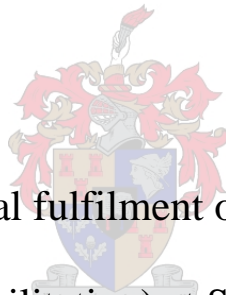


Parental compliance with therapy home programmes within a school for learners with special educational needs - an exploratory study.

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Thesis submitted in partial fulfilment of the requirements for the degree of MSc (Rehabilitation) at Stellenbosch University

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April 2005

DECLARATION

I declare that the work submitted in this assignment is my own work, that it has not been submitted in its entirety or in part for any degree or examination at any other university, and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

Full name:

Date:

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ABSTRACT

Parental compliance with therapy home programmes within a school for learners with special educational needs – an exploratory study

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MSc (Rehabilitation) Mini-thesis

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The school that was studied caters for learners with special educational needs in the Western Cape Province, South Africa. The learners at the school have a variety of physical, intellectual and learning disabilities. They receive rehabilitation inputs aimed at optimising their potential as school learners and as adults. These include occupational and speech therapy, physiotherapy, learning support and educational psychology. The therapists who work with them often utilise home programmes to involve the parents in their child's therapy and to achieve carry-over from the therapy sessions.

Among the professionals at the school there is currently a perception that therapy home programmes are poorly complied with and that the rehabilitation outcomes of the learners are being disadvantaged as a result. A need therefore arose to explore this issue.

This study aims to determine the extent of compliance with therapy home programmes by parents and learners of this school. The study also attempted to elicit factors identified by parents and therapists as inhibitors to and/or facilitators for compliance with the home programmes.

A descriptive, analytical study design was used. All therapists working at the school, as well as the parents of learners who were expected to comply with a home programme, were invited to participate. Data was collected using two self-compiled, self-administered questionnaires. A parent focus group was added later in an attempt to elicit more depth with regard to some of the issues explored.

The data was analysed using quantitative and qualitative methods. Seventy-one percent of parents reported complying at levels adequate for therapeutic benefit to be achieved. However, 25% of the parents reported complying by less than 24% of the time prescribed.

The barriers to compliance identified in this study include the quality of teamwork between the parents and the professionals, attitudinal barriers from both the parents and the therapists, the quality of training for the parents and practical difficulties.

The family-centred, collaborative model of teamwork was recommended to both the therapists and the parents to facilitate parental input at all levels of the planning and design of the rehabilitation programme.

OPSOMMING

Samewerking van ouers in tuisterapie-programme in 'n skool vir leerders met spesiale opvoedkundige behoeftes – 'n verkennende studie

N.R. Melling-Williams

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Die skool wat bestudeer is, maak voorsiening vir leerders met spesiale opvoedkundige behoeftes in die Wes-Kaapprovinsie van Suid-Afrika. Leerders met 'n verskeidenheid fisiese, intellektuele en leergestremdhede ontvang rehabilitasie-insette wat ten doel het om hulle potensiaal as leerders op skool en as volwassenes te optimeer. Hierdie insette sluit in arbeidsterapie, spraakterapie en fisioterapie, asook leerondersteuning en opvoedkundige sielkunde. Die terapeute maak dikwels gebruik van tuisprogramme wat die ouers betrek by hulle kind se terapie en ook ten doel het om 'n verlenging van die terapie-sessie te wees.

Daar is tans die persepsie by die professionele personeel by die skool dat die terapie-tuisprogramme gebrekkige aandag geniet en dat die uitkomst van die leerders se rehabilitasie daardeur benadeel word. Die behoefte het ontstaan om hierdie kwessie te ondersoek.

Die studie het daarom daarop gefokus om te bepaal in watter mate ouers en leerders van die betrokke skool saamwerk in die terapie-tuisprogram. Die studie het ook probeer om dié faktore uit te wys wat deur ouers en terapeute geïdentifiseer is as stremmend en/of fasiliterend vir die tuisprogramme.

'n Beskrywende, analitiese studie-ontwerp is gebruik. Alle terapeute wat by die skool werkzaam is en die ouers van leerders van wie verwag is om saam te werk in 'n tuisprogram, is uitgenooi om deel te neem. Twee self-saamgestelde, self-geadministreerde vraelyste is gebruik om data te versamel. 'n Ouer-fokusgroep is later bygevoeg in 'n poging om meer lig te werp op sommige van die kwessies wat ondersoek is.

Die data is deur middel van kwantitatiewe en kwalitatiewe metodes geanaliseer. Gerapporteerde samewerkingsvlakke het aangedui dat 71% van die ouers saamgewerk het op vlakke wat voldoende is om terapeutiese voordele daaruit te kan put. Vyf-en-twintig persent van die ouers het egter aangedui dat hulle minder as 24% van die voorgeskrewe tyd aan die tuisprogram bestee.

Struikelblokke vir samewerking wat in die studie geïdentifiseer is, sluit in die kwaliteit van die spanwerk tussen ouers en professionele personeel, verkeerde houdings van beide ouers en terapeute, die kwaliteit van opleiding aan ouers en praktiese probleme.

Die familie-gesentreerde, samewerkende model van spanwerk is aanbeveel, beide vir terapeute en vir ouers, om ouerlike insette op alle vlakke van die rehabilitasieprogram se beplanning en ontwerp te fasiliteer.

KEYWORDS

Special Education; rehabilitation; teamwork; children with disabilities; home programmes; compliance; parents; collaboration; facilitators; inhibitors

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DEFINITION OF TERMS

Compliance: has traditionally referred to the extent to which the child and the child's family adhere to the recommendations of the professionals involved, and is considered to be a major contributor to the effectiveness of the rehabilitation process (Cadman, Shurvell, Davies & Bradfield, 1984).

This definition stems from the medical and parent participation models. Parents are judged on their level of compliance and labelled “non-compliant” if they do not carry out the home programme as prescribed by the professional (Bazyk, 1989).

For the discussion involving the collaboration model, this author would like to redefine **compliance** as the extent to which parents adhere to *the plan made by the rehabilitation team, of which they are members*. Thus, parents have an active role to play in deciding what they are capable of doing at any one stage, but retain their responsibility to carry out their part of the agreed plan and to communicate their changing needs to the other members of the team.

Consensus: “Finding a proposal acceptable enough that all members can support it” and that “no members oppose” (Visagie, 2003).

Disability: The International Classification of Functioning, Disability and Health (ICF) (2001) uses the term “disability” to denote a state of limited participation in social roles, imposed on a person by a combination of his/her personal impairment and his/her quality of interaction with the social and physical environment.

In the South African Special Education system, however, children with disabilities are those who have an “organic, medical” impairment and/or other impairments that make it difficult for the child to cope in the mainstream school setting. These are the children who are currently being educated in the Special Education system (Education White Paper 6, 2001).

Facilitators: Factors that make it easier for something to happen (Peshawaria, Menon, Ganguly, Roy, Rajam Pillay & Gupta, 1998).

Inhibitors: Factors that make it more difficult for something to happen (Peshawaria *et al.*, 1998).

Parent-professional relationships: Three models of parent-professional relationships are identified in the current literature (Bazyk, 1989):

- **The medical model:** Intervention is provided only by health professionals and is child focused. Parents are passive recipients of advice and remain dependent on professionals.
- **The parent participation model:** Parents are required to take over some of the tasks of therapy and carry them out at home. Professionals still retain a prescriptive role.
- **The parent collaboration/family-centred model:** Parents are the consumers/clients and professionals are the service providers and consultants. Parents are considered to be an integral part of the rehabilitation team at all levels, including decision making. Parents are acknowledged for the unique knowledge they have of their child and their circumstances. Consensus decisions are reached through a process of negotiation and mutual sharing.

Rehabilitation: A process that includes all measures aimed at reducing the impact of a disabling condition on a person with a disability, and at enabling the disabled person to achieve optimal social, economic and physical integration (Faure, 2003). The ICF (International Classification of Functioning, Disability and Health, 2001) recognises that this requires inputs and/or changes to the physical, social and attitudinal environment, in conjunction with the enhancement of individual skills.

Team: A group of people from various professions [or backgrounds] who make different contributions towards the achievement of a common goal (Pritchard & Pritchard, 1994). (Parentheses added.)

Therapy home programme: A home programme is a set of activities or exercises given to parents or the child to perform at home in order to achieve carry-over from therapy and/or maintain gains achieved in therapy sessions (Sameroff & Fiese, 2000).

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CHAPTER ONE

INTRODUCTION

In South Africa, children with disabilities are currently educated and rehabilitated within the Special Education system. The school that was studied for the purposes of this thesis is one of a number of schools in the Western Cape Province catering for children with physical and learning disabilities. The focus of the existing rehabilitation programme (see Definition of Terms, page vii) within the school environment is on assisting children with disabilities to improve their inherent abilities to enable them to become optimally integrated into society.

The school was started in 1978 under the Department of Special Education and catered for learners with cerebral palsy and other physical disabilities (see Definition of Terms, page vi) who had an intelligence quotient (IQ) of above 80. Currently, about one third of the learners have a specific learning disability, about 30% have cerebral palsy, 15% have other physical disabilities, and the remaining learners are affected by a variety of other conditions.

The school provides learners with disabilities with smaller class sizes, more individualised attention per child, and access to psychologists, learning support, physiotherapy, occupational therapy and speech therapy during school hours. The school has well-resourced therapy departments, a computer room, a library and sports fields. Sport and other extracurricular activities are included in the school timetable. A boarding school is available for children who live far away, and a school bus service caters for most of the children who live locally. There is consequently very little direct contact between the school and the parents as parents are not required to physically be at the school on a regular basis.

However, the school management is constantly trying to improve the current levels of parent involvement at teacher-parent evenings, fundraising events, annual general meetings, social functions and in the school governing body. For some parents, the distances to travel to the school, their socio-economic circumstances, the physical inaccessibility of transport systems and the time that events are scheduled present

barriers to participation. Parents of learners who are in the boarding school may also find it difficult to participate, as they live far away. Other parents who have no apparent barriers to participation in school activities seem to merely lack the interest or motivation to be involved.

Learners are referred to the school via the local school clinic and are assessed in their first year at the school by all the members of the professional team (see Definition of Terms, page vii), consisting of the class teacher and all the therapists. After this assessment, the therapists prescribe therapy where they consider it necessary. Parents pay a nominal fee for these therapies. Each learner's progress is reviewed annually during a formal team meeting of all the professionals involved.

After the initial assessment and goal-setting process, feedback and information regarding the rehabilitation programme are given to the parents by the case manager (psychologist). Feedback is again given to the parents by the psychologist or class teacher, usually at the annual parent-teacher evening, after the annual review of the learners.

Therapist-parent interviews are arranged once a year, during school hours. A time of about twenty minutes is allocated per interview. At this interview, parents are advised of their child's progress, possibly given a home programme and informed of the therapists' proposed plan for future therapy. Parents are invited to make telephonic enquiries or to schedule follow-up appointments with the relevant therapist should they wish to discuss their child's therapy further.

Therapy is given to the learners either on an individual basis or in a group. These sessions are usually thirty minutes long and adhere to a timetable that is designed in collaboration with the teachers and other therapists. Many children are given therapy home programmes (see Definition of Terms, page vii) with which to continue, as it is recognised that carry-over, regular exercise and the practising of new skills are necessary for the therapy to be most effective (Bryant & Maxwell, 1997). Furthermore, the current staff-learner ratio does not allow learners to receive therapy regularly enough to make significant progress in the attainment of functional goals in the therapy sessions only. Thus, home programmes are often aimed at maintaining the

gains made in the therapy sessions in order to be able to build on these gains in the following session. This is especially important in children, because the biomechanics of their bodies are changing constantly as they grow and, therefore, the goalposts are constantly shifting.

Home programmes may be given in written form, verbally to the parents and/or verbally to the learner him/herself. Parents are almost never trained individually to perform these programmes. Programmes are adapted on an *ad hoc* basis, as and when the therapist sees fit. These adaptations will usually be sent home with the child as a “new” programme or noted in the homework or communication book.

There is a general perception among the professionals at the school that compliance (see Definition of Terms, page vi) with these home programmes is poor and that, as a result, the attainment of rehabilitation goals is significantly delayed. This perception is supported by an appreciable deterioration in, for example, the physical condition of many learners after long school holidays, and/or lack of expected improvement, and/or direct reports from the child or parent that the home programme was not followed.

As a result, therapists are frustrated that their skills are not being utilised optimally. They spend much of the limited therapy time doing maintenance-type exercises or repeating inputs that could have been consolidated at home between therapy sessions. The decrease in staff-to-learner ratios and the limited time available to meet a number of different needs for each child increase pressure. Job satisfaction and motivation levels among therapists are influenced negatively.

It was also observed that the learners themselves lose motivation for therapy if few gains are made over time. They become bored with routine exercises and frustrated at not progressing towards the functional goals they have set for themselves. While some children are old enough to understand and perform their own home programme, most need to be reminded, encouraged and corrected by a parent.

In some instances, learners have been attending therapy for some time without showing significant improvement. As a result, therapy may be terminated or

therapeutic goals may be shifted to a maintenance approach. This plateau might occur because the child has reached his optimal potential within his cognitive or physical capabilities. However, more progress might have been possible, or might still be possible, if the parents and therapists were able to better support each other with regard to the child's therapy and home programme needs. Thus, the child's final outcome might be limited by a lack of teamwork between the parents and therapists. As therapeutic gains usually impact on the quality of learning and class work, this has long-term implications for the child's future.

According to the literature, there are many factors that may impact on parental compliance with home programmes. Of these, parental expectations and beliefs, family dynamics and the parent-professional relationships are the most important (Peshawaria, Menon, Ganguly, Roy, Rajam Pillay & Gupta, 1998; Gilbride, 1993; Bailey, Buysse, Edmondson & Smith, 1992; Cadman, Shurvell, Davies & Bradfield, 1984). It therefore becomes crucial to the success of the rehabilitation process to view the child as part of a family unit. In this light, one can begin to understand how the needs and therapeutic aims of the disabled child need to be balanced within the context of the needs of the whole family.

It is clear that the parent participation model (see Definition of Terms, page vii) is currently in operation at the school. This leaves the burden of goal-setting and goal attainment almost solely with the therapist. Families are still largely dependent on therapists for decision-making and the prescription of home programmes and other management plans. However, the therapists' goals and the goals of the families are often not well aligned and families therefore may not comply optimally with the therapists' recommendations. Thus the therapist is left with the burden of guilt about the slow progress or even deterioration of the child's condition. This may lead to feelings of helplessness, "burn-out" and a loss of morale.

This reliance on parents to comply with home programmes will become even more crucial in the near future due to the recent promulgation of new policy for the implementation of an inclusive education system (Education White Paper 6, 2001). In this system, learners with mild and moderate special educational needs will be accommodated in the more inclusive, mainstream school system. Within this policy

document, no provision is made to increase the number of rehabilitation professionals employed in the education department. Therefore, the skills of state-employed therapists will be even more thinly spread in order to provide therapeutic inputs for learners in a variety of geographically separate school settings. This has major ramifications for the provision of rehabilitation services to these children. They will receive direct treatment less frequently due to the number of man-hours absorbed by the therapists' need to travel.

As a result, increasing demands will be placed on other human/team resources, such as the teachers and parents, to continue with and support rehabilitation inputs wherever possible. It is this researcher's opinion that home programmes or private sector therapy will become the focus of much of the therapeutic inputs. Therefore, it is crucial for the success of a therapeutic programme that the team functions in such a way that carry-over is achieved between therapy sessions. Allocated therapy time must be utilised optimally. Therapists will need to spend what little time they have with the child performing activities that require their unique skills, instead of doing maintenance activities. Other team members must be trained to provide maintenance.

This mutual dependence between the parents and the professionals necessitates close teamwork and the re-evaluation of traditional parent-professional roles and boundaries.

Furthermore, there is a growing body of literature in the form of policies, strategies and statements from disabled peoples' organisations that highlight the need for people with disabilities and their families to be more integrally involved in all decision-making processes that affect them (Integrated National Disability Strategy, 1997; National Rehabilitation Policy, 2000; Disability Rights Charter, 1992). Disability issues are being highlighted as human rights issues and disabled people and their families are demanding to take ownership of their own circumstances. The parent participation model is being carefully re-evaluated and replaced with the collaborative model of parent-professional interaction (see Definition of Terms, page vii) (Bazyk, 1989; Bailey *et al.*, 1992). This will have important implications for the way in which children with disabilities and their families are involved in decision-making about their rehabilitation.

Many of the staff members have been working at the school for more than 10 years. While this has created good continuity for the learners and their families and provides a wealth of experience among the staff, it also means that ways of operating are fairly entrenched and that it might be more difficult to introduce changes. Most of the teachers and therapists have trained in the medical model paradigm (see Definition of Terms, page vii), which impacts on their dealings with families and learners. Many of the teachers do not have any special education qualifications.

There is therefore a need to elicit the views of the parents and therapists regarding factors that impact on compliance in the study school in order to critically analyse the current *modus operandi* and recommend appropriate changes. This study aims to quantify the current extent of parental compliance with their child's therapy home programmes within a special education setting, and to determine the factors identified by the parents and therapists as impacting on this level of compliance.

The study results will be used to motivate for changes in the current rehabilitation team's thinking around, and approaches to, the involvement of parents and other factors that may be shown to affect the rehabilitation process. This may have significance for other teams working in similar environments and, to some extent, for all teams working in any rehabilitation setting. These settings are also likely to be affected by the above changes in the social, political and attitudinal environments and may need to re-evaluate their own services in order to be most effective under new circumstances.

In the following chapters, the existing literature on the importance of and compliance with home programmes, the facilitators of and inhibitors to compliance (see Definition of Terms, pages vii) and models of parent-professional interactions will be reviewed.

The research design and methodology will be detailed and the study results will be presented and discussed. Recommendations will also be made.

CHAPTER TWO

LITERATURE REVIEW

2a. INTRODUCTION

In this review of the literature, the researcher aims to explore the issues that impact on compliance with rehabilitation and other home programmes by the parents of disabled children. While there is much literature available on the views of parents regarding compliance, these views are mostly reported in an anecdotal manner (Campbell, 1992; Cunningham & Davis, 1986; McConkey, 1985). Descriptive situational analyses of specific settings are helpful in expanding our understanding of the issues, but cannot necessarily be generalised to other settings (Peshawaria *et al.*, 1998; Webster & Ward, 1993). Methods of measuring compliance are also inconsistent, making it difficult to compare findings (Cadman *et al.*, 1984). The majority of the literature is of American origin and the relevance to the South African setting has not been ascertained.

Several studies on the views of therapists have also been conducted, focussing on their attitudes towards working with parents (Humphry, Gonzalez & Taylor, 1992) and the extent of collaborative practice that exists (Bailey *et al.*, 1992). However, no recent surveys of parental perceptions were found to evaluate whether changes in therapists' thinking and theoretical frameworks have impacted on the way parents experience the rehabilitation process. There is little research that assesses the extent of compliance as a baseline measurement, and subsequently assesses whether the introduction of a more family-centred/collaborative model has had a positive outcome on the effectiveness of the rehabilitation process. Should changes be made to the current *modus operandi* in the study school as a result of this study, it would be recommended that a follow-up study be implemented to assess parental views on the effects of these changes.

According to the existing literature, compliance may be influenced by the following broad aspects:

- the family dynamics, practical limitations and coping strategies (Peshawaria *et al.*, 1998);

- parents' expectations and beliefs about their child's potential (Gilbride, 1993);
- parents' beliefs about the relevance and effectiveness of the rehabilitation process (Cadman *et al.*, 1984); and
- the quality of parent-professional relationships (see Definition of Terms, page vii) (Bailey *et al.*, 1992; Cadman *et al.*, 1984).

These aspects will be reviewed thoroughly in this literature study.

The review will highlight strengths and weaknesses in the existing system at the study school and will assist in the development of a comprehensive study from which recommendations for the future can be made.

2b. HISTORICAL AND EXISTING PERSPECTIVES

2b.i. The medical model

Parent-professional relationships have undergone and are still undergoing significant changes worldwide (Bazyk, 1989). Initially, these interactions were largely based on the medical model, with intervention being child-focused. Therapists provided direct therapy aimed at developing new skills within the child as a separate entity from the family. Health professionals were regarded as the experts and were responsible for all decision-making about the child's rehabilitation process (Cunningham & Davis, 1986). Parents were passive recipients of advice and were considered incapable of meeting their child's rehabilitation needs. This created dependence on professionals, as parents were increasingly made to feel incompetent and helpless (Bazyk, 1989). More recently, a shift has occurred towards the parent participation model.

2b.ii. The parent participation model and compliance

The "parent participation" model requires that parents assume some of the tasks of teachers and therapists and carry these out in the home setting (Bazyk, 1989). This shift has helped to change professionals' attitudes about parents' capabilities and helped raise confidence and skill levels among parents. The study school operates largely on this model.

Home programmes have become the accepted way of involving parents in their child's rehabilitation and promoting the transfer of skills gained in therapy to the home and the community. However, according to this model, professionals still make most of the decisions about the content of the therapy and home programme, and may still maintain a prescriptive role (Bazyk, 1989).

Compliance plays an important role in the parent participation model. Compliance refers to the extent to which the child and the child's family adhere to the recommendations of the professionals and is considered to be a major contributor to the effectiveness of the rehabilitation process (Cadman *et al.*, 1984). Parents are judged on their level of compliance and labelled "non-compliant" if they do not carry out the home programme as prescribed by the professional (Bazyk, 1989).

Studies have shown that compliance is a consistent problem. Sackett and Haynes (1976) reviewed 185 studies assessing compliance with therapeutic regimens. The studies reviewed were screened for methodological criteria, particularly with respect to bias introduced by the sampling of patients. This screening process reduced the number of studies reviewed to less than 40. The subsequent review found consistently poor compliance with long-term therapeutic interventions (35- 46%). However, the majority of studies reviewed assessed compliance with the use of prescription medication and therefore differ from this study. Compliance with rehabilitation programmes and preventative regimens was similarly low, with compliance rates of 34-67% and 15-50% respectively (Sackett, 1976).

Cadman *et al.* (1984) investigated levels of compliance and associated factors in parents/families of 30 children with "developmental handicap" identified in the community. Their study used questionnaires to gather data from the parents. The types of recommendations reviewed included therapeutic inputs, such as speech and language, motor, cognitive and behavioural programmes, as well as medical advice and recommendations on educational placement. The study population, collection of data and the type of recommendations investigated therefore closely resemble those of the current study. They reported an overall compliance with professional recommendations of 73.2%. Attempts to correlate the levels of compliance with the

characteristics of the specific child, disability, family or type of recommendation proved inconsistent and inconclusive.

A study by Arnhold, Adebonojo, Callas, Callas, Carte and Stein (1970) confirmed this finding. Compliance was found to be significantly associated with parental beliefs about the efficacy of the rehabilitation programme as a whole, their relationship with the professional involved, and their belief in their own capability and role in implementing the recommendations (Cadman *et al.*, 1984; Becker, Drachman & Kirscht, 1972).

Within the parent participation model there is a tendency to regard all parents as a homogeneous group, capable of and willing to take part in the rehabilitation process to the same extent (Bazyk, 1989). But parents differ with respect to resources, priorities, support networks, demands placed on them by their families, communities and work, and their expectations and desires for their child's future (Peshawaria *et al.*, 1998).

It may therefore be of value to review the use of this model, and/or to consider other models of parent involvement, in the light of newly developed South African policy and legislation that expects a higher level of participation from parents.

2b.iii. Policy and legislation

Despite reports of poor compliance levels in the literature and the differences between individual parents and families, South African policy now requires parents to become increasingly involved in the decision-making regarding and rehabilitation of their child. The National Rehabilitation Policy (2000) highlights the importance of “involv[ing] clients in decision making so that they can own the process and be empowered at the same time” (page 1). The policy also promotes “collaboration and partnership with people with disabilities and members of the community with regard to...rehabilitation issues” (page 13).

Historically, inadequate provision was made for parental involvement in their child's educational setting (Bornman, 1989). However, the Education White Paper 6 (2001)

now targets parental involvement as a strategic area for change so that parents “can play a more active role in the learning and teaching of their own children” (page 50).

Furthermore, the Education White Paper 6 (2001) promulgates the integration of learners with special educational needs into an inclusive education system. In 2001, 64 603 learners were accommodated in the special education system. The Education White Paper 6 (2001) quotes 1996 census data stating that a further 260 000 learners still require such intervention. This implies huge increases in the demand for the provision of therapy services in the near future. However, no provision has been made in this policy for an increase in the number of therapy personnel to address the needs of these additional learners.

This change in therapist-to-learner ratios will necessitate increased reliance on parents for cooperation with home programmes and therapy carry-over in the home environment. This, and the legislative requirements for parent involvement, will require increasing collaboration with parents and a shift towards a “family-centred” model (Bazyk, 1989) for effective rehabilitation planning and implementation. (This model is discussed in more detail under 2f.) The role of the family will become pivotal to the success of a child’s rehabilitation programme.

2c. THE ROLE OF THE FAMILY IN THE REHABILITATION OF THEIR DISABLED CHILD

For rehabilitation to have real and lasting meaning, the full commitment and collaboration of the disabled person’s family is crucial (Moore, 1984; Brolin & Wright, 1971). Therapists have come to rely increasingly on parent participation in the rehabilitation process. This is partly due to an increased understanding of the nature of family processes and dynamics and the awareness that parents play a pivotal role in their child’s rehabilitation (Sameroff & Fiese, 2000), and partly because of the increase in workload without concurrent increase in staff complements in the education system in South Africa (Education White Paper 6, 2001).

There are a number of other reasons why parents should be actively involved in the rehabilitation process of their child. Parents are the legal guardians of their child and

it is both their right and their responsibility to advocate for and make decisions on behalf of their child (National Rehabilitation Policy, 2000; Cunningham & Davis, 1986). They therefore need to be involved and supported in the process of decision-making in order to be able to make informed and appropriate choices that will benefit their child and family.

Sameroff and Fiese (2000) propose that a child's development is, to a large extent, a product of the dynamic interactions that occur between child, family and social contexts. Thus the child's experiences will depend significantly on the specific beliefs, values and personalities of the parents. The child's disability, in turn, will have a direct effect on the way that the family functions. It has further been shown that intervention programmes are most effective when they are specifically targeted towards a specific child, within a specific family, within a specific context at a specific time. Parental input is therefore essential to provide information and insight about the child's own environment and the current circumstances and capabilities of the family.

The outcome of the rehabilitation process is also largely dependent on the family's attitude towards disability and their expectations for their disabled child (Gilbride, 1993). The family will find it easier to work through their own attitudes about the disability if they are involved, and feel that their input is valued and that they are being supported in the process (Moore, 1984).

Wolery (2000) states that the efficacy of any intervention with a behavioural or educational orientation increases with increasing intensity of implementation (i.e. more hours per day, more days per week). Carr, Shepherd, Gordon, Gentile and Held (1987) support this view with regard to motor learning programmes and the improvement of physical performance. Bobath & Bobath (1996) also emphasise the importance of carry-over and practicing of new skills in the child's various environments in order to consolidate therapeutic gains.

Many parents are in the unique position of being able to influence major portions of their child's day and thus to effect greater carry-over and generalisation of skills from therapy/teaching sessions. However, it is important to remember that family priorities

need to be balanced with therapy objectives. Involving and understanding the specific needs of parents from an early stage is therefore crucial in order to achieve effective teamwork (Bailey *et al.*, 1992).

Consequently, there is an increasing need for parents to be seen as an integral part of the rehabilitation team and for parents and professionals to collaborate more constructively. In so doing, a more individualised approach can be developed, taking into account the relevant facilitators and inhibitors operational within each family unit, to ensure a more effective outcome for each child.

2d. CONTEXTUAL FACTORS

The International Classification of Disability, Health and Functioning (2001) highlights the impact that contextual factors can have on the disabled person's ability to achieve optimal physical function, quality of life and integration into the community. These include physical, socio-economic, attitudinal and personal factors.

These contextual factors may influence the parent and/or family's ability and motivation to comply with therapy home programmes. In this way, their level of compliance may act as a facilitator or barrier to optimal rehabilitation outcomes for their child.

The factors identified in the literature that facilitate or inhibit coping and compliance within families affected by disability are numerous (Sackett & Haynes, 1976; Peshawaria *et al.*, 1998). All the pertinent influences need to be taken into account within each family to facilitate the design of relevant and appropriate home programmes. For the purposes of this study, facilitators and inhibitors are understood to be opposing factors (i.e. if the absence of a support network is an inhibitor to compliance, then it is assumed that the presence of a support network will be a facilitator).

Coping is defined by Moore (1984) as “a process of achieving a balance in the family system that facilitates organisation and unity and promotes individual growth and development” (page 101). As such, it can be seen that coping and compliance are

related, in that a family that is having difficulty coping will usually find it more difficult to comply with a home programme than a family that is coping well. In the literature, factors that facilitate better coping skills within a family seem to overlap with those that facilitate better compliance. However, the decision to *not* comply may in itself be part of a family's coping mechanism if the needs of all family members are taken into account, and this decision should be respected as such (Bailey *et al.*, 1992).

Coping abilities are related to one's ability to mobilise internal strengths and external resources. This ability is highly individualised. Internal factors include faith in God, energy levels, one's perception of the situation, and one's degree of self-determination. External factors include support from the family, community and professionals, and government policy and programmes (Peshawaria *et al.*, 1998).

A study conducted by Peshawaria *et al.* (1998) elicited perceived facilitators and inhibitors to coping from 218 parents of children with intellectual impairments in India. The children ranged from newborn to above 19 years of age. The population was stratified for age into four subgroups of equal size. This range closely reflects the age groups of the learners investigated in the current study.

The parents reported that external resources made a more meaningful difference to their ability to cope than internal strengths. However, it is not clear what reasons were given to participants for the implementation of the study. Participants may have felt that the results of the study could influence the provision of new or improved services. They may therefore have rated external resources higher on their list of facilitators than internal strengths.

More parents from higher income groups reported internal strengths as significant facilitators. This possibly suggests that a basic level of services (which would be more easily accessed by higher income families) is crucial to coping before one can rely more fully on one's own internal strengths. This is a relevant factor in the South African context, where the income levels of different sectors of the population differ vastly, from very low to very high.

Inhibitors to coping identified by the parents in the above study included financial loss or difficulties, a high degree of social stigma attached to the child's disability, heavy time demands on the parents, lack of sleep, social isolation, the loss of recreational time, the severity of behavioural problems in the disabled and other children, poor accessibility of services, additional medical and other costs, other family problems, low caregiver education level and lack of information. The impact of the disability on the whole family must therefore be considered carefully (Peshawaria *et al.*, 1998; Moore, 1984).

Wikler and Stoycheff (1974) and Brolin and Wright (1971) studied compliance by families of persons with intellectual impairments and found that parental agreement with the diagnosis, the amount of stress parents have experienced in caring for their child, the type of recommendation, the child's age and sex, and the severity of the condition may be related to the extent of compliance, although inconsistently. However, limited testing of the validity and reliability of the instruments used limit the possibility of generalising these results to other settings (Cadman *et al.*, 1984).

Parents have voiced concerns about having insufficient time and energy to engage in structured activities while also fulfilling the various other roles required of them in the home (Bazyk, 1989). The difficulty for working mothers to carry out home programmes is obvious, and such demands could be a source of great stress to the mother and family (McConkey, 1985).

Parents report that the need to carry out home programmes creates role confusion, which can be undesirable (Wolery, 2000). Parents may not wish to be their child's "therapist". This may introduce tension into the relationship between the child and parent. Parents may become frustrated with their child's slow progress and the child may resent the time spent together resembling work (Bazyk, 1989). Parents also often struggle to maintain the child's interest in and cooperation with the home programme, and may feel incompetent to provide such inputs for their child.

The extra time spent with the disabled child may cause conflict within the family. Siblings and other family members may resent the time given to that child and parents need to be able to balance these demands. Arrangements must also be made for

siblings while parents attend appointments with their disabled child. Most parents report feelings of guilt about the reduced time and support given to their non-affected children (Webster & Ward, 1993).

Gilbride (1993) showed that the general attitudes of parents of a disabled child towards people with disabilities do not differ significantly from those of parents with able-bodied children. However, parents who did *not* believe that the disability is central to their child's identity and who did *not* believe that the child is inferior and incompetent because of his/her disability had higher long-term expectations for their child than those parents who believed otherwise. Thus, parental attitudes and the resultant expectations for the child's long-term capabilities (especially work-related) may limit the value placed on the rehabilitation programme and the prioritisation of the home programme within the family schedule.

Social and/or language barriers between parents and professionals may also affect compliance with a home programme. Parents may come from backgrounds and physical environments that differ vastly from that of the professional. This will have serious implications for the application of home programmes with regard to space available, noise levels, equipment available and other factors. Professionals and parents may not be able to communicate in a shared first language, or professionals may use a level of language and/or terminology that is not well understood by the parent (McConkey, 1985).

Humphry *et al.* (1992) surveyed 340 American occupational therapists working with families to investigate attitudes and issues around working with the families of their clients. The therapists worked in the areas of physical disabilities, developmental disabilities and mental health. In all areas of practice, the professionals consistently reported scheduling difficulties as the primary barrier to their involvement with families. Parents who are working may find it difficult to get time off work to attend appointments and therapists' schedules may not be flexible enough to allow for *ad hoc* meetings (Humphry *et al.*, 1992). This lack of direct contact and communication between parents and professionals may impact on compliance with rehabilitation programmes. This situation closely reflects that of the study school, where

communication is limited to appointments and telephone calls during working hours, when time is limited.

In the same study, the professionals also identified their own distrust of the parents' capabilities as a barrier to effective teamwork and therefore compliance (Humphry *et al.*, 1992). Family priorities for goals and services may not always correlate with professionals' priorities when designing a rehabilitation and home programme. This may impact on the ability and willingness of families to comply with such programmes (Bailey *et al.*, 1992).

It can be seen that there are many barriers to effective teamwork and family compliance with the rehabilitation process and home programmes. These have resulted in friction between parents and professionals and, possibly, further non-compliance. The nature of the current relationships between therapists and parents will need to be re-examined and improved upon.

2e. THE IMPORTANCE OF TEAMWORK

By implication then, the specific needs and circumstances of each family must be taken into account when designing rehabilitation and home programmes for these programmes to function effectively (Sameroff & Fiese, 2000). This necessitates negotiated decision-making and teamwork involving all stakeholders. All team members' inputs are essential to ensure that insightful programmes are designed for the optimal integration of the child into his/her specific social context.

A team is defined as "a group of people from various professions [or backgrounds] who make different contributions towards the achievement of a common goal" (Pritchard & Pritchard, 1994:13). For effective teamwork, an attitude of mutual respect and sharing is necessary to achieve an understanding of common purpose and consensus (see Definition of Terms, page vi) on issues (McConkey, 1985).

Reaching consensus is "finding a proposal acceptable enough that all members can support it" and that "no members oppose". This requires time, active participation,

good communication skills, creative thinking and open-mindedness from all team members (Visagie, 2003).

Thus, working effectively in a team presents a significant challenge, but it has several advantages over working independently. The impact of care provided by a team of people with common goals and objectives will be greater than the sum of care given by the same individuals working alone. Team members stimulate and enhance creativity and this may give rise to new and innovative solutions to problems (Visagie, 2003).

Team members can also provide mutual support to each other, both emotionally and professionally, and thus strengthen the members for the task. Working in a team provides opportunities for informal learning and guidance, and thereby raises the standard of care given. Effective teamwork ensures that the workload is shared and prevents the overlap of service provision. This allows for unique and/or specialised skills to be used most appropriately, which in turn increases job satisfaction for all involved. Teamwork encourages continuity of care and ensures that all aspects of the rehabilitation process are addressed (Visagie, 2003).

In the school rehabilitation setting, team members may include combinations of teachers, classroom aides, therapists, psychologists, social workers, medical personnel, family members and the child. The members may also require input from other service providers at various times as the need arises. Thus the team must remain a dynamic unit.

All team members, including parents, will be entitled to and responsible for the development of constructive relationships, the maintenance of open channels of communication, the sharing of accurate and comprehensive information, and respect and support. In this way, parents can be part of the process of developing common visions and rehabilitation strategies for their child and family (Campbell, 1992).

2f. THE FAMILY-CENTRED/COLLABORATIVE MODEL

The “family-centred” or “collaborative” model has evolved as an alternative to the medical and parent participation models of teamwork. In this model, parents assume a partnership role with the professionals and are directly involved in deciding on the content of the home and rehabilitation programme, and how much they are willing to do and are capable of doing within their own specific circumstances at that specific time (Sameroff & Fiese, 2000). This model requires significant changes to the traditional parent-professional relationship and, as such, presents a challenge to all involved in rehabilitation. However, if one believes that parent involvement is essential in order for the maximum potential of the child to be reached, one must consider the possible benefits of this model.

In this model, parents are involved at all levels of the rehabilitation process, giving input and participating in decision-making. All decisions are made through a process of negotiation and mutual sharing so that consensus can be reached. Parents are acknowledged for the unique experience they have of their child and their circumstances and for the skills they already have for meeting their child’s needs. The parent is the consumer or client and has the ultimate decision-making power. Professionals are seen as service providers and consultants. The professionals help the parents to acquire knowledge of the available options and skills they will need to be able to care for their child with special needs (Bazyk, 1989). The professionals need to accept and support the parents’ decisions.

Home programmes are designed in a collaborative way, with parents giving input on their priorities and what is possible and realistic for them to do. It may be necessary to adjust the programme if it is subsequently discovered to be unrealistic for the family or ineffective (Bazyk, 1989).

The family-centred or collaborative model raises awareness of specific needs within individual families, and allows for and demands increased flexibility as family differences are acknowledged. It also helps to decrease the dependence of the parents on the professionals, reduces some of the professionals’ responsibility for decisions

regarding the child, and creates a more equal balance of power within the team (Cunningham & Davis, 1986).

Barriers to this type of family involvement identified by therapists include insufficient knowledge and skills within families to enable full participation in planning and decision-making, negative or unrealistic family attitudes to the rehabilitation process, a lack of resources, and inefficient functioning of the family unit (Bailey *et al.*, 1992).

System barriers were also cited, such as those imposed by the employing institution (e.g. other priorities for managers, methods of staff appraisal, non-payment for indirect management issues), lack of resources (manpower and time) and difficulties in changing the *status quo* (Bailey *et al.*, 1992).

Professionals also identified their own limitations with regard to knowledge and skills for facilitating and maintaining collaborative relationships with parents (Bailey & Buysse, 1990).

The collaborative model is appealing in that the potential for parental involvement and the exercise of rights and responsibilities are facilitated. However, this in itself presents several challenges to parents, who are already stretched with other responsibilities for their family, as well as to therapists, who must change their attitudes and develop skills in order to appropriately inform and educate parents so that the latter are able to take their own decisions in a way that is best suited to the child, the family and the optimal outcome for all.

2g. MEASURING INSTRUMENT

The shift away from professional prescription of home programmes to a partnership with parents in goal and priority setting requires a redefinition of our understanding of compliance. It can no longer be seen as the extent to which parents adhere to the recommendations of the professionals, but rather the extent of adherence to the rehabilitation plan as set out by the team, of which the parent is a member. This presents a methodological challenge for follow-up study purposes as suggested above, and will require changes to the questionnaire items for measurement. Perhaps parent

satisfaction also needs to be measured in order to draw a more direct comparison in a follow-up study.

This study will assess the current parent participation model in the study school and the parents' and therapists' views on the functioning of the rehabilitation programme and the quality of teamwork at present. A follow-up study will have to be implemented at a later stage to assess the long-term effects if changes to the existing model are implemented.

Unfortunately, the way in which compliance is measured may introduce bias into the results (Cadman *et al.*, 1984; Sackett & Haynes, 1976). Self-reporting in a questionnaire or interview is highly subjective (Sackett & Haynes, 1976) and is open to criticism for its susceptibility to positive reporting, as are other methods such as journal keeping and direct observation. These latter two are even less likely to elicit an entirely accurate response, as parents who accept this level of intervention are likely to be those who comply most rigorously with therapy. It is therefore important to gain an understanding of the non-respondent population when testing for compliance. Despite this potentially favourable bias, and as discussed previously, the results of studies have shown consistently low compliance levels (Sackett & Haynes, 1976).

Some studies used objective data to ascertain compliance levels, such as drug levels in urine samples, or the number of pills remaining out of a specific quantity supplied (Sackett & Haynes, 1976). Because of the range of treatments given and the nature of rehabilitation therapy for neurological and learning impairments, it would be impossible to use objective measures to assess compliance in this study population. Other studies used interviews to collect data on levels of compliance with interventions (Arnhold *et al.*, 1970; Becker *et al.*, 1972). In this intimate school setting, however, it was felt that the anonymity of a questionnaire would encourage parents to report more accurately.

The researcher therefore compiled two questionnaires (see Appendices C1, C2 and D) with which to collect data from the parents and therapists. Some questions were guided by the self-compiled questionnaires in Bornman's study (1989) of parent

involvement in special educational institutions. No standardised questionnaires were found that would be appropriate for the specific setting.

2h. SUMMARY

Parents have both a right and responsibility to be integrally involved in their child's rehabilitation process at a decision-making level. Parents and therapists will have to depend on each other more in the future for the success of the programme as personnel numbers diminish and new systems for provision impact on the frequency of therapy. They must therefore invest energy in understanding each others' priorities, goals and needs in order to develop good team relationships and to achieve the optimal outcome for the child and the family as a whole.

Historical and existing models of parent-professional relationships have not facilitated good working relationships, with the result that some or all parties remain frustrated at the overall outcomes.

It has been argued that the success of the rehabilitation process for a child with a disability depends to a large extent on the ability of the team to collaborate with the parents in order to attain mutually acceptable goals. Effective collaboration may impact on parental compliance with the rehabilitation programme as a whole.

These aspects will be investigated in this study within the context of a special needs school in the Western Cape Province, South Africa, where the parent participation model is currently being used.

CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

3a. INTRODUCTION

This chapter discusses the study design, sampling techniques, instrumentation used and the processes of data collection and data analysis. The aims and objectives of the study are outlined. In conclusion, the limitations of the study and potential bias in the data are discussed.

3b. AIM OF THE STUDY

This study aims to quantify the current extent of compliance by parents of children with disabilities who received therapy home programmes at the study school. The researcher also intends to elicit factors identified by the parents and therapists that influence compliance.

3c. OBJECTIVES OF THE STUDY

The objectives of this study were to:

- determine the demographic features of the study population;
- determine the extent of compliance with therapy home programmes between October 2003 and the end of January 2004 from the responses to the parent questionnaire;
- analyse correlations between the extent of compliance and:
 - demographic features of family, severity of disability and type of home programme
 - parents' expectations and beliefs about their child's potential
 - parents' beliefs about the effectiveness and relevance of the rehabilitation process, and
 - the quality of the parent-professional relationships from the point of view of the parents;
- determine any other factors that the parents may identify as facilitators and/or inhibitors to compliance;

- determine the therapists' perceptions around the effectiveness of home programmes, the functioning of the rehabilitation team and the parent-professional relationships and to compare these with the parents' views;
- highlight possible areas of concern in the school with regard to the functioning of the home programmes; and
- raise awareness among all stakeholders in this and similar schools, and other rehabilitation settings, with regard to the strengths and weaknesses of existing and alternative teamwork models (especially the collaborative model) and rehabilitation programme design.

The results may be instrumental in the process of change to facilitate improved teamwork, parent-professional relationships and compliance with team decisions within the study school.

3d. STUDY DESIGN

A descriptive, analytical study was conducted using two self-compiled, self-administered questionnaires. Structured and unstructured questions were included in both questionnaires to obtain quantitative and qualitative data.

3e. RESEARCH SETTING

The research was conducted with the therapists and parents of learners attending a school for learners with special educational needs. Permission to perform the study was granted by the Western Cape Education Department and the school governing body (see Appendices B1 and B2).

Learners in the study population ranged in age from three (3) to eighteen (18) years. The school's learners come from geographically separate areas, ranging from the Cape Town East Metropole to Oudsthoorn, Vredenburg, Malmesbury and Strand. As a result, these learners and their families come from diverse socio-economic, ethnic and language backgrounds. The school provides teaching in Afrikaans and English. A few Xhosa-speaking learners are also enrolled at the school.

At present, the school caters for a total of 320 learners. The academic stream accommodates learners from the pre-school phase through to grade nine in 23 classes, and the practical stream of six classes caters for learners up to 18 years of age. There are 34 teaching staff, 16 clinic staff (including therapists, psychologists, learning support teachers and a nursing sister), and 30 support staff in various administrative and general assistant positions.

A study sample adhering to the inclusion criteria was selected from this population.

3f. STUDY SAMPLE

The study sample for the questionnaires consisted of two separate groups. The first group consisted of the parents of all 85 learners who were required to comply with a rehabilitation (speech, occupational or physiotherapy, psychology and/or learning support) home programme during the study period. The second group comprised the 13 therapists (speech, occupational and physiotherapists, psychologists and learning support teachers) who worked at the study school during the study period.

The 85 learners were identified through comprehensive lists provided by the therapists to the researcher. Nobody who received a home programme was excluded from the sample. Participants who, according to the therapists' records, had been asked to perform more than one home programme, given by different therapists, were supplied with duplicate copies of the relevant sections of the questionnaire. They were then requested to fill in a separate copy of the relevant sections for each home programme. A total of three (3) such learners were identified.

3f.i. Inclusion criteria

- All parents of learners from the study school who were required to comply with a rehabilitation home programme in the period from the beginning of the fourth term of 2003 to the beginning of the first term of 2004, and who consented to participate.
- All therapists working at the study school in the abovementioned period who agreed to participate.

3f.ii. Exclusion criteria

- Parents of learners who were not required to comply with a therapy home programme in the study period.
- Parents and therapists who did not wish to participate.
- The researcher, who is a physiotherapist working at the school, was excluded from the study.

Participants were informed of their rights and interests in participating in the study and were required to sign a consent form in their own language. The purpose of the study and implications for them were explained. They were also informed that refusal to participate would in no way influence the future management of their child at the school (see Appendices A1 and A2).

Confidentiality and anonymity were ensured. The parents were asked to return their responses to the school with their child, who handed it in to a central person not involved in the study. The therapists also handed in their questionnaire responses to a central person not involved in the study.

3g. STUDY PERIOD

The study period was from October 2003 to January 2004. This timeframe ensured that compliance with term-based programmes, as well as with those given over long school holidays, was assessed in the study.

3h. INSTRUMENTATION AND METHODS OF DATA COLLECTION

The two questionnaires were developed by the researcher in consultation with a statistician. The questionnaires consisted of both structured and unstructured questions in order to collect quantitative and qualitative data. The content of the questionnaires is based on factors associated with compliance as reported in the literature (see Chapter Two), clinical hypotheses about associations, and the expected feasibility of ascertainment of information in questionnaire format (Cadman *et al.*, 1984).

In the author's opinion, specifically designed questionnaires would be the most appropriate measuring instrument to elicit relevant information in the specific environment of the study school.

Certain questions relating to parent involvement in the team and the parents' perceptions about the future potential of their child were adapted from a study by Bornman (1989) that investigated parent involvement in special schools. The scaling used in the Bornman (1989) study is also appropriate for this setting. All other questions were devised by the researcher, who made use of relevant literature to guide the development of the questionnaires.

In general, demographic data and quantitative questions were asked first, followed by open-ended, qualitative questions. This was done in order to allow the participants to become comfortable with the type of questions asked and to raise awareness levels about related issues before addressing more sensitive topics. This also ensured that adequate demographic and other quantitative data had been collected even if the participants did not complete the entire questionnaire. Unfortunately, some of the qualitative questions towards the end of the questionnaire were not answered comprehensively. This might be due to the fact that the participants grew tired of filling in the questionnaire.

3h.i. Piloting process and adjustments to methodology

The self-administered questionnaires were piloted on six parents and two of the school therapists who were not part of the sample population. This process assisted in highlighting questions that needed to be revised in the questionnaires. Feedback was gathered and adjustments were made as necessary. This mostly involved changing the sequence and wording of questions, and/or simplifying the Likert scales to make the questions easier to answer.

The problem of non-response became evident during the piloting process. Of the six parents who agreed telephonically to assist with the pilot study, only three returned their questionnaires. This highlighted the need for a better system of follow up and reminders in order to facilitate a better response rate. It was therefore decided

to send the questionnaires home with the children instead of mailing them, and to ask the class teachers to regularly remind the parents to return their questionnaires. Care was taken to remind the teachers that the parents were under no obligation to participate should they choose not to.

The adapted and finalised questionnaires were sent to the sample population in March 2004. The study participants were requested to return the questionnaires within one month of receiving them. Written reminders were also sent home in the child's school homework book.

Once the questionnaires had been collected and analysed, the author felt that more depth was needed in relation to some of the issues explored in order to increase insight into the parents' experiences and views. A semi-structured interviewing schedule of questions was used to explore some of these issues further (see Appendix E).

All the parents in the sample frame for the questionnaires were invited to participate in a focus group discussion. Nine parents indicated that they were willing to participate. Seven participants who could attend at the same time were selected. These participants represented a convenient sample and do not statistically represent the total study population. The results of the focus group discussion can therefore not be generalised to the whole study population. Consent forms were signed by the participants (see Appendix A3).

3h.ii. Questionnaire for parents

The parents' questionnaire was divided into five sections:

- **Section A** asked closed-ended questions about the child's age, family composition, socio-economic status, and the parents' perceptions of the severity of their child's disability, as well as their perception of the child's future potential in terms of employment and care-dependency. Likert scales were used for several of these items.

- **Section B** explored the type of home programmes given, how they were given, how often the parents were expected to perform them and how long it took to execute them, who was responsible for doing the programme, and whether the parents understood the reasons for and agreed with the programme given. Likert scales were used.

Sections A and B explored some of the factors highlighted in the literature as possibly affecting compliance. This information was used to seek correlations with the levels of compliance reported in Section C.

- **Section C** aimed to quantify the extent of actual compliance, using a table format. Compliance was rated on four levels, as shown in Table 1 below. The ratio of reported compliance to prescribed compliance was determined to give a percentage measure.

TABLE 1: SCALE USED FOR GRADING COMPLIANCE LEVELS

| Grading | Actual level of compliance |
|---------------------------------|-------------------------------------------------|
| Non-compliance | 0-24% compliance with programme as prescribed |
| Moderately non-compliant | 25-49% compliance with programme as prescribed |
| Moderately compliant | 50-74% compliance with programme as prescribed |
| Fully compliant | 75-100% compliance with programme as prescribed |

The scales were decided on in consultation with the therapists who designed the programmes on the basis of the extent to which they expected the parents to comply in order for the home programme to be effective. It was noted that the parents were often asked to do the home programme less often than would be ideal, as the therapists were aware of their difficulties in complying.

This implies that, at times, 100% compliance with the given programme is less than the ideal for optimal therapeutic gains for the child, but that the therapist has already taken barriers to compliance into account. Thus, expecting 100%

compliance with the programme as prescribed is not considered unreasonable by the therapist.

- **Section D** asked parents to identify factors that inhibit or facilitate compliance with home programmes in a combination of closed and open-ended questions. Parents were encouraged to identify as many factors as possible in order to elicit factors that the researcher and the literature had not yet identified.
- **Section E** attempted to elicit the parents' perceptions of the functioning of the rehabilitation team and their role in this team through a series of closed and open-ended questions. The literature points to the quality of the parent-professional relationship as an important indicator of compliance and it was felt that this should be explored in some depth in the light of the existing parent participation model. Parents were also asked to suggest ways to improve the current system.

3h.iii. Questionnaire for therapists

The therapists' questionnaire explored the following aspects in a series of 17 closed and open-ended questions:

- their demographics and experience in working with children and their families;
- their perceptions of the current functioning of the home programmes, how these home programmes are given to parents, the time spent in developing the programmes and perceived levels of compliance by the parents; and
- their perceptions of the current functioning of the rehabilitation team and parent-professional relationships, beliefs about parent involvement in the team and at decision-making levels, and barriers to working effectively with the parents. The therapists were also asked to make suggestions on how to improve the current system.

This information was required in order to compare the therapists' and parents' views on these issues and to identify strengths and weaknesses in the current system as experienced by both parties.

3h.iv. Focus group for parents

The issues explored in the focus group for the parents included their views on their role in the team, in decision-making and in goal-setting. The parents were also asked about past experiences of teamwork with professionals and how they envisaged practical arrangements for the future regarding training and parent support groups, for example (see Appendix E).

The answers were reviewed and common themes were sought.

3i. DATA ANALYSIS

The data were statistically analysed in consultation with a statistician. Quantitative data from the questionnaire for the parents were analysed using Pearson's chi-squared test to determine correlations between the extent of reported compliance and:

- demographic features of family, severity of the disability and type of home programme;
- parents' expectations and beliefs about their child's potential;
- parents' beliefs about the relevance and effectiveness of the rehabilitation process; and
- the quality of the parent-professional relationships.

Where categorical data analysis was not possible, an ANOVA was done (where the residuals were not normal). A bootstrap test was done on the ANOVA to see if there was a significant difference if the non-normality was taken into account and, lastly, a Kruskal-Wallis non-parametric ANOVA was done.

The results from the questionnaire for the therapists were analysed quantitatively using percentages to represent perceptions regarding:

- the current functioning of the rehabilitation team;
- the current usefulness of therapy home programmes;
- the quality of parent-professional relationships; and
- the level of compliance with home programmes.

Qualitative data from both questionnaires were coded into themes in order to seek statistical correlations and to highlight common themes.

The parents' and therapists' views were then compared and correlated where statistically possible.

The focus group responses were reviewed using content analysis, and common themes and individual stories are reported in Chapter Four.

3j. POTENTIAL BIAS

The potential for bias in measuring compliance is great and results should therefore be used with caution.

It is possible, and indeed likely, that those parents who responded to the questionnaire were those who are more compliant by nature, as participation in the study was not obligatory. This may skew the results towards higher compliance levels than are actually true.

Of importance too is the tendency of respondents to positively report on compliance. This is sometimes overcome in other trials by using objective testing measures (e.g. urine tests in assessing the use of medication) (Feinstein, 1976). However, these types of tests are not readily available in the rehabilitation field and the results are not necessarily only influenced by compliance.

The sample consisted of all families *currently* receiving a home programme. Parents who did not comply in the past may consequently no longer be given home programmes. Their relevant responses are thus excluded from the study (Sackett, 1976), skewing the results to positive reporting.

The focus group interview was arranged in an attempt to clarify some of the issues that were answered with inadequate depth in the questionnaires. A convenient sample was used in order to coordinate suitable times for the participants. Too few parents participated in the focus group for the results to have statistical significance, however

the qualitative data collected was still considered to be of value to the study. The participants were again those who were more motivated to be involved in the rehabilitation programme. Unfortunately, this study does not sufficiently reflect the views of the parents who were less than happy with the *status quo* and who were non-compliant.

The fact that the researcher was known to some respondents might also have influenced their responses.

3k. LIMITATIONS OF THE STUDY

The study was limited to one school and the results can therefore not be generalised to other settings. However, it was felt that it was more important to obtain population-specific information to motivate for relevant and practicable change within the study school, than to be able to generalise results.

The questionnaires and interview schedule have not been tested for reliability and validity.

3l. SUMMARY

A descriptive and analytical study was designed to be implemented in a school rehabilitation setting in order to measure levels of compliance with therapy home programmes and to identify factors that influence compliance. The results will be used to highlight strengths and weaknesses in the existing rehabilitation programme and to improve the programme.

All parents and therapists who received or issued home programmes during the study period were asked to participate. Measurement was done by means of two self-compiled, self-administered questionnaires.

Quantitative and qualitative data were analysed for correlations between compliance levels and factors affecting compliance. Common themes were identified in the qualitative data.

The potential bias and limitations of the study have been discussed. A focus group interview was set up in an attempt to increase the depth of responses in order to clarify some of the issues that were raised.

The results will be discussed in detail in Chapter Four.

CHAPTER FOUR

RESULTS AND DISCUSSION

4a. INTRODUCTION

This study aims to quantify the extent of compliance by parents with their child's therapy home programmes within a special education setting, and to determine the factors that parents and therapists identify as having an impact on this level of compliance.

The actual sample and its characteristics, and the results of the study, will be presented and discussed. The results will be presented according to the following list of stated study objectives:

- i. Demographic details of the sample;
- ii. The extent of compliance with therapy home programmes between October 2003 and January 2004 obtained from parent questionnaire responses;
- iii. Correlations between the extent of compliance and:
 - demographic features of the family, the severity of the disability, and the type of home programme;
 - parents' expectations and beliefs about their child's potential;
 - parents' beliefs about the effectiveness and relevance of the rehabilitation process; and
 - the quality of the parent-professional relationships as seen by the parents;
- iv. Other factors that parents may identify as inhibitors and/or facilitators of compliance; and
- v. The therapists' perceptions with regard to the effectiveness of home programmes, the functioning of the rehabilitation team and the parent-professional relationships, and a comparison of these with the parents' views.

The views of the parents and therapists will be presented and comparisons will be made.

4b. THE SAMPLE AND ITS CHARACTERISTICS

4b.i. Parents: questionnaire respondents

The therapists identified 85 learners and their parents who had received a home programme between October 2003 and January 2004. Of these, 61 parents returned their questionnaires. However, three of these were not completed as the parents said they were not aware of having received a home programme. (This will be discussed under 4c.iv.). The actual study sample comprised of fifty-eight respondents, representing a 68% response rate for the parent questionnaires.

A second questionnaire was returned by two sets of parents, as they received two separate programmes from different therapists during the study period. Some questions may therefore have a total of 60 recorded responses.

The results, which are presented as percentages, have been rounded off to whole number values. For this reason, some of the totals will not add up to exactly 100%. All the questions were not answered by all the participants so that, in other instances, the total numbers of responses may be less than 58 or 60. “N” the total number of respondents for each question in all tables and graphs as well as in the text, whereas “n” represents the number of responses to each option.

Because the questionnaires were administered anonymously, it is not possible to compare the characteristics of the non-respondent population with those of the respondents.

The demographic data of the parent respondent are summarised in Table 2.

TABLE 2: DEMOGRAPHIC DATA OF FAMILIES (N=58)

| DEMOGRAPHIC FEATURES | | | | | | | | | | | | |
|---------------------------------------|----------------------------|----------|----------------------------|------------|-----------------------------|----------|-------------------------------|-----------|----------|----------|-----------|----------|
| AGE OF LEARNER (years) | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 17 |
| % (no.) of responses | 10 (6) | 5 (3) | 5 (3) | 19 (11) | 9 (5) | 7 (4) | 7 (4) | 14 (8) | 9 (5) | 2 (1) | 12 (7) | 2 (1) |
| GENDER OF LEARNER | MALE | | | | | | FEMALE | | | | | |
| % (no.) of responses | 64 (37) | | | | | | 36 (21) | | | | | |
| NO. OF CHILDREN IN FAMILY | 1 | | 2 | | 3 | | 4 | | | | | |
| % (no.) of responses | 12 (7) | | 48 (28) | | 29 (17) | | 10 (6) | | | | | |
| MARITAL STATUS | MARRIED PARENTS | | | | | | SINGLE PARENT | | | | | |
| % (no.) of responses | 79 (46) | | | | | | 21 (12) | | | | | |
| PARENTS’ EMPLOYMENT STATUS | FATHER EMPLOYED ONLY | | MOTHER EMPLOYED ONLY | | BOTH PARENTS EMPLOYED | | BOTH PARENTS UNEMPLOYED | | | | | |
| % (no.) of responses | 34 (20) | | 7 (4) | | 53 (31) | | 5 (3) | | | | | |
| FAMILY INCOME PER MONTH (N=55*) | R0- R2 499 | | R2 500- R4 999 | | R5 000- R9 999 | | R10 000- R19 999 | | R20 000+ | | | |
| % (no.) of responses | 16 (9) | | 24 (13) | | 29 (16) | | 16 (9) | | 15 (8) | | | |

* Three respondents chose not to answer this question

A relatively high proportion of learners in the sample were male in relation to the proportion of males in the general population (Census 2001). This closely represents the population of the school as a whole. In the total school population, the percentage of boys is 71% while that of girls is 29%. This reflects the higher incidence of specific learning disabilities, Attention Deficit/Hyperactivity Disorder, and muscular dystrophy in boys described in the literature (Serfontein, 1990; Silver, 1999).

Table 2 shows that 60% (n=33) of the parents have an income in excess of R5 000 per month. More than half of the study sample therefore falls within the top 2 million people in the country, who earn more than R3 201 per month (Census 2001). This is an indication that these families are financially relatively well resourced in the South African context. A consequence is that these families might have better access to assistance with their daily responsibilities (e.g. domestic help, personal assistance for children) than the general population of South Africa. However, in 53% (n=31) of cases, both parents work to maintain these income levels. This, in turn, might impact on the time that they have available for additional activities, such as a therapy home programme. Parents may both need to work in order to cope with the additional financial demands placed on families with a disabled member.

4b.ii. Parents: focus group participants

Only five parents participated in the focus group discussion, which aimed to elicit more detail from the parents about their experiences of teamwork with the therapists in the school. Initially nine parents indicated that they would like to participate in the focus group, but only seven could attend at the same time. A further two did not participate as one did not arrive for the group and one telephoned to cancel on the day. The demographic data obtained from the five remaining participants are summarised below:

Participant 1: Mother of a 16-year-old learner with cerebral palsy, who is in the work preparation/ life skills class. He is the youngest of three boys. His father died a year ago. He has attended the school for eight years. He was given a physiotherapy home programme.

Participant 2: Mother of a 7-year-old boy in Grade 2. He is the younger of two boys. He has attended the school for four years and was given a physiotherapy home programme.

Participant 3: The grandmother of a 13-year-old girl who has attended the school for one year and has spastic quadriplegia. The girl uses a motorised wheelchair, has physical and intellectual impairments and is in the practical stream. She was asked to do a physiotherapy home programme. The participant is the child's primary caregiver.

Participant 4: The grandfather of an 8-year-old learner who has a spinal cord injury and uses a wheelchair. The learner is currently in Grade 2. She lives with both grandparents and her two older brothers. She too was given a physiotherapy home programme. The participant's 37-year-old daughter also lives with them. She has a severe physical and intellectual disability and is only able to walk short distances. The participant is currently a member of the School Governing Body and is the child's primary caregiver.

Participant 5: The mother of a 9-year-old learner who is physically and intellectually impaired and uses a wheelchair. The boy has cerebral palsy. He lives with both parents and an older sister. He has attended the school for five years in the practical stream. He had a physiotherapy home programme to do.

All the participants were available during the morning and therefore are not employed full time. They represent a group of parents who are actively involved in the school. All expressed a high level of satisfaction with the school rehabilitation programme and reported a high degree of motivation for home programmes. The views of dissatisfied parents were therefore not represented.

All the participants had received only physiotherapy home programmes during the study period, and the sample is therefore skewed towards this type of home programme and teamwork. However, their children had all received more than one type of therapy at some time since they had joined the school. The participants were thus able to refer to teamwork with the other therapy disciplines as well.

Three of the five participants have children who are in the school's practical/life skills stream and no longer follow the mainstream academic curriculum.

The participants' responses have been integrated into the discussion under 4c.

4b.iii. Therapists

Only thirteen of the fourteen therapists working at the study school were asked to participate in the study, because the researcher did not participate in the study. Nine completed questionnaires were received. This represents a 69% response rate for therapist questionnaires.

Table 3 shows the distribution of the different therapy professions in the school and the respondents from each group.

TABLE 3: DISTRIBUTION OF PROFESSIONS

| | Education- al psycho- logy | Occupational therapy | Physio- therapy | Speech and language therapy | Learning support |
|-------------------------------------------------------------------------|-------------------------------------------|---------------------------------|----------------------------|--------------------------------------------|-----------------------------|
| No. of therapists employed at school during study period | 2 | 3 | 5 | 3 | 1 |
| No. of therapists who replied to the questionnaires | 2 | 1 | 3 | 3 | 0 |

All the educational psychologists and speech and language therapists completed and returned the questionnaires. One of the physiotherapists left the school during the study period, and one was the researcher, who was excluded from the study. Thus all the physiotherapists who were able to do so completed the questionnaire.

The occupational therapists reported that they did not generally make use of home programmes. They were, however, encouraged to participate by only answering questions they were able to in order to get their feedback on teamwork issues.

Nevertheless, two still chose not to participate. The learning support educator also did not complete a questionnaire for the same reasons.

It seems that the professions who rely more on parents to implement home programmes had a greater interest in the study topic and its impact on the quality of teamwork with the parents. These therapists would therefore be the most likely catalysts in future change.

Table 4 shows the level of clinical experience of the therapist respondents in terms of the number of years that they have been working at the study school and the number of years they have worked with children and their families.

TABLE 4: THERAPISTS' CLINICAL EXPERIENCE IN THE PAEDIATRIC REHABILITATION FIELD (N=9)

| | 1- 5 years | 6-10 years | 11-15 years | 16+ years |
|-------------------------------------------------|-------------------|-------------------|--------------------|------------------|
| Working with children and their families | 1 therapist | 1 therapist | 3 therapists | 4 therapists |
| Employed at the study school | 2 therapists | 2 therapists | 1 therapist | 4 therapists |

These results show a high degree of experience, as seven of the nine respondents have worked in the field for more than 10 years. This may indicate a high level of skill and expertise, although this cannot be assumed, as years of service do not necessarily mean that one has kept abreast of new developments. However, evidence of continued education, as can be seen in this population, strengthens the assumption. The physiotherapists attend regular monthly combined orthopaedic and medical meetings, and all have specialised in neurodevelopmental therapy (NDT). Of the school's occupational therapists two are NDT-trained and two are trained in Sensory Integration theory and practice. Two of the speech therapists are NDT-trained. The psychologists attend regular educational meetings that present feedback from recent research.

The recent introduction of compulsory Continuing Professional Development regulations by the Health Professions' Council of South Africa for all therapists requires that therapists attend courses and further learning opportunities more regularly than some may have done previously. This has facilitated more flexibility

from the school management, allowing the therapists time off work to attend such events. The extent to which these educational experiences impact on actual practice in the school environment would need to be ascertained in a study of its own.

The long periods of employment at the study school may impact on the process of change, as the staff may have become entrenched in the current way of doing things and may be resistant to change.

4c. PRESENTATION OF RESULTS

4c.i. The extent of compliance with home programmes

The parents were asked to identify how often they were *expected* to do, and how often they *actually* did, the home programmes that were prescribed during the study period. Their responses were then converted to percentages in order to quantify their levels of compliance (i.e. reported actual compliance/expected compliance).

Several respondents complied to different elements within the given home programme (e.g. putting on splints, and writing/drawing activities) to different extents. The median value of each respondent's values was therefore calculated to give an overall compliance level for each respondent.

These percentages were grouped into four categories, as shown in Table 5.

TABLE 5: CATEGORIES FOR LEVELS OF COMPLIANCE

| Level | Grading | Actual level of compliance |
|--------------|--------------------------|-------------------------------------------------|
| 1 | Non-compliance | 0-24% compliance with programme as prescribed |
| 2 | Moderately non-compliant | 25-49% compliance with programme as prescribed |
| 3 | Moderately compliant | 50-74% compliance with programme as prescribed |
| 4 | Fully compliant | 75-100% compliance with programme as prescribed |

Figure 1 shows the reported actual compliance according to these categories.

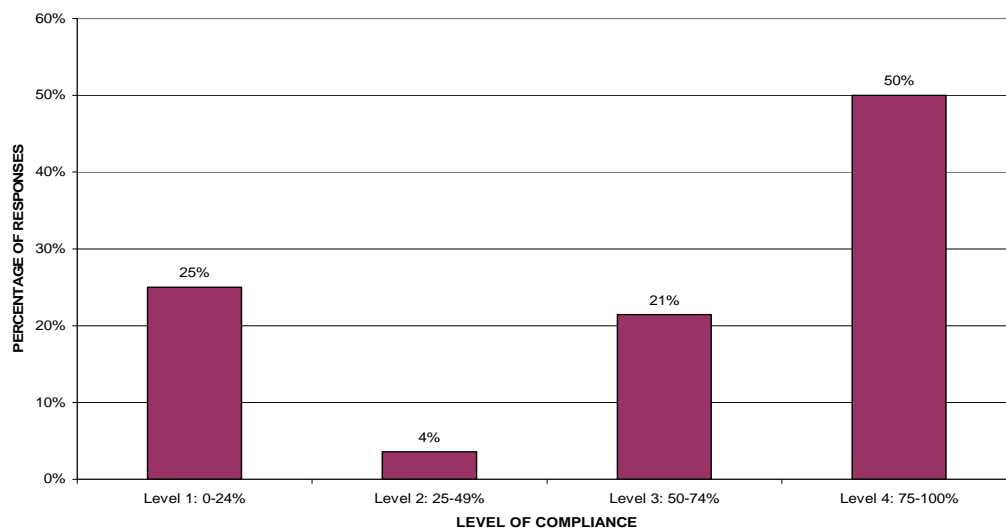


FIGURE 1: ACTUAL COMPLIANCE LEVELS REPORTED BY THE PARENTS (N=58)

- The combined data for “total compliance” and “moderate compliance” represent 71% of the programmes. These two groups complied adequately with the whole or part of programmes to have therapeutic benefit.

As already discussed in Chapter Three (page 32), the potential for bias in measuring compliance is high and the results should therefore be interpreted with care. The tendency is for positive compliance to be overrepresented. This could well be the case with these results. However, the measure of “total compliance”, at 50%, is consistent with measurements of compliance with long-term interventions, rehabilitation programmes and preventative regimens in the existing literature (Sackett, 1976).

- Parents reported “total non-compliance” with 25% of programmes. This is relatively high and has serious implications for the allocation of resources for the planning and prescription of home programmes. In order to ensure that the team functions optimally and achieves the best outcome for the child and family, changes may be necessary to:
 - the content of the home programmes themselves; or to

- the way these programmes are handed to parents (education, training, follow up and support mechanisms for parents); or to
- the way in and extent to which parents are involved in the process of designing relevant and appropriate programmes for their child and family circumstances.

Factors influencing compliance, as identified by the parents and therapists, are discussed in detail in this chapter. Compliance may be improved by addressing some of these by means of minor practical changes. Other barriers may require changes to the current structure of team meetings, working hours and daily work schedules in order to effectively include all team members and achieve optimal outcomes for the learner, the family and the professionals.

Other barriers will only be overcome by attitudinal changes from both the parents and therapists with regard to their roles and responsibilities in the team, allowing for the creation of an environment suitable for open sharing of information and skills. This will require a more appropriate teamwork model that facilitates closer collaboration, mutual respect and negotiation. Such an approach may demand increased creativity from the team members in order to work around barriers to design practicable and effective programmes that meet the needs of all the parties (Bazyk, 1989).

A comparison of the therapists' perceptions of compliance and the compliance levels reported by the parents is shown in Figure 2.

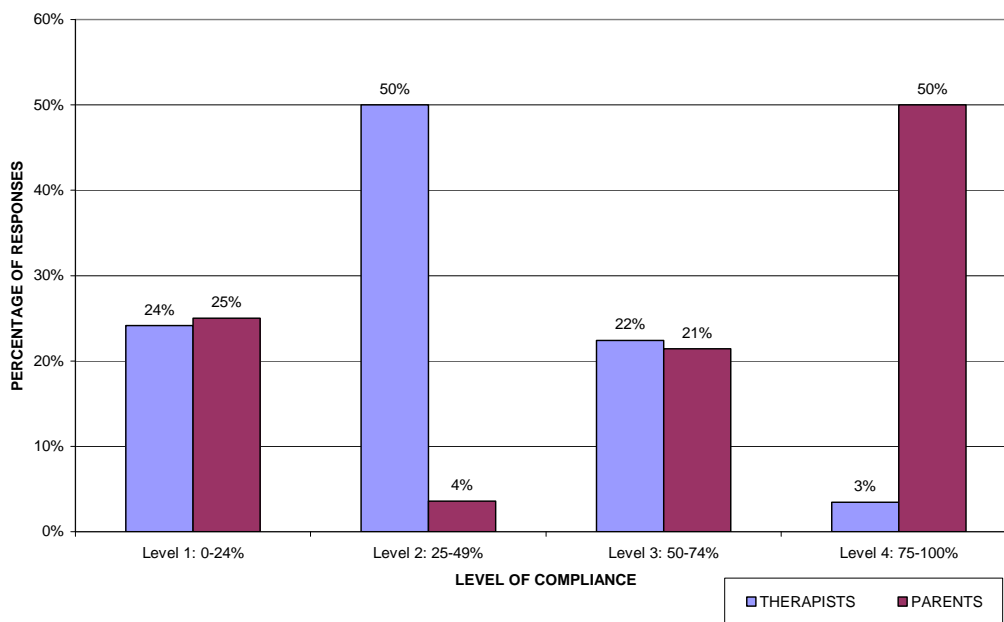


FIGURE 2: COMPLIANCE LEVELS REPORTED BY THE PARENTS VS LEVELS EXPECTED BY THE THERAPISTS

- The therapists estimated that 74% of the home programmes were inadequately complied with to have therapeutic benefit, while the parents reported only 29% in this category. The therapists assumed that only 25% of the programmes were moderately or fully complied with (i.e. 50-100% of the requested level), while parents reported 71% in this category. It appears that the therapists generally assume that home programmes are complied with less than the parents reported actually complying with them.

This clearly shows the perception that currently exists among therapists that the home programmes are poorly complied with. As discussed in Chapter One (page 3), this perception is based on an appreciable deterioration in the physical condition of many learners after long school holidays, and/or a lack of expected improvement, and/or direct reports from the child or parent that the home programme was not followed.

Therefore, if one accepts the parents' responses as an accurate reflection of actual compliance (despite potential bias in data as previously discussed), one must begin to explore other reasons why the benefits of the home programmes

do not show in the learners' progress. It might be that the parents are indeed complying with the programmes, but are carrying out the programmes incorrectly. This highlights a need for training and follow up by the therapists to improve the quality of inputs.

Alternatively, the programmes might be ineffective and the therapists may need to critically review and revise their design and prescription.

There are also cases where the natural history of the learner's condition will lead to deterioration in functional skills. Obvious examples are progressive conditions, such as Duchenne's muscular dystrophy. Less obviously, in the case of some learners with cerebral palsy, the ratio between muscle strength and gains in height and weight is held in a fine balance. This may result in functional regression at some stages as the biomechanics of the child's body change and different degrees of strength are required in order to maintain function, e.g. walking. In these cases, a maintenance programme that may have been effective for years may no longer be effective, and an increase in active therapy might be necessary. For these children, home programmes should be reviewed frequently and adapted as required. Therapists are trained to recognise these changing needs of the child but, in practice, may not always change the programme regularly enough. Furthermore as the purpose of the study was to assess compliance with rather than effectiveness of home programmes, the inclusion of these groups should not bias results.

It must be remembered that the therapists gave an overall rating for *all* potential respondents on the sample frame. The parents' responses represent only 68% of these potential respondents and possibly the more compliant of the total potential sample. Thus, the parent responses are possibly an overestimate of actual compliance for the whole study population, as discussed previously. However, the therapists must guard against negative assumptions, which may influence the parent-professional relationship. Ascribing the failure of the programmes to parental non-compliance might be an easy answer, but this may not always be the correct assumption or do justice to the complexity of the problem. Some of the other issues affecting compliance will be discussed in more detail in this chapter.

Parents were also asked to indicate how much they complied with their child's daily academic homework. The results are shown in Figure 3.

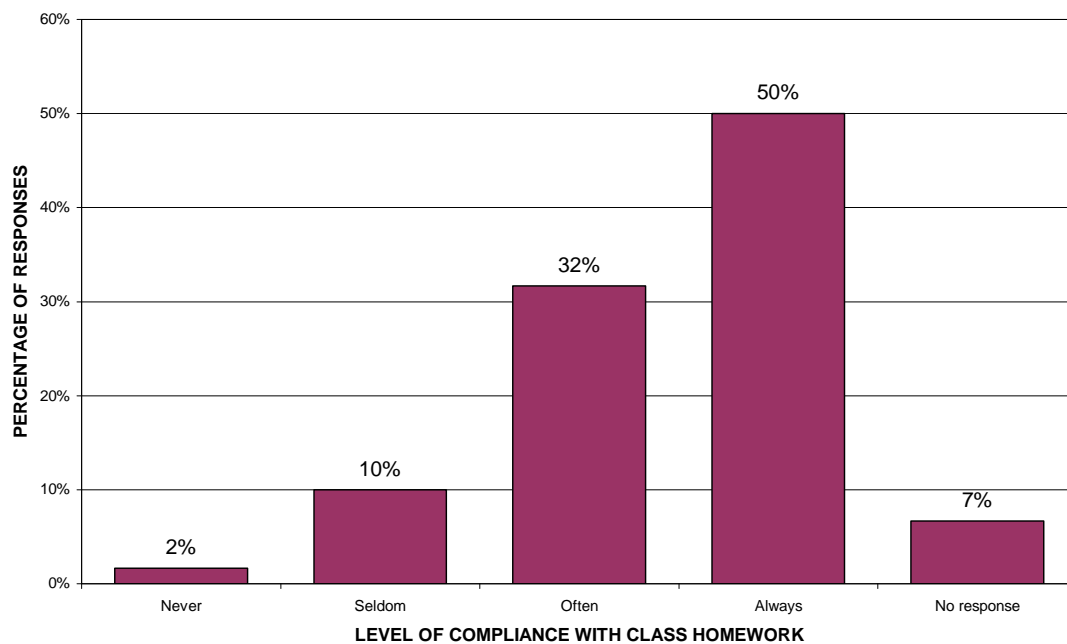


FIGURE 3: REPORTED LEVELS OF COMPLIANCE WITH ACADEMIC HOMEWORK BY PARENTS (N=58)

- The responses in Figure 3 reveal a notable difference between compliance with therapy home programmes and with academic homework. Half of the parents “always” complied with homework given and 32% (n=19) complied “often”. Only 12% (n=7) of the parents reported complying with class homework “seldom” or “never”, in contrast to the 29% of therapy home programmes that were not adequately complied with to have any therapeutic benefit (see Figure 1, page 42). It appears that the parents do not attribute the same importance to therapy home programmes as they do to the academic homework. This may reveal a lack of insight into the impact of therapy inputs on classroom outputs, and further education through structured activities or more collaborative teamwork between the parents and therapists may be required.

4c.ii. Correlations between compliance and contextual factors

Categorical data were analysed using Pearson's chi-squared test to determine correlations between the extent of reported compliance and:

- the demographic features of the family, the severity of the disability and the type of home programme;
- the parents' expectations and beliefs about their child's potential;
- the parents' beliefs about the effectiveness and relevance of the rehabilitation process; and
- the quality of the parent-professional relationship as viewed by the parents.

Where categorical data analysis was not possible, an ANOVA was done (where the residuals were not normal). A bootstrap test was done on the ANOVA to see if there was a significant difference if the non-normality was taken into account and, lastly, a Kruskal-Wallis non-parametric ANOVA was done.

- All the tests had p-values much larger than 0.05, indicating statistical non-significance.

This result reflects the literature reviewed with regard to the characteristics of the specific child, disability, family or type of recommendation. Attempts to correlate these factors with compliance levels proved inconsistent and inconclusive (see Chapter Two, page 10). However, in the literature, compliance was found to be significantly associated with parental beliefs about the efficacy of the rehabilitation programme as a whole, their relationship with the professional involved, and their belief in their own capability and role in implementing the recommendations (Cadman *et al.*, 1984; Becker *et al.*, 1972). These factors did not emerge as statistically significant in this study, possibly due to inadequate depth in the questionnaire items, or to an apparent lack of awareness among the parents of their role and rights within the parent-therapist relationship.

Despite this, much interesting information was obtained, as is clear from the following discussion.

Figure 4 shows the distribution of types of home programmes prescribed.

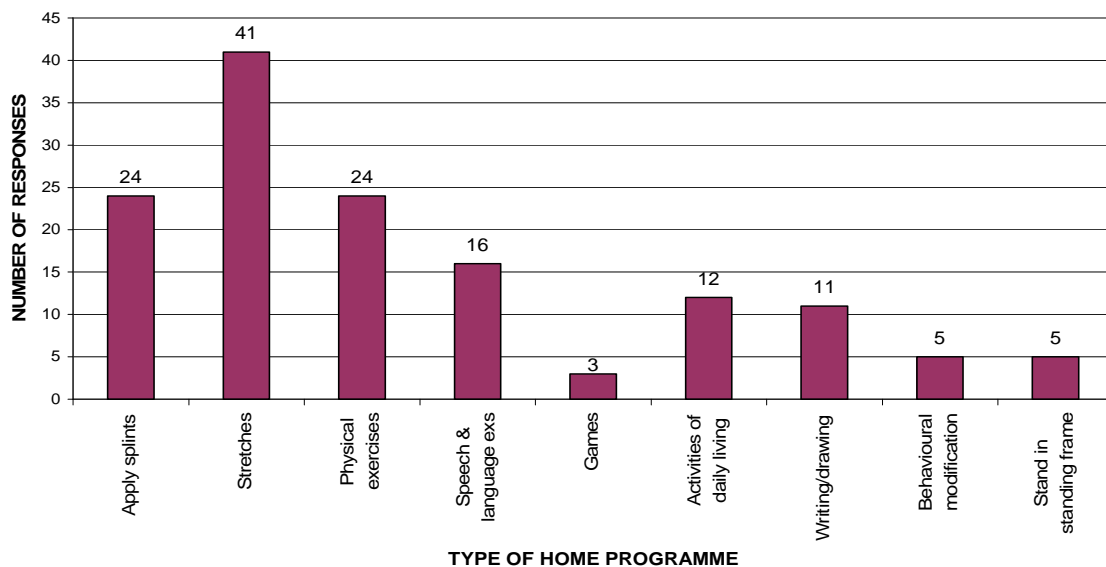


FIGURE 4: DISTRIBUTION OF TYPES OF HOME PROGRAMMES PRESCRIBED (N=60)

- The data provided above show that the vast majority of home programmes include stretches, the application of splints and physical exercises (63%; n=89). The other programme most commonly given was speech and language exercises.

Most of these require a certain amount of technique and skill to be implemented correctly. Specific training in these types of activities must be given to parents to ensure that the exercises are done effectively.

Figure 5 compares the levels of compliance with the different types of home programmes.

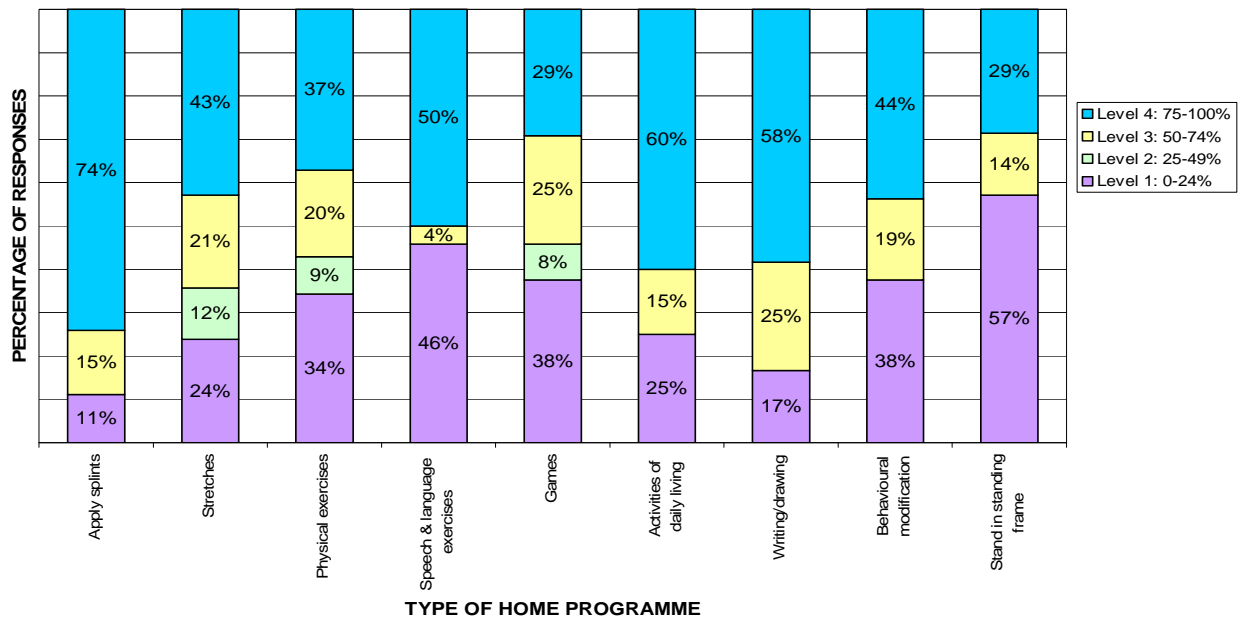


FIGURE 5: RELATIVE COMPLIANCE WITH DIFFERENT TYPES OF HOME PROGRAMMES (N=60)

The following programme types were more frequently complied with at levels adequate to achieve therapeutic benefit:

- applying splints (89% of programmes);
- writing/drawing activities (83% of programmes);
- activities of daily living (75% of programmes);
- stretches (64% of programmes); and
- behavioural modification (62% of programmes).

Most of these are programme types that integrate easily into the child and family's daily routine, e.g. putting on splints while dressing, writing/drawing while doing class homework, behavioural modification throughout the day, and activities of daily living which are, by nature, integrated. Stretch exercises generally are quick and simple to do. Conversely, those programmes which may be more disruptive in the regular family routine e.g. standing with braces were complied with to a lesser extent.

The relatively high compliance levels with easily integrated activities present a strong case for careful sharing of information, negotiation and planning when

designing a home programme so that the programme can be most effectively integrated into the rest of the family's daily routine, making compliance easier, with minimal disruption.

Interestingly, only 54% of the programmes containing games were adequately complied with, despite one parent having identified making the programme “as fun as possible” as a facilitator in the qualitative data. Perhaps the games prescribed are not really fun for the child and are rather perceived as difficult and therefore as work. Repetition of a “game” reduces enjoyment. Parents may also not have time or energy for games at the end of a day. The parents and therapists need to decide together what is practical for the home environment.

When asked about their beliefs regarding the potential and future of their child, the parents gave the responses shown in Figure 6.

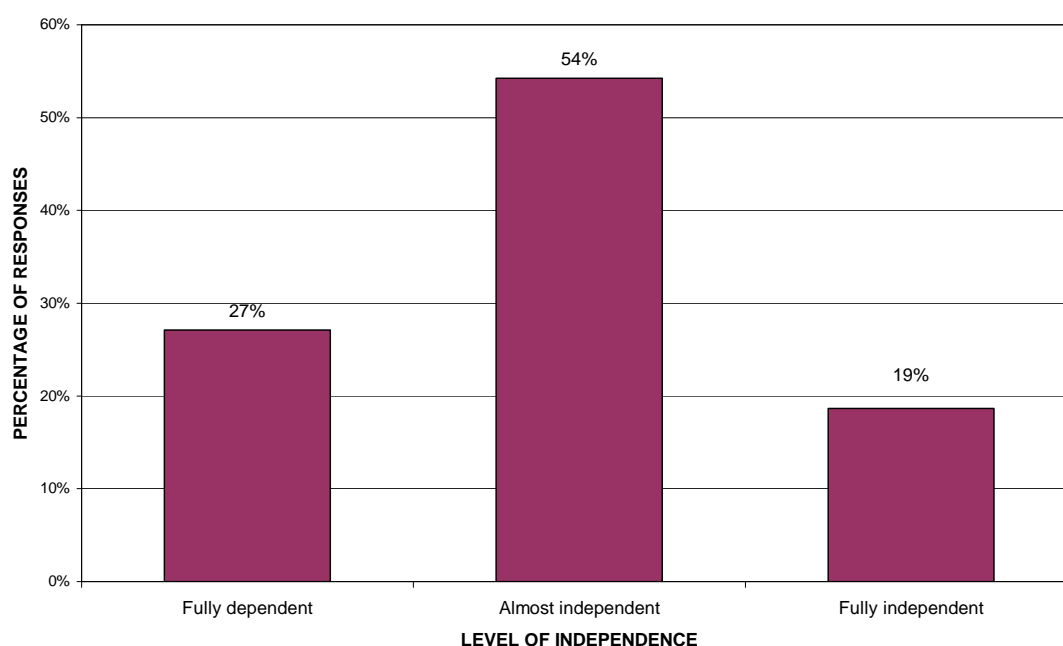


FIGURE 6: PARENTS' VIEWS ON THEIR CHILD'S FUTURE LEVEL OF INDEPENDENCE (N=58)

- Most parents (54%; n=31) said they believed their child would be almost completely independent as an adult, needing only minimal assistance.
- Complete independence was predicted for only 19% (n=11) of the learners.

- Full dependence, either in institutional care or cared for by parents and family members, was predicted for 27% (n=16) of the learners.

The parents were also asked to indicate what type of work they anticipated for their child as an adult. The results are shown in Figure 7.

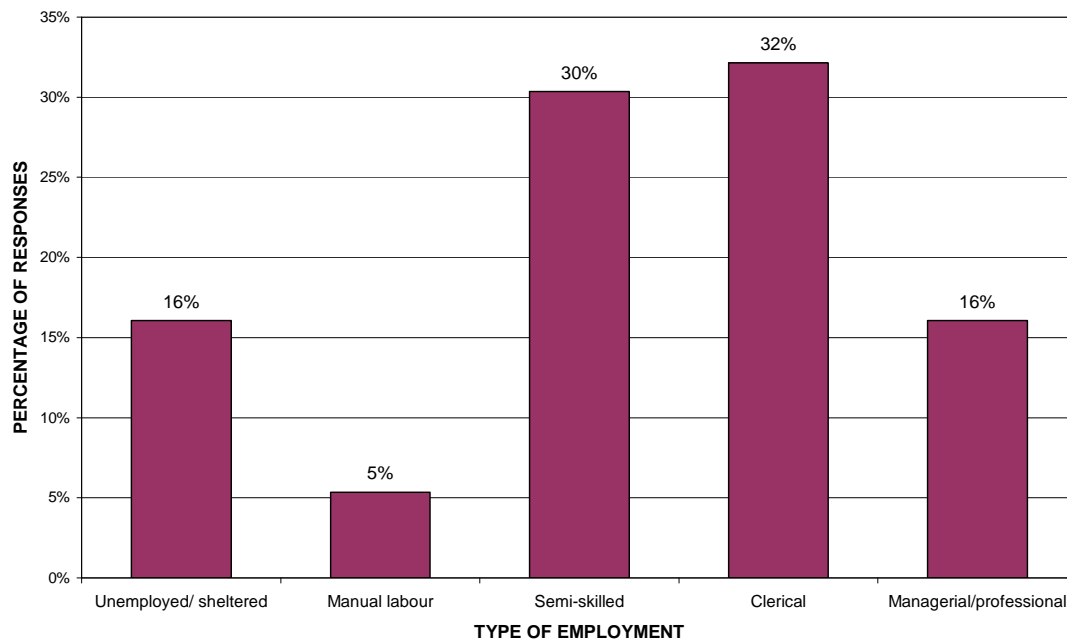


FIGURE 7: TYPE OF EMPLOYMENT ANTICIPATED BY PARENTS FOR THEIR CHILD IN THE FUTURE (N=58)

- The vast majority of parents anticipate that their child will be employed in professional/managerial, clerical or skilled labour/technical positions (78%; n=45), and that their child will be able to live almost or fully independently (73%; n=42) in the future. The parents therefore anticipate a good outcome for their child in terms of community integration and productive living. Attempts to correlate these beliefs with the reported levels of compliance with therapy home programmes did not reveal any statistical significance in this study. However, according to the literature, there is a positive relationship between positive expectations and positive compliance levels (Gilbride, 1993).

The parents responded as follows when asked about their beliefs about the rehabilitation process:

- Almost all the parents (97%; n=56) said that they believed that the home programme was relevant to their child's needs, and all the parents said they understood the purpose of the programme.
- Most of the parents (75%; n=43) said they felt their child's therapy made a "very positive difference" to their child's and their quality of life, while 25% (n=14) said that it made a "slightly positive difference".

It therefore seems that barriers other than parental beliefs about the relevance and importance of the programme must play a role in compliance with the home programmes. (These barriers will be discussed in depth under 4c.iii. on page 58.)

Figure 8 shows the qualitative responses by the parents when asked about their experience of the teamwork and how they perceived their current role in the team.

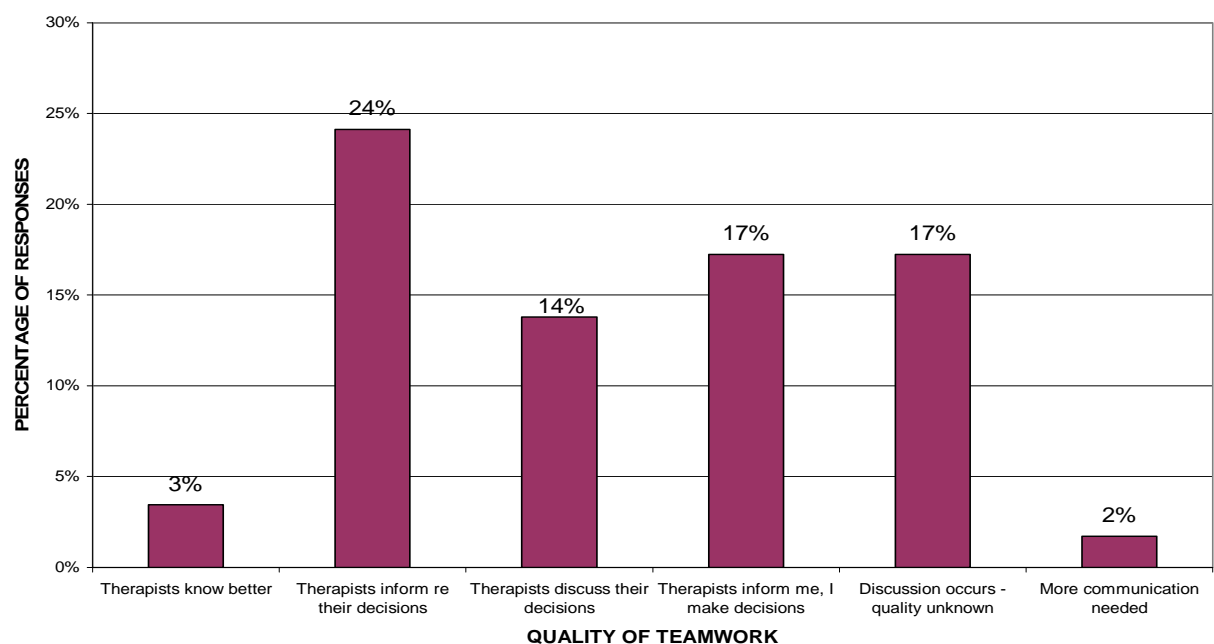


FIGURE 8: PARENTS' FEELINGS ABOUT THEIR ROLE IN THE REHABILITATION TEAM (N=58)

- Only two parents (3%) were willing to abdicate responsibility for decision-making to the therapists, as they felt that the therapists were more qualified to

make these decisions and that they “know better”. Just one parent said he/she did not see him/herself as part of the team and was happy with this.

It is encouraging that parents who feel like this are few in number, but interesting to note that both reported having contact with the therapists once a term. With the new policy requiring parents to be involved at a decision-making level (Integrated National Disability Strategy, 1997), the need to empower parents to recognise the unique contribution they can and must make to their child’s rehabilitation process, through the team structure, is highlighted.

- The largest group of parents (24%; n=14) said their role in the team was limited to being informed about decisions which had been made by the professional team. Parents therefore had little or no input in these decisions, although they were always kept abreast of events and plans. This implies that they are not active members of the team, but rather passive recipients of the prescribed treatment. Nevertheless, only four of these 14 parents said they did not feel part of the team.

This again highlights the need to empower parents to assume their role in the team and to become actively involved in the planning, goal-setting and decision-making regarding their child. The therapists and school staff will have to effect a significant change in thinking and teamwork styles in order to create an environment in which parents feel responsible and free to contribute at all levels of planning and implementation.

- Another group of parents (14%; n=8) felt that the therapists were always willing to discuss the decisions that had been made by the professional team with them. All these parents felt included as a team member.

As previously discussed, this level of involvement by the parents remains inadequate to achieve effective family-centred teamwork. An enabling environment needs to be created within the school and the rehabilitation team

to allow and motivate the parents to be more actively involved. Parents also need to be encouraged to assume their full rights and responsibilities as team members.

- Ten parents (17%) said that the therapists informed them about options and possibilities and that it was their role as parents to make the final decision. These parents also all indicated that they felt they were part of the team.

These parents seem to be the only group who are working within the collaborative/family-centred model. The group, although quite small, at least indicates that there are some parents and therapists who have understood and effectively implemented this model. It may be helpful to identify these individuals and have them participate in the parent-empowerment process.

- Only one parent directly indicated a need for more communication so that teamwork could improve, saying that he/she did not feel part of the team.
- Other parents (17%; n=10) reported that there was discussion about their child's rehabilitation. However, it was not possible to group these responses into one of the previous categories, as the quality of this discussion was not clear from the qualitative responses.

These results show a dire lack of parental empowerment in the current system. Although seventy-six percent (n=44) of parents felt they were part of the team making decisions about their child's rehabilitation and future, it appears that the quality of this teamwork is, on the whole, heavily influenced by the traditional medical model power relationships between therapists and parents. Even though most parents said they felt included, a closer analysis revealed underlying dissatisfaction with the *status quo*.

A large proportion of the sample said that, despite decisions being made about their child without their input, they were satisfied with this situation. This type of attitude contributes to parental non-involvement and the therapists' perceptions that the parents want to hand over responsibility for their child's rehabilitation to the school

instead of fully taking up their own role in the process. These issues were explored further in the focus group session.

- All five focus group participants said that the therapists were trained and “know best”. They said that the therapists are able to be more objective and realistic about the learner’s potential and therefore are more suited to making decisions about the learner. The parents expressed that they always want to get the best out of the child, and need to encourage the child, and that this clashed with their ability to make decisions objectively.

However, both participants 2 and 3 gave examples of medical doctors having predicted poor prognoses for their children. In both cases, the parents had done their utmost to prove the doctors wrong and had been successful. Thus, these parents played an important role in achieving optimal function for their child, despite the recommendations made by professionals.

- All the parents in the focus group agreed that their role in the team was to support the therapists in their work by doing the home programme regularly, by motivating the child to do the programme, and by giving feedback to the therapists on what works and what does not work. Participant 4 said that he saw it as his responsibility to work with the therapist, otherwise the child would be disadvantaged. He also felt it was more feasible to do certain parts of the programme at home than at school and that this extra input could consolidate what was done in therapy at school.
- Participants 1, 2, 3 and 4 stressed the importance of their role in integrating the child into their community, teaching life skills for coping in society, and encouraging independence. They felt they often needed practical or other advice and information from the therapists in order to do this. This information helped them gain insight into their child’s condition, and on how to handle their child emotionally and practically.

In particular, participant 4 contrasted his experiences of working with his 37-year old daughter with a physical disability without the support of a team of professionals, with his more recent experience of working with a team to meet the needs of his disabled granddaughter. He explained that this availability of information, advice, sharing of ideas and provision of exercises had made a very positive difference to their ability to cope with their granddaughter's disability.

These five parents/guardians seem to have a good idea of the contribution they can make to the team, but still see this as subject to decisions that are ultimately made by the professionals. They do not seem to see their role as being of equal importance and value as that of the therapists.

Appropriate changes will therefore need to be implemented, by both the therapists and the parents, in order to create an environment in which the parents and the therapists recognise the important role of each team member and can appropriately exercise (and limit) their rights and responsibilities within the team.

The amount of contact between parents and therapists is further proof that the parents are not an integral part of the team. Most parents (53%; n=31) reported speaking to their child's therapist once a term. Other results can be seen in Figure 9.

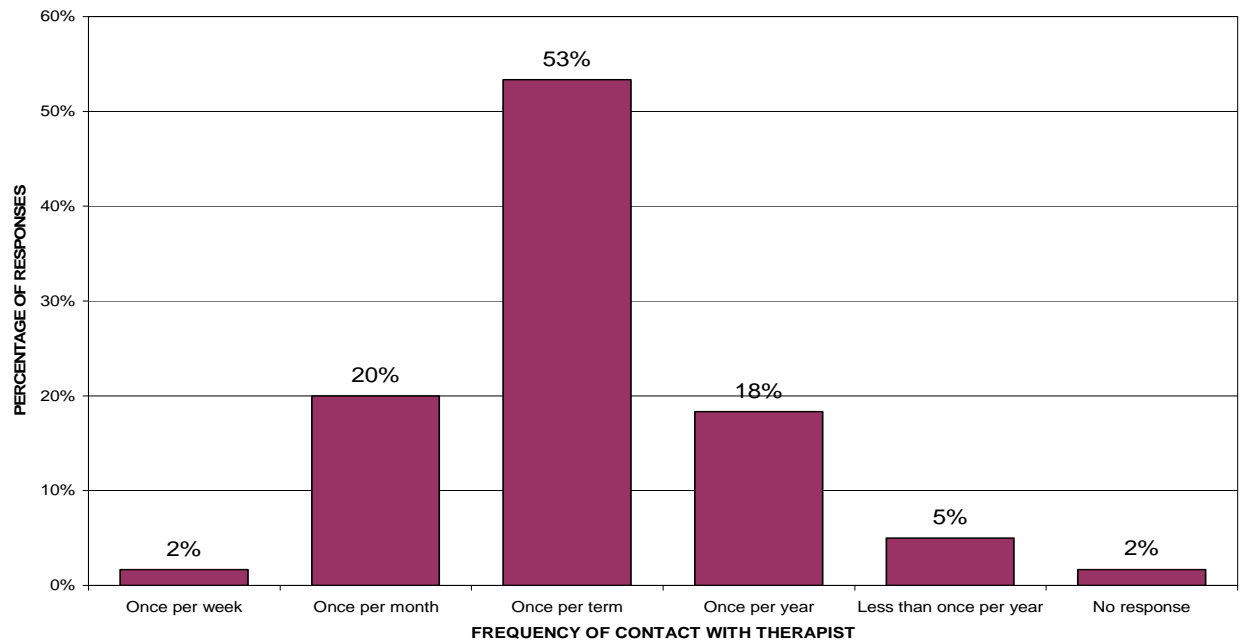


FIGURE 9: REPORTED FREQUENCY OF CONTACT WITH CHILD'S THERAPIST (N=58)

All the parents are personally invited to a parent-therapist meeting at least once a year. It should therefore be queried why some parents said they speak to the therapists less than this (5%; n=3). It may be that the parents were not able to attend a meeting within the specified time period. If this is indeed the case, one would expect the parent to request a meeting at a time that would suit him/her. It might be necessary for the therapists to be available after school hours in order to facilitate contact with these parents should they request this. Another reason might be that parents choose not to attend. According to the therapists' experience, many parents do not utilise this annual opportunity to discuss their child's progress. The therapists may need to look critically at the quality of this contact time. It may be that the parents have not found it worthwhile in the past and therefore do not feel they want to attend again. However, this 5% might represent a few parents who are really not interested.

All the parents gave positive feedback about the therapists' personality traits, indicating a high level of satisfaction with the quality of the staff employed at the school. Terms identified consistently were "approachable", "caring", "polite", "friendly", "open", "capable" and "professional". No parents marked any of the

negative options in the questionnaire. This response could have been biased by parents' fear of anonymity being breached.

All the focus group participants also indicated a high level of satisfaction with and trust in the therapists working with their children.

In the questionnaire, the parents were asked to indicate how they experience their current level of involvement in their child's therapy (N=60).

- Twenty-six parents (43%) said that they would like to be "much more involved" in their *child's therapy*, seven parents (12%) said they would like to be a "bit more involved", while 27 parents (45%) said they felt their current level of involvement was "just right". No parents indicated wanting to be less involved.
- When asked about being more involved in *making decisions* about their child's therapy and future, the parents' responses were equally split, with half wanting to be more involved and half not wanting this.

Although this was surprising, these two sets of results seem to be closely linked and confirm each other. About half of the parents reported being happy with the system as is, while approximately half felt that they wanted to be more integrally involved in the functioning of the rehabilitation team.

The above findings are interesting when compared with the following results:

- It is encouraging that forty-four parents (76%) felt they were *part of the team* that makes decisions about their child's future and therapy, while 10 parents (17%) said they did not feel part of the team.

If one assumes that the 17% of parents who felt they were not part of the team had said they wanted to be more involved, this still leaves approximately 35% of parents who have said they feel they are part of the team but are somewhat dissatisfied with their level of involvement at present.

It is clear that the quality of teamwork between the therapists and the parents needs to be addressed.

4c.iii. Contextual factors identified by parents as facilitators of and/or inhibitors to compliance

Factors identified by the parents as inhibitors to compliance from the quantitative data are shown in Figure 10.

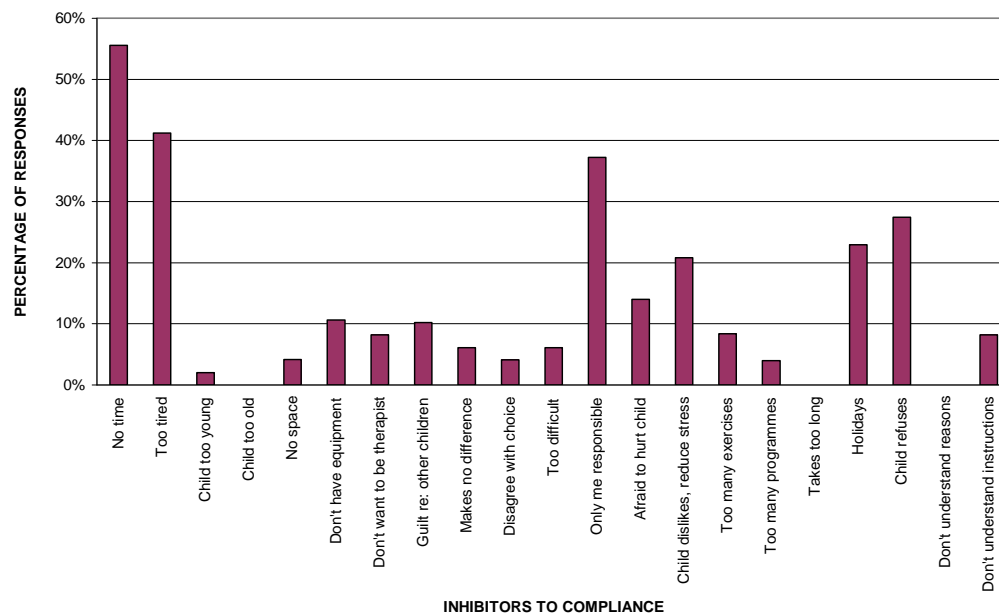


FIGURE 10: INHIBITORS TO COMPLIANCE WITH HOME PROGRAMMES AS IDENTIFIED BY THE PARENTS (N=51)

- Most parents identified a lack of time in their daily schedules for home programmes (56%; n=29) as inhibitors to compliance.

Other inhibitors that were frequently identified and are time related were:

- being too tired to do the home programme at the end of a day (41%; n=21), and/or
- having no-one with whom to share the load of doing the home programme (37%; n=19).

“Lack of time” is listed as the most common inhibitor to compliance, closely reflecting the literature reviewed in Chapter Two (Bazyk, 1989; McConkey, 1985). In 82% (n=49) of families, the mother was mostly responsible for supervising or doing the home programme with the child. Taking into account the other roles a mother must fulfil in the afternoon/evening period when a home programme would normally be done, this is likely to have a large impact on compliance (McConkey, 1985). Twenty-five percent (n=15) reported that the father also helped at times and 17% (n=10) reported that the child sometimes has to do the home programme on his/her own.

It seems that mothers bear a large part of the responsibility for doing the home programmes and often feel unsupported in this (37%; n=19). Only 21% (n=12) of the respondents were single parents. It is therefore evident that having two parents in the home does not necessarily imply that there is more support in meeting the child’s needs. Fathers need to be encouraged to be involved as much as possible and after-hours meetings may be a way of facilitating their attendance at team meetings, their awareness of their role in the team and their ownership of the process.

There seems to be a need to negotiate with the whole family to find someone who is able to regularly assist the child with the home programme if possible, or to adapt the programme to fit into the family routine with less disruption. This will require a considerable level of collaborative teamwork by and creativity from the parents and therapists.

In 53% (n=31) of the families, both parents work, while 10% (n=6) of the families have four children, 29% (n=17) have three children and 48% (n=28) have two children. In the literature, parents repeatedly report feelings of guilt about paying less attention to the other children due to one child’s disabilities (Webster & Ward, 1993). This was reported by 10% (n=5) of the respondents in this study. If necessary, programmes could be designed to include siblings. This might increase their sense of importance and help to alleviate the parents’ feelings of guilt. Care should be taken to ensure that all parties enjoy the process and do not experience it as a chore.

The above factors will all impact on the time available for parents to implement a therapy home programme as part of their daily routine and will therefore impact on compliance. However, people generally tend to make time for things that they feel are important and that make a difference to them. Parents may be using “lack of time” as a convenient excuse to avoid deeper issues around their beliefs about the effectiveness and relevance of the rehabilitation programme as a whole.

It took 60% (n=34) of the parents 5 to 15 minutes to complete the given programme, while 25% (n=14) said it took 16 to 30 minutes to complete and 14% (n=8) said it took more than half an hour to complete. A single parent (2%) had to implement the programme throughout the day. However, no parents marked “the programme takes too long” as an inhibitor to compliance in Figure 10 above. The lack of time does not seem to be related to the length of the programme, but rather to the prioritisation of the programme within the daily family routine.

In this regard, the therapists and parents need to collaborate closely to find the most effective programme that can be completed in the shortest possible time or combined effectively with other activities of daily living, as demands for time are high in a daily family schedule.

Substantial effort will therefore be needed by the therapists and parents to develop programmes that are relevant to the parents’ and family’s needs and capabilities, while also meeting the direct needs of the child. Once again, this will require close cooperation and detailed information sharing between the therapists and parents, which can only occur effectively in a collaborative teamwork model.

- Other common factors identified were that the child refuses to do the programme (27%; n=14), and that the child dislikes doing the programme and the parents do not want to create more stress in order to get the programme done (21%; n=10) (see Figure 10, page 60). Child-related reasons for non-

compliance are thus among the highest inhibitors. This was also reflected in the qualitative data, with parents identifying poor motivation from the child as an additional inhibitor.

This again points to programme design needing to be carefully evaluated and discussed with the parents and the child in such a way that the child can follow and contribute to the discussion to identify activities that he/she is motivated to do and is likely to cooperate with. Parents should feel free to discuss difficulties in implementing the programme in order to make relevant changes where possible. The therapists may need to take the initiative in following up with the parent to find out whether they experience any difficulties with the programme in their home environment. More communication and open sharing of information is required than is currently the case.

- The parents indicated that they prefer not to do home programmes during school holidays (23%; n=12). They said that it is difficult to follow the programme, as the family's usual routine is disrupted and they are often in different physical environments, making it difficult or impractical to comply.

This is a problem for the therapists, as they regularly identify regression of therapeutic gains after long school holidays, when the children have not had therapy. Home programmes are specifically prescribed over long holidays in order to minimise this deterioration. There seems to be a need to explain to the parents more carefully why home programmes are so critical in this period and to negotiate with them more fully as to what may be feasible for them. Again, more direct communication is needed between the therapists and the parents.

- Several parents (14%; n=7) said they were afraid to hurt the child and 8% (n=4) said they did not understand the instructions given. These items both reveal a lack of proper training for the parents. This is supported by another three parents, who revealed in the qualitative data that they were afraid to hurt themselves physically (e.g. back, neck, muscles).

There is a need to review how the programmes are given to the parents and to implement specific training for them in how to do the programme before expecting them to complement therapy inputs at home.

The following factors were mentioned as reasons for non-compliance by a small number of respondents in the qualitative data.

- The parent did not have the programme in writing and could not remember the exercises, or was afraid to do more harm than good to the child (n=1).

Learners frequently report that they cannot remember the exercises or that the written programme has been mislaid. All the programmes should be provided in writing and at least one session should be scheduled with the parents to explain and train them in the use of the programme. The therapists need to follow up with the parents more regularly to ensure that they are coping with the programme at home. This will provide opportunities for the parents to raise these practical problems and will increase the parents' accountability.

- The parents report that they prefer to do other exercises than those prescribed (e.g. gym, swimming, cycling) or to do exercises in other ways (e.g. while bathing, swimming) (n= 4).

The therapists need to negotiate with the parents to find the most effective way of integrating an effective therapeutic programme into the preferred exercise routine. In this way, "therapy" may become more acceptable to the child and parents. This will require creativity and input from all parties in a collaborative approach to achieve better results.

- A family decision was taken to prioritise other needs for now (n=1).

This is an important piece of information and raises the issue of the parents' right to decide *not* to do a home programme as a way of managing the needs of the entire family for a specific time. However, this decision should be made in collaboration with the whole team and not unilaterally by the parents. The

implications of this decision for the child who requires rehabilitation should be carefully explained and documented. Parents may need to accept slower progress towards goals as a result of this decision. A follow-up date should be set for review so that the needs of the child are not overlooked in the future.

Factors which some parents identified as facilitating compliance were the following:

- making the home programme as playful as possible (n=1);
- integrating the programme into the daily routine, e.g. bathing (stretches), dressing (splints) (n=4);
- having the help of a facilitator/personal assistant for the child (n=1).

Although these items were only mentioned by small numbers of parents each, they are important as positive contributors to compliance. The first two confirm the previous discussion about the need for more creativity and flexibility in designing home programmes in order to integrate them more effectively into the family routine. This may initially require more effort and time from the team members, but should ultimately achieve better results.

The issue of personal assistance for learners in and out of school is an important one and is currently being discussed by many disabled people's organisations. Currently parents are required to employ facilitators for their own children at their own expense. As a result, only financially-able families can afford a facilitator. For the population of this study, it might only be the upper two income brackets shown in Table 1. This problem needs to be addressed by education and social welfare policy makers.

The above information presents some useful guidelines for therapists but, more importantly, it highlights the individual needs of each parent and family with regard to therapy home programmes. This in itself presents a real challenge to therapists and parents to work more closely together to develop home programmes that will be effective and practicable for each of them in their own specific circumstances.

4c.iv. Therapists' perceptions of the home programmes, the rehabilitation team and the parent-professional relationships

- The majority of the therapists (78%; n=7) felt that home programmes are “essential” and 22% (n=2) felt that they are “fairly important” as part of the rehabilitation programme. However, the therapists felt that the current level of compliance with approximately 75% of these programmes was inadequate. A detailed comparison of the therapists' perceptions of compliance and the reported levels of compliance by the parents was presented in section 4c.i. (page 44).
- All the therapists (n=9) felt that parents *should* be included as part of their child's rehabilitation team and agreed that the level of involvement should be higher than it is currently.

The therapists felt that the parents should be included in the team in order to:

- increase the success of the rehabilitation programme (33%; n=3);
- improve the parents' cooperation and support for the home programmes (33%; n=3);
- increase the specificity, relevance and focus of goal-setting, planning and treatment (33%; n=3); and
- improve the parents' understanding of the therapeutic aims (22%; n=2).

Other reasons given for inclusion were:

- that parents form an integral part of the child's world (22%; n=2);
- that therapists need to know what the parents' expectations are (11%; n=1);
- that parents have the ultimate responsibility for their child as a whole (11%; n=1); and
- that it is the role of therapists to inform, but the role of parents to make decisions with regard to their own circumstances, e.g. financial resources (11%; n=1).

Most of the therapists (78%; n=7) expressed a desire to have parents “much more involved” in the decision-making about their child’s rehabilitation. Other therapists want parents to be “a bit more involved” (22%; n=2) in this process.

It thus appears that most of the therapists are highly motivated to include parents in the rehabilitation team as both members and decision-makers. However, they still feel that the parents are not involved adequately. The therapists need to critically evaluate their own contribution to this lack of involvement by parents and to the poor quality of teamwork that currently seems to exist between the therapists and the parents. They will need to play a facilitating role in changing the current system.

The therapists themselves identified several barriers to effective teamwork with the parents. These are detailed in Figure 11.

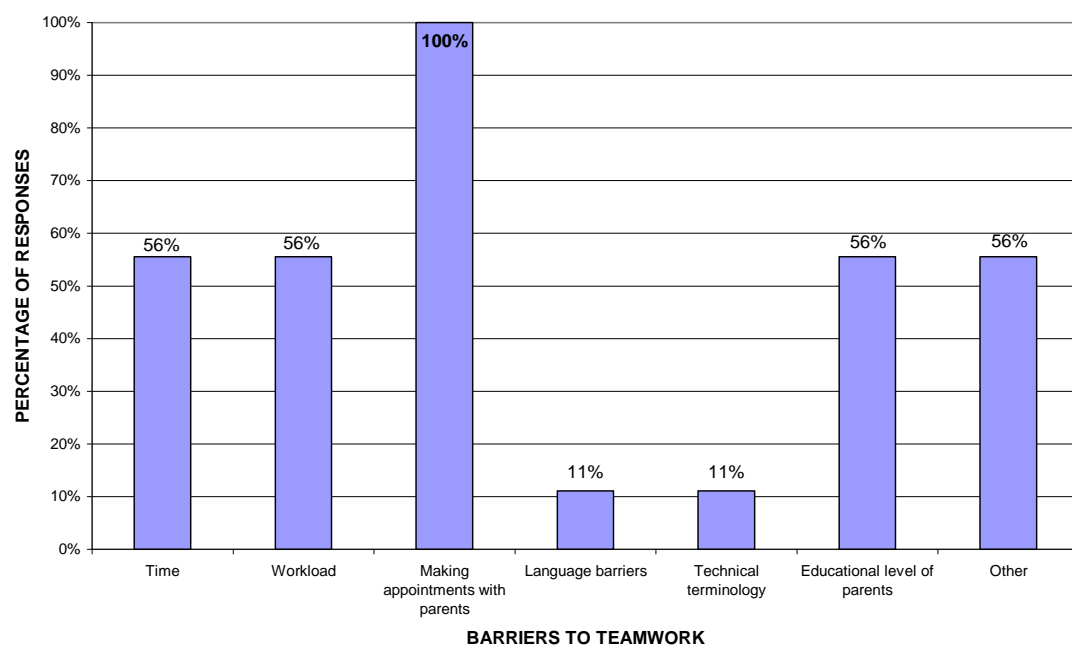


FIGURE 11: BARRIERS TO EFFECTIVE TEAMWORK AS IDENTIFIED BY THE THERAPISTS

- All the therapists (n=9) identified difficulties in scheduling appointments with the parents as a barrier to effective teamwork. This closely reflects the literature (Humphry *et al.*, 1992). The majority of the therapists (56%; n=5) also identified a lack of time and heavy workloads as inhibitors.

The therapists need to re-evaluate their working methods and schedules to achieve optimal outcomes for the learners with whom they work. A mind-shift may be necessary for the therapists to set aside regular schedules for parent-focused activities. The contact time with the parents (e.g. meetings, training, planning, counselling) needs to be seen as an integral part of the optimal management of each learner, rather than as a disruption to the direct therapy programme. This requires a shift from dependency on the therapist for direct treatment (medical model) to a 24-hour management approach in which parents and therapists both make an impact on the rehabilitation outcome. If this type of approach can be implemented effectively, the therapists will have more time available to effect change and progress in the child's condition, rather than constantly struggling to merely maintain existing functional levels.

The therapists may need to be much more flexible in the scheduling of parent meetings. Currently, parents are invited once a year for a 20-minute meeting that is scheduled within a specified two-week period. This is done in order to efficiently coordinate meetings with different professionals on the same day so that disruptions to the parents' and therapists' schedules are kept to a minimum. However, this system may create the impression that the therapists are only available during these times. The parents should instead feel free to make an appointment to see a therapist at any time during the year.

The therapists may also need to make themselves available to parents after school hours in the same way that teaching staff do. This may be the only time that some parents can attend such meetings. However, it is important to maintain a balance between accommodating the needs of both the parents and the therapy staff. After-hours activities will necessarily have to be structured and limited in terms of time and flexibility. Nevertheless, this may still be a considerable improvement for some parents, enabling them to participate more fully.

More effective teamwork and cooperation between all team members should ultimately lead to more time for effective therapy inputs and will perhaps help to manage workloads more efficiently.

- The educational levels of the parents were identified by more than half of the therapist respondents (56%; n=5) as inhibitors to effective teamwork. This also closely reflects the literature reviewed (McConkey, 1985; Humphry *et al.*, 1992).

Where parents have little formal education, more creativity is needed from the therapists to help the parents understand what their role is and why it is needed, as well as what is being done in therapy. Parents may struggle to understand more subtle conditions such as learning difficulties, Attention Deficit Disorder, Developmental Coordination Disorder, sensory integration problems and/or behavioural problems. They may feel intimidated by a professional team and have difficulty in assuming their role in the team effectively. Sensitivity, patience and flexibility are required from all team members.

Where “other factors” were identified, the therapists were asked to elaborate in the qualitative data. The following issues were mentioned:

- parents have inadequate insight into the child’s condition and unrealistic expectations (67%; n=6);
- the parents’ lack of acceptance of their child’s condition (22%; n=2);
- parents do not think their child’s problems are important (11%; n=1);
- parents must be well-informed (22%; n=2);
- parents may “think they know best” and are unwilling to try new approaches (11%; n=1).

These barriers seem to stem from the current lack of effective teamwork. Parents need to work through a process of acceptance, firstly of their child’s physical disability, and later perhaps of additional intellectual disability and/or learning problems. In order to do this, they will need ongoing support from the professional team to assist them with information, advice, counselling, and/or resources throughout this process. Close teamwork will enable the therapists to better understand where parents are in this process and what issues they are

dealing with, instead of labelling them as “lacking insight”. The therapists may be required to give the same information several times in different ways, or to work through different problems repeatedly until a satisfactory solution is found.

Participant 1 in the focus group expressed frustration at the therapists’ insistence that her son should learn to fasten buttons and shoelaces independently, causing much frustration for him, when they as parents were happy for him to use adapted methods, e.g. T-shirts and shoes with Velcro fasteners.

Negotiating through these decisions requires close relationships and a process of educating, building trust and open sharing, which can best be achieved in a collaborative team structure.

Other issues that the therapists mentioned included:

- lack of time or effort by the parents to attend team meetings, e.g. working parents (56%; n=5);
- lack of parent involvement, cooperation, commitment and interest (56%; n=5);
- poor communication from the parents, e.g. in relation to answering letters (22%; n=2).

These comments reveal a perception that the parents are not fully committed to the process and are happy to abdicate responsibility for their child’s rehabilitation to the school staff. This view was represented in the parents’ views on teamwork in Figure 8, but represents only 3% (n=2) of the parents. When assessing the quality of the existing teamwork, it seems possible that the parents feel they have little meaningful contribution to make and that their presence at such meetings is not essential. One must question the quality of interactions at these contact sessions. Do the parents feel valued in the process? Have their views been handled respectfully in the past? Did they feel that communicating their views and needs made a difference? This seems unlikely, judging from their reported experience of teamwork. These types of

experiences will impact on the parents' motivation to be actively involved in therapy-related activities.

Participants in the focus group talked about past experiences with medical doctors, who predicted that their child would be a “vegetable” or “cabbage” for the rest of his/her life and would “never” reach certain levels of function. The parents related feelings of anger and shock at this. They felt that professionals were “not God” and should choose their words more carefully. As discussed previously, several of these predictions were later shown to be untrue. These negative experiences may influence the parents' desire to be more integrally involved in team discussions.

Participant 1 described how she and her late husband experienced shock and pain after each feedback session with the staff of the school, even though they were both aware of their son's difficulties. She shared how, although these sessions were necessary, it was still difficult to hear the “reality”, even when it was only “confirming what you already know”. Other participants agreed with these sentiments. These experiences may contribute to the reluctance of some parents to be more involved at a team level.

Therapists also said that:

- parents expect therapists/the school to sort out their child's problems and do not see it as their responsibility (44%; n=4);
- the parents face logistical problems, e.g. live far away from school, work long hours, have no transport to reach the school (44%; n=4);
- socio-economic status determines other, more fundamental, priorities, e.g. providing food for the family (44%; n=4);
- the parents lack time for home programmes (33%; n=3).

There is a need to develop a culture of parental responsibility for decision-making and ultimately the holistic management of their child. There is also a need to take into account the balance between parental responsibilities to their disabled child and to the rest of the family.

Telephonic or written contact should be maintained regularly (where possible) if transport to the school is a problem. This is obviously not ideal, but is a practical reality for several families.

A few therapists also raised the following issues affecting teamwork:

- the therapists lack time to do management and administrative tasks adequately (33%; n=3);
- parents are not included in the treatment and/or planning process (22%; n=2);
- the therapists assume that parents do not really understand their child's problem and/or will choose inappropriate goals (11%; n=1).

These comments highlight the responsibilities of therapists in the teamwork process and again point to the need for change in the current teamwork model. Therapists need to recognise the unique insights that parents have, and to respect their role in the team. Parents must be included in evaluation, feedback sessions, goal-setting, planning, decision-making and the design of programmes through a process of negotiation for consensus. In this way, the rehabilitation process will be better understood and supported by all those involved, and be more effectively targeted to achieve relevant and realistic goals for the child and family.

Home programmes are given to parents in various ways, as shown in Figure 12.

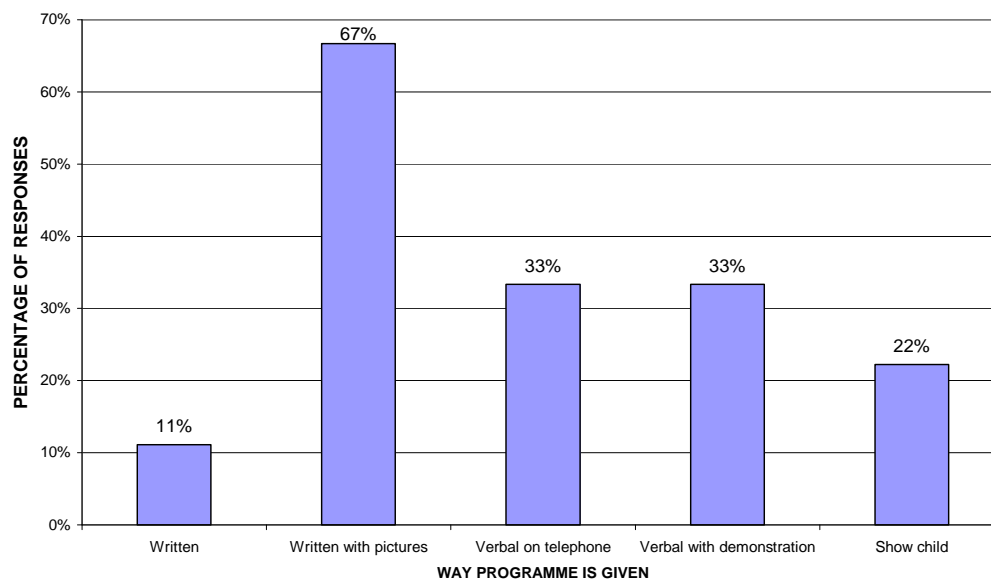


FIGURE 12: VARIOUS WAYS IN WHICH HOME PROGRAMMES ARE CURRENTLY GIVEN TO PARENTS

Figure 12 shows that the parents are seldom or never directly taught how to do a home programme. A piece of paper is usually sent home with the child and there is little or no follow up. Parents may not receive the programme via their child, as was seen in the study sample (see section 4b.i., page 35). The parents may also not understand the instructions fully, or may be complying fully but be ineffective because the programme is implemented incorrectly. This may explain the discrepancies between the parents' and therapists' perceived levels of compliance and the apparent ineffectiveness of the home programmes. It may also explain why the parents are afraid of hurting the child or themselves while doing the programme.

Participant 3 in the focus group felt that many parents "do not understand why their child is like he/she is", and that all parents should be encouraged to attend their child's therapy sessions for maybe a week to be able to understand what is being done and how to do home programmes without hurting or irritating the child. She felt there was a need for the parents to be trained. The other participants agreed with this view.

Changes will have to be made to the current system to allow time for the parents to come to the school and be taught specifically how to implement a home programme. If the therapists believe that home programmes are essential to the success of the rehabilitation programme as a whole, they need to spend time training the parents to do these programmes effectively. In some cases it might be possible to do this with a group of parents at the same time.

In addition, there is a clear need for follow up by the therapist. This will ensure that the programmes given are actually received, are understood and remain practicable and relevant.

The therapists were asked if they liaise with other therapy disciplines before giving the child a home programme to follow. The responses were as follows:

- two therapists (22%) reported liaising with their colleagues “often” when designing therapy home programmes for learners;
- fifty-six percent (n=5) said they “seldom” did this; and
- twenty-two percent (n=2) said they “never” consulted therapists from other disciplines with regard to home programme design.

This could be relevant if a learner receives home programmes from more than one discipline simultaneously. The study sample only included two such parent respondents, and the results revealed weaknesses in the interdisciplinary teamwork. This problem could be explored further, perhaps in a separate study. Weak team dynamics between professionals will also impact on teamwork with the parents.

When asked about the amount of time the therapists spent developing home programmes:

- one therapist said she spent 0-15 minutes each term per child developing home programmes;
- two therapists said they spent 16-30 minutes on home programmes;
- one spent between 31 minutes and 1 hour on this type of work; and

- five therapists reported spending more than one hour per term per child designing such home programmes.

Considering the amount of time spent developing these programmes, it is important to ensure that they are implemented correctly and effectively. The therapists need to train the parents more directly in order to maximise gains from these programmes.

The therapists will need to closely analyse their contribution to the poor quality of teamwork existing in the school. Several attitudinal barriers will need to be addressed and practical changes will have to be made, both to accommodate the parents and to encourage them to adopt their full rights and responsibilities regarding their child. This, in turn, will assist the therapists to do their work more effectively.

4c.v. Other interesting points from the focus group discussion

All the participants shared previous painful experiences in the community as a result of negative attitudes towards disability. They also expressed frustration at the lack of physical accessibility. Both these factors drain their energy levels while they try to ensure that their child enjoys everyday community activities such as shopping, watching films and going to the park. They expressed a need to educate the public more on disability.

Two participants described how the child's father, and in another case both parents, initially struggled to accept the child's disability. There is a need to include fathers more actively in teamwork so that they too can understand their child's abilities and limitations more fully.

All the participants expressed an interest in training workshops where therapists and parents could learn from each other. This would provide an opportunity for parents to share ideas and practical experiences with each other informally.

All the participants also expressed a need for parent support groups. They said they found being able to share their experiences with others who can understand how they

feel “uplifting” and encouraging. This is something that could be facilitated through the school.

4d. SUMMARY

The results presented in this chapter have highlighted several areas of concern within the existing *modus operandi* in the study school. The barriers to compliance that were identified within the school are categorised below:

- i. quality of teamwork between parents and professionals;
- ii. attitudinal barriers from both parents and therapists in relation to their roles, responsibilities and rights;
- iii. quality of training for parents in the use of home programmes; and
- iv. practical difficulties, e.g. lack of time, difficulties in scheduling appointments, type of home programme, and socio-economic barriers.

There is an urgent need for a more collaborative teamwork model to be implemented in the school in order to address these problems effectively.

More detailed recommendations will be presented in Chapter Five.

CHAPTER FIVE

RECOMMENDATIONS AND CONCLUSION

5a. Introduction

Several categories of barriers to compliance were identified in the reviewed literature. These categories were not found to be statistically significant in this study setting. Factors which did impact on compliance in the study sample relate mainly to teamwork issues between the therapists and the parents. Practical and attitudinal barriers in both the parents and the therapists will also need to be addressed. In some cases, social barriers must be circumvented through a negotiated approach.

There is a need to critically reassess teamwork structures, attitudes that have influenced the current ways of working, the way in which the home programmes are introduced to the parents and, perhaps most importantly, the level of inclusion of parents at all levels of rehabilitation programme planning and design in the school.

Recommendations with respect to these categories will be made in this chapter.

5b. RECOMMENDATIONS

5b.i. Introduce a family-centred/collaborative model of teamwork

The introduction of a collaborative, family-centred model has been argued for in this paper in order to improve teamwork between the parents and therapists to optimise the rehabilitation outcomes for the disabled child.

In this model, the parents are the ultimate decision-makers with regard to their child's rehabilitation. The therapists act as consultants and service providers, informing and discussing various options with the parents so that the latter can make an informed decision. The therapists cannot make these decisions themselves, as they are not fully aware of the values and practical needs of the whole family. Thus, the parents and therapists work together to negotiate plans and programmes that are of therapeutic value to the child, while also taking the needs of all family members into account (Bazyk, 1989). Consensus among all team members should be the ultimate goal when making decisions, planning progression and setting goals (Visagie, 2003).

Most of the parent participants in this study said they currently feel part of the team. However, only half of the respondents were satisfied with their current level of involvement. This reveals gaps in the existing teamwork mechanisms. Despite feeling that they are part of the team, many parents still feel that they have more to offer. This is understandable when one examines the quality of teamwork experienced by the parents. Only 17% (n=10) of the parents are indeed functioning as active team members in the collaborative model framework. In the majority of cases, the quality of the existing teamwork is still strongly influenced by traditional medical model power relationships, with therapists maintaining a highly prescriptive role. Although most parents had said they felt included in the team, closer analysis has revealed underlying dissatisfaction with the *status quo*.

It is the author's opinion that the family-centred, collaborative model will most effectively include all stakeholders in a child's rehabilitation process and will lead to improved compliance with team recommendations, where compliance is "the extent to which parents adhere to the recommendations agreed upon by the team, of which they are members" (see Definition of Terms, page vi).

The parents need to be fully aware of difficulties in the system with regard to appropriate placements, the availability of facilities for their child, and gaps in the education system's provision for their child's needs (Education White Paper 6, 2001). They are the ones who should be lobbying for the provision of staff, more effective integration for learners with disabilities, and/or more adaptations for their child, in order to influence policy. They are the ones who have the right and political power to demand changes for the benefit of their disabled children. The parents need to be fully informed of the difficulties experienced with the system by staff making recommendations about placements. Parents need to be included in order to be empowered.

A collaborative approach will only be successful if the parents are included in all meetings concerning their child. Parents should be invited to the initial feedback meeting, the annual review meetings and any other meetings concerning their child. Realistically, they may not be able to attend all of these, but they should be informed

of the agenda, content and outcomes of such meetings and should be given an opportunity to express their views *in absentia*.

At each meeting, a date should be decided for follow up. This may be only once a year, as is currently the case, but it should be made clear that an open-door policy exists and that any team member is free to initiate a team meeting at any time should the need arise. These meetings should be scheduled at a time most convenient for all team members to allow maximum participation.

Once a collaborative team approach has been adopted, it is possible to negotiate the type and intensity of home programmes, taking into account the resources available and the degree of parent involvement needed. This will ensure that the goals and programmes are relevant and realistic and it should elicit greater compliance and cooperation from the parents. The result should be a better outcome for the child, the family and the therapist.

In order for this to happen, a process of training in the collaborative model may need to be implemented for the staff. Therapists and other staff need to first see the value of this model in order to facilitate increased parent collaboration at team level. Parent contact time needs to be seen as an integral part of the optimal management of each learner, rather than as a disruption to the programme. The change will require significant compromise by and disruption to the comfortable *status quo* of the therapists and they will need to be well motivated to go through with the process.

It is anticipated that the process will initially be time and labour intensive but, over time, will become more streamlined and easier for all involved. Practical arrangements will need to be tried and tested and a flexible approach maintained until suitable logistical details can be agreed upon. However, the essence of the collaborative approach is flexibility and creativity in order to meet the needs of all team members most satisfactorily.

5b.ii. Address attitudinal barriers affecting the quality of teamwork

Both the parents and the therapists need to contribute actively for a collaborative rehabilitation team model to function effectively. This study revealed certain attitudes that will need to be addressed in order for this type of teamwork to be effective.

The therapists need to recognise their own contribution to the lack of effective teamwork. Medical model thinking has impacted on the way things are currently done at the school and the therapists will need to effect a considerable mind-shift so that the parents can assume their role as equal members of the team at all levels. The therapists need to recognise their dependence on the parents in order to achieve the best long-term outcome for the child. A 24-hour management approach needs to be adopted by all team members.

The therapists will also need to actively facilitate parental ownership of roles and responsibilities. They may, at times, need to refuse to make decisions on behalf of the parent, guiding them instead to a point where they can make their own decision. The therapists will also need to create space for the parents to test out this new role. The parents may be easily discouraged if they immediately meet with resistance from the therapists. The therapists therefore need to recognise the unique and important contribution and insights that only the child's parents can bring to the team. These insights need to be treated with respect, and be taken into consideration in all team processes.

Several parents said that, despite decisions being made about their child without their input, they are satisfied with this situation. This type of attitude contributes to parental non-involvement and supports the therapists' perceptions that the parents are willing to hand over responsibility for their child's rehabilitation to the school instead of fully assuming their own role in the process. This also increases the burden of responsibility for decision-making on the therapists, which can contribute to guilt feelings and burnout.

The parents need to recognise their own rights and responsibilities to be active members of the team. They need to take ownership of the important role they have in

bringing insights from the home situation, contributing to the design of realistic and practical programmes, setting goals to focus the efforts of the professional team, and giving feedback so that the programme can remain effective and relevant at all times. This level of teamwork will help the therapists to understand the dynamics of the family better, and will free the therapists from the burden of responsibility for all decision-making and progress. Parents who have already effectively adopted these roles and responsibilities could act as catalysts to empower other parents.

The presentation of this research to the parents and staff may initiate these attitudinal changes by stimulating thought and discussion around the roles and responsibilities of each team member. Training workshops (to be discussed below) could include discussion on effective teamwork. New parents in the school might initially be targeted for this type of teamwork in order to gradually phase in this model.

5b.iii. Improve the quality of training to improve the effectiveness of programmes

If therapists believe that home programmes are essential to the success of the rehabilitation programme as a whole, they need to spend time training the parents to carry out these programmes effectively. The parents identified being afraid of hurting themselves or the child, having forgotten the exercises, or not understanding the instructions as factors affecting compliance, and these factors reveal a lack of training for the parents.

Training sessions should aim to empower the parents through information and skills. The parents could be trained individually or in groups. They should be encouraged to identify their own needs for training and be involved in creating a programme for the year. This could be done by means of a short questionnaire sent home early in the school year. The parents should also be directly involved in the design of their child's own home programme.

Dates of workshops should be advertised well in advance so that the parents and therapists can make arrangements timeously. Workshops and training sessions should include motivation about the importance of teamwork, the home programmes, and the

impact of therapy on the child as a whole. All home programmes should be given in writing.

These training workshops can also act as informal support groups, where the parents can learn from one another and have an opportunity to share experiences. The parents could be encouraged to initiate community awareness programmes on disability issues through these potential support groups.

In addition, there is a clear need for follow up by the therapist to the parents. This will ensure that the home programmes are understood and remain practicable and relevant.

5b.iv. Address practical inhibitors to compliance through negotiation

The introduction of a family-centred/collaborative approach to teamwork and the subsequent contribution of the parents to the design of home programmes will help to identify and address several of these practical barriers to compliance. The programmes should be designed taking these factors into account and, with flexibility and creativity, the team should be able to circumvent the problems.

If programmes are designed to be more smoothly integrated into the family routine, they will require less energy and additional time from parents. Wherever possible, the child should be taught to do the programme on his/her own. The programmes should be as short as possible, and realistically take into account that which is feasible for the family. The parents and learners need to fully understand why the programme is necessary so that they can remain motivated. Family members other than the mother could also be trained to do the programme to relieve some of the load on the mother.

The child needs to be continually motivated and encouraged to continue with a programme. Programmes should be negotiated with the child too and, wherever possible, be fun. A home programme should become a regular part of the child's daily routine from an early age. It may be necessary to change the programme regularly to maintain the child's interest and motivation.

Programmes that are effectively integrated into the family's daily routine seem to elicit the highest levels of compliance. The programmes therefore need to be carefully designed with a keen awareness of the family's routine to facilitate compliance and maximum outcomes. The therapists need to follow up with the parents to check how the programme is working so that difficulties can be overcome and the programme is not simply discarded.

A collaborative team approach will provide opportunities to motivate parents regarding the need for a home programme during the school holidays. Team members can then negotiate the type of programme that will be feasible and appropriate for this period. Some parents, however, may be willing to accept a degree of deterioration in their child's condition during this time. The implications of non-compliance and the reasons for the parents' decisions should be explained and documented.

Scheduling difficulties need to be addressed in order to implement this model effectively. Parent-therapist evenings may need to be introduced for those parents who are unable to attend during school hours. All meetings should be planned well in advance to allow for logistical arrangements. The therapists need to communicate flexibility and availability to the parents within reasonable limits. Regular workshops, for example once a term on a Saturday morning, may help to address some parents' needs in a group setting and reduce the need for individual meetings.

Thus, the solution to many of these inhibitors to compliance is a collaborative team approach allowing for information sharing, creativity and negotiation for consensus so that the needs of all the parties are met adequately.

5b.v. Topics for further study

In the literature reviewed, no recent surveys of parental perceptions were found to evaluate whether changes in therapists' thinking and theoretical frameworks have impacted on the way parents experience the rehabilitation process. Should changes be made to the current *modus operandi* in the study school as a result of this study, it would be recommended that a follow-up study be implemented to assess compliance levels and views on the impact of these changes.

A study could also be conducted on the quality of the interdisciplinary teamwork existing in the school. This will impact on the quality of teamwork with the parents.

5c. CONCLUSION

There is evidence that a child will progress most rapidly in his/her functional goals with effective cooperation between the therapist and the family (Wolery, 2000; Carr *et al.*, 1987; Sameroff & Fiese, 2000). The current programmes are designed with too little insight into the family's situation and, as a result, are not meeting the needs and goals of the parents for the child and other family members. There is a need to involve parents integrally at all stages of decision-making to ensure that the goals of the therapy are relevant, realistic and practicable for all team members, and that barriers to compliance are addressed wherever possible.

Team members need to communicate closely in order to better understand the needs of the child and the whole family. The collaborative, family-centred model is the most appropriate teamwork model to achieve this level of mutual sharing and respect in this school. In this model, all team members can actively exercise their rights and responsibilities in the child's rehabilitation process.

Collaboration will improve the design of home programmes and should increase compliance. This approach will also facilitate respect for family decisions to comply at a limited level, if necessary, for the greater good of the whole family. However, it will require greater flexibility and creativity from the parents and therapists in designing appropriate, effective and practicable programmes.

Programmes need to be provided in writing and the parents need to be trained to ensure that the participants are able and motivated to implement the programmes effectively without fear of hurting themselves or the child. This training might be done individually or in group sessions.

The introduction of the collaborative teamwork model, with the accompanying assumption of roles and responsibilities and the targeted training of the parents, will assist in the design and implementation of relevant, realistic and effective

rehabilitation programmes. This will lead to a more holistic management approach, where the therapeutic needs of the child are addressed in the school, in therapy and at home, resulting in better functional outcomes for the child and his/her whole family.

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APPENDIX A1

PARTICIPANT INFORMATION AND CONSENT FORM

I, the undersigned, (participant's name),
confirm that:

1. I have been invited to participate in this research project initiated through Stellenbosch University, South Africa.
2. It has been explained to me that the aim of the project is to establish how much therapy home programmes are used by parents of learners who are in a special educational needs school and reasons for this.
3. It has been explained that I will need to fill in a questionnaire, on a once-off basis, answering questions about the use of therapy home programmes and my experience of the school rehabilitation programme as a whole.
4. It has been explained that all information will be treated with the utmost confidentiality and anonymity. Information may be used for a thesis, publication in scientific journals, and/or presentation(s) at professional gatherings.
5. I am aware that this is a once-off procedure that will be implemented in 2004.
6. I have been informed that I may refuse to participate in this study and that this will in no way impact on my child's rehabilitation.
7. The information above has been provided to me in the cover letter of the questionnaire, in my own language. I was invited to contact the researcher directly, so that any questions I had were answered satisfactorily.
8. There has been no force placed on me to participate in this study.
9. Participation in this study will not lead to any additional costs for myself and I will not benefit from it financially.

Signed at(place) on2004.

Participant: Witness:.....

**I HEREBY DECLARE THAT I WILL VOLUNTARILY PARTICIPATE IN
THE ABOVE STUDY**

Signed at on2004.

Participant's signature

STATEMENT BY RESEARCHER:

I, Natalie Melling-Williams, state that:

1. The information in this document has been explained to
in the cover letter attached to the questionnaire.
2. I have invited him/ her to ask me questions in the case of uncertainty.
3. This information was given in English/ Afrikaans/ Xhosa.

Signed at on2004.

Researcher's signature:.....

Witness:

STATEMENT BY TRANSLATOR:

I,, confirm that:

1. I have translated the content of this document from English to
in a manner that was a factually correct representation of the original and
which can be easily understood by the participants.

Signed aton2004

Translator's signature:

Witness:

Thank you for participating in this study. If you have any queries regarding the study,
please do not hesitate to contact me at:

Tel: 021-981 5555 (o/h) or 021-790 8569 (a/h).

Email: admin@paarlskool.org.za

Mail: Paarlskool
Private bag X09
Brackenfell
7560

Natalie Melling-Williams

APPENDIX A2

DEELNAME INLIGTING- EN GOEDKEURINGSVORM

**Ek, die ondergetekende,(naam van deelnemer),
bevestig dat:**

1. Ek genooi is om deel te neem aan hierdie navorsingsprojek, geïnisieer deur Stellenbosch Universiteit, Suid Afrika.
2. Dit aan my verduidelik is dat die doel van die projek is om te bepaal hoeveel terapie-tuisprogramme gebruik word deur ouers van leerders wie in 'n skool vir spesiale onderwys behoeftes is, en die redes hiervoor.
3. Dit aan my verduidelik is dat ek 'n vraelys sal moet voltooi op 'n eenmalige basis waarin vrae beantwoord word oor die gebruik van terapie-tuisprogramme en my ervaring van die skool rehabilitasie-program in geheel.
4. Dit verduidelik is dat alle inligting uiters vertroulik en anoniem hanteer sal word. Inligting mag gebruik word vir 'n tesis, publikasie in wetenskaplike joernale en/ of voorleggings tydens professionele byeenkomstes.
5. Ek bewus is dat hierdie 'n eenmalige prosedure sal wees wat in 2004 geïmplementeer sal word.
6. Ek ingelig is dat ek mag weier om aan hierdie studie deel te neem en dat dit op geen manier 'n impak sal hê op my kind se rehabilitasie-program nie.
7. Die bostaande inligting aan my gegee is in die taal van my keuse. Ek genooi was om die navorser direk te kontak om enige vrae te beantwoord tot my bevrediging.
8. Daar geen druk op my geplaas is om deel te neem aan hierdie studie nie.
9. Deelname aan hierdie studie nie enige addisionele koste vir myself inhou nie en dat ek ook nie finansieel daarby kan baat nie.

Geteken te(plek) op2004.

Deelnemer:..... Getuie:.....

**EK VERKLAAR HIERMEE DAT EK VRYWILLIGLIK SAL DEELNEEM
AAN BOGENOEMDE STUDIE.**

Geteken te(plek) op2004.

Deelnemer:.....

APPENDIX A3
DEELNAME INLIGTING- EN GOEDKEURINGSVORM:

Fokusgroep

**Ek, die ondergetekende,(naam van deelnemer),
bevestig dat:**

10. Ek genooi is om deel te neem aan hierdie navorsingsprojek, geïnisieer deur Stellenbosch Universiteit, Suid Afrika.
11. Dit aan my verduidelik is dat die doel van die projek is om te bepaal hoeveel terapie-tuisprogramme gebruik word deur ouers van leerders wie in 'n skool vir spesiale onderwys behoeftes is, en die redes hiervoor.
12. Dit aan my verduidelik is dat ek in 'n besprekings-groep sal deelneem op 'n eenmalige basis waarin vrae beantwoord word oor die gebruik van terapie-tuisprogramme en my ervaring van die skool rehabilitasie-program in geheel.
13. Dit verduidelik is dat alle inligting uiters vertroulik en anoniem hanteer sal word. Inligting mag gebruik word vir 'n tesis, publikasie in wetenskaplike joernale en/ of voorleggings tydens professionele byeenkomstes.
14. Ek bewus is dat hierdie 'n eenmalige prosedure sal wees wat in 2004 geïmplementeer sal word.
15. Ek ingelig is dat ek mag weier om aan hierdie studie deel te neem en dat dit op geen manier 'n impak sal hê op my kind se rehabilitasie-program nie.
16. Die bostaande inligting aan my gegee is in die taal van my keuse. Ek genooi was om die navorser direk te kontak om enige vrae te beantwoord tot my bevrediging.
17. Daar geen druk op my geplaas is om deel te neem aan hierdie studie nie.
18. Deelname aan hierdie studie nie enige addisionele koste vir myself inhou nie en dat ek ook nie finansieel daarby kan baat nie.

Geteken te(plek) op2004.

Deelnemer:..... Getuie:.....

**EK VERKLAAR HIERMEE DAT EK VRYWILLIGLIK SAL DEELNEEM
AAN BOGENOEMDE STUDIE.**

Geteken te(plek) op2004.

Deelnemer:.....

APPENDIX B1
LETTER OF PERMISSION: WESTERN CAPE EDUCATION
DEPARTMENT

APPENDIX B2
LETTER OF PERMISSION: SCHOOL GOVERNING BODY

APPENDIX C1

QUESTIONNAIRE TO PARENTS

SECTION A:

This section will help me to understand a bit about who you are and some of the challenges you face with regard to the therapy home programmes.

1. Age of child attending Paarl School: _____

2. Gender of child:

| | |
|--------------------------|--------|
| <input type="checkbox"/> | Female |
| <input type="checkbox"/> | Male |

3. Total number of children in your family: _____

4. Total number of children in your family at Paarl School at present: _____

5. Total number of your children currently receiving therapy home programmes or other homework (from Paarl School or other therapists/ schools): _____

6. Are you a single parent?

| | |
|--------------------------|-----|
| <input type="checkbox"/> | Yes |
| <input type="checkbox"/> | No |

7. Which of the child's parents are working?

| | |
|--------------------------|--------|
| <input type="checkbox"/> | Father |
| <input type="checkbox"/> | Mother |
| <input type="checkbox"/> | Both |
| <input type="checkbox"/> | None |

8. Please indicate your approximate total family income PER MONTH for the period October 2003 to December 2003 (excluding bonuses):

| | |
|--------------------------|-----------------------------|
| <input type="checkbox"/> | R0 - R2 499 per month |
| <input type="checkbox"/> | R2 500 – R4 999 per month |
| <input type="checkbox"/> | R5 000 – R9 999 per month |
| <input type="checkbox"/> | R10 000 – R19 999 per month |
| <input type="checkbox"/> | R20 000 and more per month |

9. What is the severity of your child's disability, in your opinion?

| | |
|--------------------------|----------|
| <input type="checkbox"/> | Mild |
| <input type="checkbox"/> | Moderate |
| <input type="checkbox"/> | Severe |

10. How do you anticipate that your child will live as an adult? (Please tick one only)

| | |
|--------------------------|----------------------------------------------------------------------------|
| <input type="checkbox"/> | Fully or largely dependent on institutional care, or parents or relatives. |
| <input type="checkbox"/> | Almost completely independent, but may require some assistance. |
| <input type="checkbox"/> | Fully independent. |

11. What type of employment do you expect your child to be able to have as an adult? (Please tick one only)

| | |
|--------------------------|-------------------------------------------------------------------|
| <input type="checkbox"/> | Unemployed or in sheltered employment. |
| <input type="checkbox"/> | Unskilled manual work. |
| <input type="checkbox"/> | Semi-skilled or skilled labour, trade/ artisan, technician. |
| <input type="checkbox"/> | Clerical e.g. secretarial, telephonist, office assistant. |
| <input type="checkbox"/> | Managerial or professional work (e.g. accountancy, law, teaching) |

12. Do you have people nearby who can help you raise your children
eg. grandparents, aunts/ uncles/ friends?

| | |
|--------------------------|-----|
| <input type="checkbox"/> | Yes |
| <input type="checkbox"/> | No |

SECTION B:

This section will give me some details of the type of home programme(s) you were asked to do and which ones you found easier or more difficult to do.

1. Was your child expected to carry out a home programme between the beginning of the fourth term of 2003 and the beginning of the 2004 school year?

| | |
|--------------------------|-----|
| <input type="checkbox"/> | Yes |
| <input type="checkbox"/> | No |

2. Please indicate how many programmes he/ she received in this time: _____

2.1. If you were only given ONE home programme, please continue to question 3.

2.2. If you were given MORE THAN ONE home programme, please fill in the following sections separately for EACH home programme you received. There are duplicate copies of section B3 to E4 questions supplied at the back of this questionnaire.

Eg. if your child received an occupational therapy programme AND a physiotherapy programme in this period, you must please answer these sections for EACH therapy programme on a separate form.

3. Please indicate which type of activities you were asked to do at home for this home programme. (Please tick as many blocks as are appropriate)

| | |
|--------------------------|--------------------------------------------------------------------------|
| <input type="checkbox"/> | Apply splints (brace, foot/ hand splints, night splints or others) |
| <input type="checkbox"/> | Stretches to muscles |
| <input type="checkbox"/> | Physical exercises (eg. for hands, arms, legs, whole body, eyes) |
| <input type="checkbox"/> | Speech and language exercises (eg. telling stories, saying sounds) |
| <input type="checkbox"/> | Games (eg. hopscotch/ ball games) |
| <input type="checkbox"/> | Activities of daily living (eg. tying shoelaces/ dressing self/ feeding) |
| <input type="checkbox"/> | Writing/ drawing activities |
| <input type="checkbox"/> | Behavioural modification programme |
| <input type="checkbox"/> | Standing in standing frame |

4. How was this home programme given to you? (Please tick all as appropriate.)

| | |
|--------------------------|-------------------------------------------------------------------|
| <input type="checkbox"/> | In written form only |
| <input type="checkbox"/> | In written form with pictures |
| <input type="checkbox"/> | In verbal conversation in interview/ on telephone |
| <input type="checkbox"/> | In verbal conversation with demonstration |
| <input type="checkbox"/> | Child shown activities during therapy and told to do them at home |

5. Was this home programme relevant for your child, in your opinion?

| |
|--------------------------|
| <input type="checkbox"/> |
| <input type="checkbox"/> |

Yes

No

6. How many times in a week were you asked to do this home programme?

| |
|--------------------------|
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |

Every day

2 – 5 times a week

Once a week

Only had to do programme once

7. How long did it usually take to complete this home programme?

| |
|--------------------------|
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |

5 – 15 minutes

15 – 30 minutes

More than 30 minutes

Programme needed to be carried out throughout the day

8. Did you understand the purpose of doing this home programme?

| |
|--------------------------|
| <input type="checkbox"/> |
| <input type="checkbox"/> |

Yes

No

9. Who did you decide was responsible to ensure that this home programme was done? (Please tick as many as are appropriate)

| |
|--------------------------|
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |

Mother

Father

Grandparent

Sibling (brother/ sister)

Child him/herself

Other (Please specify:_____)

10. Did your child's therapist ever let you know if your child was improving as a result of you doing the home programme well?

| |
|--------------------------|
| <input type="checkbox"/> |
| <input type="checkbox"/> |

Yes

No

SECTION C:

This section aims to work out exactly how often the home programmes are done. The more honestly you answer, the more useful the results will be.

1. I do class homework with my child as required: (Please tick one only.)

| | |
|--------------------------|--------|
| <input type="checkbox"/> | Always |
| <input type="checkbox"/> | Often |
| <input type="checkbox"/> | Seldom |
| <input type="checkbox"/> | Never |

2. Please indicate how often you ACTUALLY did this THERAPY home programme, on average. (Please tick as many as are appropriate.)

| Home programme | Never | Once a month | Between once a month and once a week | Once a week | 2-5 times a week | Every day |
|--------------------------------|-------|--------------|--------------------------------------|-------------|------------------|-----------|
| Put on child's splints | | | | | | |
| Stretched muscles | | | | | | |
| Did physical exercises | | | | | | |
| Did speech/ language exercises | | | | | | |
| Did games | | | | | | |
| Did activities of daily living | | | | | | |
| Did writing activities | | | | | | |
| Did behaviour modification | | | | | | |
| Stood child in standing frame | | | | | | |

SECTION D:

This section aims to hear from you what things make it easier or more difficult to do these home programmes.

1. Please indicate whether you agree or disagree with EACH of the following endings to this sentence: **“I do NOT always do the home programme because...**

| | Agree | Disagree |
|--------------------------------------------------------------------------------|--------------|-----------------|
| ...I do not have enough time in my day | | |
| ...I am too tired at the end of the day to do the programme | | |
| ...my child is too young to do these exercises | | |
| ...my child is too old and no longer requires exercises | | |
| ...we do not have space at home to do the exercises | | |
| ...we do not have the right furniture/ equipment to do the exercises | | |
| ...I dislike being a therapist to my child, I just want to be a mother/father | | |
| ...I feel guilty about giving so much time to one child | | |
| ...I don't believe the activities make a difference | | |
| ...I don't agree with the exercises chosen for my child | | |
| ...the exercises are too difficult for me to do | | |
| ...I am the only person responsible for doing the programme(s) | | |
| ...I am afraid of hurting my child | | |
| ...my child dislikes doing the programme and I don't want to cause more stress | | |
| ...there are too many exercises to do | | |
| ...there are too many different programmes to do | | |
| ...the programme takes too long | | |
| ...I do not want to do home programmes in the school holidays | | |
| ...my child refuses to do the programme | | |
| ...I don't understand the reasons for doing the exercises | | |
| ...I don't understand the instructions on the programme | | |

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and extend across the width of the page. There are no margins, text, or other markings on the paper.

In this section I am trying to get an understanding of what your relationship with your child's therapist is like.

| | |
|--|-----------------------|
| | Once a week |
| | Once a month |
| | Once a term |
| | Once a year |
| | Less than once a year |

2. How would you describe your child's therapist(s)? (Please underline ALL appropriate words.)

Polite; irritating; disagreeable; friendly; warm; authoritarian; bossy; open;
unfriendly; caring; uncaring; uninterested; professional; capable

Other: _____

3. How do you feel about your current level of involvement in your child's therapy?
(Please tick one only.)

- | | |
|--------------------------|----------------------------------------|
| <input type="checkbox"/> | I would like to be much more involved |
| <input type="checkbox"/> | I would like to be a bit more involved |
| <input type="checkbox"/> | It is just right |
| <input type="checkbox"/> | I would like to be a bit less involved |
| <input type="checkbox"/> | I would like to be much less involved |

4. To what extent do you think your child's therapy makes a difference to his/her and/or your quality of life? (Please tick one only.)

- | | |
|--------------------------|-----------------------------------------|
| <input type="checkbox"/> | It makes a very positive difference |
| <input type="checkbox"/> | It makes a slightly positive difference |
| <input type="checkbox"/> | It makes little difference |
| <input type="checkbox"/> | It makes no difference at all |

5. Would you approach one of your child's therapists/ psychologists/ teachers if you were unhappy about an aspect of your child's therapy? If not, why not?

6. Do you feel that you are part of the team that makes decisions about your child's therapy, and future? Why?

7. Would you like to be more involved in these decisions? Why?

8. How do you feel about the way decisions are made about your child's therapy needs and/or rehabilitation plans in the school at the moment?

9. Do you have any suggestions of ways to improve the teamwork between parents and therapists?

If your child had more than one home programme to do, please fill in the sections B3 to E4 for each separate programme (included on the loose pages at the back of this questionnaire).

THANK YOU FOR YOUR TIME IN ANSWERING THESE QUESTIONS!

Natalie Melling-Williams

APPENDIX C2

VRAELYS AAN OUERS

AFDELING A:

Hierdie afdeling sal my help om u beter te verstaan sowel as sommige van die uitdagings waarvoor u te staan kom t.o.v. die tuisprogramme.

1. Ouderdom van kind by Paarl-skool: _____

2. Geslag van kind:

| | |
|--------------------------|---------|
| <input type="checkbox"/> | Vroulik |
| <input type="checkbox"/> | Manlik |

3. Getal kinders in u gesin: _____

4. Getal kinders in u gesin wat tans leerders is by Paarl-skool: _____

5. Hoeveel van u kinders ontvang tans terapie tuisprogramme of ander tuiswerk (van Paarl-skool of ander terapeute/ skole)?: _____

6. Is u 'n enkelouer?

| | |
|--------------------------|-----|
| <input type="checkbox"/> | Ja |
| <input type="checkbox"/> | Nee |

7. Watter van die kind se ouers werk tans?

| | |
|--------------------------|--------|
| <input type="checkbox"/> | Vader |
| <input type="checkbox"/> | Moeder |
| <input type="checkbox"/> | Albei |
| <input type="checkbox"/> | Geen |

8. Dui asseblief aan u geskatte totale gesinsinkomste PER MAAND vir die tydperk Oktober 2003 tot Desember 2003 (uitsluitend van bonusse):

| | |
|--------------------------|-----------------------------|
| <input type="checkbox"/> | R0 - R2 499 per maand |
| <input type="checkbox"/> | R2 500 – R4 999 per maand |
| <input type="checkbox"/> | R5 000 – R9 999 per maand |
| <input type="checkbox"/> | R10 000 – R19 999 per maand |
| <input type="checkbox"/> | R20 000 of meer per maand |

9. Volgens u mening, wat is die graad van u kind se gestremdheid?

| | |
|--------------------------|---------|
| <input type="checkbox"/> | Lig |
| <input type="checkbox"/> | Matig |
| <input type="checkbox"/> | Ernstig |

10. Hoe voorsien u u kind se lewe as 'n volwassene? (Merk slegs een)

| | |
|--------------------------|----------------------------------------------------------------------------|
| <input type="checkbox"/> | Ten volle of grootliks afhanklik van inrigtings sorg, of ouers of familie. |
| <input type="checkbox"/> | Amper ten volle onafhanklik, maar met 'n mate van bystand. |
| <input type="checkbox"/> | Ten volle onafhanklik. |

11. Watter tipe van werksgeleentheid verwag u dat u kind sal hê as 'n volwassene?
(merk slegs een)

| | |
|--------------------------|--------------------------------------------------------------------|
| <input type="checkbox"/> | Werkloos of in beskermde arbeid. |
| <input type="checkbox"/> | Ongeskoolde hande-arbeid. |
| <input type="checkbox"/> | Half-geskoolde of geskoolde arbeid, ambagman, tegnikus. |
| <input type="checkbox"/> | Klerklik bv. sekretarieël, telefonis, kantoor assistent. |
| <input type="checkbox"/> | Bestuurs of professionele werk (bv. rekenmeester, regte, onderwys) |

12. Is daar mense in u omgewing wat kan help met die grootmaak van u kinders bv.
grootouers, ooms/ tantes/ vriende?

| | |
|--------------------------|-----|
| <input type="checkbox"/> | Ja |
| <input type="checkbox"/> | Nee |

AFDELING B:

Hierdie afdeling sal my meer inligting verskaf oor die tipe van tuisprogram(me) wat u gevra was om te volg, en wat u moeiliker/ makliker gevind het om te doen..

1. Was daar van u/ u kind verwag om 'n tuisprogram te volg tussen die vierde kwartaal van 2003 en die begin van die 2004 skooljaar?

| | |
|--------------------------|-----|
| <input type="checkbox"/> | Ja |
| <input type="checkbox"/> | Nee |

2. Dui asseblief aan hoeveel programme hy/ sy ontvang het gedurende hierdie tydperk: _____

2.3. Indien u slegs EEN tuisprogram moes volg, gaan asseblief aan na vraag 3.

2.4. Indien u MEER AS EEN tuisprogram moes volg, voltooi asseblief die volgende afdelings vir elke tuisprogram wat u moes volg. Aangeheg aan hierdie vraelys is duplikaat afskrifte vir afdelings B3 tot E4.

Bv. Indien u kind 'n arbeidsterapie program sowel as 'n fisioterapie program gevolg het gedurende hierdie tyd, moet u asb hierdie afdelings voltooi vir elke aparte terapie program gevolg.

3. Dui asseblief aan watter tipe van aktiwiteite u gevra was om tuis te doen vir hierdie tuisprogram. (Merk alle toepaslike blokkies.)

| | |
|--------------------------|-------------------------------------------------------------------------------------|
| <input type="checkbox"/> | Aansit van spalke (stutte, voet/ handspalke, nagspalke of ander) |
| <input type="checkbox"/> | Spierstrekkings |
| <input type="checkbox"/> | Fisiese oefeninge (bv. vir hande, arms, bene, hele liggaam, oë) |
| <input type="checkbox"/> | Spraak- en taal oefeninge (bv. stories vertel, klanke) |
| <input type="checkbox"/> | Speletjies (bv. "hopscotch"/ bal speletjies) |
| <input type="checkbox"/> | Aktiwiteite van daaglikse lewe (bv. vasmaak van skoenveters/ self aantrek/ voeding) |
| <input type="checkbox"/> | Skryf/ teken aktiwiteite |
| <input type="checkbox"/> | Gedragsmodifikasie-program |
| <input type="checkbox"/> | Staan in staanraam |

4. Hoe was hierdie tuisprogram aan u gegee? (Merk alle toepaslike blokkies.)

| | |
|--------------------------|---------------------------------------------------------------------------|
| <input type="checkbox"/> | Slegs in geskrewe vorm |
| <input type="checkbox"/> | In geskrewe vorm met prente |
| <input type="checkbox"/> | Verbaal tydens 'n onderhoud of telefonies |
| <input type="checkbox"/> | Verbaal met demonstrasies |
| <input type="checkbox"/> | Aktiwiteite aan kind gewys gedurende terapie en gevra om dit tuis te doen |

5. Was hierdie tuisprogram volgens u mening toepaslik vir u kind?

| | |
|--------------------------|-----|
| <input type="checkbox"/> | Ja |
| <input type="checkbox"/> | Nee |

6. Hoeveel keer per week was u gevra om die tuisprogram te doen?

| | |
|--------------------------|---------------------|
| <input type="checkbox"/> | Elke dag |
| <input type="checkbox"/> | 2 – 5 keer per week |
| <input type="checkbox"/> | Een keer per week |
| <input type="checkbox"/> | Slegs een maal |

7. Hoe lank het dit gewoonlik geneem om die program te doen?

| | |
|--------------------------|--------------------------------------------|
| <input type="checkbox"/> | 5 – 15 minute |
| <input type="checkbox"/> | 15 – 30 minute |
| <input type="checkbox"/> | Meer as 30 minute |
| <input type="checkbox"/> | Program moes dwarsdeur die dag gedoen word |

8. Het u die doel van hierdie tuisprogram verstaan?

| | |
|--------------------------|-----|
| <input type="checkbox"/> | Ja |
| <input type="checkbox"/> | Nee |

9. Wie was verantwoordelik om te verseker dat hierdie tuisprogram gedoen word?

(Merk asb alle toepaslike blokkies)

| | |
|--------------------------|---------------------------|
| <input type="checkbox"/> | Moeder |
| <input type="checkbox"/> | Vader |
| <input type="checkbox"/> | Grootouer |
| <input type="checkbox"/> | Sib (broer/ suster) |
| <input type="checkbox"/> | Kind self |
| <input type="checkbox"/> | Ander (Dui asb aan:_____) |

10. Het u terugvoering ontvang van u kind se terapeut oor u kind se vordering na aanleiding van u goeie toepassing van die tuisprogram?

| | |
|--------------------------|-----|
| <input type="checkbox"/> | Ja |
| <input type="checkbox"/> | Nee |

AFDELING C:

In hierdie afdeling wil ek graag uitvind hoe gereeld die tuisprogramme gedoen word.

U eerlike antwoorde sal bydra tot die bruikbaarheid van die resultate.

1. Ek doen klas tuiswerk met my kind soos aangedui (Merk slegs een):

| | |
|--------------------------|---------|
| <input type="checkbox"/> | Altyd |
| <input type="checkbox"/> | Dikwels |
| <input type="checkbox"/> | Selde |
| <input type="checkbox"/> | Nooit |

2. Dui asb aan hoe gereeld u WERKLIK die TERAPIE tuisprogram gedoen het (gemiddeld). (Merk alle toepaslike blokkies.)

| Tuisprogram | Nooit | Een maal per maand | Tussen een maal per week en een maal per maand | Een maal per week | 2-5 keer per week | Daaglik |
|-------------------------------------|-------|--------------------|------------------------------------------------|-------------------|-------------------|---------|
| Stutte/ spalke aangesit | | | | | | |
| Spiere gestrek | | | | | | |
| Fisiese oefeninge gedoen | | | | | | |
| Spraak- en taaloef. gedoen | | | | | | |
| Speletjies gedoen | | | | | | |
| Aktiwiteite v daaglikse lewe gedoen | | | | | | |
| Skryf/ teken aktiwiteite gedoen | | | | | | |
| Gedrags-modifikasie gedoen | | | | | | |
| Kind laat staan in staanraam | | | | | | |

AFDELING D:

Ek wil graag in hierdie afdeling uitvind wat dit vir u makliker of moeiliker gemaak het om hierdie tuisprogramme te volg.

1. Dui asb aan of u saamstem of nie met ELK van die stellings as voltooiing van die sin: **“Ek doen nie altyd die tuisprogram nie omdat...”**

| | Stem saam | Stem nie saam |
|--------------------------------------------------------------------------------------------------|------------------|----------------------|
| ...ek nie genoeg tyd het gedurende my dag nie | | |
| ...ek te moeg is aan die einde van die dag om die program te doen | | |
| ...my kind te jonk is om hierdie oefeninge te doen | | |
| ...my kind te oud is en nie meer oefeninge benodig nie | | |
| ...ons nie ruimte by die huis het om die oefeninge te doen nie | | |
| ...ons nie die regte meubels/ apparaat het om die oefeninge te doen nie | | |
| ...ek nie daarvan hou om 'n terapeut vir my kind te wees nie- ek wil slegs 'n moeder/ vader wees | | |
| ...ek skuldig voel om soveel tyd aan een kind te spandeer | | |
| ...ek nie glo dat die oefeninge 'n verskil maak nie | | |
| ...ek nie saamstem met die aktiwiteite wat vir my kind gekies is nie | | |
| ...die oefeninge te moeilik is vir my om te doen | | |
| ...ek die enigste persoon verantwoordelik is vir die doen van die program(me) | | |
| ...ek bang is dat ek my kind sal seermaak | | |
| ...my kind nie daarvan hou om die program te doen nie en ek nie verdere stres wil veroorsaak nie | | |
| ...daar te veel oefeninge is om te doen | | |
| ...daar te veel verskillende programme is om te doen | | |
| ...die program te lank neem | | |
| ...ek nie graag tuisprogramme tydens skoolvakansies wil doen nie | | |
| ...my kind weier om die program te doen | | |
| ...ek nie die rede vir die oefeninge verstaan nie | | |
| ...ek nie die instruksies van die program verstaan nie | | |

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and extend across the width of the page. There are no margins, text, or other markings on the paper.

In hierdie afdeling wil ek graag meer uitvind omtrent u verhouding met u kind se terapeut.

| | |
|--------------------------|----------------------------|
| <input type="checkbox"/> | Een keer weekliks |
| <input type="checkbox"/> | Een keer 'n maand |
| <input type="checkbox"/> | Een keer 'n kwartaal |
| <input type="checkbox"/> | Een keer 'n jaar |
| <input type="checkbox"/> | Minder as een keer 'n jaar |

Beleefd; irriterend; moeilijk; vriendelijk; warm; outoritêr; baasspelerig; oop;
onvriendelik; besorgd; onbesorgd; onbelangstellend; professioneel; bekwaam
Ander:

3. U mening oor u huidige vlak van betrokkenheid by u kind se terapie? (Merk een asb.)

| | |
|--------------------------|----------------------------------------|
| <input type="checkbox"/> | Ek sal graag meer betrokke wil wees |
| <input type="checkbox"/> | Ek wil graag effens meer betrokke wees |
| <input type="checkbox"/> | Dit is net reg |
| <input type="checkbox"/> | Ek wil effens minder betrokke wees |
| <input type="checkbox"/> | Ek wil baie minder betrokke wees |

4. Tot watter mate dink u maak u kind se terapie 'n verskil aan sy/ haar en/ of u kwaliteit van lewe? (Merk slegs een.)

| | |
|--------------------------|--------------------------------------|
| <input type="checkbox"/> | Dit maak 'n baie positiewe verskil |
| <input type="checkbox"/> | Dit maak 'n effens positiewe verskil |
| <input type="checkbox"/> | Dit maak min verskil |
| <input type="checkbox"/> | Dit maak geen verskil |

5. Sou u een van u kind se terapeute/ sielkundiges/ onderwysers nader indien u ongelukkig is oor 'n aspek van u kind se terapie? Indien nie, waarom?

6. Voel u dat u deel is van die span wat besluite neem oor u kind se terapie en toekoms? Waarom?

7. Sal u graag meer betrokke wil wees in hierdie besluite? Waarom?

8. Hoe voel u oor die manier waarop besluite tans geneem word oor u kind se terapie behoeftes en/ of rehabilitasie program in die skool?

9. Het u enige voorstelle oor maniere waarop die spanwerk tussen ouers en terapeute verbeter kan word?

Indien u kind meer as een tuisprogram gehad het, voltooi asb. die aangehegde afdelings B3-B10, C2 en E1- E4 vir elke aparte program (**ingesluit in die los bladsye aangeheg aan die vraelys**).

BAIE DANKIE VIR DIE TYD WAT U OPGEOFFER HET OM HIERDIE VRAE TE BEANTWOORD!

Natalie Melling-Williams

APPENDIX D

QUESTIONNAIRE TO THERAPISTS

1. Number of years you have worked at Paarl School: _____
2. Number of years you have worked with children and their families: _____
3. How much time do you spend each term per child developing home programmes?

| | |
|--------------------------|-------------------------|
| <input type="checkbox"/> | 0-15 minutes per child |
| <input type="checkbox"/> | 15-30 minutes per child |
| <input type="checkbox"/> | 30 minutes – 1 hour |
| <input type="checkbox"/> | More than 1 hour |

4. How important do you believe therapy home programmes are as part of rehabilitation?

| | |
|--------------------------|------------------|
| <input type="checkbox"/> | Essential |
| <input type="checkbox"/> | Fairly important |
| <input type="checkbox"/> | Indifferent |
| <input type="checkbox"/> | Not at all |

5. In what form do you give home programmes?

| | |
|--------------------------|-------------------------------------------------------------------|
| <input type="checkbox"/> | In written form only |
| <input type="checkbox"/> | In written form with pictures |
| <input type="checkbox"/> | In verbal conversation in interview/ on telephone |
| <input type="checkbox"/> | In verbal conversation with demonstration |
| <input type="checkbox"/> | Child shown activities during therapy and told to do them at home |

6. Do you liaise with the child's other therapists when developing a home programme?

| | |
|--------------------------|--------|
| <input type="checkbox"/> | Always |
| <input type="checkbox"/> | Often |
| <input type="checkbox"/> | Seldom |
| <input type="checkbox"/> | Never |

7. How many learners were expected to comply with home programmes from you between October 2003 and January 2004? _____

8. Please fill in the following table with reference to the above learners, in your opinion:

| Level of compliance: | Number of learners who complied at this level: |
|-------------------------------------------|-------------------------------------------------------|
| Did home programme 0 – 24% of the time: | |
| Did home programme 25- 49% of the time: | |
| Did home programme 50 – 74% of the time: | |
| Did home programme 75 – 100% of the time: | |

9. What factors make it difficult for you to work with parents?

| | |
|--------------------------|-------------------------------------------------------|
| <input type="checkbox"/> | Time |
| <input type="checkbox"/> | Workload |
| <input type="checkbox"/> | Making appointments with working parents |
| <input type="checkbox"/> | Language barriers |
| <input type="checkbox"/> | Technical terminology difficult to explain to parents |
| <input type="checkbox"/> | Educational level of parents |
| <input type="checkbox"/> | Other: Please specify: _____ |

10. Do you think parents should be included as part of their child's rehabilitation team?

| | |
|--------------------------|--------|
| <input type="checkbox"/> | Always |
| <input type="checkbox"/> | Often |
| <input type="checkbox"/> | Seldom |
| <input type="checkbox"/> | Never |

11. How important do you think it is that parents are directly involved in their child's team decision-making?

| | |
|--------------------------|----------------------|
| <input type="checkbox"/> | Essential |
| <input type="checkbox"/> | Fairly important |
| <input type="checkbox"/> | Indifferent |
| <input type="checkbox"/> | Not necessary at all |

12. How do you feel about the current level of parent involvement in the rehabilitation team?

| | |
|--------------------------|---------------------------------------|
| <input type="checkbox"/> | Just right |
| <input type="checkbox"/> | Need a little more parent involvement |
| <input type="checkbox"/> | Need a lot more parent involvement |
| <input type="checkbox"/> | Totally inadequate |

13. Do you give feedback to parents on achieving therapy goals with their child?

| | |
|--------------------------|--------|
| <input type="checkbox"/> | Always |
| <input type="checkbox"/> | Often |
| <input type="checkbox"/> | Seldom |
| <input type="checkbox"/> | Never |

14. In general, how do you feel about the current level of parent involvement in their child's therapy decision-making?

| | |
|--------------------------|------------------------------------------------|
| <input type="checkbox"/> | I would like parents to be much more involved |
| <input type="checkbox"/> | I would like parents to be a bit more involved |
| <input type="checkbox"/> | It is just right |
| <input type="checkbox"/> | I would like parents to be a bit less involved |
| <input type="checkbox"/> | I would like parents to be much less involved |

15. How do you feel about making decisions about a child's rehabilitation without parental involvement?

16. What do you see as barriers to good relationships with parents of children you give therapy to? (Please list as many as possible)

17. Do you have any suggestions for improving relationships between therapists and parents?

THANK YOU FOR YOUR TIME IN ANSWERING THESE QUESTIONS.

Natalie Melling-Williams

APPENDIX E

FOCUS GROUP SCHEDULE OF QUESTIONS

- What do you see as your role in this team that makes decisions about your child's rehabilitation and future?
- How do you see this team functioning ideally?
- Are you made aware of specific goals that therapists are working for with your child?
- Are these goals relevant to your desired goals/ needs of your lifestyle/ family/ etc?
- Would you make any changes to the way goals are set for your child? How would you like this to be done?
- Results from questionnaires showed that 50% of parents wanted to be more involved in their child's therapy, and 50% were happy as is... Why do you think this is the case?
- What have been your previous experiences of involvement/ contact with the school and therapy staff? Eg parent-therapist meetings, school functions, parent evenings
- Do you have any suggestions for improving teamwork?
- How would you respond to an offer of training courses in specific topics eg ADHD, choosing wheelchairs/ other appliances, improving fine motor function, etc?