

**The range of communication models used by Allied Health Professionals (AHPs) - specifically Occupational Therapists (OTs), Physiotherapists (PTs) and Speech and Language Therapists (SLTs) as part of their advice-giving strategies with parents of pre-school children with Cerebral Palsy (CP): An exploratory study**

**by**

**Aline Macready**

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## **ABSTRACT**

### **Research purpose**

To explore the range of communication models used by Allied Health Professionals (AHPs) - specifically Occupational Therapists (OTs), Physiotherapists (PTs) and Speech and Language Therapists (SLTs) - with parents of pre-school children with Cerebral Palsy (CP), and utilise data to develop a coded checklist to be utilised as an instrument for future research in this field.

### **Method**

In November 2010 three Nominal Group Technique (NGT) sessions with AHPs were conducted. NGT was selected as being the most effective approach to elicit contributions from all participants and generate a list of items relevant and meaningful to the question posed. Uni-professional group NGT sessions were held as previous work had indicated contrasting perspectives across AHPs. The researcher synthesised the generated items and integrated these with previously published conceptual models of interaction to develop a coded checklist. Validation took place by asking participants from the NGT sessions to review the checklist and make relevant comments.

### **Results**

The NGT sessions generated 57 separate items in total, these were categorised in themes and subthemes. The researcher identified single, dual and multiple strategy approaches. This gave an indication of the complexity of the advice giving strategies used by AHPs in their work with parents.

## **Conclusion**

This small pilot study has generated some indicative data relating to therapists' reported advice-giving practices. It was also possible to compare the items from the three groups and identify some similarities and differences in their way of working with parents. Some careful conclusions were drawn about the conceptual models of communication used by the AHPs, and a coded checklist was created as an instrument for future research.

## **Key words:**

AHP, parents, Nominal Group Technique, models of communication, advice-giving strategies

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## **ABBREVIATIONS**

AHP	Allied health professional
CAMHS	Children and Adolescent Mental Health Service
CP	Cerebral Palsy
CDC	Child Development Centre
CPD	Continuous Professional Development
DCD	Developmental Coordination Disorder
NGT	Nominal Group Technique
OT	Occupational Therapist
PT	Physio Therapist
SEN	Special Educational Needs
SENCO	Special Needs Coordinator
SLT	Speech Language Therapist

## CHAPTER 1-INTRODUCTION

Cerebral Palsy (CP) affects 1:400 children; 2000 babies from all social and ethnic groups are diagnosed in Britain every year (Hicks and Macnair 2010).

CP is a non-progressive permanent disorder of movement and sensation.

*“an umbrella term covering a group of non-progressive but often changing motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of its development”.*  
(Mutch et al 1992, p.549: cited in Parkes, Donnelly and Hill 2001)

Common symptoms of CP include difficulties with; walking, writing, eating, talking, dressing, problems with balance and coordination, difficulty controlling and maintaining posture and visual difficulties and hearing problems. The condition itself will not become better or worse, however the impact on movement and posture can change. As many as one in three children and adolescents with cerebral palsy also have epilepsy (Macnair and Hicks 2011).

CP is sometimes described according how the body is affected:

- Spastic - Difficulty with moving limbs, problems with posture and general movement
- Athetoid - Involuntary movements such as twitches or spasms
- Ataxic - Difficulty co-ordinating muscle groups, causing problems with balance and walking etc.

CP is incurable; however therapy can help to manage the condition better.

There are a number of different health professionals who will be involved with children with Cerebral Palsy and their families, such as Occupational Therapists (OT), Physiotherapists (PT) and Speech and Language Therapists (SLT), and this will depend on the severity of the condition (Parkes et al 2001).

## **1.1-HISTORICAL PERSPECTIVES OF PROFESSIONAL –CLIENT RELATIONSHIP**

Historically people who were seeking help and advice from medical professionals were referred to as *patients*. Health care professionals perceived themselves as experts, and expected their patients to comply with prescription of treatment, usually in the form of medication. Over time, terminology changed, and currently patients are called *clients* or *service users*, these two terms tend to be used interchangeably.

The medical profession has been one of the most powerful in society and this might have been one of the reasons that communication and relationships between health care professionals and clients is characterised by a power imbalance (Davis and Fallowfield 1991). Clients traditionally were not given the opportunity to feedback on therapy or interventions, which may have resulted in clients not following health – related advice, as they were unhappy with the way they were communicated with by health care staff (Ley 1988).

There are many reasons for clients not complying with advice received from professionals and there is a particular strong correlation between clients not being happy with the manner professionals have communicated and non-compliance (Korsch, Gozzi and Francis 1968). The term non-compliance suggests that the professional knows best and the client should do what they are being told, and so the inequitable relation continues, and breeds the rigid relationship between health care professionals and clients and continues this unbalanced relationship (Stimson 1974).

Clients in one study were helped to rehearse questions they wanted to ask of health professionals, and although this empowered the clients, they were perceived as being more anxious and angry by the professionals (Roter 1979). Although another explanation was that health care professionals viewed the lack of questioning by clients as an indication that they didn't want further information (Ley, Jain and Skilbeck 1975).

The language and medical terminology used by professionals is often very ambiguous and adds to the communication difficulties between professionals and clients. Even medical and dental undergraduates were shown to have difficulty understanding medical terminology (Boyle 1970, Tring and Hayes - Allen 1973).

It is suggested that supplementary methods of communication, such as audio-visual presentations may be very useful, when working with clients (Midgeley and Macae 1971). This method is used by a North West Paediatric Occupational Therapy Department, to complement their consultation/therapy sessions for parents of children with Developmental Coordination Disorders (DCD). Parents are invited to an information session; they are shown a power point presentation, and invited to participate in a practical session, with a variety of activities to gain a better understanding of DCD. This particular way of working with parents is sometimes referred to as the transplant model (Cunningham and Davis 1985, Appleton and Minchom 1991, Watts Pappas and McLeod 2009).

A major influence on the whole client – professional relationship shift, has been the ‘The Health of the Nation’ strategic paper (DoH 1992), which encouraged health care professionals to work in a partnership manner with their clients and promote independence.

Health care professionals have struggled with this, especially within the existing medical culture of the expert model. There is evidence of resistance among health care professionals to truly work in partnership (Watts Pappas and McLeod 2009). This was corroborated in a recent event in the North West where multi-agency professionals, including AHPs and parents worked together to identify what parent participation barriers were and how to remove those barriers and work more closely together:

*‘Many willing professionals, but fear of loss of control that they might have – fear of the power shift’*

and

*‘Professionals accepting that they could benefit from parent participation and working together’ but this is not happening’.*

Quotes from parents and professionals at a regional parent participation workshop event 2010 (appendix XV).

## **1.2-MODELS OF DISABILITY**

Defining disability is a complex issue, with religious, cultural, medical, social, political and financial influences. For example, some religious beliefs are that people with disabilities were possessed by the devil, yet others perceived disability as ‘a blessing’ (Dovey and Graffam 1987). It will not be possible to discuss all these models in detail; however it is important to recognise that the views and beliefs people hold on disability may affect the way professionals work with disabled people and parents of children with disabilities such as CP.

The two models which have sparked a debate, and which is continuing to be held are the medical and social model of disability.

### **1.2.1-Medical Model**

The medical model stems from the belief that the disabled person is the problem, their body is not 'normal' and needs to be cured or cared for, and it justifies the way in which disabled people have been systematically excluded from society (Swain, French and Cameron 2003). It concentrates on the disability or illness rather than on people's needs (MacKean, Thurston and Scott 2005). This view ensures that control lies firmly with professionals, and has neglected to understand the importance of communication between professionals and their clients (Davis, 1993, Davis, Day, and Bidmead 2002, Swain, Clark, Parry, French and Reynolds 2004, Davis and Day 2010).

Health care professionals have perceived themselves as the expert who will take the lead, ask relevant questions, diagnose and treat the condition. Clients have been expected to answer the questions in order for the professional to diagnose a condition or illness, furthermore clients have been expected to accept the opinions of the professionals and adhere to treatment (Oliver 1990, Swain et al 2004).

Speech and Language Therapists' understanding of clients who had difficulty swallowing (Dysphagia) had been developed within the clinical and hospital settings prior to 1992 and found its roots within the medical model of disability. 'The Health of a Nation paper' (DoH1992) encouraged changes, and for professionals to work towards the biopsychosocial model of disability

(Krawczyk 2005). The increased client involvement has proven difficult for therapists, as they had not been trained to discuss clients' opinions, explore solutions and empower clients and use their emotional skills to work in partnership with clients. Although it was thought that the major drive within the NHS could support therapists to provide a quality person-centred approach for clients with dysphagia and their carers (Krawczyk 2005). The person-centred approach is firmly on government's agenda, not only for AHPs but also social care professionals, and this care approach would fit well in the Family-centred approach (Andrews and Andrews 1986, Hanna and Rodger 2002, Dunst 2002, MacKean et al 2005, Watts Pappas and McLeod 2009).

The Medical Model was used to explain that illness was always as a result of abnormalities in the body's functions, and thus if a part of the body was not working it should be 'fixed' (Swain et al 2004). One of the shortcomings of this model is that the focus is on acute illness and the theory of 'fixing' or replacing the broken body parts does not fit well, when developing and understanding and treatment for chronic illnesses and/or disabilities. The model also ignores factors such as cultural and social aspects of people's lives (Hughes and Paterson 1997). Over recent years we have seen an increase of children with chronic and complex conditions and this model of providing interventions for acute and infectious illnesses does not sit comfortably with paediatric health professionals or families (MacKean et al 2005).

### **1.2.2-Social Model**

The social model presents an opposite view from the medical model and the notion of individual blame and a body that needs to be cured. It firmly puts the

responsibility with society and claims that social barriers disable people, not their impaired bodies (Oliver 1990, Hughes and Paterson 1997).

*“it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society”.* (UPIAS 1976, p3)

One criticism of the social model of disability is that by putting the emphasis on the social environmental barriers, it denies the actual limitations of the body and how this affects people as individuals (Paterson and Hughes 1999). The medical and social model are on opposite sides of the debate, each approaching the disability issue differently. The medical model puts the blame on the individual who requires treatment of a therapeutic or medical nature. The social model searches for society to find the solution as it is society that disables the person.(Oliver 1995, cited in Hughes and Paterson 1997). Table 2:1 illustrates the contrast between the medical and social model of disability.

Table 2.1 Binary Opposites of the medical and social model(Hughes and Paterson 1997, p 330)

<b>The biological</b>	<b>The social</b>
<b>impairment</b>	Disability
<b>the body</b>	Society
<b>Medicine</b>	Politics
<b>Therapy</b>	Emancipation
<b>Pain</b>	Oppression
<b>the medical model</b>	the social model

The comparisons above might suggest it is a simplistic debate, however, as stated earlier, (1.3) the subject of disability is extremely complex, with many aspects to this debate and as such it will not be possible to explore all of these in this study.

### 1.3-MODELS OF COMMUNICATION

Communication is complex, and a plethora of research has been carried out on the subject (Hartley 1999, Van der Voort and Duck 2000), to name but a few.

There are many elements connected with communication such as body language, clarity of speech, but also different media for communication purposes such as email and social networks. However, this study is particularly concerned with the face to face communication models of AHPs. The researcher will focus on actual models of communication, as effective therapy/interventions are not solely dependent on the knowledge of the therapist, but are correlated with the way professionals communicate and the quality of their relationships with the client (Swain et al 2004, Davis et al 2002, Davis and Day 2010).

*“In principle, individual workers should be selected for their qualities and skills needed to relate to and communicate effectively, as well as for their technical expertise associated with their specific profession”.*  
(Davis et al 2002, p7)

Although this research study is not exploring the effectiveness of the therapy/interventions of the AHPs, in the light of the communication models it will be impossible to completely ignore it.

The literature search has identified a number of communication models:

- The expert model or therapist-centred model (Cunningham and Davis1985, Appleton and Minchom 1991, Davis and Fallowfield (Ed) 1991, Davis 1993, Davis et al 2002, Watts Pappas and McLeod 2009, Davis and Day 2010).
- The transplant model, (Cunningham and Davis1985, Appleton and Minchom1991, Davis et al 2002), also known as parent-as-therapist aide,

(Watts Pappas and McLeod 2009), or family- allied (McBride, Brotherson, Joanning, Whiddon and Demmitt 1993).

- The family-centred model (Andrews and Andrews 1986, Hanna and Rodger 2002, Dunst 2002, MacKean et al 2005, Watts Pappas and McLeod 2009).
- The family-friendly model, (McBride et al 1993, Hanna and Rodger 2002, Watts Pappas and McLeod 2009).
- The partnership model (Buchan, Clemerson and Davis 1988, Appleton and Minchom 1991, Davis and Fallowfield 1991, Buchan 1998, Davis et al 2002, Swain et al 2004, Watts Pappas and McLeod 2009, Davis and Day 2010).

### **1.3.1-The Expert model:**

The expert or therapist- centred model (Appleton and Minchom 1991, Davis, 1993, Davis et al 2002, Watts Pappas and McLeod 2009, Davis and Day 2010), is based on the notion that therapists know best and parents should just do what they have been told. Parental involvement is seen as a necessity to elicit relevant information and they should carry out what the therapist has told them ( (Davis and Fallowfield 1991). Unfortunately this lack of a relationship often falls short when setting goals for example, as there are discrepancies between professionals' and parents' priorities and goals for their children (Marteau, Johnston, Baum and Bloch 1987).

A further potential danger of this model is that important facts about the child's difficulties may be missed, as it neglects to acknowledge that parents have knowledge and expertise too. Professionals may not have regard for parents' views and needs and see these as a low priority and do not think that information sharing is important. The expert model can cause particular

problems, when working with parents of children with psychological difficulties, as the professional will not get a complete picture of the relationship between the child and family, the possible reasons for the child's psychological difficulties and will be unable to set realistic effective goals (Buchan et al 1988, Davis, 1993, Davis et al 2002, Davis and Day 2010).

The lack of respect for parents' views and knowledge of their children may result in high levels of dissatisfaction and non-compliance to proposed goals (Ley 1982, Attride- Sterling et al 2001), and may actually be viewed by therapists as being disrespectful of their knowledge and expertise.

*'For the expert, this may serve only to emphasise the patients' lack of expertise and, of course, the disrespect within which they are held' (Davis and Fallowfield 1991, p16).*

Another negative aspect of this approach is that it may create a dependency of parents on their therapists and a feeling of disempowerment (Cunningham and Davis 1985, Watts Pappas and McLeod 2009), to the extent that parents might not feel capable of taking care of their child (Dunst 1985, Davis and Day 2010).

No real advantages of this model have been identified in current research (Watts Pappas and McLeod 2009), although some parents expect the professionals to solve the problem, and may perceive this process as supportive (Davis and Day 2010). For professionals the benefits may be more significant, for example, they are in charge of arranging the time and venue for meetings. The process is almost self indulgent for professionals as it confirms their knowledge, expertise and their role in helping parents.

### **1.3.2-The Transplant Model**

The transplant model (Cunningham and Davis 1985, Appleton and Minchom 1991, Davis et al 2002), also known as parent-as-therapist aide (Watts Pappas and McLeod 2009), and family- allied (McBride et al 1993). This model still identifies professionals as experts; however it recognises the value of parents as a resource/aide to therapists to be utilised. Professionals' expertise can be:

*'uprooted and transplanted into the care of the parents, where it might, so to speak, grow and be fruitful' (Cunningham and Davis 1985 p12).*

All decisions about objectives, goals, how to carry out the activities and how to teach the parents are made by professionals, like the expert model. The difference is that parents participate in the treatment activities, and the professionals seek feedback from parents to plan the next stage of the treatment. Parents therefore are more likely to feel confident in their ability to support their child, unlike the expert model.

A clear illustration of therapists using this model is the Portage Service, where they work with parents in their own home and teach them methods to support behavioural management for children with mental health disabilities for example (O'Dell 1974, Dessent 1984, Russell 2007).

The Hanen program 'it takes two to talk' is another example of therapists using their expertise and transplanting this into parents. The program's aim is to provide parents with an intensive training program on how to help their children develop improved communication skills (Pepper and Weitzman 2004).

This way of working has some clear advantages, as it helps parents feel they are able to help their child. As parents help in the assessment of the child, it is more likely that the therapist gets a more comprehensive picture of the problems (Cunningham and Davis 1985).

There are however some disadvantages with this model. Professionals can presume that all parents and their understanding are identical and as such not be sensitive to parents' individual needs, understanding, skills parents have or not have etc. (Turnball and Turnbal 1990, Davis et al 2002, Watts Pappas and McLeod 2009).

Furthermore parents may not feel they are able to communicate how they feel and this can be misleading to professionals working with those parents.

*There are distinct groupings of parents who have common patterns when they deal with professionals. How they appear and behave does not necessarily correspond with how they feel'.*

(Gascoine 1995, cited in Blamires, Robertson and Blamires 1997, p31)

This model does not encourage parents to share their inability to carry out certain activities, due to not understanding what is expected of them, not having time or resources, and could be perceived as parents being non-compliant (Giller Gajdosik and Campbell 1991).

### **1.3.3-The Family-Centred Model**

The family-centred care approach find its roots in North America, where parents of children with chronic illness and/ or disabilities wanted to have more say in their children's treatment and care (MacKean et al 2005). The model takes the view that the whole family is the client, rather than just the child. The

family as a unit is interdependent; therefore therapy aims, goals and interventions should consider the impact on the family (Andrews and Andrews 1986). Parents as well as other family members should be involved in the planning (Bailey McWilliam and Winton 1992, Hanna and Rodger 2002).

The principles of the model are for '*effective collaborative partnerships with parents*' (Hanna and Rodger 2002, p16), although this is not easy to establish, due to the traditional 'expert' view of professionals, not using a common language, and life experiences. Furthermore the whole concept of family centred care needs to focus on effective high quality relationships between AHPs and parents (McWilliam, Tocci, and Harbin 1998).

One advantage of this model is that therapists recognise that parents' have unique knowledge about their child, which may enhance the outcomes (Hanna and Rodger 2002), as well as the fact that parental involvement may increase a greater sense of confidence and self esteem.(Dunst and Trivette 1996).

Unlike the transplant model the family-centred model recognises families' uniqueness, and is needs-led (Dunst 2002), although many professionals struggle with this notion, as they still see themselves as the experts.

*' Further research needs to be planned as to begin to bridge the current disconnect between the perspectives of family-centred care 'experts' and families themselves' (MacKean et al 2005, p 83).*

Some professionals perceive the concept of parents making decisions about their child's treatment problematic, and wonder if parents are actually in a position of making decisions about their child's health and treatment (Appleton

and Minchom 1991). Some go as far as to say that not all parents have their child's best interest at heart, and actually harm the child:

*'The occurrence of child abuse is a harsh reminder that the needs of parents and their children is not always isomorphic'. (Allan and Stefanowski 1987p 135: cited in Watts Pappas and McLeod 2009).*

#### **1.3.4-The Family-Friendly Model**

This model has been developed, as a result of parents and professionals having some difficulty with the family-centred approach (McBride et al1993, Watts Pappas and McLeod 2009). In particular with the decision making process, as it is argued that there are some ethical concerns about parents having the ultimate decision making power, for example, if parents decisions might actually be harmful to the child in therapists' views, although the view of therapists could be perceived as an expert approach(Cunningham and Davis1985, Appleton and Minchom 1991, Davis and Fallowfield (Ed) 1991, Davis 1993, Davis et al 2002, Watts Pappas and McLeod 2009, Davis and Day 2010).

There are many similarities between the family-centred and family friendly approach, although there are some noticeable differences. The main one is the fact that although the families' needs are taken into consideration, the therapy is child orientated rather than family focussed, and the professionals are firmly in charge of the goal setting rather than the parents (Watts Pappas and McLeod 2009).

Advantages include that parents are involved in the activities, and the parent-therapist relationship is important which will allow for a more needs-led approach (Hanna and Rodger 2002). The therapists are ultimately making the

decisions, for care and interventions and the child's and family's needs are viewed separately and are firmly based on evidence based outcomes.

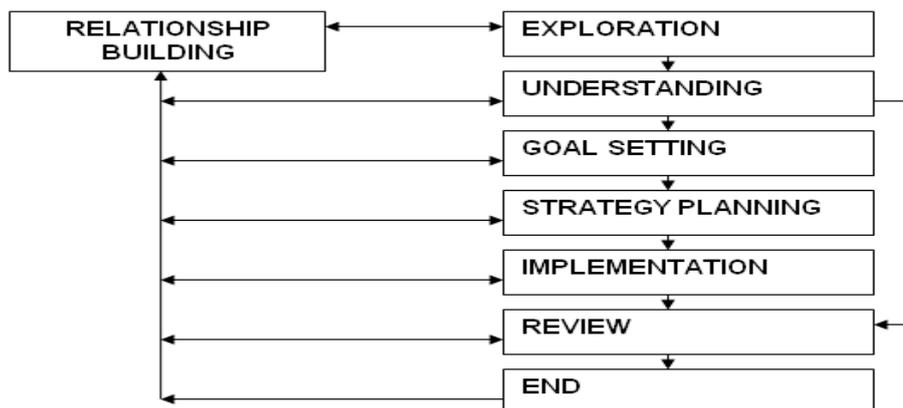
Professionals being in the driving seat once more could also be viewed as a disadvantage, parents may feel less confident in their own ability, feelings of being rail-roaded into decisions and they may not agree with this power imbalance (Davis and Fallowfield (Ed) 1991). One could argue that this approach provides a tokenistic approach to parental involvement, and is not as family friendly as it sets out to be.

#### **1.3.5-The Partnership Model:**

The model is characterised by a process where the relationship between the professional and parent is central, and without this relationship the helping process is meaningless.

The partnership process is the relationship and during the therapy/helping sessions we should continuously check our relationship, as can be seen in the fig 1.1

Figure 1.1 The Dynamics of the Helping Process (Davis and Day 2010, p51)



The objectives are to help clients manage their problems effectively and able to better help themselves. The models' principles are based on Egan's Model of Helping

*' the goal of helping is not to "solve" problems, but to help the troubled person manage them more effectively or even transcend them by taking advantage of new possibilities in life'(Egan 2007, p5).*

The benefits of professionals working with parents in this way is that there will be more than one solution to the problem. The professional does not assume to know all the issues for this child and family. It supports professionals by allowing them to admit when they don't know something. The benefit for parents is that they are supported to change the constructs about themselves and feel empowered in the knowledge that they are the expert on their child (Kelly 1991, Davis et al 2002, Davis and Day 2010).

When scrutinising the models of communication in light of the medical and social models of disability, it is concluded that any medical intervention is based within the medical model of disability; furthermore, especially the expert and transplant models of communication are closely linked to the medical model of disability, as there is little thought about the impact of the impairment and

adapting the environment, and emphasis is on the therapy interventions of the child and the expert professional- parent relationship. The family-friendly approach gives all decision making powers to the parents, and focuses more on the impact on the whole family unit. This would suggest that this model has an approach more linked to the social model of disability. Professionals however struggle with the whole notion of being an advisor with expertise (Dunst 2002, Watts Pappas and McLeod 2009). It is not clear from the literature whether therapists and parents work in a partnership manner, or whether the perceptions of therapists about the parents' ability to make those kind of decisions influences the relationship. The family-centred model, advocates that negotiations between therapists and parents take place about goals and therapy interventions, although therapists have ultimate power (Watts Pappas and McLeod 2009). It could be argued that this model embraces partnership working as negotiations between therapists and parents take place about goal setting and interventions, although literature does not describe in detail how these negotiations take place. This would suggest that although medical interventions take place, thought is given about the impact of the impairment of the child. On the other hand, the decision making power is back with the therapists and this could be interpreted as a more expert model approach. The partnership model of communication is much more linked to the social model of disability (Buchan et al 1988, Davis and Fallowfield 1991, Davis, Spurr Cox, Lynch, von Roenne and Hahn 1997, Davis et al 2002, Davis and Day 2010), as the relationship with parents is key, and the professional is perceived as a parent helper with expertise. It is not possible to completely get away from the medical model of disability, as medical interventions continue to take place to a greater or lesser extent, dependent on the child's impairment.

There are other models such as the Therapeutic Alliance, which seems to be between the family-centred, family-friendly and partnership model approach. Table 2.1 draws attention to the characteristics, advantages and disadvantages of the discussed models of interaction, although it is difficult to clearly define where one model ends and another begins, it may be more helpful to view the 'Family-Orientated Approaches' (Dunst 2002, p140) as a continuum rather than individual stand alone models. Davis suggested the following about the transplant model:

*'I'm not at all sure now how useful it is to think of this (the transplant model) as a model. We talked about it at some length in Cunningham and Davis as an intermediary between an expert model and partnership. Since then I have concentrated on what could be considered two ends of a continuum (i.e. expert and partnership) with transplant somewhere in the middle'(Davis, June 2010).*

Table 1.2: Summary of models of communication

Models of communication	Characteristics	Advantages	Disadvantages
<b>Expert Model</b>	Professional knows best. Professional asks questions they deem important Parents' views are not important Professionals will tell parents what to do No sharing of information Parents are expected to carry out instructions without questioning anything	May meet the parent's expectations for expert advice to solve their problems May give the relief of having another person take over responsibility Relatively straight forward and predictable job for the professional Likely to reward the professional's own need for esteem, competence and success	It ignores/denies expertise of the parent/ being helped It ignores/denies control to the parent being helped, It may increase the parent's feeling powerlessness and inadequacy May increase inappropriate dependency May be dissatisfying for the parent May lead to poor communication between the professional and parent helped  Parents may feel incompetent and not able to solve a problem Danger of missing important facts about the child's condition Parents' perception that professional has all the answers
<b>Transplant model</b>	Professional is the expert Professional sees the parent as a resource Professionals teach parents strategies Professionals make all the decisions Parents participate in the therapy activities Parents are asked for feedback	Professionals concentrate holistically on the child Increase parents' compliance and satisfaction Parents may feel empowered	Professionals need to develop skills besides their professional area of work: Giving clear instructions Building positive relationships Parents may feel disempowered due to not being able to carry out the activities, i.e. no time, resource issues
<b>Family centred model</b>	Interventions focus on supporting child and family. The parents make the decisions, even if therapists do not agree with goals. Professionals act as advisor Building positive relationships are important and recognise all families are different.	Providing support for the child may also have benefits for the family as a whole. Parents may increase in confidence and feel empowered. Positive relationships will positively affect the outcomes for the child.	Parents' decisions may not be most appropriate for the child. Some parents want support from an 'expert' Not all parents want or are able to participate. Parents may feel overwhelmed with the responsibilities.

	Family may choose not to be involved in the interventions.		This can affect the relationship negatively between professionals and parents. More time consuming because of the need to negotiate goals and interventions
<b>Family friendly model</b>	Parents are given the opportunity to be involved in the planning and interventions. Professionals hold on to the decision making responsibility. Focus of interventions is on the child in contrast to the family centred approach. The recognition that some interventions are depending on family involvement. Interventions focus on it being a positive experience for the child.	Process is supportive of parents and encourages involvement. Family involvement may lead to more needs-led approach. Professional overall responsibility and decision making will safeguard the child's rights and achieve evidence-based care. Professionals' feeling of being respected is left intact.	Parents are no longer in charge. Parents feel 'rail-roaded' into decisions they don't agree with. Back to some extent to the expert model.
<b>Partnership Model</b>	Relationship between professional and parent is central Exploring issues together Goal setting is a joint process	Parent is more likely to engage Accords explicit power/control to them, with positive consequences for their self esteem and low self-efficacy Encourages the parent to express their views openly, improving the quality and accuracy of information shared Expectations are explored, expressed and negotiated to endeavour to set appropriate goals Likely to enhance the outcomes Parent feeling empowered Professional may feel relieved that they don't need to know all the answers	Professionals might feel it is too time consuming Professionals might feel disempowered The relationship has to be actively worked on More emotionally demanding, reducing professionals' ability to distance him/her self or avoid hearing problems Likely to require higher degrees of sensitivity, skilled listening, understanding and active communication Requires further training and subsequent support

The literature review showed a number of studies describing and evaluating the communication models used between therapists and parents of children accessing therapy from the Children and Adolescent Mental Health Service (CAMHS), (Buchan et al 1988, Davis and Spurr 1998, Davis and Rushton 1991, Braun, Davis and Meltzer 2007). However very little research has been identified about the communication models used by therapists with clients and parents of children with physical disabilities, (Watts Pappas and McLeod 2009, Swain et al 2004).

Furthermore much of the research discussed, concentrates on models of communication in a global context, the advantages and disadvantages of particular models, and the extent of the effectiveness (Andrews and Andrews 1986, McBride et al 1993, Ketelaar, Vermeer, Helders and Hart 2001, Swain et al 2004, MacKean et al 2005, Watts Pappas and McLeod 2009).

There is however little discussion about the actual specific behaviours associated with these models, such as: how professionals actually work with parents, and what models of communication they use, in their advice-giving strategies when showing parents how to help their child stand, what steps they undertake to build an effective relationship, and how to challenge unhelpful constructs, apart from the partnership model.

The partnership model characteristics, the qualities of the helper, and how to effectively support parents has been extensively described, and professionals can receive training to help them acquire skills. However research mainly describes the way professionals work with parents of children involved with

Child and Adolescent Mental Health Services and not children and parents accessing other AHPs such as OT, PT and SLT (Cunningham Davis 1985, Buchan et al 1988, Davis and Fallowfield 1991, Davis, 1993, Davis et al 1997, Buchan, 1998, Davis and Spurr 1998, Attride-Sterlinf et al 2001, Davis et al 2002, Davis and Day 2010). To date no research is available to suggest that AHPs from services such as OT, PT and SLT work/not work and should/should not work within the same framework as AHPs from CAMHS.

## **CHAPTER 2-METHODOLOGY/STUDY DESIGN**

### **2.1-RESEARCH QUESTION, AIMS AND OBJECTIVES**

#### **Aim:**

To explore the range of communication models used by Allied Health Professionals (AHPs) - specifically Occupational Therapists (OTs), Physiotherapists (PTs) and Speech and Language Therapists (SLTs) as part of their advice-giving strategies with parents of pre-school children with Cerebral Palsy (CP).

Advice giving strategies are used to describe the communication models between therapists and parents, once children have been assessed and they have attended at least one therapy session.

#### **Objectives:**

1. To critically review the published literature for the range of models of communication between healthcare professionals and parents/service users to derive questions for Nominal Group Technique (NGT)
2. To use NGT to generate items from AHPs and parents regarding their views of current practices for interaction & advice-giving activities / behaviours etc
3. To synthesise and integrate the items generated from NGT and the models of interaction to develop a coding checklist for video observations of AHP practice
4. To observe and code routine clinical practice of AHPs working with the parents of these children
5. To review/reflect on video observations and map these against NGT items and conceptual models of interaction

6. To make recommendations for clinical practice applications as well as future research.

## **2.2-REFLECTIONS OF STUDY DESIGN**

The purpose of research is to gain a deeper understanding of a particular topic by posing a question. For testing a hypothesis, the question asked will be much more specific than in the case of a research that is exploring a particular topic (Crookes and Davies 2004).

Research design should be based on the research question and how this best can be answered. A quantitative method tends to be used to establish numeric data, for example how many parents are satisfied with the service AHPs provide.

Using an exploratory research approach on the other hand is more helpful when one wants to gain a deeper understanding of a particular problem and explore the experiences of people (Creswell 2007, Crookes and Davies 2004, Grbich 2007). For example if one wants to explore parents' experiences of using a Child Development Centre.

This research is an exploratory study to gain an insight into the different communication models, therapists use with parents, and therefore well suited to a qualitative method.

The researcher considered a number of qualitative study methods such as case studies, observations, interviews, focus groups and Delphi technique to

establish the most appropriate method for this research study. These methods are discussed in some detail below.

### 2.2.1-Case studies

A case study is an in-depth study and can identify specific problems or experiences of a person or group of people or an event (Creswell, 2007, Denscombe 2007). Case studies concentrate on the depth, specific issues, uses a number of methods to gather data (table 5.1).

Table 2.1 Case study research characteristics (Denscombe 2007 p37)

Case study research characteristically emphasises		
Depth of study	Rather than	Breadth of study
The particular	Rather than	The general
Relationships/processes	Rather than	Outcomes and end-products
Holistic view	Rather than	Isolated factors
Natural settings	Rather than	Artificial situations
Multiple sources	Rather than	One research method

Case studies can be used to initially identify key issues and can then be followed up by further investigation in the form of a survey (Bell 1993), thus using multiple methods as suggested by Denscombe (2007), for example, to identify the key issues for parents in accessing services for their disabled child.

The aim of this study was to generate sufficient items to develop a coded checklist; it would require a number of case studies from all three AHP groups to achieve this. Furthermore as previously identified case studies require the use of a number of different methods, such as interviews, observations or surveys, which would be very time consuming. Although one should not dismiss the use of case studies on the ground of time it would be naive not to take it into consideration. The use of the case study approach might be better suited to explore the advantages and disadvantages of the different advice giving

approaches once initial research has identified advice giving strategies used by AHPs,

### **2.2.2-Observations**

Observations could be useful to test out a hypothesis or validate a coded checklist. As such, this method could be used in combination with other methods, such as NGT and Delphi. However, to base this research study solely on using this method might cause some difficulties in terms of validity. People might not behave the way they would do when unobserved, thus their behaviour might change as a result of being observed rather than because of a research intervention, referred to as the Hawthorne effect (Crookes and Davies 2004). A further limitation is that it might be subjective and not easy to interpret, people could be watching the same event but could construe in it almost opposite ways, as was reported by Davis et al 2002)

It might also require a large number of observations to allow the generalisation of observed practice.

### **2.2.3-Interviews**

Interviews can be used as a longitudinal research; participants can be interviewed at regular intervals and can be used to gain an insight in an individual's experience over a period of time (Grbich 1999). A disadvantage of this technique is that it can create a social desirability bias, as the relationship between researcher and participant might have an effect on the manner in which questions are asked and responses are given, for example, the participant may be keen to please (Borg 1981).

*'Eagerness of the respondent to please the interviewer, a vague antagonism that sometimes arises between interviewer and respondent, or the tendency of the interviewer to seek out answers*

*that support his preconceived notions are but a few of the factors that may contribute to biasing of data obtained from the interview. These factors are called response effect by survey researchers.'*  
(Borg 1981, p8).

To conduct a structured interview the researcher requires developing a number of questions or one could use a less structured interview although this might not generate data relevant to the research question. The researcher suggests that this method is not suitable for this study, as it might not generate sufficient items to explore the advice giving strategies of AHPs.

#### **2.2.4-Focus Group**

Focus groups are semi-structured group interviews, involving 6-12 participants. Using a focus group method is an effective way to explore the experiences of people as well as their knowledge, and gain an understanding of the what, how and why of people's thinking (Kitzinger 1995). The method is particularly useful for exploring people's knowledge and experiences and can be used to examine not only what people think but how they think and why they think that way. One advantage of this method is that it people with literacy difficulties can fully participate (Kitzinger 1995, Gbrich 1999). As such this might have been useful for eliciting parents' views, as some might not have good literacy skills. A disadvantage of this method is that some participants might be very vocal, whereas others may feel not able to contribute; this has been the experience of the researcher in her work with parents. This would therefore not give an overall participatory viewpoint, and it is more difficult to manage for the researcher.

The above-mentioned methods are all valid to carry out a qualitative research study, however literature describing research in health, and especially when wanting to explore the views of service providers as well as service users, favoured Delphi or NGT. The advantages of these mixed method approaches are that they can be used to develop a consensus on a topic, establish areas of priority and identify particular problems (Van de Ven and Delbeck 1974, Gallagher, Hares, Spencer, Bradshaw .and Webb 1993, Carney, McIntosh and Worth, 1996, Walker and Selfe 1996, Potter et al 2004, Roddam and Selfe 2009).

#### **2.2.5-Delphi Technique**

The Delphi technique is a structured group process, participants are given an initial questionnaire and generate ideas independently, which is analysed by the researcher, feedback together with a further questionnaire is given to the participants. This process can be iterated a number of times. The more the process is iterated, the more refined the views will be, and the more likely it is to gain consensus about the topic (Van de Ven and Delbecq 1974). The Delphi technique requires much time from participants in responding a number of times to the feedback. The researcher has to develop a questionnaire, analyse the reponses, write a feedback report, and develop a further questionnaire. Given the time scale for the study and the aspiration to gain the views of parents as well, this method was not suitable.

### **2.3-DESCRIPTION AND STRENGTHS OF NOMINAL GROUP TECHNIQUE**

NGT is identified as a mixed method approach as it can produce both qualitative and quantitative data. This approach lends itself to elicit the views of

service providers as well as service users. The format of the session is such that it removes the potential for bias derived from professional hierarchies that might occur in less structured group interactions (Randall and Dunham 1998).

It is a structured group interview approach that follows a particular format, described as a 5-stage process (Potter et al 2004):

- Introduction and explanation
- Silent generation of ideas
- Sharing ideas
- Group discussion
- Voting and ranking

This research study is exploring the advice-giving strategies by AHPs and the purpose is to elicit participants' ideas about the subject matter. As such it is not necessary to conduct the whole NGT process described above, but merely the first three phases (Roddam & Selfe 2009). The remaining two phases would have been particularly useful if the research question was trying to reach a consensus about the effectiveness of identified advice-giving strategies or the strategy most utilised by AHPs (Van de Ven & Delbecq, 1974, Bartunek & Murnighan 1984, Potter et al, 2004).

The advantages of using this particular method are that it creates an equal partnership and allows all participants to contribute equally in a non-judgemental forum. The process focuses on one particular question and generates focused responses in a structured and systematic way. It is time efficient as no discussion takes place. As participants generate their items in silence it is reported that 'better' ideas will be generated compared to those

using different methods such as focus groups (Randall and Dunham 1998), where more vocal participants may potentially dominate the discussions.

Some of the disadvantages are that the process is rather regimented, the process can only be utilised as a single-purpose, single-topic meeting. No discussion takes place, which does not allow for elaboration of items generated, although clarification of comments is encouraged. This approach does not allow for discussion, which can stunt the further development of any ideas (Research Evaluation Team 2007, Randall and Dunham 1998); although that was not the aim of the current study.

## **CHAPTER 3-METHODS**

The NGT method was selected as the most appropriate method and sessions would be conducted with uni-professional groups (OT, PT, SLT) as this would produce a more comprehensive picture of AHP advice giving models for each of the identified groups, and would allow contrasting perspectives across AHPs as previous work had indicated (Roddam & Selfe 2009). The ideal number of participants for each NGT session would be 6-10 participants as identified by a previous study (Taylor-Powell 2002).

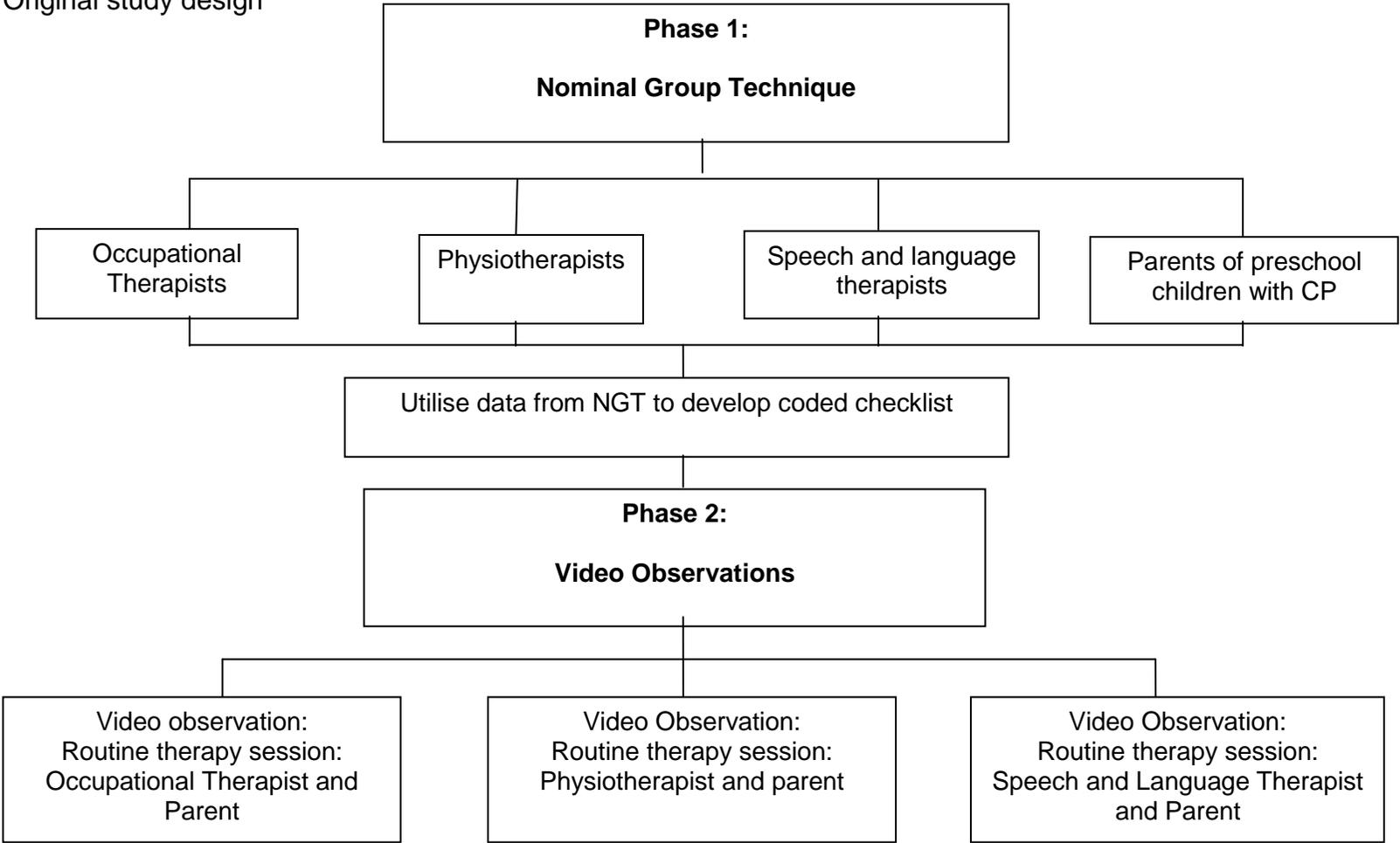
### **3.1-STUDY DESIGN**

The original study design consisted of two phases (fig 3.1)

Phase one was to hold four NGT sessions, three with therapists (OT, PT, SLT) and one with a group of parents. A coded checklist developed from the

analysed data would be utilised in phase two to observe and code routine clinical practice of AHPs working with the parents of these children.

Fig 3.1: Original study design



### **3.1.1-Inclusion criteria for therapists**

Therapists from OT, PT and SLT providing therapy to preschool children with CP, from a PCT in the North West will be invited to participate. The researcher has not met any of the therapists or worked within the identified PCT prior to the research study.

### **3.1.2-Inclusion criteria for parents**

Parents of pre-school children with CP, who receive therapy from at least one of the AHP services, are to be recruited through the AHPs. The AHPs will be directed to recruit families who have attended a varying number of therapy sessions to ensure a representative spread regarding the length of time receiving therapy. Parents needed to have attended at least one therapy session excluding the initial assessment. Parents who speak English as an additional language will be excluded from this study, as this would affect the communications between therapists and parents, and therefore influence the outcome. Families who had only attended their initial assessment, but not received any therapy sessions will also be excluded, to ensure that parents have some understanding of the process of the therapy session.

### **3.1.3-Recruitment of participants**

Prior to the recruitment of the AHP participants contact had been made with the Research and Development Manager to seek approval from the PCT to carry out the study. Discussions took place about the most appropriate manner to recruit potential AHP participants and parents, how the data would be stored and how and when findings would be disseminated. Careful consideration was given to the recruitment of potential therapist participants as it was a time of

major restructuring within the PCT, and some therapists would be changing their job roles. It was agreed one of the Clinical Managers would be involved and initially liaise between the therapists and researcher, once the researcher had gained the necessary ethical approval and the Research Passport.

The researcher anticipated to recruit between 6 and 10 participants for each of the NGTs, as this number was ideal (Potter et al 2004). In case of too many potential participants indicating their willingness to take part, participants would be selected at random, and unsuccessful participants would be notified, as indicated in the information leaflets (Appendices I and II).

The researcher contacted the Clinical Manager on a number of occasions and a date was set in October 2010 for the first NGT session with OTs to take place, after an area team briefing. The researcher emailed the clinical manager confirming the venue, time and sent the AHP information leaflet (Appendix II). The clinical manager agreed that she would email all therapists at least 48 hours before the NGT session, as agreed in the protocol.

The researcher came prepared to facilitate the NGT session, bringing all relevant equipment such as consent form, leaflets in case therapists had forgotten to bring their copy, A4 cards with the NGT question printed (appendix VI), pens for therapists to use and the script (Appendix VII) to ensure all NGT sessions were facilitated in the same way.

It was not possible to hold the NGT session with the OT AHPs, because there were a number of difficulties. The team briefing went on a little longer than

anticipated and some therapists had to leave. The clinical manager had not managed to send the necessary information to the therapists as per research protocol which had been approved by IRAS.

The researcher used the time to brief potential participants and handed out hard copies of the information leaflet. It was agreed with two of the clinical managers present, that the researcher would contact the therapists directly to organise mutually convenient dates on which to conduct the NGTs. At that moment it was uncertain which therapists would fall within the participant inclusion criteria. The clinical managers only identified eight possible therapists in total over the three disciplines, but thought that it would be possible to use a snowball technique where the therapists could identify more colleagues who met the required eligibility criteria. After discussion with the supervisory team, it was agreed to hold the sessions, even if only one participant per NGT session could be recruited.

The researcher contacted the identified therapists via email as well as by telephone and was able to confirm dates for all three NGT sessions.

### **3.2-DATA COLLECTION**

Three NGT sessions were held in November 2010. The numbers of recruited participants were very low (3 OTs, 3 PTs, and 1SLT respectively). The researcher had prepared for the session as previously discussed (3.2).

At the start of each of the NGT sessions the researcher explained that participants needed to concentrate on routine therapy sessions after the initial assessment sessions. The question was read out and participants were given a

card with the question for them to record the ideas (appendix VI). Therapists silently generated items for 10 minutes, and the researcher invited them to read out an item at the time, while the researcher recorded their exact words on a flipcharts (Appendices IX, XI, XIII) and transcripts (appendices VIII, X, XII). The researcher suggested that if they wanted to add further items at that stage that it would be fine to do so.

### **3.2.1-NGT session PT**

The researcher introduced herself, and confirmed how much time participants were able to commit (3 in total). The session was somewhat rushed, as one participant was 15 minutes late, and another one had to leave early. The therapists were asked to read the information once more and were invited to ask questions. The therapists were a little concerned about the video observation and in particular that a copy would be given to the parent, as usual practice for the service was to keep a copy with the clients' file. The researcher explained that it was best practice in research that all participants who took part in any video recordings would receive a copy of the tape. The researcher assured the therapists, that they would also receive a copy and it would be appropriate to keep that copy in the file.

Once the therapists had agreed to participate and signed the two consent forms, the researcher introduced the session, using the prepared script (Appendix VII). Once the silent generation of items had taken place the researcher used a round robin method to illicit the items from the therapists and record them on a flipchart (appendix VIII AND IX).

The researcher was conscious of the time constraints and explained ten minutes before the first therapist had to go, that although it was agreed at the start that their notes would not be collected at the end, the researcher would be happy to collect their cards if they had not had time to share all ideas. She emphasised that it was their choice and it was not a requirement. The therapists felt that they had shared their ideas and decided to keep their notes.

At the end of the session, which lasted 40 minutes, the researcher thanked all participants and handed them parent information leaflet (Appendix I) and asked them to think about parents of preschool children who might be willing and able to participate. This caused a little miscommunication as they presumed preschool literally meant when children start school, as some children with CP start school at 2 ½ years old. The researcher explained that the age range was children under 5 years old i.e. under compulsory school age. Therapists were also concerned about the exclusion of parents whose first language was not English, as they had a number of children from BME backgrounds on their caseload. Once therapists' questions were answered, the researcher agreed to contact the therapists once all three NGT sessions had been held.

### **3.2.2-NGT session OT**

The three therapists also had some concerns about the video observations, such as the video ownership, but were satisfied when the researcher explained the situation.

The researcher followed the same format as the previous session (appendix VII) and therapists generated many different items, adding their ideas once the

researcher invited them to share their thoughts and recorded them on the flipchart (Appendix XI) transcript (Appendix X).

Just as the previous session, the researcher explained that she would contact them once the last NGT had taken place. One of the therapists asked the researcher to confirm her attendance, as she wanted to utilise this as part of her Continuous Professional Development (CPD).

### **3.2.3-NGT session SLT**

One therapist was able to attend the session. She explained that the service does not work much with individual children and parents, as their service does not provide a 'feeding and swallowing' clinic at present for children with CP. They do assess children individually; however they work in a group situation, using the Hanen program (Pepper and Weitzman 2004), and the Derbyshire Language scheme (Knowles and Masidlover 1982). As such it would not be appropriate to video record a therapy session.

The actual NGT session was carried out in the same manner as the other two, and although the researcher was concerned about the amount of possible items one therapist would generate, this was unfounded as the therapist generated thirteen items, although less than her colleagues from OT and PT, items were more complex e.g. more multi strategy approaches in comparison. The researcher recorded all items on a flipchart (Appendix XIII), transcript of the session (Appendix XII).

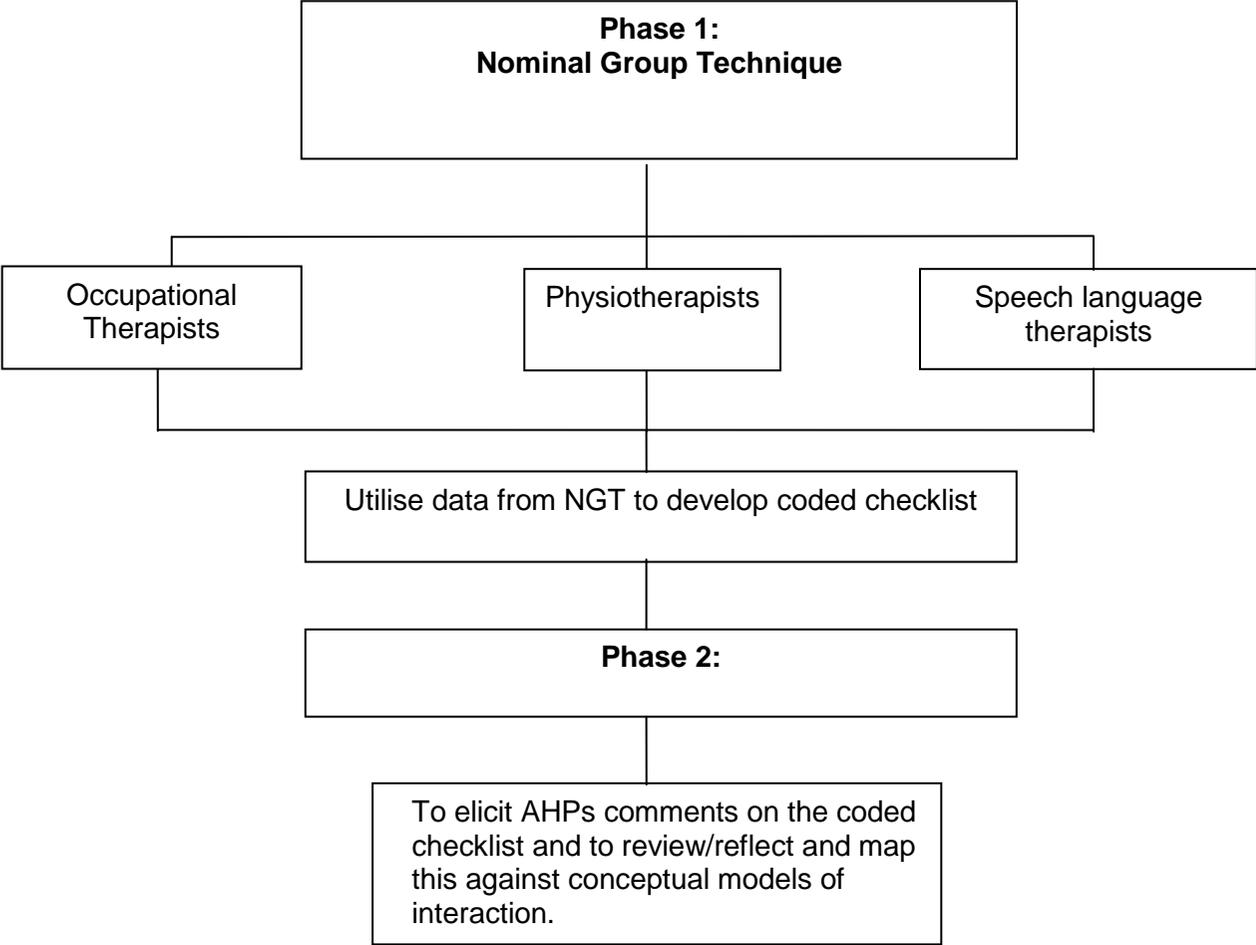
### **3.2.4-NGT session Parents**

The researcher contacted all the therapists who participated in the NGT sessions, to ask them to invite parents. Unfortunately therapists were not able to recruit any parents. There were a number of reasons given, such as the exclusion of parents whose first language was not English, as the PCT is based in an area with large numbers of families from BME backgrounds. Therapists also reported that they were reluctant to ask certain parents because they appeared rather stressed. A further issue was the timing, as it had taken over 4 months to hold the AHP NGT sessions; it was the beginning of December before the researcher was able to contact the therapists to ask them to invite parents. Two dates were provisionally booked in January 2011; however they were cancelled as no parents had indicated that they wanted to participate.

The inability to recruit parents for the NGT session had a significant effect on phase two of the research design (fig3.1).It required making changes to the study design (fig 3.2) and seeking approval from IRAS, as it would not be possible to carry out video observations of routine clinical practice and reviewed/reflected on video observations and mapped these against NGT items and conceptual models of interaction.

Letters were sent to all AHPs who attended the NGT sessions, explaining the changes (Appendix V). It was agreed to undertake respondent validation by asking the AHPs who had participated in the NGTs to review and comment on the coded checklist.

Fig: 3.2 Revised study design



### 3.3-DATA ANALYSIS

NGT data analysis lent itself for utilising both qualitative and quantitative methods, as the process of generating items is a qualitative approach and the ranking and voting is quantitative (Potter et al 2004). For the purpose of this research, it would not be necessary to carry out the voting and ranking, and a qualitative data analysis approach is most suited.

*“Qualitative analysis is typically inductive in the early stages ... figuring out possible categories, patterns and themes.”*  
(Patton 2002: p 453)

The first phase was to carry out the three NGT sessions. To make sense of the collected data and identify themes the researcher used an inductive content analysis (Potter et al 2004). This process would be carried out in an iterative manner, using a process of noticing, collecting and thinking (Seidel1998). This cycle allowed for themes to emerge, being coded and new codes to be discovered. Once themes were identified and all items were colour coded, it was possible to compare the themes from all three NGT sessions.

The next stage was to synthesise and integrate the items generated from the NGT with the conceptual models of interaction to develop a coded checklist.

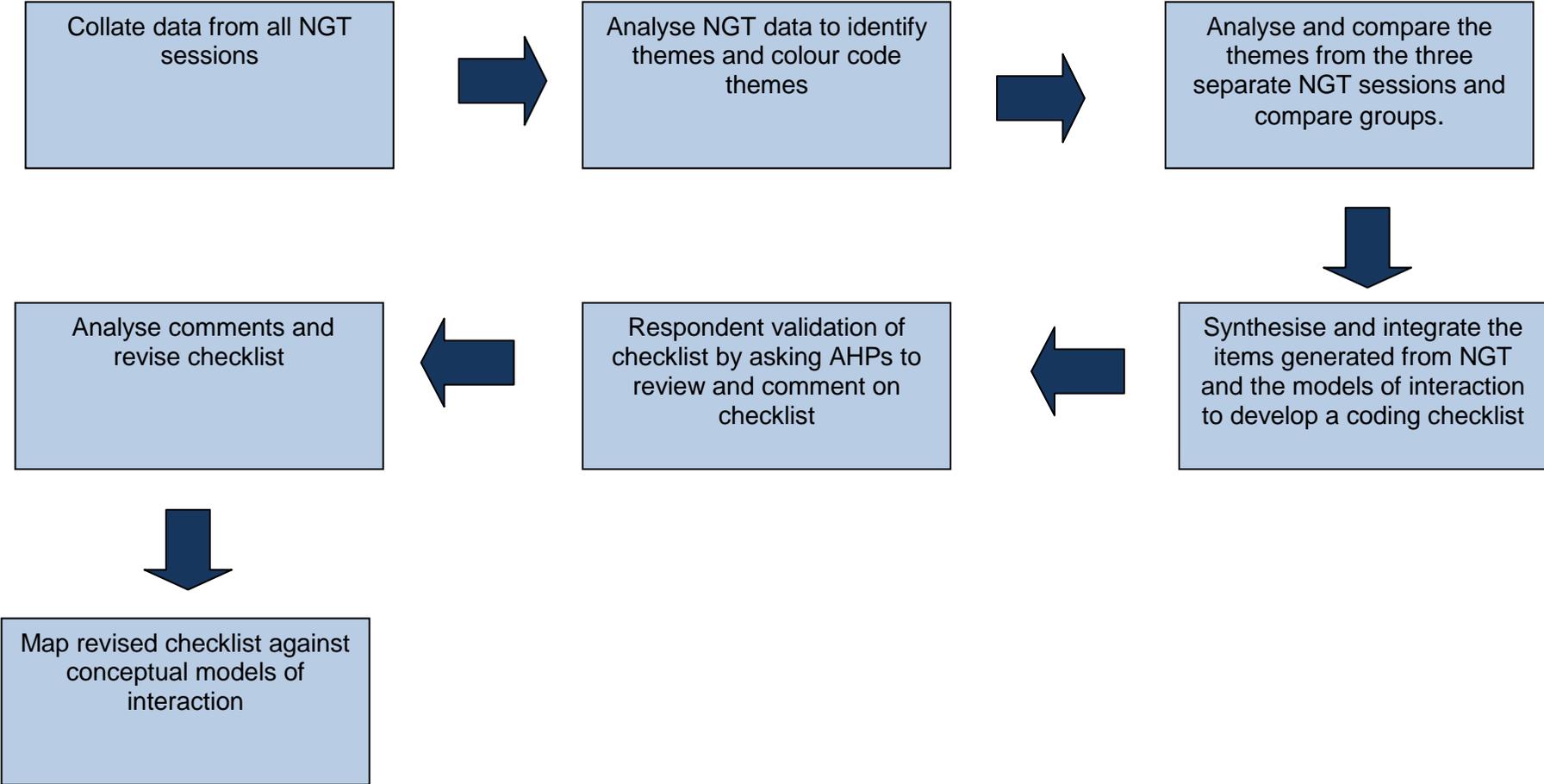
Phase two was to ask participants to review and comment on the checklist items and in particular to: Confirm the face validity of the items listed, identify any ambiguous items, and contribute any supplementary items.

The responses from the AHPs were collated and analysed, and informed the revision of the checklist. The wording and format of the finalised checklist

would reflect its purpose of becoming a research instrument for future studies in field.

Lastly the researcher reviewed and reflected on the revised checklist and mapped this against conceptual models of communication.

Fig 3.3: Data analysis plan flow chart



An inductive content analysis process was utilised to identify emerging themes, this involved a process of noticing any similarities and differences between the generated items, collecting and ordering these accordingly, thinking about the emerging patterns (Seidel 1998). The process was iterated a number of times to allow for new themes to emerge. Once all items had been allocated to the various themes and the researcher was confident no further themes could be identified, the themes were colour coded (Appendix XV, Tables; 4: 1, 4.2, 4.3, 4.4), it was possible to scrutinise the analysed data for any possible differences and similarities between the three AHP disciplines (Fig 4.4 and tables 4: 5 and 4.6).

The generated items were synthesised and integrated with the conceptual models of communication to develop a coded checklist (table 4.7)

### **3.4-VALIDATION OF CODED CHECKLIST**

Therapists were contacted electronically, with attachments to the letter explaining that changes had been made to the study design (fig 3.2), and a copy of the coded checklist (table 4.7). Therapists were no longer required to recruit parents, instead therapists were asked to give their views about the coded checklist and comment on:

- a) Confirm the face validity of the items listed,
- b) Identify any ambiguous items,
- c) Contribute any supplementary items.

Hard copies of the checklist were also sent to the individual therapists, together with instructions, including a self addressed envelope to ensure anonymity. Therapists were given two weeks to give a response.

### **3.5-REVISED CODED CHECKLIST**

Not all therapists who took part in the NGT sessions had returned their comments. (n3 from 7). To increase the credibility of the validation for the proposed checklist items, the three members of the researcher's supervisory team offered to independently complete the validation exercise. This contributed the supplementary perspectives of experienced clinicians from each of the three AHP groups (OT, PT and SLT).

The responses from the AHPs who took part in the NGT and the AHPs known to the researcher were collated and analysed. A coded checklist was revised and mapped against conceptual models of interaction.

## **CHAPTER 4-RESULTS**

### **4.1-OVERVIEW AND ANALYSIS OF THE THREE NGT SESSIONS**

The three NGT sessions with AHPs generated 57 separate items in total, (20 - OT, 24 - PT and 13 - SLT).

#### **4.1.1-Data analysis of NGT session with OT**

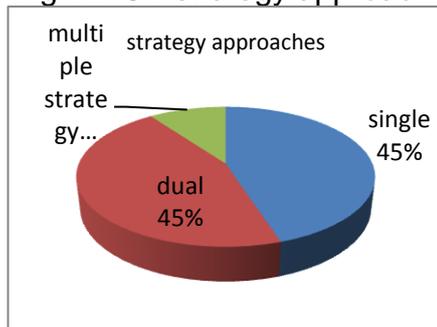
Twenty separate items were generated during the OT NGT session (table 4.1).

Table 4.1 NGT- OT item generation

	OT – NGT SESSION		
1	Care Aims- episodes of care to set goals with parents: talk to the parents, ask them what their goals are, bring these together, write them up, ask parents to look at it, make changes and ask to sign them	11	Encourage parent – dressing – encourage the child to assist, crossing midline, transferable skills, isolated skills – transferred – generalised. Backward chaining, example, child getting a jumper on, child assisting with the last action.
2	Demonstrate physically with the child, for example change of position.	12	Printed sheets from books and reputable websites etc. eg fine motor skills when it does not need to be child specific
3	Position child is having at present – change position by therapist – hand over hand with parent to experience the feeling of that and why the change of position is desirable and what it will lead to.	13	Letters are given when parents refuse interventions such as lifting and handling, identify what they don't want to do and have them sign that. Identify the risks to not adhering, list of consequences.
4	Asking parent to repeat what therapist has demonstrated, whatever the technique may be and give constructive comments.	14	Goal planning, joint meeting between OT=PT, joint episodes
5	Child with Hemiplegic to move efficiently in a more functional manner. Show and give further encouragement to parent and give more ideas.	15	Include demonstration on the effects of effort and stress on tone. Guidelines on best times i.e. not before bedtimes, when child is tired, sick etc.
6	Child specific photos – give parent the photos of their child, of the therapy advice program, so parents have pictures with verbal cues. Used for example for changes of position, moving and handling, position of play and dressing	16	Parental diaries for lycra garments and sleep systems, tell parent what to record. When, time of day, what did the child do, effect to tone, in tables.
7	Pictorial stickman with arrows: where parents need to put their hands i)Arrows for directions of force ii)In conjunction of therapist doing it 'on' the parent	17	Offer visit to nursery/other carers to repeat advice at parent's request or therapist feels it would benefit.
8	Use of OT assistant to further demonstrate and/or reiterate – when setting up goals and give advice, clear written pictorially. To put into/continue to put into practice. Dependent on factors such as: Competence of OT assistant and parent Complexity of child, and tolerate it.	18	Using specific pieces of equipment to demonstrate functional improvement, child is or example: a child having difficulty balance in the sitting position, use of chair will free the child's hands.
9	Pictorial pre-made advice sheets on positioning, dressing, moving and handling (generic, not child specific – facilitated on a doll)	19	Introduce parent to other families with permission, with adaptations, showing how it can work
10	Discuss skills acquisition – lead to other activities	20	Advise to attend other commercial centres such as a soft play centres, parks

The OTs identified nine single strategy approaches (table 4.1 items 2, 9, 10, 12, 13, 14, 17, 19, 20) nine dual strategy approaches (table 4.1 items 3, 4, 5, 6, 7, 11, 15, 16, 18) and two multiple strategy approaches (table 4.1 items 1, 8). The researcher colour coded each separate item to aid the analysing of the data (Appendix XV).

Fig 4.1 OT strategy approaches



The researcher identified that OTs used many different advice giving strategies approaches with parents, and categorised these into three main themes (verbal communication, physical demonstration and written information), in which a number of activities and a number of single activities (goal setting, use of equipment, use of assistant, introduce to other families, joint planning between therapists, offer visit to childcare setting, work in partnership with parents).

**Verbal communication:**

Activities: they discussed issues with parents (table 4.1 items 10, 13), gave advice (table 4.1 items 15, 16, 20), gave feedback (table 4.1 item 4), and used verbal cues (table 4.1 item 6). All these items are themed as verbal communication; however there were some distinguishing features, and tell us something about the relationships with the parents, and all the different aspects of verbal communication.

**Physical demonstration:**

Activities: Practical demonstration (table 4.1 items 2, 3, 5, 15, 18) hand on/over hand demonstration (table 4.1 item 3), practical demonstration on the parent (table 4.1 item 7) and the parent demonstrating to the therapist (table 4.1 item 4).

**Written information:**

Activities: child specific information (table 4.1 items 6, 7, 8), parent specific information (table 4.1 items 13, 16), pre written (table 4.1 items 9, 12).

**Single activities:** There were two items identified under the goal setting theme, but all single themes featured one item.

**Goal setting/ discussion:** (table 4.1 items 1 and 8)

**Working in partnership with parents:** (table 4.1 item 1).

**Use of OT assistant:** (table 4.1 item 8)

**OT offered visit to nursery:** (table 4.1 item 7).

**Use of equipment:** (table 4.1 item 18).

**Introducing parents to other families:** (table 4. item 19).

**Joint planning between therapists:** (table 4.2 item 14).

**4.1.2-Data analysis of NGT session with PT**

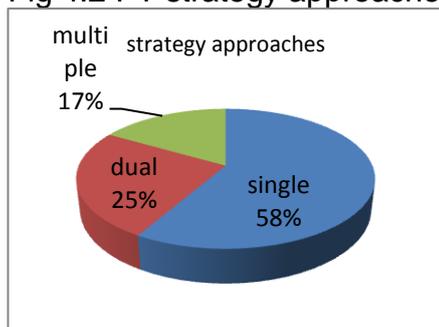
Twenty four items were generated, (table 4.2).

Table 4.2 NGT – PT item generation

	PT – NGT SESSION		
1	Demonstration- showing what to do, or what I plan to do	13	Discussion how the family runs, to see how to incorporate therapy activities into daily life
2	Verbal explanation together with physical demonstration	14	Ask parents what their goals are – a child with splints – parent didn't feel they were doing what she had expected, so the splints were altered, even though PT felt the splints were ok.
3	Picture handout/photo program, for example putting the child on their tummy	15	Discuss how often and where to do the therapy activities, for example after Botox/post op stretching activities – in school, clinic, outdoors
4	Balance – demonstrate to the parent how to do that	16	Discussion current progress and where they want to be and how to get there – goal – parent has an unrealistic expectation
5	Parents to show how to stand the child up, after having shown it to the parent	17	Using pt assistant to support parents to achieve goals- can be at home/clinic or preschool
6	Advice giving – How to stand up, eg the parent is showing what to do and help the parent for example giving instructions such as move your had a little this way	18	Explain the goals in relation to normal development
7	Show them how to motivate a child – suggestions such as playing on the ball, sing a nursery rhyme, using appropriate toys	19	Talk about normal movement- explain therapy goals – if unrealistic ask parents how they move, for example getting out of bed
8	Giving different options to a particular goal, and see what parents prefer, such as standing up	20	Provide information about the condition – drip feed
9	Physio exercise, can be in different locations, such as the park, tumble tots, at home	21	Explain short/long term goals and breaking down the tasks e.g. parent what child to walk, but is not rolling over yet.
10	Hand on hand support – sitting exercise, the child is wriggling a lot, guide the mother's hand, often to show how much pressure to use	22	Explain goals in light of standardised assessment (GMFM) Gross Motor Functional Measure and show verbal and physical – helpful to show the GMFM as it's like an outsider supporting evidence based
11	Physical and verbal prompts – hand on hand help to stand up, stretch, firm or not firm	23	Explain goals, why and how it will help the child to function- the reason why we put the child on prone is to develop head control and good develop movement
12	Written explanation- pre made handouts or individually written. Capable parent- have agreed to have just written instructions without pictures	24	Review progress and adapting goals, i.e. when you have worked on a goal for 6 months but no progress, this can be when parents identified the goal

PT identified fourteen single strategy approaches (table 4.2 items 1, 3, 4, 9, 10, 13, 15, 17, 18, 19, 20, 21, 23, 24), six dual strategy approaches (table 4.2 items 2, 5, 7, 8, 14, 16), and 4 multiple strategy approaches (table 4.2 items 6, 11, 12, 22), (fig 4.2). Please refer to table 4.4 and appendix XV for actual colour coding of the items.

Fig 4.2 PT strategy approaches



The researcher identified thirteen items under the main theme of verbal communication, nine items under the main theme of practical demonstration, four under the main theme of written information, and three single activities (goal setting, use of assistant, teach parents), (table 4.4 appendix XV).

**Verbal communication:**

Activities: discussion with parents (table 4.2 items 8, 13, 14, 16), gave advice (table 4.2 items 6, 11, 15, 19, 20, 22), verbal explanation (table 4.2 item 2) and verbal prompt (table 4.2 item 11).

**Physical demonstration:**

Activities: practical demonstration (table 4.2 items 1, 2, 4, 11, 22), hand on hand (table 4.2 items 10, 11) and parent demonstrate (table 4.2 items 5, 6).

**Written information:**

Activities: Child photo/specific (table 4.2 items 3, 12), pre made information (table 4.2 item 12), and individually written (table 4.2 item 12).

**Single activities:**

**Goal setting/discussion:** Eight items (table 4.2 items 8, 14, 16, 18, 21, 22, 23, 24).

**Teach parents:** (table 4.2 items 6 and 7).

**Use of assistant:** (table 4.2 item 17).

#### **4.1.3-Data analysis of NGT session with SLT**

Thirteen items were generated in total and appeared more complex in terms of multiple strategy approaches.

SLT service in this particular PCT didn't provide swallowing therapy and approaches described in table 4.3 were associated with the language development of preschool children with CP. It is provided in a group parent teaching environment. Individual sessions are used for reviews and discussion of video observations and goal setting.

Table 4.3 NGT – SLT item generation

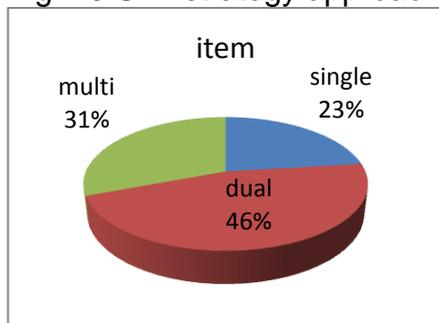
	SLT – NGT SESSION		
1	Explanation given to the parent about how the child's communication is worked on as part of a holistic approach with parents and therapists working in partnership. This work is never in isolation, but always in partnership not only with the parent but also OT and PT. Aim of each block of therapy is to empower those in the child's environment, to work on child's communication during daily activities.-	8	The therapists also use the Derbyshire Language scheme, to carry out ongoing assessments where the child is at. E.g. using a comprehension program – demonstrate to the parent with the child, give the information in written format, this is also shared with portage and nursery to reinforce and generalise the comprehension. Also liaise with OT/PT to ensure that they are able to do their work at the appropriate level.
2	Different ways to empower the parents. The role of the SLT is to 'train' the parents to be the child's therapist	9	Expressive/Comprehension, we also use key word signing. During the Hanen course they think about different ways to support communications. Result, if signing is helpful, parents are invited to keyword signing workshop, and they incorporate Maketon and Signalong. If parents want, they can sign up for a Signalong foundation course (16 hours).
3	Using the Hanen "IT TAKES TWO TO TALK". We give a leaflet to explain the program, loan copies of the handbook and DVD. The program is evidence based for working with parents of children with CP	10	Communication books and files are used to facilitate the child making choices and helps the child to become an active communicator. Discuss the vocabulary with the parents and advice is given how to use the file.
4	Invite parents to attend a parent course (generally when child is 18months +). 8 group sessions, during which the therapist teaches strategies to the parent, and parent and therapist set goals. During the course 3 video sessions are recorded. The aim is looking at how parents implement the strategies and set individual goals for the parent and child. There is also close liaising with other therapists, portage and nursery.	11	Objects of reference – Comprehension and giving choices. It is discussed and a handout given about the episode of care plan. This is also discussed with Portage.
5	In the group sessions, the therapist teaches the strategies first, then how to apply these. How to set appropriate communication goals.	12	Episode of care- Identify with the family the goals and sub-goals Reviews can take place at the nursery, and this can be discussed with the parent over the phone, but only when SLT is completely certain where they are up to and parents are realistic about the next goal, and knows the parent well. Otherwise a discussion takes place with the parent when, where to meet to discuss the next goal.
6	Hanen divides children into: Child discovers – non intentional communication Communicators – Intentional communicators without words First word users Combiners a) Parents are asked to use the charts within the handbook to decide what kind of communicator the child is.	13	SLT works very closely with other professionals to facilitate communication in their sessions.
7	Therapists encourage parents to buy the handbook, as it allows the growth of the child, and appropriate strategies and goals.		

Items generated by the SLT show 3 single strategy approaches (table 4.3 items

7, 9, 13), 6 dual strategy approaches (table 4.3 items 2, 3, 5, 6, 10, 12) and 4

multiple strategy approaches (table 4.3 items 1, 4, 8, 11) (fig 4.3). Please refer to table 4.4 and appendix XV for actual colour coding of the items.

Fig 4.3 SLT strategy approaches



The researcher identified six items under the main theme of verbal communication, one item under the main theme of practical demonstration, three under the main theme of written information, and seven single activities (goal setting, teach parent, video observation, work in partnership with parents, work in partnership with professionals, loan equipment) (table 4.4 appendix XV).

**Verbal communication:**

Activity: discuss with parents (table 4.3 items 1, 11, 12), empower parents (table 4.4 items 1, 2), encourage parents (table 4.3 item 7).

**Practical demonstration:**

Activity: practical demonstration (table 4.3 item 8).

**Written information:**

Activity: individually written (table 4.3 item 8), pre written information (table 4.3 items 3, 8).

**Single activities:**

**Goal setting:** Three (table 4.3 items 4, 5, 12).

**Teach parent:** Six items (table 4.3 items 2,4, 5, 6, 8,9).

**Video observation:** one item (table 4.3 item 4).

**Work in partnership with parents:** one item (table 4.3 item 1).

**Work in partnership with professionals:** five items (table 4.3 item 1, 4, 8, 11, 13). **Loan equipment:** one item (table 4.3 item 3).

## 4.2-COMPARISONS BETWEEN THE NGT GROUPS

Analysing the data from the NGT sessions and comparing the groups was not straight forward, as there were many different items given to describe similar strategy approaches.

The researcher created a comprehensive colour coded key across all three NGT sessions (table 4.4), to capture the subtle differences in the advice giving activities, such as seven slightly different verbal communications, three written, four physical, and eleven single activities.

Table 4.4 colour key

Discuss with parents	Verbal explanation/ cue	Written individual information	Parent demonstrates to therapist	Introduce to other families
Give advice	Verbal prompt	Teach parents	Use of equipment	Work in partnership with professionals
Encourage parents	Set goals with parents	Practical demonstration	Use of assistant	Joint planning between therapists
Empower parents	Written pre-made information	Hand on/over hand demonstration	Recording video observation	Offer visit to childcare setting
Give feedback to parents	Child specific / photo information	Practical demonstration 'on' the parent	Loan equipment	Work in partnership with parents

There were 25 different strategy activities identified. This clearly demonstrated the complexity of the behaviours associated with the advice giving strategy

approaches. The purpose of the colour coded key (table 4.4) was to support the identification of the different themes and activities utilised by all AHP groups and to allow all groups to be compared see appendix XV .

#### **4.2.1- Comparative findings**

The researcher compared the three AHP groups in terms of the item generation; identifying fourteen different single, seventeen dual and eleven multiple strategy approaches (table 4.5). There were fifty seven items generated in total across the three NGT groups (tables 4.1, 4.2, 4.3), some items were utilised by more than one AHP group and as such the table shows 42 different strategy approaches.

The table (4.5) illustrates that there were three single approach strategy items that two AHP groups had in common: both OT and PT identified '*discuss with parents*', '*set goals*' and '*practical demonstration*'. SLT did not have any single activity approach items in common with the other two AHP disciplines.

There was one dual strategy approach item that PT and SLT had in common, '*set goals / discuss with parents*'. OT and SLT both identified '*individual written information / give advice*' as a dual strategy approach item.

None of the three AHP groups identified multiple strategy approach items in common with each other. (table 4.5)

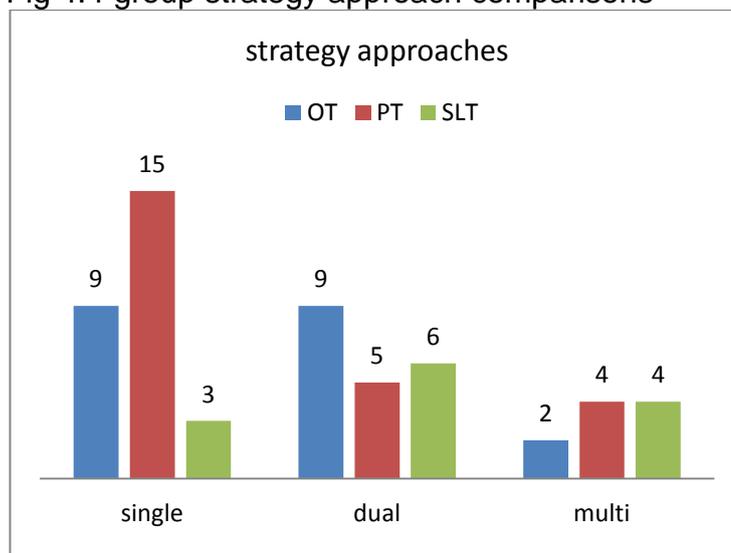
Table 4.5 NGT item group comparisons

<b>Single advice giving item</b>		<b>OT</b>	<b>PT</b>	<b>SLT</b>
Discussion with parents	1	1	1	
Give advise	2	1	3	
Teach parents	3			1
Encourage parent				1
Child specific/ photo information	4		1	
Written pre-made information	5	1		
Written individual information	6	1		
Hand on hand demonstration	7		1	
Practical demonstration	8	1	2	
Use of assistant	9		1	
set goals with parents,	10	1	4	
Introduce parent to other families	11	1		
Offer visit to childcare setting	12	1		
Work in partnership with professionals	13			1
Joint planning between therapists	14	1		
<b>Dual advice giving items</b>		<b>OT</b>	<b>PT</b>	<b>SLT</b>
Encourage parent/teach parents	15	1		
Empower parents / teach parents	16			1
Verbal explanation practical demonstration	17		1	
set goals with parents, discuss with parents	18		3	1
Teach parents / written individual information	19			1
Teach parents/ set goals with parents	20			1
Written individual information / give advice	21	1		1
Written pre-made information / loan equipment	22			1
Written pre-made information/ practical demonstration on the parent	23	1		
Child specific/ photo information/verbal explanation/cues	24	1		
Practical demonstration/ give advice	25	1		
Practical demonstration/ encourage parents.	26	1		
Practical demonstration / teach parents	27		1	
Practical demonstration / hand over hand demonstration	28	1		
Parent demonstrates to therapist /give feedback	29	1		
Parent demonstrate to therapist, practical demonstration	30		1	
Use equipment / Practical demonstration	31	1		
<b>Multiple advice giving items</b>		<b>OT</b>	<b>PT</b>	<b>SLT</b>
Give advice/ parent demonstrate to therapist /teach parents	32		1	
discuss with parents/ work in partnership with parents/ work in partnership with professionals/ empower parents	33			1
Discuss with parents child specific / photo information. work in partnership with professionals	34			1
set goals with parents /discuss with parents/ written individual information/ work in partnership with parents	35	1		
Set goals with parents/ give advice/ practical demonstration	36		1	
Teach parents . practical demonstration, written pre made information /work in partnership with professionals	37			1
Teach parents/ set goals with parents/record video observation /work in partnership with professionals	38			1
Child specific/photo information discuss with parents/ give advice	39			
Written pre made information/ child specific/photo information/ discuss with parent/ written individual information	40		1	

Practical demonstration/ verbal prompts – hand on hand demonstration	41		1	
Use of OT assistant/ practical demonstration/ set goals with parents/ give advice / written individual information	42	1		

PT identified single strategy approaches most frequently (15) and more often than the other two groups, whereas OT tended to utilise dual strategy approaches (9) more than the other groups, but as frequently as single activity. SLT only generated 13 items, and used dual activity (6) most frequently and more often than PT. PT and SLT equally utilised multiple strategy approaches in their work with parents (4). (Fig 4.4)

Fig 4.4 group strategy approach comparisons



#### 4.2.2-Comparative group findings of strategy approaches

Table 4.6 was developed by the researcher to examine the strategies approaches utilised by the AHP groups and the frequency these were used. There were 57 items generated, but 95 separate advice giving strategies were identified, as some items described dual or multiple strategy approaches. The findings are discussed below.

Table 4.6 comparison group strategy approach and frequency

Themes	Strategy approaches	OT	PT	SLT
Verbal communication	Discussion with parents	Yes (2)	Yes (5)	Yes (3)
	Give advice	Yes (3)	Yes (5)	Yes (1)
	Encourage parents	Yes (2)	No	Yes (1)
	Empower parents	No	No	Yes (2)
	Give feedback	Yes (1)	No	No
	Verbal cue	Yes (1)	Yes (1)	No
	Verbal prompt	No	Yes (1)	No
<b>Total</b>		<b>9</b>	<b>12</b>	<b>7</b>
Written information	Written pre made information	Yes (3)	Yes (1)	Yes (2)
	Child specific written information	Yes (1)	Yes (1)	Yes (2)
	Written individual information	Yes (2)	Yes (1)	Yes (1)
<b>Total</b>		<b>6</b>	<b>3</b>	<b>5</b>
Physical demonstration	Physical/practical demonstration	Yes (5)	Yes (7)	Yes (1)
	Hand on hand demonstration	Yes (1)	Yes (2)	No
	Practical demonstration on parent	Yes (1)	No	No
	Parent demonstrate to therapist	Yes (1)	Yes (2)	No
<b>Total</b>		<b>8</b>	<b>11</b>	<b>1</b>
	Set goals with parents	Yes (2)	Yes (6)	Yes (3)
	Use of equipment	Yes (1)	No	No
	Teaching skills	Yes (1)		Yes (6)
	Use of assistant	Yes (1)	Yes (1)	No
	Video observation	No	No	Yes (1)
	Loan equipment	No	No	Yes (1)
	Introduce to other families	Yes (1)	No	No
	Working in partnership with professionals	No	No	Yes (5)
	Joint planning between AHPs	Yes (1)	No	
	Working in partnership with parents	Yes (1)	No	Yes (1)
	Offer visit to setting	Yes (1)	No	No
<b>Total</b>		<b>8</b>	<b>13</b>	<b>11</b>
<b>Total items</b>		<b>31</b>	<b>34</b>	<b>30</b>

**Verbal communication:**

Within this main theme PT identified discussion and advice giving as the most recurrently utilised activities within this theme and more frequently than the other two groups. These two activities were the only two that all three groups utilised. SLT was the only group to identify that they empower parents. OT was the only group who mentioned that they provide feedback to parents (table 4.6).

**Written information:**

All three groups identified to utilise all three activities within this main theme, although OT was the only group who identified to give parents a letter to sign if they refuse interventions (table 4.1 item 13).

**Physical demonstration:**

OT identified that they used all activities within this main theme. Practical demonstration like PT was used most frequently, they identified that they don't use practical demonstration on the parent as a strategy approach. SLT confirmed to use practical demonstration as the only strategy approach within this main theme (table 4.6).

**Single activities:**

SLT generated items suggesting that they utilise teaching parents and working in partnership with professionals as the most recurrent single strategy approach. They also utilised video observation, loan equipment and working in partnership with parents. PT only identified two approaches, setting goals with parents as the most frequently used one, and use of assistant. OT utilised most

of the single strategy approaches however less frequently than the PT and SLT (table 4.6).

One could argue that some of the generated items did not describe actual advice-giving strategies, but illustrated conceptual models of communication '*we work in partnership with parents*' and '*we also liaise with other professionals*' and '*joint planning meetings*' (table 4.5 item 14, table 4.6).

### **4.3-SUMMARY OF FINDINGS**

All three AHP groups identified strategy approaches used in their work with parents. From the generated data one can conclude that all three AHP disciplines have some similar strategy approaches, although the combinations of the strategy approaches differ significantly different (table 4.6).

Both OT and PT use assistants, although they utilise the assistant differently (table 4.5).

All three AHP groups set goal with parents, although the manner in which this is executed differs, PT identified goal setting in six separate items (table 4.2 items 8, 14, 16, 18, 21, 22, 23, 24), although most of these identified dual or multiple strategy approaches. For example '*goal setting*' in relation to GMFM two other approaches were used '*discuss with parents*' and '*physical demonstration*', another item identified '*goal setting*' in combination with '*give different options to a particular goal and see what parents prefer*' (table 4.5).

SLT identified five items of partnership working with other therapists and professionals such as portage or nursery staff (table 4.3 items 1, 4, 8, 11, 13), neither of the other two AHP disciplines identified partnership working, although OT did generate an item about joint goal planning with PT (table 4.1 item 14).

Both OT and PT identified a number of items describing physical demonstrations; however the actual strategy approaches were different. OT utilised practical demonstration in combination with parent demonstrating to therapist, use of an assistant, advice giving, using equipment, therapist doing it on the parent and clear written pictorial information (table 4.1 items 2, 3, 3, 4, 7, 8, 15, 18). PT on the other hand used physical demonstration in combination with verbal explanation, teaching the parent, verbal prompts, setting goals (table 4.2 items 1, 2, 4, 5, 6, 7, 11, 22). PT used physical demonstration on two occasions as a single strategy approach (table 4.2 items 1, 4), OT only identified one (table 4.1 item 2).

SLT didn't work with individual parents, apart from reviews, and used specific programs such as Hanen (Peppe, and Weitzman 2004), and Derbyshire Language Scheme (Knowles and Masidlover 1982). Teaching and training was used on a number of occasions (table 4.3 items 2, 4, 5, 6, 9). The other two AHP disciplines identified working on an individual basis with children and their parents, although the therapists did not use the term teaching, the researcher interpreted 'gave *suggestions*' and 'gave *instructions how to move their hand*', from the PT items as teaching parents skills (table 4.2 items 6, 7), OT identified teaching parents to '*backward chain*' together with '*giving encouragement*', which the researcher interpreted as teaching parents skills (table 4.1 item 11).

SLT only identified two single strategy approach items (table 4.3 items 7, 13), compare to OT eight single strategy approach items (2, 9, 10, 12, 13, 14, 17, 19, 20), and thirteen for PT (table 4.2 items 1, 3, 4, 9, 10, 13, 15, 17, 18, 19, 20, 21, 23, 24).

#### **4.4-CODED CHECKLIST DEVELOPMENT AND VALIDATION**

One of the objectives of the study was to devise a coded checklist (table 4.7), which could be utilised as a research instrument for future studies. The researcher used two phases to develop the checklist, firstly she developed a checklist for validation and once comments from therapists were analysed (appendix XVI) the refined coded checklist was created (appendix XVII)

Initially the analysed data (appendix XV) together with the literature about the models of communication were synthesised and integrated with the models of communication (table 4.14). The researcher endeavoured to capture the differences of the strategy approaches as well as the combinations of the approaches. The theme headings on the checklist (table 4.7) correspond with items on the colour coded key (table 4.4), (verbal instruction, written information, practical demonstration, utilise assistant, observing video recording, loaning equipment to parents, working in partnership). The '*combination of activities*' was not identified as a specific activity as the researcher wanted to capture some of the complexities surrounding the advice giving strategies. Table 4.5 illustrated that AHPs used a number of dual and multiple strategy approaches and these differed between the three AHP groups.

**Table 4.7 Coded Checklist for therapists to make comments**

<b>THEME</b>	<b>Activity</b>	<b>FACE VALIDITY OF ITEMS</b> <i>Can you confirm that this describes an approach which you have used/may use when working with parents?</i>	<b>AMBIGUOUS DESCRIPTIONS</b> <i>Please can you indicate any of these descriptors which seem unclear, and suggest alternative or additional wording to more accurately reflect the nature of the approach you have taken/would take when working with parents</i>
<b>Verbal instruction</b>	You talk to parents about how the family functions, to see how to incorporate therapy activities into daily life		
	Explain goals, why and how it will help the child to function		
	You set goals together		
	Discuss skills acquisition		
	Discuss current progress, explain the child's goals in relation to "normal" progress		
	Explain short/long term goals and breaking down the tasks e.g. parent what child to walk, but is not rolling over yet.		
	Discuss with parents the child's current progress and where they want to be and how to get there		
	Review progress and adapt goals		
	Advise them to attend other treatment centres/providers, commercial centres such as a soft play centres, parks		
<b><i>Can you add any supplementary descriptions of approaches you use which are similar but slightly different to these listed above?</i></b>			
<b>Written information</b>	Give a pre-prepared advice/information leaflet		
	Give a handout given about the episode of care plan		
	Printed sheets from books and reputable websites etc.		
	Give written advice/ information which you have specifically prepared for their child		

	Give photos of the child in therapy to aid parents to undertake practice/exercises		
	Give leaflets with pictorial stickmen with arrow to aid parents to undertake practice/exercises		
	You ask the parent to keep a diary for lycra garments and sleep systems, tell parent what to record. When, time of day, what did the child do, effect to tone, in tables.		
	You give a letter to parents when they refuse interventions such as lifting and handling, identifying the risks.		
<b>Can you add any supplementary descriptions of approaches you use which are similar but slightly different to these listed above?</b>			
<b>Practical demonstration</b>	Demonstrating the practice activity to the parent and the parent demonstrating it back to you		
	Hand-on-hand guidance		
	Show and give further encourage the parent and give more ideas.		
	Demonstrating/modelling the activity with the child and then asking the parent to repeat/join in the activity whilst the therapist observes		
	Parent undertakes the practice exercise/s with the child and therapist gives feedback		
	Verbal instruction with written information for parent to use as prompts		
	You 'teach' parents to become their child's therapist in group activities.		
	You demonstrate to parents how they can improve their child's functions using specific pieces of equipment.		
	Introduce the parents to other parents, showing how adaptations work		
<b>Can you add any supplementary descriptions of approaches you use which are similar but slightly different to these listed above?</b>			

<b>Utilise Therapist assistant</b>	Use assistant to further demonstrate and/or reiterate activity– when setting up goals and advice.		
	Use assistant to support parents to achieve goals- can be at home/clinic or preschool		
<b>Can you add any supplementary descriptions of approaches you use which are similar but slightly different to these listed above?</b>			
<b>Observing video recording</b>	You video record a session where the parent carries out an activity with the child		
	You observe the video recording with the parent to look at how they implement the strategies and set individual goals for the parent and child.		
<b>Can you add any supplementary descriptions of approaches you use which are similar but slightly different to these listed above?</b>			
<b>Loaning equipment to parents</b>	You give the parents a handbook or video on loan		
<b>Can you add any supplementary descriptions of approaches you use which are similar but slightly different to these listed above?</b>			
<b>Working in partnership</b>	Liaising with other therapists, including Portage and nursery staff		
	To set episodes of care goals with parents, you talk to the parents, ask them what their goals are, bring these together, write them up, ask parents to look at it, make changes and ask to sign them.		
	Ask the parents what goals they want to work on.		
	You give different options to a particular goal, and see what parents prefer.		
<b>Can you add any supplementary descriptions of approaches you use which are similar but slightly different to these listed above?</b>			
<b>Combination of activities</b>	Discuss options with parents and a handout is given about the episode of care plan. This is also discussed		

	with Portage		
	You give a verbal explanation, together with a practical demonstration		
	You ask the parent to repeat what you have demonstrated, and give constructive comments.		
	Use communication books and files to support the parent and help the child making choices. Discuss the vocabulary with the parents and advice is given how to use the file.		
	Help parent hand over hand technique to experience the difference and discuss why the change is desirable		
<b><i>Can you add any supplementary descriptions of approaches you use which are similar but slightly different to these listed above?</i></b>			

***Please can you add below any further descriptions of approaches you have used/may use when working with parents?  
Thank you***

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Once the coded checklist was ready (table 4.7), it was emailed to all seven therapists who participated at the NGT sessions. Copies were also sent via the post, with a sae included, to their actual work places, to ensure not only confidentiality but also anonymity was achieved.

#### **4.4.1-Coded checklist validation and analysis**

The researcher distributed the coded checklist together with the letter explaining the change to the study design and instructions, to all seven participants both via email and postal copies.

Participants were asked to respond within a two week period. The researcher reminded them by email three days before their response was due, however after the identified time frame, only one checklist had been returned. A couple of therapists emailed to explain that their workload was great and clinical activities had to take priority. The researcher was able to utilise the expertise of the supervisory team as they are experienced clinicians from each of the three AHP groups as they offered to independently complete the validation checklist.

In total six checklists were returned (NGT participants n3, other therapists n3). One of the respondents did not acknowledge the use of the particular advice giving strategies as identified on the coded checklist, however made some general comments about the checklist statements.

Therapists were asked to make specific comments (see 3.5). The researcher collated the responses and used different colours to identify the responses from each of the therapists (Appendix XVI). The tables below were developed to

show possible consensus of therapists using the advice giving strategies, the checklist themed headings were used for each of the tables (4.7 – 4.12).

Table 4.8 coded checklist response: verbal instruction

Theme: verbal instruction		
1	You talk to parents about how the family functions, to see how to incorporate therapy activities into daily life	Yes n5
2	Explain goals, why and how it will help the child to function	Yes n5
3	You set goals together	Yes n5
4	Discuss skills acquisition	Yes n5
5	Discuss current progress, explain the child's goals in relation to "normal" progress	Yes n5
6	Explain short/long term goals and breaking down the tasks e.g. parent want child to walk, but is not rolling over yet.	Yes n5
7	Discuss with parents the child's current progress and where they want to be and how to get there	Yes n5
8	Review progress and adapt goals	Yes n4 not as often as I would like due to time constraints, n1
9	Advise them to attend other treatment centres/providers, commercial centres such as a soft play centres, parks	Yes n3 Not as often as I should, n1 No, n1

Five therapists acknowledged that they carried out seven of the nine verbal communications activities. One therapist commented that he/she would like to review progress and adapt goals more frequently (8), as well as advice parents to attend other treatment centres/providers etc. (9) and one therapist responded that he/she did not advise parents about other treatment centres. (Table 4.8, appendix XVI)

Therapists also commented on the wording of some of the statements, and felt that one item was repeated.

Table 4.9 coded checklist response: written information

Theme: Written information		
1	Give a pre-prepared advice/information leaflet	Yes n4 Sometimes n1
2	Give a handout about the episode of care plan	Yes n4 Occasionally n1
3	Printed sheets from books and reputable websites etc.	Yes n4 No n1
4	Give written advice/ information which you have specifically prepared for their child	Yes ++ n1 Yes n4
5	Give photos of the child in therapy to aid parents to undertake practice/exercises	Yes n3 No n2
6	Give leaflets with pictorial stickmen with arrow to aid parents to undertake practice/exercises	Yes n 3 No n2
7	You ask the parent to keep a diary for lycra garments and sleep systems, tell parent what to record. When, time of day, what did the child do, effect on muscle tone, in tables.	Yes n3 No n2
8	You give a letter to parents when they refuse interventions such as lifting and handling, identifying the risks.	Yes n2 No n3

The written information did not receive the same consensus. There was only one statement that all 5 therapists acknowledged as carrying out (table 4.9 item 4). There were a number of items that four therapists confirmed (table 4.9 items 1, 2, 3). One of the respondents commented that a number of the items were not relevant to SLT. Another therapist suggested that children use lycra garments/equipment for longer periods of time and as a result diaries are not kept as often anymore (table 4.9).

Table 4.10 coded checklist response: practical demonstration

<b>Theme: practical demonstration</b>		
1	Demonstrating the practice activity to the parent and the parent demonstrating it back to you	Yes n5
2	Hand-on-hand guidance	Yes n4 No n1
3	Show and give further encouragement to the parent and give more ideas.	Yes n5
4	Demonstrating/modelling the activity with the child and then asking the parent to repeat/join in the activity whilst the therapist observes	Yes n5
5	Parent undertakes the practice exercise/s with the child and therapist gives feedback	Yes n5
6	Verbal instruction with written information for parent to use as prompts	Yes n5
7	You 'teach' parents to become their child's therapist in group activities.	Not sure n1 Yes n2 No n2
8	You demonstrate to parents how they can improve their child's functions using specific pieces of equipment.	Yes n3 No n1 Occasionally n1
9	Introduce the parents to other parents, showing how adaptations work	Yes n1 No n 2 Would love to, but again time doesn't permit

There were 5 items that received consensus of five therapists (table 4.10 items 1, 3, 4, 5, 6). The lack of time is mentioned a number of times throughout the feedback across the themes as a reason for not doing it as frequently as they would have liked (Appendix XVI).

Table 4.11 coded checklist response using assistant/video recording/loan equipment

<b>Theme: using an assistant</b>		
1	Use assistant to further demonstrate and/or reiterate activity– when setting up goals and advice.	Yes n2 No n3
2	Use assistant to support parents to achieve goals- can be at home/clinic or preschool	Yes n4 No n1
<b>Theme: video recording</b>		
3	You video record a session where the parent carries out an activity with the child	Yes n5
4	You observe the video recording with the parent to look at how they implement the strategies and set individual goals for the parent and child.	Yes n4 No n1
<b>Theme: Loan equipment</b>		
5	You give the parents a handbook or video on loan	Yes n3 No n2

Not all therapists made use of assistants, and SLT in particular commented that assistants were more likely to be used in the classroom setting, but not working directly with parents. (Table 4.11)

Although all five therapists confirmed that they video record the parent carrying out activities with the child (table 4.11 item 1), only four reviewed the video with the parents (table 4.11 item 2).

Three therapists loan equipment, although it might be a toy or game rather than more formal equipment. (appendix XVI and table 4.11)

Table 4.12 coded checklist response: working in partnership

Theme: working in partnership		
1	Liaising with other therapists, including Portage and nursery staff	Yes n5
2	To set episodes of care goals with parents, you talk to the parents, ask them what their goals are, bring these together, write them up, ask parents to look at it, make changes and ask to sign them.	Yes n4 Should do n1
3	Ask the parents what goals they want to work on.	Yes n5
4	You give different options to a particular goal, and see what parents prefer.	Yes n4 No n1

All therapists confirmed that they liaise with other therapists and other professionals (table 4.12 item 1), although this item was generated from the SLT NGT, neither of the other two groups identified this way of working.

Therapists also reached a consensus about asking parents what goals they want to work on (table 4.12 item 3), however one therapist acknowledged that he/she should set episodes of care goals with parents, ensuring that the goals of therapists and parents are brought together (table 4.12 item 2).

Table 4.13 coded checklist approach: combination of activities

Approach: combination of activities		
1	Discuss options with parents and a handout is given about the episode of care plan. //This is also discussed with Portage//	Yes n3 Occasionally n1
2	You give a verbal explanation, together with a practical demonstration	Yes n4 Varies n1
3	You ask the parent to repeat what you have demonstrated, and give constructive comments.	Yes n3 Sometimes n2
4	Use communication books and files to support the parent and help the child making choices. Discuss the vocabulary with the parents and advice is given how to use the file.	Yes n3 No, n1
5	Help parent hand over hand technique to experience the difference and discuss why the change is desirable	Yes n3 No n2

Therapists were divided about the combination of activities, and comments such as: varies, sometimes and occasionally were used, rather than a clear yes or no. Item one and four only received four responses. (appendix XVI and table 4.13)

#### 4.5-REVISED CODED CHECKLIST

The therapists made some explanatory comments about the manner in which their service worked or they as individuals, for example: under the theme heading 'use of assistant' – "*SLT assistants probably not often working directly with parents, more often in the classroom setting*" (appendix XVI and table 4.11 item1).

The researcher made sure that the revised checklist reflected the comments made about all themed statements.

Questions were asked, such as: '*you set goals together*' – '*with who the child or the parent*'? Feedback was very helpful as there were times when the

researcher was clear about what she was asking, however this might not always been supported by the therapists (appendix XVI and table 4.8:3).

They also made some suggestions about some of the language used, such as 'normal' preferred term 'expected' (appendix XV1 and table 4.8 item 5).

The researcher had endeavoured to separate out some of the subtle differences that the NGT generated items had suggested however the therapists commenting on the coded checklist and felt that some entries appeared to be duplicated. The researcher took all feedback on board.

The researcher revised the coded checklist (appendix XVII), to reflect the comments from the therapists; she grouped some of the items together to ensure there was no duplication of items. For example:

Appendix XVII Item 4 *The therapist gives:*

- i. The parent a pre-prepared advice/information leaflet*
- ii. The parent a printed sheet from a book or website, if appropriate to the child's targets*
- iii. The parent written advice/ information which he/she has specifically prepared for their child*
- iv. The parent photos of the child in therapy to help them carry out undertake practice/exercises at home*
- v. Leaflets with pictorial stickmen and arrows to aid parents to undertake practice/exercises*
- vi. Verbal instruction with written information for parent to use as prompts*

In another example is that the original coded checklist (table4.7) item read: 'you video record a session where the parent carries out an activity with the child', comments from one of the therapists suggested: 'In a number of specific parent

*training programmes, not in routine therapy*'. The researcher changed the item to capture the comments:

*The therapist video records a session where the parent carries out an activity with the child:*

- i. In a number of specific parent training programmes.*
- ii. In routine therapy*  
(Appendix XVII item 22)

Some items were split for clarity for example coded checklist (table 4.7) read '*Liaises with other therapists including portage or nursery staff*'.

Comments suggested that therapists might liaise with other therapists but not with portage or nursery staff, the researcher subdivided this item, to acknowledge which professionals therapists liaise with:

*i.e. The therapist liaises with:*

- i. Other therapists*
- ii. Portage staff*
- iii. Nursery staff*  
(appendix XVII item 25)

The researcher revised the format of the checklist altogether (appendix XVI).

The original coded checklist (table 4.7) was developed to illicit the views of therapists in terms of face validity, ambiguous descriptions and supplementary descriptions of therapist approaches with parents. However the revised coded checklist had a different purpose. It was envisaged that the checklist might be utilised as a research tool in future research studies. It was important that the coded checklist reflected this change of use (appendix XVII).

#### **4.6-MAPPING REVISED CODED CHECKLIST AGAINST CONCEPTUAL MODELS OF COMMUNICATION**

The researcher identified statements used by AHPs together with characteristics of the models of communication, and map the revised coded checklist against the conceptual models of interaction (table 4.14).

The researcher identified models of communication by scrutinising the items from the revised coded checklist. (Appendix XVII). Some items describe an activity, rather than a specific behaviour; such as the therapist reviews the child's progress with the parents and adapt goals (table 4.7 item 6).

Table 4.14 revised checklist map against conceptual models of communication

Models of communication		Themes from revised coded checklist
<b>Expert model</b>	1.	The therapist gives specific information in response to parents' request.
	2.	The therapist give the parent a pre-prepared advice/information leaflet
	3.	The therapist gives a letter to parents when they refuse interventions such as lifting and handling, identifying the risks.
	4.	The therapist gives a letter to parents when they refuse interventions such as for a child with eating/drinking difficulties; might specify risks
	5.	Discusses with parents the importance that they work with their own child, not just expect the therapist to solve all the child's problems
	6.	The therapist demonstrates to parents how they can improve their child's functions using specific pieces of equipment
	7.	The therapist introduces the parents to other parents, to show how adaptations work
	8.	The therapist uses a therapy assistant to further demonstrate and/or reiterate activity– when setting up goals and to give advice.
	9.	The therapist uses a therapy assistant to support parents to achieve goals-at home, clinic or preschool
	10.	The therapist video records a session where the parent carries out an activity with the child in a number of specific parent training programmes and in routine therapy
	11.	The therapist observes the video recording with the parent, to look at how they implement the strategies and sets individual goals with the parent for the child
<b>Transplant model</b>	12.	The therapist gives the parent photos of the child in therapy to help them carry out undertake practice/exercises at home
	13.	The therapist gives leaflets with pictorial stickmen and arrows to aid parents to undertake practice/exercises
	14.	The therapist gives verbal instruction with written information for parent to use as prompts
	15.	The therapist demonstrates the practice activity to the parent, gives a verbal explanation, the parent demonstrates it back to the therapist, has built the targets into fun games, models how to play and encourages the parent to join
	16.	The therapist demonstrates therapy activities to parents by using hand on hand guidance technique so the parent can experience the difference
	17.	The therapist encourages parents; gives them ideas how to incorporate practice opportunities as part of daily routines.
	18.	The therapist demonstrates/models the activity with the child, asks the parent to repeat/join in the activity, observes the parent with the child, gives feedback to the parent

	19.	The therapist 'teaches' the parent to become their child's therapist in group activities
<b>Family-centred model</b>	20.	Therapists talks to the parents about their daily routines: Asks who the child spends time with e.g. grandparents, siblings etc Discusses how they can incorporate therapy activities into daily life
<b>Family-friendly model</b>	21.	The therapist explains the goals to parents, why and how it will help the child
	22.	The therapist advises parents to attend other treatment centres/providers or commercial centres such as a soft play centres, parks
	23.	The therapists gives the parent written advice/ information which he/she has specifically prepared for their child
	24.	The therapist asks the parent to keep a diary for lycra garments and sleep systems, and tells the parent what to record, when, time of day, what did the child do, effect on muscle tone.
	25.	The therapist uses communication books and files to support the parent and help the child making choices, advices how to use the file, discusses the vocabulary with the parents.
	26.	The therapist makes a 'communication passport' for the child to keep with them.
	27.	The therapist asks parents to keep a record of things the child says relevant to their targets, e.g.. List of new words learned/need; examples of complex sentences, new phrases etc.
<b>Partnership model</b>	28.	The therapist discusses options with parents, gives a handout of the episode of care plan and discusses this with Portage
	29.	The therapist discusses current progress of the child, explains the child's goals in relation to expected progress, emphasises the importance of small steps, explains short/long term goals and break tasks down e.g. parent wants child to walk, but is not rolling over yet, reminds parents of long term aims as they often anxious about these; but focuses on short term goals.
	30.	The therapist reviews the child's progress with the parents and adapt goals, (Informal reviews or agreed formal review e.g. after 6 weeks)
	31.	The therapist liaises with other therapists and/or portage staff and/or nursery staff
	32.	To set episodes of care goals with parents the therapist talks to the parents and asks them what their goals and what they want to work on, Gives different options to a particular goal and sees what parents prefer, brings these together, writes them up and asks parents to look at it, makes changes if needed and asks parents to sign them.

#### **4.6.1-Expert model:**

Some clear examples of an expert strategy approach were identified in item 3 (table 4.13) '*the therapist will give a letter to parents when they refuse interventions*'. Others are not as clear and have to be judged on face value such as '*The therapist demonstrates to parents how they can improve their child's functions using specific pieces of equipment*' (table 4.14 item 6). The therapist, the expert, is showing parents, although the approach might also suggest a combination of expert and transplant model, as the therapist is 'transplanting' knowledge into the parent by showing them how to use equipment.

A further example of the expert model could be found in item 1 (table 4.13): '*the therapist gives specific information in response to parents' request*'. It could be construed that the therapist did not deem it necessary to share information with the parents, or checked for understanding.

There were eleven items in total identified as falling within the expert model (table 4.13 items 1 – 11).

#### **4.6.2-Transplant model**

There were eight items identified under this model of interaction (table 4.13 items 12-19). Some could be identified clearly, such as '*the therapist 'teaches' the parent to become their child's therapist in group activities*' (item 19) and '*The therapist demonstrates therapy activities to parents by using hand on hand guidance technique so the parent can experience the difference*'. (item 16).

#### **4.6.3-Family Centred model**

From the data available it was not straight forward to recognise the approach or distinguish it with the family friendly model, as most items generated by the NGTs did not clearly identify whether the parent or therapist had the ultimate decision making power, or whether it was family or child centred.

There was just one item generated by the PT NGT session:

*'Ask parents what their goals are – a child with splints – parent didn't feel they were doing what she had expected, so the splints were altered, even though PT felt the splints were ok.'* (table 4.3:14)

Just one item was identified in the revised coded checklist.

*'Therapists talk to the parents about their daily routines: Asks who the child spends time with e.g. grandparents, siblings etc and discusses how they can incorporate therapy activities into daily life'* (table 4.13 item 20).

As previously discussed from this item it is not transparent who has ultimate power, although the parents probably decide which daily routine activities will be used to incorporate therapy.

#### **4.6.4-Family-friendly model**

Seven items were identified (table 4.13 items 21-27). The items are not completely describing the family-friendly model; however there are a number of features in statements such as

*'The therapist uses communication books and files to support the parent and help the child making choices, advices how to use the file, discusses the vocabulary with the parents'* (table 4.13 item 25).

There is support for the parent, but the child is central, and a discussion takes place.

#### 4.6.5-Partnership model

There were five items identified (table 4.13 items 28-32). SLT identified working in partnership in 5 separate items, once specifically with parents and four with AHPs and other professionals (table 4.4: items 1, 4, 8, 11 and 13).

Interestingly OT, even though they didn't specifically state that they work in partnership with parents, identified that when they set goals with parents they *'ask what the parents' goals are and what they want to work on, bring these together, write them up, ask parents to read the document and make changes if necessary and then sign them* (table 4.1 item 1).

These characteristics are very much a partnership way of working.

The available data appeared to suggest that therapists advice giving strategy approaches do not neatly fall within one particular model of interaction, but they utilise a combination of models or more accurately on the continuum of models (Dunst 2002, Davis 2010) and this may be dependent on the therapy activity and/or the preference of the therapist.

## CHAPTER 5-DISCUSSION

The aim of the study was to gain a better understanding of the different approaches therapists use when giving advice to parents of preschool children with CP, using NGT to generate items which would be utilised to develop a coded checklist, gain respondent validation, revise the checklist, and map items against the conceptual models of communication. This checklist tool was developed by integrating the theoretical themes in the literature, with the empirical data from this small-scale study, for the purpose of providing a research instrument for further studies in this field.

### 5.1-DISCUSSION OF FINDINGS

The NGT respondents generated 57 items in total, and gave a flavour of the strategy approaches therapists used and its complexity. Three overarching themes emerged (verbal communication, practical demonstration and written information), with a number of activities, and findings will be discussed under those headings.

Many items were very complex and required dual and multiple approaches. For example: '*set goals with parents*' was identified as a single activity, however this approach was very rarely carried out in isolation. It is interesting to note that OT identified setting goals part of their advice giving strategies on 6 separate occasions compared to PT (2) and STL (3).

There were six respondents who returned their comments on the checklist, (3 from NGT participants, and 3 from therapists known to researcher). One

respondent did not confirm or deny utilising any of the strategies identified on the checklist. The researcher will use 5 = 100% in terms of reaching consensus.

The coded checklist validation highlighted some interesting findings such as a number of items gaining a 100% consensus (table 4.11 item 3 and table 4.12 items 1 and 3). For example, SLT was the only group identifying video recording during the NGT session, however when the item was included on the checklist there was 100% consensus.

Another item that gained a 100% consensus (Table 4.9 item 5) *'give written information which you have specifically prepared for their child'*, although one respondent commented that it takes a long time, and would only be used if no other materials were available. (Appendix XVII). Some therapists felt that their practices were hindered by time constraints, and might suggest that therapists might on occasions feel forced to utilise a certain approach, due to time constraints. This was confirmed by other comments such as: *'not as often as I would like due to time constraints*, and *'not as often as I should*, and *'occasionally'*, and *'sometimes'*.

It could be argued that AHPs work within the constraints of a medical model to some extent, and that this will influence their working practice.

The literature review identified five specific models of interaction (1.4), and there were some clear patterns emerging from the generated items. Each of the models will be discussed in relation to the findings.

### 5.1.1-Expert model

Respondents identified seven different sub themes or strategy approaches when using verbal communication. On the surface it is possible to conclude that the different verbal communications in combination with other approaches show characteristics of all five discussed models of communication. For example:

*'Discusses with parents the importance that they work with their own child, not just expect the therapist to solve all the child's problems'.*

The tone of this statement would suggest an expert approach; the parent has become dependent on the therapist to 'solve the problems', although it could be argued that this is a transplant approach; the therapist expects the parent to work with their own child. A partnership approach might have sounded like: the therapist challenges unhelpful constructs such as the idea that the therapist is expected to solve the problems, and negotiates goals, and tests those to ensure these were achievable.

A clear example of an expert strategy approach can be found in table 4.1 (item 13)

*'you give a letter to the parents when they refuse interventions such as lifting and handling, identifying the risks',*

On the coded checklist validation (table 4.9 item 8) one respondent commented that they would deploy this method, another commented that SLT uses a management plan for child with eating/drinking difficulties; might specify risks.

The statement indicates an expert approach (Cunningham and Davis1985, Appleton and Minchom 1991, Davis and Fallowfield (Ed) 1991, Davis 1993, Davis et al 2002, Watts Pappas and McLeod 2009, Davis and Day 2010). It almost suggests that the therapist has decided what the parent needs to do, the parent refuses, so the therapist makes the parents sign a letter. It indicates a

clear power imbalance (Davis and Fallowfield (Ed) 1991), furthermore it suggests a non-compliance form the parents (Ley 1988).

One of the respondents commented that they only occasionally give parents a handout about the episode of care (Table 4.8:2). This could be perceived as an expert model approach: the therapist perceives that parents only need certain information. Although the respondent didn't indicate the why and when, which might have given an insight and indicate a different model of interaction. This could also be said about item 1 (table 4.13) '*The therapist gives specific information in response to parents' request*'.

A further example of an expert approach is that a therapist commented to only sometimes giving a handout of the episode of care plan. The therapist commented on the fact that this was sometimes due to time constraints. It could be argued that the 'expert' therapist only gives a handout about the episode of care plan occasionally due to time constraint as it will be very low priority. However the therapist who believes that working in partnership is worthwhile and rewarding will make time to carry out this activity, knowing that in the long run it is time effective as there will be a much higher compliance rate (Ley 1988).

### **5.1.2-Transplant model**

Four activities were identified to describe the different practical demonstrations. By nature practical demonstration, particularly in combination with '*doing it on the parent*' and '*the parent demonstrating to therapist*' and '*hand over hand technique*' would suggest that these fit within the transplant model (Cunningham

and Davis 1985, Appleton and Minchom 1991, McBride et al 1993, Davis et al 2002, Watts Pappas and McLeod 2009).

OT utilised activities under the main heading of physical demonstration most frequently (11), PT (8) and SLT (1). It is not surprising that SLT used this approach minimally, given their area of work. Furthermore practical demonstrations appeared to be a complex strategy approach and there were only 4 items out of 19 generated items that had a single approach, many of them were multiple strategy approaches.

### **5.1.3-Family-centred model**

The researcher did not identify many items that could be classed as a family-centred approach. This could be contributed to the statements not specifying who had ultimate power, whether the approach was family or child centred etc. There was one clear item generated by PT see Sec 4.5.3, (table 4.2, item 14). Although it could be argued that the therapist allowed the parent to make the ultimate decision as it would not be detrimental to the child.

Item 20 (table 4.14) suggests that the therapist takes a family centred approach, by asking about family routines, and although the therapist may make suggestions about the how and when therapy can be incorporated in daily routines, the parents have ultimate say whether those ideas suit, or they identify other suitable routines.

#### **5.1.4-Family-friendly model**

The identified family-friendly items (table 4.13 items 21-27), nearly all involve written information, either given by the therapist, or the parent keeping a diary. Although it could be said that these items might suggest a family friendly approach, the researcher argue that the items all identify a child centred approach, such as

*'The therapist gives the parent written advice/ information which he/she has specifically prepared for their child', and 'The therapist makes a 'communication passport' for the child to keep with them'.*

The only item not involving written information is item 21 (table 4.13)

*'The therapist explains the goals to parents, why and how it will help the child'.*

It is however child orientated.

#### **5.1.5-Partnership Model**

Therapists identified the joint working with colleagues from other disciplines (table 4.2 item 14) as a strategy approach, to ensure goals identified did not contradict therapy across the disciplines. It could be argued that this did not identify an advice giving strategy used with parents, although therapists perceived joint working as an integral part of working with parents and it has some characteristics of the partnership model (Cunningham and Davis 1985, Buchan et al 1988, Appleton and Minchom 1991, Davis and Fallowfield (Ed) 1991, Buchan 1998, Davis 1993, Davis et al 2002, Davis and Meltzer 2007, Watts Pappas and McLeod 2009, Davis and Day 2010).

There were a number of examples identified by SLT about the partnership strategy approach, not just with parents but also with therapists and other professionals. Although SLT uses the term partnership working (table 4.3 items

1, 4, 8, 11, 13), the items do not describe exactly how they work in partnership. It is interesting however, especially since they utilise the Hanen program (Pepper and Weitzman 2004) which is based on teaching parents and thus firmly based within the transplant model, (Cunningham and Davis 1985, Appleton and Minchom 1991, McBride et al 1993, Davis et al 2002, Watts Pappas and McLeod 2009). Although it could be argued that the philosophy of the Hanen program is about working in partnership with parents and professionals.

OT on the other hand did not use the term he partnership, however the description of item 1 (table 4.1) clearly described strategy approaches indicative of the partnership working model (Cunningham and Davis 1985, Buchan et al 1988, Appleton and Minchom 1991, Davis and Fallowfield (Ed) 1991, Buchan 1998, Davis 1993, Davis et al 2002, Davis and Meltzer 2007, Watts Pappas and McLeod 2009, Davis and Day 2010).

It is important to note at all items were generated by AHPs, and that it lacks the perceptions of service users. This may influence the interpretation of the reported-models of communication, as research suggests that people construe the same event differently (Cunningham and Davis 1985, Kelly, 1991, Davis 1993, Davis et al 2002, Davis and Day 2010), furthermore parents may deceive professionals, as the way parents portray themselves to professionals does not correspond with the way they feel (Gacoine 1995: cited in Blamires et al 1997).

Given the complexity of the advice giving strategies, it is not surprising that each discipline identified their unique manner of working with parents, and no items within the multiple strategy approach were exactly the same. SLT generated items identified four multiple strategy approaches activities, with four identified themes within each one. OT identified two items with four themes. PT's identified three multi combination activities with three identified themes within them.

## **5.2-REFLECTIONS ON STUDY CONDUCT AND RECRUITMENT**

The NGT sessions were conducted with uni-professional groups (OT, PT, SLT) as this would produce a more comprehensive picture of AHP advice giving models for each of the identified groups, and would allow contrasting perspectives across AHPs as previous work had indicated (Roddam & Selfe 2009). It was anticipated that each NGT session would have 6-10 participants as this was identified as the ideal number of participants (Taylor-Powell 2002).

NGT and coded checklist validation were identified as the most appropriate methods to collect data for this research study. There were significant issues surrounding participant recruitment of both therapists as well as parents; which will be discussed below. It resulted in changing the design of the study, for which IRAS approval was gained. The researcher asserts that the study design was carefully thought out, and appropriate based on evidence (Van de Ven & Delbecq, 1974, Bartunek & Murnighan 1984, Potter et al, 2004 Roddam & Selfe 2009).

It is never easy to predict how many participants a research study will attract, as there are many influences determining the willingness of people to take part, such as interest of the research question and available time.

### **5.2.1-AHP recruitment**

The researcher endeavoured to recruit between 6 – 10 participants per NGT group as this is considered ideal (Potter et al 2004), and had carefully considered the most appropriate way to recruit therapists. Meetings had taken place with PCT staff to identify the site, appropriate venue and method of recruitment. It was agreed that one of the clinical managers would liaise with therapists and coordinate dates for meetings. Even though the researcher had been meticulous in her efforts to recruit a sufficient number of participants, participation was very poor.

The researcher experienced a poor response for the second phase even though therapists had been contacted prior to IRAS approval. The researcher had contacted the therapists to encourage them to support this part of the study, however only three therapists returned their responses. (Appendix XVI).

However the researcher was supported by the supervisory team, who are all experienced therapists from each of the AHP groups, which resulted in richer data. It is recommended that further research is required with a wider group of AHP respondents, to increase the credibility of these findings. The responses allowed the researcher to revise the coded checklist and this could be utilised as an instrument for further research as intended. (Appendix XVII).

### **5.2.2-Parent recruitment**

The limited number therapist participants contributed to the failure to recruit any parents, as many children received therapy from all three disciplines.

Therapists had agreed to liaise with each other and identify parents.

Unfortunately this proved to be unsuccessful. Therapists identified a number of issues. It was the beginning of December, which is not a good time for parents.

Children with more severe CP often start at a specialist nursery at an early age, and therapy would be accessed at school. The exclusion criteria for parents, whose first language was not English, also lowered numbers, as the PCT is in an area with a large BME population.

Therapists reported that they were reluctant to ask certain parents due to those parents being rather stressed and struggling emotionally. In light of research relating to the models of communication it could be perceived that therapists' perceptions of parents is not necessarily correct (Gascoine 1995: cited in Blamires et al 1997), and see themselves as experts and need to protect parents (Cunningham and Davis 1985, Appleton and Minchom 1991, Davis and Fallowfield (Ed) 1991, Davis 1993, Davis et al 2002, Watts Pappas and McLeod 2009, Davis and Day 2010). The researcher doesn't suggest that parents would have agreed, however therapists took the decision away from the parents, which could be disempowering.

The researcher considered whether the reluctance of therapists to recruit parents could be associated with therapists not being comfortable about being observed, even though the researcher endeavoured to assure therapists that

the purpose for the observation was to validate the Items generated by the NGT sessions and not to identify best practice.

The lack of participants, and particularly not recruiting parents had a domino effect on the study design, as it was not be possible to observe video recordings of routine therapy sessions between parents and the different therapists. (table 3.2).

In future studies the researcher would use a different parent participation strategy. Some therapists had identified that a number of children attended specialist provisions. The researcher would produce clear concise posters and distribute these to schools, CDC, other clinics libraries etc., encouraging parents to opt into the study. NGT session could be held in the setting after a parent open day or sports day for example. This method would ensure confidentiality, and alleviate therapists from having to recruit and add to their workload and parents would not have to make an additional journey.

### **5.3-ETHICAL CONSIDERATIONS**

Rigorous ethical consideration is paramount in any research, but particularly when research involves human subjects. Ethics Committee approval was gained for this research, prior to commencing any actual data collection, from the university on 24 June 2010, Central Lancashire Primary Care Trust RM& G approval was gained on 14 July 2010, as well as external NHS Research Ethics Committee. (IRAS approval No: 10/H1016/19 date 22 April 2010 and amendments approval date 5 April 2011).

Researchers themselves need to abide by the ethical principles such as respect, competence, responsibility, honesty and integrity (The Ethics Committee of the British Psychological Society 2009).

### **5.3.1-Informed consent**

Participants for this research were fully informed about the aims and objectives of the research, what their participation would involve, that their employment would not be adversely affected, their right to withdraw at any time, any benefits and risks involved (Appendix II). Participants were asked to sign the consent form once they were happy to participate (Appendix IV).

### **5.3.3-Respect for all participants**

All participants were treated with equal consideration, and respected for their experiences and knowledge. The research process was carried out in such a manner which avoided practice that was unfair or prejudiced.

### **5.3.4-Confidentiality**

All statements were recorded without people's names and were anonymous. The researcher made all participants aware of the limitations of maintaining confidentiality, for example in case of child protection.

### **5.3.5-Data collection and analysis**

Care was taken that responses from participants from all NGT sessions were recorded on flipcharts in participants' own words and all data has been kept securely and in line with university requirements. Analysis has been robust and

rigorous to ensure that it was accurate and conveyed the research findings and acknowledged any potential limitations.

### **5.3.6-Researcher bias**

The researcher recognised that, as a result of being a parent of disabled children and working with parents of disabled children, she has experienced many positive relationships with AHPs, and some negative ones, and as such the researcher believes that working in an equal partnership is the most effective and preferable manner of working with parents. Furthermore, the researcher is a facilitator for the family partnership training model, described in Chapter 1.4.5 (Buchan et al 1988, Davis et al 2002, Davis and Day 2010). To ensure that personal bias was kept to a minimum, the experience of the supervisory team was utilised to counter balance the researcher's own bias, as well as critiquing all identified models of communication with equal rigor.

### **5.3.7-Method**

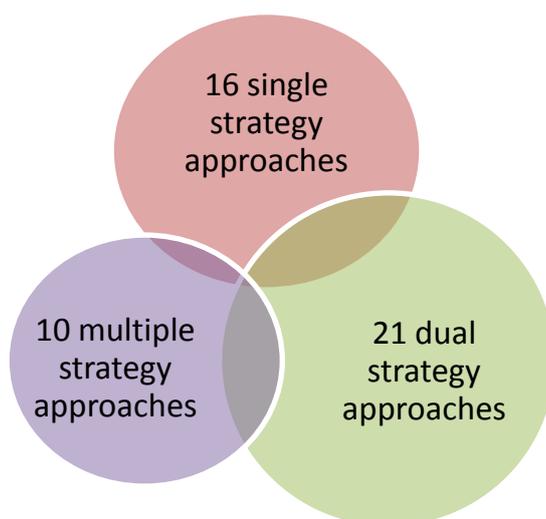
The NGT process eliminated the possible bias from the researcher due to the fact that one particular question was posed and participants were asked to silently generate as many ideas that sprung to mind. This process also eliminated bias from participants that might arise in focus groups or other unstructured group interactions, as it would more difficult to manage an equal process in terms of contributions from participants (Randall and Dunham 1998, Research Evaluation Team 2007). For example, one particular participant could be very forceful and dominant, or on the other hand, a quiet less confident participant might not contribute at all.

## CHAPTER 6-CONCLUSION AND RECOMMENDATIONS

### 6.1-CONCLUSION

The study set out to explore the advice giving strategies of AHPs used with parents of preschool children with CP and to develop a coded checklist other researchers could utilise as a research instrument for future studies. Although some difficulties were experienced the study did highlight the complexity of advice giving strategies and therapists regularly utilised dual and multiple strategy approaches in their work with parents( fig 6.1).

Fig 6.1 total combined strategy approaches



The researcher was able to develop a coded checklist (table 4.7) utilise responses made by AHPs (appendix XVI) and map the revised checklist (appendix XVII) against conceptual models of interaction (table 4.14).

#### 6.1.1-Strengths and limitations of the research study

The study has highlighted that the therapists use a number of strategy approaches in their work with parents. The researcher is of the opinion that all

therapy interventions are based within the medical model of disability; the findings have shown that therapists' approaches lie much more within the combination of the both (Krawczyk 2005).

Although the data sample was relatively small due to the small number of therapists participating and no parents, the study identified that therapists' reported approaches fit the models of communication, see table 4.14.

The researcher recognises that there were a number of limitations to this study. The lack of participant recruitment had a domino effect on the study design, which in turn affected the outcomes, and allowed the researcher to draw careful conclusions about the models of interaction used by AHPs.

The timing of the study might have influenced the lack of participant recruitment, the PCT was in a flux of restructure, therapists changed job roles, and large workloads.

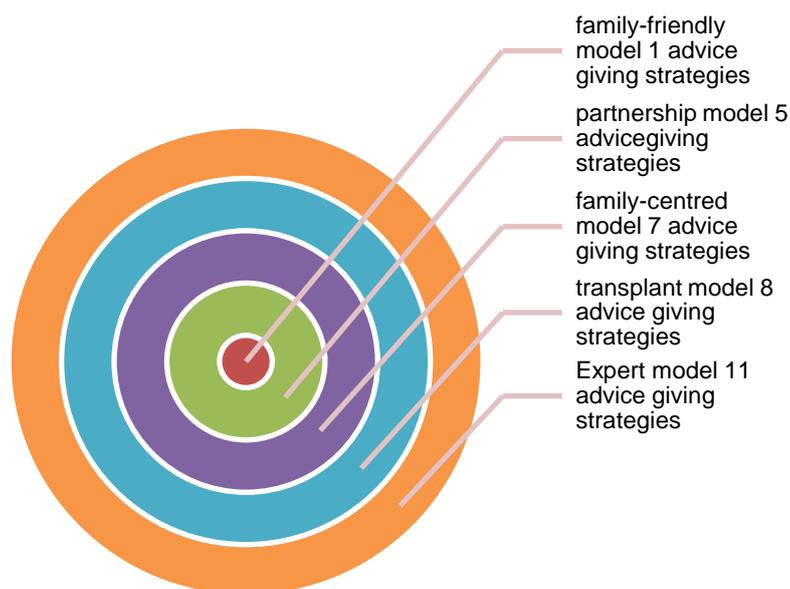
The recruitment of parents was reliant on the goodwill of therapists, although factors such as time of the year played a role. One factor was that therapists took a somewhat expert view in terms of not asking some parents. They perceived that parents were too stressed to participate and thus taking the decision making out of parents hands.

Given the opportunity, the researcher would have changed the recruitment process, particularly of parents, by allowing parents to opt in rather than rely on invitations of therapists, as this might have increased participation.

A particular limitation of the revised study design is that the validation of the checklist through comments, did not allow the researcher to directly observe the manner in which therapists spoke to parents, their body language etc. The revised study (fig 3.2) could have been improved by inviting parents to participate with the recorded video observations of routine therapy session, even though they had not participated in the NGT. Recruitment through an opt in method, would have avoided therapists reluctance to invite parents, and parents might have agreed as it would not have involved additional time. The observations would have given an insight into the manner in which the identified activities were carried out. Another option would have been to invite larger number of respondents to comment on the coded checklist (table 4.7), indicating whether they were OT, PT or SLT. This would have allowed to compare practices more robustly and validated the use of the approaches, in terms if being used across disciplines and as common practice.

It has only been possible to gain a snapshot view of the therapists' advice giving activities and make some careful presumptions about the models of communication used by AHPs , as discussed previously (chapter 5)(fig 6.2).

Fig 6.2 Models of communication used by AHPs



It is recognised that there is a danger of making assumptions which are not necessarily representative of parents' experiences of the advice giving strategies described by AHPs, as we all construe events very differently. For example: Parents' experience of working in partnership may be very different from professionals' views as was illustrated in a report investigating the perceptions of communications between parents of children with special educational needs (SEN) and Special Needs Coordinators (SENCOs) (Rathbone 2001, Davis et al 2002).

## 6.2 RECOMMENDATIONS FOR CLINICAL PRACTICE

This study has highlighted the importance of a positive relationship between therapists and parents (Buchan, Clemerson and Davis 1988, Appleton and Minchom 1991, Davis and Fallowfield 1991, Davis et al 2002, Swain et al 2004, Watts Pappas and McLeod 2009, Davis and Day 2010), and quality information as this will increase parents carrying out the activities (Korsch, Gozzi and Francis 1968, Ley 1988). It will be important that AHP departments review their

practices in an attempt to ascertain the different advice giving approaches are used by therapists and how effective these are. This study has not been able to establish whether some practices are common, or only used sporadically, such as asking parents to sign a letter if they refuse interventions.

It is important for therapists to realise that parents do not always feel the way they appear (Gascoine 1995: cited in Blamires et al 1997), however a partnership approach encourages parents to share their priorities which will allow therapists together with parents set achievable goals and therapy activities relevant the child (Buchan, Clemerson and Davis 1988, Appleton and Minchom 1991, Davis and Fallowfield 1991, Davis et al 2002, Swain et al 2004, Watts Pappas and McLeod 2009, Davis and Day 2010).

Joint working with colleagues across other AHP disciplines to discuss children receiving therapy from a number of APHs will encourage a consistent approach with parents in terms of providing them with relevant meaningful information, no confusion about the condition, prognosis and will increase the uptake of parents carrying out the required therapy activities at home (Korsch et al 1968, Ley 1988)

The literature review about the different models of interaction identified the advantages and disadvantages of the different approaches, it is clear that no AHP service or therapist can completely get away from the medical model of disability by the sheer notion that medical interventions are provided. Having said that, it is possible to work within the constraints of this and provide a service characterised by an approach of recognising that parents have

expertise as well and building positive relationships between therapists and parents will increase parents' compliance and ultimately a positive outcome for the child and the family.

### **6.3 RECOMMENDATIONS FOR FURTHER RESEARCH QUESTIONS**

This research study has highlighted the complexity of the interactions between therapists and parents of preschool children with CP. There is a plethora of evidence about the different models of communication, although, much of the research has focussed on the general principles of the models of working with families of children with a variety of illnesses including CP (Cunningham and Davis 1985, Andrews and Andrews 1986, Buchan, Clemerson and Davis 1988, Appleton and Minchom 1991, Davis and Fallowfield (Ed) 1991, Davis 1993, McBride et al 1993, Davis et al 2002, Dunst 2002, Hanna and Rodger 2002, , Swain et al 2004, MacKean et al 2005, Watts Pappas and McLeod 2009, Davis and Day 2010).

There is limited evidence available investigating the actual activities which constitute the models of communication (Cunningham and Davis 1985, Buchan, Clemerson and Davis 1988, Davis and Fallowfield (Ed) 1991, Davis 1993, Davis et al 2002, Watts Pappas and McLeod 2009, Davis and Day 2010), and the focus has been on children accessing CAMHS and children with psychological difficulties, although these aspects could be associated with physical disabilities. Therefore future research should concentrate on the models of communication between therapists and parents of children accessing AHP services associated with physical disabilities, as this may identify whether if the needs of these parents differ from parents accessing CAHMS. The coded

checklist developed with the limited data could be used as a starting point in gaining a more informed insight into the advice giving activities utilised by AHPs.

### **6.3 SUMMARY OF KEY FINDINGS**

- The NGT sessions highlighted the complexity of the advice giving strategies and identified a number of themes and activities (table 4.4, appendix XV)
- The therapists regularly used single, dual and multiple strategy approaches in their advice giving strategies with parents (fig 6.1).
- There is a trend to view the models of communication as a continuum rather than five different models with a clear beginning and an end (Dunst 2002, Davis 2010).
- Therapists' approaches favoured the use of a combination of all five models of communication (table 4.14, fig 6.2).
- The expert model was used most frequently, although it can't be claimed to be the dominant model of communication, as the transplant model was also frequently used by AHPs.
- A comprehensive coded checklist for using in future observational research has been developed. (appendix XVII).

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## CHAPTER 8-APPENDICES

### APPENDIX 1- INFORMATION SHEET FOR PARENTS



#### Advice giving strategies used by Allied Health Professionals to parents of pre-school children

### INFORMATION LEAFLET FOR PARENTS / GUARDIANS v2

We would like you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you.

#### Why is the study being carried out?

This study aims to find out some of the factors that promote active partnership working between you and your therapists. There has been very little research into what might be the best ways for therapists to give information to parents, so this study has two main aims:

- to find out more about how Occupational Therapists, Physiotherapists and Speech and Language Therapists give advice and support to families of pre-school children who have a diagnosis of Cerebral Palsy .
- to find out from the parents of pre-school children with Cerebral Palsy examples of how your therapists have given you information, advice and support .

#### Who is doing the research?

The research is being done by Ms Aline Macready, as part of a post-graduate qualification. Aline has ten years experience working with families of children with a variety of special educational needs and disabilities. The research has been approved by an NHS ethics committee, the University of Central Lancashire and by Central Lancashire Primary Care Trust.

#### Selecting participants

You have been invited to take part because you are the parent of a pre-school child with Cerebral Palsy who is receiving therapy from at least one Allied Health Professional (Occupational Therapist and/or Physiotherapist and/or a Speech and Language Therapist).

#### What is involved in this study?

The study will be in two parts:

Firstly, we will invite up to ten parents to meet in a suitable, convenient venue. We will ask you some questions to find out about the ways you have been given information and advice by Occupational

Therapists, Physiotherapists and Speech and Language Therapists. We will also carry out this exercise with three separate groups of therapists. This will help us to make a list of the whole range of ways in which therapists give information and advice. The list of items will be recorded on a flipchart during the session and no items will be attributed to any individual. Direct quotes may be used, but will not be attributable to any participant.

We are looking for 10 parents who will agree to take part. If we have more parents than this, we will choose participants at random. If you are not chosen we will let you know and thank you for your interest. Next we will select 3 parents at random and will make a short video of a routine therapy session (one each for Occupational Therapy, Physiotherapy and Speech and Language Therapy). We will use these videos simply to check to see if we can add anything to the list advice-giving strategies from the group interviews. We will give a copy of the video to each parent and therapist who take part, but will not show the videos to anyone else. Everyone who has taken part will receive a summary of the report when the study has been completed.

### **Do I have to take part?**

No, it is up to you to decide and whether you choose to take part or not, it will not affect your child's therapy care. Please take time to read the information and talk to your family. You can also speak to your child's therapist(s) or contact Aline Macready via the University of Central Lancashire. We want everyone to have at least 48 hours to consider your decision. If you agree to take part, we will ask you to sign a copy of the consent form when you arrive for the meeting (see form attached).

The session will take place on Monday 10 January 2011 at 10am.

Venue: Broadoaks Child Development Centre, Balcarres Road, Leyland, PR25 3ED

If you like to take part, please contact Aline Macready by 6 January on **(0151)334-6660** or mobile **07903064527** or email: [AMacready@uclan.ac.uk](mailto:AMacready@uclan.ac.uk)

### **How much time will it take?**

The group interview will take about one hour. The video sessions will not require any additional time, as the videos will be made by the therapists themselves during the normal therapy sessions.

### **When and where is the research taking place?**

The project is expected to start early in 2010. The dates and times will be confirmed with you and the therapists nearer the time. The study will be completed by July 2011.

The research is taking place in Central Lancashire Primary Care Trust. A suitable venue for the interview session will be agreed nearer the time. The video observations will take place at your usual therapy venue.

## **Will I receive “out of pocket” expenses?**

We will reimburse you with public transport fares or car parking fees for attending the group session. As the video sessions will be part of your routine therapy, we will be unable to provide expenses for these. Receipts for expenses must be submitted. We are unable to cover other costs such as child-minding.

## **What are the possible risks and benefits of taking part in this study?**

We do not envisage that there will be any risks in taking part in this study. The study findings will help us to understand better how therapists can work with families in the future. The completion of the study will not affect any planned therapy sessions with your therapists.

Everyone who takes part will receive a summary of the study findings. If you are chosen for the video session you will receive a copy of the videotape after the session.

## **What will happen if I don't want to continue with the study?**

You can decide not to take part at any stage – even if you have signed the consent form. You don't have to tell us why you have changed your mind. Your decision to withdraw will not affect you, or the care you or your child receive in any way.

If you change your mind after the group interview session, we will continue to use the information because it is completely anonymous and cannot be traced back to you. If you take part in a video session and then change your mind, we will destroy the information and it will not be included in the study.

## **What can I do if I am not happy with the study?**

If for any reason you are not happy with any aspect of the study please ask to speak to one of the research team who will do their best to answer your questions.

Ms Aline Macready: email [AMacready@uclan.ac.uk](mailto:AMacready@uclan.ac.uk)

Dr Hazel Roddam: email [HRoddam@uclan.ac.uk](mailto:HRoddam@uclan.ac.uk) Tel: 01772 895484

If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. Details can be found on the university website: [www.uclan.ac.uk](http://www.uclan.ac.uk)

## APPENDIX II- INFORMATION SHEET FOR AHPS



### Advice giving strategies used by Allied Health Professionals to parents of pre-school children

#### INFORMATION LEAFLET FOR ALLIED HEALTH PROFESSIONALS v2

We would like to invite you to take part in our study.

Before you agree to participate we will explain the rationale for the research, and other relevant information.

#### **A brief introduction to the research team**

The research will be carried out by Ms Aline Macready, as part of an MSc qualification. Aline has ten years' experience working with families of children with a variety of special educational needs and disabilities. Aline will be supervised by Dr Hazel Roddam and Professor James Selfe from the University of Central Lancashire and Ms Clare Wright, the Clinical Research Manager from James Leckey Design Ltd. The research has been approved by an NHS ethics committee, the University of Central Lancashire and by Central Lancashire Primary Care Trust.

#### **Why is the study being carried out?**

This study aims to find out some of the factors that promote active partnership working between parents and therapists. There has been very little research into what might be the best ways for therapists to give information to parents, so this study has two main aims:

- to find out more about how Occupational Therapists, Physiotherapists and Speech and Language Therapists give advice and support to families of pre-school children who have a diagnosis of Cerebral Palsy.
- to find out from the parents of pre-school children with Cerebral Palsy examples of how their therapists have given them information, advice and support.

#### **Selecting participants**

Your employer is supporting this study and has given permission for AHPs from this Primary Care Trust to participate. You are invited to take part as a therapist who works with pre-school children with a diagnosis of Cerebral Palsy, and we very much value your views.

## **What is involved in this study?**

The study will be in two parts:

The first part of the study will be an information gathering exercise using Nominal Group Technique (NGT) sessions. NGT is a structured group interview approach which has been selected as being the most effective approach to gain information from all participants. The NGT sessions will be carried out with uni-professional groups (Occupational Therapists, Physiotherapists and Speech and Language Therapists). Each group will have between 6-10 participants. There will also be one NGT group for parents of pre-school children with CP who currently receive therapy from one or more of these three services. This will help us to generate a list of the advice-giving strategies reported from all participants' perspectives. The list of items will be recorded on a flipchart during the session and no items will be attributed to any individual. Direct quotes may be used, but will not be attributable to any participant.

We are looking for 10 therapists who will agree to take part. If we have more therapists than this we will choose participants at random. If you are not chosen we will let you know and thank you for your interest.

Secondly we will make three short videos of routine therapy sessions (one each for Occupational Therapy, Physiotherapy and Speech and Language Therapy). We will use these videos simply to validate the self-reported items generated by the NGT sessions. We will give a copy of the video to each parent and therapist who took part, but will not show the videos to anyone else. Everyone who has taken part will receive a summary of the report when the study has been completed.

## **Is participation compulsory?**

No, it is your decision and whether you choose to take part or not it will not affect your employment at the PCT. You might find it helpful to discuss any concerns with colleagues and/or line manager. You can also contact Aline Macready via the University of Central Lancashire. We want everyone to have at least 48 hours to consider your decision. If you agree to take part, we will ask you to sign a copy of the consent form when you arrive for the meeting (see form attached).

If you would like to take part please contact Dr Hazel Roddam (details below) by (date)

### **How much time will I need to allocate?**

Initially you will be asked to identify possible parents, and give them the information leaflet about the study. The NGT session will take about one hour. The therapists who agree to participate in the video session will not require any additional time, as it will be a routine therapy session. Aline will set up the video camera prior to the therapy and tidy up at the end. To ensure that intrusion is kept to a minimum, we would ask the therapist to video the session, so some additional time might be needed to familiarise yourself with the camera.

### **When and where is the research taking place?**

The project is expected to start early in 2010. The dates and times will be confirmed with you and the parents nearer the time. The study will be completed by July 2011.

The research is taking place in Central Lancashire Primary Care Trust. A suitable venue for the interview session will be agreed nearer the time. The video observations will take place at your usual place of work.

### **How will the study findings be reported?**

All the information will be used to write a comprehensive report as part of the academic requirements. Any published reports will not identify the Primary Care Trust, and will anonymise all participants. You will receive a summary of the report when the study has been completed. If you have participated in the video, you and the parent will also receive a copy of the video.

### **What are the possible risks and benefits of taking part in this study?**

We do not envisage that there will be any risks in taking part in this study. The information you and others have given during the Nominal Group Technique, and the video recordings will give us an idea how Allied Health Professionals can best work with parents of preschool children with Cerebral Palsy. The information might also be used to carry out further studies.

### **What will happen if I don't want to continue with the study?**

You can decide not to take part at any stage – even if you have signed the consent form. You don't have to tell us why you have changed your mind. Your decision to withdraw will not affect you in any way.

If you change your mind after the group interview session, we will continue to use the information because it is completely anonymous and cannot be traced back to you. If you take

part in a video session and then change your mind, we will destroy the information and it will not be included in the study.

### **What can I do if I am not happy with the study?**

If for any reason you are not happy with any aspect of the study please ask to speak to one of the research team who will do their best to answer your questions.

Ms Aline Macready: email [AMacready@uclan.ac.uk](mailto:AMacready@uclan.ac.uk)

Dr Hazel Roddam: email [HRoddam@uclan.ac.uk](mailto:HRoddam@uclan.ac.uk) Tel: 01772 895484

If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure.

Details can be found on the university website: [www.uclan.ac.uk](http://www.uclan.ac.uk)

## APPENDIX III- CONSENT FORM FOR PARENTS



### CONSENT FORM FOR PARENTS / GUARDIANS v2

**Title of Project:**

Advice giving strategies used by Allied Health Professionals to parents of pre-school children with Cerebral Palsy: an exploratory study.

**Researcher:** Aline Macready

**Academic Supervisor:** Dr Hazel Roddam

**FHREC No:**

Please initial box

1. I confirm that I have read and understand the information leaflet for Parents/ Guardians (v2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I give consent to take part in the discussion group.
4. I give consent to be video-recorded in the above-mentioned study if I am selected.
5. I understand that all data gathered during the study will be stored in accordance with the Data Protection Act (1998) and retained for a period of 5 years in a secure data archive at the University of Central Lancashire.
6. I understand that reports from this study will not contain any identifiable personal information. Direct quotes may be used, but will not be attributable to any participant.

Name of participant

Date

Signature of participant

Name (person taking consent)

Date

Signature (person taking consent)

When completed: 1 for Parent / Guardian, 1 for Child's case notes & 1 for  
Researcher.

## APPENDIX IV-CONSENT FORM FOR AHPS



### CONSENT FORM FOR ALLIED HEALTH PROFESSIONALS v2

**Title of Project:**

Advice giving strategies used by Allied Health Professionals (AHPs) to parents of pre-school children with Cerebral Palsy: An exploratory study.

**Researcher:** Aline Macready

**Academic Supervisor:** Dr Hazel Roddam

**FHREC No: CA 160**

Please initial box

1. I confirm that I have read and understand the information leaflet for AHPs (v2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.
3. I give consent to take part in the discussion group.
4. I give consent to be video-recorded in the above-mentioned study if selected.
5. I understand that all data gathered during the study will be stored in accordance with the Data Protection Act (1998) and retained for a period of 5 years in a secure data archive at the University of Central Lancashire.
6. I understand that reports from this study will not contain any identifiable personal information. Direct quotes may be used but will not be attributable to any participant.

Name of Participant

Date

Signature

Name of person taking consent

Date

Signature

When completed: 1 for participant & 1 for researcher.

## APPENDIX V-AMENDED INFORMATION LETTER FOR AHPS



Dear Colleagues,

Date: 20 April 2011

***Advice giving strategies used by Allied Health Professionals to parents of pre-school children with Cerebral Palsy: An exploratory study.***

I am writing to you as you attended a Nominal Group session as part of this research project. I e-mailed afterwards to thank you for your contributions and to explain that I would no longer be seeking to recruit any families to take part in this study.

I would now like to ask if you would agree to assist me by reviewing the checklist I have generated from the items raised in all the NGT sessions. This should take no more than 30 minutes of your time.

Originally my research data collection identified two phases. The first phase was to hold four structured group (NGT) sessions with AHPs (OT, PT, SLT) and parents.

The three sessions with the therapists have been completed. In line with the protocol, the therapists agreed to recruit parents who met the inclusion criteria. Unfortunately after a number of attempts by yourselves, you reported that you were unsuccessful in recruiting parents to take part in the structured group session. This also means that I have no families who are willing for their child's therapy session to be video-recorded, which was the second phase of my project, for the purpose of checking the themes I have developed.

I have now analysed the data generated from the therapist NGT sessions and a number of themes have emerged, which have been developed into a coded checklist. As it will not be possible to use video recordings of routine therapy

sessions to test my checklist against the NGT items I would like to ask you for your continued support.

Please review and comment on the checklist items on the attached document. In particular can I ask you to:

- a) Confirm the face validity of the items listed,
- b) Identify any ambiguous items,
- c) Contribute any supplementary items.

Please return your response in the pre-paid envelope provided 2 May 201, if possible.

As previously agreed it is your decision to participate and whether you choose to take part or not it will not affect your employment at the PCT. In due course you will receive a summary of my findings for your information.

I would like to take this opportunity to thank you for your continued support with my research project.

Yours Sincerely,

Aline Macready

Email: [AMacready@uclan.ac.uk](mailto:AMacready@uclan.ac.uk)

## **APPENDIX VI-NGT QUESTION FOR PARENTS AND AHPS**

### **(Parents)**

“Please give examples of the ways in which your therapists have explained your child’s therapy goals to you and have shown you how you can best help your child to work on these”.

### **(AHPs)**

“Please give examples of the ways in which you have explained the child’s therapy goals to the parents and have shown how they can best help the child to work on these”.

## APPENDIX VII-SCRIPT FOR NGT SESSIONS

### General introduction...

Welcome and thank you for coming today.

I am going to explain what we are going to do.

Firstly, I would like to ask you to have another look at the information sheet about our project.

Please ask me if you have any questions and then please sign the consent form to show that you are happy to take part.

I will then start the session by reading out a specific question, and we have a copy of this for each of you as well.

We will then take up to ten minutes for everyone to write down your own ideas in answer to the question. Those notes are yours to keep.

Then we will ask everyone to take it in turn to read out one item at a time from your list, which I'll write up on the flipchart, and we'll keep going round the group until we have no new items to add. I might ask a question to clarify the item, and so can others in the group. I would like to stress though that this is not an opportunity to have a discussion.

If you think of something else when someone is speaking, it's fine to add that to your list and then contribute that on your next turn.

After all consent forms signed and group ready to begin ...

I'll just very briefly recap of the purpose of this project:

Our aim is to gather as many examples as possible of the different ways in which therapists give advice about therapy practice activities to parents.

We don't want to focus on the sessions when the/your child had their first assessments and the therapists talked about what those results mean;  
We do want to focus on the range of therapy activities you have been working on recently.

*NGT QUESTION:*

*(AHPs) "Please give examples of the ways in which you have explained the child's therapy goals to the parents and have shown how they can best help the child to work on these".*

*(Parents) "Please give examples of the ways in which your therapists have explained your child's therapy goals to you and have shown you how you can best help your child to work on these*

ILLUSTRATIVE EXAMPLES IF REQUIRED:

*Therapists:*

*Eg "How did you describe a seating posture to the parent? Did you give a leaflet, showed them, or asked the parent to demonstrate on your instructions?"*

*Parent: how did your therapist describe a seating posture to you to do at home,*

Ten minutes before the end of the session:

First of all I would like to thank you all for your contributions. Can I just check that everybody has had the opportunity to share all the items you have written down?

If not,

I did say at the start of this session that I would not collect your written notes; however it does seem a shame not to use all the items. , if you agree I can collect your notes, but I need to stress that you don't have to.

Can I also ask for you to introduce the project to your families, here is a parent information sheet for your use. Once all the AHP NGT sessions have been completed I will be able to set a date and venue for the parent NGT session. At that stage I will contact you and ask for you to recruit families who are able and willing to participate.

The project will be completed in June 2011, and you will all receive a copy of the summary report, probably in the Summer Term.

Thank you once again for attending this session and contributing to this project.

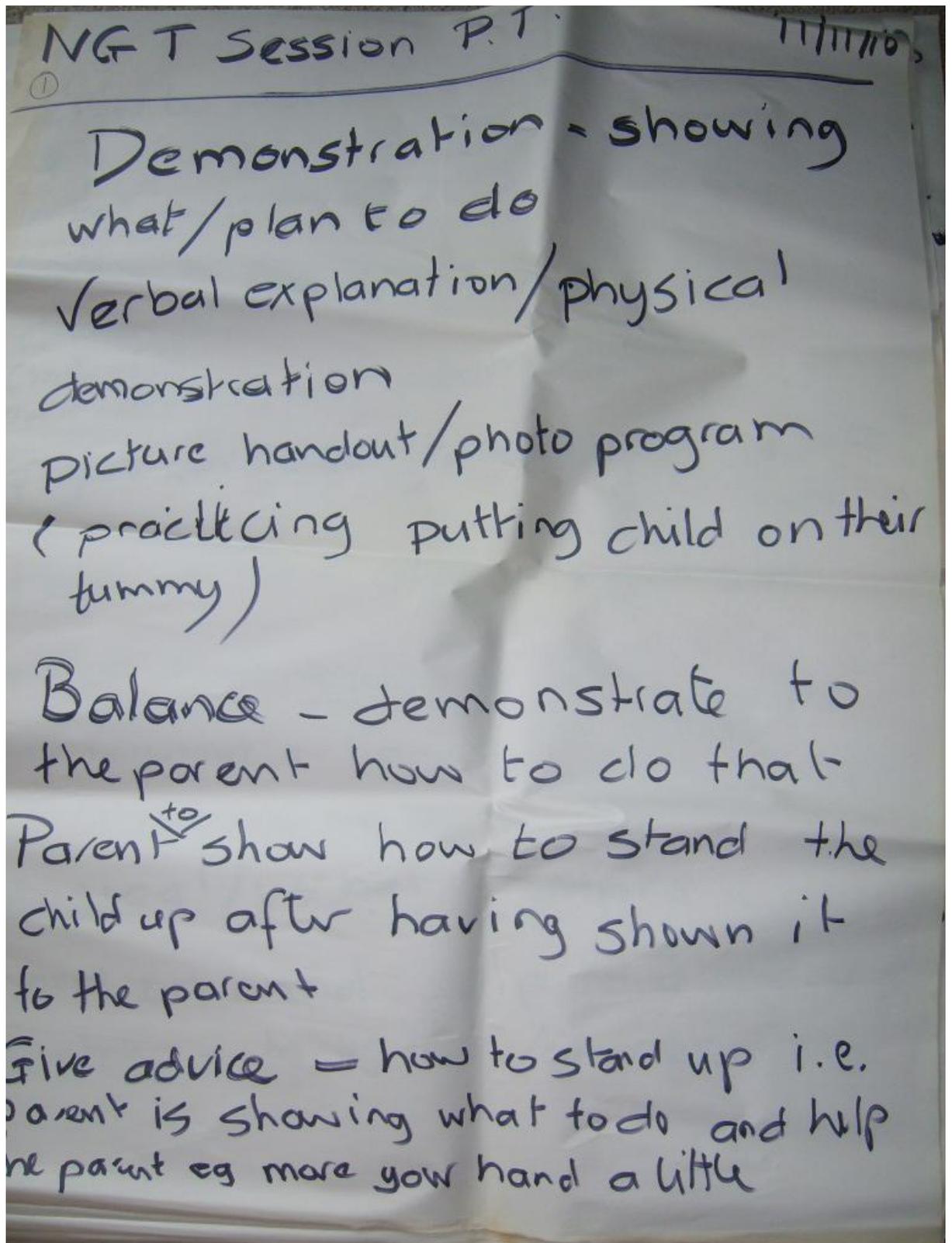
## APPENDIX VIII-TRANSSCRIPT NGT SESSION WITH PT

Date: 11 November 2010

3 therapists present

- Demonstration- showing what to do, or what I plan to do
- Verbal explanation together with physical demonstration
- Picture handout/photo program, for example putting the child on their tummy
- Balance – demonstrate to the parent how to do that
- Parents to show how to stand the child up, after having shown it to the parent
- Advice giving – How to stand up, eg the parent is showing what to do and help the parent for example giving instructions such as move your hand a little this way
- Show them how to motivate a child – suggestions such as playing on the ball, sing a nursery rhyme, using appropriate toys
- Giving different options to a particular goal, and see what parents prefer, such as standing up.
- Physio exercise, can be in different locations, such as the park, tumble tots, at home
- Hand on hand support – sitting exercise, the child is wriggling a lot; guide the mother's hand, often to show how much pressure to use.
- Physical and verbal prompts – hand on hand help to stand up, stretch, firm or not firm
- Written explanation- pre made handouts or individually written. Capable parent- have agreed to have just written instructions without pictures
- Discussion how the family runs, to see how to incorporate therapy activities into daily life
- Ask parents what their goals are – a child with splints – parent didn't feel they were doing what she had expected, so the splints were altered, even though PT felt the splints were ok.
- Discuss how often and where to do the therapy activities, for example after Botox/post op stretching activities – in school, clinic, outdoors

- Discussion current progress and where they want to be and how to get there – goal – parent has an unrealistic expectation
- Using pt assistant to support parents to achieve goals- can be at home/clinic or preschool
- Explain the goals in relation to normal development
- Talk about normal movement- explain therapy goals – if unrealistic ask parents how they move, for example getting out of bed
- Provide information about the condition – drip feed
- Explain short/long term goals and breaking down the tasks e.g. parent what child to walk, but is not rolling over yet.
- Explain goals in light of standardised assessment (GMFM) Gross Motor Functional Measure and show verbal and physical – helpful to show the GMFM as it's like an outsider supporting evidence based
- Explain goals, why and how it will help the child to function- the reason why we put the child on prone is to develop head control and good develop movement
- Review progress and adapting goals, I.E. when you have worked on a goal for 6 months but no progress, this can be when parents identified the goals.



## APPENDIX X-TRANSCRIPT NGT SESSION OT

23 November 2010

3 Therapists present

- Care Aims- episodes of care to set goals with parents: talk to the parents, ask them what their goals are, bring these together, write them up, ask parents to look at it, make changes and ask to sign them
- Demonstrate physically with the child, for example change of position.
- Position child is having at present – change position by therapist – hand over hand with parent to experience the feeling of that and why the change of position is desirable and what it will lead to.
- Asking parent to repeat what therapist has demonstrated, whatever the technique may be and give constructive comments.
- Child with Hemiplegic to move efficiently in a more functional manner. Further encourage the parent and give more ideas.
- Child specific photos – give parent the photos of their child, of the therapy advice program, so parents have pictures with verbal cues. Used for example for changes of position, moving and handling, position of play and dressing
- Pictorial stickman with arrows: where parents need to put their hands
  - i. Arrows for directions of force
  - ii. In conjunction of therapist doing it 'on' the parent
- Use of OT assistant to further demonstrate and/or reiterate – when setting up goals and advice, clear written pictorially. To put into/continue to put into practice. Dependent on factors such as:
  - Competence of OT assistant and parent
  - Complexity of child, and tolerate it.
- Pictorial pre-made advice sheets on positioning, dressing, moving and handling (generic, not child specific – facilitated on a doll)
- Discuss skill acquisition – lead to other activities
- Encourage parent – dressing – encourage the child to assist, crossing midline, transferable skills, isolated skills – transferred – generalised. Backward chaining, example, child getting a jumper on, child assisting with the last action.
- Printed sheets from books and reputable websites etc. eg fine motor skills when it does not need to be child specific
- Letters are given when parents refuse interventions such as lifting and handling, identify what they don't want to do and have them sign that. Identify the risks to not adhering, list of consequences.
- Goal planning, joint meeting between OT=PT, joint episodes

- Include demonstration on the effects of effort and stress on tone. Guidelines on best times i.e. not before bedtimes, when child is tired, sick etc.
- Parental diaries for lycra garments and sleep systems, tell parent what to record.
- When, time of day, what did the child do, effect to tone, in tables.
- Offer visit to nursery/other carers to repeat advice at parent request or therapist feels it would benefit.
- Using specific pieces of equipment to demonstrate functional improvement, child is or example: a child having difficulty balance in the sitting position, use of chair will free the child's hands.
- Introduce parent to other families with permission, with adaptations, showing how it can work.
- Advise to attend other commercial centres such as a soft play centres, parks

APPENDIX XI-FLIPCHART NGT-OT

NGT Session - OT 23/11/10

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Care aims - episodes of care  
to set goals with parents.

talk to parent  
ask what their goals are  
bring together - write that up - ask  
parents to look at it - make changes  
and ask to sign them.

Demonstrate physically with the child  
eg change of position.  
position child is having at present  
change position by Therapist - hand  
over hand with parent to experience  
the feeling of that and why the  
change of position is desirable and  
what it will lead to

## APPENDIX XII-TRANSCRIPT NGT SESSION WITH SLT

29 November 2010

1 SLT present

- Explanation given to the parent about how the child's communication is worked on as part of a holistic approach with parents and therapists working in partnership. This work is never in isolation, but always in partnership not only with the parent but also OT and PT. Aim of each block of therapy is to empower those in the child's environment, to work on child's communication during daily activities.
- Different was to empower the parents. The role of the SLT is to 'train' the parents to be the child's therapist
- Using the Hanen "IT TAKES TWO TO TALK". We give a leaflet to explain the program, loan copies of the handbook and DVD. The program is evidence based for working with parents of children with CP
- Invite parents to attend a parent course (generally when child is 18months +). 8 group sessions, during which the therapist teaches strategies to the parent, and parent and therapist set goals. During the course 3 video sessions are recorded. The aim is looking at how parents implement the strategies and set individual goals for the parent and child. There is also close liaising with other therapists, portage and nursery. (Therapist has given a program handout)
- In the group sessions, the therapist teaches the strategies first, then how to apply these. How to set appropriate communication goals.
- Hanen divides children into:
  - I. Child discovers – non intentional communication
  - II. Communicators – Intentional communicators without words
  - III. First word users
  - IV. Combiners

Parents are asked to use the charts within the handbook to decide what kind of communicator the child is.
- Therapists encourage parents to buy the handbook, as it allows the growth of the child, and appropriate strategies and goals.
- The therapists also use the Derbyshire Language scheme, to carry out ongoing assessments where the child is at. E.g. using a comprehension program – demonstrate to the parent with the child, give the information in written format, this is also shared with portage and nursery to reinforce and generalise the comprehension. Also liaise with OT/PT to ensure that they are able to do their work at the appropriate level.
- Expressive/Comprehension, we also use key word signing. During the Hanen course they think about different ways to support communications. Result, if signing is helpful, parents are invited to keyword signing workshop, and they

incorporate Maketon and Signalong. If parents want they can sign up for a Signalong foundation course (16 hours).

- Communication books and files are used to facilitate the child making choices and help the child to become an active communicator. Discuss the vocabulary with the parents and advice is given how to use the file.
- Objects of reference – Comprehension and giving choices. It is discussed and a handout given about the episode of care plan. This is also discussed with Portage.
- Episode of care- Identify with the family the goals and sub-goals (The therapist gave two copies of plans to illustrate) Reviews can take place at the nursery, and this can be discussed with the parent over the phone, but only when SLT is completely certain where they are up to and parents are realistic about the next goal, and knows the parent well. Otherwise a discussion takes place with the parent when, where to meet to discuss the next goal.
- SLT works very closely with other professionals to facilitate communication in their sessions.

N.B. Central Lancashire does not provide a 'feeding and swallowing' service at present. Children are referred to Liverpool or Manchester for this service. The service is however provided in West Lancashire.

APPENDIX XIII-FLIPCHART NGT-SLT

NGT 29/11/10 STL (5)

Central Lane at present do not have a "feeding and swallowing" service. Families are referred to L'pool or Manchester (service in W Lancs)

Objects of reference - Comprehension on giving choices - discuss and give handout and write in episode plan (discuss with portage)

Episode of care - identify with family the goals and sub goals (see handouts)

review - may be at nursery and discuss with parent over the phone (certainly if ET is known where they are up to and realistic about next goal), and know they can do well)

## APPENDIX XIV-EVALUATION OF AHDC WORKSHOPS

### Aiming High for Disabled Children Parent Participation workshops March 2010:

#### **Background:**

There is a big drive from Central Government recently not only to consult with parents, but also parental participation at a strategic level, to ensure that services for disabled children are meeting the needs of families. Alongside Aiming High, Government commissioned Brian Lamb to evaluate how schools and Local Authorities provide support for children with special educational needs and disabilities. His enquiry resulted in many recommendations to ensure parental confidence in service delivery. (Lamb, B. Dec 2009) Government has been very quick to respond to the recommendations and in February 2010 the 'Improving Parental Confidence in the Special Educational Needs System: An implementation plan' was published. Although this plan concentrates on the needs of children in terms of educational provision, it is far reaching and the report has clearly marked links between this implementation plan and the Aiming High agenda.

Aiming High focuses on very specific areas referred to as the core offer under the following headings:

- Information
- Transparency
- Participation
- Assessment
- Feedback

(Aiming High for Children: supporting families, March 2007)

The facilitator's brief was to focus specifically on parental participation. She was asked to facilitate two separate days with parents and professionals within a particular region. It was expected that the two days would generate the appropriate information to write a parent participation strategy template and a self-evaluation checklist.

The facilitator was asked to identify the barriers to parental participation on day one. Although this might be perceived as a negative activity, it was felt that it was important to gain an insight from both parents and professionals what they perceived the barriers were to meaningful participation.

#### **Day one:**

It was agreed that we would hold a session for parents in the morning and one for professionals in the afternoon. Although the groups were larger than was recommended for Nominal Group Technique (NGT) sessions, (23 in the morning and 22 in the afternoon), it was agreed to try and use the NGT principles (Potter et al 2004).

Parents and professionals were separated for a number of reasons, often parents feel that they cannot be completely honest, in fear of either being judged, or in case it might have an effect on how professionals will work with

their child in the future. Incidentally this was one of the items generated and quite a number of parents ranked that one. Research from Roddam and Selfe (2009) suggest that carrying out NGT using uni- professionals can generate contrasting views; it was felt the same could be true for parents and Aiming High professionals.

**The question posed was:**

*What do you think the barriers are to parent participation from a parent's perspective and from a professional's perspective?*

The question was agreed in the hope that this might be the start of both parents and professionals showing an understanding for each other, and might generate empathy. Parents were less keen to generate silently, and were seeking approval from facilitators (three in total), if they were allowed to say this etc. They did however generate many different items, both from a parental perspective and professionals' point of view. They enjoyed the discussion and were very clear in prioritising items.

The session was repeated in the afternoon with multi-agency professionals. Although the professionals were more composed and able to work in isolation, feedback from some professionals was that they could have been given the question beforehand and brought the answers with them. Others felt that this was a 'novel' way to generate data. All facilitators felt that they appeared to be missing the purpose of the workshop and wanting more of a 'talking shop'. It was interesting that parents and professionals had very similar thoughts both from their own, as well as the other groups perceptive. All participants were asked to score the statements 10-1, however we did not ask them to vote and re-rank. We felt that given the purpose of the exercise, it was important that even if nobody had voted for a particular item, participants could find their statement back.

After both sessions the facilitator initially wrote up all items, (278 in total) and distinguished between am and pm and parents' and professionals' perspective. A basic chart was developed:

Am/pm parents/prof votes	item	ranking	number of
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This produced some items with and some without votes, but all were included as especially for parents it was important that they felt that their views were valued.

The charts were then ordered according to the highest votes, still keeping the am/pm separate. The purpose was that this allowed the participants to see and compare the items. Participants were amazed how many items were exactly the same for parents as well as professionals. It showed that both parents and professionals had some insight about each others' perceptions. It also allowed participants (some for the first time) to see that for example parents receive short notice to attend a meeting, however this was also an issue for professionals. This session already created a better understanding for each others' roles and limitations.

The information was emailed to all participants within 2 days, to ensure that they received feedback speedily, given that the second event was to be held the following week.

The next phase was to take a closer look at the statements. The facilitator used the item order for ease as well as ensuring that all statements were still included. This aided to identify emerging themes and sub themes:

- Emotional barriers – with sub headings such as frustration, trust, attitude, respect, confidence, power imbalance.
- Practical barriers - lack of time, childcare, location of meetings and financial reward or lack thereof
- Communication - Lack of information, jargon used, lack of feedback
- Knowledge and understanding - lack of specialism, expertise, lack of training

Some themes were alone standing such as partnership working, parent forums. Once the facilitator had ordered items according to themes it was possible to gain a better insight of the meaning and it enabled the facilitator to write a brief summary, as well as a comprehensive document, ordered in themes and sub themes. This report was emailed to all participants a couple of days before the second day.

### **Day two:**

The facilitator was able to identify the issues causing the most difficulty. This day both parents and professionals were brought together for the whole day, taking school times etc into consideration.

The themes generated from the NGT sessions were utilised to generate 10 questions, these were written on flipcharts and placed on tables. We placed 3 flipcharts on each table with post-its and markers for people to choose from. Participants were asked to mix with people from different authorities to create opportunities to share good practice. Groups were moved to different tables every ten minutes, till all tables had been visited by all groups.

The regional parent participation strategy template and self evaluation monitoring checklist was developed from the generated data from both days.

It was interesting to note that a number of participants, who had been negative about the NGT session, changed their views and made these known on day two. The feedback was that they were overwhelmed with the wealth of quality information that had been generated.

### **Personal learning:**

The facilitator had read and re-read much of the research around using NGT, and was a little concerned about the process. It was clear that unless it was properly executed, it was a pointless exercise. When the facilitator was approached about facilitating this project and write up a parent participation strategy, it seemed an excellent opportunity to gain some experience in facilitating and NGT session, in preparation for the research study. The brief was to generate information, ensuring that all participants had been given the opportunity to contribute, it was the right method.

It was appropriate and justified to hold separate parents' and professionals' sessions on day one. Although the groups were big, (much bigger than recommended), and more difficult to manage, it worked well, as we had 3 facilitators. It was also appropriate not to re-rank, as the purpose of the exercise was not carry out a research, but merely to extract information,

ensuring that all participants had the opportunity to contribute. Emailing participants in stages and quickly has supported the success of day two and hopefully beyond.

The facilitator was pleased to have had the opportunity to 'trial' an NGT session, as it helped her to recognise how important it was to be clear about what participants needed to do, and to ask the right question, to ensure it generated the information needed to write the parent participation strategy.

It was difficult to manage such a large group and in particular with parents, as they did not just read from their script but elaborating quite a bit. It required sensitive redirecting back to their script. It was easier to manage the professionals. This experience highlighted the importance of the size of the group as well.

#### References:

Department for education and skills (2007) *Aiming high for children: supporting families*. HM Treasury

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Potter, M., Gordon, S., Hamer, P. (2004). *The Nominal Group Technique: Useful consensus methodology in physiotherapy research*. New Zealand Journal of Physiotherapy 32 (3): p 126-130

Roddam, H. and Selfe, J. (2009) *Evaluation of the Care Aims Model service initiative launch*. Report for Central Lancashire (NHS) Primary Care Trust

## APPENDIX XV-THEMES FROM ALL THREE NGT SESSIONS

	NGT – OT	NGT - PT	NGT - SLT
1.	Care Aims- episodes of care to set goals with parents: talk to the parents, ask them what their goals are, bring these together, write them up, ask parents to look at it, make changes and ask to sign them	Demonstration- showing what to do, or what I plan to do	Explanation given to the parent about how the child's communication is worked on as part of a holistic approach with parents and therapists working in partnership. This work is never in isolation, but always in partnership not only with the parent but also OT and PT. Aim of each block of therapy is to empower those in the child's environment, to work on child's communication during daily activities.-
	Demonstrate physically with the child, for example change of position	Verbal explanation together with physical demonstration	Different ways to empower the parents. The role of the SLT is to 'train' the parents to be the child's therapist
	Position child is having at present – change position by therapist, hand over hand with parent to experience the feeling of that and why the change of position is desirable and what it will lead to.	Picture handout/photo program, for example putting the child on their tummy	Using the Hanen "IT TAKES TWO TO TALK". We give a leaflet to explain the program, loan copies of the handbook and DVD. The program is evidence based for working with parents of children with CP
	Asking parent to repeat what therapist has demonstrated, whatever the technique may be and give constructive comments.	Balance – demonstrate to the parent how to do that	Invite parents to attend a parent course (generally when child is 18months +). 8 group sessions, during which the therapist teaches strategies to the parent, and parent and therapist set goals. During the course 3 video sessions are recorded. The aim is looking at how parents implement the strategies and set individual goals for the parent and child. There is also close liaising with other therapists, portage and nursery.
	Child with Hemiplegic to move efficiently in a more functional manner. Show and give further encouragement to parent and give more ideas.	Parents to show how to stand the child up, after having shown it to the parent	in the group sessions, the therapist teaches the strategies first, then how to apply these. How to set appropriate communication goals.
	Child specific photos – give parent the photos of their child, of the therapy advice program, so parents have pictures with verbal cues. Used for example for changes of position, moving and handling, position of play and dressing	Advice giving – How to stand up, eg the parent is showing what to do and help the parent for example giving instructions such as move your had a little this way	Hanen divides children into: Child discovers – non intentional communication Communicators – Intentional communicators without words First word users Combiners

			a) Parents are asked to use the charts within the handbook to decide what kind of communicator the child is.
Pictorial stickman with arrows: where parents need to put their hands i) Arrows for directions of force ii) In conjunction of therapist doing it 'on' the parent	Show them how to motivate a child – suggestions such as playing on the ball, sing a nursery rhyme, using appropriate toys		Therapists encourage parents to buy the handbook, as it allows the growth of the child, and appropriate strategies and goals.
Use of OT assistant to further demonstrate and/or reiterate – when setting up goals and give advice, clear written pictorially. To put into/continue to put into practice. Dependent on factors such as: Competence of OT assistant and parent Complexity of child, and tolerate it.	Giving different options to a particular goal, and see what parents prefer, such as standing up.		The therapists also use the Derbyshire Language scheme, to carry out ongoing assessments where the child is at. E.g. using a comprehension program – demonstrate to the parent with the child, give the information in written format, this is also shared with portage and nursery to reinforce and generalise the comprehension. Also liaise with OT/PT to ensure that they are able to do their work at the appropriate level.
Pictorial pre-made advice sheets on positioning, dressing, moving and handling (generic, not child specific – facilitated on a doll)	Physio exercise, can be in different locations, such as the park, tumble tots, at home		Expressive/Comprehension, we also use key word signing. During the Hanen course they think about different ways to support communications. Result, if signing is helpful, parents are invited to keyword signing workshop, and they incorporate Maketon and Signalong. If parents want, they can sign up for a Signalong foundation course (16 hours).
Discuss skills acquisition – lead to other activities	Hand on hand support – sitting exercise, the child is wriggling a lot; guide the mother's hand, often to show how much pressure to use.		Communication books and files are used to facilitate the child making choices and help the child to become an active communicator. Discuss the vocabulary with the parents and advice is given how to use the file.
Encourage parent – dressing – encourage the child to assist, crossing midline, transferable skills, isolated skills – transferred – generalised. Backward chaining, example, child getting a jumper on, child assisting with the last action.	Physical and verbal prompts – hand on hand help to stand up, stretch, firm or not firm		Objects of reference – Comprehension and giving choices. It is discussed and a handout given about the episode of care plan. This is also discussed with Portage.
Printed sheets from books and reputable websites etc. eg fine motor skills when it does	Written explanation- pre made handouts or individually written. Capable parent- have		*Episode of care- Identify with the family the goals and sub-goals Reviews can take place at the

not need to be child specific	agreed to have just written instructions without pictures	nursery, and this can be discussed with the parent over the phone, but only when SLT is completely certain where they are up to and parents are realistic about the next goal, and knows the parent well. Otherwise a discussion takes place with the parent when, where to meet to discuss the next goal.
Letters are given when parents refuse interventions such as lifting and handling, identify what they don't want to do and have them sign that. Identify the risks to not adhering, list of consequences.	Discussion how the family runs, to see how to incorporate therapy activities into daily life	SLT works very closely with other professionals to facilitate communication in their sessions.
Goal planning, joint meeting between OT=PT, joint episodes	Ask parents what their goals are – a child with splints – parent didn't feel they were doing what she had expected, so the splints were altered, even though PT felt the splints were ok.	
include demonstration on the effects of effort and stress on tone. Guidelines on best times i.e. not before bedtimes, when child is tired, sick etc.	Discuss how often and where to do the therapy activities, for example after Botox/post op stretching activities – in school, clinic, outdoors	
Parental diaries for lycra garments and sleep systems, tell parent what to record. When, time of day, what did the child do, effect to tone, in tables.	Discussion current progress and where they want to be and how to get there – goal – parent has an unrealistic expectation	
Offer visit to nursery/other carers to repeat advice at parent's request or therapist feels it would benefit.	Using pt assistant to support parents to achieve goals- can be at home/clinic or preschool	
Using specific pieces of equipment to demonstrate functional improvement, child is or example: a child having difficulty balance in the sitting position, use of chair will free the child's hands.	Explain the goals in relation to normal development	
Introduce parent to other families with permission, with adaptations, showing how it can work	Talk about normal movement- explain therapy goals – if unrealistic ask parents how they move, for example getting out of bed	
Advise to attend other commercial centres such as a soft play centres, parks	Provide information about the condition – drip feed	

		Explain short/long term goals and breaking down the tasks e.g. parent what child to walk, but is not rolling over yet.	
		Explain goals in light of standardised assessment (GMFM) Gross Motor Functional Measure and show verbal and physical – helpful to show the GMFM as it's like an outsider supporting evidence based	
		Explain goals, why and how it will help the child to function- the reason why we put the child on prone is to develop head control and good develop movement	
		Review progress and adapting goals, i.e. when you have worked on a goal for 6 months but no progress, this can be when parents identified the goal	

## APPENDIX XVI-CODED CHECKLIST COLLATED RESPONSES FROM THERAPISTS

### Coded Checklist collated responses from therapists

THEME		FACE VALIDITY OF ITEMS <i>Can you confirm that this describes an approach which you have used/may use when working with parents?</i>	AMBIGUOUS DESCRIPTIONS <i>Please can you indicate any of these descriptors which seem unclear, and suggest alternative or additional wording to more accurately reflect the nature of the approach you have taken/would take when working with parents</i>
<b>Verbal instruction</b>	You talk to parents about how the family functions, to see how to incorporate therapy activities into daily life	Yes Yes Yes Yes	Would not use the word 'functions' with the parents. Would ask who the child spends time with regularly eg grandparents, siblings, friend, nursery etc.
	Explain goals, why and how it will help the child to function	Yes, Yes Yes Yes	
	You set goals together	Yes, Yes Yes Yes	Always acknowledge parents' priorities and try to incorporate these. <b>Especially now we use the 'care aims' approach</b> <i>With who the child or the parent?</i>
	Discuss skills acquisition	Yes Yes Yes Yes	Talk about normal development, plus emphasis on importance of small steps i.e. setting achievable goals/targets <b>usually discuss progress in terms of how individual child has achieved, not always as per 'normal'</b> <i>seems a bit vague could you give an example</i> Skills acquisition seems inherent in points 5&6 below – do you mean general normal development of skills?

	Discuss current progress, explain the child's goals in relation to "normal" progress	Yes Yes Yes Yes	Instead of normal could you say expected
	Explain short/long term goals and breaking down the tasks e.g. parent want child to walk, but is not rolling over yet.	Yes Yes Yes Yes	Always remind parents of long term aims as they often anxious about these; but focus on short term goals  Instead of normal could you say expected
	Discuss with parents the child's current progress and where they want to be and how to get there	Yes Yes Yes Yes	Is this not the same as 5
	Review progress and adapt goals	Yes Yes Yes Yes	Generally agree to review date (eg after 6 weeks) but informally more often. Not as often as I would like due to time constraints
	Advise them to attend other treatment centres/providers, commercial centres such as a soft play centres, parks	Yes Yes No Yes Yes	May give specific advice/ information regarding other services  Not as often as I should
<b>Can you add any supplementary descriptions of approaches you use which are similar but slightly different to these listed above?</b>		Note difference between: Onward referral with parents' agreement Specific information provided on request General advice cautionary if not directly requested by parents	
<b>Written information</b>	Give a pre-prepared advice/information leaflet	Yes Yes Yes Sometimes Yes	NB. Generally limited availability in SLT, some departments make their own
	Give a handout about the episode of care plan	Yes Yes Yes	*Usually this would be notes written by SLT for each child

		Occasionally Yes	Reword
	Printed sheets from books and reputable websites etc.	Yes Yes Yes No Yes	If appropriate to targets: there are some good materials available <u>but</u> only for a limited number of activities . reword
	Give written advice/ information which you have specifically prepared for their child	Yes ++ Yes Yes Yes	*This takes a lot of time to prepare for each child but is only alternative if no SLT materials are available.
	Give photos of the child in therapy to aid parents to undertake practice/exercises	No Yes No Yes Yes	Not relevant in SLT
	Give leaflets with pictorial stickmen with arrow to aid parents to undertake practice/exercises	No Yes No Yes Yes	Not relevant in SLT
	You ask the parent to keep a diary for lycra garments and sleep systems, tell parent what to record. When, time of day, what did the child do, effect on muscle tone, in tables.	No No Yes Yes	Not relevant for SLT but see below ** This appears to happen less and less though at one stage it happened lots: think this is to do with children having garments/equipment longer term therefore diary seem to fall by wayside in tables – what do you mean?
	You give a letter to parents when they refuse interventions such as lifting and handling, identifying the risks.	No No No Yes	Only similar thing in SLT is a management plan for child with eating/drinking difficulties; might specify risks.
	<b>Can you add any supplementary descriptions of approaches you use which are similar but slightly different to these listed above?</b>	** Ask parents to keep a note of things the child says relevant to their targets, eg. List of new words learned/need; examples of complex sentences, new phrases etc.	
<b>Practical</b>	Demonstrating the practice activity to the parent and	Yes	SLT targets normally built into fun games etc:

<b>demonstration</b>	the parent demonstrating it back to you	Yes Yes Yes Yes	Get the parent to join in so all playing together – SLT models how to play.
	Hand-on-hand guidance	No Yes Yes Yes Yes	Not relevant to SLT
	Show and give further encouragement to the parent and give more ideas.	Yes Yes Yes Yes	Very often try to describe/suggest other practice opportunities as part of daily routines.
	Demonstrating/modelling the activity with the child and then asking the parent to repeat/join in the activity whilst the therapist observes	Yes Yes Yes Yes	
	Parent undertakes the practice exercise/s with the child and therapist gives feedback	Yes Yes Yes Yes	In some SLT programmes (eg Hanen), parents agree to be videoed with their child then play the video back with SLT to reflect on the interactions during the session.
	Verbal instruction with written information for parent to use as prompts	Yes Yes Yes Yes	Should this item go in the section group above re written information?
	You 'teach' parents to become their child's therapist in group activities.	Not sure No Yes No Yes	Often very important to discuss with parents that it's essential <u>they</u> work with own child, not just expect SLT to "fix the problem".
	You demonstrate to parents how they can improve their child's functions using specific pieces of equipment.	No Yes Yes Occasionally	Not relevant to SLT

		Yes	
	Introduce the parents to other parents, showing how adaptations work	No No Yes	not relevant re “adaptations”, but may run therapy groups for children which give parents opportunity to meet each other. Also parent – only groups eg Hanen for training. Would love to, but again time doesn't permit
<b>Can you add any supplementary descriptions of approaches you use which are similar but slightly different to these listed above?</b>			
<b>Utilise Therapist assistant</b>	Use assistant to further demonstrate and/or reiterate activity– when setting up goals and advice.	No Yes No No Yes	SLT assistants probably not often working directly with parents, more often in the classroom settings.
	Use assistant to support parents to achieve goals- can be at home/clinic or preschool	Yes Yes No Yes Yes	SLT assistant can be used for extra practice in class but not likely in nursery or home.
<b>Can you add any supplementary descriptions of approaches you use which are similar but slightly different to these listed above?</b>			
<b>Observing video recording</b>	You video record a session where the parent carries out an activity with the child	Yes Yes Yes yes	In a number of specific parent training programmes, not in routine therapy. Again used to, but less frequent due to time
	You observe the video recording with the parent to look at how they implement the strategies and set individual goals for the parent and child.	Yes Yes No Yes	Exactly as above; <u>not</u> in routine practice in clinic or class.
<b>Can you add any supplementary descriptions of approaches you use which are similar but slightly different to these listed above?</b>			
<b>Loaning equipment to parents</b>	You give the parents a handbook or video on loan	Yes No Yes No	But more likely to be a toy or game to use with child

		Yes	
<b>Can you add any supplementary descriptions of approaches you use which are similar but slightly different to these listed above?</b>			
<b>Working in partnership</b>	Liaising with other therapists, including Portage and nursery staff	Yes Yes Yes Yes	Universal practice in SLT for this group of children.  I am not sure if this constitutes an advice giving strategy to parents
	To set episodes of care goals with parents, you talk to the parents, ask them what their goals are, bring these together, write them up, ask parents to look at it, make changes and ask to sign them.	Yes Yes Should do Yes	
	Ask the parents what goals they want to work on.	Yes Yes Yes yes	
	You give different options to a particular goal, and see what parents prefer.	Yes No Yes Yes Yes	
<b>Can you add any supplementary descriptions of approaches you use which are similar but slightly different to these listed above?</b>			
<b>Combination of activities</b>  This section seems to be repeating what has already occurred if I was filling this out for	Discuss options with parents and a handout is given about the episode of care plan. //This is also discussed with Portage//	Yes Yes Occasionally Yes	Separate out this last sentence, as may not always be relevant Varies, depends on child, family, circumstances, usually send written info to portage
	You give a verbal explanation, together with a practical demonstration	Yes Varies Yes Yes	

real I might be a bit vexed by that		yes	
	You ask the parent to repeat what you have demonstrated, and give constructive comments.	Sometimes Yes Yes Sometimes Yes	
	Use communication books and files to support the parent and help the child making choices. Discuss the vocabulary with the parents and advice is given how to use the file.	Yes No Yes No yes	Also make a 'communication passport' for the child to keep with them. Will discuss preferred language or communication technique i.e. sign
	Help parent hand over hand technique to experience the difference and discuss why the change is desirable	No Yes No Yes Yes	Not relevant for SLT
<b>Can you add any supplementary descriptions of approaches you use which are similar but slightly different to these listed above?</b>			

<b>Please can you add below any further descriptions of approaches you have used/may use when working with parents? Thank you</b>

**APPENDIX XVII-REVISED CODED CHECKLIST**

	<b>THEMES</b>	<b>Please confirm you have observed/asked the therapist carry out the approach in their work with parents?</b>	<b>Please add any additional comments, such as descriptions of approaches you have observed/asked which are similar but slightly different.</b>
	<b>VERBAL COMMUNICATION</b>		
	The therapist talks to parents about their daily routines: Asks who the child spends time with e.g. grandparents, siblings, etc.,		
	Discusses how they can incorporate therapy activities into daily life.		
	The therapist gives specific information in response to parents' request		
	The therapist explains the goals to parents, why and how it will help the child		
	The therapist: Discusses options with parents		
	Gives a handout of the episode of care plan.		
	Discusses this with Portage		
	The therapist discusses current progress of the child: Explains the child's goals in relation to expected progress.		
	emphasises the importance of small steps		
	Explains short/long term goals and break tasks down e.g. parent wants child to walk, but is not rolling over yet.		
	Reminds parents of long term aims as they often anxious about these; but focuses on short term goals		
	The therapist reviews the child's progress with the parents and adapt goals Informal reviews		
	Agreed formal review e.g. after 6 weeks		

	The therapist advises parents to attend: other treatment centres/providers		
	commercial centres such as a soft play centres, parks		
	<b>WRITTEN INFORMATION</b>		
	The therapist gives: The parent a pre-prepared advice/information leaflet		
	The parent a printed sheet from a book or website, if appropriate to the child's targets.		
	The parent written advice/ information which he/she has specifically prepared for their child		
	The parent photos of the child in therapy to help them carry out undertake practice/exercises at home		
	Leaflets with pictorial stickmen and arrows to aid parents to undertake practice/exercises		
	Verbal instruction with written information for parent to use as prompts		
	The therapist asks the parent to keep a diary for lycra garments and sleep systems, and tells the parent what to record, when, time of day, what did the child do, effect on muscle tone.		
	The therapist: Uses communication books and files to support the parent and help the child making choices. .		
	Advices how to use the file		
	Discusses the vocabulary with the parents		
	Makes a 'communication passport' for the child to keep with them.		
	The therapist asks parents to keep a record of things the child says relevant to their targets, e.g... List of new words learned/need; examples of complex sentences, new phrases etc.		
	The therapist gives a letter to parents when they refuse interventions :		
	Lifting and handling, identifying the risks.		
	For a child with eating/drinking difficulties; might specify risks		

<b>PRACTICAL DEMONSTRATION</b>			
	The therapist: Demonstrates the practice activity to the parent		
	Gives a verbal explanation		
	The parent demonstrates it back to the therapist		
	Has built the targets into fun games		
	Models how to play and encourages the parent to join		
	The therapist Demonstrates therapy activities to parents by using hand on hand guidance technique so the parent can experience the difference		
	Discusses why the change is desirable		
	The therapist encourages parents; gives them ideas how to incorporate practice opportunities as part of daily routines.		
	The therapist demonstrates/models the activity with the child: Asks the parent to repeat/join in the activity		
	Observes the parent with the child		
	Gives feedback to the parent		
	The therapist 'Teaches' the parent to become their child's therapist in group activities.		
	Discusses with parents the importance that they work with their own child, not just expect the therapist to solve all the child's problems		
	The therapist demonstrates to parents how they can improve their child's functions using specific pieces of equipment		
	The therapist introduces the parents to other parents, to show how adaptations work		
<b>USING A THERAPIST ASSISTANT</b>			
	The therapist uses a therapy assistant to further demonstrate and/or reiterate activity– when setting up goals and to give advice.		
	The therapist uses a therapy assistant to support parents to		

	achieve goals- At home		
	Clinic		
	Preschool		
	Other please specify		
<b>VIDEO RECORDING AND OBSERVATION</b>			
	The therapist video records a session where the parent carries out an activity with the child: In a number of specific parent training programmes.		
	In routine therapy		
	The therapist observes the video recording with the parent: To look at how they implement the strategies		
	Sets individual goals for the parent and child.		
<b>LOAN EQUIPMENT</b>			
	The therapist loans equipment to parents:		
	Handbook		
	Video		
	Game		
	Toy		
	Other please specify		
<b>WORKING IN PARTNERSHIP</b>			
	The therapist liaises with :		
	Other therapists		
	Portage staff		
	Nursery staff		
	To set episodes of care goals with parents the therapist: Talks to the parents and asks them what their goals and what they want to work on		
	Gives different options to a particular goal and sees what parents prefer.		

	Brings these together		
	Writes them up and asks parents to look at it		
	Makes changes if needed and asks parents to sign them.		