school staff. Physical impairments can, however, impact on the child's ability to '*make use of educational facilities*' in terms of access to the curriculum or to the environment and in this way argued to be a 'special educational need'.

Although there has been extensive research in the field of SEN, the literature is sparse on how 'physical needs' are viewed within this framework. Even though physical impairments may be defined as 'special educational needs' (DfES 2001b), there has been little research into how the child's needs are met within school, or whether their needs are viewed primarily in terms of inclusion necessitating access to the curriculum and mainstream environment to provide equal opportunities, or more holistically in terms of their health or physical wellbeing. In my study it was clear that the schools identified the child's physical impairment as their 'special educational need' and consequently part of their Statement of SEN. On the whole the child's 'needs' were focused on their ability to function in school such as with mobility issues, access to the environment and curriculum and with assistance necessary for self help skills. They

also included other developmental areas indirectly affected by their physical impairment, such as social relationships and self esteem.

As well as the child's SEN being viewed in terms of function and access in school, their needs were also viewed in terms of their physical development. From the health service perspective, therapeutic interventions such as muscle strengthening (e.g. Eek *et al.* 2008), prevention of secondary musculoskeletal impairments (Pountney *et al.* 2009) and maintenance or development of function and skill repertoire (Mayston 2005), were considered to be important in maximising a child's physical potential. In this study physiotherapy and OT interventions were considered necessary to meet the child's 'special educational needs' and thus a legal requirement to be met by the school (DfES 2001b).

Parents therefore considered it a right for their child to receive therapy at school and viewed school as the main environment for this to be carried out. Although the trend is towards schools managing children with SEN without a Statement (DCSF 2008), specifying therapy as a legal requirement, parents may still continue to expect their child's therapy needs to be met in school. Recent health and other government policies regarding children, e.g. Every Child Matters programme (DfES 2004a), have taken a more holistic approach to a child's development. They endorse the view that a child's physical needs are integral to their overall development and well being, and thus a matter for schools to address.

In this study the 'special educational needs' of the child were thus viewed as the therapeutic management of their physical impairments as well as the impact of these impairments on their education and participation in school. One of the most important findings was that school staff perceived the child's 'special educational needs' in these two quite separate ways, impacting on how their physical needs were managed within the school environment and on inter-agency working.

Collaborative working

As in Mukherjee *et al.*'s (2000) study, where they found that teachers viewed health and education to be two separate worlds, aspects of the child's physical needs that were viewed as 'health' related, were considered to be the responsibility of the therapy services. This included therapeutic interventions such as motor programmes or the use

of some specialist equipment such as standing frames or wheelchairs. On the other hand, where the child's physical impairments impacted on their participation within school activities or the environment, the class teacher was more likely to view this as their responsibility. Sam's teacher, for instance, decided what type of mobility equipment he should use for his PE lesson or when out at play. Although this may appear to be a sensible way of viewing the child's needs, in doing so, their needs were not considered in a holistic way, with consequences for knowledge exchange and effective collaborative working.

An important finding of this study was how different models of managing the child's physical needs in school impacted on an integrated approach. One aspect of this was the model of service provision utilised by the therapy services in schools. Although there have been studies exploring various models of practice for therapists working in schools, there has been little research into the current model of practice within schools in the UK. Most research has been within SALT services, which often use a consultative model of practice in mainstream schools (Dockrell *et al.* 2006). Other countries use models such as integrated models of therapy (Hanft and Pilington 2000; Sekerak *et al.* 2003) where therapists work with teachers within the classroom, or direct models working directly with the child. The therapists in my study primarily followed a consultative therapy approach (Sandler 1997), involving indirect intervention with school staff carrying out therapy programmes or management strategies with the child (Hartas 2004). On occasions the therapists worked directly with the child, such as for assessment purposes, setting up of equipment or for more complex therapeutic interventions.

I have been able to identify from the case studies some of the difficulties regarding the efficacy of this consultative model alongside a SEN framework in the mainstream setting. This model relies on school staff identifying difficulties and seeking therapist's advice on various aspects of the child's physical management within school, such as transfers, mobility, fine motor skills, self help skills, and seating. Although therapists can anticipate some of the difficulties the child may face within school, they need to be proactive in finding out about difficulties in the classroom, in PE or out in the playground they may not have considered. This model therefore relies on school staff

having sufficient knowledge to recognise that a child has a difficulty in function or participation and that a therapist's advice may be beneficial.

As identified by Baxter *et al.* (2009) in their study on SALTs working in schools, one of the most important factors influencing the efficacy of the consultative model was effective communication. Over the last decade there has been a rapid growth in the employment of TAs to provide additional support for children within the classroom, and to undertake specific activities to support children with SEN (Alborz *et al.* 2009).

Although there has been research into the work of TAs, with regard to the child with physical impairments most research has focused on their work with the child in class (e.g. McVittie 2005; Egilson and Traustadottir 2009). I have been unable to identify research exploring how TAs work collaboratively with therapists to manage the physical needs of the child in class or undertake therapy interventions with them at school.

In this case study, the model of provision for the child with cerebral palsy involved TAs taking responsibility for therapeutic or 'health' aspects of the child's SEN. As a consequence, the therapists usually liaised directly with the TA or in the case of Zac, the SENCo, to discuss physical management strategies or to teach specific therapeutic interventions. Their physical needs were therefore viewed within an SEN framework with TA time allocated to meet the child's specific needs. The class teacher had very little contact with therapists except for at the annual review meeting. Although they might have viewed themselves as responsible for the child's holistic management, most verbal advice from therapists was given to the TA even for aspects of the child's physical management outside of their therapy programme. This is in accordance with the findings of Mahon and Cusack (2002) that teachers had little contact with therapists. Although the therapists in my study considered that they made themselves available for the teachers to ask for their advice, teachers rarely did so. Lack of time has been highlighted in other studies as impacting on inter-agency communication (Lightfoot *et al.* 1999), but it was the perception of responsibilities as well as relationships between therapy and school staff that appeared to be equally important factors. Class teachers did not consider it their role to be involved with details of the child's therapy programme and consequently relied on TAs to liaise with the therapists for this and all other aspects of the child's physical needs.

Relationships between school staff and therapists have been found to be critical markers of successful communication (Sekerak *et al.* 2003). As adequate relationships did not develop between the therapists and the class teachers, there was little direct sharing of information and learning, which affected how teachers managed the child on a daily basis and planned for their physical needs. The responsibility for the child's physical management within the classroom was either shared between the class teacher and the TA or entirely that of the TA. Although TAs did share some of their knowledge gained from therapists with the class teacher, there were many factors hindering this exchange of information such as insufficient time and organisation of teaching support time. Inadequate relationships impacted on how confident teachers felt in seeking out therapists for advice and meant that therapists chose to liaise directly with the TA with whom they had a good relationship.

As class teachers were rarely involved with the therapists, they made decisions impacting on the child's functioning and participation using knowledge gained either from previous experience or from written reports. Although studies have highlighted the importance of written information for schools from health professionals (Mukherjee *et al.* 2000, 2002), in my study this information was only shared once a year at the annual review meeting and therefore could not take into account the child's changing needs. Perhaps due to more traditional communication links, teachers were more likely to ask for advice from other teaching colleagues regarding the management of the child's physical needs rather than from therapists.

As class teachers were responsible for curriculum planning it was important that they consulted others when making decisions affecting the child's physical management or participation. Sekerak *et al.* (2003) concluded from their research that therapy needs to be planned for when the child is in an optimal state and not just fitted in when possible. On the whole in my study the planned activities for the whole class influenced when the child would undertake their therapy so that the child would miss out on as little as possible. If the class teacher consulted the TA with regard to when or how to fit therapeutic interventions into the child's day, the child was more able to participate in class activities. When the teacher did not involve the TA in curriculum planning the assistant was often powerless within the classroom situation to facilitate participation for the child.

Class teachers viewed all activities within the classroom and the general curriculum as their responsibility, yet for the child with cerebral palsy, rarely consulted therapists in these matters. Sekerak *et al.* (2003) proposed that it is important for therapists to be involved in aspects of school such as the planning of space within the classroom environment, but this was not the case in this study. It was a similar scenario for other areas of the child's participation such as PE lessons, mobility in the playground or school trips, where the therapists were rarely consulted. Sam's teacher, for example, did not consider asking the physiotherapist for advice when he started swimming lessons even though he had obvious difficulties with this. Although therapists did advise on some aspects of the child's functioning and participation, by not working in the classroom or communicating directly with the teacher, their influence in this respect was limited.

Studies exploring multi-agency and inter-agency working in children's services have identified issues affecting collaboration and the complexity of inter-agency relationships (Farmakopoulou 2002; Robinson and Cottrell 2005). Farmakopoulou (2002) argues that unequal power relations due to differences in information exchange or resources may affect partnership working. In my study information exchange was affected by what information different staff groups sought as well as by how this was shared. Schools were responsible for how much resource to allocate to meet the child's needs including time for liaison with the therapists. Therapy services in turn had resource limitations reflected in the number of visits a therapist could make to a school and time to support staff. Although therapists expressed good working relationships with all the schools in this study, by following a consultative model of practice they missed many opportunities to identify and consult on aspects of the child's functioning and participation. By only having one review meeting per year to discuss all aspects of the child's needs, schools relied on relationships between therapists and TAs to collaboratively problem solve situations as they occurred.

Policy guidance over the past decade (e.g. SEN Code of Practice (DfES 2001b); Aiming High for Disabled Children (2007)) has emphasised the importance of working with parents and of joint goal setting with families including the child. Studies exploring collaborative goal setting with families have found that it contributes to improved working relationships, adherence and thus effectiveness of interventions (Carter *et al.*

1994; King *et al.* 2004). Collaborative goal setting between the family, school and therapy services with regard to a child's physical needs has, however, not been well researched within the SEN model of practice.

In my study, by viewing therapeutic provision in school in terms of fulfilling the requirements of the child's Statement of SEN, the child's physical management at home was considered to be a separate matter. School staff rarely knew what physical management strategies were undertaken at home and this did not appear to be discussed in school reviews. Not only therapeutic interventions, but other strategies affecting the child's function and participation were not always shared between home and school. Schools worked to a SEN framework where the child's 'health' needs at home were the responsibility mainly of the therapy services and therefore not a matter to be involved in, even if they were undertaking similar interventions at school. When a parent did not appear to be following therapeutic advice at home, one school in this study took a child-centred approach by ensuring that at least at school, her therapeutic needs were met. School staff were however, more likely to involve parents when there were problems with equipment or if therapy impacted on other activities at school, although participation was viewed as largely a school responsibility. Although all the children had goals set in their IEP, these were not always collaboratively made nor involve the child or the parents. How children were consulted in the management of their physical needs is discussed in the two following themes.

In contrast to this model, the physiotherapists tried to take a more holistic, family-centred approach (King *et al.* 2004) to the child's overall physical management, trying to balance the physical needs of the child at school with activities at home. This role would be in keeping with the ICF model (WHO 2001) where a child's health needs are viewed not only within the concept of body structures and functioning, but the impact of this and other factors such as the environment, on their activity limitations and participation. The contrast to the SEN model is illustrated in figure 9.1. For the child with cerebral palsy, physiotherapy and OT interventions aim to influence all areas of the child's functioning and participation (Palisano *et al.* 2004). Current guidance for paediatric physiotherapists (APCP 2009 p.21) promotes their role in inclusion so that advice is provided to schools when '*physical difficulties could impact on [the child's] day to day educational life, whether it is in relation to access to the curriculum, or in*

being able to participate in every day school life, in order to maximise function, participation and inclusion'. Therapists in this study therefore considered their role not only to provide or to advise on therapeutic interventions but to support school staff in the child's everyday functioning and participation. In reality however, with the consultative and SEN models of practice resulting in little collaboration with the class teacher, they missed many opportunities to consult on participation.

Figure 8.1 SEN model/ICF model for meeting physical needs of child

SEN model	ICF model
Identify child's SEN within context of school	Needs identified within context of home, family and school
Identify necessary provision	Multi-agency collaboration to consider needs within appropriate environment
Seek advice/support from outside agencies	Multi-agency collaboration
Provision within school (school responsibility)	Provision within different environments dependent on environmental and personal factors (joint responsibility)

This study has identified how the child's additional physical needs were viewed within the SEN policy framework. By viewing the child's physical impairments as their 'special educational needs', schools acknowledged their responsibility for meeting these needs within the school day. 'Health' needs were however, viewed quite separately from their other needs impacting more directly on school life. This view influenced how information and knowledge was shared particularly between class teachers and therapists. This in turn affected the child's participation and inclusion, and how collaborative goals could be set between all parties.

8.2 Theme two: Achieving the goal of participation

The concept of participation was an overarching theme common across all cases in this study. This is not a surprising finding as participation has become a key goal in the drive towards inclusion in society (Inclusion International 1996) and thus within schools: inclusion has been described as increasing the participation of pupils within the cultures and curricula of mainstream schools (Booth *et al.* 1997). The concept of participation however, is not a simple one and needs to be viewed in a multi-dimensional way. In the context of health, participation is defined in the ICF as ‘involvement in life situations’ (WHO 2001). This definition of participation focuses on the performance of an individual, describing what an individual does (with or without assistance) in his or her current environment. It conceives functioning and disability as the dynamic interaction between health conditions and contextual factors. For the child with cerebral palsy, participation within school may not just be matter of providing suitable physical access or specialist equipment (as might be indicated by a SEN framework), but is influenced by the dynamic interaction of the child’s personal abilities and difficulties, and the environment in which they are aiming to participate. The environment cannot be viewed as solely the built environment, but encompasses social factors, attitudes of those involved with the child, as well as organisational frameworks and practice. A more holistic view of the management of the child’s physical needs therefore should consider their needs within the context of participation.

In line with the move towards increasing inclusion, there has been a growth in the number of studies exploring the participation of children with physical disabilities in mainstream schools. These studies have aimed to measure how much a child participates within the school environment (e.g. Simeonsson *et al.* 2001) or to identify barriers to participation (Hemmingsson and Borrell 2002; Law *et al.* 2007). A few studies have explored children’s personal experiences of participation at school (Goodwin and Watkinson 2000; Asbjornslett and Hemmingsson 2008).

These studies have identified some of the factors influencing participation such as access to the environment, adaptation of activities or the curriculum, and attitudes of staff. Although these were also highlighted in my study, I found that one of the main issues with participation was the dilemma of managing the child’s complex needs within an ethos of inclusion. As Lewis and Norwich (2005 p.5) argue, there needs to be

a 'continua of teaching approaches' to meet the different needs of individual children ranging from 'normal' adaptation in class teaching to a greater degree of adaptation for those with significant difficulties. In my study the child's needs were often managed alongside the needs of other children by adapting the class activity or by using specialist equipment to aid mobility or function. In this way the child could participate with the class in a similar fashion to other children. This approach however, did not always accommodate for the child's individual needs. As Lewis and Norwich point out sometimes the child needs to take part in programmes such as a physiotherapy exercise programme that have separate or distinctive curricular goals. It is possible that by meeting this individual need, the child will miss out in some way from the rest of the class' activities. This dilemma of balancing meeting individual needs with inclusion and the need for priorities will be discussed through the issues of adult support, specialist equipment and classroom and teaching practices.

Effect of adult support

Children with cerebral palsy often rely on the assistance of adults to support them within the school environment. Studies have explored the impact of TA support for children with SEN (e.g. McVittie 2005; Takala 2007), but as Egilson and Traustadottir (2009) note there has been little work exploring how help is provided for children with physical impairments in this setting. In this study, each child had a designated TA to support them within the classroom, but they were also supported at times by other staff such as teachers, other assistants or lunchtime staff. How adults viewed their role with the child and the way in which they gave help, impacted on the child's participation.

In line with Egilson and Traustadottir's study (2009), I found that the designated TAs did not have a specific job description for their role with the child. A recent review of studies on the role of TAs in the UK did not detail any issues relating to how children with physical needs are supported in schools (Alborz *et al.* 2009). In my study TAs perceived their role primarily in terms of facilitating the child's functional performance by assisting them with physical activities that they were either unable or found difficult to perform by themselves or by adapting work to facilitate access to the curriculum. They also acknowledged an important role in providing therapeutic input for the child. In managing the child's physical needs, they did not receive any specialist training other than that provided by the visiting therapists and information was often passed from one

member of staff to another. This was therefore a diverse role, requiring flexibility, knowledge and sensitivity to know when and how to offer support to the child to facilitate their participation.

Where TAs position themselves in relation to the child has been found to be an important influence on the child's participation (Hemmingsson *et al.* 2003). In my study, by sitting right next to the child, TAs were readily available for assistance if the child asked for it and more likely to notice if the child was struggling or unable to perform an activity. An adult sitting next to the child, however, did impact on the child's social participation. Josie for example, was more likely to talk to her assistant than to her peers and other children would often talk through Zac's assistant rather than directly to him. Over-dependence on assistants has been expressed as a concern (Farrell *et al.* 2000), but in my study schools tried to prevent this by only offering adult support for part of the day, by the TA working more generally within the classroom or by a number of assistants supporting the child.

Schenker *et al.* (2006) argue that the presence of a TA also decreases the opportunity for the child to interact with the class teacher. Although the close proximity of the assistant might influence how the teacher interacts with the child, my data showed that the responsibility the class teacher considered they had for the child's learning and participation was an important factor. In the cases where the class teacher considered that they were responsible for this, they developed a closer relationship with the child. Where this was not the case, as with Zac, the class teacher did not involve herself in his learning and relied on the assistants to facilitate his participation in all class activities.

How class teachers perceived their role with the child therefore had an impact on the child's participation. If the class teacher followed a more SEN model and left the child's 'special educational needs' to be managed primarily by their TA, they did not involve themselves in the child's participation. Class teachers who took a more inclusive approach perceived their role as ensuring the participation of all children in their class. Sam's class teacher for example, often involved him in class activities by turning his chair to face the right way or using different mobility equipment. The child's participation was particularly facilitated where the class teacher and TA worked collaboratively. Sam's class teacher again was proactive and on one occasion explained

the 'drawing a silhouette' activity to his TA prior to the lesson so that she could think about how to adapt it for Sam to fully join in.

'Floating' around the classroom to give support as necessary has been recommended by Farrell *et al.* (2000). Although this might promote social participation by enabling more interaction with peers, I found that when this was the case, the TA often missed opportunities to assist by being too far away or too busy to notice. For the child with a physical difficulty, limited mobility affected them in different ways. Sam's TA considered that all she needed to do was to 'set him up' in his seat and at the table, so that he could work independently with his peers. This was possible for much of the time, but at other times, he had to rely on his peers for assistance, as he could not fetch his book from the other side of the classroom or access the learning materials in the same way as the others.

Although school staff were positive about encouraging the child to use their peers to support them, this participation in a peer community of support rarely seemed to occur. It was more likely to be the adult who would ask other children to help. Josie's class teacher for example, often asked one of the children in her class to help her with her writing, move her chair for her or wait behind with her until she was ready. This was in contrast to Sam's class teacher, who although similarly positive about participation rarely asked any of the children to help Sam. Instead, she would help him herself or ask another adult to do so. The children with cerebral palsy were generally reluctant to ask other children to help them unless they were offered help, and preferred to wait for adult assistance. Teenagers with physical disabilities have also voiced that they do not want to be helped more than necessary and feel 'useless' (Doubt and McColl 2003 p.146). It may be that for the child to use their peers for support they need to feel confident that this will be done willingly and that they have sufficient control to only be helped for activities when it is required.

It was not only in class where the child's social participation was affected by the presence of adults, but also at break times. I found that school staff often tried to positively influence the child's social participation by facilitating independent mobility without an adult by their side. In many ways this meant that the child was then able to socialise in a similar way to their peers. The child with mobility difficulties however, does not always have equal opportunities to socialise and play as their able-bodied

peers. This was sometimes due to lack of access to all areas of the playground, but also due to differences in their physical ability. Sometimes it was important therefore that staff did not stand back, but positively assist in influencing their participation.

Studies exploring pupils' views of their support needs highlight the importance of school staff who understand their difficulties (Mukherjee *et al.* 2000). In my study, where the child was not always supported by their designated TA, knowledge of the child's abilities was most important in facilitating the child's participation. When the adult knew the child well, they were more likely to positively affect their participation by organising the appropriate equipment, situations or activities where the child could join in and be involved. They would adapt activities to suit the child or ensure the appropriate equipment was available for the child to use. If the adult was unsure of the child's needs as in the case of stand-in assistants or teachers, they sometimes used equipment they felt was the safest rather than the one more likely to ensure participation. In one of the case sites, teachers did not encourage the child to join in, perhaps in case they were asking the child to do something beyond their capabilities. As Hart (1996 p.94) argues, the language of special needs can 'raise doubts in teacher's minds about the relevance of their own expertise and resources'.

It was not only understanding the child's physical abilities and difficulties that was an important factor in the child's participation, but whether staff allowed the child choice and autonomy in their participation. Consulting children in matters which affect them has become integral to many policy developments (e.g. Article 12 of the UN Convention on the rights of the Child 1989; NSF for Children and Young People 2004). As Skar and Tamm (2001) point out, the assistant can act in a variety of roles with the child such as 'parent', 'friend' or in a more professional capacity, influencing the way in which they allow the child to make their own decisions. In my study I found that the children knew when and how they wanted to participate, but sometimes needed their TA to facilitate this. Listening to the child was therefore an important factor in this (echoing Franklin and Sloper 2009). When adults asked for the child's views and acted on them, the child was helped to participate in activities of their choosing. This was particularly the case for break times when the child was more likely to be given a choice about who to sit next to for lunch or which equipment to use in the playground.

Adults sometimes acted in what Skar and Tamm (2001) describe as a 'parent' role, whereby they would make decisions for the child or perhaps ask the child's opinion but then not act upon it. This was more likely to be the case for activities relating to the curriculum, perhaps as this was considered to be the teacher's or an adult responsibility. Similarly for 'health' interventions within lesson time, the child was given little choice as to when or where they should use specialist equipment or undertake their therapy programme. These interventions had to be 'fitted into' the school day and thus considered to be the responsibility of the class teacher or SENCo to organise. As identified 'needs' within an SEN framework, these were requirements to be met within school.

Enabling the child's participation was therefore a delicate balance between providing help when necessary, allowing the child autonomy in decisions regarding their participation, and enabling social interactions to occur.

Use of equipment

There has been little research into how specialist equipment for children with physical impairments impacts on their participation in school. All the children in this study used equipment at some time in school to meet their therapeutic needs, increase their functional performance or facilitate independence and participation. This included equipment such as a supportive seat or standing support, equipment to aid written output or fine motor skills, and mobility equipment. This study highlighted the conflicting priorities for the use of equipment and the need to consider its use within the context of participation. Although in all cases, school staff were generally positive about using equipment and for the child to have the same opportunities as others to participate, I found that specialist equipment could both facilitate and hinder participation.

Mobility aids such as powered wheelchairs have been found to be important in facilitating a child's independence and social participation (Bottos *et al.* 2001). In my study I found that this equipment facilitated the child's participation by allowing them to socialise without an adult being present and this was sometimes the only time during the day when they did not have an adult by their side. It enabled more autonomy as to where the child wished to go in the playground and with whom they wished to play.

There were tensions, however, as to how such equipment was used particularly inside the school building. Space was an important factor influencing whether staff facilitated use of this equipment. School staff voiced concerns regarding manoeuvring equipment indoors due to the possible disturbance to other children or from a safety point of view. Even though Sam, for example, was able to move independently either in his walker or powered chair, he was not facilitated to do so within the classroom. On the odd occasions when he did, rather than being in a static chair, he was able to make his own decision about where he wanted to go within the classroom or to whom he wished to talk.

Conflicting priorities was an important issue regarding whether equipment was used. It took time to transfer a child into different pieces of equipment and often staff decided that it would be better for the child to participate in the activity at the same time as others in the class, rather than spend the time transferring into mobility equipment. It was easier, for example, to wheel Sam to the next room in his manual chair rather than spend time transferring him into his walker so that he could walk there himself.

Although maintaining muscle strength was a therapy goal for him, as was independence, these goals conflicted with the goal of participating in the activity at the same time as the other children. Inclusionists such as Mittler (2000) might argue that the school needs to make adjustments in their practice to ensure that the needs of the child are met, rather than the child having to 'fit in' and keep up with the pace of the class. The child's needs for mobility were often not considered within the class activity.

This study highlighted the importance of considering the goal for the use of equipment and balancing this with other goals. Was it more important for the child to practice motor skills, develop independence or be doing an activity at the same time as other children? A standing frame for example, might improve the child's ability to write or have a therapeutic benefit by improving bone density (Bush *et al* 2009); yet impact on the child's social interactions by the child being at a different height from their peers. When this was considered school staff would plan for the child to use their standing frame when the whole class were doing more solitary activities rather than group work. If use of equipment was viewed just as an activity which needed to be 'fitted into' the day whenever possible to meet the child's 'health need', then the child was more at risk of isolation. Planning for the use of equipment was therefore an important factor in

deciding on goals and facilitating participation. These decisions were often discussed in planning meetings although these were usually only held once a year and without the involvement of the child. Much of the time therefore on-the-spot decisions were made by the individual member of staff. How much they consulted the child depended on their personal attitude towards autonomy.

Decisions as to the use of equipment required not only planning but the involvement of all parties including the child. The child was often asked for their view on which equipment they would like to use particularly in a break-time situation. It may be that in these situations it was felt that the child should have the same choices as other children would have. When decisions were made regarding use of mobility aids within lesson time or of a computer to aid written work, school staff were less likely to ask the child for their view. As Allan (2008 p.103) has pointed out, despite policies to promote children's rights and their views of their experience in school, power relations determine that these rights are 'minimalist' and that they have little control over important issues such as how lessons are taught or the curriculum. The child with a physical impairment was therefore possibly treated as all children, with few decision-making powers.

Classroom organisation and teaching practice

For the child with physical difficulties, participation at school may require adaptations to the curriculum, classroom or school environment. As Barton (1997) argues, inclusion is about altering existing school systems and practice to ensure the participation of all pupils. In this study I found that there were many instances where staff adapted and differentiated the curriculum in creative ways to enable the child to participate. This required knowledge of the child's strengths as well as their difficulties to be able to make appropriate adjustments. Physical education was a particularly difficult area for inclusion. As Hemmingsson and Borell (2001) concluded in their study on environmental barriers in mainstream school, children with physical impairments face barriers to participation originating from how learning is organised and carried out in schools. Although my purpose in this study was not to explore teaching practice as such, I identified how some classroom practices particularly impacted on the participation of the child with a physical impairment. I also highlight

the tensions between meeting the child's individual needs and the collective needs of the class.

I found that when class teachers considered the child's needs in the planning of the class activities, they were more likely to ensure that the child had the space, assistance or right equipment to enable them to participate. When Josie had plasters on her legs for instance, her class teacher made sure that her special chair was brought into assembly to enable her to sit with the other children. Zac's teacher on the other hand did not consider how he might play the drums in the music room where the rest of his class were sitting on the floor. As he did not have his usual classroom table to lean on, he had to sit at a table away from the group. Any change of room or movement around the classroom therefore required thought and preparation as to how best the child with mobility difficulties could fully participate. This was a difficult task and often on-the-spot-decisions were made instead to enable the child to keep up with the class' activities.

Similarly to Hemmingsson and Borell's study (2001), I identified that the way school activities are organised can affect a child's participation. In my study specific classroom practice, such as sitting on the floor or moving tables to work with different children, was often an issue for participation. When other children had the opportunity to come to the front of the class for example, the child with cerebral palsy often could not do so due to lack of space, time or assistance. 'Carpet time' meant that the other children sat on the floor in front of the teacher and unless the teacher made space for a wheelchair or the child was in equipment that could be moved, they were often sat away from the group. At times when the teacher considered the child's needs, their equipment was more likely to be accommodated for and space made so that the child could be part of the group. The child was more likely to be engaged in the activity when they were included in the group with the other children. During lapses in inclusive thinking, participation was less likely to be facilitated. Zac, for instance, often lost concentration and looked around the room when he was placed out of view of the class teacher.

Moving tables to work with different groups of children appeared to be common practice in this study with implications for the child with cerebral palsy compared to other children. Sam, for instance, often had to rely on others to assist him with his fine

motor skills or to fetch things for him in the classroom. Unless his TA was readily available to help him in these situations, the relationships he had with the other children in his group affected how confident he felt to ask for their assistance. Although he usually used a sloping desk top at his usual table to facilitate his writing, when he moved to a different one this was sometimes forgotten. When the class activity was not a static one, but required some movement around the environment, I found that the child without independent mobility was often at a disadvantage when left on their own to work in a group.

As Hemmingsson *et al.* (1999) found, the teacher's style determined the working pace of the class. In my study, when the teacher placed an emphasis on time, the child with cerebral palsy was often at a disadvantage. Children with cerebral palsy usually have slower fine motor skills (Hemmingsson and Borell 2002) and therefore, even if they are able to complete an activity they require additional time to do so compared to other children. I found that if the teachers were aware of this, they would put strategies in place to allow the child to finish the activity at another time.

Physical education lessons are one area of the curriculum identified by pupils with physical impairments as presenting difficulties with participation (Mukherjee *et al.* 2000). A study by Goodwin and Watkinson (2000) on inclusive PE, found that children wanted activities to be adapted to suit their needs and abilities even though they might be performing activities differently. Lending support to these findings, Sam for instance did indoor PE in his walker and although could not perform the same dance movements as the others in his class, enjoyed moving about in his walker as best he could. Zac on the other hand, did not have PE lessons with his class, but with others from the special support unit. For the child with limited motor skills, there was a tension between finding meaningful activities for him in the PE class and doing more specialist PE adapted to his needs. Zac however, was not asked his opinion as to whether he would prefer PE with his class or with the others from the unit. Perhaps as Asbornslett and Hemmingsson (2008) found in their study, children might feel that sometimes it is more important to be where activities are happening to feel part of their peer group, than to meet their individual needs.

Even for more physically mobile children, when PE involved more competition as in team games or races, teachers expressed difficulties in knowing how to include the child

with cerebral palsy. Sports day was a particular challenge. A review of National Curriculum PE (Smith and Thomas 2006) found that team games do not lend themselves easily to some pupils with SEN. The teachers in my study tried to include the child with cerebral palsy by encouraging them to join in, in whatever way they were able to. The emphasis on participation was for them to do 'their best' with the activities given to the whole class. Although this meant that the child was able to participate in some way in the class activity, it did not however always meet the child's individual need to develop their physical skills. Sam's teacher for instance expressed enthusiasm for him to develop skills in wheelchair basketball. Instead of practising different skills or skills at his level in the class PE lesson however, he was pushed around by his TA in his manual chair to keep up with the pace of the class. In contrast to this, it may be argued that although Zac did not participate in his class PE lesson, by attending his specialist PE lesson, he was instead encouraged to develop skills at his individual level. PE lessons therefore highlighted the tension between the goal of participation in the class activity and addressing the child's individual physical development. It also emphasised the issue of 'difference' which will be discussed in the following theme.

Integrating therapy goals into everyday life is a key aim of therapeutic intervention in schools (APCP 2009). For example, by practising motor skills in a variety of situations and thereby providing repetition of skills and movement opportunities, motor learning is thought to be enhanced (Larin 2000). The school environment therefore provides ideal opportunities for practising motor skills such as walking, balance activities and fine motor skills. In this study I found that there were occasions where therapeutic goals were integrated into the school activity with a positive impact on the child's participation, whilst in other instances, by promoting therapeutic goals the child's participation was adversely affected. Practising driving skills in a powered wheelchair or walking skills for example, may be an important goal for independence, but could potentially interfere with social participation if break time is used for practice. Performing physiotherapy exercises within the classroom meant that Josie did not miss out on her lessons, but she felt that this interfered with her ability to concentrate and learn. There was therefore a need for careful consideration of how to integrate therapy goals with those of education.

This study showed how facilitating the participation of the child with cerebral palsy within the mainstream school environment was a complex balance of many factors. School staff had to balance meeting the child's individual needs alongside their active participation in activities. Data highlighted how a holistic view of the child's needs is necessary to balance these needs and make decisions regarding priorities.

8.3 Theme three: Being the same, being different

The third important theme identified in this study impacting on a holistic approach to the child, was that of 'difference': how this was viewed from the child's perspective and by others, and the effect of differing views on the management of the child's physical needs. The 'dilemma of difference' is an issue that has been identified by a number of scholars (e.g. Artiles 1998; Norwich 2008). Norwich (1993), for example, found in his study of teachers' views of children with disabilities that there was a tension between identifying a child as being 'different' with all the stigma and possible negative consequences that may come with it, or not doing so and risk not meeting the child's individual needs. As many writers argue (e.g. Morris 1993) 'difference' can be viewed in both positive and negative ways. By recognising that a child has individuality with individual interests and needs, their difference can be viewed in a positive manner. On the other hand, 'difference' may be viewed as something that is not valued, resulting in the person being perceived as being of lower status or in some way unequal. Allan (2008 p.66) has proposed that a 'shift towards a more affirmative conceptualisation of difference could be useful for inclusion, possibly reducing the fear of difference or reverence to those who present differently'.

Although this 'dilemma' has been discussed in the literature with regard to a child's academic ability, there has been little research exploring its impact on the management of the child with physical needs in school. How does it impact on the use of different equipment or views of specialist activities such as therapy programmes? In this study, it could be argued that the child's needs were viewed on a 'continuum of difference'. In one respect a child's difference was clearly identified through the SEN process with specialist provision provided, whilst at the other end of the spectrum a child's 'difference' was viewed to be within the normal range of variation in the class. This view of 'difference' affected how schools made decisions to meet the child's individual needs. A central theme found in all the cases was a striving to treat differences, even

when recognised, in as similar a fashion as possible to the rest of the class. Staff deemed it important that the child should 'be the same' whenever possible.

The child's view of 'difference'

Gaining the child's view of their experiences of mainstream school has been a growing area of research in recent years. Many policies (e.g. SEN Code of Practice (DfES 2001b), Aiming High for Disabled Children (DoH 2007)) advocate the importance of listening to the child and involving them in decisions around their education and care in school. Although there have been studies exploring children's views of their school experiences (e.g. Curtin and Clarke 2005; De Schauwer *et al.* 2009), this case study focussed specifically on issues relating to their physical needs. The important findings were firstly, that the child often viewed their 'difference' in a different way from the adults around them and secondly, that they were rarely consulted in decisions where their 'difference' was a key factor.

As found by Asbjornslett and Hemmingsson (2008), the children in my study wanted to be where activities were happening and to be included in all the class activities. Participation in terms of being part of their peer group was a common goal. This meant that sometimes they had to perform different activities from their peers or perform the same activity in a different way. For example, Josie could not always join in with all activities in PE lessons and was therefore given different activities to do instead. She was very accepting of this as she, like the other children in this study, understood their physical limitations. The important finding was that the children prioritised their participation in class activities over any concern about their 'difference'. The children were realistic about their abilities and their difficulties and joining in was more important to them than whether they were able to perform activities in a similar way to others. The children accepted their 'difference' and to them this was not necessarily a barrier to participation.

Adults too often prioritised the child's participation over their 'difference' by enabling the child to use specialist equipment within lessons or by giving the child different activities to perform. This depended, however, on the adult's view of 'difference' and whether they viewed the child's participation or performance of an activity to be more important. It may be that staff's concerns about how Zac looked in his walker and their

own personal discomfort with this (Oliver 1996), were barriers to him participating in PE with his class. They also considered that he could not really 'do anything' and therefore felt that he could participate more actively when in a specialist PE lesson separate from his class. Zac on the other hand, would have preferred to do PE with his class even though he could only move in a limited way in his walker. Although he also enjoyed his specialist PE lessons, it was more important to him to be part of his class than to be able to perform more in a separate activity.

As Williams and Downing (1998) point out, a child's sense of belonging can be affected by how much they participate in activities alongside their peers. An important finding in my study was that for the child, 'being the same' meant that they were allowed to do similar activities to others even if they had to be performed in a different way. They did not want to be given entirely different activities to do instead of the class activity. As has been found in other studies, e.g. De Schauwer *et al.* (2009), children appreciate activities being adapted for them, yet still want to do similar activities. Josie for example, was unable to perform the maypole dances with her plasters on, but she did not want to do her physiotherapy exercises instead. She understood her limitations yet was much happier when her teacher enabled her to join in with one of the dances by holding her hand and moving round as best she could. Although this might change as she matures, at this time she was more concerned about participation than 'difference'. It seemed important to the children that they were given the opportunity to enjoy the same experiences as others.

Sometimes the child did do different activities from the rest of their class such as individual therapy programmes or use specialist equipment such as a standing frame. Echoing De Schauwer *et al.*'s participants (2009), the children in my study were very aware of their disabilities and the reasons why they did different activities from others in the class. Although they did not choose to have therapeutic interventions, they were generally positive about their need for it and were usually happy to undertake these activities at school. They were less concerned about any negative consequences of identifying their 'difference' than how this impacted on the prioritisation of this activity over the class' activities. It seemed that as long as the child considered the therapeutic intervention to be an important 'need' for them, they were accepting of the need to do something 'different', even if it meant that they had to be withdrawn from the class to

do so. The child however, was rarely consulted in timetabling or planning for their needs creating the potential for a conflict in priorities.

Although school staff were aware that the child might feel sensitive regarding their difference, I found that there was a reluctance to talk directly to the child about this. This may be due to staffs' own difficulties in facing disability issues as well as a view of the child's competence. Instead, decisions were made which impacted on how their physical needs were addressed using the adult's own judgements as to how the child might feel. It may be that, as Morris (1993) writes, able-bodied people may feel guilty about their own and others' physical ability, and therefore do not wish to point out differences. By not talking to the child, however, sometimes decisions were made regarding their physical management which negatively affected their feelings of 'difference'. Josie's class teacher, for example, was concerned that Josie would stand out in sports day as she would be last in the running race. She did not discuss this with Josie however, and instead made the decision that she would not do the race. Talking to the child about their view of their 'difference' was therefore found to be a difficult concept.

A 'continuum of difference'

In this study I found that the child's 'difference' was perceived by others in a number of different ways, impacting on how or whether they were addressed. This 'continuum of difference' ranged from one end where the child's 'difference' was readily identified and viewed to influence their function or participation to the other where their 'difference' was less readily acknowledged. Where the child's 'difference' was identified, the school would use specialist equipment, adapt the curriculum or provide additional support. From an essentialist view of disability, they were identifying 'needs' within a SEN framework and providing appropriate provision to meet these needs (Marks 1999). This perspective on difference was most likely when a child's 'difference' could not be managed in any other way, such as if a child could only walk with the use of a walking frame.

From this perspective, it could be argued that a child's 'difference' was viewed in a positive manner, by acknowledging their difference and making appropriate adjustments or provision as necessary. School staff would identify that a child had a difficulty in

some way and adapt the curriculum to enable the child to participate more fully or facilitate access. Sometimes they would go further to acknowledge the child's 'difference', not with the aim of enabling them to 'be the same' as other children, but to offer the child additional or different opportunities to their more able-bodied peers. Josie's headteacher, for example, arranged additional swimming lessons for her with an outside agency providing specialist sport facilities for children with disabilities. Even though swimming was not an activity her class was undertaking at this time, she considered that Josie had particular individual needs and therefore required different resources. As Shakespeare (2006) argues, sometimes there is a need to create more than a level playing field and additional arrangements are necessary to compensate for the child's difficulties.

It is argued in the disability studies literature (e.g. Morris 1993; Oliver 1996) that disabled people have historically been portrayed in a negative fashion, as abnormal human beings, or with afflictions viewed as abhorrent. In my study the child was usually viewed positively, but there were examples where school staff felt embarrassed by abnormal movements, strange or unusual equipment, affecting their management of the child. One of Zac's TAs, for example, felt embarrassed about using his communication aid as this equipment appeared too strange for her and she was self-conscious about using it with other children. Likewise, as his wheelchair was large and awkward to move, she would not move him nearer to the front of the class as she did not wish to draw attention to his 'difference'. In contrast to this attitude, other TAs did not worry about making the child 'stand out' in this way, as long as the child wished to do so. Being concerned about how the child's 'difference' might be accentuated or make them 'stand out' from others was therefore found to be an important barrier to how adults facilitated the child's participation.

Another important finding from this study was that whenever possible school staff would take the 'difference blind' or 'normalization' approach to meeting the child's needs (Roaf and Bines 1989 p.20). If a child's difficulties were such that they could still manage to function in a similar way to others in the class and participate in some way, they were less likely to be given additional support or equipment, or for activities to be adapted for them. For example, children with cerebral palsy often have fine motor difficulties, and although able to write, find it difficult to keep up with the pace of the

class. There is a dilemma here to either encourage the child to continue to write, albeit slowly so that the child can work similarly to the rest of the class, or use assistive technology where there is a risk of accentuating the child's 'difference'. This view that the child always wanted to 'be the same' and not 'be different' was prevalent in all cases. As has already been discussed, the child may have a different view to this, perhaps prioritising the achievement or speed of a task and in doing so risk being 'different', over struggling to do activities in exactly the same way as others.

Hemmingsson *et al.* (2009) found in their study of the use of assistive technology devices in school that children wanted to use ICT equipment more than they were facilitated to do so in class by their teachers. It may be that it is as important to respect children's desires rather than focus only on their needs (Allan 2008). In this study the child was rarely consulted over their views in this respect and instead decisions were made on their behalf.

Sometimes the child's 'difference' was viewed as an extension of differences seen within the class. In these circumstances, it was found that schools usually opted for a more collective approach to meeting different needs by grouping children with similar difficulties. This may appear to be a sensible approach as there is less risk of the child being stigmatised as 'being different' and separate resources are not required. Sam, for instance, was to start a writing group with others in his class to address his fine motor difficulties with writing. The problem with this approach from a therapeutic perspective however, is that school staff need to know when a child is not reaching their potential and if their difficulties do require 'different' resources. Although a study by Priest and May (2001) on the use of laptops did not identify attitudes to difference as an important factor in their use at school, I found that attitudes were important when the child's difference was less marked and they could 'manage' without a laptop. For the consultative model of therapy to be effective, school staff required sufficient knowledge of a child's impairment and potential for development to know when to access specialist knowledge or equipment.

In this study, by viewing 'being the same' as the optimum way forward, the child's 'difference' was sometimes ignored or not noticed. In one situation this might mean that the child was able to 'fit in' and be taught in a similar way to others in their class. In another situation this would create barriers to participation or learning for the child

by not meeting their individual needs. For example for the child without independent mobility, if learning required any movement around their environment, they were at a disadvantage by not acknowledging any assistance the child might require.

‘The dilemma of difference’ for the child with cerebral palsy was therefore one of meeting their individual needs at the same time as facilitating their sense of community within their class. The child’s own awareness of their ‘difference’ and how this affected their participation was often different from adults supporting them at school. There was however, very little involvement of the child’s views to influence how their physical needs were managed in school.

8.4 Limitations of the study

- As discussed in Chapter 4.2, one of the main limitations of a case study approach is that the findings are not generalisable in the same sense as in other quantitative research designs. I used purposive sampling to choose case sites where I could explore the phenomena I was interested in. The data produced are specific to these case sites, but the in-depth detail should enable others in similar situations to make use of the findings. Although I analysed the findings from all case sites to form my conclusions, they are not a representative sample of the larger population. As several authors argue however (e.g. Bassey 1999), I have used the findings from this study to put forward empirical statements which may be useful in other similar contexts and situations.
- Time limitations meant that I was only able to study three case sites. With more time I could have explored different situations and added to the findings from this study. Similar findings would strengthen the findings discussed here.
- Spending more time in the field in each case site would have added to my understanding of each case. I would have been able to follow up situations requiring more explanation and observe more situations to confirm or offer alternative explanations. In particular, as it takes time to develop relationships and trust with children, it took a few days before I was able to have more relaxed conversations with the child in the case. With more time I would have been able to explore the child's views in more depth.
- The cases were studied at particular times of the school year which may have produced different data compared to another time of the year. I wanted to ensure that I did not study a case when there were new staff at the beginning of the year, but the situations in real life are that there are often staff changes in a school. Any observation period cannot represent the changing situations over a whole year or even the different experiences of a child's primary school life. I tried instead to visit the school when the parents and school staff considered that it was a time when the child was experiencing as usual a school week as possible.
- Although I had informal discussions with many of the school staff, I was not able to speak to all those who were involved with the child during the course of the week. This may have produced different data as they may have held another

perspective on the situations. I did not include conversations with the other children in the class or out in the playground due to ethical permission.

Exploring their views more thoroughly would have added a different dimension to my data.

- The cases were conducted in primary schools and these findings may not be relevant for understanding issues within secondary school. In these schools there are different issues of mobility around school and transport of equipment due to frequent changes of classroom.
- As this was an exploratory study, it adds to the understanding of issues rather than guidance for practice. Further research is necessary to evaluate the effectiveness of current or different working practices.

8.5 Conclusion

This study has identified many complex issues in the management of the physical needs of the child with cerebral palsy within the mainstream school environment. It points to the need to view the child with a physical disability in a more holistic way: not just as a child with ‘additional’ physical needs requiring specialist input or equipment, or as a child to be ‘included’ within a mainstream class. The physical impairments of the children in this study affected many areas of their school life requiring consideration within the different contexts of the school day. In viewing the impact of the physical needs of the child in a more holistic way, their many competing needs or ‘desires’ (Allan 2008 p.97) can be considered within the context of their life at school and outside.

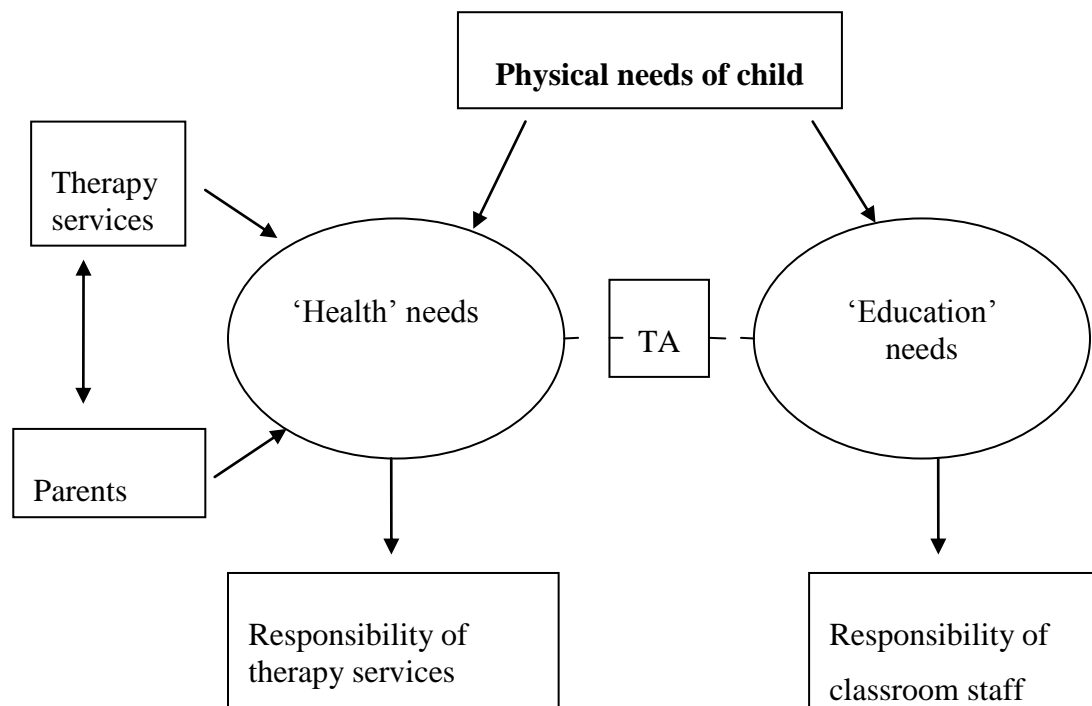
The most important finding in this study was that how physical impairments are viewed within the current SEN approach, inhibits a more holistic view of the child with physical impairments. It encourages the child’s needs to be compartmentalised, so that inter-agency practice only impacts on some areas of the child’s life at school, affecting communication and knowledge exchange of their needs. Rather than viewing the child’s physical needs within the context of their whole life both in and out of school, the SEN process focuses solely on school provision hindering a more holistic view of how their needs may be managed. By viewing the child’s SEN as ‘educational provision’ and therefore a school responsibility, the child’s and parent’s views, were often not sought in how this was provided for or how priorities were made.

In this study I found that the child’s physical needs were viewed in two quite separate ways; either as ‘health’ needs or as ‘education’ needs. The child’s ‘health’ needs were viewed within a SEN framework and regarded as the responsibility of the therapy and SEN services. By considering the child’s physical impairments as their ‘special educational needs’, this became a school responsibility involving schools ‘seeking help’ to meet these needs (SEN Code of Practice, DfES 2001b). In this way one might argue that it put the schools ‘in the driving seat’ with the power over where knowledge and information was sought and how this was used (Farmakopoulou 2002). Schools liaised with therapy services and parents primarily for the child’s ‘health’ needs, even though their physical impairments impacted on many areas of their school life. This aspect of the child’s physical needs was viewed essentially within a medical model of disability

with problems identified and appropriate provision organised to meet these needs. The child's 'health' needs were consequently managed quite separately by designated staff, impacting on how any knowledge and information gained in this area influenced other areas of their school life. The consultative approach to inter-agency working added towards the power balance, as schools decided where therapy services were involved in other aspects of the child's schooling and in this way influenced priorities for the child.

In contrast to this, where the child's physical function impacted on their learning or participation in school, this was considered as 'education' needs and the responsibility of classroom staff. Schools did not readily seek advice from therapists or from parents for the 'education' aspects of the child's physical needs even if this impacted on their school life. Teaching assistants were involved in both aspects of the child's physical needs, as they worked directly with both therapists and the child. Due to their position as an assistant however, they were not always involved in decisions guiding physical management strategies for the child. Figure 8.2 illustrates the model of practice found in this study.

Figure 8.2 How the child's needs were viewed



As the class teacher was not involved in the child's 'health' needs, they did not develop adequate communication links to gain knowledge and understanding in this area. With regard to the physical needs of the child, even parents had mainly indirect communication links with the class teacher via the TA, SENCo or therapists. As found in Baxter *et al.*'s study (2009) on SALT input in schools, communication links between class teachers and therapists were uni-directional with information primarily flowing one way from therapists to the class teacher. It was only at the annual review meeting that the class teacher and therapists would communicate directly. This meant that if the teacher was experiencing any dilemmas in managing the child's needs within class, they did not usually involve the therapists. Where communication was more direct, as between therapists and TAs or the SENCo and information was passed both ways (Hartas 2004), there was more joint decision making regarding the child's physical management.

Although the SEN process endorses a collaborative approach between all those involved with the child, including the child, without a more holistic approach there were many barriers to this. There was generally only one meeting annually to discuss the child's needs collaboratively with the emphasis on ensuring that the child's 'health' needs were met within school. Joint planning for the child's needs was seen as an important process, but in reality many decisions were made on a daily basis. The child, parent and therapist's views were in many ways valued, yet they were not involved in decisions considered to be a school responsibility: planning for the child's needs within the curriculum, how they were supported or how their needs were prioritised.

IEPs were generally not viewed as useful documents for sharing goals or priorities and therefore there was little commitment to ensuring that this was a truly collaborative process. It may be that as the child's 'health' needs were viewed as the responsibility of the therapy services, schools did not feel that they needed to be involved in setting goals for this aspect of the child's needs. IEPs were more likely to incorporate the management of the child's physical needs within class activities. Although paediatric physiotherapy guidance for working in schools (APCP 2009) advocates that therapy goals should be incorporated into a child's IEP, these do not integrate easily into this current system.

The physical management of the child with cerebral palsy within the mainstream school environment therefore calls out for a more holistic approach. As Shakespeare (2006) argues, the experience of a disabled person results from a relationship between factors which are intrinsic and individual to the person and extrinsic factors arising from the wider context in which the person finds themselves. Management of the child's needs is therefore influenced by intrinsic factors such as their physical impairment, personality or self motivation, but also by extrinsic factors such as staff attitudes, access within school, professional care or assistive devices. This interactional model is in accordance with the ICF model (WHO 2001) where the child's body structures and functions, activity limitations and participation are all influenced by environmental and personal factors.

This interactional model highlights how the management of the child necessitates an individual approach within the context of their family and school. Each child in this study not only had different levels of impairment, but different attitudes towards their abilities and limitations, and thus their physical management. Likewise their parents had differing aspirations and attitudes towards meeting their child's physical needs in school and at home. Each school although all positive towards meeting the needs of the child, had different extrinsic factors influencing how these should be managed. How one child might feel happily included in one school and consider their needs fully met may therefore differ from the experience of another child in a different school.

A more holistic approach to the management of the physical needs of the child in school would need to encompass both intrinsic and extrinsic factors relevant to the child. In this way, the management of their physical needs may be considered within the context of their whole life both in and out of school. The views of the child and their parents need to be integral to decisions regarding their physical management so that interventions may be balanced between home and school. Although schools may have more expertise in learning, the child and their parents have the most knowledge and experience of the child's physical abilities and limitations. There needs to be more collaboration regarding how these may impact on the child's functioning and participation in school. Communication links between class teachers and therapists require strengthening so that knowledge and information regarding the child's physical

management may be shared and thus impact on the child's functioning, inclusion and prioritisation of activities.

Discussing priorities with the child and their parents would highlight the need to consider how to balance the therapeutic aspects of the child's physical needs with their learning and inclusion. Although it may be possible for many physical activities to be integrated into the school day, such as the use of postural management or mobility equipment, others require further consideration. A child may be able to practice their sitting control for example within a classroom setting, but in doing so, may affect their learning and concentration. The children in this study undertook physiotherapy activities at school as was dictated by their Statement of SEN, but it may be that some children, particularly as they mature, might choose aspects of their 'health' needs to be met out of school so that other educational goals may be prioritised.

I now discuss the implications of this study for practice, policy and further research.

- The child and their parents need to be more involved in the everyday decisions that impact on the child's physical management. Rather than this being viewed as primarily a school responsibility, their voices need to influence how decisions are made on a daily basis. Adults need to be more aware of the differing views children may hold regarding 'difference' and how they see their needs prioritised. Communication is required at formal and informal levels to ensure that collaborative decisions influence practice.
- Using the interactional model, an individual approach is necessary to meet the needs of each child with cerebral palsy in varying circumstances. Decisions regarding the child's physical management therefore require a collaborative approach between the child, parents, school and therapy services.
- Viewing the child's physical management in a more holistic way should facilitate discussions regarding responsibilities in this area: how and where can the child's physical needs be best met? Parents need to consider how they wish to balance responsibilities in this area and how they and their child wish physical needs to be prioritised within school. This would assist therapists to target their interventions more effectively both within school and at home.
- Teachers require a level of understanding of the child's physical needs to be able to adapt the curriculum and activities to ensure inclusion of the child. Without

their involvement, the teaching assistant is not always in a position to facilitate this for the child. They need to understand how the child's physical limitations impact on their daily life in school, on participation and when physical or educational goals need to be prioritised. Closer working between therapists and teachers would facilitate this.

- As the child's physical impairments may impact on many different activities during the day, decisions need to be made as to how to balance their physical goals or other learning goals. These decisions would help to determine whether assistance is given to the child, specialist equipment is used or the child is left to work independently or with their peers.
- Even if obvious barriers such as physical access or lack of equipment are removed or minimised, there needs to be an understanding that children with mobility or motor control limitations face many subtle barriers within the everyday classroom situation. Being unable to physically move around the classroom environment has implications on their independent learning, development of social skills and group participation. How children are supported and facilitated to learn and participate therefore requires careful consideration.
- Communication links between therapists and class teachers require developing so that the child's participation can be further facilitated in class. This will enhance class teachers' confidence and understanding of the child's physical abilities and limitations to inform decisions and priorities made on a day to day basis. It will enable therapists to gain a greater understanding of the child's life at school and where their specialist knowledge may be beneficial. This should involve spending time in the classroom to observe everyday practice and challenges school staff face in managing the child's physical needs. This does of course have resource implications for therapy services and class teachers.
- Developing these links will facilitate the integration of therapy into everyday classroom situations. Developing a physical management programme for the child within class collaboratively with the child and all those involved with them, would enable integration of therapy alongside other learning. It would identify where therapeutic activities may be fitted in without adversely affecting

other learning or participation. It would also identify activities where goals need to be prioritised.

- How therapy goals are incorporated into the child's IEP requires careful consideration. For the child with complex needs, their IEP can only include a few targets to focus on and not encompass all their physical needs. A physical management programme however, should address these needs either through a therapeutic programme or within activities in class. The targets in the IEP should therefore be those that are considered most important to focus on at the specific time.
- The role of therapists within school settings need to be re-considered within SEN policy to incorporate a clearer role with inclusion. Although physiotherapists have a therapeutic role with the child to address their 'health' needs, they also need to be involved with the child's physical management in many other activities within school. Physiotherapists need to communicate this role to school staff so that they are not just viewed as addressing solely the child's 'health' needs.
- This study points to the need for further research in the following areas: a) how children and young people view their own therapeutic needs to be best managed within their lives both at school and out of school, b) What the additional issues are in managing the young person's physical needs in secondary school? And c) evaluation of a more holistic model of practice.

Examiners request for reflection

The role of the paediatric physiotherapist

Throughout the course of this PhD, I have reflected on my role as a physiotherapist working with children with cerebral palsy in mainstream primary schools: how I work within schools; why my experience might vary in different settings; and how this study has changed my views on practice. In this study, I focused on exploring how the child's physical needs are managed within the school setting rather than on interventions or practice outside of school. However, as school is only one environment where a child spends their time, I have reflected on my role in the child's life both in and out of school.

When I began this study, my aim was to focus on how the child's 'physiotherapy' needs were met in school. As a clinician I was working within a SEN framework where the emphasis in my role was placed on delivering therapeutic interventions within school. In this role I was concerned about school staff's training needs, about their competence and supervision to effectively manage a child's 'health' needs within the school environment. During the first phase of the study however, I realised that there was little clarity about what constituted 'physiotherapy' for the child. For some, 'physiotherapy' meant just exercise programmes and therefore the role of the physiotherapist was primarily to train school staff to deliver these in school. For others, it also meant enabling the child's physical function within the school environment and the incorporation of their physical goals within school activities. I realised that not only 'physiotherapy', but the physiotherapist's role, was not clearly defined. The important findings from this first phase were that participants were concerned that the child's physical difficulties impacted on their inclusion and participation and that their physical development was not always promoted on an everyday basis. I therefore decided in the second phase of this study to broaden my focus from the 'physiotherapy' needs of the child at school, to include how schools managed the day-to-day physical needs of the child within an ethos of inclusive mainstream education.

As teaching assistants and teachers are instrumental in managing the child's physical needs on a daily basis in school, I have reflected on their roles and how physiotherapists may best support them. What are the elements of 'physiotherapy' that can be

effectively taught to relatively untrained staff and how can staff promote the child's physical development throughout the school day alongside their education? I found in this study that parents, in contrast to physiotherapists, were rarely concerned that the child's 'physiotherapy' was undertaken by school staff rather than their physiotherapist. Is it that 'physiotherapy' at school has to be a matter of simple exercises so that they can be taught to relatively untrained staff to be carried out in this environment? Does the child however have other needs which cannot be met by school staff?

Over the course of this study, I have continued to practise clinically as a paediatric physiotherapist. Conducting this research has changed my personal approach to working with children in schools: I know that I have started to place more emphasis on facilitating their participation and inclusion; and ensuring that the child's voice is included in decision making whenever possible. Although my perceived role in school is often to manage physical interventions or the use of specialist equipment, I have thought more carefully how these interventions might fit into the child's life in school and helped school staff to consider how to balance these within the child's curriculum. I have talked more to the child and their parents about how they might wish these therapeutic interventions to be balanced between home and school.

I have tried to facilitate a more interactional approach with all those involved with the child. I have encouraged discussion about how to meet their physical needs across environments so that collaborative decisions can be made to suit the child's individual needs rather than focussing on the requirements of the SEN system. I have endeavoured to explain my role as a physiotherapist both in and out of school more clearly to others, what level of 'physiotherapy' school staff are effectively able to deliver and facilitated discussions regarding the impact of integrating physical goals within the school environment. I know that in my role I am sometimes not able to influence a more holistic view of the child's needs than purely the need for therapy programmes or the use of mobility equipment. There are many challenges therefore as to how physiotherapists can change thinking about the impact of a child's physical difficulties in all areas of their school life and how they can influence the child's participation and inclusion in school on a day-to-day basis.

Qualitative research methods and methodology

Prior to embarking on my PhD I had had little experience of qualitative research. I had previously only been involved in quantitative studies and felt comfortable with a more positivist approach. I knew however, that I needed to take a different approach to answering the questions in this research study and therefore set about exploring new methodologies and methods. My initial challenge was in getting to grips with an entirely different way of thinking and I struggled with understanding the many different methodologies and philosophical arguments. I initially found it difficult to connect how this understanding and learning would help me to develop a research strategy for my study.

I feel that over time, the many pieces of this puzzle gradually seemed to fit together. Through my reading and many discussions with my peers and supervisors, I eventually found a position with which I felt comfortable: a position which fitted my understanding of the nature of 'knowledge' and 'truth' and one which I felt I could coherently argue in my thesis. I was finally able to see the importance of this and how I needed to develop a logical path from my chosen methodology through to the methods I would use to collect and analyse my data. This was a major hurdle for me but one which then helped me to make decisions on methodology and methods. Writing the thesis was an important process in helping me to reflect on these decisions so that I could present a rational argument for my research process.

Another important challenge was how I engaged with theory in this study. When I came to this study, I had particular concerns in the field of physiotherapy in schools and had specific research questions. I did not start this study from a particular theoretical stance as is often the case in other qualitative studies. Although I had read widely about many different areas of theory relevant to my study, I had not taken the decision to use one particular theory to shape my study. My difficulties came when I had collected the data, but could not move forward from a descriptive stage of data analysis. At this point I began to re-read much of the literature I had previously read regarding different theories as well as other theories which were new to me. Through my reading and discussion with my supervisors, I decided that the theories of inclusive education and the social model of disability would be most relevant to my study and would help me in my analysis. By using these theories as a 'frame' for my data, I felt that I was able to

move from the descriptive stage of data analysis to looking at my data in alternative ways. I was able to see ways to link my data with the different theoretical debates within these theories, helping me to move forwards with my analysis.

I explored different research methodologies before deciding to use the case study approach. I found however, that case study best suited the research area I wished to explore and the type of questions I wished to ask. As I came from a health service perspective, I explored case study research within health as well as within education. It was initially quite a challenge to decide which type of case study approach would be most suitable within the primary school environment and what I could expect to be achieved from using this approach. Through reading many other studies, particularly within educational case study, I was able to see where to position my own study and which methods to use.

Writing up case study research however, within the confines of the PhD examination regulations, presented a significant challenge for me. Although I understood the need to convey my study in a concise manner, I felt it was equally important to include the detail necessary to demonstrate the complexity of methods required for this type of study and to fully report the findings. With the word number limitation, I was not able to include as many of the vignettes as I would have liked, which I consider would have added more depth to the data and examples of practice within the field. I was not able to fully explain some of the methods used in both phases of the study such as details of how I developed my topic guides or focus group methods. During the viva process however, I was given the opportunity to explain these methods more fully and to talk about some of the examples in the vignettes that I had not been able to include.

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Appendices

Appendix 3.1: Invitation letter to parents (phase 1)

Dear parent,

I am a children's physiotherapist and am currently conducting a research project for my PhD at the University of Southampton, on physiotherapy for children with cerebral palsy. I am writing to you to invite you to take part in this study. I am currently undertaking a research project looking at how physiotherapy services for children with cerebral palsy can be improved, both in and out of school. I am planning to hold discussion groups in order to hear the views and experiences of parents such as yourselves, as to how you feel that your child's physiotherapy needs are being managed at the present time. The following topics will be discussed during the session:

- Physiotherapy at school – who does the exercises with your child? Are you happy with the current system?
- Communication between school, therapists and home
- Physiotherapy out of school- how does that work for your child?

Each discussion group will consist of approximately 6 parents from the XXX area and last about one hour. It will be held at XXX Hospital, Child Development Centre. The session will be led by myself and a tape recorder will be used so that the discussions can later be analysed. There will not be any names used when the project is written up so that discussions cannot be traced back to any one person. The enclosed information sheet provides more detail about the research project.

If you would like more information about this project, please either telephone me on the above number or discuss your concerns with your child's physiotherapist. If you are willing to attend a discussion group, please use the attached slip and send it back to myself using the SAE provided. If however, you decide not to participate, your child's physiotherapy will not be affected in any way. Thank you for your time.

Yours sincerely

Sarah Crombie

Chartered paediatric physiotherapist , LREC 03/12/4a

Appendix 3.2: Topic guide for focus groups with parents

Parents were given four main areas for discussion. Other questions were used during the conversations for guidance.

Views on your child's physiotherapy at school

How is physiotherapy managed in your child's school? Is it during breaks or is your child taken out of class? How does it fit in?

Are there any issues in PE?

Does your child miss lessons? Do you/they mind?

Are they taken out of class? Do they mind?

Views on how physiotherapy is carried out at school

Physiotherapist / school staff?

Are they trained? Who by?

Understanding the child's problem

Views on training

Views on teaching assistants and physiotherapy

Helping the child during the day in other activities

Communication between physiotherapists, school staff and parents

How does this happen?

Are there any issues?

How could this be improved?

Physiotherapy out of school

How does this happen? After school appointments, holiday appointments?

Views on out of school physiotherapy

How does child feel about physiotherapy after school?

Anything else important we've left out or that you'd like to add.

Appendix 3.3: Invitation letter to physiotherapists

Dear

I am a paediatric physiotherapist currently conducting a research project for my PhD at the University of Southampton. I am writing to you as I understand that you work with a child with cerebral palsy who attends a mainstream school. I am currently undertaking a research project looking at how physiotherapy services for children with cerebral palsy can be improved, both in and out of school. I would like to hold discussion groups with staff such as yourself in order to hear how you feel these children's physiotherapy needs are being managed at the present time. The following topics will be discussed during the session:

1. Physiotherapy at school – how is this managed in your area? What do you feel is your role in this?
2. The role of the school staff with the child within school
3. What are the benefits/difficulties of managing a child's physical needs within the school environment

The discussion group will consist of approximately 6 physiotherapists and last about one hour. It will be held at XXX Hospital, Child Development Centre. The session will be led by myself and a tape recorder will be used so that the discussions can later be analysed. There will not be any names used when the project is written up so that discussions cannot be traced back to any one person. The enclosed information sheet provides further detail on the research project.

If you would like more information about the project, please telephone me on the above number. If you are willing to attend a discussion group, please return the slip provided and send it back to me in the SAE. You are under no obligation to take part in this study. Thank you for your time.

Yours sincerely

Sarah Crombie

Chartered paediatric physiotherapist

Appendix 3.4: Topic guide for focus groups with physiotherapists

How is physiotherapy managed for children with CP in mainstream schools?

What is your role in schools?

What is your input in schools and how often do you go in?

Who else is involved in the child's physiotherapy?

How do you think physiotherapy fits in with school life?

Do you think the children miss out on school activities due to the need or timing of physiotherapy?

Role of the school staff/teaching assistants

Do you feel that the SENCOs/teaching assistants understand the children's problems?

How competent do you feel school staff are in carrying out specific exercises/activities with the children at school?

What do you think their role should be in the physiotherapy management of these children?

What do you think their training needs are?

Communication

How do you feel your service and the schools communicate and work together? Are there difficulties?

How could this be improved?

How are the child's needs communicated with their parents?

What improvements/changes might benefit the child both in and out of school?

What about physiotherapy after school or in the holidays?

Training for school staff

Any improvements in practice

Any issues we haven't discussed which you think are important

Appendix 3.5: Invitation letter to school staff

Dear

I am a paediatric physiotherapist currently conducting a research project for my PhD at the University of Southampton. I am writing to you as I understand that you work with a child with cerebral palsy who attends a mainstream school. I am currently undertaking a research project looking at how physiotherapy services for children with cerebral palsy can be improved, both in and out of school. I would like to hold discussion groups with staff such as yourself in order to hear how you feel these children's physiotherapy needs are being managed at the present time. The following topics will be discussed during the session:

4. Physiotherapy at school – how is this managed in your area? What do you feel is your role in this?
5. The role of the school staff with the child within school
6. What are the benefits/difficulties of managing a child's physical needs within the school environment

The discussion group will consist of approximately 6 physiotherapists and last about one hour. It will be held at XXX Hospital, Child Development Centre. The session will be led by myself and a tape recorder will be used so that the discussions can later be analysed. There will not be any names used when the project is written up so that discussions cannot be traced back to any one person. The enclosed information sheet provides further detail on the research project.

If you would like more information about the project, please telephone me on the above number. If you are willing to attend a discussion group, please return the slip provided and send it back to me in the SAE. You are under no obligation to take part in this study. Thank you for your time.

Yours sincerely

Sarah Crombie

Chartered paediatric physiotherapist

Appendix 3.6: Interview schedule for school staff

Role of the physiotherapist

What is the role of the physiotherapist who comes into your school?

(What do you expect from them? What are their responsibilities towards the child and to the staff in your school? How do you hope they will help you to manage the child in your school?)

Are there any areas where you feel a physiotherapist could be more helpful either to you or to the child in school?

Responsibility for physical development

Who has the responsibility in school for the child's physical development? (Who is responsible for their physical progress as opposed to educational?)

Who has the responsibility for liaising with the physiotherapist? (Responsibility to ensure physiotherapy advice is carried out?)

Physiotherapy in school

Does anyone do specific physiotherapy exercises with the child in school?

Is this a shared responsibility or is one person allocated to this task?

What does this involve?

How are these exercises or activities taught to school staff?

How does the child's physical needs/physiotherapy fit into the school day? Are there parts of the school day which the child misses out on due to their physical needs? How do you think the child feels about this?)

How do you manage children going out of the classroom for individual activities?

(What about other children with different needs?)

Competency and training

Are the child's physical needs incorporated into their IEP? Who decides on these and how does it work?

Do you/school staff have any concerns about carrying out these activities with the child? How well taught do you feel you are to carry out these exercises? (How competent they feel about having a child with this disability.)

Are there times when you have felt you needed more support or advice about the child's physical side? How would you normally go about getting this support?

Are there areas where you would like more specific advice or training about the child's physical needs?

If you were starting with a new child in school, what advice or training do you feel you would need in order to understand the needs of a child with CP?

How helpful do you feel it would be for your physiotherapist to do any formal training for school staff about the child's physical needs?

Communication

How do you and your physiotherapist communicate about the child?

How do you communicate with parents about what happens in school? (Do they know what goes on in school? Is physiotherapy out of school linked with what goes on in school?)

Home/school book or regular meetings? Can you think of ways communication between all could be improved?



West Sussex Local Research
Ethics Committee
Warren Browne Unit
Southlands Hospital
Upper Shoreham Road
Shoreham
West Sussex
BN43 6TQ

Tel No (01273) 446041
Fax No (01273) 446049

12 May 2004

Mrs Sarah Crombie
10A Record Road
Esmworth
Hants
PO10 7NS

Dear Mrs Crombie

Full title of study: Physiotherapy for children with cerebral palsy attending mainstream schools – perceptions of parents, physiotherapists and school staff.

REC Reference Number: Chichester LREC 03/12/4a
SSA Number: 16/04

Chichester LREC¹ gave a favourable ethical opinion to this study on 15/01/2004.

Notification of no objection to the conduct of this research have been received from local site assessor, following site-specific assessment. The Chairman has confirmed the extension of the REC's favourable opinion to the new site listed below:

<i>Principal Investigator</i>	<i>Title</i>	<i>Research site</i>	<i>Site assessor</i>
Mrs Sarah Crombie	Superintendent Paediatric Physiotherapist	Worthing and Southlands Hospitals NHS Trust	West Sussex LREC

¹ Chichester LREC has merged with Worthing LREC. The new committee is now called West Sussex LREC.

Conditions of approval

The favourable opinion is given for the study to be conducted at the above site(s) provided that you comply with the conditions set out in your previously issued approval letter. You are advised to study the conditions carefully.

Management approval

The Chief Investigator or sponsor should inform the principal investigator at each site of the favourable opinion by sending a copy of this letter. The research should not commence until management approval from the relevant host organisation has been confirmed at each site.

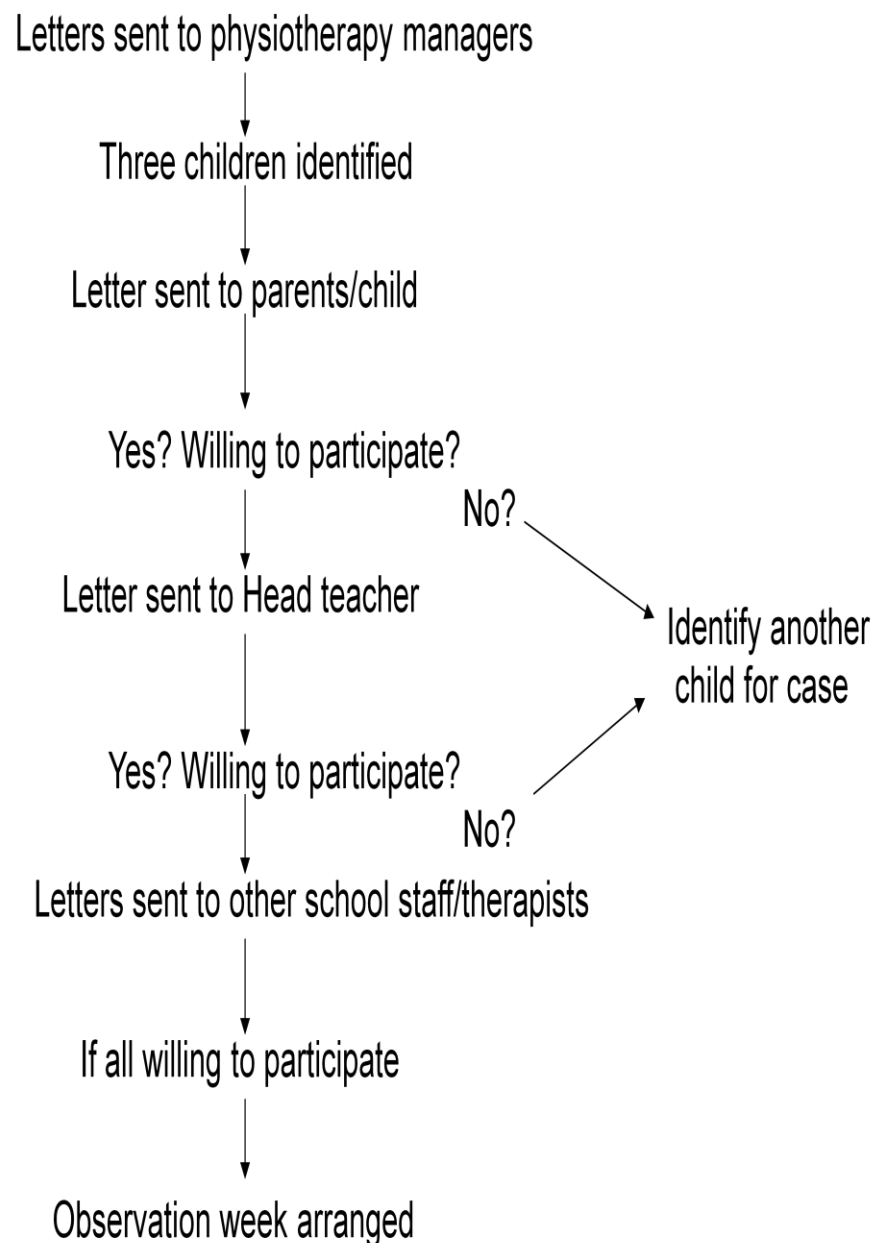
Statement of compliance (*from 1 May 2004*)

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Yours sincerely,

Dr Andrew Nayagam, FRCP
Chair. West Sussex LREC

Procedure for recruitment



Appendix 4.2: Parent invitation letter (phase two)

Dear

I am a children's physiotherapist and am currently conducting a research project for my PhD at the University of Southampton. I am writing to you, as I understand from your physiotherapist, that you have a child with cerebral palsy who attends a mainstream school. I am currently undertaking a research project looking at how schools manage the physical needs of children with cerebral palsy within the mainstream setting.

In order to do this, I would like to spend a week with your child observing her normal school activities. This would involve observing activities in the classroom, PE sessions, any therapy sessions, outdoor play and breaks. It would not involve any intervention by myself, as I will only be observing. I will be interested in how your child is managed throughout the day: how any extra support is organized, how the school use advice from therapists and how your child's physical needs are addressed.

During the week, I will be talking to the class teacher and teaching assistants about these issues, and with your permission, I would also like to talk to your child about their views on what happens in school. This may be informal chats during the week as things come up, as well as a short half hour chat at another time, to ask them more about their views. The half hour chat can be held at home or at school, whichever your child prefers. If it is at school, you will be welcome to attend, or ask a member of staff to be there. If you and your child agree, I would like to tape record this conversation so that I can remember what was said.

After I have spent the week in school, I would like the opportunity to talk to you as a parent, about your views on how your child's physical needs are addressed at school. This would involve a one hour interview, which could be held at school or at home, whichever you would prefer. With your permission, I would like to tape record this so that I can remember our conversation. All information will be confidential and no names will be used in the study.

I enclose an information sheet with more detail about the research project for you and a simpler version for your child. If any of you have further questions please telephone me on the above number. If you and your child are willing to participate in this study, please use the reply slip and send it back to myself using the SAE provided. I will then contact you to arrange a convenient time for a meeting. If however, you decide not to participate, your child's physiotherapy will not be affected in any way. Thank you for your time.

Yours sincerely

Sarah Crombie

Chartered paediatric physiotherapist

LREC no: 06/Q1911/3 Version 1

INFORMATION SHEET

Study title

The management of children with cerebral palsy in mainstream schools

I am a children's physiotherapist and PhD research student. My interest is in finding out how the physical development of children with cerebral palsy may best be managed in the school setting. You are being invited to take part in a research study in your child's school to investigate this. Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and family if you wish. Please ask me if there is anything that is not clear or if you would like more information. Thank you for reading this.

What is the purpose of this study?

Children with cerebral palsy often have on-going physical needs during their school years. They may need assistance by school staff to aid their mobility, practice and develop their physical skills, access classroom and school activities or to support their learning. Some staff work closely with a physiotherapist or occupational therapist to continue to develop the child's motor skills during the school day. One school however, may approach supporting a child's needs very differently from another school. There are currently no national guidelines for managing children with physical disabilities such as cerebral palsy in mainstream school and there has been little research in this field. The aim of this study therefore, is to identify the factors which contribute to the optimum management of the child's physical needs in school.

Why have we been invited?

Your child with cerebral palsy attends a mainstream school and I would like to spend some time at your child's school observing how they manage his/her physical needs. The study aims to observe activities in the classroom, during PE, physiotherapy sessions or outside in the playground. Your child has first hand experience of being a child at school with additional needs and his/her views on how these are managed at school will be important to explore. As a parent, you will also have views on how your child is managed at school.

What do we have to do?

Please read the information leaflet enclosed with your child to discuss the reasons for this study and what it will involve. If you and your child are willing to take part, please return the reply slip attached using the SAE. A meeting will then be set up at school to which you will be invited, so that you will be clear about what will happen during the study. This meeting will explain that I plan to be in the school for one week observing the management of your child's physical needs. This may include

all normal activities your child does during their week. Your child's views through their eyes will be important to explore and I may wish to ask him/her some questions during the week about this.

Following this observation week, I would like to have an opportunity to discuss some of the aspects of your child's management with them and therefore your child will be invited for a short interview. This can be held either at school or at home, whichever is preferable to you both. If it is at school, you may accompany them if you and your child wish or ask a member of staff who your child is comfortable with to attend. The interview will last for approximately half an hour and discussions will relate to the following issues:

What your child feels about the support given to them at school

What their views are on physiotherapy at school

How much choice they are given about how they are helped at school

If they feel they miss out on some aspects of school life

If there are any changes they would like to make

I would also like to invite you for an interview to discuss similar issues. This can be held either at your child's school or at your home at a time convenient for you. The interview will last for approximately one hour.

With your permission, both interviews will be tape recorded so that they can later be analysed. If you or your child do not feel comfortable with any of the discussions, either during the observation week or during the interviews, please tell me. Remember that you are free to leave at any time and if you wish, any information involving you both will not be used in the study. If there are issues brought up during the interviews which you feel you need to explore further, I would be pleased to help you contact the correct person to provide support.

Do we have to take part?

No. It is up to you to decide whether or not you wish to take part. If you do, you will be asked to sign a form to say that you are happy about this and that you have talked to your child and they are happy to take part too.

Will our taking part in this study be confidential?

Yes. All information collected will be kept confidential. There will be no names used in any report or publication written up from this study.

What will happen to the results of this study?

The results of this study are likely to be published within 2 years of the start of the study. I will send you receive written feedback on the results.

Who is organizing and funding this research?

This research is being funded by the University of Southampton and the Chartered Society of Physiotherapy.

Who has reviewed this study?

This study has been reviewed by the West Sussex Local Research Ethics Committee.

Who can I contact for further information?

If you would like any further information about this research study, please contact

Sarah Crombie. Telephone number:

If you have a concern about the management of your child's physical needs in school, please contact your child's teacher in school or your child's physiotherapist.

What do I do now?

If you and your child are willing to take part in this study, please return the reply slip enclosed using the SAE. I will then contact you to arrange a meeting to discuss exactly what will happen in the study.

Please contact me if there are any areas of this study which are unclear. Thank you for taking the time to read about this study.

Date:

Appendix 4.3: Child leaflet

Hello



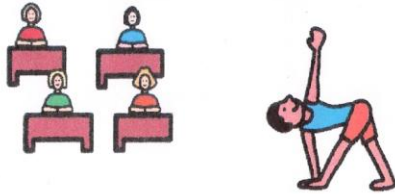
My name is Sarah Crombie and I'm a physiotherapist. I'd like to find out about all the things that go on in your school during the day.

I would like to talk to children like you who sometimes need help with walking or who do special exercises at school.



I'm really interested in spending some time in your class and when you do PE. or your

exercises. If it is OK with you, I'd like to be with you when you do some of these things.



When I'm with you I'll try not to get in the way, but if I do please tell me!

I want to be able to understand more about helping children to do well at school and I'd like to know what you think.

If you are happy for me to spend a few days with you at school please let your mum or dad know.

I'll come into school to say hello so you and your mum or dad know who I am.

If you don't want to do this, or decide later not to join in, that's okay. I won't mind.

Hope to see you at school.

Thanks

Sarah Crombie



Appendix 4.4: Invitation letter to head teacher

Dear

I am a children's physiotherapist and am currently conducting a research project for my PhD at the University of Southampton. I am writing to you, as I understand from your physiotherapist that you have a child with cerebral palsy who attends your school. I am currently undertaking a research project investigating the physical management of children with cerebral palsy within the school setting. There are currently no national guidelines for managing children with physical disabilities in school and this project aims to identify important factors in their physical management.

In order to do this, I would like to spend a week with the child observing his/her normal school activities. This would involve observing activities in the classroom, PE sessions, any therapy sessions, outdoor play and breaks. It would not involve any intervention by myself. I would however, at convenient times, like to discuss issues around the management of the child's needs with the staff involved. As a follow up to this week, I would like the opportunity to talk in more depth with the staff involved with the child, to hear about management strategies for meeting the child's needs. All information will be confidential with no names used in any publications. There will be an opportunity for the findings to be shared with the staff at the end of the project. The enclosed information sheet provides more detail about the research project.

I would like the opportunity to discuss this research further with you, so that I can explain the study more fully and you may be clearer about the involvement of the child and your school staff. If you would like a meeting to discuss this, please use the reply slip and send it back using the SAE provided, email or telephone me on the above number. I will contact you to arrange a convenient time for a meeting. The child and his/her parents will be sent a separate letter asking for their consent in this study. If however, you decide not to participate, the child's physiotherapy will not be affected in any way. Thank you for your time.

Yours sincerely

Sarah Crombie

Chartered paediatric physiotherapist

West Sussex Local Ethics Committee approval number: LREC 06/Q1911/3

Version 1 16.01.06

Appendix 4.5: Invitation letter to therapists

Dear

I am a children's physiotherapist and am currently conducting a research project for my PhD at the University of Southampton. I am writing to you, as I understand from your therapy manager, that you manage a child with cerebral palsy in a mainstream school. I am currently undertaking a research project looking at how the physical needs of children with cerebral palsy are managed in the mainstream setting.

In order to do this, I would like to spend a week with the child observing his normal school activities. This would involve observing activities in the classroom, PE sessions, any therapy sessions, outdoor play and breaks. It would not involve any intervention by myself. During this week, if you happen to attend the school, I would like to observe any intervention and have the opportunity to talk to you about your role in the management strategies used in the school. As a follow up to this week, I would like to talk to you further about your views on how the child's physical needs are met within the school. This would involve a one hour interview, which could be held at school or at your health service base. With your permission, I would like to tape record this. All information will be confidential and no names will be used in any publication.

The enclosed information sheet provides more detail about the research project. If you have any questions however, please telephone me on the above number. If you are willing to participate in this study, please use the reply slip and send it back to myself using the SAE provided, email or telephone me on the above number. I will contact you to discuss the study further. If however, you decide not to participate, you are under no obligation to take part. Thank you for your time.

Yours sincerely

Sarah Crombie

Chartered paediatric physiotherapist

West Sussex Local Ethics Committee approval number: 06/Q1911/3

Appendix 4.6: Interview questions for SENCo, case study 1

Role

1. How do you view your role with Zac? (re: Clicker practice. Does she take on some aspects of his management?)
2. What do you consider to be the class teacher's role in Zac's physical management?
3. How would you clarify what you are responsible for and what class teacher is responsible for?
4. Can you tell me about how you liaise with class teacher regarding Zac? (how regular? What aspects of his management do they discuss? IEP, therapy goals? use of clicker?)
5. Do the therapists talk to the class teacher directly or through you? (e.g. problems with figure ground, liaison with other teachers? e.g. maths teacher)
6. How do the other teachers learn about Zac's difficulties? Do they read reports from others e.g. educational psychologist, SALT, OT, physio
7. How is differentiation of work for Zac organised? Are the SSAs responsible? Is she involved or is it up to the teacher and SSA? E.g. decision regarding group for maths, spellings etc how is this monitored?
8. How do you check that Zac understands the work set? E.g. reading, for class teacher
9. How is the IEP used at school? Just with class teacher or are SSAs involved? How is it drawn up and who is involved? Who sets priorities?

Therapy

10. How are therapy programmes/goals shared with the SSAs? Teachers?
11. Do they get together for regular liaison?
12. Clicker – what is their long term goal with this? Communication aid? Use for school work? Involvement of SALT in school?
13. Coming out of class for physical activities E.g. put into stander, physio programme. Is she involved in these decisions?
14. How is it decided where the SSA should sit and how much she should support Zac?

Participation

15. Are there any areas of the curriculum where you feel Zac finds it difficult to participate? E.g. writing activities, stories, PE
16. Has there been any disability awareness session with the class or as a school?
17. How do other teachers/staff in the school know how to respond to Zac/involve him? E.g. how he answers questions, assembly.
18. What are the issues in involving Zac in school trips?
19. What do you consider to be the main challenges in managing a child with Zac's difficulties?
20. Are there any issues we haven't discussed which you think are important?



West Sussex Local Research Ethics Committee

Brighton & Hove City Teaching PCT
1st Floor, Prestamex House
Preston Road
Brighton
East Sussex
BN1 6AG

Telephone: 01273 545373
Facsimile: 01273 545372

02 May 2006

Mrs Sarah Crombie
Superintendent Paediatric Physiotherapist
Royal West Sussex Trust
St. Richard's hospital, Spitalfield Lane
Chichester
PO19 6SE

Dear Mrs Crombie

Full title of study: An investigation into factors which optimise the management of children with cerebral palsy (CP) in mainstream school
REC reference number: 06/Q1911/3

Thank you for your letter of 26 April 2006, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application Parts A and B		02 February 2006
Application	2	22 May 2006
Investigator CV		01 January 2006
Protocol	1	02 February 2006

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/Q1911/3

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Dr J R Quiney
Chair

Email: nischinth.cherodian@wash.nhs.uk

Enclosures: Standard approval conditions

Copy to: Martina Dorward
Research Governance Manager
University of Southampton
Highfield
Southampton

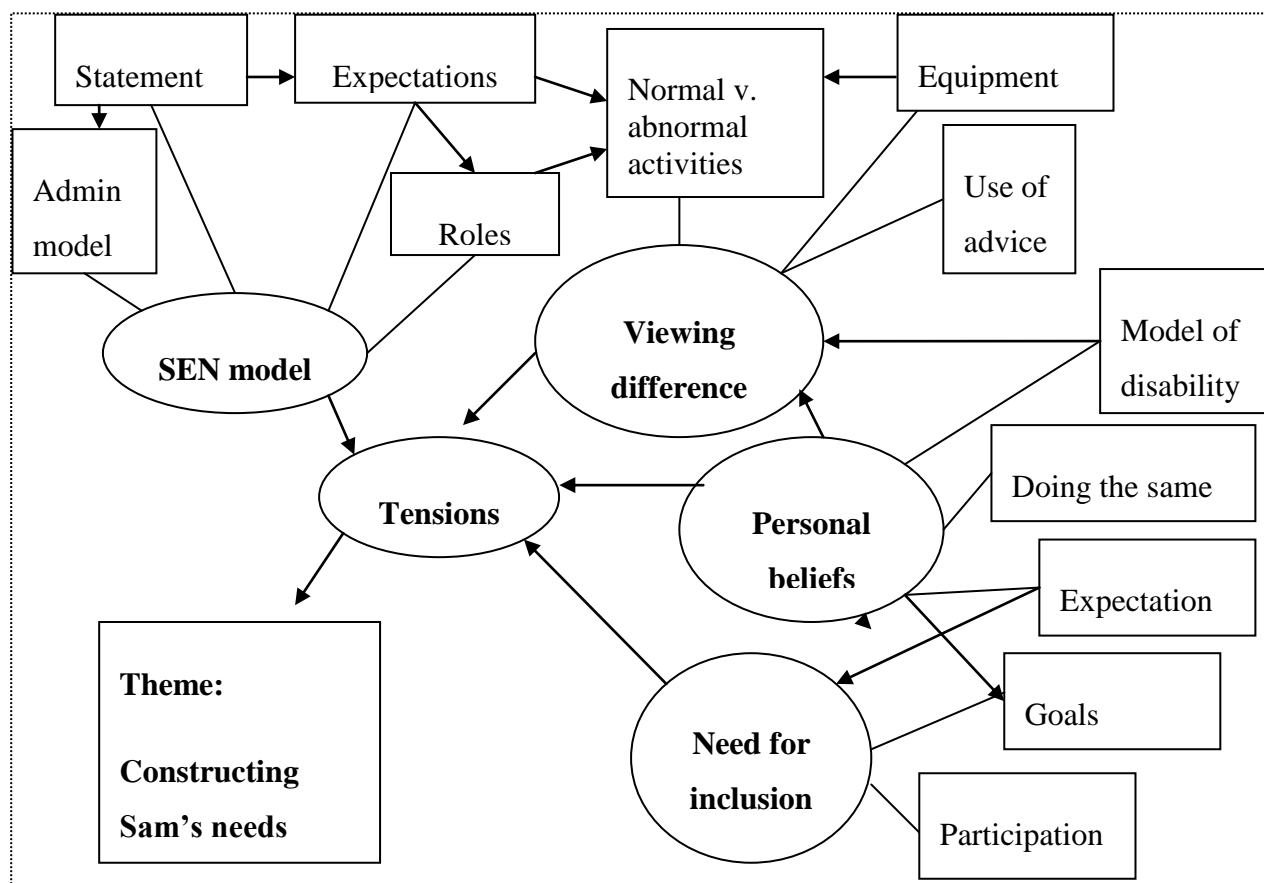
R&D Department for Royal West Sussex NHS Trust

SF1 list of approved sites

Appendix 4.8 Sources of codes used for the concept of ‘Planning’ in the third case study

Category	Codes	FN	Doc	HT	CT	TA	OT	PT	Child	Mother
	Physical needs				x	x		x		
	TA role	x			x	x			x	
	Physiotherapy	x			x	x		x	x	x
	Responsibility	x		x	x	x		x	x	
	Missing out	x			x	x		x		x
Planning	Integrated goals	x			x	x			x	
	Independence	x								
	Balancing priorities	x			x	x	x			x
	Beliefs					x				
	Inclusive ethos	x			x					
	Knowledge	x			x	x				
	Liaison					x		x		
	Equipment use				x					

Appendix 4.9 Example of a network map from case study 2: theme of constructing Sam's needs



The main components of the concept 'SEN model' were: the SEN statement and how this was used and interpreted; participant's expectations of the SEN process; the perceived and actual roles within SEN provision; and practices of the SEN process. The arrows show where these components linked to another e.g. expectations of what the SEN Statement would provide in school impacted on whether the child's activities were viewed and treated as being part of 'normal' classroom activities or SEN activities. The solid lines show that all these components constituted part of the 'SEN model' concept.

Appendix 4.10 Table of main codes and data sources from case study 3

(first seven columns are interview or informal discussion data sources)

Code	Head teacher	Class teacher	TA	Child	Parent	OT	PT	FN
Independence		x	x	x	x	x	x	x
TA role	x	x	x	x	x	x	x	x
Responsibility	x	x	x	x	x	x	x	x
Peer support	x	x	x	x				x
Participation	x	x	x	x	x	x	x	x
Missing out		x	x				x	x
Inclusive ethos	x	x	x	x	x		x	x
Self-awareness	x	x	x	x	x	x	x	x
Beliefs	x	x	x	x	x	x		
Physiotherapy	x	x	x	x	x	x	x	x
Balancing priorities		x	x					x
Knowledge	x	x	x				x	x
Equipment use	x	x	x	x	x	x	x	x
Goals	x	x	x	x			x	x
Time		x	x			x	x	
Needs	x	x	x	x	x	x	x	x
Difference	x	x	x	x	x	x	x	x
Statement	x	x	x		x	x	x	

Liaison		x	x		x	x	x	x
Relationships	x	x	x		x	x	x	
Use of advice	x	x	x		x	x	x	x
Disability rights	x	x		x	x	x	x	